

PDF hosted at the Radboud Repository of the Radboud University Nijmegen

The following full text is a publisher's version.

For additional information about this publication click this link.

<http://hdl.handle.net/2066/200640>

Please be advised that this information was generated on 2019-12-15 and may be subject to change.

Perceptions of staff and family of the quality of life of people with severe to profound intellectual disability

Karin C. J. M. de Geus-Neelen^{a,b}, Wietske M. W. J. van Oorsouw^a, Lex A. H. C. Hendriks^{a,c} and Petri J. C. M. Embregts^d

^aDepartment of Tranzo, Tilburg School of Social and Behavioral Sciences, Tilburg University, Tilburg, The Netherlands; ^bS&L Zorg, Roosendaal, The Netherlands; ^cSchool of Pedagogical and Educational Science, Faculty of Social Sciences, Radboud University, Nijmegen, The Netherlands; ^dDichterbij Innovation and Science, Gennep, The Netherlands

ABSTRACT

Background: Staff and relatives often act as advocates for people with severe to profound intellectual disability (ID). Since staff and relatives make proxy judgements about quality of life for people with severe to profound ID, it is important to know how well the perceptions of the two groups correspond with each other.

Method: Fifty-one staff-family dyads completed the QOL-PMD questionnaire. Agreement between proxies was assessed using the proportion of observer agreement (*Po*) and Wilcoxon signed-rank tests.

Results: Proxies agreed relatively strongly about the applicability of questionnaire items. There was also relatively strong agreement about the client's QOL, except for items related to internal, subjective experiences (e.g., sexual fulfillment, pain).

Conclusion: People with severe to profound ID are not able to report their QOL well. Because the people making proxy judgements about their QOL are not in good agreement on some of the most critical subjective indicators, careful information exchange about these indicators is important for improving the QOL of people with ID.

KEYWORDS

Quality of life; intellectual disability; proxy; staff; family


Care for people with intellectual disability (ID) is strongly influenced by the quality of life (QOL) paradigm (Claes, Van Hove, Van Loon, Vandeveld, & Schalock, 2010; Schalock, Verdugo, Bonham, Fantova, & Van Loon, 2008). Policy, health-care organisations and researchers are increasingly focussing on QOL domains to understand and support the needs of people with ID (Gómez, Verdugo, Arias, Navas, & Schalock, 2013; Luckasson & Schalock, 2013). Therefore, QOL assessments are increasingly used in individual support planning and evaluation. Because such assessments are based on individual perceptions and influenced by subjective goals and expectations (Claes et al., 2010), QOL assessments are, ideally, directly provided by people with ID themselves.

However, people with severe levels of ID are not able to verbally express their own perceptions of QOL indicators, making self-report difficult (Berenschot & Blijleven, 2003; Crocker, Smith, & Skevington, 2015). Although proxy information might be biased compared to self-report, or even invalid, Verdugo, Schalock, Keith, and Stancliffe (2005) have stressed that the use

of proxies might be the best possible alternative for the particular population of people with severe ID. Nowadays, it is common for both staff and relatives to speak on behalf of people with severe ID and serve as their proxies (McGillivray, Lau, Cummins, & Davey, 2009; Petry, Maes, & Vlaskamp, 2005; Watson, 2012).

It is relevant, in this context, that the role of family members in the lives of people with ID has changed (Embregts, 2011). Relatives increasingly act as advocates, information seekers, support evaluators, spokespersons, and providers of social support, guidance and financial assistance (e.g., Dunst & Dempsey, 2007). Furthermore, personal contributions of relatives to health-care services (e.g., assisting trips and hospital visits) are accepted and even expected more often. Because of their lifelong connection, relatives are a rich source of information that adds to that provided by staff (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004).

Because staff and relatives make proxy judgements about quality of life for people with severe to profound ID, it is important to know how well the perceptions of the two groups correspond, here referred to as proxy

CONTACT Karin C. J. M. de Geus-Neelen  k.d.geus@slzorg.nl

© 2017 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.

agreement. Schalock and Keith (1993) and Stancliffe (1999) have reported agreement between staff and relatives on QOL indicators, but other groups have reported conflicting results (Nolan, Luther, Young, & Murphy, 2014; White-Koning, Grandjean, Colver, & Arnaud, 2008). Discrepancies and low correlations were, for example, found in psychological well-being and social support when staff and relatives assessed the QOL of people with ID. Crocker et al. (2015) and Sneeuw, Sprangers, and Aaronson (2002) found that there was greater overall proxy agreement between staff and relatives in the physical domain than in social or environment domains. In addition, De Geus-Neelen, van Oorsouw, and Embregts (2014) reported lack of agreement in the domains of self-determination and rights. Parents of individuals with severe ID tended to assess the quality of these domains more positively than staff members. Overall, proxy agreement about the QOL of people with severe ID is ambiguous.

