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# Domains of Quality of Life of People with Profound Multiple Disabilities: the Perspective of Parents and Direct Support Staff

Katja Petry\*, Bea Maes\* and Carla Vlaskamp†

\*Centre for Disability, Special Needs Education and Child Care, Katholieke Universiteit Leuven, Leuven, Belgium and †Section of Orthopedagogics, University of Groningen, Groningen, The Netherlands

Accepted for publication 5 August 2004

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*Background* This study considered the general validity of the basic domains of quality of life that appear in theoretical models, in relation to people with profound multiple disabilities. The authors examined how parents and direct support staff operationalized these basic domains for people with profound multiple disabilities. They investigated the effect of the support setting and age of people with profound multiple disabilities on this operationalization.

*Methods* A number ( $n = 76$ ) of parents and direct support staff of people with profound multiple disabilities were interviewed. Transcripts were analysed in depth.

*Results* Results showed that the five basic domains as described within the model of Felce & Perry [Research in Developmental Disabilities (1995) vol. 16, pp. 51–74; *Quality of Life in Health Promotion and Rehabilitation Conceptual Approaches, Issues and Applications* (1996a) Sage Publications; *Quality of Life. Vol. I: Conceptualization and Measurement* (1996b) American Association on Mental Retardation] were identified spontaneously by more

than half of the respondents as being salient for the quality of life of people with profound multiple disabilities. When asked explicitly, this value rose to between 88.2 and 100%. The operationalization of these basic domains by parents and direct support staff differed in several aspects from operationalizations for other target groups. Neither age nor support setting turned out to have a significant effect on the operationalization.

*Conclusions* The results supported the multidimensionality of quality of life and the validity of the basic domains for people with profound multiple disabilities. The content of the domains of quality of life differed, however, to a considerable extent for people with profound multiple disabilities. Furthermore, these people are extremely dependent on others for the gratification of their needs and therefore for their quality of life.

*Keywords:* profound multiple disability, quality evaluation, quality of life

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## Introduction

Over the past few decades, the concept of quality of life has increasingly been applied to people with intellectual disabilities. During these years, a number of core ideas and principles have emerged in the international literature regarding the conceptualization and the application of this concept (Schalock *et al.* 2002). One of these core ideas pertains to the multidimensionality of quality of life. Quality of life has a multi-element structure consisting of different domains. In the international quality of life literature, a number of domains or dimensions of well-being have been identified, including: (i) social relationships and interaction, (ii) psychological well-being

and personal satisfaction, (iii) employment, (iv) self-determination, autonomy and personal choice, (v) recreation and leisure, (vi) personal competence, community adjustment and independent living skills; (vii) residential environment, (viii) community integration, (ix) normalization, support services received, (x) individual and demographic indicators, (xi) personal development and fulfillment, (xii) social acceptance, social status and ecological fit, (xiii) physical and material well-being and (xiv) civic responsibility (Hughes *et al.* 1995). Schalock *et al.* (2002) mentioned eight core domains of quality of life in their consensus document on quality of life: (i) emotional well-being, (ii) interpersonal relations, (iii) material well-being, (iv) personal development,

(v) physical well-being, (vi) self-determination, (vii) social inclusion and (viii) rights. These and a lot of other conceptualizations differ slightly in nature, diversity and elaboration of the domains mentioned.

In this study, we adopt the domains of quality of life as described in the model of Felce & Perry (1995, 1996a,b). These authors distinguish five domains of quality of life divided into several sub-domains: (i) physical well-being (health, personal safety, fitness, mobility); (ii) material well-being (finance and income, housing quality, transport, security and tenure); (iii) social well-being (personal relationships, community involvement); (iv) development and activity (competence, productivity and activity) and (v) emotional well-being (positive affect, fulfillment–stress; mental health, self-esteem, status and respect, faith and belief, sexuality) (Felce & Perry 1995, p. 53). The present study explores the question as to whether these domains of quality of life are applicable to people with profound multiple disabilities.

People with profound multiple disabilities have such learning disabilities that hardly any standardized tests are applicable for a valid estimation of their intellectual capacity. They also possess profound neuromotor dysfunctions like spastic tetraplegia. In addition to profound intellectual and physical disabilities, sensory impairments are also frequently experienced (Nakken & Vlaskamp 2002). People with profound multiple disabilities need support in almost every aspect of their daily life. This high level of dependency is reinforced by the fact that they have difficulties in communicating as to when and how support should be given. Their low level of functioning, their complex and specific needs and their high level of dependency make their daily life, in large part, different from that of people with milder or without disabilities. Therefore, it may be possible that what constitutes their quality of life is also different. This leads us to question the validity of the basic domains of quality of life and their operationalization for this target group.

