

Parents' Perceptions and Judgment Formation Process of Their Infants' Quality of Life

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Abstract

Purpose: We explored parents' perceptions and judgment formation processes concerning their infants' health-related quality of life (HRQOL). **Method:** The PedsQL™ Infant Scales—an instrument specifically designed for infants aged 1 - 24 months—were translated into Japanese. Forward and backward translations were performed, evaluating the semantic and conceptual equivalencies. Parents with infants younger than two-years-old were recruited and interviewed using think-aloud and probing techniques. Participants completed the questionnaire while speaking aloud about what came to their mind, what they thought each question meant, and how they reached each answer. **Results:** Seven mothers and three fathers participated. The median age was 33.4 (28 - 43) years. Four had infants younger than six-months-old. All infants were healthy. Parents' perceptions of their infants' HRQOL varied across their ages. Some parents with infants younger than six months experienced difficulty discussing "emotional functioning" and "cognitive functioning" because their infants were too young to articulate the actions mentioned in the items. In those cases, the parents responded, "never a problem". Seventy-five percent of parents recalled their infants' daily "physical functioning", while only 58% recalled "physical symptoms". Some parents' perceptions and judgment formation were compromised by their own perceptions. For example, they answered "often a problem" when the items were problematic to themselves instead of to their child. However, many distinguished their infants' HRQOL from their own perceptions, indicating they understood the intention of the questionnaire. **Conclusion:** Parents' formed judgement may compromise by

their own perceptions. The result of this study will be helpful in improving healthcare communication and interpreting parents' judgments of their infants' HRQOL in future studies.

Keywords

Health-Related Quality of Life, Infant, Judgment Formation, Perception, Scale Translation

1. Background

Health-related quality of life (HRQOL) has become a commonly accepted concept in the fields of healthcare practice and research since the World Health Organization [1] defined health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”. Although HRQOL is generally evaluated by self-rating, this method of measurement is challenging when applied to young children because children's cognitive skills differ with age [2]. Parental proxy reports are thus needed when the child is too young to complete the HRQOL instrument themselves. Given the immature cognitive and language skills of young children, most child-based quality of life (QOL) instruments have been developed for children who are aged approximately eight years, with proxy reports (usually parents) used to gain information about younger children.

The Pediatric Quality of Life Inventory version 4.0 (PedsQL) Generic Core Scales were developed by Dr. J. W. Varni in the USA, and were designed as a generic scale to be utilized non-categorically across pediatric populations for measuring core health dimensions (physical, emotional, social, and role) delineated by the WHO. PedsQL places emphasis on children's perceptions because it is a self-reporting measurement model; although, the Parent Proxy-Report that was developed to parallel the Child Self-Report was also considered. The PedsQL™ Infant Scales were designed as a generic HRQOL instrument specifically for healthy and ill infants aged 1 - 24 months. The new PedsQ™ Infant Scales comprises physical functioning, physical symptoms, emotional functioning, social functioning, and cognitive functioning [3]. Research shows that systematic distortion of parental reports of children's behavior stems from perceived stressful life events [4], anticipation of the baby during pregnancy [5], and maternal depression [6] [7]. In using such a scale, researchers need to be assured that the measurement reflects what is being asked because it is proxy-report. We thus explored parents' perceptions and judgment formation processes concerning their infants' HRQOL.

2. Methods

2.1. Participants

Ten parents were recruited in-person by the investigators using snowball sam-

pling. The inclusion criteria were as follows: parents (mothers or fathers) aged >20 years; living with the infant (aged >one month but <two years) at the time of the interview; willing to participate; and able to read, understand, and communicate in Japanese (*i.e.* their native language). Efforts were made to cover diverse demographic backgrounds of participants and their infants, such as parents' education, income, employment status, and sex; as well as their infants' age, and sex. The exclusion criterion was parents with infant who has severe health conditions.

2.2. Overall Process

The methodological design for this study employed a qualitative approach, following the guidelines for linguistic validation of the PedsQL™, provided by the Mapi Research Institute ("Linguistic validation of the PedsQL: A quality of life questionnaire", 2002). The PedsQL™ Infant Scales (Appendix I and Appendix II) were translated into Japanese using forward and backward translation techniques. Then, a professional expert panel discussed and evaluated the clarity and conceptual equivalence of the translated questionnaire by comparing it to the original. Seven Japanese health professionals (pediatric nurses, clinical psychologists, and a nurse-midwife, including bilingual/bicultural researchers) critiqued the translated questionnaire for content validity and clarity of each item before pretesting with parents. The original developer of the PedsQL™ in the U.S. was consulted when possible discrepancies between the English and Japanese versions required clarification. After determining possible difficulties in the Japanese pilot version of the questionnaire, 10 parents with infants younger than two-years-old were recruited and interviewed using think-aloud and probing techniques.