In the present study, we focus on proxy agreement about the QOL indicators of people with severe or profound ID. Staff and family perceptions were measured using the Quality of Life of People with Profound Multiple Disabilities scale (QOL-PMD). Two research questions were formulated: (a) Do staff and family agree on the applicability of QOL-PMD items for their client or relative? (b) Do staff and family agree in their judgements of the QOL of their client or relative based on the items of the QOL-PMD?

Methods

Design

In this study, we compared similarities in perceptions of staff and families (i.e., proxy agreement) on QOL of individuals with severe or profound ID. Perceptions were based on ratings on the 55-item QOL-PMD questionnaire. Fifty-one staff-family dyads completed the questionnaire once-only. Each dyad fulfilled the questionnaire regarding one particular individual with severe or profound ID. This study was approved by the Psychological Ethics Committee of Tilburg University [EC-2014.08].

Participants

Fifty-one dyads of staff and family members participated in this study. Each dyad was related to one client with severe to profound ID. The clients' IQ level was assessed by using the Snijders Oomen Non-Verbal Intelligence Test (SON) (Snijders & Snijders-Oomen, 1975), and clients' level of verbal communication was assessed by the

subscale "language" of the Dutch Social Functional Scale (SRZ, Kraijer & Kema, 1994). According to the fifth edition Diagnostic and statistical manual of mental disorders (DSM-V, American Psychiatric Association, 2013), 33 participants had severe levels of ID (i.e., IQ < 40; SRZ < 6) and 18 participants in the present study had profound levels of ID and profound multiple disabilities (PMD, IQ range < 25; SRZ = 3). Participants were unable to verbally self-report in relation to QOL-questionnaires because people with severe to profound ID do not have the skills required for introspection and higher-order judgement concerning their life situation (Selai & Rosser, 1993). Clients were living in a 24-hr support residence in the South-West of the Netherlands. Inclusion criteria required that clients were not able to self-report, each client lived at his or her current home for at least 6 months, and had at least one family member who was involved in his or her life (i.e., lives within 30 km and visits the client at least once a month). Out of 51 clients, 20 were men and 31 were women. The average age of clients was 49 years ($SD = 16$ years; range 17–85 years). Eighteen clients showed severe forms of challenging behaviour, which mainly consisted of physical and verbal aggression towards others. All clients had extensive support needs and received a daily-activity program at their residence. Clients themselves were not actively involved in this study.

The group of staff members consisted of 8 men and 43 women, with an average age of 35 years ($SD = 9$ years; range 24–54 years). Staff members worked on a regular basis, at least twice a week and had extensive and direct contact (due to physical impairments) with their client. Following high school, 32 staff members finished a 3-year professional training program and 19 staff members finished a 5-year professional training program in the domain of social work. Training programs concerned courses at college and were finished with a certificate. All certified participants were employed as direct-care staff. Their working experience in supporting people with ID ranged from 1 to 15 years ($M = 5$ years, $SD = 4$ years). Table 1 contains information about the education and job types of staff members.

The family group consisted of 51 relatives (19 mothers, 3 fathers, 8 brothers, 16 sisters and 5 cousins).

Table 1. Participating staff members: job type and education level.

Staff members	<i>N</i>
Job type	
Staff	26
Mentor	17
Care-manager	8
Education	
3-year professional training (college)	32
5-year professional training (college)	19

Table 2. Participating family members: relation to client, distance and number of visits

Family members	N
Relation to the client	
Mother	19
Father	3
Sister	16
Brother	8
Other	5
Distance to the client	
<10 km	14
=10 km	23
≤20 km	11
≤30 km	3
Visits	
Twice a week	3
Once a week	14
Once every two weeks	17
Once a month	17

They had an average age of 58 years ($SD = 9$ years; range 39–75 years) and each family member lived close (i.e., <30 km) to their relative. Sixty-four percent of the group met their relative on a regular basis (twice a week [6%]; once a week [27%]; or once every two weeks [33%]), while 33% of the group met their relative once every month (see Table 2).

Measures

Demographic characteristics

Demographic characteristics of staff and relatives were obtained by a self-developed questionnaire. Both staff and relatives completed this written questionnaire individually. Demographic characteristics of clients were based on their personal files.

Quality of life of people with profound multiple disabilities

The QOL-PMD (Petry, Maes, & Vlaskamp, 2009a) was used to measure the QOL of participants in the present study. This proxy instrument contains 55 items divided into 6 subscales: (1) Physical well-being (e.g., The person is well-rested in the morning); (2) Material well-being (e.g., The person stays in rooms that are geared to his needs, for instance with regard to lighting); (3) Communication and influence (e.g., The person has influence on his or her direct environment); (4) Social well-being (e.g., The person has positive social contacts that are meaningful to him or her outside the context of professional support); (5) Development (e.g., The person optimally uses his or her communicative abilities); and (6) Activities (e.g., The person participates in activities in the open air). The full list of questions is shown in Table 3.

