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Nieuwenhuijse, Appolonia M.; Willems, Dick L.; van Goudoever, Johannes B.; Olsman, E.

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Parent perspectives on the assessment of quality of life of their children with profound intellectual and multiple disabilities in the Netherlands

A.M. Nieuwenhuijse^{a,b,*}, D.L. Willems^a, J.B. van Goudoever^c, E. Olsman^d

^a Department of Ethics, Law and Humanities, Amsterdam UMC, Academic Medical Centre, University of Amsterdam, Amsterdam, the Netherlands

^b Omega, Day Care Centre for Persons with PIMD, Amsterdam, the Netherlands

^c Amsterdam UMC University of Amsterdam, Vrije Universiteit, Emma Children's Hospital, Department of Paediatrics, Amsterdam, the Netherlands

^d Section of Spiritual Care & Chaplaincy Studies, Department of Mediating Good Life, Protestant Theological University, Groningen, the Netherlands

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ABSTRACT

Background: Assessing Quality of Life (QoL) of persons with profound intellectual and multiple disabilities (PIMD) is challenging, yet QoL plays an important role in medical decision-making processes concerning persons with PIMD. The perspectives of parents of children with PIMD on the assessment of their QoL have not been studied.

Aim: To explore the perspectives of parents on the assessment of QoL of their children.

Methods: We conducted a qualitative study, forming three focus groups with 22 parents of children with PIMD to explore their views on what is necessary to assess QoL of their children and subsequently, who is best suited to assess QoL.

Results: Parents describe a long-term relationship of the assessor with family (child and parents), with trust as an important aspect, as a requirement to assess QoL. Parents consider family members, preferably the parents themselves as the best assessors of QoL, followed by siblings. Professional caregivers, mostly mentioned by name, are considered the next alternative. Most parents thought that physicians do not know the child well enough to assess their QoL.

Conclusions: In conclusion, the parents of children with PIMD in our study consider trust and a long-term relationship essential for assessing QoL.

1. Introduction

The assessment of Quality of Life (QoL) of persons with profound intellectual and multiple disabilities (PIMD) is difficult because their communication is mostly presymbolic or protosymbolic, such as movements, sounds, body postures, facial expressions or muscle tensions (Maes et al., 2007). This communication is not always easy to understand. In order to come as close as possible to the lived experiences of persons with PIMD, their communication needs to be interpreted with the aim of assessing their QoL. Persons with PIMD have profound intellectual disabilities (estimated IQ < 20) and severe physical disabilities (Nakken & Vlaskamp, 2007). Most persons with PIMD have additional sensory impairments such as visual and hearing problems and medical comorbidities (Zijlstra & Vlaskamp, 2005). Furthermore, they are dependent on others for all activities in daily life.

* Corresponding author at: Department of Ethics, Law and Humanities, Amsterdam UMC, Academic Medical Centre, University of Amsterdam, Amsterdam, the Netherlands.

E-mail address: a.m.nieuwenhuijse@amsterdamumc.nl (A.M. Nieuwenhuijse).

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Since the beginning of this century, the QoL of persons with intellectual disabilities (ID) has been a subject of academic interest (Cummins, 2005; Schalock, 2004; Schalock et al., 2008, 2002). Petry et al. (2001) developed a procedure for evaluating QoL for persons with PIMD. This procedure was implemented in several studies on QoL of individuals with PIMD and resulted in a questionnaire to measure their QoL (Petry et al., 2009a, 2009b).

In a previous literature review, we found more instruments that have been developed to assess QoL (Nieuwenhuijse et al., 2017). Besides the QoL-PMD (Petry et al., 2009a, 2009b), we found the Mood, Interest and Pleasure Questionnaire (Petry et al., 2010; Ross & Oliver, 2003) and the San Martin Scale (Verdugo et al., 2014) but behavioural observations with regard to happiness (Favell et al., 1996; Green & Reid, 1996), pleasure (Petry & Maes, 2006) and emotions (Vos et al., 2013) have also been used. The assessors were mostly familiar to the persons with PIMD, with parents and direct support staff mentioned most frequently. In addition, unfamiliar observers were mentioned and triangulation with familiar and unfamiliar assessors was seen as a good assessment practice (Petry & Maes, 2006). The role of parents in assessing QoL of persons with PIMD is sometimes questioned critically (Green & Reid, 1996; Hartnett et al., 2008; Petry et al., 2007, 2009a; Verdugo et al., 2014). A background of this critique is that studies in groups of persons with less severe intellectual disabilities suggested that proxy outcomes differed from self-assessments (Cummins, 2002; Heal & Sigelman, 1996; Stancliffe, 1995).

