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"I love my sister, but sometimes I don’t": A qualitative study into the experiences of siblings of a child with profound intellectual and multiple disabilities

Jorien Luijkx, Annette A. J. van der Putten and Carla Vlaskamp

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ABSTRACT

Background Many previous family quality of life studies have relied on parental information for understanding if and how having a sibling with profound intellectual and multiple disabilities (PIMD) influences the sibling’s quality of life. In the current study, children had the opportunity to describe both positive and negative aspects of having a sibling with PIMD.

Method Photo elicitation interviews were conducted with 18 children (6–13 years old) and thematically analysed using the following domains: joint activities, mutual understanding, private time, acceptance, forbearance, trust in wellbeing, exchanging experiences, social support, and dealing with the outside world.

Results Overall, the children described both positive and negative experiences, indicating that having a sibling with PIMD influenced their quality of life in multiple ways. Most mentioned were experiences classified in the joint activities domain.

Conclusion Having a sibling with PIMD influences the life of the interviewed children both positively and negatively. Both the opportunity for shared activities with the sibling with PIMD and moments of private time are important for sibling quality of life.

Introduction

International human rights conventions state that children with disability have equal rights concerning family life as children without disability (United Nations, 2006). Family systems theory describes families as interactive, interdependent, and reactive: if something happens to one member of the family, it affects all family members (Seligman & Darling, 2009; Turnbull & Turnbull, 2001). As the majority of children with an intellectual disability (ID) are raised at home by their family, a child with an ID not only influences the wellbeing of the main caregiver(s) (both positively and negatively; Hastings & Taunt, 2002) but also affects the other family members (such as siblings) and the family as a whole.

In the last decade, the conceptualisation of family quality of life (FQOL) has received considerable attention in developmental/ID research. The concept FQOL describes the quality of life of all family members and the quality of life of the family system, and how family members interact and influence each other (Poston et al., 2003; Summers et al., 2005; Turnbull, Brown, & Turnbull, 2004). It is important to understand the influence of a child with an ID on his/her family (life), and this information can be used as an outcome for policy and services. Although there is still some lack of conceptual clarity regarding FQOL (Perry & Isaacs, 2015), several studies have been executed to gather information on FQOL (Brown et al., 2006; Summers et al., 2005). In these studies, the parents or main caregivers were asked to describe their family’s quality of life on behalf of themselves and other family members such as siblings (Brown, Anand, Fung, Isaacs, & Baum, 2003; Hoffman, Marquis, Poston, Summers, & Turnbull, 2006). Siblings are important persons in the lives of their brothers and/or sisters. Sibling relationships are likely to be the longest of family relationships (Cicirelli, 1994), and also when one of the children has an ID. In adulthood, many siblings stay involved in the lives of their brother or sister with ID, and often take on caring roles, especially when parents are no longer able to (Ormsdor & Seltzer, 2000). This makes the wellbeing and involvement of the sibling in the life of a person with an ID very important.

A diverse range of studies have focused on the wellbeing of siblings of children with ID. In a meta-analysis on the functioning of siblings of children with an ID, Rosciter and Sharpe (2001) stated as a main outcome a statistically significant but small negative effect for having a
sibling with ID. Previously conducted sibling studies have used several methods for accessing the experiences of siblings, namely, by parent reports and sibling self-reports. The FQOL studies (Brown et al., 2006; Hoffman et al., 2006) have incorporated parental views of the experiences of the sibling of a child with ID, as have other studies (Rossiter & Sharpe, 2001). This is odd, as research has also shown that siblings and parents have a different view on the influence of a child with ID on his/her sibling (Guite, Lobato, Kao, & Plante, 2004). In studies where siblings were the primary informants, children were more positive in their self-reports about their relationships with their sibling with a disability than their mothers in parent reports (Guite et al., 2004).

The difference between parent reports and sibling self-reports highlights the importance of asking siblings directly about their experiences too. In several studies into sibling experiences the premise that having a sibling with a disability must be negative or bad for children has been questioned (Hastings & Taunt, 2002; Stoneman, 2005). This supports the view that siblings are not or not only impacted negatively by having a brother or sister with a disability, but also benefit (Taunt & Hastings, 2002). Cuskelly and Gunn (2003) stated that sibling relationships involving a child with a disability may be even more positive than those between comparable siblings. Their study revealed that siblings of a child with a disability showed less unkind behaviour, and more positive sibling interactions were reported (Cuskelly & Gunn, 2003).