The multiple-choice questionnaire provided three choice options: ([A] “this item is applicable to the client”,

[B] “this item is not applicable to the client”, [C] “I don’t know if this item is applicable to the client”). These three choice options resulted in nominal scores. If an item was judged to be applicable to the client (choice option A), the participant continued by rating his or her agreement with the content of the item on a 3-point Likert scale (0 = disagree; 1 = partly agree; 2 = agree). If participants had rated an item as “this item is not applicable to the client”, or “I don’t know if this item is applicable to the client”, the scores were indicated as missing values in the analyses of the second research question. Petry, Maes, and Vlaskamp (2009b) examined the psychometric properties of the QOL-PMD. The QOL-PMD demonstrated good internal consistency, based on high alpha values for both of the informant groups and for the total group (range $\alpha = 0.90$ – 0.92). Furthermore, the results of Petry et al. (2009b) provided preliminary evidence for the construct validity of the QOL-PMD. In our study, the internal consistency of the QOL-PMD was calculated with Cronbach’s alpha and considered sufficient for staff members ($\alpha = 0.76$) and good for family members ($\alpha = 0.92$).

Procedure

Following the permission of the Board of the participating care organisation for people with ID, the Psychological Ethics Committee of Tilburg University authorised the research team to conduct the study [EC-2014-08]. Consequently, the selection of staff-family dyads started with a random selection of clients. Following the selection of clients, related case-managers were invited for a meeting, at which the purpose and procedure of the research project was explained. Thereupon, the case-managers selected the relatives most intensively involved in the care of the client. The first author sent an introductory letter, consent letter, demographics questionnaire, the QOL-PMD, and a stamped addressed envelope to the relatives of the selected clients. Case-managers subsequently approached these relatives to ask whether the letters and questionnaires had arrived, whether they were willing to participate, and whether there was any need for assistance. As a final reminder, case-managers phoned relatives who had not responded within two weeks of sending the package. After permission from relatives had been obtained and their informed consent and completed questionnaires were resent, staff members were invited to complete the demographic questionnaire and QOL-PMD. Staff members were selected by case-managers, based upon their working experience and knowledge of the particular client. All data were anonymously imported into an SPSS dataset for statistical analyses,

Table 3. Proportion observer agreement on the items of the QOL-PMD by staff and family member dyads (“applicable” or “not applicable”).

Domain Items	Po
<i>Physical well-being</i>	
The person is well-rested in the morning	1*
The individual's physical health status is good	1*
During the last year, the individual's problems arising from physical impairments have decreased	.71
The person experiences no problems during daily activities due to sensory impairments	.79
The person experiences no discomfort from feeding problems	.92*
The individual's mental health status is good	.96*
<i>Material well-being</i>	
The person has privacy	.96*
The person has all technical aids and adaptations that he needs regarding communication	.65
The environment outside the living group is adapted to the individual's abilities and limitations	.78
The person stays in rooms that are geared to his needs and wishes with regard to decoration	.82*
The person has all technical aids and adaptations that he needs regarding activities and leisure	.73
He stays in rooms that are geared to his needs with regard to for example lighting	.81*
The person receives tasty and balanced nutrition	1*
The person stays in rooms that are accessible	.98*
The person stays in rooms that are safe	1*
<i>Communication and Influence</i>	
The person expresses his preferences with regard to activities and actions	1*
The person makes clear his feelings, needs and wishes. The person is “heard”	.98*
The person makes a contribution to the communication process on his own initiative or as a reaction	.81*
The person expresses his preferences with regard to nourishment	1*
The person understands what the people in his environment want to make clear	1*
The person expresses his preferences with regard to direct staff or group members	1*
The person can follow the presence of support staff during the day	1*
The person has influence on his direct environment	.93*
The person can recognise and anticipate what is happening around him	.92*
<i>Social well-being</i>	
The person regularly makes use of community services and facilities	.92*
He has positive social contacts which are meaningful to him outside the context of professional support	.96*
The person has positive social contacts which are meaningful to him with group members	1*
The person is regularly involved in activities and action with the direct support staff that he prefers	.78
The person has good contact with his parents or direct family members	.98*
The person lives in a community	.94*
The person expresses affection toward people in his direct environment	1*
The person is regularly involved in activities with the group members that he prefers	.89*
<i>Development</i>	
The person optimally uses his intellectual abilities	.98*
The person receives developmental stimulation or education or is employed	.94*
The person optimally uses his socio-emotional abilities	.98*
The person gets the opportunity to perform activities and actions	1*
The person optimally uses his sensory abilities	1*
The person acquires new skills or experiences by participating in activities	.93*
The person optimally uses his communicative abilities	.96*
The person optimally uses his physical abilities	.94*
The person optimally uses his adaptive behaviour skills	.94*
<i>Activity</i>	
The person participates in activities that he can mentally cope with	.98*
The person participates in activities that interest him	.94*
During daytime, the person seldom has to occupy himself	1*
The person actively engaged in activities	.98*
The person is never asleep during daytime because of a shortage of activation	.80*
The person experience sufficient variation in the range and place of activities	1*
The person participates during the day in several group or individual activities	.98*
The person participates in activities that he can physically cope with	.98*
The person participates in activities in open air	.96*
The person participates in activities that are offered in leisure and cultural facilities in the community	.88*

Note. Four QOL-PMD items are excluded due to >15% answering with “I don't know if this item is applicable”.