However, a recent overview of the literature suggests that parents - in most instances - know their child best and act as spokesperson for their child with PIMD (Kruithof et al., 2020). Especially in medical decisions concerning their child, such as major surgery, tube feeding, and withholding or sustaining life supportive treatment, in which QoL plays a crucial role, this advocacy role of parents is well-described (Kruithof et al., 2022; Zaal-Schuller et al., 2018). Thus, while the literature on measuring QoL of persons with PIMD remains somewhat critical of parents as assessors of their child's QoL, the literature on medical decision-making for persons with PIMD underscores the important role of parents in this regard. However, the perspective of parents on the assessment of QoL of their child¹ with PIMD has not been described before. Furthermore, the perspective of parents on the role of other (familiar and unfamiliar) assessors has not been explored.

Therefore, the objective of this study is to explore parents' perceptions on the assessment of QoL of their child. The research questions were: 1) What, according to parents, are necessary conditions for persons to be able to assess the QoL of their child? 2) Who, according to parents, can best assess the QoL of their child?

2. Materials and methods

We performed a qualitative study with three focus groups consisting of 22 parents of children with PIMD. This study was conducted in March 2018 in the Netherlands. We used phenomenology as our methodological orientation, because we wanted to describe the significance of experiences of the parents (Bradbury-Jones et al., 2009; Tong et al., 2007). In the analysis, we followed Braun and Clarke's phases: familiarisation with the data, coding, searching for themes, reviewing themes and defining themes (Braun & Clarke, 2006). We used focus groups because we wanted to explore similarities and differences between parents and to provoke discussion on these topics (Rosenthal, 2016).

2.1. Recruitment and research ethics

Our sampling consists of elements of purposive, convenience and snowball sampling (Etikan et al., 2016; Parker et al., 2019). Purposive, because we were aiming to obtain variation in age of participants' children with PIMD and their living place, (either at home or in a residential care facility). Convenience, because we searched for parents of children with PIMD who would be willing to talk about QoL of their child. Snowball sampling because one parent suggested another parent. Finally, three parents (including one parent whose child was deceased) heard about our study and signed up. Parents were approached via psychologists from our professional network and via national networks of parents and professional caregivers. When parents had expressed an interest in the study, they were approached by the first author via e-mail or telephone and they received detailed written information. Remaining questions were answered, after which the appointment for the focus group was made. All parents signed a letter of consent, in which they confirmed that they had been informed about the study and their rights, including the right to withdraw at any moment and assurance of anonymity. The Medical Ethics Committee of the Academic Medical Centre granted a waiver for our study, confirming that it was not subject to the Medical Research Involving Human Subjects Act (WMO).

2.2. Participants

The parents of nineteen children were approached for the focus groups. One parent did not respond to the email, and the parents of two children had to be excluded because their son or daughter did not belong to the target group. For characteristics of participants' children ($n = 16$), see Table 1. Twenty-two parents participated in the focus groups and in six cases, both the father and mother participated (fathers: 12, mothers: 10). The parents all lived in the west or central part of the Netherlands and they all spoke Dutch.

¹ The word 'child' refers to offspring, which includes adult children.

Table 1
Characteristics of participants' children (n = 16).

