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# QUALITY OF LIFE OF TYPICALLY DEVELOPING SIBLINGS OF PEOPLE WITH PROFOUND INTELLECTUAL AND MULTIPLE DISABILITIES IN POLAND

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**Abstract:** Family quality of life (FQOL) is a concept that is gaining increasing importance in family support programmes. However, for some countries, this concept has been insufficiently explored in relation to families with children with intellectual and developmental disabilities. The aim of this study was to ascertain the perceived QOL of siblings of children with profound intellectual and multiple disabilities (PIMD) living in Poland. The study relies on a qualitative research approach. Semi-structured interviews were conducted with 18 siblings aged 6 to 15, followed by thematic analysis. The siblings identified the following nine domains as dimensions that impacted their QOL: joint activities, mutual understanding, private time, acceptance, forbearance, effect on well-being, exchanging experiences, social support, and dealing with the outside world. The children described both positive and negative experiences, indicating that having a sibling with intellectual and developmental disabilities affected their QOL in diverse ways.

**Keywords:** quality of life, siblings, children with profound intellectual and multiple disabilities, Poland, qualitative research, family studies

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A family is a community of individuals involved in complex interactions resulting from close social ties. Consequently, its respective members strongly influence the quality of family relations (Seligman & Darling, 2009). In fact, intellectual disability in a family member affects not only the person with the intellectual disability but also the family as a whole (Brown & Faragher, 2018; McHale et al., 2016; Petalas et al., 2015; Zaidman-Zait, 2020).

Most prior research on families of a child with an intellectual disability has mainly focused on the parents, while other family members have received less attention (Hodapp et al., 2017). In recent years, there has been a surge of interest in sibling research (Davys et al., 2016; Kruithof et al., 2020; Lee & Burke, 2018; Lee et al., 2019; Lindahl et al., 2019; Luijkx et al., 2016). However, sibling-centred research is still in its infancy, and further exploration is needed to do justice to the perspective of siblings of people with intellectual disabilities.

In the present study, siblings were queried on their experiences of having a brother or sister with profound intellectual and multiple disabilities (PIMD). Their feedback allowed us to determine their family quality of life (FQOL). The concept of FQOL captures the QOL of all family members and the QOL of the family system, as well as the mutual impact and interactions of family members (Poston et al., 2003; Summers et al., 2005; Turnbull et al., 2004). Within the family, the QOL of individuals is in constant interaction with the FQOL as a whole, each informing and altering the other (Zuna et al., 2018). In this dynamic interplay, the experience of disability in the family affects family members, their perceptions of their QOL, and their interactions with the community at large (Boelsma et al., 2018).

Existing research by Fleary & Heffer (2013) implies that there is extreme difficulty in maintaining consistency in the categorisation of the psychological well-being of children and adolescents with an ailing or disabled sibling across various sibling conditions. According to Luijkx, et al.'s (2016) study involving siblings of individuals with PIMD, having a brother or sister with PIMD affected their lives both positively and negatively. At the same time, these researchers found that both joint activities performed with a sibling with PIMD and moments of private time contributed to the QOL of typically developing children and adolescents. In addition, the cultural milieu also contributes to individual QOL (Schippers et al., 2015). Consequently, it seems imperative to study families of an individual with PIMD and the realities of their members' lives in diverse settings (Ravindran & Myers, 2011; Tsai et al., 2016). However, the literature review on siblings of people with intellectual and developmental disabilities conducted by Múries-Cantán et al. (2022) revealed a scarcity of published data bearing on QOL. This incongruence is all the more substantial given that most of the comparable studies have been carried out in Anglo-Saxon or Western European countries (cf. Múries-Cantan et al., 2023). Whereas this topic has received coverage in North and South American countries (Brown, 2016; Diener et al., 2015; Kao et al., 2012), Western Europe (Mouzourou et al., 2011; Todd et al., 2004), as well as Australia (Brown et al., 2004) and Asia (Chan & Lai, 2016), it seems understudied in Central and Eastern Europe.

Accordingly, the study at hand is aimed at bridging this gap by targeting the situation of the young siblings of individuals with PIMD who are based in Poland. This context seems all the more salient for the analysis of the issue of identity in individuals with a disability, as most such people in Poland live in family homes due to the dominant traditional family model (Krause et al., 2010). Alongside their parents, siblings play a major role in caring for and supporting children with PIMD (Hall & Rossetti, 2018).

