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EXPERIENCES AND SUPPORT NEEDS OF FAMILIES RAISING ADOLESCENTS WITH PROFOUND INTELLECTUAL AND MULTIPLE DISABILITIES DURING THE TRANSITION TO ADULTHOOD

**Nicole Luitwieler, Jorien Luijkx, Cees P. van der Schans,
Annette A. J. van der Putten, and Aly Waninge**

Abstract: There is a lack of knowledge about families raising adolescents with profound intellectual and multiple disabilities (PIMD) during the transition to adulthood. This study explores the experiences and support needs of these families throughout this transition. A qualitative design was used, consisting of semi-structured interviews with mothers ($N = 10$) of children aged 10 to 23 with PIMD. The interviews were analyzed via a coding scheme based on a theoretical framework for family quality of life (FQOL) and stages of adolescence. Positive and negative experiences and distinct support needs were examined in the FQOL domains and stages of adolescence. These families have a unique need for information on development and participation opportunities for children with PIMD, and how to support them. Other needs and experiences expressed, such as dealing with hormonal changes and with being transferred from paediatric to adult care services, were consistent with other families with support needs. The obtained knowledge can be used to improve support for families with an adolescent child with PIMD. In addition, future research in this area is recommended and should be grounded in a family-centred, strengths-based, longitudinal approach.

Keywords: adolescence, adulthood, transition, profound intellectual and multiple disabilities, intellectual disability, family quality of life

Nicole Luitwieler MSc (corresponding author) is a researcher at the Hanze University of Applied Sciences, Zernikeplein 7, 9747 AS Groningen, The Netherlands.
Email: n.m.van.den.dries-luitwieler@pl.hanze.nl

Jorien Luijkx PhD is an assistant professor at the University of Groningen, Department of Pedagogy and Educational Sciences, Faculty of Behavioural and Social Sciences, Grote Kruisstraat 2/1 9712 TS Groningen, The Netherlands. Email: j.luijkx@rug.nl

Cees P. van der Schans PhD is a professor at the Hanze University of Applied Sciences, Groningen, and University Medical Centre of Groningen, University of Groningen, Hanzeplein 1, 9713 GZ Groningen, The Netherlands. Email: c.p.van.der.schans@pl.hanze.nl

Annette A. J. van der Putten PhD is a professor at the University of Groningen, Department of Pedagogy and Educational Sciences, Faculty of Behavioural and Social Sciences, Grote Kruisstraat 2/1 9712 TS Groningen, The Netherlands. Email: a.a.j.van.der.putten@rug.nl

Aly Waninge PhD is an associate professor at the Hanze University of Applied Sciences, Groningen, and University Medical Centre of Groningen, University of Groningen, Hanzeplein 1, 9713 GZ Groningen, The Netherlands. Email: a.waninge@pl.hanze.nl

During adolescence, teenagers are preparing for adult life, and they are expected to gradually develop emotional, personal, and financial independence (Christie & Viner, 2005), with the ultimate goal of finding their place in society (Dumontheil, 2016), which may include gaining employment, living independently, and earning their own money. According to current insights, adolescence generally occurs between the approximate ages of 10 and 24 (Dorn, 2006; Sawyer et al., 2018). This transitional phase can be broadly categorized into three developmental stages — early adolescence, middle adolescence, and late adolescence — each associated with specific characteristics and developmental tasks (Christie & Viner, 2005; Curtis, 2015; Salmela-Aro, 2011). The beginning of adolescence, triggered by increasing levels of sex hormones, is marked by visible physical changes in a young person, including a growth spurt and the appearance of sexual characteristics (Dorn, 2006; Spear, 2000). Throughout adolescence, identity exploration and gaining more independence are crucial to ensuring that adolescents will eventually be able to assume adult roles and responsibilities (Markovitch et al., 2017). While developing their identities, adolescents tend to spend more time with their peers, in addition to possibly rebelling against their parents and exhibiting risk-taking behaviour (Reyna & Farley, 2006). Family support has been identified as an important predictor of positive adjustment in adolescence (Branje, 2022; Telzer et al., 2013), and the process of raising an adolescent to adulthood is often accompanied by numerous changes and challenges (Collins & Steinberg, 2006; Crone et al., 2016) that may affect the entire family (Li et al., 2017; Ryan et al., 2023).

For adolescents with profound intellectual and multiple disabilities (PIMD), it is not self-evident that the process of developing towards independent adult life will be entirely fulfilled, given the complexity of their disabilities. Individuals with PIMD have severe or profound intellectual disabilities combined with severe or profound motor disabilities (Nakken & Vlaskamp, 2007). Many of these individuals also have several sensory impairments (Van Splunder et al., 2003) and health problems (e.g., epilepsy, spasticity, gastroesophageal reflux; van Timmeren et al., 2016), thus requiring ongoing specialized and intensive care, as well as support from others (e.g., family members and professionals; Nakken & Vlaskamp, 2007; Schalock et al., 2021). Nevertheless, persons with PIMD are regarded as being capable of active engagement with and involvement in the activities of daily life, and of having social relationships (Hanzen et al., 2020; Hanzen et al. 2022). Moreover, despite any practical difficulties that may arise, these experiences are considered important for individuals with such complex disabilities (Hanzen et al., 2017; Mansell & Beadle-Brown, 2012). It is also assumed that having opportunities to influence daily life (e.g., expressing personal needs or being recognized by others) enhances the quality of life for people with PIMD (Kuld et al., 2023; van Tuyll van Serooskerken et al., 2022; Hanzen et al., 2022; Petry & Maes, 2009).

The current body of knowledge on the transition from adolescence to adulthood for young people with PIMD and their families is limited and fragmented (Luitwieler et al., 2021). Research conducted in this area has focused largely on medical and allied health care, including the prevalence of delayed puberty (Calcaterra et al., 2019) and problems associated with transferring from paediatric to adult care (Bindels-de Heus et al., 2013; Ryan et al., 2023; Toulany et al., 2022). According to previous studies of families with children with severe or profound intellectual disabilities, the broad transition from adolescence to adulthood may be accompanied by increased administrative burden, concerns for the future, and — consequently — considerable stress for their relatives (Gauthier-Boudreault et al., 2017; Jacobs et al., 2018; Ryan et al., 2023). However, positive results have also been associated with this transitional phase in individuals with intellectual disabilities. For example, parents have reported personal growth for both themselves and their children with intellectual disabilities, along with improvements in social support from others (Rapanaro et al., 2007).