2.3. Data Collection

Cognitive testing was used to assess the ways in which the participants understood the items, recalled information and events, made decisions concerning their children's QOL, and provided responses to researchers [8] [9] [10] [11]. We used this method to improve the clarity, content validity, and semantic equivalence of the translated questionnaire and to prevent future response errors.

We employed three types of cognitive interviewing techniques: the think-aloud technique, probing questions, and debriefing [12] [13]. For the concurrent, unguided, think-aloud technique, participants were asked first to complete the PedsQL™ Infant Scales, while speaking aloud about what came to their mind in the process and what they thought each question meant. They had to answer each item using a five-point Likert response scale (0 = *never* [a problem]; 1 = *almost never*; 2 = *sometimes*; 3 = *often*; and 4 = *almost always*), and any difficulties their infant experienced over the past month. They were also asked how they reached each final answer in the questionnaire. After answering all the questions, participants were asked to provide their overall impressions of the questionnaire. All in-

interviews were conducted in a private room by the research team members. Interview data were digitally recorded and transcribed verbatim. Participants received a 1000-yen bookstore gift card (\$10 approximately) as a token of appreciation.

2.4. Data Analysis

The transcripts were analyzed focusing on parents' cognitive processes in making judgments on their children's QOL, using the four stages proposed by Tourangeau [8]: question interpretation, memory retrieval, judgment formation, and response editing (Table 1). The interpretation stage was classified for all the items of each of the subscales by either 1) the participants comprehended the meaning of the item correctly and applied it to their child, 2) comprehended with their own modified interpretation and not exactly what the item refers to, or 3) did not understand what the item means and could not apply it to their child. Memory retrieval was classified for all the items of each of the subscales by either 1) the participants could recall relevant information or 2) they could not recall information. The latter may be because the child was too young. Judgment formation was classified for all the items of each of the subscales by either 1) making a cognitive judgment using relevant information, 2) making a judgment with modified interpretation of the items, or 3) judging that there is "no problem" because there is no evidence of a problem. Response editing was not analyzed because our aim was not to validate the PedsQL™ scale itself. The study protocol was reviewed and approved by the IRB of the University of Tokyo. The informed consent was obtained in writing with the ethical statements provided by Institutional Review Board in accordance with the Declaration of Helsinki.

3. Results

3.1. Participants' Characteristics (Table 2)

Participants were seven mothers and three fathers. Participants' infants were aged younger than 5 months (#4, #5, #6, and #8), 5 - 10 months (#3 and #7), or ≥15 months (#1, #2, #9, and #10). No infant had any health problems. It took parents 6 - 24 minutes to complete the questionnaire with the think-aloud protocol. After answering the scales, participants were interviewed with probing questions. It took 46 - 100 minutes to complete the whole interview. One parent

Table 1. The four stages used to analyze the transcribed data.

Stage	Definition
1. Question interpretation	A respondent correctly comprehends and interprets the question, including the response options; and, in some cases, his/her ability to follow instructions
2. Memory retrieval	A respondent recalls relevant information that is necessary to answer the question
3. Judgment formation	A respondent makes a cognitive judgment to answer the question
4. Response editing	A respondent provides an answer to the question

Table 2. Participants' demographics (N = 10).

Characteristic	n
Parents' age range	
Mothers (aged 28 - 38 years)	7
Fathers (aged 31 - 43 years)	3
Infants' sex	
Female	6
Male	4
Infants' age range	
2 - 6 months	5
7 - 12 months	1
13 - 18 months	3
19 - 24 months	1

took 100 minutes for the interview because she had multiple children and she responded to each item concerning for each of her children. When asked whether they preferred a self-administered questionnaire or an interview for responding about their children's HRQOL, most participants preferred a self-administered questionnaire; although, many who came up with queries during questionnaire commented that an in-person interview mode would be helpful.

