Paediatric health related quality of life : a European perspective : instrument development, validation, and use in clinical practice

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Clinicians' perspective on quality of life (QoL) assessment in paediatric clinical practice

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If respondents do not believe that QoL information is clinically relevant, it appears unlikely that it will be easily incorporated into routine clinical practice (K.M. Taylor, 1996).

Abstract

This study was undertaken to investigate paediatric clinicians' views on and use of quality of life (QoL) assessment in clinical practice. A survey was conducted among members of the Dutch Paediatric Association via e-mail. Over half of the 303 respondents (57%) believed that it was possible to use QoL questionnaires in clinical practice. The majority indicated that assessing QoL was beneficial and that it was especially necessary to assess QoL in children with a chronic disease (82%). Although only a minority (17%) currently used QoL questionnaires, most respondents would want to use QoL questionnaires in the future (76%). Obstacles that prevent the use of QoL questionnaires are the extra time needed for assessment, the unavailability of standardized questionnaires and insufficient knowledge about QoL. This survey shows that paediatric clinicians are positive towards QoL assessment, but that certain obstacles prevent the use of questionnaires. Thus, to facilitate future use, QoL questionnaires need to be developed from the perspective of the paediatrician. This means that they need to be developed for clinical use and brought to the attention of the paediatric health care community, demonstrating their validity to child health care.

Introduction

Questionnaires designed to measure quality of life (QoL) have been developed and tested since the 1970s [1]. They are increasingly being used as assessment and outcome measures in clinical research trials in adults [2]. Assessment of QoL has also improved in the paediatric field. There is an increase in the availability of generic and disease-specific questionnaires for use in children and adolescents [3-6]. However, QoL is seldom included as an outcome measure in paediatric clinical trials or in clinical practice [7-9].

Until recently most investigators have concentrated on the development and validation of QoL questionnaires for research. At present an increasing number of investigators have expressed their interest in using QoL questionnaires for individual assessment and see the implementation of individual QoL questionnaires into clinical practice as the current challenge in the field of QoL research [1,10-12]. In adult research QoL assessment has already proven to be helpful. Evidence has indicated that QoL assessment is beneficial as an aid to patient management. This includes improving the clinician-patient relationship and communication, better monitoring changes in patients, screening for potential problems, and if necessary, referring to other professionals [11,13-18]. Unfortunately, the paediatric field lacks studies that provide proof that QoL assessment has similar benefits for the child's health.

There is some information on the attitude of clinicians towards using QoL measurements for patient care. This research comes mostly from the adult oncology field [14,19-25]. Walsh's survey (1988) showed that although clinicians believe that QoL can be measured, only a few used a specific method or were aware of available instruments [25]. In the study by Taylor et al. (1996) the majority of respondents considered it important to collect QoL information from their patients but they tended to do this informally. Only 7% routinely assessed the QoL of their patients in a structured manner [24]. Identified obstacles for QoL assessment were: time and resource constraints (money and human resources), lack of evidence-based intervention studies on their benefit to patient care, a perceived lack of appropriate instruments, lack of knowledge, unavailable interpretation guidelines and a belief that QoL assessment is unnecessary [15,18,22,24]. No literature was found on paediatricians' views on QoL assessment in clinical practice, and there is no indication that paediatric health care professionals implement available QoL questionnaires on a regular basis. The objective of this study is to assess the use of QoL questionnaires and the perspective of paediatric clinicians towards QoL assessment in paediatric care.

Material and methods

The aim was to evaluate (a) the paediatric clinicians' perspectives on quality of life and QoL questionnaires in clinical practice, (b) their willingness to assess QoL and (c) the obstacles preventing the use of QoL questionnaires. As the familiarity with QoL questionnaires and their terminology was assumed to be minimal, we did not use a specific QoL concept but referred to QoL in general. We designed a questionnaire (see appendix) based on earlier studies [22-25]. Questions regarding the clinicians' gender, age, profession, years of working experience, sub-specialization and hospital affiliation were included. A pilot test was carried out among clinicians for comprehension, ease of use and completion time.