At the level of the sub-domains, models of quality of life often contain indicators such as income, status, productivity and autonomy. Viewed from the perspective of people with profound multiple disabilities, these outcomes may be less relevant. There may, however, be some important aspects for this target group that are not mentioned in the general models of quality of life. Several authors, therefore, argue that the basic domains of quality of life that are relevant for and applicable to people with and without disability, should be 'translated' into specific indicators that take

into account the special needs of people with profound multiple disabilities (Ouellette-Kuntz & McCreary 1996; Vlaskamp 2000). In the present study, we attempted to find out if this is a valid assumption. In addition, we wanted to explore if the operationalization of quality of life for people with profound multiple disabilities differs depending on the characteristics of the target group such as age and the context in which they live. We selected these characteristics because it is stated that quality of life differs for the individual over time and that people are best understood within the context of the environments that are important to them. An essential idea is that people, places and surroundings can promote and enhance a good life. In turn, individuals' interests and values can emerge in part from the environment in which they live (Schalock *et al.* 2002).

To be more specific, in the present study, we consider the following three questions:

**1** *Are the basic domains of quality of life that are mentioned in the model of Felce & Perry (1995) valid and relevant for people with profound multiple disabilities, according to parents and direct support staff?*

**2** *How do parents and direct support staff operationalize these basic domains for people with profound multiple disabilities?*

**3** *What is the effect of variables such as 'support setting' and 'age' of people with profound multiple disabilities on this operationalization?*

At this moment, the answers to these questions cannot be found by reviewing the literature. Few models of quality of life are described that are applicable to people with profound multiple disabilities at the level of the indicators. Interviewing people with profound multiple disabilities concerning this matter is not an option because this group of people does not have the required skills to express their subjective experiences verbally (Selai & Rosser 1993). Making use of non-verbal means of communication, direct observation or working with respondents who are acquainted with profoundly multiple-disabled people ('proxies') are alternatives. The literature however yields conflicting results concerning the value of using a proxy approach. Several researchers have attempted to evaluate consumer-proxy agreement by comparing proxy responses with self-reports from people who can respond for themselves. In some of these studies, the answers given by people with an intellectual disability regarding their quality of life turned out to be of strong disagreement with those given by their proxies (Stancliffe 1995; Heal & Sigelman 1996; Rapley *et al.* 1998); others find a greater concordance (McVilly *et al.* 2000). But as Stancliffe (2000) has pointed

out that: 'It remains an open question as to whether findings of agreement between proxies and self-reports from verbal individuals can be generalized to non-verbal people with profound mental retardation who cannot respond for themselves' (p. 90). Despite these issues, we decided to take a proxy approach using parents and direct support staff of people with profound multiple disabilities because it gives us the opportunity to get a picture of the validity and the content of the domains of quality of life for people with profound multiple disabilities.

## Methods

In this exploratory study, we chose a qualitative research design, and to be more specific, qualitative multiple case studies. This kind of case study does not attach great importance to particulars, but uses comparison to bring to the fore what is common to a group (Stake 1995, 1998).

### Participants

The proxies we selected were parents and direct support staff who were in touch with people with profound multiple disabilities, on a daily basis. Their experiential expertise was very valuable. In selecting direct support staff, we stipulated that they should be 'familiar faces' in a sense that the respondents must have been supporting the person for at least 6 months and be in regular close contact with him/her. The proxies were selected by care facilities and services that were acknowledged for this target group, because almost all people with profound multiple disabilities make use of these care facilities and/or services. For sampling, we used the following variables: interviewee (parents, direct support staff), age of the person with profound multiple disabilities (child: 0–18 years, adult: >18 years) and the kind of support the person was receiving (day care, 24-h care). The group 'day care' consisted of people with profound multiple disabilities living with their parents and receiving some form of professional support or schooling during the day. The people with profound multiple disabilities in the group '24-h care' all lived in an institution or a community-based home and some of them attended day care centres or schools.

The method that has been used is that of purposeful sampling, in particular 'maximum variation sampling' (Patton 1990; Cohen *et al.* 2000). This implies that cases were selected with the intention of maximizing the width of variation of the data regarding essential features. The

sample we drew was not an exact representation of reality, as certain categories of respondents (e.g. parents of adults with profound multiple disabilities in day care) would have been under-represented. We aimed at a more or less equal distribution of the respondents across the variables in order to maximize the variation width in the sample to obtain maximum information. In total, 76 interviews were completed. We interviewed 40 parents and 36 direct support staff members of 42 children and 34 adults with profound multiple disabilities, of which, 36 received a form of day care and 40 were in 24-h residential care (Table 1).