Additional insight into the ways in which families with children with PIMD experience the transition from adolescence to adulthood is needed in order to improve the support provided to families during this dynamic phase. The usual problems of parenting adolescent children are made more complex in these families who are already facing major challenges when supporting their children with PIMD, and improved support during this transition is likely to enhance their quality of life. Hence, this study explores the experiences, both positive and negative, and support needs of families raising children with PIMD throughout the transitional phase from adolescence to adulthood.

Methods

The present study is part of a larger study by Lahaije et al. (2023a) on the support needs of families who have children with PIMD aged 0 to 30. For the larger study, participants were recruited through a combination of convenience sampling and purposive sampling, because it is difficult to recruit a large sample of families of children with PIMD (Maes et al., 2021). The aim was to reach families with children with PIMD aged 0 to 30 while also ensuring representation across various developmental categories — child, adolescent, and young adult — among the children. Initially, families were recruited by making appeals through social media channels and assessing responses. If there were fewer responses in a particular developmental category, explicit targeting of that category was conducted, also using targeted recruitment through patient organizations and the personal networks of the authors. Both the present and the larger study are part of a research project aimed at investigating and improving the quality of life for families with children with PIMD.

Study Design

The present study was conducted according to a qualitative, descriptive design (Sandelowski, 2002), including semi-structured interviews to identify the experiences and support needs of families with adolescents with PIMD. Semi-structured interviews are an effective data-collection method for exploring and deepening one’s understanding of complex and sensitive issues (DeJonckheere & Vaughn, 2019).

Participants

The inclusion criteria for study participants for the larger study were as follows:

- The primary caregiver of a child (0–30 years) with PIMD: profound intellectual disability (i.e., estimated IQ of < 25 points, or developmental age < 24 months), and severe or profound motor disability (i.e., level IV or V on the Gross Motor Functioning Classification System [GMFCS; Palisano et al., 1997], or a similar level of motor performance);
- Living in the Netherlands.

The current sample was drawn from the larger sample, based on the age (10–24) of the child with PIMD. Our final sample consisted of 10 mothers between the ages of 37 and 57 ($M = 46.5$, $SD = 6.5$), and their children with PIMD, who were between the ages of 10 and 23 ($M = 14.5$, $SD = 5.2$). Nearly all mothers were of native Dutch background (90%). The characteristics of these mothers, their families, and the children with PIMD are described in more detail in Table 1.

Table 1. *Characteristics of Participants: Families, Parents and Children With PIMD*

Characteristics	*n*
Family	
Number of family members	
3	1
4	3
5	5
6	1
Household	
One-parent	1
Two-parent	9
Parent	
Highest level of education	
Secondary Professional Education	1
University of Applied Sciences	5
University	4
Country of birth	
The Netherlands	9
Other	1
Work	
Part-time (0–35h)	6
Full-time (>35h)	2
No paid work	2
Division of hours per week spent taking care of child with PIMD	
Primary parent spent more hours than other parent/caregiver	6
Primary parent spent the same amount of hours as parent/caregiver	4
Child with PIMD	
Developmental stage of adolescence	
Early (10-13y)	5
Middle (14-17)	2
Late (18-24)	3

Characteristics	*n*
Gender	
Female	5
Male	5
Country of birth	
The Netherlands	9
Other	1
Living situation	
Partly at home and partly at respite home/care	3
Fully at home	6
Other	1
GMFCS level	
IV	5
V	5
Day care	
At care institution/day care facility/school	9
No	1
Supportive communication tools	
Sign language	1
Symbols/pictograms	1
Talk button	1
Other	1
No support	6
Additional disabilities and health issues	
Visual impairment	5
Hearing problems	2
Epilepsy	8
Reflex	5
Chronic respiratory infection	2
Difficulties chewing and swallowing	7
Chronic Constipation	6
Behavioural problems	2
Sleeping problems	7
Nasogastric feeding	5
Scoliosis	5
Frequent serious illness	2
Other	1

Ethical Approval

Both the larger study and the present study were approved by the Hanze Ethical Advisory Committee (HEAC) after independent review. Participants were informed in writing about relevant ethical aspects of the research, including the right not to answer questions if it would make them feel uncomfortable and the right to withdraw from the study. Participants received no financial compensation for their participation. All participants granted online informed consent to participate in the present study, and oral agreement was recorded at the beginning of each interview.

Procedure and Data Collection

The data for the larger study, which also served for the present one, were collected between January and May 2021. The participants, all of whom had previously been involved in other parts of the research project, were contacted by email to participate in this interview study. In all, 10 individual semi-structured interviews with mothers of adolescents between the ages of 10 and 24 were conducted by the first author, NL (n = 5), and a colleague PhD student, SL (n = 5). Due to COVID-19 restrictions, the interviews took place online with video conferencing, or by telephone, depending on the participant's preference.

An interview protocol with predefined main themes was developed (see Appendix A). Open-ended questions were used to allow participants to express their experiences and perspectives in their own words, as well as to enhance the in-depth exploration of topics (Kallio et al., 2016). The protocol was pretested by SL in a pilot interview with a sibling of a person with an intellectual disability. The pretest did not reveal any need for adjustments. All interviews were preceded by a standard introduction, after which participants were requested to provide information about themselves and the composition of their families. The participants were then asked to share their experiences (positive and negative) and support needs during their child's transition to adulthood from a family perspective. They were asked to talk about their current experiences, as well as to reflect on previous experiences. Such reflection was intended to improve their understanding of the present situation, any changes, and their expectations for the future. Moreover, participants were asked about their needs for family support. In regard to the transitional phase, they were asked about the types of support they had received as a family, and about what had and had not worked out well or what they had lacked. Furthermore, participants were asked about products they thought should be developed to support families like their own. Factors known to be related to the quality of life of families with children with PIMD were identified in advance (Lahaije et al., 2023b, Luitwieler et al., 2021). If participants did not mention these factors spontaneously during the interview, they were introduced by the interviewers. At the end of each interview, participants were provided with the opportunity to make further comments.

Data Analysis

The data analysis used in this study is consistent with the analysis applied to the entire available dataset of the larger study on support needs (Lahaije et al., 2023a). The data were prepared by transcribing the interview recordings. To verify the accuracy of the transcripts, they were submitted to the participants for a member check (Birt et al., 2016). For the present study, the interviews that met the inclusion criteria were subsequently selected from the larger dataset and coded with the Atlas.ti software (version 9). The coding process was performed by three coders: NL, SL, and a master's student of Pedagogical and Educational Sciences (AS). A combination of deductive and inductive coding was applied, thereby enhancing the depth of the data analysis (Bingham & Witkowsky, 2022).