*Po ≥ .80.

and archived in accordance with the guidelines of Tilburg University.

Analyses

SPSS version 20.0 was used to conduct statistical analyses. First, we explored the dataset for accuracy in

the answers by conducting descriptive analyses. Internal consistency of the QOL-PMD was calculated with Cronbach's alpha, which is generally considered as acceptable with $\alpha > 0.7$ (Nijdam, 2003). Exploration of the dataset revealed that staff and relatives used the response option “I don't know if this item is applicable to the client” relatively often (>15%) for four particular

items: “The person experiences no discomfort due to side effects of the administered medication”; “The person has no pain”; “The person express his preference with regard to mobility”; and “The individual’s sexual needs are fulfilled”. As a result of the high proportion of responses of “I don’t know if this item is applicable to the client” for these four items, they decreased the power of the analysis, as such, these items were excluded from the analyses for both research questions, and are presented separately at the end of the results section. Finally, the data also proved to be skewed. Pols and Bosveld (2003) stressed that in the case of 2×2 crosstabs with results that appear paradoxical because of skewed data (i.e., the bias-effect of kappa), the proportion of positive agreements should be presented instead of kappa. Therefore, to answer the first research question, the observer agreement (e.g., applicable or not applicable) was calculated for the 51 items of the QOL-PMD. To answer the second research question, a Wilcoxon signed-rank test was conducted.

Results

Proxy agreement about the applicability of QOL-PMD items

To answer the first research question (Do staff and family members agree on the applicability of QOL-PMD items for their client or relative?), the proportions of positive agreement between staff and family members were calculated for each item. Dyads in which one of both partners (i.e., staff or family member) had rated the item as “I don’t know if this item is applicable to the client”, were treated as missing in the present analyses. Thereupon, dichotomised scores (i.e., [“this item is applicable to the client”] and [“this item is not applicable to the client”]) of staff-family dyads were visualised in 2×2 crosstabs for each item. Due to missing values, the N of each crosstab ranged from 40 to 51 dyads who had rated the item. Table 3 presents the P_o for each item of the QOL-PMD and shows that P_o ranged from 0.65 to 1. Because the literature does not provide P_o -acceptability levels, Landis and Koch’s guidelines (1977) were followed, which suggest choosing the highest degree of agreement ($P_o \geq .80$). P_o scores were $\geq .80$ for 45/51 items (88%), including all items in the domains communication and influence, development, and activity. Across these 45 items, 95% of the dyads unanimously considered the item “applicable to the client”, and 1% of the dyads unanimously considered the item “not applicable to the client”. Only six out of 51 items had P_o scores $< .80$. These items come from the physical, material and social well-being domains.

Proxy agreement about quality of life based on the QOL-PMD

To answer the second research question (Do staff and family members agree on their judgement regarding the quality of life for their client or relative based on the items of the QOL-PMD), the analyses solely focused on dyads that agreed in rating the item as “being applicable to the client”. The number of dyads that remained ranged from 12 to 51 per item across all domains. Higher mean item scores represented more agreement with respect to an item. Table 4 shows the results of the Wilcoxon signed-rank tests and shows that dyads agreed on 45/51 items (88%). This implies that staff-family dyads disagreed significantly regarding the content of only six items that were divided across five domains (i.e., all domains except physical well-being). Staff members had higher mean scores compared to family members for the items: “The person expresses his preferences with regard to activities and actions” ($M_{\text{staff}} = 1.63$, $SD_{\text{staff}} = .53$; $M_{\text{family}} = 1.49$, $SD_{\text{family}} = .51$) and “The person participates in activities that he can physically cope with” ($M_{\text{staff}} = 1.86$, $SD_{\text{staff}} = .35$; $M_{\text{family}} = 1.60$, $SD_{\text{family}} = .61$). Mean scores of family members were higher compared to staff for the items: “The person stays in rooms that are accessible” ($M_{\text{staff}} = 1.67$, $SD_{\text{staff}} = .55$; $M_{\text{family}} = 1.84$, $SD_{\text{family}} = .42$); “The person has positive social contacts which are meaningful to him outside the context of professional support” ($M_{\text{staff}} = 1.27$, $SD_{\text{staff}} = .82$; $M_{\text{family}} = 1.53$, $SD_{\text{family}} = .62$); “The person is regularly involved in activities and actions with the direct support staff that he prefers” ($M_{\text{staff}} = 1.02$, $SD_{\text{staff}} = .69$; $M_{\text{family}} = 1.42$, $SD_{\text{family}} = .72$); and “The person optimally uses his socio-emotional abilities” ($M_{\text{staff}} = 1.37$, $SD_{\text{staff}} = .71$; $M_{\text{family}} = 1.52$, $SD_{\text{family}} = .63$).