Another point of attention is the target group used in sibling studies and the influence of characteristics of the child with ID on the experiences of the sibling. Many sibling studies have used a heterogeneous group of children as participants; for example, siblings of children with all severities of ID (Moyson & Roeyers, 2012). Other studies have focused on a very specific group, or compare several target groups. Ormond and Seltzer (2007), for example, showed that adult siblings of persons with autism experience less emotional closeness than adult siblings of persons with Down syndrome. The results of this study suggest that siblings of children with a disability cannot be seen as one homogeneous group.

It is important to know how the experiences of siblings vary across different disabilities (Stoneman, 2005), especially when the disability is more severe. Parents of children with intensive supports need to spend more time and effort in taking care of their child with a disability (Curran, Sharple, White, & Knapp, 2001), which can result in less attention for the typically developing child. Furthermore, the way siblings interact and play with each other also depends on the severity of the disability for a substantial part (Stoneman, 2005) and therefore colours the experiences of a typically developing child. Children with profound intellectual and multiple disabilities (PIMD) are dependent on others in all aspects of daily life, because of their low cognitive level (developmental age below 24 months) and their severe or profound motor disabilities and sensory impairments (Nakken & Vlaskamp, 2007). Therefore these children have little or no apparent understanding of verbal language and may use other means of communication, such as sounds or body language (Hostyn & Maes, 2013). This combination of severe disabilities makes raising a child with PIMD a highly intensive and lifelong task and a target group that is highly vulnerable (Tadema & Vlaskamp, 2010). Siblings of children with PIMD should therefore be seen as a distinctive group of siblings.

It is, however, unclear how (young) children with this combination of severe disabilities influence the lives of their siblings (either positively or negatively). In the current study, we asked siblings of children with PIMD to describe positive aspects as well as negative aspects in order to get a comprehensive view of their lives as siblings of children with PIMD. This study focuses on outcomes for young siblings (between 6 and 13 years old) of children with PIMD. We define outcomes as impacts (either positive or negative) experienced by the siblings as a result of having a brother or sister with PIMD.

In this study the main question is: How do children without disability experience (both positive and negative) having a brother or sister with PIMD? Insight into the impact that having a brother or sister with PIMD has for a child expands the knowledge about FQOL for this specific target group, which can be used in improving the support for parents and siblings of children with PIMD and can be a useful indicator of outcomes of policy initiatives on FQOL. Research into the positive and/or negative experiences of siblings of a child with PIMD is also important because of the future role of these siblings in the lives of their brother or sister with PIMD. Childhood experiences might influence the way these persons fulfil their future caregiving role and continuing involvement in the lives of their brother or sister with PIMD, especially when parents are no longer able to fulfil such a role.

Method

Participants

Inclusion criteria in this study were the age of the typical developing child (between 6 and 13 years old) and the type of disability of their sibling (profound ID and significant motor disabilities as described by Nakken & Vlaskamp, 2007). We used a convenience sample and participants were recruited in various ways. First,
families who participated in a previous study of the Research Centre on Profound and Multiple Disabilities, University of Groningen, the Netherlands, and met the inclusion criteria (n = 9) were contacted by email to ask for their participation, of which four families agreed to participate. Next, a support organisation in the northern part of the Netherlands agreed to select 25 families raising a child with PIMD (who received support from their organisation) who potentially met the inclusion criteria. They were asked to participate by mail. This resulted in two families who agreed to participate and met the inclusion criteria, 15 who did not respond, three families who did not want to participate, and five families who wanted to participate but did not meet the inclusion criteria. Finally, families were asked to participate by social media, 15 families self-administered to participate online and, after providing more information about the inclusion criteria, eight of these families actually participated.

From these families (n = 14), 18 siblings of children with PIMD participated in this study (for participant characteristics, see Table 1). In four cases, two siblings from the same family participated. All families consisted of two parents, and the ethnicity of all families was Dutch.