### Measures and procedure

The proxies were questioned by means of a semi-structured interview consisting of open questions. This type of interview was chosen to provide enough structure to ensure that all subjects were covered for each of the interviewees and to minimize interviewer effects (Patton 1990). The interview guide consisted of an introduction that situated the interview within the research project as a whole and two main parts. In the first part of the interview, the respondents themselves fully decided which domains and indicators of quality of life they brought up. The following questions were asked: (1) 'You have or you take care of a child/an adult with profound multiple disabilities. Can you give us some examples of what a good quality of life should consist of for your child/the person you are taking care of?' (2) 'Which factors related to support influence the quality of life of your child/ the person you are taking care of? What would give him/her a better quality of life?' In the second part, we checked more specifically the importance and the interpretation of the domains of quality of life as defined in Felce & Perry's model (1995, 1996a,b). The following questions were asked: 'Do you think that factors concerning "a certain domain" influence the quality of life/ the well-being of your child/the person you are taking care of? If so, which factors? Can

**Table 1** Description of the sample

	Children		Adults		Total
	Day care	24-hr care	Day care	24-h care	
Parents	16	8	6	10	40
Direct support staff	10	8	4	14	36
Total	26	16	10	24	76

you give an example? If not, why don't you think so? Are there any aspects of support bound up to this according to you?' The interviews were conducted by trained interviewers who had the necessary knowledge of semi-structured qualitative interviews. Each interview was taped with the respondent's consent. The interviews were recorded as exactly and completely as possible retaining the words of the interviewee as well as those of the interviewer. This facilitated a replication of the analysis.

### Data analysis

To answer the questions regarding the conceptualization and the operationalization of quality of life for people with profound multiple disabilities, we subjected the interview data, which were fully transcribed, to a qualitative content analysis. We opted for a cross-case analysis, because any description of common parameters of quality of life of people with profound multiple disabilities tends to be generalized across individuals. Data analysis consisted of the identification of domains, categories and recurrent themes, generated and, in some cases, shared across research participants and settings (Marshall & Rossman 1995). The transcribed material was analysed in a series of steps. First, the data were divided into units of analysis. A unit of analysis is mostly a single sentence or a fragment or some consecutive sentences that express one theme or thought. All transcripts were read three times to ensure familiarity with the material, and on the fourth reading, a first coding was carried out. For this first coding, a coding scheme was developed, consisting of the five domains of quality of life as described in the model of Felce & Perry (1995, 1996a,b) (physical well-being, material well-being, social well-being, emotional well-being and development and activities). The coding scheme turned out to be sufficiently broad enclosing all the units of analysis. Below, we give some examples of the coding of the interview data:

Developing, acquiring new skills is very important for the quality of life of my son. If he can expand his capabilities, he feels good.

Code: Domain – 'Development and Activities'.

In the past, she never had epileptic fits. Now she has and everything has changed. At this moment, her epilepsy is very severe. Last Sunday, she had six epileptic fits, but some days it is even more. If

she has lots of fits, she loses contact with us and isolates herself. She suffers a lot.

Code: Domain – 'Physical Well-being'

Subsequently, a process of open coding was undertaken within each domain to identify indicators. This type of coding enabled us to identify a large number of indicators from the mass of data. All the indicators covering the same topic (e.g. the indicators that deal with health-related issues) were grouped into sub-domains. In this way, a categorization was obtained consisting of five domains of quality of life, each of them divided into sub-domains with their accompanying indicators. During the whole process, we took care of 'peer debriefing' to take into account the matters pertaining to content, methodology and ethics (Patton 1990).

We examined these qualitative research data from a numerical point of view. Therefore, we calculated the proportion of respondents who mentioned a certain domain as being important for the quality of life relative to the total number of respondents. Subsequently, the proportion of respondents who reported indicators regarding a certain sub-domain as being important was determined relative to the number of respondents who mentioned this particular domain as being important. These statistics gave an impression of the importance of a sub-domain within a domain. Finally, in order to verify the effect of the variables, i.e. type of respondent, age and support setting chi-square tests ( $P < 0.05$ ) were executed.

## Results

### Domains of quality of life

Table 2 shows the number of respondents who spontaneously or when asked explicitly, named a basic domain that, in their opinion, was important for the quality of life of people with profound multiple disabilities.

