

The perspectives of professional caregivers on quality of life of persons with profound intellectual and multiple disabilities: a qualitative study

A.M. Nieuwenhuijse^{1,2}, D.L. Willems¹, J.B. van Goudoever^{3,4} and E. Olsman^{5,6}

¹Section of Medical Ethics, Department of General Practice, Amsterdam UMC, Academic Medical Centre, University of Amsterdam, Amsterdam, The Netherlands; ²Omega, Day Care Centre for Persons with PIMD, Amsterdam, The Netherlands; ³Department of Paediatrics, Emma Children's Hospital, Amsterdam UMC, Academic Medical Centre, University of Amsterdam, Amsterdam, The Netherlands; ⁴Department of Paediatrics, Amsterdam UMC, VU University Medical Centre, Amsterdam, The Netherlands; ⁵Section of Ethics & Law of Healthcare, Department of Neurology, Leiden University Medical Centre, Leiden, The Netherlands; ⁶Hospice Bardo, Department of Spiritual Care, Hoofddorp, The Netherlands

Persons with Profound Intellectual and Multiple Disabilities (PIMD) are supported by professional caregivers for a large part of their lives. However, the perspectives of professional caregivers on good or poor Quality of Life (QoL) of persons with PIMD have hardly been explored. To explore the perspective of professional caregivers on QoL of persons with PIMD, we performed a qualitative study, conducting semi-structured interviews with eleven professional caregivers and thematically analysed them. In the interviews, these professional caregivers described examples of good and poor QoL. Good QoL was mostly described in emotional terms such as happiness, pleasure and enjoying things. Poor QoL was mostly described in physical terms such as pain, sickness and shortage of breath. The capability of persons with PIMD to influence the environment was described as an element of good QoL. Furthermore, these professional caregivers described how they assessed QoL. They 'sensed' QoL, they tested it (trial and error) and discussed QoL of persons with PIMD with colleagues. Participants emphasized the dependency of persons with PIMD on professional caregivers. Furthermore, these professional caregivers described feelings of failure and powerlessness if they could not assess or fulfil the needs of persons with PIMD. We conclude that these professional caregivers use their (tacit) knowledge to understand QoL of persons with PIMD. The relationship between QoL of persons with PIMD and professional caregivers needs more investigation, because of its consequences both for the persons with PIMD and the professional caregivers.

Keywords: Quality of life, profound intellectual and multiple disabilities, developmental disabilities, ethics, qualitative research

Introduction

Quality of Life (QoL) is a central principle in the support of persons with Profound, Intellectual and Multiple Disabilities (PIMD). Persons with PIMD are individuals with profound intellectual disabilities (IQ < 20) and profound neuromotor dysfunctions, sometimes with sensory impairments and even medical problems such as seizures, respiratory and feeding problems (Nakken and Vlaskamp 2007). They are totally dependent on others in all aspects of daily life.

QoL of persons with Intellectual Disabilities (ID) has been a subject of academic interest since the beginning of this century (Cummins 2005, Schalock 2004, Schalock *et al.* 2002, 2008). In accordance with Verdugo *et al.* (2005), Petry and Maes (2009) describe that QoL is used as a conceptual framework for assessing quality outcomes, as a social construct that guides quality enhancement strategies and as a criterion for assessing the effectiveness of these strategies (Petry and Maes 2009, Verdugo *et al.* 2005). In addition, in a previous study was found that QoL of persons with PIMD also affects ethical deliberations on medical decisions (Zaal-Schuller *et al.* 2018). In those situations not only

Correspondence to: Marga Nieuwenhuijse, Department of General Practice, Section of Medical Ethics, Amsterdam UMC, Academic Medical Centre, University of Amsterdam, P.O. Box 22700, 1100 DE, Amsterdam, The Netherlands. Email: a.m.nieuwenhuijse@amsterdamumc.nl

© 2020 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group
This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

perspectives on good QoL are important, also views on poor QoL, or concerns on QoL are relevant.