**Qualitative research design and photo elicitation interview**

Several studies indicate that young children are capable of being active research participants (Danby, Ewing, & Thorpe, 2011; Mandleco, 2013) and share accurate personal experiences (Pyle, 2013). In this study, we were interested in how children themselves describe their experiences with having a sibling with PIMD. We used a qualitative research design, as we were more concerned with exploring and understanding the richness and variety in experiences of being a sibling from the sibling’s own point of view than with producing a large standardised dataset. The experiences we were trying to access may not come to light in written surveys or more traditional words-only interviews; therefore, in this study, we chose to use the photo elicitation interview (PEI) method as described by Harper (2002) and Mandleco (2013). PEI is a method in which participants take photographs of their life and talk about those photographs in an interview. This method produces another kind of information, since the child’s memory is stimulated in different ways than through verbal-based interviews (Clark-Ibáñez, 2004; Mandleco, 2013). It also gives structure to the interview, creates a comfortable atmosphere, and lessens (some of) the awkwardness as there is something to focus on (Clark-Ibáñez, 2004). Because the children take the photographs themselves, they decide on the topics they want to talk about and this diminishes the power differential between interviewer and child (Pyle, 2013).

**Data collection**

Prior to the data collection in families with a child with PIMD, a pilot study (n = 8) was performed with siblings of children with a chronic disease (diabetes type 1) to test the suitability of the method for the current goal of the study and the instructions for the siblings, both with positive results (Dirks, 2014). Also, the research proposal of the (pilot) study was discussed and subsequently approved by the Ethics Committee of Pedagogical and Educational Sciences of the University of Groningen. After conducting the pilot study, the current study was carried out. A team of four interviewers carried out the interviews, and were prepared for interacting with families with a child with PIMD by studying families with PIMD, listening to audio recordings of home visits of the pilot study, and practising with open-ended questions.

The participating families were visited twice at home by the interviewer. During the first visit to the family, both the parent(s) and the participating sibling(s) were present. Considerable time was taken to get to know each other and for the family to get comfortable around the interviewer. The interviewer ensured the family understood the aim of the study and what was expected from the family and in particular the participating sibling(s). The interviewer explained that confidentiality and privacy were guaranteed, in accordance with the Ethical Principles Code of the Ethics Committee of Pedagogical and Educational Sciences (2012) of the University of Groningen. Thereafter, the assignment was explained

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Typically developing child (n = 18)</th>
<th>Sibling with PIMD (n = 14)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (in years)</td>
<td>M (SD) n %</td>
<td>M (SD) n %</td>
</tr>
<tr>
<td>6–7</td>
<td>9.1 (2.1) 3 16.7</td>
<td>9.3 (3.6) 3 16.7</td>
</tr>
<tr>
<td>8–9</td>
<td>8 44.4</td>
<td>8 57.1</td>
</tr>
<tr>
<td>10–11</td>
<td>5 27.8</td>
<td>5 35.7</td>
</tr>
<tr>
<td>12–13</td>
<td>2 11.1</td>
<td>2 14.3</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>9 50.0</td>
<td>8 57.1</td>
</tr>
<tr>
<td>Male</td>
<td>9 50.0</td>
<td>6 42.9</td>
</tr>
<tr>
<td>Position in relation to child with PIMD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Older</td>
<td>8 44.4</td>
<td>8 57.1</td>
</tr>
<tr>
<td>Younger</td>
<td>9 50.0</td>
<td>9 64.3</td>
</tr>
<tr>
<td>Missing</td>
<td>1 5.6</td>
<td>1 7.1</td>
</tr>
</tbody>
</table>
to the family. Because the concept of “quality” is hard to understand and/or difficult to explain to young children, the participating siblings were given the following assignment: “take approximately 15–20 photographs of moments you like to be a sibling of a child with PIMD and photographs of moments when you think it is tough to be the sibling of a child with PIMD.” The participating sibling(s) was/were asked to take photographs during the next week on two weekdays and two weekend days. All children used a camera available in their family. Parents were instructed to remind their child/children to take photographs during the agreed upon period, rather than suggest that certain images be photographed. The participating sibling received a copy of the photography assignment. Parents and siblings were informed that participating was voluntarily and that their privacy was guaranteed. Thereafter, parent(s) and the sibling(s) were asked if they still wanted to participate in the study, and if so, parent(s) gave their written consent and the sibling(s) gave their written assent. Finally, a second appointment for a home visit with the same interviewer was made between 1 and 2 weeks after the first appointment. During the second visit, the participating sibling was interviewed based on the photographs he or she took. The interviews were recorded and took place at the child’s home in a quiet location of their choice, to avoid disruptions and to allow the child to talk freely about his or her experiences. First, the sibling was reminded of the purpose of the interview. After this explanation, the sibling was asked to select the most important photographs (max. 10) he or she took, to ensure that the interviews were conducted with a manageable number of photographs. Then, the sibling was asked to identify each of the photographs and tell the interviewer why the photograph was important and what the photograph represented. An interview guide with open-ended questions was used for clarification and follow-up questions. Questions were posed to encourage children to talk freely and explain more about their experiences with a sibling with PIMD. These questions were not asked in a particular sequence but rather were posed when they were applicable to the situation. When all photographs were discussed, the interviewer asked the sibling what photographs he or she would like to have taken but did not, and this photograph was discussed afterwards. Finally, the interviewer took time to end the interview and evaluate the interview with the child.