Secondary analyses of excluded items

Four items of the QOL-PMD were considered missing and excluded from the analyses of the research questions (see analyses in the Methods section). Because of the potential relevance of the ambiguous judgements of these items, Table 5 presents the frequencies and the P_o of these four items.

Almost half of the staff and family members indicated the item “The individual’s sexual needs are fulfilled” with the answer “I don’t know if this item is applicable to the client”. The relatively low P_o value of this item (i.e., .53) indicates that staff-family dyads did not agree. Although P_o values were higher for the remaining three items (“The person experiences no discomfort due to the administered medication”; “The person has no pain”; “The person expresses his preference with regard to mobility”), they were still below .80. For these items, family members

Table 4. Wilcoxon Signed-rank test of the items of the QOL-PMD by staff-family member dyads.

Domain Items	Z	p
<i>Physical well-being</i>		
The person is well-rested in the morning	-1.807	.071
The individual's physical health status is good	-1.500	.134
During the last year, the individual's problems arising from physical impairments have decreased	-.378	.705
The person experiences no problems during daily activities due to sensory impairments	-1.384	.166
The person experiences no discomfort from feeding problems	-.361	.718
The individual's mental health status is good	-.539	.590
<i>Material well-being</i>		
The person has privacy	-.842	.400
The person has all technical aids and adaptations that he needs regarding communication	-1.406	.160
The environment outside the living group is adapted to the individual's abilities and limitations	-.892	.373
The person stays in rooms that are geared to his needs and wishes with regard to decoration	-.915	.360
The person has all technical aids and adaptations that he needs regarding activities and leisure	-.984	.325
He stays in rooms that are geared to his needs with regard to his needs with regard to for example lighting	-.361	.718
The person receives tasty and balanced nutrition	-1.604	.109
The person stays in rooms that are accessible	-2.066	.039*
The person stays in rooms that are safe	-1.311	.190
<i>Communication and Influence</i>		
The person expresses his preferences with regard to activities and actions	-2.000	.046*
The person makes clear his feelings, needs and wishes. The person is "heard"	-1.000	.317
The person makes a contribution to the communication process on his own initiative or as a reaction	-.714	.475
The person expresses his preferences with regard to nourishment	-1.710	.087
The person understands what the people in his environment want to make clear	-1.606	.108
The person expresses his preferences with regard to direct staff or group members	-1.292	.196
The person can follow the presence of support staff during the day	-.775	.439
The person has influence on his direct environment	-.046	.963
The person can recognise and anticipate what is happening around him	.000	1
<i>Social well-being</i>		
The person regularly makes use of community services and facilities	-1.058	.290
He has positive social contacts which are meaningful to him outside the context of professional support	-2.120	.034*
The person has positive social contacts which are meaningful to him with group members	-.426	.670
The person is regularly involved in activities and action with the direct support staff that he prefers	-2.295	.022*
The person has good contact with his parents or direct family members	-1.165	.244
The person lives in a community	-.163	.870
The person expresses affection toward people in his direct environment	-1.602	.109
The person is regularly involved in activities with the group members that he prefers	-1.604	.109
<i>Development</i>		
The person optimally uses his intellectual abilities	-.034	.973
The person receives developmental stimulation or education or is employed	-.406	.685
The person optimally uses his socio-emotional abilities	-1.978	.048*
The person gets the opportunity to perform activities and actions	-.535	.593
The person optimally uses his sensory abilities	-1.107	.268
The person acquires new skills or experiences by participating in activities	-.297	.767
The person optimally uses his communicative abilities	-1.000	.317
The person optimally uses his physical abilities	-1.454	.146
The person optimally uses his adaptive behaviour skills	.000	1
<i>Activity</i>		
The person participates in activities that he can mentally cope with	-1.641	.101
The person participates in activities that interest him	-.191	.849
During daytime, the person seldom has to occupy himself	-.343	.732
The person actively engaged in activities	-.771	.440
The person is never asleep during daytime because of a shortage of activation	-1.311	.190
The person experience sufficient variation in the range and place of activities	-.390	.696
The person participates during the day in several group or individual activities	-.699	.485
The person participates in activities that he can physically cope with	-2.968	.003*
The person participates in activities in open air	-.398	.691
The person participates in activities that are offered in leisure and cultural facilities in the community	-.932	.351

Note. Four QOL-PMD items are excluded due to >15% answering with "I don't know if this item is applicable".

* $P < 0.05$.

answered with "I don't know if this item is applicable to the client" more often than staff.

Discussion and conclusion

The present study explored how similar different groups of proxies' perceptions of the QOL of people with severe

or profound intellectual disability were. Dyads of staff and family members agreed quite strongly that QOL-PMD items were suitable to assess the QOL of their client or relative. This means that both staff and family members indicated the items as "*being applicable to the client*". Discrepancies occurred when one of the proxies rated an item as "*not applicable*" and the other proxy

Table 5. Proportion of observer agreement to the response option “I don't know” ($N > 15\%$).