In a literature review, we found that QoL of persons with PIMD is often assessed through questionnaires and behavioral observations (Nieuwenhuijse *et al.* 2017). The assessors usually were familiar to the persons with PIMD, most often parents and professional caregivers. Some authors argued that triangulation between familiar and unfamiliar assessors was seen as a good assessment practice (Petry and Maes 2009). However, the assessment of QoL of persons with PIMD is difficult because these persons cannot describe their QoL themselves, nor can they confirm or deny the outcome of the assessment of their QoL.

Not only the assessment of QoL of persons with PIMD is challenging, also caring for them is difficult, because they cannot communicate when and how support should be given. In addition, caring for persons with PIMD is a heavy task for parents (Tadema and Vlaskamp 2010) and an informal network is often lacking (Kamstra *et al.* 2015). Consequently, parents share their care with the professional caregivers of persons with PIMD (Axelsson *et al.* 2014). Furthermore, because of their medical problems, medical professionals regularly care for them as well (Seliner *et al.* 2016). Research showed that the support offered by professional caregivers requires partnership with the parents (Jansen *et al.* 2013), although a recent study showed that, in the view of mothers, professional caregivers often lack the specialist knowledge or skills required to understand the needs of persons with PIMD (Adams and Jahoda 2019).

Other research showed how the support offered by professional caregivers influences the QoL of persons with PIMD (Petry *et al.* 2007, Zijlstra *et al.* 2001). Petry *et al.* (2007) found out that, besides characteristics of the settings and the internal organization of the support, characteristics of the support staff itself influenced QoL of persons with PIMD. Furthermore, research explored the perspectives of professional caregivers on different domains of QoL of persons with PIMD (Petry *et al.* 2005). Petry *et al.* (2005) asked support staff to give examples of elements of good QoL and how QoL of persons with PIMD could be improved.

Hence, professional caregivers play an important role in the care of persons with PIMD and in their QoL. Not only are they one of the assessors of QoL of persons with PIMD, they also influence QoL of persons with PIMD. However, in medical decisions, not only good QoL or the improvement of QoL is important, but also views on poor QoL or on reasons for concerns of QoL are relevant. Since professional caregivers may be confronted with medical decisions concerning persons with PIMD and the dilemmas associated with this, their perspective not only on good QoL but also on poor QoL of persons with PIMD is important. Therefore, the

objective of this study was to explore professional caregivers' perception on good and poor QoL of persons with PIMD.

Materials and methods

We performed an exploratory study with a qualitative design, using semi-structured interviews with professional caregivers of persons with PIMD and analysed these thematically (Braun and Clarke 2006, Tong *et al.* 2007). A qualitative design was most appropriate because we searched for experiences and perceptions. In the analysis, we followed Braun and Clarke (2006)'s phases: familiarisation with the data, coding, searching for themes, reviewing themes and defining themes.

Recruitment

Professional caregivers in the Netherlands are part of a team caring for persons with PIMD, mostly in residential care facilities and day care centres. Some of the professional caregivers coordinate the care around the person with PIMD and are the primary person responsible for this care and our study focused on these professionals. They mostly have a pedagogical or nursing background and we used both purposive and snowball sampling to recruit them. We aimed to recruit participants from both residential care facilities and day care centres and we wanted to achieve a variety of age, both of the caregiver, and of the person they cared for. We approached psychologists and managers in the networks of professionals working with persons with PIMD and asked them to search for professional caregivers working with persons with PIMD in their institutions, who might be interested in participating in the study. One participant heard about the research through others and signed up. Participants were given detailed information on the study by the first author via email and when they answered that they were (still) interested, the first author called them. In this telephone conversation, we checked whether the participant was responsible for the care of persons with PIMD and whether the information about the research was clear. Once they agreed to participate, this was confirmed by letter and an appointment for an interview was made.

Research ethics

Our study has been conducted in accordance with the relevant passages in the World Medical Association Declaration of Helsinki. The Medical Ethics Committee of the Academic Medical Centre granted a waiver for our study because it was not subject to the Medical Research Involving Human Subjects Act. Professional caregivers gave oral consent after having read the information letter specifying participants' rights, like their right to withdraw from the study at any moment and the assurance of anonymity. We confirmed their oral consent in writing.

Table 1. Summary of the interview guide.

The focal question during the interview is:

When do professional care providers think that a person with PIMD has a good quality of life and when does a person with PIMD have a poor quality of life. Do they ever have concerns on the quality of life? Why?