The problematic state of existing research on siblings is further compounded by the fact that the participants of previous studies were recruited from among a heterogeneous group of siblings of children with different degrees of intellectual disability (Moyson & Roeyers, 2012). The mode of sibling interactions is conditional upon the severity of the brother or sister's disability (Stoneman, 2001). Recent studies indicate that different disability profiles or diagnoses impact the family system in distinct manners (Donley et al., 2018; McConkey et al., 2023; Mestre et al. 2024). This is also true for siblings (Hastings, 2016), highlighting the importance of focusing on specific subgroups of children. Therefore, research should predominantly target the relationship characteristics underlying the children's positive or negative adaptation (McHale et al., 2012). The rationale behind embarking on the study of children with PIMD is that they are fully dependent on others due to their low level of cognitive development (developmental age of less than 24 months) and their severe or profound motor dysfunction and sensory impairment (Nakken & Vlaskamp, 2007).

The aim of this study was to investigate how children with PIMD affect the life circumstances of a typically developing brother or sister. The study stands out against many previous efforts which harvested data from parents to shed light on whether and how having a sibling with PIMD affects the typically developing child's QOL (cf. Floyd et al., 2009; Walton & Ingersoll, 2015) in that it collects data on what the children themselves have to say. To get a comprehensive picture of their lives, the siblings of children with PIMD were asked to cite positive and negative facets of living with a brother or sister with PIMD. The central research question posed was: How do those 6- to 15-year-old (elementary school) brothers or sisters of children with PIMD living in Poland perceive and describe their QOL as siblings? The results of this study can expand the body of knowledge about the life circumstances of siblings of individuals with PIMD, which, in turn, can be acted on to provide better-targeted support to siblings of children with such disabilities.

## Method

Of principal interest in this study were the self-reported experiences of dealing with children with PIMD produced by their siblings themselves. The intention driving the research was to understand the richness and diversity of the experience of being a sibling from the sibling's own point of view (Corbin & Strauss, 2008).

***Participants***

The research data comprised information obtained from interviews with typically developing siblings of children with PIMD. Inclusion criteria included the age of typically developing individuals (between 6 to 15 years old) and having a sibling with PIMD. This age range corresponded to elementary and secondary school children.

The study relied on a partial convenience sample, with participants recruited in a variety of ways. Initially, subjects were recruited from families that had contributed to previous studies regarding the situation of families caring for people with PIMD in Poland. Families profiled as matching the requisites of the study received an email soliciting their participation. Twelve families were invited to participate in the study, all of whom agreed to participate. To reach out further, we approached one of the organisations working for people with intellectual disabilities in Poland with a request to spread the word about the study among its members (families caring for people with PIMD). The information sent to families included full details of the study and the profile of eligible candidates, and included a short questionnaire about the age and gender of the child with PIMD and their sibling, as well as the nature of the multiple disabilities of the former. Another six subjects were successfully enrolled in the study by drawing on the database of a facilitating organisation.

Table 1. *Characteristics of Participants and Their Siblings with Profound Intellectual and Multiple Disabilities*

| Sibling participant | Age | Gender | Relationship with the child with PIMD | Brothers/sisters with PIMD | Age |
|---|---|---|---|---|---|
| P1 | 6 | M | younger | sister | 9 |
| P2 | 7 | M | elder | sister | 5 |
| P3 | 7 | M | younger | brother | 11 |
| P4 | 6 | F | younger | brother | 9 |
| P5 | 8 | M | twin | sister | 8 |
| P6 | 9 | F | elder | sister | 7 |
| P7 | 11 | F | elder | brother | 8 |
| P8 | 6 | M | younger | brother | 8 |
| P9 | 11 | F | elder | brother | 10 |
| P10 | 10 | F | younger | sister | 14 |
| P11 | 7 | M | elder | brother | 6 |
| P12 | 12 | F | elder | brother | 10 |
| P13 | 11 | F | younger | brother | 14 |
| P14 | 12 | M | twin | sister | 12 |
| P15 | 14 | M | elder | brother | 11 |
| P16 | 15 | F | elder | sister | 11 |
| P17 | 11 | F | elder | brother | 9 |
| P18 | 15 | M | elder | brother | 13 |

A total of 18 participants (siblings of children with PIMD) were enrolled in this study. All participants were based in one of the provinces located in central Poland. The siblings recruited included an equal number of males and females, ranging in age from 6 to 15 years. In regards to the siblings diagnosed with PIMD, who were aged 5 to 14, the brothers ($n$ = 9) outnumbered the sisters ($n$ = 7) by a small margin. As for the parents, 14 of them completed the received questionnaire. Four parents refused to complete the questionnaire but agreed to their child's participation. In two cases, the refusal was justified by a reluctance to share information about their family. In a further case, parents claimed that they were concerned about being identified by people in the community. In one case, no reason was given for the refusal. The respondents were mothers ($n$ = 10) and fathers ($n$ = 4). The sociodemographic characteristics of the study participants and their families are detailed in Tables 1 and Table 2.