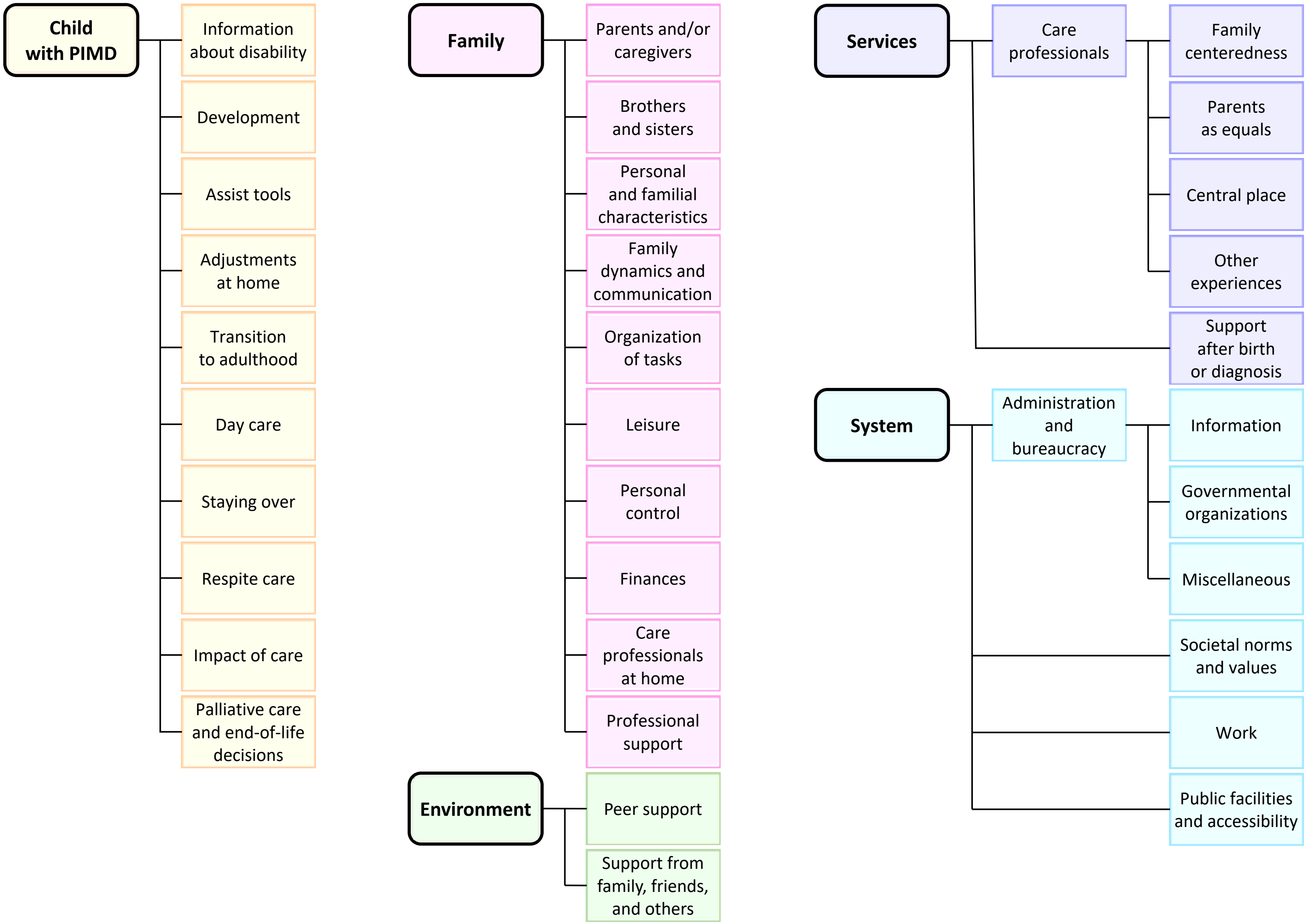
The coding scheme was developed according to the theoretical family quality of life (FQOL) framework developed by Zuna et al. (2010). The FQOL framework is based on four key concepts: Systemic, Performance, Family-unit, and Individual-member. Each category of concept interacts with the others; together, they predict FQOL. This FQOL framework was chosen because it offers a comprehensive understanding of how various aspects of family life interact to influence overall quality of life. It provides knowledge regarding exactly where support is needed, along with practical guidelines for professionals, and it recognizes that family dynamics can change over time.

First, fragments from three randomly selected interviews were chosen to be open-coded by the three coders (NL, SL, and AS). The coders then compared and discussed their results during a joint meeting and tried to group the assigned codes into overarching domains based on the four concepts in the theoretical FQOL framework (Zuna et al., 2010). The coders jointly decided to transform the Systemic, Performance, Family-unit, and Individual-member concepts into five FQOL domains: System, Services, Environment, Family, and Child with PIMD. The System domain represents the impact of public authorities, government services, and employers (and contact with these entities), as well as the impact of societal norms and values and the accessibility of society. Performance concepts were split into two separate domains: Services and Environment. The Services domain relates to the support received by these families from health care professionals, and the Environment domain represents social support received from peers, family, friends, and significant others (e.g., a church community). The reason for this split was that, based on our interviews and previous studies (e.g., Lahaije et al., 2023b), families consider both forms of support important, but social support did not fit well into the original set of FQOL concepts (Zuna et al., 2010). Furthermore, a distinction was made between the Child with PIMD domain, which represents descriptive aspects of the child, and the Family domain, which concerns descriptive aspects of the family unit, parents, and siblings. Thereafter, subcategories, with extended definitions, were formulated for each of the five FQOL domains.

The initial coding scheme was then discussed with the other authors, which led to the refinement of the subcategories and definitions. Interview fragments that could relate to more than one category were placed in the category that seemed most relevant. The final coding scheme includes five FQOL domains and 33 subcategories (see Figure 1). Detailed descriptions of these domains and subcategories are provided in Appendix B. Based on this coding scheme, all fragments meeting the inclusion criteria for the present study (*N* = 781) were coded by NL, SL, and AS.