All basic domains were named spontaneously by more than half of the respondents, and, except for material well-being, by more than three of four respondents. The domain of physical well-being and that of social well-being were mentioned spontaneously by 98.7 and 100% of the respondents, respectively. The importance attributed to physical well-being can be explained by the specific physical and motor limitations of people with profound multiple disabilities. The significance of social well-being may be a consequence of the extreme dependence and the idiosyncratic way of

**Table 2** Domains of quality of life

	<i>Spontaneously named</i>			<i>Named when asked explicitly</i>		
	<i>Parents</i>	<i>Direct support staff</i>	<i>Total</i>	<i>Parents</i>	<i>Direct support staff</i>	<i>Total</i>
Physical well-being	100 (40)	97.2 (35)	98.7 (75)	100 (40)	100 (36)	100 (76)
Material well-being	57.5 (23)	58.3 (21)	57.9 (44)	95 (38)	94.4 (34)	94.7 (72)
Social well-being	100 (40)	100 (36)	100 (76)	100 (40)	100 (36)	100 (76)
Development and activities	87.5 (35)	91.7 (33)	89.5 (68)	100 (40)	100 (36)	100 (76)
Emotional well-being	82.5 (33)	72.2 (26)	77.6 (59)	87.5 (35)	88.9 (32)	88.2 (67)

Values are represented as % (*n*).

communicating of people with profound multiple disabilities. Long-standing affective relationships and good communication are of great importance for this target group.

The domain of development and activities was mentioned spontaneously by 89.5% of the respondents. When being asked explicitly about the importance of this domain for the quality of life of people with profound multiple disabilities, this value rose to 100%. The domain of emotional well-being was mentioned spontaneously by 77.6% of the respondents. When explicitly asked, 88.2% of the respondents considered emotional well-being to be relevant.

The domain of material well-being stood out: it was cited spontaneously by the least number of parents and direct support staff (57.9%). This value rose to 94.7% when asked explicitly. Respondents apparently did not connect material well-being to quality of life spontaneously. Nevertheless, they all considered this domain to be important in a direct as well as in an indirect manner. Directly, because having adequate aids and living with adequate infrastructure improves the quality of life of people with profound multiple disabilities and indirectly, in that material aids facilitate care and as such improve the quality of life of people with profound multiple disabilities.

In Table 2, the values have been subdivided according to the type of respondent (parent or support staff). In none of the domains was a statistically significant difference found between parents and direct support staff, either in the column 'spontaneously named' or in the column 'named when asked explicitly' (chi-squared test,  $P > 0.05$ ). We conclude that parents as well as direct support staff consider the five basic domains of quality of life, as described in the model of Felce & Perry (1995, 1996a,b) to be relevant for the quality of life of people with profound multiple disabilities. These findings confirm, on the one hand, the multidimensionality of the

concept and on the other, the validity of the basic domains of quality of life for people with profound multiple disabilities.

### Operationalization of the basic domains of quality of life

In this section, we examined how parents and direct support staff operationalized the five basic domains of quality of life for people with profound multiple disabilities. Therefore, we categorized all quality of life indicators that were named by the respondents into sub-domains. Table 3 shows the sub-domains of every domain and the percentage of the respondents who gave concrete indicators on that sub-domain. The description of the sub-domains is solely based on the analysis of the interviews with the respondents. It is not based on the literature or other sources of information, nor does it reflect our opinion concerning this matter.

#### Physical well-being

##### *Mobility*

Indicators related to the sub-domain 'mobility' were reported by 96% of the respondents. This high percent-

**Table 3** Sub-domains of physical well-being

<i>Physical well-being</i>	100 (76)
Mobility	96 (73)
Health	93.4 (71)
Hygiene	90.8 (69)
Nourishment	86.8 (66)
Rest	56.6 (43)

Values are represented as % (*n*).

age may be explained by the severe motor disabilities that limited the activities of people in our research group extremely. Respondents felt that developing and maintaining motor skills are very important for their independence and quality of life. Moreover, it is necessary to thoroughly examine the physical problems people with profound multiple disabilities may cope with, and to prevent or treat them. Changes in posture too were, according to the respondents, of crucial importance for the quality of life of people with profound multiple disabilities.

### Health

Indicators related to health were mentioned by 93.4% of the respondents as part of physical well-being. A large proportion of people with profound multiple disabilities had many and sometimes life-threatening medical problems such as problems with nourishment, epilepsy, pneumonia, problems of the urinary system and sleeping problems. Respondents stated that these medical problems affect the quality of life of these people considerably. Their medical vulnerability requires a multidisciplinary approach with a continuous observation and a regular inspection of important bodily functions and processes in order to treat and prevent medical problems and pain. This process is, according to parents and direct support staff, complicated by the fact that many people with profound multiple disabilities have difficulties communicating whether and where they have pain.