Table 2. *Family Demographics*

| Characteristic | No. of parents ($n$ = 14) |
|---|---|
| Age | |
| 30–40 | 2 |
| 41–50 | 10 |
| 50–60 | 2 |
| Gender | |
| Woman | 10 |
| Man | 4 |
| Relationship with the participant who is a sibling | |
| Biological mother | 10 |
| Biological father | 4 |
| Family type | |
| Marriage with 2 children | 9 |
| Marriage with 3 children | 5 |
| Education level | |
| Elementary education | 1 |
| Vocational education | 6 |
| Secondary school education | 4 |
| Higher education | 3 |
| Employment | |
| Full-time or part-time employment | 4 |
| None (social welfare allowance) | 10 |

### *Data Collection*

Before the study, a pilot study was carried out on a sample of two interviewees to validate the relevance of the method for the study objective and to test sibling interview instructions. Accordingly, slight modifications were made to the original version of the interview instructions.

A semi-structured interview schedule was developed to help guide the discussion in the study proper. Incorporated in the schedule were the author's previous research experiences, as well as the expertise of fellow researchers and the literature on the subject (Kruithof et al., 2020; Lee et al., 2019; Lindahl et al., 2019; Luijkx et al., 2016; Moysona & Roeyersa, 2012).

Between June and October 2019, semi-structured interviews were conducted with participating siblings of people with PIMD (one interview was conducted with each interviewee). They were asked to recount how their lives were affected by having a sibling with PIMD. The researcher covered the same themes with each participant, opening the interview, introducing himself, and presenting the most crucial information related to the study. However, the interview proceeded in a manner suitable for the needs and age of the participants, and the interviewees were allowed to speak freely. The interviews lasted between 45 and 90 minutes and were conducted at the subjects' homes. In total, 18 interviews were conducted.

The conversations were not limited to predetermined topics only. In order to get more nuanced answers (Clarke et al., 2015), all questions were open-ended. Meanwhile, a number of more detailed prompts were included in the interview instructions to help direct the discussion as required. It was admissible for younger children to draw, play games, and have access to toys and other conversation-stimulating incentives (Cameron, 2005). In addition, some parents helped the children get ready for the interview, offered emotional support, and coached their children about the interview topic (Irwin & Johnson, 2005). Each interview began with an opening question designed to make participants feel at ease and able to express themselves. Moreover, a closing question designed to end the session on a positive note was also incorporated.

***Data Analysis***

All interviews were audiotaped and transcribed verbatim. The transcripts were analysed thematically in NVivo 12 (Miles et al., 2014). Nvivo, which the author considered to be a particularly straightforward, faster, and visually appealing method of coding data, was used to assist with the organisation and enumeration of the instances of codes and themes. Transcription of the interviews began immediately after the onset of the data collection process. Some of the notes made during transcription influenced and helped refine subsequent interviews with other participants. Particular questions were reworded. Some were treated as more substantial than originally thought. Reflections and field notes drafted after the interviews were also brought into consideration. This material served to enrich the interviews with relevant information.

The researcher used a line-by-line approach to open-code each piece of text, comparing each data unit to previously coded data to ensure it represented a novel idea (Creswell, 2013). The researcher compared codes and developed a codebook. Upon reaching this point, the article by Moyson and Roeyers (2012) was drawn upon for further analysis. The article stood out as a salient backdrop to the current research, consolidating previous work on the QOL of siblings of children with intellectual disabilities. Thereupon, the results of the study at hand were revisited and arranged into nine domains of sibling QOL.