It is important to ask the interviewee to think about an existing person/situation. This allows you to ask in-depth questions about tangible aspects. Avoid speaking in general terms!

2. The questions

1. Can you tell me your first thoughts about “quality of life”, for the group that we are discussing?
2. Do you know someone who has a good quality of life? Whilst thinking about this person, can you tell me more about them?
 - Describe the situation
3. What do you notice about this person?
4. Do you know someone who you think has a poor quality of life? Whilst thinking about this person, can you tell me more about them?
 - Describe the situation
5. What did you notice about the child/the adult?
6. Have you ever had concerns about a person’s quality of life?
 - Describe the situation
7. Why did you think that?

Table 2. Characteristics of participants (n = 11).

Gender	Female	n = 11
Age	25–34	n = 4
	35–45	n = 6
	46–50	n = 1
Workplace	Residential care facility	n = 6
	Day care centre	n = 4
	Hospital	n = 1

Data collection

The interviews were conducted by trained interviewers (AMN, first author: 8; EO, supervising author, 2; EH, member of the project group: 1; GG, member of the project group: 1) using the same interview guide (Table 1). The face-to-face interviews took place at the workplace of the participants and took approximately 50 min each (mean 53 min, range 31–71 min). All interviews were audio-recorded and transcribed verbatim.

Data analysis

In analysing the data, we used MaxQDA software. In the analysis process, we used both deductive and inductive coding. We used a coding tree that was composed in previous research on QoL of persons with PIMD (deductive coding), and added new codes that were derived from the data (inductive coding) (Nieuwenhuijse *et al.* 2019). First, the first author AMN coded all the interviews and constructed a coding tree based on both the deductive and inductive coding. Second, the supervising author EO coded two interviews and compared his coding with the coding of AMN. This resulted in some refinements of the coding tree. [Supplementary file 1](#) demonstrates the distinction between codes based on previous research and the codes based on the inductive coding process (the codes based on inductive coding are in italics). Then, the first author interpreted the fragments belonging to the codes

and grouped them under different themes. After that, she discussed the results of this interpretation and the themes with DLW and EO. Based on this discussion the analysis was refined and this was continued during the whole process. The analysing process finally led to four themes, which will be presented below.

Participants

Thirteen participants were approached by telephone, of which one was excluded because he did not work with the target group. Twelve professional caregivers were interviewed. However, one interview was excluded because the interview revealed that the participant worked with persons with only intellectual disabilities and not with PIMD. Characteristics of the respondents are provided in Table 2.

Results

Four major themes were found. First, descriptions of good and poor QoL. Second, ways of assessing QoL. Third, dependency of persons with PIMD on their environment and its influence on their QoL. Last, how this dependency influenced professional caregivers and their emotions.

Good and poor QoL

In the interviews, we asked professional caregivers to speak about persons with good and poor QoL and their concerns on QoL. Professional caregivers described good QoL in terms of being happy, having the ability to enjoy things, being relaxed, developing and having contact. In their description of good and poor QoL, most professional caregivers uttered hesitations, stressing that it is very difficult to know something about QoL in persons with PIMD, because they are unable to speak for themselves. While speaking about QoL of a person with PIMD, some participants questioned their own interpretations immediately. In the following quote

most of these aspects come along [P11 = Participant 11, I = Interviewer].

P11: [An example of a person with a good QoL is] a cheerful girl. She is developing in various fields, such as motor skills and communication. Yes, basically in everything. And she is developing in leaps and bounds, but we also have a girl that is progressing in very small steps. And if development is possible, in other words that they feel safe and comfortable enough for development to be possible.

I: So if I understand you correctly, an important component for you when considering quality of life is that a child develops in small or large steps?

P11: Yes, or that the child.... Well, that is very tricky when you put it like that, because sometimes you don't see any development. But they are content, they are having a good day basically. That you can see that the child is happy or that they... Even if the signals are not very strong but you see that the child experiences things as being pleasant. I think that if a child is crying the whole day or the child is only moaning and groaning, then you have to wonder what their quality of life is and how you could improve that by sorting things out

Another aspect of good QoL mentioned by several professional caregivers was the capability of persons with PIMD to have influence on their surroundings. They mentioned different examples of having influence such as, making choices in what they want to eat, drive away in their wheelchair, showing that they are not feeling well by moaning. The more a person with PIMD can show what he or she wants and the professional caregiver understands these signals, the better QoL there is according to these professional caregivers.