**Analysis**

After the interviews were conducted, they were transcribed verbatim. We coded the transcripts with Atlas.ti Version 7 (Friese, 2013) and then conducted a thematic analysis. We first developed a theory-driven coding system, in which the domains used were derived from Moyson and Roeyers’ (2012) study into sibling quality of life (see Table 2). After familiarising ourselves with the data, based on both data and theory, more detailed subdomains were generated by the researcher. This resulted in a coding system that was used to code all interviews. After coding the interviews, we reviewed and refined the codes for the (sub)domains into our final coding system (see Table 2). Thereafter, we reviewed the coded fragments for every subdomain. In order to facilitate the reliability of the codes, two researchers independently coded the transcript of two interviews, and the two documents were compared with one another (with a 75% interrater reliability as result).

**Results**

In the following section, the experiences of siblings of a child with PIMD are described per domain as shown in Table 2.

**Joint activities**

The domain most mentioned by the siblings is joint activities, which describes how they spent time with their brother or sister with PIMD and how they experienced these activities. Children with PIMD need help in all aspects of daily life, which has consequences for the activities they can participate in. All siblings described activities that were not possible to do together with their brother or sister. Many siblings \((n = 15)\) described feelings of sadness because they were not able to do these activities with their brother or sister with PIMD; other siblings predominantly described why it is not possible for their brother or sister to join in this activity. A sibling stated: “I don’t like this photograph, because you can see that my brother can’t walk. So we can’t really do something together like football, or playing tag. That’s a pity.” Another sibling explained in the following: “We can’t take her into the city. She doesn’t have so much patience. Then she really starts crying, she wants to go, she doesn’t like standing still. I don’t like that, because we can’t do anything that way.”

Even though the children have severe disabilities, their siblings \((n = 13)\) also referred to regular, non-adapted activities with their brother or sister with PIMD. A sibling described: “I find it really cosy when we sit on the couch together and watch television and then he watches TV too. That kind of thing I really enjoy.” According to the siblings, the majority of joint activities described cannot be done without adaptation to the needs of their
brother or sister with PIMD. In the interviews, they described how regular activities were adapted to the needs of their brother or sister and also described special games they played together. One sibling explained: “We have a special bike for the wheelchair, you can put the wheelchair behind the bike and so she can come along when we are cycling.” Another sibling explained:

We play together with a stick horse. My sister is lying on the ground and when we pass with the horse she is laughing a lot and sometimes we help her so she can hold the stick horse a little bit too.

According to the children, care-related activities formed a part of the joint activities between siblings (n = 14). Many siblings did not explain how they felt about helping. Five siblings explained that they enjoyed helping their brother or sister, and two siblings mentioned that they do not like helping their brother or sister.

On the weekends, I always open her curtains when she is awake. Then, I open the doors of her bed and join her. When her probe tubes are attached in the right manner, I take her out of her sleeping bag so she can play.