The analysis used a multistage open and axial coding process guided by the constant comparative method (Strauss & Corbin, 1990). The method of constant comparison was used comprehensively, specifically comparing all data to emerging codes and organising the latter into categories (Creswell, 2013; Creswell & Creswell, 2020, 2022). This allowed the inductive data analysis process to be systematic and rigorous. During this process, the main findings and their interdependencies were discussed by the author with other researchers who assisted the study author at various stages of the research and analysis process as consultants and advisors. Coding compliance among the outcomes obtained by the author and fellow investigators was analysed using the NVivo Coding Comparison Query tools. The discussions served to recode the data and refine previously generated codes, categories, and themes.

### *Ethical Considerations*

Ethical clearance was obtained from the research ethics committee at the University of Lodz prior to the commencement of the study. The consents and assents obtained concerned both previous research and the information derived from it, which was used in the recruitment of participants for the current research, as well as the NGO-facilitated participant enrolment. The reported procedures complied with the World Medical Association's Code of Ethics (Declaration of Helsinki) bearing on research involving human subjects. All study participants and their legal guardians were briefed about the study design and their rights, including the right to withdraw from the study at any time. Prior to the interview, participants were presented with informed consent and assent forms advising them that any participation was voluntary and that they could discontinue or skip any questions at any time for any reason. Since the participants had not yet reached the age of 18, apart from their assent, an additional written consent of at least one parent was obtained.

All data have been anonymised to protect the confidentiality of participants. The data anonymisation was ensured by permanently deleting all names, surnames, proper names, and the like, or by replacing such information with other data that rendered it impossible to identify the interviewees.

## Results

Research results have been arranged around the nine domains of the QOL of siblings as described by Moyson and Roeyers (2012): (a) joint activities; (b) mutual understanding; (c) private time; (d) acceptance; (e) forbearance; (f) effect on well-being; (g) exchanging experiences; (h) social support; and (i) dealing with the outside world.

All quotes from the interviewees were originally in Polish and were translated into English for publication purposes. During translation, the meaning of the interviewees' statements was preserved, but minor language corrections were made.

The domain with most participant mentions was joint activities. The children described how they spent time with their brother or sister with PIMD and reported the accompanying experiences. Most siblings ($n$ = 12) talked about joyful moments and activities shared with their brothers or sisters:

> Whatever we do together always brings me joy. I enjoy every moment we can spend together, for example, when we play or watch TV. (P7)

Siblings appreciated opportunities to pursue activities together with their brothers or sisters. To put this in perspective, the majority of siblings ($n$ = 10) saw themselves as having to accommodate the needs of their brothers or sisters when engaging in joint activites:

> She [sister] can't just ride a bike, but we do have a special cart that we hook up to the bike, and then we can pull her and go on a trip together. (P10)

At the same time, almost all the siblings interviewed ($n$ = 15) reported that some activities were impossible to undertake with their brothers or sisters. Many ($n$ = 11) described feeling sad when they were unable to share these activities with their brother or sister:

> I would very much like it if we could always be together, but it is impossible. And this is very sad. (P6)

Most siblings followed up on that response by indicating that they strive to be forgiving in situations involving specific activities they cannot do with their brothers or sisters. However, some siblings ($n$ = 8) admitted that they sometimes get angry about being unable to do certain things because their brother or sister with PIMD would be unable to join in:

> Ultimately, it is simply impossible to do some things together. For example, we can't take her out for shopping because she quickly gets upset and starts crying. I don't like it because then we can't do anything. (P14)

***Mutual Understanding***

Many participants ($n$ = 15) described one or more situations in which they could clearly comprehend what their brother or sister wanted, meant, or felt. The interviewees went on to elucidate that they knew how to communicate with their sibling and could tell what made them happy or sad. Some suggested that they owed such insights to a genuine mutual bond:

> I understand her very well. All I have to do is take a look at her, and I know what she wants at any given moment. This is the kind of bond that unites us. (P16)

Equally many participants ($n$ = 15) admitted that they sometimes found it difficult to understand their brother or sister and could not figure out what he or she meant or wanted:

> When she is sad or in tears, I can't just ask her: What's going on? She won't understand. (P5)

Notwithstanding the above, a decisive majority of the interviewees ($n$ = 12) had developed their own ways of communicating with their brothers or sisters, often by means of specific words, gestures, or facial expressions, and sometimes by means of special pictograms:

> We have our own language and our own way of communicating. This works best. Although others don't understand us then [laughs], but my sister and I understand one another perfectly. (P6)

***Private Time***

The vast majority of the participating siblings ($n$ = 14) emphasised the importance of spending time with their brother or sister with a disability. Nevertheless, some of them were open about also enjoying time away from their brother or sister:

> Yes, it's nice when I can be with my brother. He is so sweet, and we understand each other well. But I also want to be alone sometimes, to have some privacy and time just for myself. (P9)

In many cases, participants ($n$ = 13) recalled situations when a brother or sister was not present at home, away either for rehabilitation or at a community daycare centre, leaving their siblings free to spend some time only with their parents:

> When my sister is away from home, I can spend some time with my parents. I really like it then. We can finally do something that we typically don't have the chance to do when my sister is with us. (P6)

Several interviewees ($n$ = 7) clarified that they cannot always do what they want because of their brother or sister's disability. Furthermore, two of them complained about missing more frequent contact with their parents and wished it were possible to receive greater attention from them:

> I am well aware that my parents need to pay more attention to my brother. He cannot take care of himself. But sometimes I wish they would spend a little more time with me too. I miss that. (P11)

### *Acceptance*

Learning to accept that a brother or sister is different emerged as a significant theme in most of the participants' statements ($n$ = 13):

> I already have some experience. I know what it's like and how difficult it is sometimes to come to terms with having a disabled sibling. But if you don't go ahead and just accept the way it is and that there's nothing you can do about it, you'll only make yourself more and more miserable and, most likely, depressed. (P18)

Many participants ($n$ = 12) also indicated that being able to accept their brother or sister's disability helps them not only to cope with different situations but also to benefit from them to some extent:

> Having to learn [to deal] with the fact that you have a disabled sibling is one thing. But sometimes there are upsides too, that is, to having just such a sibling. For instance, you can take advantage of various additional forms of assistance, but also, in practice, you can get something done almost everywhere free of turn, without waiting. (P17)

However, in spite of their acceptance of their brother or sister's disability, some interviewees ($n$ = 6) emphasised that there are times when it is challenging to be a sibling of a person with PIMD, which can cause distress and feelings of sadness:

> When my friends talk about all the things they have done together with their brother or sister, I cannot take part in the conversation. I can't do these things with my sister, and then I feel sad. (P2)

### *Forbearance*

The interviewees typically mentioned that being a sibling of a brother or sister with PIMD requires much patience and being calm and collected in various situations. They also stressed that they had learned how to retain composure over the years, even under challenging circumstances:

> I have become accustomed to his exceptional behaviour. That's just the way it is most of the time, and not much can be done about it. There's nothing to get upset about because, after all, he doesn't do it on purpose or out of spite. (P3)

Nevertheless, many participating siblings ($n$ = 14) described one or more situations in which they found it difficult to cope with their brother or sister's behaviour:

> I think I can handle many situations, although it's not always easy. Sometimes, however, he is so annoying that I'm starting to lose it. (P13)

Several interviewees ($n$ = 5) noted needing more patience and self-control than siblings of brothers or sisters without a severe disability. They specifically noted that adapting to their brother or sister's needs could sometimes be difficult:

> Usually, everything is fine, but sometimes I don't know how to cope. He won't understand me the way I want him to, even if I keep telling him something repeatedly. (P8)

### *Effect on Well-Being*

The participants were likely to express concern about their brother or sister's physical and mental state. A significant proportion ($n$ = 13) also shared how they are affected by the mood and well-being of their brother or sister:

> It's very important for me that X [brother with PIMD] feels his best. Whenever he is smiling, I can smile as well. (P12)

The interviewees ($n$ = 8) were equally concerned about their brother or sister's health. Several of them ($n$ = 5) brought up feeling sad that their brother or sister was excluded from certain activities and pursuits due to their health or their psychological or physical limitations:

> It's painful, and I can't get over it if I can't take her [sister with PIMD] somewhere. I know she can't join us, but it's sad when that happens. (P1)

Some interviewees ($n$ = 5) indicated that the well-being of their brother or sister was important to them, and that they were willing to take specific measures to improve it as far as possible given the limitations imposed by their sibling's condition:

> My brother cannot do many things that I and others can. But I try to make sure we can do as many things together as possible, even if it's not that straightforward. When I see how happy he is and how he is enjoying himself, that is the greatest joy and the greatest reward for me. (P12)

### *Exchanging Experiences*

Only a few of the siblings surveyed ($n$ = 4) mentioned that they knew other people who also had a brother or sister with PIMD. Only two of the siblings reported a willingness to meet such individuals:

> I haven't had the opportunity to meet other siblings, but I think if I did, I could talk to someone who has a similar situation and just enjoy being understood. (P14)