### Hygiene

The hygiene of people with profound multiple disabilities was mentioned by 90.8% of the respondents as very important for quality of life. According to the respondents, it is necessary to change these people thoroughly and regularly, to wash them, to brush their teeth, to avoid bedsores and to put on clean, attractive and comfortable clothing. Hygiene takes much of the day time but it is essential and should be used for giving personal attention. Respondents felt that attention should be paid to the way personal care is provided: at a quiet pace, without any disturbing elements, in a pleasant atmosphere.

### Nourishment

Varied, sufficient and tasty nourishment at regular intervals is generally considered to be a basic need. Therefore it is not surprising that 86.8% of the respondents mentioned indicators regarding nourishment also,

because nourishment is not always a matter of course for people with profound multiple disabilities. Some of them had problems digesting or are drip-fed. Respondents mentioned that it was important that support staff have a good knowledge of the way drinks and food were best provided. People with profound multiple disabilities had, according to the respondents, strong preferences for certain food and dislike others. Taking these preferences into account, improved their quality of life.

### Rest

Sufficient rest during the day and a good night's rest were considered to be important factors for a good quality of life by 56.6% of the respondents. People with profound multiple disabilities sleep or rest a lot during the day, from a short nap to a siesta at noon. Sleeping comfort plays an important role according to parents and direct support staff. Most of the people with profound multiple disabilities indicated whether they were tired. Respondents felt that it was important to pay attention to and respect these signals. Undertaking an activity when they were tired was senseless. Parents and direct support staff noted that people with profound multiple disabilities needed more rest as they get older.

### Material well-being

#### Living environment

Almost 90% of the respondents mentioned indicators regarding the living environment of people with profound multiple disabilities in the domain of 'material well-being'. The living environment must meet certain requirements regarding accessibility, safety and comfort. All rooms must be large enough to place all technical aids. Attention must be paid to the room temperature, ventilation, lighting, humidity and hygiene. Besides this, respondents felt that the atmosphere of the room is at least as important. The atmosphere can be improved by material factors such as furnishing, adequate lighting and music (Table 4).

**Table 4** Sub-domains of material well-being

<i>Material well-being</i>	100 (72)
Living environment	88.9 (64)
Technical aids	86.1 (62)
Transportation	41.7 (30)

Values are represented as % (n).

### Technical aids

Adequate technical aids were considered to be extremely important for the material well-being of the target group by 86.1% of the respondents. These technical aids were designed to offer good posture and comfort, to prevent medical problems and to provide the opportunity of taking part in activities and having pleasant experiences. According to the respondents, these aids should meet requirements regarding functionality, safety, user-friendliness, comfort and appearance. When using them it is necessary to keep checking whether the material is well adapted. The people in the target group had difficulties pointing out problems. Besides technical aids for the person with the disability himself, respondents also attached a lot of importance to technical aids for the caregivers. Caretaking is facilitated by aids such as an intercom system, a high/low bed, a high/low bath, a high nursing table and a help for lifting. Parents felt the need to be informed sufficiently and in time of the existence, the purchase and the maintenance of suitable technical aids. This kind of information may prevent inappropriate purchases.

### Transportation

Of the respondents, 41.7% considered appropriate means of transportation to be important for the quality of life of people with profound multiple disabilities. Adequate means of transportation is often decisive for making excursions or going home for the weekend. Transportation should be safe and comfortable.

### Social well-being

#### Communication

According to almost all the respondents (98.7%), good communication was a crucial sub-domain in the quality of life of people with profound multiple disabilities (Table 5). To be able to express oneself and to be understood was of vital importance to them. It enabled the person to express feelings and wishes, to make choices and to influence and control his environment. People with profound multiple disabilities communicate through idiosyncratic and often small and hard to notice behavioural signals. Consequently, parents and direct support staff felt that it was extremely important for these people that their communicative behaviour was observed, interpreted and answered adequately. In interpreting their communicative behaviour one needs

**Table 5** Sub-domains of social well-being

<i>Social well-being</i>	100 (76)
Communication	98.7 (75)
Basic security	80.3 (61)
Family bonds	77.6 (59)
Social relationships	71.1 (54)
Individual attention	64.5 (49)
Social participation	38.2 (29)

Values are represented as % (*n*).

to connect to the person's environment and abandon one's own norms and values. Adequate interpretations were furthermore improved by consulting others. Finally, the respondents mentioned that in responding it was appropriate to wait for the profoundly multiple-disabled person to react and to question the interpretation, if necessary.