Parent	Age child	Living place child
P 1	10	home
P 2	10	home
P 3	20	RCF
P 4	20	RCF
P 5	17	home
P 6	9	home
P 7	22	home
P 8	24	RCF
P 9	21	home
P 10	13	deceased
P 11	13	home
P 12	13	home
P 13	44	RCF
P 14	44	RCF
P 15	15	RCF
P 16	19	home
P 17	15	RCF
P 18	24	RCF
P 19	43	deceased
P 20	27	RCF
P 21	51	RCF
P 22	51	RCF

2.3. Data collection

Before we conducted the focus groups, we interviewed five mothers of children with PIMD to set up a guideline for the focus group (the mothers did not participate in the focus groups). Besides asking them to tell us about the QoL of their child, we shared our view on the topics of the focus groups with them and asked if they had suggestions and additions. In addition, we used our previous literature review study and empirical study on the topic (Nieuwenhuijse et al., 2017, 2020) which together with the input from the mothers, led to a guideline (Fig. 1).

The first author (behavioural scientist), accompanied by the second (ethicist) or the fourth author (theologian) of this paper conducted the three focus groups, which all took place at a day care centre for persons with PIMD. The children of the participants did not attend this day care centre. Focus groups took between 2 and 2.5 h each. They were audiotaped and transcribed verbatim.

2.4. Analysis

The transcribed focus groups were analysed using the qualitative data analysis software, MaxQDA. First, AMN and EO read all the transcripts and searched for themes in the familiarisation phase. For example, the role of physicians revealed during this phase. In the second round AMN and EO coded the focus groups using codes derived from previous empirical research on QoL of persons with PIMD and the responses in the focus groups (Nieuwenhuijse et al., 2017, 2020). [Supplementary file 1](#) demonstrates the distinction between the codes derived from previous research (deductive coding) and the codes based on the responses in the focus groups (inductive coding) (Skjott Linneberg & Korsgaard, 2019). The codes in italics are the codes derived from previous research. After coding the focus groups, the fragments belonging to the codes were placed per code in an excel file and studied thoroughly. Then AMN grouped the fragments in themes and discussed them with EO and DW. This led to one change of theme. Initially, we used the statements we offered the focus groups for discussion as a theme. However, parents mentioned other difficulties in assessing QoL of their child. For this reason, we considered the overall theme: "Difficulties in assessing QoL of their child" more appropriate than only the entanglement between the QoL of the child and the QoL of the parents. The themes continued to be discussed until consensus was reached. Eventually, the analysis led to four themes, which will be presented below. As we also interviewed five mothers, we expected - in line with a publication by Fusch and Ness (2015) - that two focus groups would be enough to achieve data saturation. In order to verify this, we conducted a third focus group, which confirmed the saturation because no new themes were identified.

3. Findings

Four major themes were found: what is necessary to assess QoL, who can assess QoL, the role of physicians, and difficulties in assessing QoL.

3.1. What is necessary to assess QoL

When discussing 'what is necessary to make statements on the QoL of your child,' parents mentioned two main aspects: there had to be a relationship with the child and a relationship with the parents.

Guideline focus groups parents

Discuss statements

The literature reveals that there are varying opinions about the role of the parents in measuring quality of life. It is also evident that physicians assign a high priority to the client's surroundings (parents, family) when assessing the child's quality of life and when making decisions. This raises a number of questions, which we will discuss based on a number of statements. If you agree with the statement, please stand on this side (point). If you disagree, please stand on the other side.

Statements

1. **I think that my child and I are so interconnected that our quality of life is difficult to disentangle.**
2. **My quality of life plays a role in decisions about my child.**

Who can assess the quality of life of your child and why?

Who can make statements about the quality of life of your child? We will use yellow Post-Its for this topic, so that the parents can each write their thoughts down individually on a separate Post-It.

These will then be clustered on a sheet of paper and discussed – what are the correct clusters?

Next, we will discuss the specifics:

- Why are these people allowed to make statements about the quality of life of your child?
- Who is not allowed to make statements about this and why not?

Point that have not been discussed

Afterthoughts and specifics.

Fig. 1. Summary of the interview guide.

3.1.1.1. Relationship with the child

Parents in the focus groups mentioned that persons who can assess the QoL of their child had to know their child very well or thoroughly, of which knowing the child for a long time was an aspect. *'The physiotherapist who has been coming here for 15 years'* or *'The home carer who has been coming here for 35 years.'* Another aspect was contact with their child on a regular basis, preferably several days a week. Mostly, parents referred to persons who took care of their child on a daily basis. [I 1 and I 2 are the authors leading the focus

groups, P 1 until P 22 are the parents in the focus groups].