The participants who already knew others with a brother or sister with a disability confirmed that such friendships foster sharing experiences. They also made a point of benefiting from acquaintance with other siblings of people with PIMD; they appreciated the opportunity to share

advice and useful information with them, and even gain a better understanding of matters relevant to their common situation while accepting and looking at things from a different perspective:

> I went on rehabilitation holidays together with my parents and my brother, and once there, I got to know other children who had disabled siblings. And we would play together, but I also had the opportunity to talk about things and even to observe how they were getting on with their brother or sister. (P15)

***Social Support***

Since parents are typically closely involved in almost every family situation, they were seen as a go-to source of support and assistance by the majority of the interviewees ($n$ = 11). At the same time, some participants ($n$ = 7) — while acknowledging that their brother or sister required more attention or care from their parents — nevertheless felt that parents should endeavour to treat all their children equally:

> My parents are always attending to X [sibling with PIMD], and understandably so as he requires a lot of care and time to be taken care of. But I think parents should pay attention to all their children and treat them the same way. (P11)

The participating siblings indicated how important it was for them to have another typically developing brother or sister. Three interviewees explained that they felt fortunate to have a "normal" sibling with whom they could share their impressions and experiences, but also their responsibilities:

> I feel empowered to have another healthy brother to spend time with, who understands me like no one else and with whom I can do things together. (P9)

Meanwhile, other subjects ($n$ = 2) spoke of the sadness associated with not having a typically developing brother or sister:

> Sometimes, I feel sad that I don't have one more sister or brother to play with like other children do with their siblings. (P6)

Several interviewees ($n$ = 6) also pointed out the high importance of having supportive friends. A small number ($n$ = 5) disclosed reliance on support from their extended families — grandparents and, in one case, cousins:

> I am particularly lucky that my grandparents live close to us and are involved in looking after X [brother with PIMD]. But they also attend to me and play with me and help me with my homework. (P11)

None of the participants mentioned having received professional assistance, which may be due to the fact that aid such as counselling is not readily available in Poland for siblings of people with PIMD.

### *Dealing with the Outside World*

The participants were exposed to responses to their brother or sister from the outside world. For some of the interviewees ($n$ = 9), the outside world and its failure to grasp the nature of their brother or sister's disability were sources of stress:

> When we go out for a walk with her, people really stare at her and at us. This is very upsetting, and it makes me feel really bad. (P10)

Several subjects ($n$ = 7) recounted various types of experience encountered during school time. Some spoke of positive relationships with peers, while others reported that some fellow students refrained from contact with them:

> My schoolmates know me and my brother. They treat me in an ordinary way and do not make me uncomfortable because of my brother. (P15)

> Occasionally, people whom I didn't know so well, but who knew that I had a disabled sibling, simply avoided me and kept at a distance. (P10)

## Discussion

The primary focus of this study was to investigate how individuals with PIMD affect the life circumstances of a typically developing brother or sister. To achieve this end, it was pivotal to obtain information on perceptions of their QOL from siblings of people with PIMD.

This study contributes to the literature on the subject in several respects. As most previous studies on the QOL of siblings have relied on indirect information from caregivers (predominantly parents), the outcome of the present study, in which siblings were interviewed directly, provides an added value for investigating FQOL. Our methodological choice is validated by the suggestions of Barak-Levy et al. (2010), who ascertained that confining the protocol to posing questions to children elicits relevant and useful information concerning their own experiences. Despite their tender age, the interviewed children and adolescents related internal experiences, casting light on their quality of life in the context outlined in this article. Thus, in accordance with previous research, they bore testimony to the fact that it is desirable to collect the opinions of all family members: everyone can have slightly different perceptions of other members and entertain a different view of their quality of life (Francisco Mora et al., 2020; Gardiner & Iarocci, 2015; Luijkx et al., 2016; Wang et al., 2004).

This study contributes to the literature on the QOL of siblings of children with disabilities by bringing to the fore the circumstances of siblings of children with PIMD in a Central European country. Previous research findings show that siblings' QOL is influenced by specific social contexts and cultural values, as manifested by social attitudes towards disability and social reactions to people with disabilities. Smilar experiences to those of the participants in me study were reported by siblings in the study by Múries-Cantan et al. (2023), who reported encountering

stigma in the form of strangers' stares or disrespectful behaviour towards people with disabilities.This study also reveals that the QOL of siblings of people with PIMD was closely linked with their status within the family and with the support they received from family members. The results thus substantiate the observations made by Boelsma et al. (2017), who found that lack of support and attention from their extended family and the local community negatively affected the FQOL of familes having one or more children with an intellectual or developmental disability. However, a sound rapport within the immediate family, and a positive role played by the extended family proved vital for siblings, a finding also recognised in studies conducted in other European countries (Mouzourou et al., 2011; Múries-Cantan et al., 2023).