Another sibling explained:

In the morning when I sit on the couch and mum comes down with D. she asks me, can he sit with you for a while? I say ok, but after a while I want to do something too, but then he has fallen asleep. I feel sorry to wake him up, so I just sit there. This happens quite often and I find it really cute if he lies there with me. But sometimes it’s a bit annoying, because I can’t do anything myself.

Mutual understanding

Many (n = 15) siblings described one or more situation(s) in which they understand what their brother or sister wants, means, or feels. The siblings explained that they know how to interpret the communication of their brother or sister and know what makes them happy or sad.

When she doesn’t sleep long enough, she gets really tired and then she sucks on her lips or her arm. During the day she is lying on the couch and sucking her arm. It’s kind of a little sign which says, “I want to go to bed.”

Also, many siblings (n = 15) referred to moments when they find it difficult to understand their brother or sister. They explained how they are unaware what their brother or sister means or wants. A sibling described: “When he cries, we can’t just ask him, What is going on? Are you scared? Because he doesn’t understand, he just continues crying.” One of the topics referred to by the siblings is feeling understood by their brother or sister. Four siblings explained that their brother or sister sometimes understands them, whereas two siblings would like their brother or sister to understand them better. Many siblings did not mention this topic. A sibling stated: “I like this picture! Often when he hurts you, he gives you a kiss in his

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Table 2. Coding system describing the number and percentage of coded fragments within a domain.

<table>
<thead>
<tr>
<th>Domains of sibling quality of life</th>
<th>Operationalisation of the domain (subdomains)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Joint activities (n = 170; 34.1%)</td>
<td>No joint activity (n = 56)</td>
</tr>
<tr>
<td></td>
<td>Non-adapted joint activity (n = 26)</td>
</tr>
<tr>
<td></td>
<td>Adapted joint activity (n = 55)</td>
</tr>
<tr>
<td></td>
<td>Care-related activities (n = 33)</td>
</tr>
<tr>
<td>2. Mutual understanding (n = 91; 18.3%)</td>
<td>Understanding what sibling wants, mean, feels (n = 67)</td>
</tr>
<tr>
<td></td>
<td>Not understanding what sibling wants, means, feels (n = 16)</td>
</tr>
<tr>
<td></td>
<td>Feeling understood by the sibling (n = 4)</td>
</tr>
<tr>
<td></td>
<td>Not feeling understood by the sibling (n = 4)</td>
</tr>
<tr>
<td>3. Private time (n = 44; 8.8%)</td>
<td>Spending time without the sibling (n = 30)</td>
</tr>
<tr>
<td></td>
<td>Personal hobbies (n = 6)</td>
</tr>
<tr>
<td></td>
<td>Lack of time for personal activities because of the sibling (n = 6)</td>
</tr>
<tr>
<td></td>
<td>Lack of time with parent(s) because of the sibling (n = 2)</td>
</tr>
<tr>
<td>4. Acceptance (n = 63; 12.7%)</td>
<td>Accepting the disability in their own way (n = 32)</td>
</tr>
<tr>
<td></td>
<td>Difficulties with accepting the disability (n = 21)</td>
</tr>
<tr>
<td>5. Forbearance (n = 40; 8.0%)</td>
<td>Seeing advantages of having a sibling with a disability (n = 10)</td>
</tr>
<tr>
<td></td>
<td>Dealing/coping with behaviour of the sibling (n = 7)</td>
</tr>
<tr>
<td>6. Trust in wellbeing (n = 62; 12.4%)</td>
<td>Finding it hard to deal with behaviour of the sibling (n = 32)</td>
</tr>
<tr>
<td></td>
<td>Trust in wellbeing of the sibling and the use of aids (n = 27)</td>
</tr>
<tr>
<td></td>
<td>Concern about welfare of the sibling (n = 10)</td>
</tr>
<tr>
<td>7. Exchanging experiences with other siblings of children with a disability (n = 0; 0.0%)</td>
<td>Feeling happy when the sibling is happy or sad when not (n = 25)</td>
</tr>
<tr>
<td></td>
<td>–</td>
</tr>
<tr>
<td>8. Social support (n = 13; 2.6%)</td>
<td>Other brother(s) or sister(s) (n = 2)</td>
</tr>
<tr>
<td></td>
<td>Missing a typically developing sibling (n = 4)</td>
</tr>
<tr>
<td></td>
<td>From other relatives (n = 2)</td>
</tr>
<tr>
<td></td>
<td>From friends (understanding or not) (n = 5)</td>
</tr>
<tr>
<td>9. Dealing with the outside world (n = 15; 3.0%)</td>
<td>Support and help from wider circle (n = 4)</td>
</tr>
<tr>
<td></td>
<td>Difficulties with wider circle, frustrations, staring (n = 11)</td>
</tr>
</tbody>
</table>