P4: Well, how can this client influence his or her own happiness? And that is very difficult, because in most cases this is very minimal, the influence that they can have in their lives. For example, when it comes to making decisions, but also about having a say in what happens to them.

I: In what sense do you mean. Do I understand you correctly, that you mean: if you have more of an influence then this usually means a greater quality of life? Or is that not the case?

P4: Yes, I do tend to think that way, yes. I think it would be great if that were possible. Yes, I am really basing that on my own situation. But place yourself in their situation, everything in their lives happens to them. We decide where you go, what you look like, whether you have a bath or not, what you eat, what you drink. Everything! Whether someone wipes your nose or not. If you have some sort of tool to make yourself understood, whatever that is or however that is achieved, then I think that would be fantastic! Then that is something that belongs to you and not because somebody else thinks that, it is yours.

In their description of poor QoL, these participants mentioned mostly physical elements such as experiencing pain, suffering, shortness of breath, illness or a combination of elements. Apart from these physical elements, some of them mentioned 'unhappy', 'excessive sleeping', 'no contact' and 'not visited by parents'.

P2: [An example of a person with PIMD with a poor QoL was] a very vulnerable girl, who often - almost always - had some physical ailment. She often had a cold or there was a problem with her tube feeding or, well all sorts of physical ailments that she was struggling with. And she did not like being touched, she found that very difficult. Her parents did not visit her often, they also found it very difficult. So yes, a girl who was always very vulnerable and difficult to have any form of contact with. It was hard for her to express what she liked and did not like. One thing that she did not like was being touched, that was very clear. But it was very difficult to see what she did like

How professional caregivers assessed QoL

When answering the questions in the interviews, participants not only described good or poor QoL, they also described spontaneously how they found out about QoL. Several participants mentioned that they 'read their faces', or that they 'felt' whether the person with PIMD was feeling well. Other participants described how they 'saw' it. In addition, some participants mentioned that they used their intuition to find out about the QoL of a person with PIMD. Stated differently, participants described in various ways that they 'sensed' QoL of the persons with PIMD.

P7: I find this a very difficult topic. It is very hard to say whether a client's quality of life is good.

I: What makes it difficult?

P7: Because they cannot express themselves, I think. It is something that we... We express our feelings. And my feeling may differ from that of a colleague. Because you are really trying to read their faces. And we base our judgement on that.

P11: Yes, that is very tricky, because that is very often the case with this target group, that you have to do everything based on your intuition.

Besides this 'sensing' QoL, participants described other ways of finding out QoL, for example by testing it using trial and error. Some participants mentioned that they discussed QoL of the person with PIMD with colleagues. The following quote is an example of how they used trial and error.

P7: Look, if I see that she is in pain - or I think that she is - then I say: "I will give paracetamol", but that does not help, that makes it tricky. And that to me is the most difficult about PIMD, that you are constantly on the lookout, what could it be? ...Is it the hip? And then - to be on the safe side - we go to the doctor again to check whether it is not dislocated, because she also has a hip problem. And you start ticking things off to check whether there are no physical problems, whilst in her case it could also be psychological. And yes, that is very difficult to determine. And that is why, with her, we are really trying to rule things out. We had a period in which we tried paracetamol. See whether things improve if she receives regular doses of paracetamol for a month. Now the antidepressants. After that, we will try dipiperon [antipsychotics]. And so, to conclude the entire story, maybe this is simply who this girl is and we need to accept that.

Dependency

Professional caregivers also described QoL of persons with PIMD as dependent on their social environment, which included family members and participants themselves. Participants felt the urge to know or understand the needs of their clients with PIMD and some of them referred to the importance of training to improve this. If they succeeded in finding out the needs, this contributed to good QoL. In other words, 'being understood' in their needs was an aspect of good QoL of persons with PIMD. Consequently, the more the person with PIMD was able to express his needs, the easier it was to fulfil these needs and contribute to good QoL according to participants.