One of the domains most often referenced by the siblings was "mutual activities", showcasing the relevance of being able to spend time with a brother or sister with PIMD and achieve a successful interaction. However, the study reveals a discrepancy between what siblings would like to do with their brother or sister and the activities they can actually pursue. This is in keeping with the studies by Moyson and Roeyers (2012) and Luijkx et al. (2016), in which siblings complained that they were sometimes unable to follow their activity of choice with their brother or sister due to the latter's disability. Nonetheless, as Eiser et al. (2000) observed, people scale down their expectations to what they perceive as possible and thus can maintain a reasonable QOL even under adverse life circumstances. The same was true for the interviewed siblings of children with PIMD. The participants disclosed that they were trying to bridge the gap between experiences and expectations by adapting to the disability, coping with specific experiences, and learning to accept their brother or sister's limitations.

A further notable conclusion of this study concerns the domain of "mutual understanding". Children with PIMD use specific expressions for communication, such as vocalisations, body movements, and facial expressions, along with more subtle signals (Hostyn & Maes, 2013; Nakken & Vlaskamp, 2007). The evidence from this study suggests that siblings can understand their brother or sister's behaviour and communication intentions. This aligns with the findings of a study by Nijs et al. (2016). Although the siblings were adept at comprehending and accommodating the ability level of their brother or sister, they also pointed out that it was sometimes difficult for them to accept his or her disability. Likewise, Luijkx et al. (2016) found that siblings reported struggling to accept their brother or sister's disability because of the associated disadvantages. It should be kept in mind that this disapproval did not typically seem to originate from an incapacity to come to terms with the brother or sister's disability, but rather corresponded to the outside response the disability elicited. Indeed, a consensus emerges from both previous studies and the present research as to the malleability and evolution of acceptance approaches over the course of a sibling's life (Hayden et al., 2023).

In contrast to a study by Moyson and Roeyers (2012), the siblings interviewed in this study rarely mentioned exchanging experiences with other siblings of children with disabilities, or participating in activities dedicated to minors in similar situations. Nonetheless, these findings are in line with research conclusions reached in the studies by Luijkx et al. (2016), Múries-Cantan et

al. (2023), and Nijs et al. (2016). What holds relevance for the participants of this study is the relatively small number of support programmes in Poland dedicated to siblings of people with PIMD. However, this problem is not specific to Poland but occurs in other countries as well, including those of the Benelux Union as Okma et al. (2015) emphasised in their study.

Overall, these results indicate that the interviewees recounted both positive and negative experiences of having a sibling with PIMD. Negative experiences mainly concerned practical matters, such as the inability to perform certain activities with a brother or sister, which is consistent with the study by Luijkx et al. (2016). This study's participants also reported that their brother or sister's disability could trigger negative responses from the outside world, illustrating a dynamic proposed in a study by Stalker and Connors (2004). Nevertheless, the current study manifests that the interviewees were eager to embrace many aspects of life that were potentially affected by having a brother or sister with PIMD. Furthermore, for some typically developing siblings, these factors may even prove favourable to their well-being.

An issue not to be overlooked is the socioeconomic status of the family, which can affect the outlook of the family as a whole, and thus the relationships among family members, including between siblings (see Ben-Arieh & Frones, 2007). The data pertinent to the families involved in this study revealed that the majority of parents were unemployed and dependent on allowances. Emerson et al. (2010) showed that the socioeconomic circumstances of families have a direct impact on the QOL of parents of children with early cognitive delay; one can assume that the same is true of siblings of people with PIMD, although that claim falls outside the scope of this research. Finally, it is worth noting that some issues identified in the QOL literature, such as physical and mental well-being, moods and emotions, self-perception, autonomy, and relationships with parents, failed to emerge in this study and were not unequivocally referenced by the siblings of people with PIMD. The absence of some themes in the interviewees' accounts only serves to support the conclusion reached in other studies: that children's perspectives on QOL are narrower than those of adults (Eiser & Morse, 2001; Bat-Chava & Martin, 2002; Guite et al., 2004; Houtzager et al., 2004; Houtzager et al., 2005).