#### Basic security

Indicators regarding basic security were mentioned by 80.3% of the respondents as an important aspect of social well-being. Respondents felt that a secure attachment with a sensitive responsive parent and/or direct support staff had a great impact on the quality of life of people with profound multiple disabilities. For each of these people, it was extremely important that there was someone who understood them, knew their signals and their likes and dislikes. According to the respondents, this relationship must be familiar and predictable by implementing measures such as programming certain fixed rituals, announcing what is going to happen and adjusting the pace. They also needed a secure and recognizable environment characterized by structure and flexibility. Parents and direct support staff considered this basic security to be necessary for people with profound multiple disabilities to function optimally and to open up to other experiences.

#### Family bonds

The most important attachment relationship that people with profound multiple disabilities had was usually that with their parents. According to the respondents, parents remained, without doubt, the most constant figures in the life of their child. They knew their child best and were the greatest teachers to others. A good bond with their parents and with the larger family was therefore considered to improve the social well-being by 77.6% of

the respondents. Because people with profound multiple disabilities are so heavily dependent on support, their parents often share caregiving with professional support staff. Therefore, it is important that a person with profound multiple disabilities has a similar bond of attachment with a member of the direct support staff in a care facility. Regular changes in direct support staff disrupt this kind of bonding.

### *Social relationships*

People with profound multiple disabilities have the competence to engage in and maintain meaningful relationships. They seek contact and want others to be near them. Indicators concerning the subdomain of social relationships were mentioned by 71.1% of the respondents as part of the domain of social well-being. The relationship between the person and other people with profound multiple disabilities was difficult to assess according to parents and direct support staff. The fact of living in a group is often more important than individual contacts with other group members.

### *Individual attention*

Because of their extreme dependence and their limited communicative skills, in particular, people with profound multiple disabilities need a lot of individual attention. Indicators concerning this sub-domain were therefore cited by 64.5% of the respondents as an important aspect of social well-being.

### *Social participation*

Of the respondents, 38.2% considered indicators regarding social participation to be important for the social well-being. They emphasized the development of a large social network to give the person with profound multiple disabilities the opportunity to make social contacts inside as well as outside the care facility. The person needs to participate in social activities and make use of public services.

## **Development and activities**

### *Involvement in activities*

All the respondents thought that indicators regarding the involvement in activities were important for the quality of life of people with profound multiple disabilities (Table 6). A comprehensive range of activities gives

**Table 6** Sub-domains of development and activities

<i>Development and activities</i>	100 (76)
Involvement in activities	100 (76)
Influence and choices	82.9 (63)
Development	40.8 (31)

Values are represented as % (n).

these people the opportunity to broaden their life experiences. In the choice and the performance of activities, we need to take into account the person's state of health, the person's age, what a person can cope with at that moment, the person's capabilities and limitations and the person's interests and preferences. Respondents stated that people with profound multiple disabilities remain indoors for the largest part of the day. Nevertheless, outdoor activities and excursions are highly appreciated.

### *Influence and choices*

Exerting influence on the environment and making choices was mentioned by 82.9% of the respondents as part of the domain of development and activities. People with profound multiple disabilities know very well what they want and do not want and have the competence to make choices according to parents and direct support staff. The problem, however, is that they have difficulties communicating their choices. Respondents felt that it is important to take as much account as possible of the person's choices and to enable the person to control the environment. Controlling the environment is also possible by making the environment recognizable and predictable because people with profound multiple disabilities may have difficulties in grasping situations and sudden transitions.

### *Development*

Development was mentioned by 40.8% of the respondents as important for a good quality of life. This need for self-actualization applies to this target group despite their extreme dependency. Respondents said that it is important that they can develop their competencies, maintain their capabilities and stop regression. Developing their potential and skills increases the independence and the quality of life of people with profound multiple disabilities. It gives these people more confidence and self-esteem.



## Emotional well-being

### Positive effect

People with profound multiple disabilities need a warm, sensitive approach. The importance of this aspect of life was acknowledged by 82.1% of the respondents (Table 7). They believed that well-being was affected by the degree to which direct support staff felt committed and could express attention, warmth and affection. Most of the people with profound multiple disabilities like bodily contact but parents and direct support staff are sometimes frightened by their physical appearance, malformations and medical vulnerability.

### Individuality

Indicators regarding individuality were acknowledged to be important for the emotional well-being by 62.7% of the respondents. People with profound multiple disabilities are not a complex of mental, motor and perhaps other limitations but they are individuals with their own character and temperament. The individuality of people with profound multiple disabilities requires therefore an individual approach and support.