P 10: I choose the person with primary responsibility in the day-care facility and the person with primary responsibility in the institution she is living, all the home aides,² why these three? Because I think they're best equipped to assess our daughter's daily wellbeing, because they see her at least a few days per week, care for her, sit with her... unlike the doctors and hospitals, the physiotherapists surrounding them, the general practitioners... they may have an impression of her, but it's too fragmented, so I don't think that these doctors and therapists have an adequate understanding of what daily life entails for a child like our daughter.

However, not only the quantity of time spent with their child was a requirement, but also the quality, for example, reciprocity was mentioned. Some parents described it as a sensitivity a person had for their child and the reciprocity there was between this person and their child. One parent called it love.

P 13: I think you can also look at your child, how your child responds to that care provider. I think that also plays a role: the interaction we as parents observe. Very simple, some people love their job and perform tasks in a loving way and others simply think: well, I need to put food in that child and then I'm done.

P 14: Yes, that is being very blunt, but you can notice quite quickly when someone...

P 13: ... whether they're doing it with love.

P 9: What I'd like to add is - I see that with one or two, they really have a connection with [name child], where you really see them connect with each other... Eye contact and you can see her enjoying the care that she's receiving at that time. You see a lot more interaction.

3.1.2. Trust based relationship with the parents

The parents mentioned several times that they have to trust persons who assess the QoL of their child, when the assessors are not themselves. They frequently mentioned that they had a relationship with these persons. One parent explained the necessity of trusting the assessor because of the advocacy role that he had to take for his daughter.

P 16: These are people who I trust and have a relationship with.

P 19: But I think that we try to put ourselves in that position [as a substitute for the daughter] that we say that because: my [name child] cannot tell you that, so someone has to say it for her: 'I do trust you and I don't trust you.' So, I think that we say that on behalf of the child, because we think: that is someone who is important or valuable to our child. Speaking for myself, I say these things because I try to observe from her perspective: who is valuable to her.

Conversely, if there was no relationship with the parents, the parents did not want him or her to say anything about the QoL of the child. The quote below is an example of this.

P 16: What I really hate is officials. And by that I mean persons who think they can have an opinion about my daughter or about me because of their official position. 'I'm your daughter's supervisor and I think'... or 'I am your doctor and I think...' Or 'I am...' whatever the case may be. Their reasoning is based on their position and not on: I am in this together with you, I want to build a relationship with you or whatever you tell me; I am visiting you, I also want to get to know your daughter, you know.

3.2. Who can assess QoL?

We asked the parents in the focus groups 'who can make statements about the QoL of your child'. This question means both 'who is capable of making statements' and 'who is allowed to make statements.' When answering this question, all parents in the focus groups mentioned themselves first. Next, they mentioned familiar others such as brothers and sisters or other family members or friends of the child or family. Parents also mentioned professionals. These professionals knew the child well, such as home cares or someone from the day-care centre or the residential facility. In general, the professionals were mentioned by name. Table 2 shows the individuals who can assess QoL in sequence of frequency mentioned.

When asked who *cannot* say something about the QoL of their child, some parents mentioned care institutions, municipality, officials and authoritative sources, and with emphasis: physicians. The role of physicians will be described in detail below.

3.3. The role of physicians

Parents in all the focus groups spontaneously mentioned the (role of the) physicians. This role of physicians provoked a lot of discussion in the focus groups. Some of the parents were very explicit in their hesitation about the involvement of physicians in the

² In Dutch day care centres and RCF, one care professional usually has primary responsibility for the (coordination of the) care of a few persons with PIMD. At home, parents use 'home aids' to support them in the care for their child.

Table 2
Who can assess QoL in sequence of mentioning?.