### *Strengths and Limitations*

The core strength of this study that it gives precedence to the siblings of individuals with PIMD, whereas many previous studies relied exclusively on information from parents (cf. Floyd et at., 2009; Walton & Ingersoll, 2015).

There are also certain limitations with respect to the applicability of the findings presented above. First, only a small sample size was examined. A larger sample could have broadened the scope of the findings; the sample size was insufficient for generalisation of the study's conclusions. Second, the interviews were conducted with the siblings of people with PIMD, with the result that the conclusions do not directly apply to people who have a brother or sister with another type of disability. It should, therefore, be kept in mind that siblings of children with other disabilities will not necessarily follow the same pattern in determining their QOL. Third, this was an interview-

based study, based on discussions that were presumably influenced by contextual factors that cannot be replicated or generalised. Fourth, the study partly relied on a convenience sample drawn from an earlier study. Finally, the study was performed in Poland, and its results may not be relevant in other countries. It is therefore recommended that future studies on the QOL of siblings of children with PIMD be carried out in other countries.

Subject to these limitations, however, the results of this study complement those obtained by Moyson and Roeyers (2012), Luijkx et al. (2016), or Múries-Cantan et al. (2023). Furthermore, as Brown (2016) put it, if "the research is repeated in various situations in different countries and the results are similar, then the data should surely be taken seriously and acted upon" (p. 3). Therefore, the results of this study should be viewed within a broader context of growing knowledge of siblings' perceptions of their QOL. This research responds to the need for further research in the field of QOL and FQOL across diverse populations in multiple countries and situations (Brown, 2016).

***Practical Implications and Directions for Further Research***

The centrepiece of this study was the examination of the personal experiences of elementary school-age siblings of children with PIMD. It would be instructive for future research to follow up on the lives of the children participating in this study by interviewing them again at a later stage to see how their experiences evolve over time. It would also be worthwhile to repeat this study with siblings of children with other disabilities, such as autism spectrum disorder or a physical disability. Due to the specificity of various disabilities, we can assume that their siblings will define their QOL in distinct ways. More importantly, future research should offer guidelines on how to provide assistance to the siblings of individuals with PIMD. Thus, psychological measures and other forms of support that can have a protective effect on the development of siblings of children with PIMD should also be addressed in prospective research. Another area open to investigation is the ability of siblings of persons with such a disability to explicitly and directly express emotions. Still other aspects to be considered include the development of parental sensitivity and the establishment of an appropriate parent–child relationship. It might also be of interest to consider the ways in which specific characteristics of people with PIMD impact the feelings and QOL of their siblings (see, e.g., Fleary & Heffer, 2013). Exploration in these areas would not only complement existing research but would also allow for a more holistic view of the family and its members as coexisting and interdependent on each other.

The findings of this research also have important implications for families, siblings, and children with PIMD. The siblings require information, training, and access to individual assistance just as much as parents do (Hall & Rossetti, 2018). The results of this study show that the QOL of siblings can be improved by allowing them to develop the skills to interact with their brother or sister, understand them better, and cope with the reactions of the outside world. Several studies have previously highlighted the importance of support groups and workshops for siblings of children with intellectual disabilities (e.g., Dodd, 2004; Lobato & Kao, 2002; Naylor & Prescott,

2004; Smith & Perry, 2005). This study supports the argument for the importance of offering professional help and social support to siblings of people with PIMD. It is imperative to provide more diverse and adequate fallback options for siblings of persons with PIMD; for stability, that support should be based on systemic solutions undertaken by state institutions and non-governmental organisations (Nijs et al., 2016).

### *Conclusion*

The study of sibling QOL provides insight into the experience of being a sibling of an individual with PIMD. It affords a more accurate description of the impact that a child with PIMD has on their siblings. This focus on QOL can serve to assist siblings as well as to extend and evaluate sibling and family support programmes. Typically developing siblings are more likely to contribute positively to the QOL of their parents and brothers and sisters with PIMD if they receive adequate support. Sealing the argument for attending to the needs of typically developing siblings of people with disabilities is the attested fact that doing so increases the likelihood that such siblings will be eager to play a part in the lives of their disabled brother or sister not only now, but also in the future (Boelsma et al., 2017; Boelsma et al., 2018; Luijkx et al., 2016).

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