3.2. Parents' Responses to Each of the Subscales of the PedsQL™

All participants were confused when the items were asked. Those with infants younger than five-months-old had no idea how to even approach certain items; for example, whether their infant could experience "being sick to his/her stomach" or "feeling tired". They often said that their judgment regarding their infants' QOL may be too subjective and that others might have judged/answered differently. The following results were described according to five scales 1) physical functioning, 2) physical symptoms, 3) emotional functioning, 4) social functioning, and 5) cognitive functioning (Table 3). Within these scales, participants' narratives were divided into three stages—interpretation, memory retrieval, and judgement. The N values in Table 3 represent responses to items. For example, Physical Functioning consisted of 6 items for those aged 1 - 12 months and 9 items for those aged 13 - 24 months, that means, $6 \times 6 + 9 \times 4 = 72$ responses. These N values give us percentages for the levels of interpretation, memory retrieval, and judgment among the subscales as shared in the following paragraphs.

3.2.1. Physical Functioning (e.g. Feeling Tired, Difficulty Walking, etc.)

There were six items for infants aged 1 - 12 months and nine items for infants aged 13 - 24 months. When the question was difficult to comprehend, usually

Table 3. Response rate to each of the subscales of the PedsQL™.

		n	%
Physical functioning (N = 72)			
Interpretation	Comprehend correctly	63	88%
	Modified comprehension	8	11%
	Do not comprehend	1	1%
Memory retrieval	Recall relevant information	54	75%
	Do not recall information	18	25%
Judgment	Make a cognitive judgement by relevant information	44	61%
	Make judgement with modified interpretation	12	17%
	Make judgement “no problem” due to lack of evidence	16	22%
Physical symptoms (N = 100)			
Interpretation	Comprehend correctly	88	88%
	Modified comprehension	8	8%
	Do not comprehend	4	4%
Memory retrieval	Recall relevant information	58	58%
	Do not recall information	42	42%
Judgment	Make a cognitive judgement by relevant information	52	52%
	Make judgement with modified interpretation	14	14%
	Make judgement “no problem” due to lack of evidence	34	34%
Emotional functioning (N = 120)			
Interpretation	Comprehend correctly	107	89%
	Modified comprehension	12	10%
	Do not comprehend	1	1%
Memory retrieval	Recall relevant information	84	70%
	Do not recall information	36	30%
Judgment	Make a cognitive judgement by relevant information	66	55%
	Make judgement with modified interpretation	23	19%
	Make judgement “no problem” due to lack of evidence	31	26%
Social functioning (N = 44)			
Interpretation	Comprehend correctly	41	93%
	Modified comprehension	3	7%
	Do not comprehend	0	0%
Memory retrieval	Recall relevant information	31	70%
	Do not recall information	13	30%
Judgment	Make a cognitive judgement by relevant information	30	68%
	Make judgement with modified interpretation	6	14%
	Make judgement “no problem” due to lack of evidence	8	18%

Continued**Cognitive functioning (N = 60)**

Interpretation	Comprehend correctly	52	87%
	Modified comprehension	7	12%
	Do not comprehend	1	2%
Memory retrieval	Recall relevant information	42	70%
	Do not recall information	18	30%
Judgment	Make a cognitive judgement by relevant information	36	60%
	Make judgement with modified interpretation	11	18%
	Make judgement "no problem" due to lack of evidence	13	22%

because infants were too young, participants interpreted with modified comprehension (11%). For example, concerning difficulty participating in active play, one parent said, "*Well, that is hard to decide. I am not sure whether not being able to join in a play with other children would be a problem for the child because he is too young. I guess it is too early for him to feel that [is] a problem (#2).*"

Seventy-five percent of parents could recall relevant information. Participants answered each item relatively easily when they could recall their infants' daily behaviors. However, parents tended to answer whether their infants could express their physical condition instead of how much of that condition would be a problem to the infants. When the item responses were classified as modified comprehension, the judgment would be based on a modified interpretation (17%).

3.2.2. Physical Symptoms (e.g. Being Sick to His/Her Stomach, Having Gas, etc.)

There were 10 items each for both infants aged 1 - 12 months and infants aged 13 - 24 months. For some items, they were unsure of what was being asked. Four percent of the response for interpretation was, "do not comprehend", which was the largest proportion among other subscales. For example,

"'Being sick to his/her stomach', does this mean having a stomach-ache? Or throwing up? I do not understand (#4)."

"I, at least, never observed that kind of situation. What does it mean? I guess because I have never seen it, it is not a problem (#8)."

This led to parents' inability to recall relevant information. The proportion of not recalling the relevant information was the largest among the other subscales (42%). Thus, 34% of the participants said, "no problem" because there was no evidence of the problem.

3.2.3. Emotional Functioning (e.g. Feeling Afraid or Scared, Crying a Lot, etc.)

There were 12 items each for both infants aged 1 - 12 months and infants aged 13 - 24 months. Participants who found it difficult to apply the question to their infants used modified comprehension (10%).