Domain Item	N Staff	N Family	Po
<i>Physical well-being</i>			
The person experience no discomfort due to the side effects of the administered medication	5	10	.78
The person has no pain	9	12	.75
<i>Communication and Influence</i>			
The person express his preference with regard to mobility	6	8	.72
<i>Social well-being</i>			
The individual's sexual needs are fulfilled	24	20	.53

rated the same item as “*applicable*”. Such discrepancies were found for six items that belonged to the domains of material, physical, and social well-being. Consequently, to assess agreement on the *extent* to which items were applicable, we focused solely on dyads that agreed on rating the item as “*being applicable to the client*”. Strong proxy agreement was found on the extent in which these items were applicable. Significant differences were only found on six items (across all QOL domains, except physical well-being). The present findings are supported by earlier research in which differences in agreement levels were explained by the extent to which assessments of indicators of QOL domains are objective or subjective (e.g., Balboni, Coscarelli, Giunti, & Schalock, 2013; Crocker et al., 2015; Koch et al., 2015; Sneeuw et al., 2002). Objective assessments are expected to be easier, which should increase agreement between staff and family members. For example, emotional feelings are more difficult to estimate on behalf of the client compared to facts about participation in open-air activities. The difficulty of making subjective assessments is a major reason for the debate about the use of self-report versus proxy reporters for QOL appraisal (Verdugo et al., 2005).

Four items received the response “*I don't know if the item is applicable to the persons with ID*” relatively often. These items related to subjective, internal perceptions of the individual with ID (i.e., sexual fulfillment, pain, discomfort). The contrast between subjective and objective estimations could explain the difficulty of judging these items. It is very important to have insight into the subjective perceptions of people with severe to profound ID, but the severity of their ID makes it very difficult for them to report these subjective perceptions. Greer et al. (1986) and Fanurik, Koh, Schmitz, Harrison, and Conrad (1999), for example, found that staff and relatives were not able to describe whether and to what extent children with cognitive impairment experienced pain. This inability is of vital importance. Because it is hard for staff to recognise non-verbal behaviours as indicators of pain, people with ID are often undertreated for

pain (Baldrige & Andrasik, 2010). Additional explanation is needed in the case of difficulties in judging sexual fulfillment. Research suggests that the sexual and relationship needs of people with ID have mostly been overlooked (Brown, Schalock, & Brown, 2009). However, Rushbrooke, Murray, and Townsend (2014) found, in their review that staff commonly experience concerns, fear, uncertainty, and anxiety in supporting sexuality and intimate relationships of people with ID. Parents quite often appeared to judge sexuality to be “not applicable” for their child (Cummins, 2002). Such fears and uncertainties for both staff and family members might result in barriers to discussing the sexuality of individuals with ID. The challenge for the partnership between staff and family members is how to obtain an assessment of internal needs (such as pain, discomfort and sexual fulfillment) from persons with ID who are unable to self-report.

The following limitations should be taken into account when interpreting the results of this study. First, the sample size of this study was small and based on only one health-care organisation. Therefore, the outcomes are not sufficient to represent the general population. However, the systematic approach taken has enabled a thorough exploration of participants' perceptions in the present study. Second, the study included only family members who were relatively closely involved in the lives of individuals with ID (i.e., living within 30 km and visiting the client at least once a month), which might have resulted in false-positive outcomes. In general, family members are usually not as strongly involved.

This study has a number of implications for clinical practice. First, we have identified few differences in proxy agreement in the applicability of QOL items. We have also found strong proxy agreement in the extent to which items were applicable. These findings are relevant because collaboration between staff and family is necessary for the effective support of people with ID (Turnbull & Turnbull, 2001). With respect to proxy agreement and staff-family collaboration, special attention should be paid to the subjective, internal perceptions of individuals with ID (e.g., sexual fulfillment, pain, discomfort) because these perceptions seem to be more difficult to assess on behalf of the client. Careful information exchange about these perceptions is especially important for individual support. According to Olson and Schober (1993), disagreement between proxies reflects the variation in views of direct-care staff and relatives. Judgements of proxies determine whether actions will be taken to improve QOL. Disagreement between proxies is at the heart of the challenge in getting a true indication of a person's QOL. In addition,

all partners involved should realise that the construct of QOL is not static but changes over time (Petry et al., 2005). Even though dyads agreed, it is important to maintain as good a collaboration as possible. Staff and family members need to complement one another to provide the best QOL possible for the person with ID.

Research is needed to further explore the subjective well-being and internal needs (e.g., pain, discomfort and sexual fulfillment) of people with severe or profound ID who are unable to self-report. At the same time, such further research should preferably also contribute to the development of a reliable and valid instrument to assess the most critical indicators of the subjective QOL of this population. This research should also include family members who are not as strongly involved. Extending the study to these family members with a larger sample size might provide more robust evidence of similarities and differences in the perspectives between staff and family members in collaborative partnerships. In addition, future research should be extended to include the perceptions of clients with mild intellectual disability.