The registry of members of the Dutch Paediatric Association (n=1780) was used to identify the study group. Members mainly include house-officers, paediatric registrars, paediatricians and retired paediatricians. Between May and July 2002, the self-administered questionnaire was emailed to those members for whom an email address was available (n=1036). A reminder was sent a month after the first mailing. The electronically returned questionnaires were directly converted into a format of the Statistical Package for the Social Sciences (SPSS), the input of the mailed questionnaires was done by hand. Descriptive statistics were generated with the SPSS 10.0. The Pearson X^2 test was used to calculate the statistical difference within the population.

The heads of the paediatric departments of each of the eight university hospitals in the Netherlands were also contacted and asked to participate in a semi-structured interview addressing issues on QoL assessment and its future clinical use.

Results

Of the 1036 emailed members, 362 replied (35 %), either by email or mail. A total of 303 questionnaires were used for the analysis. The other 59 responses were excluded, mostly because the questionnaire was not attached to the email or an empty questionnaire form was returned. Some of these respondents indicated that they thought the questionnaire was not applicable to them or did not want to participate.

Demographics

The demographic characteristics of the study group are listed in Table 1. The studied population had a larger proportion of paediatricians and more respondents from university hospitals.

The respondents' perspectives on quality of life and QoL questionnaires

Sixty-nine percent of the respondents were familiar with the existence of QoL questionnaires for children. Most had heard of them through the literature (40%) and from conferences (32%). Aspects that were seen as most important for QoL were physical functioning, social contact, pain, self-respect and daily life activities. The majority of the respondents (72%) thought it was possible to assess QoL in a research setting, only 57% thought this was possible in a clinical setting. Sixty-one percent of responders indicated that they always assessed the patient's QoL informally during their consultation. Most clinicians did not use any formal method to assess QoL, only a few indicated ever using a paper (17%) or a computer-aided (6%) QoL questionnaire. If valid and reliable QoL questionnaires would be available to them in the future, 76% would find them useful.

Demographic	**Group**	**Studied population (n=303)**	**Dutch Paediatric Association (n=1477)**
Gender (*p* = 0.06)	Male	54%	48%
Age (y)	<30	10 %	
	30-39	34 %	
	40-49	28 %	
	>50	28 %	
Profession (*p* = 0.01)	House officer	3%	7%
	Paediatric registrar	16%	19%
	Paediatrician	73%	48%
	Retired	2%	11%
	Other	6 %	15%
Years of work experience	<5	30%	
	6-10	19 %	
	11-20	22 %	
	>20	29%	
Sub-speciality	Yes	49%	
Affiliation (*p* = 0.00)	University Hospital	57%	28%
	Community Hospital	35%	35%
	Other/combination	8%	37 %

Table 1. Demographics of the studied population (n = 303) compared to the remaining members of the Dutch Paediatric Association (n = 1477).

The majority (71%) indicated that a specialized nurse could be primarily responsible for the assessment of a patient's QoL. The paediatrician, the psychologist and the hospital play specialist were also seen as suitable assessors of QoL by 58%, 56% and 50% of the respondents, respectively. Ideal methods of assessing QoL (formally and informally) were found to be the doctor's consultation (64%), a paper QoL questionnaire (53%) and a computer-aided QoL questionnaire (50%).

Willingness to assess QoL

Although 76% of the respondents indicated that they would want to use QoL questionnaires in the future, only 60% expected to actually do this. QoL assessment was found relevant for use in paediatrics, clinical research and especially for children with a chronic disease. Eighty-two percent of the respondents think it is necessary to formally assess QoL in children with a chronic disease (Table 2).

Patient group	**Not necessary**	**In some cases**	**Necessary**
Children at outpatient clinic	16	79	4
Admitted children	12	79	9
Acutely ill children	63	36	1
Chronically ill children	1	17	82
Children with unrecognised complaints	8	57	35

Table 2. Opinions on the necessity to measure QoL in different patient groups (%).

Obstacles preventing the use of QoL questionnaires

Respondents were asked which main obstacles would prevent them from using QoL questionnaires in the future. The main obstacles were the extra time needed for assessment, the unavailability of standardized questionnaires and their insufficient knowledge about QoL (Table 3). When asked whether they think they now have the skill and knowledge to use QoL questionnaires, 70% answered negatively.