Who, in sequence of mentioning	Specification
Parents ^a	Not applicable
Siblings	Not applicable
Close family members	Grandparents or parents' brothers, sisters or sisters-in-law. Sometimes nieces or nephews.
Professionals	Almost all parents mentioned one or more professionals, mostly by name
Others	Friends of the parents, respite care parents, the child's care coach,
Physicians	Some mentioned the parents' general practitioner, 1 mentioned the paediatrician.

^a Including spouses who were not the biological parent.

assessment of QoL of their child, whilst some of them took a slightly more nuanced approach. According to most of the parents in the focus groups, physicians can say nothing or very little about the QoL of their child. The main reason for their stance was that physicians did not know their child sufficiently enough because they only saw him or her during office hours or when (s)he was very ill. In other words, physicians experience only unusual moments and never ordinary life.

I 1: How much do you actually need? I mean: a doctor does not see your child often enough. But how much time do you need to get a good impression? Do you need to observe the child for 24 h?

P 9: I think that you should have almost daily interaction.

P 10: Yes, at least a few times per week and I do think that it would be good for doctors to spend a week with parents like us, with these children. Just spend a week from early morning to late in the evening: what is that like?

P 12: So, the problem is that it's not only fragmented, but also that they experience the unusual moments/situations, but never ordinary life. That's the point.

Another reason was that physicians did not have experience with the target group to which their child belonged. Therefore, these physicians did not know the particular details of persons with PIMD. Furthermore, parents felt that most physicians understood only one small aspect and not the whole child.

P 3: I am not sure whether you have the same experience, but in an emergency situation, you first need to get through this army of medics in training, who completely overreact, because [child's name] has all these abnormal values, the saturation is never good enough, the blood test results are not good. Everything is abnormal and you need to explain every single time: Read the medical file. Ask us for advice. Sounds familiar?

P 7: But these doctors, you generally have a whole team of them, they only understand one small aspect, be it a neurologist or a pulmonologist or whatever.

However, the conversations between parents in the focus groups revealed that physicians do communicate their view on QoL of the child to the parents. For some parents this was puzzling and seemed difficult because from their point of view, physicians cannot assess QoL of their child. This was even more difficult when physicians did not ask the opinion of the parents on the QoL of their child first. Above that, physicians' opinion on QoL of their child felt like a judgement for some parents.

P 6: But I think, what bothers us is that a doctor already has an opinion or a judgement on your child's quality of life. Without asking any questions first. I think that this is a very important aspect. But I do think that it's very important for doctors to acknowledge this and to be open to discuss it, but in a way that it's not presented as a judgement or an opinion about your child's quality of life, because I think all the parents agree with me that they [parents] are most capable of understanding their child's quality of life.

This seemed even more complicated when QoL was used in combination with decisions on medical treatment. Parents shared their experiences with each other in the focus groups and did not always agree on this subject. One parent had the feeling that physicians decided in end-of-life-decisions and based their decision only on *their* view on QoL of the child. Other parents however, disagreed and experienced a shared decision with physicians. The quote below reveals that in end-of-life-decision this mother had a different experience.

P 10: What makes me angry, is that in the lives of our children, the doctors and therapists give you so many responsibilities about medicines, about making decisions about: how is your child doing and what should or should not happen to your child? They give you all this responsibility, you have to deal with everything yourself and call us if you can't manage and as soon as you say, 'Wait a second, stop. We want to talk about this: what is the quality of life and what are we going to pursue, what are we not going to pursue? What are the options?' Then they often reply: 'Yes, but that is for us to decide.' And then I think: yes, but...

P 11: We don't share that experience. [Name child] received anti-seizure medication at some point he completely turned in on himself and then I said: We can live with the seizures, but we are going to stop the medication and the only thing that the

neurologist said was: 'We'll increase the dose one more time, just to be sure that it is not working.' Then we said: 'Ok, one more step.' And after one week: if it's not working, we will stop the medication and that was fine.

P 10: Those types of decisions too. We've always been able to discuss these decisions with the doctor, but then I'm really referring to end-of-life decisions. In those cases, you as a parent are called to a halt, you're allowed to share your opinion, but the final decision rests with the doctor, whilst all those other responsibilities [are yours to deal with].