Acknowledgements

We would like to thank relatives of clients and support staff of S&L Zorg for their participation in this study.

Disclosure statement

No potential conflict of interest was reported by the authors.

Funding

This work was supported by S&L Zorg.

References

- American Psychiatric Association (APA). (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.
- Balboni, G., Coscarelli, A., Giunti, G., & Schalock, R. L. (2013). The assessment of the quality of life of adults with intellectual disability: The use of self-report and report of others assessment strategies. *Research in Developmental Disabilities, 34*, 4248–4254. doi:10.1016/j.ridd.2013.09.009
- Baldrige, K. H., & Andrasik, F. (2010). Pain assessment in people with intellectual or developmental disabilities. Using alternative methods to assess pain when the patient can't provide a self-report. *American Journal of Nursing, 110*, 28–35. doi:10.1097/01.NAJ.0000391236.68263.90
- Berenschot, L., & Blijleven, E. (2003). *Wie wordt er beter van? Vraagstelling in de zorg* [Who gets better from there? Demand in care]. Breukelen: NYFER.
- Blue-Banning, M., Summers, J. A., Frankland, H. C., Nelson, L. L., & Beegle, G. (2004). Dimensions of family and professional partnerships: Constructive guidelines for collaboration. *Exceptional Children, 70*, 167–184.
- Brown, R. I., Schalock, R. L., & Brown, I. (2009). Quality of life: It's application to persons with intellectual disabilities and their families-introduction and overview. *Journal of Policy and Practice in Intellectual Disabilities, 6*, 2–6. doi:10.1111/j.1741-1130.2008.00202.x
- Claes, C., Van Hove, G., Van Loon, J., Vandeveld, S., & Schalock, R. (2010). Quality of life measurement in the field of intellectual disabilities: Eight principles for assessing quality of life-related personal outcomes. *Social Indicators Research, 98*, 61–72. doi:10.1007/s11205-009-9517-7
- Crocker, T. F., Smith, J. K., & Skevington, S. M. (2015). Family and professionals underestimate quality of life across diverse cultures and health conditions: Systematic review. *Journal of Clinical Epidemiology, 68*, 584–595. doi:10.1016/j.jclinepi.2014.12.007
- Cummins, R. A. (2002). Proxy responding for subjective well-being: A review. *International Review Research in Mental Retardation, 25*, 183–207. doi:10.1016/S0074-7750(02)80009-X
- De Geus-Neelen, C., van Oorsouw, W. M. W. J., & Embregts, P. J. C. M. (2014). Individueel wonen. Een kans op meer keuzemogelijkheden en minder vrijheidsbeperking voor mensen met een ernstige verstandelijke beperking en gedragsproblemen? [Individual living. A chance of more choice opportunities and less restrictive interventions for people with severe intellectual disabilities and challenging behaviour?]. *Orthopedagogiek: Onderzoek en Praktijk, 53*, 477–492.
- Dunst, C. J., & Dempsey, I. (2007). Family-professional partnerships and parenting competence, confidence, and enjoyment. *International Journal of Disability, Development and Education, 54*, 305–318. doi:10.1080/10349120701488772
- Embregts, P. J. C. M. (2011). *Zien, bewogen worden, in beweging komen* [Seeing, being moved, start moving]. Tilburg, the Netherlands: PrismaPrint.
- Fanurik, D., Koh, J. L., Schmitz, M. L., Harrison, R. D., & Conrad, T. M. (1999). Children with cognitive impairment: Parent report of pain and coping. *Journal of Developmental and Behavioral Pediatrics, 20*, 228–234. doi:10.1097/00004703-199908000-00005
- Gómez, L. E., Verdugo, M. A., Arias, B., Navas, O., & Schalock, R. L. (2013). The development and use of provider profiles at the organization and systems level. *Evaluation and Program Planning, 36*, 80–87. doi:10.1016/j.evalprogplan.2013.05.001
- Greer, D. S., Mor, V., Morris, J. N., Sherwood, S., Kidder, D., & Birnbaum, H. (1986). An alternative in terminal care: Results of the national hospice study. *Journal of Chronic Diseases, 39*, 9–26. doi:10.1016/0021-9681(86)90103-7
- Koch, A. D., Vogel, A., Becker, T., Salize, H. J., Voss, E., Werner, A., ... Schützwohl, M. (2015). Proxy and self-reported quality of life in adults with intellectual disabilities: Impact of psychiatric symptoms, problem behaviour, psychotropic medication and unmet needs. *Research in Developmental Disabilities, 45-46*, 136–146. doi:10.1016/j.ridd.2015.07.022
- Kraijer, D. W., & Kema, G. N. (1994). *SRZ, Sociale redzaamheidsschaal voor zwakzinnigen* [Social functioning scale for people with intellectual disabilities] (5th ed.). Lisse, the Netherlands: Swets & Zeitlinger.