Perceived obstacles	**Percentage of respondents**
Extra time needed for assessment	59
Unavailability of standardized questionnaires	55
Insufficient knowledge about QoL	48
No assistance in administering questionnaires	41
Inexperience with questionnaires	40
Needed training in interpretation	40
Insufficient information on questionnaires	30
Needed training in administration	27
Resistance from child or parents	20
Own priorities are different	16
Availability of extra working space	15

Table 3. Perceived obstacles preventing paediatricians from using QoL questionnaires (%).

Subgroup analysis

The respondents who were familiar with the existence of QoL questionnaires (n=206) were significantly more positive about their use. They were more likely to see the possibility of their use in a clinical setting (p=0.00) and in research (p=0.023) and were also more positive about using QoL questionnaires in the future (p=0.049) than the respondents who were not familiar with QoL questionnaires. They also scored significantly higher on the feeling that they had the skill and knowledge to use QoL questionnaires (p=0.033). However, they saw the unavailability of standardized questionnaires as a larger obstacle (p=0.038). Respondents who worked at a university hospital (n=171) were significantly more familiar with the existence of QoL questionnaires than the group working in a community hospital (p=0.007). Respondents with less than 10 years of work experience (n=147) and registrars (n=58) were significantly less familiar with the existence of QoL questionnaires (p=0.03 and p=0.019, respectively). They also scored significantly higher on the obstacle: 'inexperience with questionnaires' (p=0.001 and p=0.008, respectively).

Interview with heads of the paediatric departments

Seven of the eight heads of the university paediatric departments participated in an individual semi-structured interview. They believed that most paediatricians were aware of the existence of QoL questionnaires, but suspected that most of them see QoL questionnaires primarily as a research instrument and that they perceive the use of QoL questionnaires to be subjective and unreliable for clinical use. They propose that paediatricians are only open to innovation when they can see the benefit and effectiveness of a new method. They stated, therefore, that it was important to further validate existing questionnaires and demonstrate their benefit in clinical practice. They indicated that implementation of QoL questionnaires in clinical practice would be prevented by the following problems: limited time and manpower, insufficient finances, lack of standardization, insufficient knowledge and unproven benefit. For these reasons, it was implied that paediatricians would probably not administer the questionnaires. They said that the professionals who could facilitate the assessment, analysis and interpretation of QoL questionnaires were registrars, specialized nurses and psychologists.

Discussion

The aim of the current study was to explore the clinicians' view on QoL assessment in paediatric clinical practice. Similar to earlier studies, we found that clinicians are positive towards the use of QoL questionnaires, but that assessing QoL formally is uncommon [23,24]. The respondents saw the assessment of QoL in children with a chronic condition as especially important, and they believed that assessment should mainly be a task for the specialized nurse. It was stressed both by the survey and semi-structured interviews with the heads of paediatric departments that greater acceptance of QoL measurement is reliant upon evidence-based research that shows that QoL questionnaires are valid, reliable and beneficial and that standardized questionnaires should be easily accessible and provide ample information on interpretation and use.

While the majority of the respondents indicated that they would be interested in using QoL questionnaires, only a few currently used them and a small majority expected that they would actually use them in the future. This can be explained by the number of obstacles that they expect to encounter, such as the unavailability of standardized questionnaires, limited time for assessment and insufficient knowledge about QoL. These obstacles were similar to those found by others outside the paediatric field [18,19,22,24]. To stimulate clinical implementation, it is thus important to do more research on validating questionnaires and provide evidence of their benefit for clinical practice. If, in the future, paediatricians have access to valid questionnaires in areas they indicate are important, such as the QoL assessment of children with a chronic disease, this is likely to substantially increase their use.