“I have never seen them feeling sad. I do not think this question is for my child (#2).”

“I suppose if the child is left alone, he might feel sad. I guess the item is asking something like that (#3).”

“‘Feeling angry’, well it is OK to feel angry if it is not too extreme, so, I guess my child’s level of getting angry is not a problem (#10).”

“If he is feeling sad, it would be a problem, I don’t really know how he feels, so, I will call it a problem somewhat (#8).”

“He often wakes up during the night. He does not sleep through for more than two hours. I do not think that is causing himself a problem, but I have hard time putting up with it (#6).”

“Sometimes. He cries because he cannot fall asleep, so, I think this [is] a bit of a problem. [It is] for me, too (#4).”

Parents’ perception and judgment formation processes were compromised by their own emotional conditions, which were classified into “make judgment with modified interpretation” (19%).

“I would call it a problem not because my child feels it but because I get upset (#2, #6).”

“‘Difficulty sleeping mostly through the night’, my child has this problem and I guess it is not a problem for him, but I have difficulty with this, so, it is a problem (#6).”

“‘Crying or fussing when left alone’, he cries when that happens, but I think it is perfectly alright for him to cry and I feel that he has grown, so, it is not a problem (#7).”

“‘Feeling cranky’, I guess this means not being happy? I guess then it would be a slight problem (#8).”

3.2.4. Social Functioning (e.g. Not Smiling at Others, Not Making Eye Contact with a Caregiver, etc.)

There were four items each for infants aged 1 - 12 months and five items for infants aged 13 - 24 months. These items were easy for parents to comprehend. Nearly all (93%) of the participants understood what was asked, which resulted in making judgments with relevant information.

“My child smiles to the family member and with others. Well, they don’t smile at first, but when she is comfortable, she starts to smile back. I see no problem (#5).”

“He laughs when [he] is being tickled. No problem with that (#6).”

“I don’t have any problem with my child not making eye contact. He really put[s] his eyes on a person when he wants something (#1).”

3.2.5. Cognitive Functioning (e.g. Difficulty Naming Familiar Objects, Not Imitating Caregivers’ Actions, etc.)

There were four items for infants aged 1 - 12 months and nine items for infants aged 13 - 24 months. One mother did not understand what the items meant,

while others interpreted them in their own ways. In addition, when participants could not retrieve information, or when their infant had not yet reached the age to display the action, they judged the item as “never a problem”.

“I have not intentionally tried before, but I think he can imitate me if I point out and say ‘tummy’ (#2).”

“I feel that she is copying me, but maybe it is because I am her mother and see it favorably. She is still very small, so, even if she does not repeat what I say, it is not a problem (#4).”

“Whether he imitates my facial expressions? He would, and even if he does not, that is not a problem (#9).”

4. Discussion/Conclusions

Participants began to distinguish their infants’ HRQOL and their own perceptions of their infants. They came to understand the true intention of the questionnaire which was to evaluate infants’ QOL rather than parents’. In discussing infants’ developmental stages, Mahler stated that, “until the infant is five-months-old, they are in the autistic phase (*i.e.* not responsive to outer stimuli) [14]”. Therefore, parents find it hard to judge their child’s QOL and they thus use themselves as the template (Figure 1). Kitamura suggested that “judging children’s emotional temperament is subject to assessment bias derived from parents’ own emotions such as anger and depression [15]”. This suggests that parents may psychologically “project” their own negative or hostile feelings onto their child.

We found that, when the question items were difficult to comprehend, parents’ memory retrieval was affected. Participants tended to judge “no problem” when they could not find apparent evidence. This tendency was strong for “physical symptoms”. In contrast, when parents understood the questions or comprehended them using their own interpretation, they judged according to their judgment criteria and answered “no problem” in most of the cases. The tendency was strong in physical functioning, emotional functioning, and cognitive functioning. Therefore, it is necessary to be aware that even if the report is “no problem”, there are cases where parents say this because they do not understand the question or there is just no apparent evidence yet. In addition, children’s emotional functioning may be being interpreted in a biased way; for example son’s study, among the three raters—mothers, fathers, and teachers—the effects