The initial intercoder agreement (ICA) of the coding based on the developed scheme was measured according to the simple proportion agreement method, which is considered acceptable in the case of qualitative explorative studies that do not require comparative statistics (Kurasaki, 2000). Although there is no standard for an acceptable ICA, several studies have argued that an agreement of at least 70% is sufficient (Fahy, 2001; Kurasaki, 2000). For this purpose, NL and AS each coded the same 200 fragments, and SL and AS coded another set of 200 fragments in

Figure 1. *Visualization of Coding Scheme With FQOL Domains and Subcategories*



two different rounds, first with 16 interviews and then with 19 interviews. In both rounds, the percentage of agreement was calculated between NL and AS (40.4% and 76.4%, respectively) and between SL and AS (36.4% and 36.0%, respectively). Because the agreement on the codes was too low after both rounds (< 70%), the coding process was redefined to reach an acceptable level of agreement. Specifically, the three coders (NL, SL, and AS) discussed the codes in a joint session, which led to a few minor adjustments in the subcategories. After the joint session, the three coders independently coded 30 additional fragments. This iterative process was repeated twice until an acceptable level of agreement (78.3%) was reached among the three coders.

The coded fragments were subsequently categorized into the early, middle, and late stages of adolescent development, with corresponding age categories (Christie & Viner, 2005; Curtis 2015; Salmela-Aro, 2011), as changes during adolescence are typically expected to occur in line with chronological age. It remains to be explored whether similar patterns and sequences indeed apply to individuals with PIMD. Finally, all coded and categorized fragments were further categorized by type of experience (positive or negative) and support need.

Results

The total number of interview fragments (*N* = 781) assigned to the FQOL domains and subcategories is presented in Table 2, categorized by developmental stage of adolescence. The results reveal experiences and needs across all FQOL domains and developmental stages of adolescence. The needs are expressed as support needs, not as suggestions for concrete products. Table 2 shows a general overview of how often a domain or subcategory was mentioned relative to other domains and subcategories, and how prominently a topic was represented within a specific domain and during a specific adolescence phase. These findings are further described, along with an indication of whether each result relates to all stages of adolescence (abbreviated as A) or to a specific stage: early (E), middle (M), or late (L).

System

With regard to their relationships with public authorities (e.g., health insurers, local authorities), several mothers (A) provided examples demonstrating that these relationships were often characterized by misunderstanding and distrust. Some mothers felt as though they repeatedly had to prove the intensive and specialized nature of their children's support needs to these authorities. Other mothers stated that they regularly encountered obstacles, including lack of understanding or a delayed response (e.g., when applying for a new wheelchair or orthosis in the short term due to a child's growth spurt):

> Oh, that happened to me once with the municipality. I thought, uhm … Then she said, "Oh, are you applying for something new already?" Yeah, then I think, "I'm not doing it for fun, you know …" Yeah, he's outgrown his wheelchair or his situation is quite erratic; it's simply different now, six months later. That's just how it is. It's so annoying to get questions like that.

Table 2. *Total Number of Fragments Classified by FQOL Domains and Subcategories, Categorized by Developmental Stage of Adolescence*

		Stages of adolescence			Total
FQOL domain	Subcategory	Early (*n* = 5)	Middle (*n* = 2)	Late (*n* = 3)	All stages
System					
	Administration/bureaucracy	36	6	26	68
	Societal norms/values	2	0	0	2
	Work	7	0	6	13
	Public facilities/accessibility	8	0	0	8
Subtotal		53	6	32	91
Services					
	Care professionals	60	16	52	128
	Support after birth/diagnosis	22	7	2	31
Subtotal		82	23	54	159
Environment					
	Peer support	22	5	28	55
	Support from family/friends/etc.	26	15	16	57
Subtotal		48	20	44	112
Family					
	Parents/caregivers	5	4	7	16
	Brothers/sisters	14	4	13	31
	Personal/familial characteristics	40	8	13	61
	Family dynamics/communication	5	1	2	8
	Organization of tasks	11	4	10	25
	Leisure	5	5	7	17
	Personal control	10	0	10	20
	Finances	0	0	5	5
	Care professionals at home	2	5	9	16
	Professional support	12	1	18	31
Subtotal		104	32	81	217
Child with PIMD					
	Information about disability	7	2	1	10
	Development	3	2	5	10
	Assist tools	7	2	9	18
	Adjustments at home	3	0	0	3
	Transition to adulthood	9	8	20	37
	Daycare	18	10	16	44
	Staying over	10	8	6	24
	Respite care	7	0	4	13
	Impact of care	16	4	21	41
	Palliative care/end-of-life decisions	2	0	2	4
Subtotal		82	36	84	202
Total		369	117	295	781

System

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Two mothers (E, L) expressed a need for more trust and more possibilities for customization in contacts with public authorities. Three mothers (M, L) stated that they had also experienced good relationships with public organizations.

All 10 mothers reported having experienced administrative burdens in their contacts with public authorities, and some expressed a need to spend less time on these tasks. One mother (M) expected the burden to increase even further when her son reached the age of 18. Another (L) described how her family had faced additional administrative tasks since her son turned 18:

> I also wasn't really aware that, when he turned 18, it would immediately be accompanied by a lot of responsibility, by another big wave of administration again.

Several mothers (A) reported that the information they had needed from public authorities during their children's adolescence was often complex and difficult to find. Two mothers (E, M) indicated that this administrative effort had caused feelings of stress and uncertainty within their families. A few mothers (A) said they would like relevant information to be made more easily accessible and provided more proactively to their families at key moments, such as when transferring from paediatric to adult services. Other mothers (M, L) reported examples of good practices, including the proactive attitude of the Care Administration Office.

Two mothers (E) pointed out the importance of wheelchair (or other) accessibility in society since their children had become taller and heavier, and they explained how this had negatively affected their family's participation. Due to the size of their children, they emphasized the need for fully accessible changing areas in public restrooms and other locations:

> Just going somewhere on a whim; things can happen. For example, when you've got a baby covered in poop, it's inconvenient. It's different when you've got such a big boy of 11 up to his neck in diarrhoea, with nowhere to go to take care of it …

Finally, one mother (L) described how mothers wishing to reenter the workforce after a long absence often had no idea how to deal with this situation and that they could use some help:

> So yeah, you're a little uncertain about that, about what the possibilities on the job market are. You've been out of that job market for years, so you have no idea what the possibilities are. And you haven't built up any rights, because you've been out.

Services

Several mothers (A) described positive experiences in their contacts with health care professionals (e.g., situations in which professionals had sufficient knowledge of the increasing complexity of care or showed interest in family members other than the child with PIMD). In addition, others (A) mentioned negative experiences in their contacts with professionals (e.g., a lack of time during consultations or an exclusive focus on the child with PIMD or medical matters). A few mothers (M, L) explained that, over the years, they had built up a great deal of knowledge about their children, and they would like professionals to acknowledge this. One mother (E) noted that young professionals seemed more willing to treat parents as equal partners in the care and support of their children, and another (E) outlined the decisive role of education and policy when it comes to professionals working in partnership with parents:

> Seeing parents as experts and just dealing with the tension that this can cause, I think this should really receive more attention in training. I also think it should be addressed in institutional policies or visions.