I: Your first thought about quality of life for this group?

P8: Well, that they feel understood in what they express. I find that really important. That you really try to meet their needs. I think that this does give them quality of life. You sometimes hear examples of people who do not experience love. That they are unable to function at all.

I: And what is the difference between a lack of love and not being understood? Is that the same?

P8: Yes, I think that they are related.

I: So because you simply feel a lot of love for someone?

P8: Yes, but love is also not possible if you are simply not understood. If someone is not understood. If you look at how we use that training to really look at their needs... then you really start to meet their needs. I find that very beautiful.

Emotions of the respondents

In several interviews participants mentioned emotions related to this dependency or the search for the needs of their clients. These emotions occurred mostly when they could not fulfil the needs of persons with PIMD, or they could not find out the needs for good QoL. Some participants became emotional while describing the dependency of persons with PIMD and the impact this has on the relationship between the person with PIMD and the professional caregiver.

P1: I think that this is mainly due to the fact that these clients are so dependent on us, on our interpretations and our observations. But if you don't know whether someone is able to express himself, because something is holding him back, or whether it has something to do with pain, then what? I find that tricky.

I: But what you describe is that his quality of life could be determined by the relationship that he has with you and by what is possible in that relationship.

P1: Yes, I think so.

I: Yes, that is more or less what you are describing.

P1: But I think that if more - oh, now I am becoming a bit - if you could find more time. Yes, I am becoming emotional.

I: If you could give them even more time, then they would have a better quality of life?

P1: Yes, I think that if you were to see this client.

I: If you had more time?

P1: Well, maybe not so much more time, but greater continuity. If you look at your own family situation - and of course this isn't a family situation, but I think that is what these clients actually need, a small group of people surrounding them and caring for them. And learning to understand them. But of course, that group is quite large. And this is actually great for some clients, this diversity. And of course, you should not compare it directly to a family. But sometimes I do wonder, with all the varying contacts it is sometimes hard to build a relationship. And in the case of that one boy, the second client that I mentioned, I think that is really a shortcoming.

Several professional caregivers mentioned situations in which they knew the needs for good QoL of persons with PIMD but could not fulfil these needs. In these cases, they uttered feelings of frustration and experienced failure. There was usually an organisational reason for not being able to meet the needs of the persons with PIMD, such as staff shortages or lack of time.

P6: Well, living in an institution definitely has an effect on the quality of life, because when you live in an institution you are faced with time constraints.

I: And how is that for you?

P6: Frustrating! Yes. Frustrating. And that has a major effect on me, which in turn impacts on the way in which I interact with that child. In other words, it affects the quality of how I care for someone. Yes, so where the client lives is a major topic when it comes to quality of life. And not only when it comes to time, but a lot of other factors too: type of people, level of education.

P7: And you really notice that and I think it also has an effect on the quality of life. We have a girl that is quite tense as far as muscle tone is concerned, so it would be ideal if she could take a bath every day. That is great for her, because then she can relax, well then she probably (inaudible), but you do not have that time.

Some participants mentioned emotions when they were no longer able to find ways to achieve good QoL in persons with PIMD. For example, if they did not know how to achieve happiness. Some participants mentioned feelings of powerlessness.

P10: In my opinion, when I think about it, it is the moment when you experience a sense of being powerless. That's what I think.

I: If you start feeling powerless?

P10: Yes, when you no longer know how to make someone happy, like the girl that cried the whole day.

I: Yes. That is quite possible.

P10: That's what I think.

I: And what is that then? In the moment that you feel powerless? (pause) Yes, because what was it you said just now? That you no longer know how to make someone happy?

P10: Yes. That you are no longer able to make the client feel happy, or safe.

P2: Well yes, I think the word "powerlessness" too. Yes. That you can pull out all the stops and if nothing helps. Or if another colleague also does not succeed. Nobody is able to achieve that bit of relaxation or that bit of pleasant life for him or her. Then it feels like a heavy burden.

Discussion

In this study, we explored professional caregivers' perceptions on QoL of persons with PIMD. We found examples of good and poor QoL. The quotes revealed that professional caregivers 'sensed' QoL in different ways, and they tested it (trial and error) and discussed QoL of persons with PIMD with colleagues. Working with persons with PIMD, as our findings suggest, can touch their professional caregivers, especially when they do not know how to achieve good QoL for these persons.