Following on from this, most parents did see an important role for physicians, which was as critical counterpart. Stated more specifically, as an experienced medical counterpart. Some parents wanted to discuss medical situations and decisions concerning their child with the physicians from different viewpoints. In most cases, the physicians mentioned the various medical options and the parents weighed these options from the perspective of QoL of their child.

P 6: It said so in his protocol. I said: 'But I'm not going to accept that. This is not a child like all the other children that you see, who plays outside in the school playground and that sort of thing'. So, then I had a very long conversation with this doctor and what it boiled down to was that medicine was life-prolonging. I said: 'But her life expectancy with this syndrome is normal, as far as you know, so she could live up to 80 years old, but I don't know if I would want that, because then she'll outlive me. So can we talk about that?' In the end, we made the joint decision not to give that medicine. I said: 'If it were to improve her quality of life right now, if she were short of breath at the moment and she would be given medicines and no longer be short of breath, then I would want the treatment now', but he said: 'That's not what it is for at all.' And then I said: 'Then it's very clear to me.' And fortunately, he agreed with me. So I think that's a very good example of a doctor, how he can empathise with you as a parent and respect and accept that you have the right to an opinion on this.

3.4. Difficulties in assessing the QoL of their child

Although all parents mentioned themselves as the one who could assess the QoL of their child best, in their discussions with each other, they spoke about difficulties in describing or assessing the QoL of their child. The most important reason was that these children do not verbalise their QoL. Parents mentioned that they had to 'read' their child. Parents usually learned to do so, but it remained difficult, especially when their child was not well. In fact, some parents described their concerns whether they understood their child well and one parent admitted that sometimes he made a guess.

P 19: And I agree with you, actually we are the ones who need to determine whether that is still quality of life or not, because you cannot ask her. At the same time, this is the most difficult and frustrating part, that you cannot communicate properly, that you need to trust your instincts of who she is and I think that we - as parents, because we have known her the longest - are most likely to sense what is going on, but quite often we are also just making a guess. I find that tricky sometimes. Yes.

Another aspect that was discussed in the focus groups was the relationship between the QoL of their child and their own QoL. Parents reacted differently to these theses. Some of them described that their QoL was completely entangled with the QoL of their child. Some parents mentioned that some decisions they made had more to do with their own QoL than with the QoL of their child. Mostly these were decisions about the child spending a period in a respite care home or moving to a residential care facility. All parents mentioned that the QoL of their child should prevail above their own QoL when their child was in hospital. Some parents described that their QoL and the QoL of their child could be seen as separate aspects.

P 6: I do not think that my quality of life depends entirely on my child's quality of life. Of course these things are related, but my quality of life is also related to that of my husband and my other child and my husband's children and a lot of other factors. So she is certainly a factor, but it is not true that you cannot examine (name child) quality of life without examining my quality of life... I think that these are separate aspects.

One parent mentioned other persons as a critical counterpart, which helped her to sharpen her opinion on QoL of her child. Furthermore, these persons could help her to disentangle her own QoL from that of their child or helped her to make decisions. This mother emphasised that she was the one making the decisions concerning her child, but that a critical view of someone else may help.

P 20: I would like to respond to that, because I'm also aware that I sometimes have a blind spot regarding [name child], that I think that I always know better and of course that is true in 99 % of cases, but for that one percent I would like to receive input from others, including others not listed on the 'yes list.' That it makes you think about things again and discussing with your friends: yes, what is that actually, Quality of Life? And for whom? For me? For him? Just for anyone in general. Where are the boundaries? It is always good to receive input from a different angle. Look, ultimately, I decide, but I have no problem with somebody suggesting a completely different idea that makes you think: yes, I'm going to think about that. Does that affect my opinion and my decision? Sometimes it does, sometimes only partially. So that's important, that I don't develop tunnel vision about how the treatment or other aspects are progressing. I think that this is important for me personally.