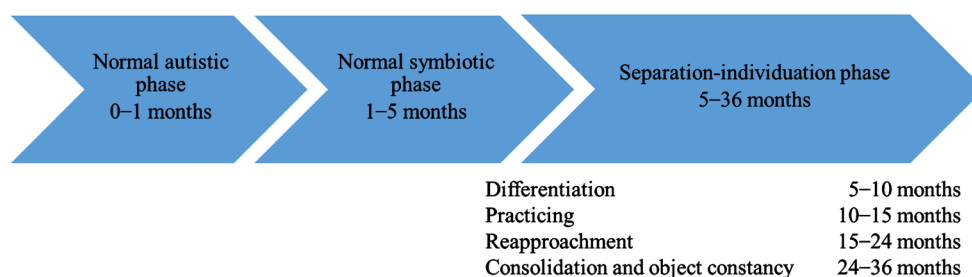


Figure 1. Infants’ development stages (Mahler et al., 1975).

it may have been rated lower owing to the effects of a parent's mood. In Ferguson of depression were only evident in mothers [16]. In the current study, there are limitations. The size of the samples was too small to compare the rating results of mothers and fathers; therefore, future research needs to consider this matter.

In addition to the small sample size, the participants were all from Metropolitan Tokyo, and were not representative of all Japanese parents. Future investigators should involve participants from different regions for the issue of generalization. This study, however, was the first report and deeply explores parents' comprehension and judgment processes when assessing their infants' HRQOL. The findings from this study will be helpful in improving healthcare communication and interpreting how parents gauge their children's HRQOL. In future studies, parents' personal attributes, including personality, anxiety, and mood, should be examined to interpret their biases in answering the questionnaire.

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Conflicts of Interest

The authors declare no conflicts of interest.

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PedsQL™ Infant Scales Parent Report for Infants (aged 1 - 12 months)

In the past ONE month, how much of a problem has your child had with ...

Physical Functioning (*problem with ...*)

1. Low energy level
2. Difficulty participating in active play
3. Having hurts or aches
4. Feeling tired
5. Being lethargic
6. Resting a lot

Physical Symptoms (*problems with ...*)

1. Having gas
2. Spitting up after eating
3. Difficulty breathing
4. Being sick to his/her stomach
5. Difficulty swallowing
6. Being constipated
7. Having a rash
8. Having diarrhea
9. Wheezing
10. Vomiting

Emotional Functioning (*problem with ...*)

1. Feeling afraid or scared
2. Feeling angry
3. Crying or fussing when left alone
4. Difficulty soothing himself/herself when upset
5. Difficulty falling asleep
6. Crying or fussing while being cuddled
7. Feeling sad
8. Difficulty being soothed when picked up or held
9. Difficulty sleeping mostly through the night
10. Crying a lot
11. Feeling cranky
12. Difficulty taking naps during the day

Social Functioning (*problem with ...*)

1. Not smiling at others
2. Not laughing when tickled
3. Not making eye contact with a caregiver
4. Not laughing when cuddled

Cognitive Functioning (*problems with ...*)

1. Not imitating caregivers' actions
2. Not imitating caregivers' facial expressions
3. Not imitating caregivers' sounds
4. Not able to fix his/her attention on objects

Appendix II

PedsQL™ Infant Scales Parent Report for Infants (aged 13 - 24 months)

In the past ONE month, how much of a problem has your child had with ...

Physical Functioning (*problem with ...*)

1. Low energy level
2. Difficulty participating in active play
3. Having hurts or aches
4. Feeling tired
5. Being lethargic
6. Resting a lot
7. Feeling too tired to play
8. Difficulty walking
9. Difficulty running a short distance without falling

Physical Symptoms (*problems with ...*)

1. Having gas
2. Spitting up after eating
3. Difficulty breathing
4. Being sick to his/her stomach
5. Difficulty swallowing
6. Being constipated
7. Having a rash
8. Having diarrhea
9. Wheezing
10. Vomiting

Emotional Functioning (*problem with ...*)

1. Feeling afraid or scared
2. Feeling angry

3. Crying or fussing when left alone
4. Difficulty soothing himself/herself when upset
5. Difficulty falling asleep
6. Crying or fussing while being cuddled
7. Feeling sad
8. Difficulty being soothed when picked up or held
9. Difficulty sleeping mostly through the night
10. Crying a lot
11. Feeling cranky
12. Difficulty taking naps during the day

Social Functioning (*problem with ...*)

1. Not smiling at others
2. Not laughing when tickled
3. Not making eye contact with a caregiver
4. Not laughing when cuddled
5. Being uncomfortable around other children

Cognitive Functioning (*problems with ...*)

1. Not imitating caregivers' actions
2. Not imitating caregivers' facial expressions
3. Not imitating caregivers' sounds
4. Not able to fix his/her attention on objects
5. Not imitating caregivers' speech
6. Difficulty pointing to his/her body parts when asked
7. Difficulty naming familiar objects
8. Difficulty repeating words
9. Difficulty keeping his/her attention on things