In describing good and poor QoL, we found the same elements as we found in previous research on the perception of physicians on QoL of persons with PIMD (Nieuwenhuijse *et al.* 2019). Good QoL was mostly described in emotional terms such as happiness, pleasure and enjoying things. Poor QoL was mostly described in physical terms such as pain, sickness and shortage of breath. This is also in line with the QoL domains of emotional well-being and physical well-being, described by others (Felce and Perry 1995, Schalock *et al.* 2008). Furthermore, the findings suggest that the capability to influence the environment of persons with PIMD is an element of good QoL. In these cases, the person with PIMD is able to express what (s)he wants, or professional caregivers are able to find out the needs of the person with PIMD. This finding highlights an aspect of QoL that is hardly captured by the domains we found in a previous literature review (Nieuwenhuijse *et al.* 2017). However, this aspect of QoL may be worth further exploring, because it could be an important aspect of QoL of persons with PIMD.

Our study suggests that professional caregivers assess QoL mainly by sensing it: our participants saw it, read faces, felt it or they based it on their intuition. These findings could be seen as descriptions of how professional caregivers develop knowledge on QoL of persons with PIMD, which is mostly tacit knowledge. These findings are in line with Reinders (2010) describing the importance of tacit knowledge in care (Reinders 2010). Interestingly, our study suggests that not all of their knowledge is tacit: sometimes, professional caregivers verify their knowledge by testing it (using trial and error) and discussing with colleagues. Their use of (tacit) knowledge may be a valuable addition to the current assessment methods of QoL, which focus mostly on objective measurement of QoL, and it deserves further scrutiny in future studies.

Several of our participants described the relatedness between the QoL of persons with PIMD and

themselves. Reinders (2010) already argued that a high quality of relationship between professional caregiver and client was necessary for good care. Our findings also suggest that QoL of persons with PIMD is dependent on that relationship. In previous research, one of the physicians stated that persons with PIMD 'cannot make their own QoL' (Nieuwenhuijse *et al.* 2019). This relationship between QoL of persons with PIMD and the professional caregiver could be described in different ways. In an epistemic sense, it means that the professional caregivers have the knowledge on QoL of persons with PIMD. In an instrumental sense, the professional caregiver knows and uses instruments to improve QoL in persons with PIMD. This is comparable with a surgeon, whose surgical intervention is an instrument to cure a patient. In a constitutive sense, the professional caregiver is the source of QoL of the person with PIMD. Our findings indicate that all these descriptions apply to the relationship between the professional caregiver and QoL of persons with PIMD. On the other hand, maybe these different descriptions cannot be separated from one another and go together.

Being a source of QoL may feel like a huge responsibility for professional caregivers though, and it may explain the emotional reaction of some of them. The experiences of failure and powerlessness illustrate that caring for the QoL of persons with PIMD has an impact on professional caregivers. In the literature, emotional demands are described as one of the predictors of burn-out in persons working with people with intellectual disabilities (Kowalski *et al.* 2010, Kozak *et al.* 2013). In addition, the impact of feelings of powerlessness is described in the literature (Milberg *et al.* 2004). Professional caregivers in our study experienced failure when they were unable to fulfil the needs of persons with PIMD, due to circumstances such as lack of time or workload. We are not sure that residential care facilities and day care centres in our country are always aware of this relatedness between the QoL of persons with PIMD and their caregivers and the impact it may have on caregivers. Our study supports awareness of these issues, which may help to reduce the threats to the continuity of care for those who are fully dependent on others.

Understanding the needs of persons with PIMD was very important according to our participants. Some of them mentioned the benefits of specialised training to 'understand' persons with PIMD. The necessity of programmes in which the needs of persons with PIMD are systematically examined and further explored in activities and goals is also mentioned in the literature (Poppes *et al.* 2002, Vlaskamp *et al.* 2007, Vlaskamp and van der Putten 2009). In addition, if professional caregivers improve their understanding of the needs of persons with PIMD, this can provide greater satisfaction and enjoyment of work. Furthermore, consultation and

intervention or supervision may help professional caregivers to improve their understanding of persons with PIMD and bring emotional responses more into perspective.