Note. Total coded fragments = 498.
own way afterwards. He can’t give a normal kiss, but he gives you a little lick on your cheek.”

**Private time**

According to the siblings, they enjoyed spending time with their brother or sister, but also spent time without their brother or sister with PIMD. Although the siblings did not mention this domain often, many siblings (n = 15) referred to moments when their sibling was not around because of (professional) support or a respite service, which resulted in private time with their parents. Six siblings also referred to hobbies in which their brother or sister did not participate. For example, “When my brother is away, I have some quiet time with mum and we can play a board game for example. It is nice and quiet when he is not around.” Another sibling explained:

We went on holiday without my sister. For me it was a little bit odd, she left to the respite care but didn’t know we were leaving for our holiday, because she doesn’t understand it when we tell her we are leaving. I missed her a little bit and it is really different without her. But it was also a lot of fun; we could do lots of fun things with mum and dad.

On the other hand, four siblings explained that they are not always able to do what they want because of their brother or sister with PIMD. Three siblings mentioned that they do not like it when their parents are busy with the care-related tasks for their brother or sister with PIMD, as illustrated in the following: “This is something I don’t like, mum is on the phone. She is busy consulting the healthcare agency for my brother. It drives me crazy!”

**Acceptance**

Many siblings (n = 14) gave examples of how they saw their brother’s or sister’s disability and/or explained the benefits of having a sibling with PIMD. One sibling, for example, explained: “I never fight with him. And he is very sweet. And he is never annoying.” Another sibling explained:

For me it’s normal. If my brother did not have his disabilities, he wouldn’t be my brother. Because my brother has a disability I look at people with a disability differently. Other people think that this person looks funny. And I only think, “bad luck, to have a disability.” I feel for them, but they can’t do anything about it, you have to make the best of it.

Ten siblings explained that they found it difficult to accept the disability of their brother or sister. They referred to feeling sad because their sibling won’t develop the way they have or will develop. A sibling described: “I don’t like it that she can’t walk, that she can’t eat the same food, that she can’t talk and that one of her eyes is blind and one is not. And that she can’t swim.” Another sibling stated: “There are moments when I think, ‘I don’t want her to be like this. I want her to be just like me.’ But it feels a bit weird; I can’t imagine what she would be like.”

**Forbearance**

Many siblings (n = 14) described one or more situation(s) in which they found it hard to deal with the behaviour of their brother or sister with PIMD. Siblings also told of moments when their brother or sister was annoying, peculiar, or irritating, or when they had to adapt to make sure their sibling behaved well. A sibling described: “I made a picture of my hair, because she is pulling my hair sometimes and I don’t like that.” Another sibling explained: “It’s nice that she is not at home at some days, because she makes a lot of noise. She makes really loud sounds and sometimes I’m fed up with it.”

**Trust in wellbeing**

Children with PIMD frequently need aids in order to participate in daily life and ensure they feel well. Many siblings (n = 10) referred to these aids and how it helped their brother or sister. For example:

This is a mobile hoist. I find it really special we have one in the house. It comes in really handy, for example, when I’m home alone with my sister. And in a couple of years, he will be too heavy, also for my parents, and we really need it to lift him up.

Another sibling explained:

This is her playpen. I think it is really important because this way she can be with us in the living room, otherwise she can only lie in bed in her bedroom. And if she has to sit on the couch she would fall off all the time.