Limited time for the completion of the questionnaires in the clinical setting is a major problematic aspect. Administering QoL questionnaires and scoring them takes extra time. A possible solution would be to further develop computerized questionnaires that can be used in the clinical setting. These can easily be administered, supply automatic data analysis and give instant results with a possibility to compare them to earlier measurements or a norm population [16,26,27], thus eliminating one of the major obstacles to questionnaire use. Being familiar with QoL questionnaires was associated with a more positive attitude towards their use. Thus, steps need to be taken to inform clinicians and other professionals about available questionnaires and the possibilities for their use in clinical practice. This is especially important for clinicians who have just started their careers and clinicians working in community hospitals. This indicates the importance of QoL data being reported in journals familiar to paediatric clinicians. It was also indicated how important it is to introduce a more multidisciplinary approach towards QoL assessment, as respondents noted the specialized nurse as someone who would be an appropriate person to administer QoL questionnaires.

The major limitation of this study is that the findings are related to a sample, which represents the opinion of only 17 % of the Dutch Paediatric Association. However, the response rate in our study (35%) was higher than the percentage (26%) achieved in a recent study by McMahon et al (2003). They compared a fax, post and email survey of paediatricians and found that their response rate, after 2 mailings, was 26% for email, 41% for post and 47% for fax [28]. Our response rate might have been improved if we had sent reminders by postal mail; however, time and financial factors prevented this at that time. Another aspect influencing the response rate was that there was no possibility to check whether the email addresses were actually being used. We also found that some of the respondents were inexperienced in opening, completing and returning an attached file via email. Theoretically, members already interested in QoL issues might be more likely to return the questionnaire, which would lead to a more positive attitude towards QoL assessment. However, we propose that the representativeness of the sample might be reasonable. Our main argument is that the results from two sources, responses from the departmental heads and the survey group, correspond. The survey also consisted of a large number of respondents who were not familiar with QoL questionnaires (30%) or found it was not (yet) possible to use QoL questionnaires in clinical practice (37%), indicating that the group represented a wide range of experience with QoL measurement.

Conclusion

This study demonstrates the necessity of taking the clinicians' perspective into account in the development of QoL questionnaires for clinical practice. The paediatric clinicians in this survey were interested in QoL assessment and felt that this was especially necessary in the treatment of children with a chronic disease. However, they identified a number of obstacles for the use of QoL questionnaires. Thus, if QoL questionnaires are to become an important part of the patients' assessment, more consideration needs to be given to the obstacles, to their use in the clinical setting, and to promoting the questionnaires to the health care community.

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Appendix

Questionnaire

Instructions

In this questionnaire you will find questions on the use of quality of life (QoL) measures within paediatrics. Each part of the questionnaire will be clarified with explanatory text. For the question you can tick that box that in your opinion is most appropriate. There are no right or wrong answers. What you think is of importance. Completing the questionnaire will take 10 minutes.

It is difficult to give an exact definition of quality of life (QoL) . Through the years several definitions have been presented. We have selected several subjects. Which of the following subjects are according to your opinion most important for QoL? (maximal 5 answers possible)

☐ Physical functioning
☐ Vitality
☐ Treatment load
☐ Pain
☐ Limitations
☐ Autonomy
☐ Home situation
☐ Daily life activities
☐ Future
☐ Religion
☐ Self respect
☐ Body image
☐ Mobility
☐ School functioning
☐ Satisfaction
☐ Emotions
☐ Cognition
☐ Social contacts
☐ Illness load
☐ Creativity
☐ Coping
☐ Other.......

We are curious about your opinion on measuring QoL with the help of questionnaires.
Do you think QoL can be....

	Yes	Not yet	No	No opinion
Defined?	☐	☐	☐	☐
Objectified?	☐	☐	☐	☐
Validly measured? (measure what it should measure)	☐	☐	☐	☐
Measured reliably? (continuously measure the same)	☐	☐	☐	☐
Used in the clinic?	☐	☐	☐	☐
Used in research?	☐	☐	☐	☐

In what way do you currently form an opinion on the child and parents QoL during (outpatient) consultation?

	Never	Sometimes	Always
Intuition	☐	☐	☐
Clinical experience	☐	☐	☐
In your consultation	☐	☐	☐
From another health care workers consultation	☐	☐	☐
A paper questionnaire	☐	☐	☐
A computerised questionnaire	☐	☐	☐
Other	....		

What, in your opinion, would be the ideal way to form an opinion of a child and parents QoL?