4. Discussion

In this study, we asked parents in focus groups what is necessary to assess QoL and consequently, who can assess QoL of their child with PIMD. We found that all parents mentioned themselves first as the ones who could assess their child's QoL best. After that, they

mentioned brothers and sisters of the child, relatives of the parents and lastly, professional caregivers, mostly mentioned by name. The persons who parents think can assess QoL are those who have a relationship with both their child and themselves. The relationship with their child is not only built on time and frequency (quantity), but also on, for example, reciprocity between the caregiver and the child (quality). In the relationship with the parents, trust appears to be the most important aspect.

These findings differ from assessment practices we found in our earlier literature review (Nieuwenhuijse et al., 2017). In six of the included articles, QoL in persons with PIMD was assessed by familiar assessors as well as unfamiliar assessors (Favell et al., 1996; Green & Reid, 1996; Lyons, 2005; Petry & Maes, 2006; Vos et al., 2010, 2013). Furthermore, we found that triangulation of assessors, which included unfamiliar assessors, was mentioned as a good assessment method (Petry & Maes, 2006). The parents in the current study did not seem to think unfamiliar assessors are necessary. In fact, they mentioned the opposite namely, that the assessor has to know the child very well, otherwise (s)he cannot assess QoL of the person with PIMD. Stated differently, building a relationship with the child is necessary to assess the QoL of that child in the parents' view. Triangulation of assessors who know the child thoroughly however, may help the assessment process. After all, assessing the QoL of their child was difficult according to some parents in our study. In addition, one parent described that a critical counterpart could help to sharpen her opinion on QoL of her child and to disentangle the QoL of her child and her own QoL. The entanglement between QoL of the parents (FQoL) and the QoL of their child forms a subject of other studies (Luitwieler et al., 2021; Summers et al., 2005). Nevertheless, some parents in our focus groups referred to the entanglement of their own QoL and QoL of their child, while other parents rather made a distinction between QoL of themselves and their child.

The role of physicians was mentioned frequently and spontaneously, both during the focus groups and in the interviews with the five mothers preceding this study. Therefore, this topic deserves scrutiny here. Why did parents mention physicians so often and apparently had mixed feelings about them? Although we did not explore the reason for this attention for physicians, there are some examples described in literature that might contribute to the difficulties parents experience in relation to physicians. For example, persons with PIMD are hospitalised frequently and thus parents and children often interact with physicians. This hospitalisation places a burden on both the child and the parents (Seliner et al., 2016), together with the cause of hospitalisation.

Another example why parents may have mixed feelings about their interaction with the physicians might be that the transfer from childhood to adulthood does not progress smoothly between physicians and therefore many different physicians may be involved in the medical care of adult persons with PIMD (Bindels-de Heus et al., 2013).

In relation to our findings, most participants thought that physicians could not assess QoL of their child. The reasons they mentioned were that physicians did not know the child well enough and did not see the child on a regular basis nor long enough. Other reasons were that, many physicians were believed to not know the target group and to lack a holistic overview due to their highly specialised profession.

Some parents experienced negative feelings when physicians made statements on the QoL of their child, predominantly regarding end-of-life decisions. Probably, this had to do with the position of parents and physicians in this process. Other literature regarding the position of parents and physician in decision-making processes both confirm and contradict our results. Sullivan et al. (2014) confirm our findings, namely the wish of some parents in our study for the physician to be their medically experienced counterpart and support them to be the end-of-life decision-maker for their child (Sullivan et al., 2014). Other research shows that there is no consensus in the parents' preferences regarding their influence on treatment decisions for their child, although this research was not limited to end-of-life decisions (Lipstein et al., 2012). Zaal-Schuller et al. (2018) recommended that parents and physicians should more frequently discuss their view on QoL of persons with PIMD. Our findings however, did not confirm this. We found that these parents did have hesitations to discuss the QoL of their child with physicians. In their review of the literature, Zaal-Schuller et al. (2016) reported that a long-lasting relationship between parents and physician contributed to mutual trust and facilitated the decision-making process. This finding is in line with our finding that a long relationship and mutual trust are also important for assessing the QoL of persons with PIMD. The importance of relationships is in line with findings reported by others. Watson et al. (2017), for instance, found that a strong association between supporter responsiveness and relational closeness is important in supported decision-making in persons with severe and profound intellectual disabilities. Wightman et al. (2019) also described the importance of relationships. They introduced the "relational potential", referring to the potential of persons with PIMD to be in caring and loving relationships with their parents. They describe that this capacity of a loving relationship between parents and child can be an ethical justification for opting for life-sustaining treatment of children with PIMD if parents ask for this, instead of narrowly focusing on their capabilities or cognitions when making such decisions (Wightman et al., 2019).