Few siblings (n = 7) talked about the moments they worried about the wellbeing of their brother or sister. One sibling described: “Sometimes when I come home there is an ambulance in front of the house, I know it’s for my sister and it fills me with dread.” Many siblings (n = 13) explained how they were affected by the mood and wellbeing of their brother or sister with PIMD. A sibling explained:

In this picture you can see her smile. I took this picture because I like it when she is happy. She’s playing with her fingers, something she does quite often and she smiles really happy which makes me happy too.
Another sibling described:

She has to take a lot of medication. She has something which causes some kind of seizure and then she is acting strange. She becomes really stiff and it gives me an uncomfortable feeling. I usually tell mum and dad about the seizure.

Exchanging experiences

None of the siblings mentioned a desire to exchange their private experiences with others. None of the siblings described special sibling meetings, having contact with siblings of other families with a child with a disability, or missing these persons or events in their life.

Social support

Social support is not a domain the siblings talked much about. Two siblings explained that they feel happy for having a healthy sibling to share experiences with too. On the other hand, three siblings referred to feeling sad about not having a sibling without disability, because they missed someone to play with or don’t have anyone to share responsibilities with. One of these siblings described: “It’s great that I have another sister. Someone who feels the same as I do and has the same experiences, that’s nice.”

A few (n = 4) siblings talked about how their friends responded to their brother or sister with PIMD. They explained that some friends were supportive, whereas others were scared or made fun of their sibling. A sibling described:

When I started a new school, I showed him to my new friends. It was a bit uncomfortable because they didn’t know how to respond. I do get it. He’s really disabled; you can see it in his face. And perhaps it would scare me too if I were one of them.

Dealing with the outside world

This theme describes experiences concerning people in the wider circle around the child who are aware that he or she has a sibling with PIMD. Nine siblings explained how the outside world reacted to their brother or sister with PIMD; for example, strangers or classmates staring or making fun of their brother or sister. Other siblings explained that their peers considered it normal for them to have a brother or sister with a disability. For example, “Sometimes when I am at hockey I don’t like it. One boy said, ‘soon you’ll start looking like your sister.’ But then I got really mad. The coach did send him away because of what he said.” Another sibling explained:

I think they find it a bit strange. But the children from football know who he is, because he usually makes a lot of sounds. You can see that he has a disability because of the way he looks, but he can’t do anything about it. They are quite relaxed about it. People who don’t know him stare at him, but then I think “come on, you can see what’s going on.”

Discussion

The aim of the study was to get a comprehensive view of the lives of siblings of children with PIMD, and consequently understanding the impact of having a brother or sister with PIMD on a (young) child (both positively and negatively). Results of the current study show that the siblings interviewed described personal experiences in all domains of sibling quality of life, except “exchanging experiences with other siblings of children with a disability” (Moyson & Roeyers, 2012). Most experiences were classified in the “joint activities” domain, and the fewest experiences in the receiving social support and dealing with the outside world domains. Overall, the siblings described both positive and negative experiences, indicating that having a sibling with PIMD influenced their quality of life in multiple ways. Negative experiences mainly concerned practical consequences, like the inability to do certain activities with their brother or sister with PIMD. Siblings also indicated that it is sometimes difficult to accept the disability of their brother or sister. Positive experiences were shared about activities together with their brother or sister and the joy they felt when their sibling is content. This corresponds with Rossiter and Sharpe’s (2001) review study, in which the authors concluded that there is at most a minor negative effect on siblings but that positive aspects are present as well.

In this study we used the PEI method (Harper, 2002), which results in unique findings and gives new insights into the quality of life of siblings of children with a disability (and siblings of children with PIMD in particular). The PEI method uses photographs as a starting point for conducting interviews, which gave the children the opportunity to elaborate on their personal experiences. Because the siblings took the photographs themselves, this gave them the power to decide on the topics discussed. On the other hand, some other limitations with regard to the methodology of this study can be formulated. First of all, the PEI method limits the interview topics, as siblings decide what topics are discussed. This might have resulted in missing information on certain topics. Second, we used a convenience sample in this study, which might have biased the sample. The sample cannot be classified as representative and therefore
findings cannot be generalised to all siblings of brothers and sisters with PIMD. Due to the young age of the siblings, asking them directly for their participation was limited. Even though the siblings agreed to participate themselves, it was one of their parents who signed up for this study, which possibly caused a preselection of participating siblings. Third, even though we instructed parents to only remind the siblings to take photographs and not suggest images, we noticed during the PEI that some parents had influenced the photographs taken. One sibling, for example, explained: “I don’t know why I made this photograph; mum thought it would be a good example but I don’t really know.” Although some photographs were suggested by one of their parents, the explanation of the photograph was still given by the sibling from their own perspective, which kept the influence of their parents limited.