	Not	Sometimes	Useful
Intuition	☐	☐	☐
Clinical experience	☐	☐	☐
In your consultation	☐	☐	☐
From another health care workers consultation	☐	☐	☐
A paper questionnaire	☐	☐	☐
A computerised questionnaire	☐	☐	☐
Other	…….		

Several questionnaires to measure QoL in children have been developed in the last years
Are you familiar with the existence of these questionnaires?

☐ No
☐ Yes, (more answers possible)

☐ While at university
☐ While specializing
☐ From literature
☐ During courses
☐ At a conference
☐ Other

In this next part we are curious about your opinion on the importance of quality of life questionnaires in the care for children and their parents. How relevant do you find the use of QoL questionnaires for:

	Not	Hardly	A little	Considerable	Very
Routine treatment	☐	☐	☐	☐	☐
Treatment of the child with a chronic disease	☐	☐	☐	☐	☐
Treatment of a child with unexplainable complaints	☐	☐	☐	☐	☐
Clinical research	☐	☐	☐	☐	☐
Improvement of the general health of a child	☐	☐	☐	☐	☐
Certain choices in your treatment	☐	☐	☐	☐	☐
Paediatrics	☐	☐	☐	☐	☐

Paediatricians in Holland:

	Never	Seldom	Sometimes	Often	Always
Think that questionnaires need to be included in the treatment	☐	☐	☐	☐	☐
Find it praiseworthy/commendable when I use QoL questionnaires	☐	☐	☐	☐	☐
Have influence on my choice to use QoL questionnaires	☐	☐	☐	☐	☐

In my opinion:

	No	Yes
It is completely my own choice whether I use QoL questionnaires	☐	☐
I have the skill and knowledge to use QoL questionnaires	☐	☐

Assuming that valid and reliable QoL questionnaires will be available in the future what would you in general think about using these QoL questionnaires your self?

	1	2	3	4	5	
Not useful	☐	☐	☐	☐	☐	Very useful
Very time-consuming	☐	☐	☐	☐	☐	Very time-saving
Very uninteresting	☐	☐	☐	☐	☐	Very interesting

Can you indicate what aspects would keep you from using QoL questionnaires in clinical practice? (several options)

- ☐ Your own priorities are different
- ☐ Insufficient knowledge about QoL
- ☐ Inexperience with questionnaires
- ☐ Resistance from child and parents
- ☐ Insufficient information on questionnaires
- ☐ Availability of standardized questionnaires
- ☐ Availability of extra working space for assessment
- ☐ Extra time for assessment of the questionnaire
- ☐ Training in administering the questionnaire
- ☐ Training in the interpretation of the questionnaires
- ☐ No assistance in administering the questionnaire
- ☐ Other.......

Do you think it is necessary to formally measure QoL through standardized questionnaires in …

	Not necessary	Necessary in some cases	Necessary
Children at the outpatient clinic	☐	☐	☐
Admitted children	☐	☐	☐
Acutely ill children	☐	☐	☐
Chronically ill children	☐	☐	☐
Children with unexplainable complaints	☐	☐	☐
Other	....		

What discipline should, according to you, be primarily be responsible for the administering QoL questionnaires from children and their parents. (more answers possible)

- ☐ Paediatrician
- ☐ General nurse
- ☐ Specialised nurse (e.g. diabetes nurse)
- ☐ General practitioner
- ☐ Social worker
- ☐ " Well baby" health clinic
- ☐ Teacher
- ☐ Psychologist
- ☐ Hospital play specialist
- ☐ Other.......

Assuming that in the near future valid and reliable quality of life questionnaires (paper or computer) will be available in paediatrics.

Would you want to use QoL questionnaires in your treatment?

☐ Certainly not ☐ Probably not ☐ Maybe ☐ Probably will ☐ Surely will

Do you plan to use QoL questionnaires in your treatment?

☐ Certainly not ☐ Probably not ☐ Maybe ☐ Probably will ☐ Surely will

Do you expect to really use QoL questionnaires in your treatment?

☐ Certainly not ☐ Probably not ☐ Maybe ☐ Probably will ☐ Surely will