Nearly all mothers (A) mentioned issues related to the transfer of their children from paediatric to adult services, as well as to the support they had or had not received in this situation. Two mothers (E, M) of children who had not yet made this transfer indicated that they did not know what to expect and that they had no idea of where they could turn with their questions. Another mother (L) of a child who had completed the transfer mentioned that it had gone quite smoothly and that their family had been well supported by professionals (e.g., at the daycare centre). Two other mothers (L) stated that the transfer had brought considerable extra work and stress to their families, as they had been forced to sort out a lot of issues on their own. From that moment on, they had experienced a lack of coordination, and it had been less obvious which professional they should consult with which question. Two mothers (M, L) stated that their families should have been better supported in this transfer by professionals (e.g., at the daycare centre) and materials (e.g., flyers, checklists, websites), and that timely preparation would have been helpful. Physicians specialized in the field of intellectual disabilities (ID physicians) were mentioned by one mother (E) as appropriate coordinators of adult health care, given their expertise:

> We thought the paediatrician was a bit one-sided. It was also because this paediatrician really didn't know much at all about intellectual disabilities, and she was always very honest about that. You could also ask an intellectual disability physician about behaviour or about issues relating to behaviour and epilepsy. You could also ask about puberty.

Environment

All mothers who were interviewed stated that engaging with people in similar situations was important to their families, as such relationships allowed them to experience recognition and exchange useful tips. Several mothers (A) said that most of their contacts with other families of children with PIMD were online, primarily through Facebook. In addition, some mothers (E, L) expressed a desire to attend physical meetings with other parents for more exchange around topics relating to particular phases (e.g., transferring from paediatric to adult services, future care planning), and two mothers (E, L) noted that such meetings could also be beneficial to siblings. Some mothers (A) felt that parents' associations or their child's daycare centre should take the initiative in organizing these types of meetings (as had happened in the past), and two (M, L) reported having taken this initiative themselves. Finally, two mothers (L) expressed a need to share their knowledge and experiences with other, less experienced, parents:

> Yeah. Yeah, I follow that; I'm active with it [Facebook groups]. I also enjoy being able to help people with it, so I also keep an eye out when people ask things that I happen to have experience with.

Nearly all mothers (A) observed that they continued to value their relationships with family members and friends, even though their experiences as parents of children with PIMD differed from those of their peers, and that these relationships had changed over time. Some mothers (A) explained that, through the years, their lives as families with children with PIMD had increasingly diverged from those of families without such children, and that this had made it increasingly difficult for "outsiders" to understand their struggles. For this reason, some had started to ask family members and friends more frequently for practical support (e.g., caring for their children and performing chores in the house) and less often for emotional support:

> But, for example, friends. Yeah, at first, they're obviously interested, but at some point, they also don't understand that these concerns are always there. So then you actually shift your conversation partner from a friend or family member to a fellow sufferer.

A few mothers (E, M) explained that, as their children had grown, their physical and medical care had become more burdensome and complex. In addition, family members and friends had also become older, making it more difficult, or even impossible, for some to continue providing the same level of practical help.

Family

Several mothers (A) described how many years of caring for a child with PIMD had impacted their family lives and those of individual family members. A few mothers (A) stated that, during the adolescence of their children, they had started to realize the true weight of their care tasks and what the consequences were. Some mothers (A) stated that they or their partners had already experienced burnout, and others had noted that they were currently experiencing a lot of stress because of always being “on”. A few mothers (A) expressed concerns about the impact on their other children of growing up with a sibling with PIMD.

A few mothers (A) mentioned that, although family members were able to support each other, they sometimes needed professional help, which they found beneficial. Two mothers (E, M) pointed out the symbiotic relationships that had emerged within their families, and emphasized the importance of autonomy and building one’s own life, both for the child with PIMD and other family members.

One mother (M) wondered whether full participation in society should always be held up as an attainable goal:

> If that’s the greatest goal, it just doesn’t seem right to me. And it also fails to acknowledge how hard it actually is — the actual support that she needs.

Nearly all mothers (A) provided examples illustrating differences in the experiences of family members during adolescence. For example, one mother (E) explained how caring for her adolescent child still gave her fulfilment, while her husband had told her at some point that he had had enough of still having to change diapers. Another mother (L) of three daughters described how her youngest daughter had demonstrated involvement with the care and support of her sister with PIMD, while this had never been the case with her eldest daughter. Moreover, one mother (L) explained that it had become more difficult for her to meet the needs of all her children, due to the increasing diversity of their needs:

> And then, when they’re small, you can still get everything together, and then you go to the petting zoo together, and everybody’s happy. But when they get a bit older, their needs are very different, and it’s hard to keep all those balls in the air. Yeah, it’s a lot of juggling.

Several mothers (A) explained that, for leisure activities, their families had become increasingly dependent on available facilities (e.g., accessible cottages for holidays) and support (e.g., respite care). Some mothers (A) reported that they had chosen to spend their family holidays without the child with PIMD, as it allowed greater relaxation for the child and/or the rest of the family.

Several mothers (A) described how they were concerned about the future of their families (e.g., whether the child with PIMD would move out, and how to hand over care tasks). In contrast, other mothers (A) stated that they were not so concerned with the distant future, due to the limited or uncertain life expectancy of their children.

Two mothers (M, L) reported having difficulty discussing the future with family or friends, or with their other children, because they expected others not to understand or because they did not wish to burden them with such matters. A few mothers (M, L) expressed a desire to have a central point (e.g., website or office) where they could find information and obtain advice regarding issues that would arise in the future, such as the need to find suitable residential facilities. One mother (L) explained that, when making preparations for the future, she would like to have support from someone well-acquainted with her child and family:

> Well, I just think someone who just really also, who knows you well and who also says, uhm, well, “What does this mean for the future? What can we take over for you if you’re no longer there?” Because we now have a general agency, and I don’t like that idea. And I just sincerely hope that we have a long time to live, and I also really hope that we survive [child’s name].

Child With PIMD

Regarding their children with PIMD, some mothers (A) stated that the intensity and complexity of care (e.g., physical care, sleep deprivation, health issues) had remained the same or increased during adolescence, and that additional support was necessary to continue this care in the longer term. They explained that respite care and assistive devices (e.g., a hoist) could help to reduce the care burden.