- Landis, J. R., & Koch, G. G. (1977). The measurement of observer agreement for categorical data. *Biometrics*, 33, 159–174.
- Luckasson, R., & Schalock, R. L. (2013). Defining and applying a functionality approach to intellectual disability. *Journal of Intellectual Disability Research*, 57, 657–668. doi:10.1111/j.1365-2788.2012.01575.x
- McGillivray, J. A., Lau, A. L. D., Cummins, R. A., & Davey, G. (2009). The utility of the personal wellbeing index intellectual disability scale in an Australian sample. *Journal of Applied Research in Intellectual Disabilities*, 22, 276–286. doi:10.1111/j.1468-3148.2008.00460.x
- Nijdam, A.D. (2003). *Statistiek in onderzoek. Beschrijvende technieken 1* [Statistic in research. Descriptive techniques 1]. Houten, the Netherlands: Wolters-Noordhoff.
- Nolan, R., Luther, B., Young, P., & Murphy, N. A. (2014). Differing perceptions regarding quality of life and inpatient treatment goals for children with severe disabilities. *Academic Pediatrics*, 14, 574–580. doi:10.1016/j.acap.2014.02.012
- Olson, G. I., & Schober, B. I. (1993). The satisfied poor. Development of an intervention-oriented theoretical framework to explain satisfaction with a life in poverty. *Social Indicators Research*, 28, 173–193.
- Petry, K., Maes, B., & 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. doi:10.1111/j.1468-3148.2004.00209.x
- Petry, K., Maes, B., & Vlaskamp, C. (2009a). Measuring the quality of life of people with profound multiple disabilities using the QOL-PMD: First results. *Research in Developmental Disabilities*, 30, 1394–1405. doi:10.1016/j.ridd.2009.06.007
- Petry, K., Maes, B., & Vlaskamp, C. (2009b). Psychometric evaluation of a questionnaire to measure the quality of life of people with profound multiple disabilities (QOL-PMD). *Research in Developmental Disabilities*, 30, 1326–1336. doi:10.1016/j.ridd.2009.05.009
- Pols, J., & Bosveld, H. E. P. (2003). Beoordelaarsbetrouwbaarheid (niet) meten met behulp van Cohens Kappa? [Calculating inter-rater reliability by using Cohen's Kappa?]. *Tijdschrift voor Medisch Onderwijs*, 22(5), 229–234. doi:10.1007/BF03056615
- Rushbrooke, E., Murray, C. D., & Townsend, S. (2014). What difficulties are experienced by caregivers in relation to the sexuality of people with intellectual disabilities? A qualitative meta-synthesis *Research in Developmental Disabilities*, 35, 871–886. doi:10.1016/j.ridd.2014.01.012
- Schalock, R. L., & Keith, K. D. (1993). *Quality of life questionnaire*. Worthington, OH: IDS Publishing.
- Schalock, R. L., Verdugo, M. A., Bonham, G., Fantova, F., & Van Loon, J. (2008). Enhancing personal outcomes: Organizational strategies, guidelines, and examples. *Journal of Policy and Practice in Intellectual Disabilities*, 5, 276–285.
- Selai, C. E., & Rosser, R. M. (1993). Good quality quality? – Some methodological issues. *Journal of the Royal Society of Medicine*, 86, 440–443.
- Sneeuw, K. C., Sprangers, M. A., & Aaronson, N. K. (2002). The role of health care providers and significant others in evaluating the quality of life of patients with chronic disease. *Journal of Clinical Epidemiology*, 55, 1130–1143. doi:10.1016/S0895-4356(02)00479-1
- Snijders, J. T., & Snijders-Oomen, N. (1975). Snijders-Oomen non-verbal intelligent scale. SON, 2, 5–7. Groningen, the Netherlands: Wolters-Noordhoff.
- Stancliffe, R. J. (1999). Proxy respondents and the reliability of the quality of life questionnaire empowerment factor. *Journal of Intellectual Disability Research*, 43, 185–193. doi:10.1046/j.1365-2788.1999.00194.x
- Turnbull, A. P., & Turnbull, H. R. (2001). *Families, professionals, and exceptionally: Collaborating for empowerment* (4th ed.). Upper Saddle River, NJ: Prentice-Hall.
- Verdugo, M. A., Schalock, R. L., Keith, K. D., & Stancliffe, R. J. (2005). Quality of life and its measurement: Important principles and guidelines. *Journal of Intellectual Disability Research*, 49, 707–717. doi:10.1111/j.1365-2788.2005.00739.x
- Watson, J. (2012). Supported decision making for people with severe to profound intellectual disability, ‘we’re all in this together, aren’t we’. In C. Bigby & C. Fyffe (Eds.), *Services and families working together to support adults with intellectual disability. Proceedings of the sixth roundtable on intellectual disability policy* (pp. 38–48). Bundoora: La Trobe University.
- White-Koning, M., Grandjean, H., Colver, A., & Arnaud, C. (2008). Parent and professional reports of the quality of life of children with cerebral palsy and associated intellectual impairment. *Developmental Medicine and Child Neurology*, 50, 618–624. doi:10.1111/j.1469-8749.2008.03026.x