### Respect, status and self-esteem

Respect, status and self-esteem were important aspects of emotional well-being according to 50.7% of the respondents. People with profound multiple disabilities need to be treated with respect. They have a right to an equal place in society. A respectful and positive approach has a beneficial effect on the quality of their life. Parents said that they can discern from small signs whether people respect their child, for instance, by announcing what is going to happen or by greeting or addressing the child. A feeling of self-esteem is also mentioned by the respondents as being important for the quality of life of people with profound multiple dis-

abilities. The focus lies on these people's possibilities and not just on the complex of severe limitations. Measures need to be taken to present a positive image of people with profound multiple disabilities to the society.

### Atmosphere

People with profound multiple disabilities are extremely sensitive to the atmosphere according to parents and direct support staff. The atmosphere is affected by relational factors such as the functioning of the team of direct support staff, and stress but certainly also by material factors such as the furnishing of the environment, adequate lighting and music. Indicators regarding atmosphere were cited by 41.8% of the respondents as part of emotional well-being.

### Effect of variables on the proportion of respondents that mention sub-domains

In this section we evaluate the effect of variables such as 'support setting' and 'age' of people with profound multiple disabilities on the proportion of respondents that mentioned certain sub-domains of the basic domains of quality of life.

As to the variable 'support setting' there was no significant difference between sub-domains mentioned by the respondents for people with profound multiple disabilities in a day care and those in a 24-h care facility (chi-squared test,  $P > 0.05$ ). The same was true for the variable 'age' (chi-squared test,  $P > 0.05$ ). There is no statistically significant difference between the operationalization made by respondents of profoundly multiple-disabled children and the one made by respondents of adults with profound multiple disabilities. Neither 'support setting' nor 'age' turned out to have an effect on the importance of particular domains and sub-domains of quality of life.

## Discussion

In the present study, we wanted to verify whether the basic domains of quality of life that are found in current models, are relevant for people with profound multiple disabilities according to those who are directly concerned with them. We were able to answer this question affirmatively with regard to the five domains of quality of life as described in the model of Felce & Perry (1995, 1996a,b). The domains of physical well-being, material well-being, social well-being, emotional well-being and development and activities were mentioned

**Table 7** Sub-domains of emotional well-being

<i>Emotional well-being</i>	100 (67)
Positive affect	82.1 (55)
Individuality	62.7 (42)
Respect, status and self-esteem	50.7 (34)
Atmosphere	41.8 (28)

Values are represented as % (*n*).

spontaneously by more than half of the respondents as being important for the quality of life of people with profound multiple disabilities. When explicitly asked about the importance of a certain domain, this value rose to between 88.2 and 100% (according to domain). The acknowledgement by proxies of the importance of these basic domains confirms on the one hand the multidimensionality of quality of life and on the other hand the validity of the basic domains of quality of life for people with profound multiple disabilities. Each of the five basic domains as described in the model of Felce & Perry (1995, 1996a,b) was, according to parents and direct support staff, an important aspect of the quality of life of people with profound multiple disabilities and therefore needed to be included in the assessment of their quality of life.

Next, we examined how parents and direct support staff operationalized the different domains of quality of life for people with profound multiple disabilities. When we compared this operationalization to the sub-domains that were mentioned by Felce & Perry (1995), we noticed some differences.

The first difference concerned the type of subdomains parents and direct support staff mentioned. They named many indicators related to hygiene, nourishment, rest, technical aids, communication, basic security and individual attention. These categories were not included as subdomains in the model of Felce & Perry (1995) but they are especially important to people with profound multiple disabilities according to the respondents, because of their limitations and dependency on support in these particular areas. The proxies, on the other hand, mention only few if any indicators regarding the categories fitness, personal safety, finances and income, stress, mental health, sexuality and faith. To conclude that these aspects are not important for the quality of life of people with profound multiple disabilities is nevertheless premature and even dangerous. Further research should focus on the question of whether these issues really are not relevant for the quality of life of people with profound multiple disabilities or whether the proxies are unable to comment on these issues which are salient to people with profound multiple disabilities.

Secondly, when we compared the operationalization of our respondents with the general models of quality of life, they differed, in that people with profound multiple disabilities are extremely dependent on others for the gratification of their needs and therefore for their quality of life. The content of the domains of quality of life was partly the same for people with profound

multiple disabilities as for people with a less severe disability but, due to their limitations, people with profound multiple disabilities cannot realize them without the support of others. To gratify their needs on several domains of quality of life they need a secure relationship with a sensitive responsive parent and/or direct support staff.

A third and last point of difference concerned the content of the sub-domains. The content of the sub-domains geared to people with profound multiple disabilities differs from the content of the sub-domains for other target groups. For instance: people with profound multiple disabilities exert influence on their environment in different ways from people without or with a less severe disability.