A few mothers (A) mentioned that they had noticed changes in their children that they attributed to adolescence (e.g., growth spurt, changes in behaviour and preferences), while others (A) had not noticed such changes. Two mothers (E) expressed a need for information and support from health care professionals (e.g., daycare centres, physicians) to cope with such changes:

> Yeah, she really is … at any rate very much going through a growth spurt, including in terms of her behaviour. She can really be a handful, but physically as well. I think she’ll start having her period within a few months. When that happens, you lose your baby a little bit. In my opinion, it really is a new phase.

Some mothers (A) felt that it was important for their children to continue to be challenged to develop themselves and to be actively involved in daily activities during their adolescence, and they believed that this should be the responsibility of health care professionals in collaboration with parents:

> … well, anyway, that she can do what she’s capable of doing herself. The transfers. You could also lift her for everything or put her in a hoist, but for what she can do herself, make sure to have her do it.

In contrast, other mothers (M, L) were convinced that their children had few if any developmental opportunities, and some described their children as “(big) babies”. These mothers mainly wanted their children to stay as comfortable as possible, in some cases due to limited life expectancy. Two mothers (M, L) explicitly mentioned they did not necessarily wish their children a long life; for one, this was due to doubts about her child’s quality of life, and for the other, because she wanted to take care of her child herself to the very end.

Some mothers (A) mentioned that their children had already been living somewhere else at least part-time, while other parents were looking for suitable places for their children to live. Several mothers (M, L) referred to a lack of residential facilities that would meet the complex care-related (or other) needs of their children and the wishes and needs of the parents, or they noted that it was unclear to them where they could find such places. A few mothers (M, L) stated that, as a result, their children were forced to live at home for longer; a few had joined a parent initiative (i.e., a self-organized initiative by parents focused on housing solutions for their children).

Discussion and Conclusion

The main goal of the present study was to generate insight into the experiences and support needs of families with a child with PIMD during the transition from adolescence to adulthood. Experiences and needs were identified in all domains of FQOL, but most commonly in the Family domain and the Child with PIMD domain; experiences and needs in these domains often had an impact in the other domains (System, Services, Environment) as well. Most experiences and needs reported referred to the early and late stages of adolescence. Most of the experiences in the System domain and the Child with PIMD domain were negative, including administrative burdens, problematic relationships with public authorities, and an increase in the impact and complexity of care. In addition, the families were dealing with issues related to adolescence in their children with PIMD, including behavioural and hormonal changes (e.g., growth spurts) and children moving out of the parental home. This raised concerns about the quality of life and the developmental potential of their children. In all of these areas, the mothers in our study expressed a need for more support from services and public authorities.

Most of the experiences relating to the Service domain and the Environment domain were positive. Beyond the support they received from peers and relatives, mothers were also appreciative when professionals paid attention to the entire family and drew on the parents' experiential knowledge, although this did not always occur. In the Family domain, positive and negative experiences were about equal. The mothers reported having experienced considerable stress during their children's adolescence, with a peak around the transfer to adult care. In most cases, family members were able to support each other although, at times, professional help was needed. Family participation became more difficult when the children were in early adolescence, and specialized support and equipment were needed. During late adolescence, mothers realized that their future perspectives were likely to differ from those of other families, and they expressed a need for support from professionals and relatives in this regard as well.

Some results of the present study are comparable to issues relating to transitions in other families, regardless of whether a child has a disability. For example, when their children are going through adolescence, all families are confronted with hormonal changes in their children (e.g., Dorn, 2006) and children leaving the parental home (e.g., Seiffe-Krenke, 2006). In addition, as in other families with children who require health care services, these mothers considered it important for professionals to pay attention to the entire family and for their experiential knowledge to be involved in the process (Aarthun et al., 2019; Hsu et al., 2019).

Other results from this study are consistent with those of previous studies conducted on families with children with other types of disabilities. The mothers in our study mentioned the problems they had experienced through contacts with public authorities that had caused extra work and stress for their families. They also referred to the impact of the accessibility (or inaccessibility) of society on their families' participation. These points are also reflected in research conducted on families with children with different types of intellectual or physical disabilities (e.g., Colver et al., 2012; Jacobs et al., 2018).

The transfer of an adolescent from paediatric to adult services (usually around age 18) emerged as an important and challenging turning point for some of the families in the present study. This transfer is accompanied by major changes, including a different organization of care and support. Mothers in our study reported the transfer involved more administration and stress, concerns for the future, and changing support needs. These transition problems have also been observed in other populations of people with disabilities, including cerebral palsy, spina bifida, and hydrocephalus (Sattoe et al., 2017; Singh & McDonald, 2018; Solanke et al., 2018).

Finally, some findings of the present study appear to be unique to families with children with PIMD, including wide differences in approaches to supporting these children and their developmental potential. Some of the interviewed mothers considered it important for their children to continue to be encouraged in their development and to be actively involved in daily activities during adolescence. Others did not see any developmental opportunities for their children and focused on good care and comfort instead. Such potential differences in perspective between families are also reflected in other studies involving families with a child with PIMD (e.g., Hauwert, 2018). Such differences should be taken into account when supporting these families, as they could provide direction for answering their questions and meeting their support needs. Nevertheless, several studies have recommended paying attention to the developmental needs of people with PIMD, even when those needs are not immediately apparent, as this could enhance their quality of life (Hauwert, 2018; Maes et al., 2011).

The mothers who participated in the present study became especially aware of the differences between their experiences and those of other families as their children with PIMD entered and proceeded through adolescence. The mothers explained that their families experienced obstacles to participation as their children became increasingly and permanently dependent on family members and equipment (e.g., wheelchairs). They also experienced a need to reshape the future of their families, as the development of their children with PIMD became increasingly divergent from that of their other children. While such differences are less pronounced and less visible at younger ages, they increase during adolescence, creating a growing sense of being different from "normal" families. These findings also correspond to those of previous studies, which indicate that the experience of "difference" increases in prominence in accordance with the severity of the intellectual (or other) disability (Jacobs et al., 2018). The feeling of being different can generate a sense of ambiguity in those supporting people with disabilities (Bigby et al., 2009; Dunn et al., 2007). For example, it has been demonstrated that the siblings of a child with a severe or profound intellectual disability are likely to struggle with the feeling of being part of a family that is simultaneously different and normal (Jacobs & MacMahon, 2017).