The strength of this study is that it not only provides insight into how professional caregivers view QoL in persons with PIMD, but that it also reveals the influence of the relationship between the person with PIMD and the professional caregiver on the QoL of persons with PIMD. Moreover, our findings may provide valuable additions to the current assessment instruments. However, this research was conducted with eleven Dutch respondents and therefore provides information about working in Dutch care organisations. We do not know whether there would be a different outcome in other countries or cultures. A second point to note is that all participants were female. However, because this reflects the field, we do not see that as a limitation.

We conclude that this study provides insight into professional caregivers' perspectives on QoL of persons with PIMD. They develop and use their (tacit) knowledge to assess QoL of persons with PIMD. The relationship between QoL of persons with PIMD and their professional caregivers deserves further attention in future studies. Paramount to these are the findings on professional caregivers' experiences of failure and powerlessness, when working with persons with PIMD and trying to assess and fulfil their needs for good QoL. These findings demand recognition of the work of professional caregivers in caring for persons with PIMD. This means enough training and supervision, organisation models that facilitate to build a relationship with persons with PIMD and recognition of any moral distress and its impact on the caregivers and the care they give. Management of both day care centres and residential care facilities should take their responsibility in providing the necessary conditions so that professional caregivers can do their job properly and without unnecessary moral distress.

Acknowledgements

This study is part of a research project entitled 'Quality of Life in persons with Profound Intellectual and Multiple Disabilities'.

The authors thank Prof. Dr. M.F. Verweij, Wageningen University, for his suggestions on the distinctions between epistemic, instrumental and constitutive relationship between QoL of the person with PIMD and her professional caregiver (see Discussion). In addition, we would like to thank Drs. C.L. Nieuwenhuijse-Ward for proof-reading the text.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

This work was supported by the NWO, The Netherlands Organisation for Scientific Research under Grant 319-20-004.

References

- Adams, T. and Jahoda, A. 2019. Listening to mothers: Experiences of mental health support and insights into adapting therapy for people with severe or profound intellectual disabilities. *International Journal of Developmental Disabilities*, 65, 135–142.
- Axelsson, A. K., Imms, C. and Wilder, J. 2014. Strategies that facilitate participation in family activities of children and adolescents with profound intellectual and multiple disabilities: Parents' and personal assistants' experiences. *Disability and Rehabilitation*, 36, 2169–2177.
- Braun, V. and Clarke, V. 2006. Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77–101.
- Cummins, R. A. 2005. Moving from the quality of life concept to a theory. *Journal of Intellectual Disability Research*, 49, 699–706.
- Jansen, S. L. G., van der Putten, A. A. J. and Vlaskamp, C. 2013. What parents find important in the support of a child with profound intellectual and multiple disabilities. *Child: Care, Health and Development*, 39, 432–441.
- Felce, D. and Perry, J. 1995. Quality of life: Its definition and measurement. *Research in Developmental Disabilities*, 16, 51–74.
- Kamstra, A., van der Putten, A. A. and Vlaskamp, C. 2015. The structure of informal social networks of persons with profound intellectual and multiple disabilities. *Journal of Applied Research in Intellectual Disabilities*, 28, 249–256.
- Kowalski, C., Driller, E., Ernstmann, N., Alich, S., Karbach, U., Ommen, O., Schulz-Nieswandt, F. and Pfaff, H. 2010. Associations between emotional exhaustion, social capital, workload, and latitude in decision-making among professionals working with people with disabilities. *Research in Developmental Disabilities*, 31, 470–479.
- Kozak, A., Kersten, M., Schillmöller, Z. and Nienhaus, A. 2013. Psychosocial work-related predictors and consequences of personal burnout among staff working with people with intellectual disabilities. *Research in Developmental Disabilities*, 34, 102–115.
- Milberg, A., Strang, P. and Jakobsson, M. 2004. Next of kin's experience of powerlessness and helplessness in palliative home care. *Supportive Care in Cancer: Official Journal of the Multinational Association of Supportive Care in Cancer*, 12, 120–128.
- Nakken, H. and Vlaskamp, C. 2007. A need for a taxonomy for profound intellectual and multiple disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 4, 83–87.
- Nieuwenhuijse, A. M., Willems, D. L., van Goudoever, J. B., Echteld, M. A. and Olsman, E. 2017. Quality of life of persons with profound intellectual and multiple disabilities: A narrative literature review of concepts, assessment methods and assessors. *Journal of Intellectual & Developmental Disability*, 44, 1–11.
- Nieuwenhuijse, A. M., Willems, D.L. and Olsman, E. 2019. Physicians' perceptions on Quality of Life of persons with profound intellectual and multiple disabilities: A qualitative study. *Journal of Intellectual & Developmental Disability*.
- Petry, K. and Maes, B. 2009. Quality of life: People with profound intellectual and multiple disabilities. In: J. Pawlyn and S. Carnaby, eds. *Profound intellectual and multiple disabilities. Nursing complex needs*. Oxford: Wiley-Blackwell, pp.15–36.
- Petry, K., Maes, B. and Vlaskamp, C. 2005. Domains of quality of life of people with profound multiple disabilities: The perspective of parents and direct support staff. *Journal of Applied Research in Intellectual Disabilities*, 18, 35–46.
- Petry, K., Maes, B. and Vlaskamp, C. 2007. Support characteristics associated with the quality of life of people with profound intellectual and multiple disabilities: The perspective of parents and direct support staff. *Journal of Policy and Practice in Intellectual Disabilities*, 4, 104–110.
- Poppes, P., Vlaskamp, C., de Geeter, K. I. and Nakken, H. 2002. The importance of setting goals: The effect of instruction and training on the technical and intrinsic quality of goals. *European Journal of Special Needs Education*, 17, 241–250.
- Reinders, H. 2010. The importance of tacit knowledge in practices of care. *Journal of Intellectual Disability Research*, 54, 28–37.