A possible limitation of our study is that we only had parents in our focus groups who were willing to talk about the QoL of their child, which could be an inclusion bias. Especially since we asked psychologists to search for parents whom they thought would be willing to talk about QoL of their child. Furthermore, some parents signed up themselves when they heard about this study. This being said, we do not feel that our potential selection bias invalidates our findings, because it is probable that other parents would be at least as concerned as our respondents about trust and about others deciding on the QoL of their child. In addition, the findings of this study can only very prudently be generalised to other contexts. The liberal, Dutch climate, when it comes to medical-ethical issues, influences the context of this study. On the one hand, that may be an advantage because parents feel free to discuss these topics. On the other hand, this climate is perceived by some other societies as reprehensible, because of the risks of the slippery slope. Consequently, future studies are required to explore the experiences and ideas of parents in other countries and contexts. A strength of our study is our methodological approach, which included pre-discussions with parents and involved focus groups, in which parents stimulated and supported each other to talk about their own ideas and experiences. This empowered them to raise their struggles with physicians and at the same time, they felt free to talk about their own experiences, even when these contradicted the experiences of other participants.

5. Conclusion

Our conclusion is that, according to parents in our study, only persons who know their child thoroughly, have a relationship with their child and with them, and whom they trust are allowed to assess the QoL of their child. If a physician does not have this relationship, he or she is not allowed to assess QoL of their child. When physicians nevertheless share their view on QoL, this may feel as a verdict or judgement for parents. This conclusion requires future studies that explore the roles of parents and physicians (including physicians' final responsibility by law) in shared decision-making, the mutual sharing of views on QoL and the development of the role for physicians as an experienced medical counterpart. These roles should be explored further whilst ensuring that both physicians and parents retain their responsibility.

What this paper adds

Assessing Quality of Life (QoL) of persons with profound intellectual and multiple disabilities (PIMD) is challenging, because their communication is always nonverbal and needs to be interpreted with the aim of assessing their QoL. Although challenging, it is important because QoL plays an important role in medical decision-making processes concerning persons with PIMD. Parents play an important role in these medical decision-making processes. However, the perspective of parents on the assessment of QoL of their children has not been explored before. Therefore, we conducted three focus groups with 22 parents of children with PIMD to explore their view on what is necessary to assess QoL of their children and subsequently, who is best suited to assess QoL.

The parents in our study consider a long-term relationship with trust as an important aspect as a prerequisite for assessing QoL of their children. Furthermore, they consider family members, preferably themselves, as best equipped to assess the QoL of their children. While parents saw professional caregivers as capable of assessing the QoL of their child, they thought that physicians do not know the child well enough to assess QoL.

Nevertheless, according to the Dutch law, physicians bear the final responsibility in medical decision-making. Future studies should explore the roles of parents and physicians in relation to shared decision-making. In doing this, both the expertise of parents and that of physicians should be taken into account, whilst ensuring that both physicians and parents retain their responsibility.

CRedit authorship contribution statement

Appolonia M. Nieuwenhuijse: Conception and design of the work, data collection, data analysis and interpretation, drafting the article, revision of the article, final approval of the version to be published. **Dick L. Willems:** Conception of the work, data analysis and interpretation, critical revision of the article, final approval of the version to be published. **Johannes B. van Goudoever:** conception of the work, critical revision of the article, final approval of the article. **Erik Olsman:** Conception and design of the work, data collection, data analysis and interpretation, revision of the article, final approval of the version to be published.

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Data Availability

No data was used for the research described in the article.

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Disclosure statement

The authors declare that they have no conflicts of interests.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.ridd.2023.104536](https://doi.org/10.1016/j.ridd.2023.104536).

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