Developmental issues (e.g., the onset of puberty and the transition to adulthood) may also trigger feelings of enduring sorrow for parents of children with chronic conditions. This is because differences are likely to become more apparent during these transitions, thereby leading parents to think and worry more about the future (Coughlin & Sethares, 2017). Finally, in light of these issues, one could question the relative applicability of the main developmental stages of adolescence used in the present study to individuals with PIMD. This is because the stages usually centre on a child's pursuit of increasing independence. The findings of the current study illustrate that parents raising adolescents with PIMD are consistently confronted with the extensive support needs of their children. These caregiving responsibilities and their complexity do not diminish as the children grow older, but rather seem to increase during the transition to adulthood, contrary to the usual pattern of increasing independence during adolescence. Since the needs of families raising children with PIMD do evolve throughout these stages, it is important to recognize and understand the different developmental phases of children with PIMD and how those phases affect their families.

Strengths and Limitations

The strengths of the present study include the use of a theoretical framework in a systematic approach to collecting and analyzing data with the assistance of multiple coders. Additionally, this study is among the first to focus in depth on the experiences and needs of families with a child with PIMD during the transition from adolescence to adulthood across the different domains of FQOL while encompassing a broad age range (10–23 years). Previous studies in this area have used other theoretical frameworks, addressed other questions, or focused on the transfer from pediatric to adult medical care (Bindels-de Heus et al., 2013; Gauthier-Boudreault et al., 2017; Jacobs et al., 2018).

The rather homogeneous composition of the sample, which consisted of mothers of almost exclusively native Dutch background, can be considered a limitation of the study. Because they are usually the primary caregivers, mothers tend to be overrepresented in many family studies (e.g., Chogani et al., 2021). The use of convenience sampling in combination with purposive sampling may have contributed to the lack of diversity in our sample, as these parents may have been more accessible to the researchers. Unfortunately, it is often difficult to recruit fathers and families with different cultural backgrounds in these kind of studies (Maes et al., 2021), limiting the generalizability of the findings. Caution should therefore be exercised when generalizing the results to other family members (e.g., fathers, siblings) or to people of other cultural backgrounds.

It is also unclear whether this lack of generalizability could have been resolved with such a small sample even if it had been more diverse, given the wide diversity existing within the total population. Most qualitative studies are small in scale and are therefore unable to reflect the full diversity of the population in each sample. Each study nevertheless contributes to the overall picture (Allmark, 2004).

In addition, subdividing our data into different age categories (i.e., stages of adolescent development) may be arbitrary, given the lack of scientific consensus regarding the applicable age ranges; moreover, these ranges depend on the theoretical paradigm of the study (e.g., biological, cognitive, social, or emotional) as well as on culture and context (Sawyer et al., 2018). It remains to be explored whether patterns and sequences that apply to the general population can indeed be applied in a similar fashion to individuals with PIMD. Nevertheless, the categorization of our data into the various stages of adolescent development allows for a better understanding of the experiences and needs of families raising adolescents with PIMD, thereby contributing to the theoretical knowledge of these families, and substantiating their needs for support.

A final limitation is that this study took place during the COVID-19 pandemic. This may have affected the rate of participation, as previous studies have indicated that the relatives of children with disabilities experienced more stress and less social support during this period (Grumi et al., 2021; Willner et al., 2020).

Implications for Practice

The knowledge generated by this study could be used to improve the support provided to families with adolescent children with PIMD. Public authorities (e.g., health insurers, local authorities) should respond to the needs of these families and forge improved relationships with them by ensuring better communication and provision of information, thus enhancing mutual understanding and trust. Additionally, to improve the societal participation of families with children with PIMD, local and other authorities should make public areas more accessible. Desirable changes would include improving wheelchair accessibility and installing changing areas in public restrooms that are equipped to provide care for larger children and adults with PIMD who require lying-down assistance. Moreover, the establishment of specialized regional transition clinics for PIMD could offer an integrated approach tailored to the specific needs of families during the transition to adulthood, including assistance with transferring care from paediatric to adult health care settings. Finally, based on the results of this study, we recommend adopting a life-course approach, one that proceeds from a transdisciplinary and lifelong perspective (i.e., with no boundaries related to age and/or discipline), to the development of support facilities for families with children with PIMD. Such efforts should devote specific attention to issues and needs associated with the adolescent phase (e.g., the transfer from paediatric to adult care).

Implications for Research

Further research is needed to either confirm the presence of shared family perspectives with regard to the results of this study or to establish the existence of unique perspectives based on family roles (e.g., mother, father, siblings) or cultural background. In light of our results, future studies should also address the provision of support that would foster cooperation between parents and health care professionals in encouraging adolescents with PIMD to become more actively engaged in everyday life. In addition to meeting the needs of parents, this could enhance the quality of life for individuals with PIMD. Follow-up research is also needed to identify the best way to support these families in terms of future care planning. The families in our study had experienced several problems in this area, including having difficulty in finding the necessary information and in discussing this topic within their networks [i.e., family members and friends]. They also expressed a need for additional support.

Finally, all future research addressing the families of adolescents with PIMD should proceed from a family-centred, strengths-based, longitudinal perspective. Such a perspective is consistent with current views on providing support to these families by establishing positive partnerships, building on the knowledge and strengths of various family members, and seeing them as resourceful and resilient, rather than emphasizing problems and pathology (Kuo et al., 2012; Lahaije et al., 2024; Walsh, 2003).

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Appendix A

Interview Protocol

Before the Interview

- approach participant by email
- make an appointment
- confirm appointment and send information brochure
- in case of online interview: have the participant sign online consent form
- in case of live interview: print consent form

During the Interview

- prepare recording equipment
- ensure quiet environment, e.g. phone on quiet mode

Good morning/afternoon, before we start the interview I would like to have your permission to record it. During the interview I will also make notes. You may have read all the information in the information brochure, but I would like to reaffirm that everything you say will be completely anonymous. Do you consent to this interview being recorded?

- in case of live interview: have the participant sign the consent form
- start recording
- have the participant give oral consent

First of all, I would like to thank you kindly for your time. My name is (…) and I will be interviewing you today about the support of families like yours. This interview is part of the project <PROJECT NAME>. The goal of this project is to increase the well-being of families with a child with PIMD. This will be done by first finding out how the family quality of life of these families is formed (by questionnaires), and what their support needs are (by interviews such as this one). We will then use this knowledge to create products together with parents, other relatives, and care professionals that will help to increase the family quality of life. By what you tell us today, you will help us to create products that are specifically attuned to the wishes and needs of families like yours.