Although the lives of the siblings are influenced (both positively and negatively) by having a brother or sister with PIMD, the results also show that these children’s experiences do not seem to differ much from children growing up in a family without a brother or sister with PIMD. Many aspects of life that might have been influenced by having a brother or sister with PIMD seem to have been accepted by the siblings, or the siblings had grown accustomed to them or were not aware of being in a special situation. One of the siblings, for example, said: “Many things are very normal to me, so I didn’t know if it was special enough to photograph for this study.”

The results of this study indicate a gap between what siblings would like to do together with their brother or sister and activities that they are able to do together. This is consistent with the study of Moyson and Roeyers (2012), and might even be a more prominent problem for the siblings in this study, as numerous activities are only possible for children with PIMD when they are thoroughly adapted (if possible at all) because of their disabilities. Adapted activities that are possible together with their brother or sister with PIMD were mainly described as positive experiences. As sibling relationships are predominantly based on shared experiences (Campbell, Connidis, & Davies, 1999), joint activities are important for sibling quality of life. Enabling these joint activities (such as the use of an adapted car or bike) is therefore of great importance. The results of this study also stress the importance of (professional) support (e.g., respite care, day activities), to relieve the family for a period of time in order to create moments of private time for the typical developing child and his or her family.

Another important finding from this study concerns the mutual understanding domain. Children with PIMD use idiosyncratic expressions to communicate, such as vocalisations, body movements, facial expressions, and other subtle signals (Hostyn & Maes, 2013; Nakken & Vlaskamp, 2007). The results of this study indicate that siblings are well able to understand the behaviour and communicative intentions of their brother or sister with PIMD. This corresponds with the study by Nijs, Vlaskamp, and Maes (2016). The knowledge siblings possess about interacting with their brother or sister with PIMD should be studied in more detail and can be of great value for professionals supporting the child with PIMD, and professionals may consider adding such information into an individual support plan.

Contrary to the study of Moyson and Roeyers (2012), the siblings in this study did not mention any exchange of experiences with other siblings of children with a disability, or participating in special sibling activities. Possibly, the PEI method did not encourage siblings to talk about this type of support, as the children made photographs for only a short period of time and these activities might not have occurred during this period. It can also imply that siblings of children with PIMD are not aware of special sibling support programs, or do not need (or feel the need) to participate in these kind of activities (Okma, van Dijken, Vergeer, & Naafs, 2015). Moreover, few support programs for siblings with a brother or sister with a disability in this age range exist (Okma et al., 2015). Opportunities to share experiences with fellow siblings of children with a disability can be of great importance, as several siblings in this study indicated problems in dealing with the behaviour of their brother or sister and accepting their disability. As the knowledge concerning support needs of siblings is limited (Naylor & Prescott, 2004), future research should focus more specifically on the support needs of (young) siblings with a brother or sister with PIMD and the effects of support on siblings. In this study, the main focus was on the personal experiences of young siblings (primary school age). Although adult relationships between siblings with and without severe disabilities are still described as close in more than half of the cases in the study by Rossetti and Hall (2015), it is unknown if the experiences with having a sibling with severe disabilities are stable or will change over time. It would be interesting for future research to follow these children longitudinally and interview them again as adolescents and adults, to see how their experiences evolve over time.

A discrepancy exists between the domains used in studies on sibling quality of life and the domains used in studies on FQOL (Brown et al., 2006; Moyson & Roeyers, 2012). This confirms the suggestion that the perspective of siblings is rather different – and more positive – from that of their parents or the family as a
whole (Guite et al., 2004; Sharpe & Rossiter, 2002). This highlights the importance of reviewing the used methods in measuring FQOL. The perspective of parents only on FQOL does not seem to cover the perspective of siblings. FQOL should therefore be seen as a concept that consists of the perspective of all members of the family.

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References