- Schalock, R. L. 2004. The concept of quality of life: What we know and do not know. *Journal of Intellectual Disability Research*, 48, 203–216.
- Schalock, R. L., Bonham, G. S. and Verdugo, M. A. 2008. The conceptualization and measurement of quality of life: Implications for program planning and evaluation in the field of intellectual disabilities. *Evaluation and Program Planning*, 31, 181–190.
- Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L., Keith, K. D. and Parmenter, T. 2002. Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Report of an international panel of experts. *Mental Retardation*, 40, 457–470.
- Seliner, B., Latal, B. and Spirig, R. 2016. When children with profound multiple disabilities are hospitalized: A cross-sectional survey of parental burden of care, quality of life of parents and their hospitalized children, and satisfaction with family-centered care. *Journal for Specialists in Pediatric Nursing*, 21, 147–157.
- Tadema, A. C. and Vlaskamp, C. 2010. The time and effort in taking care for children with profound intellectual and multiple disabilities: A study on care load and support. *British Journal of Learning Disabilities*, 38, 41–48.
- Tong, A., Sainsbury, P. and Craig, J. 2007. Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19, 349–357.
- Verdugo, M. A., Schalock, R. L., Keith, K. D. and Stancliffe, R. J. 2005. Quality of life and its measurement: Important principles and guidelines. *Journal of Intellectual Disability Research*, 49, 707–717.
- Vlaskamp, C. and van der Putten, A. 2009. Focus on interaction: The use of an Individualized Support Program for persons with profound intellectual and multiple disabilities. *Research in Developmental Disabilities*, 30, 873–883.
- Vlaskamp, C., Hiemstra, S. J. and Wiersma, L. A. 2007. Becoming aware of what you know or need to know: Gathering client and context characteristics in day services for persons with profound intellectual and multiple disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 4, 97–103.
- Zaal-Schuller, I. H., Willems, D. L., Ewals, F. V. P. M., van Goudoever, J. B. and de Vos, M. A. 2018. Considering quality of life in end-of-life decisions for severely disabled children. *Research in Developmental Disabilities*, 73, 67–75.
- Zijlstra, R., Vlaskamp, C. and Buntinx, W. 2001. Direct care staff turnover: An indicator of the quality of life of individuals with profound multiple disabilities. *European Journal on Mental Disability*, 22, 39–55.