These three points of difference allow us to conclude that the domains of quality of life are universal but that their operationalization differs considerably for people with profound multiple disabilities. This confirms the argument that the basic domains of quality of life that are relevant for and geared to people with and without disability, should be 'translated' into specific indicators that take into account the special needs of people with profound multiple disabilities (Ouellette-Kuntz & McCreary 1996; Vlaskamp 2000).

Finally, we checked the effect of variables such as support setting and age of the profoundly multiple-disabled person on the operationalization of the basic domains of quality of life by parents and direct support staff. After statistical analysis neither 'support setting' nor 'age' seemed to have a significant effect on the operationalization of quality of life made by the proxies. To conclude that the operationalization of quality of life should be similar for all profoundly multiple-disabled people regardless of age or the context in which they live is however premature. Further research into this matter is necessary.

The present study gives an overview of domains, sub-domains and indicators of quality of life that are salient for people with profound multiple disabilities according to parents and direct support staff. An issue inextricably bound up with this overview is the measurement of these aspects of quality of life. A core principle is that quality of life measurement is based upon both common human experiences and unique, individual life experiences. Therefore, both objective and subjective (perceptual) measurements are necessary for a full measurement (Schalock *et al.* 2002). Although this applies incontestably for people with profound multiple disabilities, it is much more difficult to determine the degree of satisfaction and happiness these individuals experience.

Rendering one's own subjective experiences requires several skills which they do not possess. Not only is the individual required, through a demanding task of introspection to consider his or her physical, psychological and social well-being, but also on some measures to make a higher-order judgment concerning his or her attitude to his or her life situation (Selai & Rosser 1993). To get an insight into the subjective perspective of people with profound multiple disabilities on their life experiences, an in-depth knowledge and intimacy with their idiosyncratic expressions is necessary (Maes *et al.* 2003). Therefore, measures that involve self-reports are often replaced by the knowledge and experiences of proxies (Goode & Hogg 1994). However, using a proxy-approach in quality of life assessment is considered to be not valid as an indication of a person's own perception of his or her life (Schalock *et al.* 2002). The concordance between subjective and proxy ratings seems to be more of a problem in evaluations of emotional experiences and personal preferences, than for more objective issues (Perry & Felce 2002).

Alternative approaches to the subjective appraisal of quality of life of people with profound multiple disabilities involve direct observation or video-observation (Goode & Hogg 1994). One can identify expressions of (dis)satisfaction or (dis)like of people with profound multiple disabilities by participatory observation in their own natural setting (Hogg *et al.* 2001; Maes *et al.* 2003). An individual relationship with the participant seems to be necessary in order to open up to the idiosyncratic expressions of people with profound multiple disabilities. Identification and verification of a person's subjective experience in different situations and from different sources of information is called for in order to confirm the interpretations (Maes *et al.* 2003). Despite the difficulties with regard to the subjective measurement of quality of life for this target group, we believe the subjective experience of these people themselves is highly important. We therefore seek to compare in further research the findings by proxies with data obtained from direct contacts with people with profound multiple disabilities.

Finally, there are some methodological aspects of the study that require discussion. First of all, we selected 40 parents and 36 direct support staff of 76 people with profound multiple disabilities in order to maximize the variation and to obtain as much information as possible. However, interviewing a parent as well as a direct support staff member of the same person with profound multiple disabilities would have given us a better insight into the concordance between both perspectives.

The second point of discussion regarding the methodology pertains to the relativity of the given percentages and statistical analyses. First of all, the basic domains as well as the sub-domains are not mutually exclusive categories. An example is the overlap of the sub-domains 'communication' and 'influence' because good communication is a necessary condition for influencing the environment. As a consequence, one unit of analysis could contain references to diverse sub-domains. Furthermore, the respondents' verbal skills and experience with interviews was probably an important factor, especially for open questions. For questions regarding the importance of certain domains and their specification this was less likely to be the case.

In further research the proposed categorization in domains, sub-domains and indicators of quality of life of people with profound multiple disabilities will be presented for assessment in a Delphi-format to a group of international theory-, practice- and experience-experts. Finally, this should result in a questionnaire and a procedure for evaluating the quality of life of people with profound multiple disabilities (Maes *et al.* 2002).

## Correspondence

Any correspondence should be directed to Katja Petry, Centre for Disability, Special Needs, Education and Child Care, Katholieke Universiteit Leuven, Vesaliusstraat 2, B-3000 Leuven, Belgium (e-mail: katja.petry@ped.kuleuven.ac.be).

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