I am going to ask you questions about the support of your family in the past, present, and future. What matters is what is helping, or has helped you, but also what can be improved. You can also indicate that you do not need support for specific aspects, or instead that you have missed it. For every question you may think about your family as a whole, but also about individual members. For support you may think about formal support (physicians, nurses), but also informal support (family, friends), and what you have done for yourselves. There are no right or wrong answers. My goal is to limit the interview to one to one and a half hours, but we can always pause if you want to. Do you have any further questions?

Introduction

1. As an introduction: could you paint me a picture of your family? How should other people know you?

Past

2. Looking back, what has helped your family in terms of support in the past? You may think about what others did for you, but also what you did for yourselves.
3. Looking back, what could have been improved, or what did you miss, in the support of your family?

Present

4. What is presently helpful in the support of your family? What is going well?
5. What do you presently need, or could be improved, in the support of your family?

Future

6. What kind of support do you expect to need in the future?
7. Do you have any ideas for a product that we could develop? What is something you want or would have wanted?
8. Is there anything else regarding support needs you would like to share (for example something you can recommend)?

- end recording

Thank you kindly again for your time. What did you think about the interview? Do you have any suggestions to improve the interview?

Supplementary Topics

The following topics are (possible) factors that play a role in family quality of life, and in the support needs of families. Comments on one or more of these topics may be requested if they have not been mentioned.

- role of professionals (family-centredness, communication)
- support from family/friends/neighbours
- family interaction and communication
- coping skills
- personal norms and values (including religion)
- societal norms and values
- characteristics of child with PIMD
- specific needs of different family members

Appendix B

Subcategories and Subthemes by Domain

Domain subcategory	Subtheme	Explanation
System		
Administration/ bureaucracy	Information	Information on applications, personal budget, the Long-Term Care Act, etc.: Is it known? What is missing? Is it clear? Where is it? General information and topics that cannot be classified in any of the following subthemes.
	Governmental organizations	Positive and negative experiences with government agencies (including Zorgkantoor, Sociale Verzekerings Bank, municipality, care institution, health insurer): What is going well? What could be better? What is important? What problems are you encountering? Also: (a) how the system is set up; and (b) indications not addressed under "Support after birth or diagnosis", which may include eligibility criteria, procedural requirements, or specific needs that influence families' interactions with governmental organizations.
	Administration miscellaneous	Other issues concerning administration/bureaucracy. Also administrative burden in general.
Societal norms and values		Norms, values, comments, etc. from society about people with disabilities and about informal care. Societal perspective on disabilities.
Work		Employer attitudes towards intensive informal care and its impact. Ability or inability to find work. Why people do or do not want to work, and what is important in this regard.
Public facilities/ accessibility		Changing places, building accessibility, etc. Present or not, necessary or not.
Services		
Contact with care professionals	Family centredness	Do professionals see the whole picture? What do parents think is important and unimportant in this regard? Attention from professionals to individual family members.
	Parents as equals	That parents (and their knowledge) are or are not seen as equal to professionals. Why it matters.
	Central position	One person who has contact with all professionals/agencies. Key figure/central point of contact.
	Other experiences with professionals	Other experiences with professionals that do not fit any of the above subthemes.
Support after birth or diagnosis		Initial support and guidance after birth or diagnosis. What parents missed, or what helped them. Specifically addresses first steps/getting started. Co-pilots, home team, etc.
Environment		
Peer support		Contact with peers; their practical and emotional support or lack thereof. What you get, or not get, out of this. Who do parents see, or not see, as peers?

Domain subcategory	Subtheme	Explanation
Support from family/friends/ neighbours/ colleagues/ church, etc.		Contact with family/friends/etc.; their practical and emotional support or lack thereof. Also, how they cope with disabilities.
Family		
Parents and/or caregivers		Everything concerning parents and interrelationships within the family. What is or is not going well; what is and is not important.
Siblings		Everything concerning siblings within the family. Amongst other things, their role within health care. Also, problems with siblings.
Personal/family characteristics		Everything about perspectives on life, attitudes, personality traits, religion, prior knowledge, views of disability, etc.
Family dynamics/ communication		Communication and openness between family members. What choices have been made? What is going well? What is important?
Organization of tasks		Choices made within the family about the division of tasks. Also, choices concerning the division of hours of work and care responsibilities of parents.
Leisure/ family time		Everything concerning relaxation, holidays, and leisure time for the family, as well as for individual members. What is important, what is going well, and what is needed. Information on what there is and where to find it. For example: Villa Pardoes in the Netherlands.
Personal control		Making one's own decisions, maintaining control, assuming direction, etc. Being able to arrange one's life according to one's own direction/freedom. Wanting to take control, but also having to take control.
Finances		Everything concerning financial matters (that is not covered in subthemes above or below).
Care professionals in the home		Choices concerning professionals in the home, how and what. Why and why not.
Professional support		Support in the form of family coaches, relationship therapists, psychologists, social workers, etc.
Child with PIMD		
Diagnosis		Knowledge and information, or their lack, about the condition and its progress. Also, the diagnosis and how it came about.
Development		Everything concerning the development of the child with PIMD. Practical information: what is possible, where can it be found, etc. This focuses on what is offered to the child, not the natural development of the condition, which falls under the clinical picture.
Assistive devices		Everything concerning assistive devices: what there is, where it can be obtained, what it looks like, etc.
Adjustments in the home		Adaptations made in and around the house related to care (e.g., hoist, extension).
Transition to adulthood		Questions surrounding the transition to adulthood/18+: what needs to be arranged, housing, etc. Also, puberty.

Domain subcategory	Subtheme	Explanation
Daycare		Everything concerning day activities, child daycare centres, etc. Why parents made this choice, how they like it, what is happening, how it is set up, etc.
Overnight stay		Everything about overnight stays. Is there enough information about how to prepare? Why parents make this choice, etc.
Respite care		Needs concerning respite care. Why and why not, what form is preferable, whether enough information is available, etc.
Impact of care		Physical and/or emotional impact of care on personal health and on family, for matters not covered above.
Palliative care/ end-of-life decisions		Everything concerning palliative care and end-of-life decisions. Availability of good support, what choices were made and why, what is missing, what is needed. What is their QOL? Also, child comfort team.

Note. Based in part on ecological systems theory and the FQOL model developed by Zuna, N., Summers, J. A., Turnbull, A. P., Hu, X., & Yang, H. (2010). Theorizing about family quality of life. In R. Kober (Ed.), *Enhancing the quality of life of people with intellectual disabilities* [Social indicators research series, Vol. 41] (pp. 241–278). Springer Nature (Netherlands).