The Quality of My Life Questionnaire: The Minimal Clinically Important Difference for Pediatric Rheumatology Patients

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ABSTRACT. Objective. To determine parent-child agreement for the Quality of My Life (QoML) questionnaire. To establish construct validity of the QoML questionnaire. To determine the minimal clinically important difference (MCID) for the Quality of Life (QOL) and Health-Related Quality of Life (HRQOL) scales. Methods. A total of 136 families of children with inflammatory arthritis were interviewed. The QoML questionnaire was completed for the child's current state of health, and under 2 hypothetical scenarios, where (1) there is a hypothetical small improvement, and (2) there is a hypothetical small deterioration in health. The differences between the original QOL and HRQOL scores and hypothetical improvement and deterioration scores, respectively, were calculated to give MCID scores.

> Results. In total, 131 families completed the questionnaires. Intraclass correlation coefficients for parent proxy report and patient self-report of the QOL and HRQOL were 0.63 and 0.40, respectively. Correlations of QOL with pain and disease severity were moderately negative (r = -0.55 and -0.56, respectively, p < 0.0001). Correlations of HRQOL with pain and disease severity were strongly negative (r = -0.66 and r = -0.68, respectively, p < 0.0001). The MCID for improvement on the QOL was 7 mm, and for the HRQOL 11 mm. The MCID for deterioration in QOL was -33 mm, and for HRQOL

> Conclusion. The QoML questionnaire demonstrated fair parent-child agreement and good convergent construct validity. MCID scores will enable clinicians to interpret QoML questionnaire results in a clinically meaningful way. (First Release Dec 15 2006; J Rheumatol 2007;34:581–7)

Key Indexing Terms:

QUALITY OF MY LIFE QUESTIONNAIRE CONSTRUCT VALIDITY PARENTS CHILDREN HEALTH RELATED QUALITY OF LIFE MINIMAL CLINICALLY IMPORTANT DIFFERENCE

The assessment of quality of life (QOL) is an increasingly important issue in research that involves children with chronic illnesses. For these individuals, the measurement of QOL provides a meaningful way to determine the effect of healthcare when cure is not possible. QOL outcome measures have been widely used in clinical research, and their contribution to routine clinical practice is now becoming recognized¹. Using QOL measures in clinical practice helps to ensure that treatment plans and evaluations focus on the patient rather than the disease¹.

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Knowing that physical measures alone cannot be relied upon to gauge the effect of a particular treatment strategy on patients, researchers now face the challenge of finding optimal tools to quantify QOL; the nature of the construct makes it all the more challenging. The term "health-related quality of life" (HRQOL) has frequently been used interchangeably with QOL. However, in the setting of pediatric rheumatology, patients and parents interpret HRQOL and QOL as different constructs that provide independent information². HRQOL might be best defined as the "patient-reported quality of health." The use of the term QOL is ubiquitous³. The World Health Organization recently defined QOL as "the perceptions of individuals of their own position in life in the context of the culture and value systems in which they live, and in relation to their own goals, expectations, standards, and desires"4. QOL has also been described as a value-based, subjective evaluation of current life circumstances⁵.

The "Quality of My Life" (QoML) questionnaire was developed to measure an individual's QOL and HRQOL as separate constructs. The development of the questionnaire was initiated following Gill and Feinstein's critical appraisal of the quality of QOL instruments³. They found that QOL was defined conceptually in only a minority of articles, and that patients' values were not taken into account in the majority. They also reported that none of the investigators in the stud-

ies they reviewed made an effort to distinguish the overall QOL from QOL affected by health or illness (i.e., HRQOL). These findings prompted Gill and Feinstein to recommend that 2 global ratings be used, one for overall quality of life and the other for health-related quality of life. They also advocated that patients be allowed to rate the severity and importance of their problems. These recommendations were incorporated into the QoML questionnaire. The QoML questionnaire — by providing patient values to global assessments of health and life — is expected to provide additional and complementary information beyond traditional HRQOL tools. Global scales differ from multi-attribute questionnaires; using a global scale, respondents must determine for themselves which aspects of life (or health) should receive the most weight in determining their own OOL (HROOL), whereas in traditional questionnaires those choices have been made by the developers, or by groups of patients during the questionnaire development process.

Both components of the QoML questionnaire (i.e., the QOL and HRQOL components) have been shown to have face validity and convergent construct validity in a preliminary study of pediatric rheumatology patients². HRQOL and QOL were shown to be related but distinct constructs. The QoML questionnaire was also found to be broadly applicable to pediatric patients with a variety of rheumatologic conditions². Our study was undertaken in part to further validate the QoML tool.

Another important issue for an evaluative instrument like the QoML questionnaire is its responsiveness or ability to measure the changes within individuals over time⁶. Investigators wish to be confident they will be able to detect small but important changes in health. These differences, however, need to be placed in a meaningful context for health professionals, for patients, and for their families. Jaeschke, et al have suggested the term "minimal clinically important difference" (MCID)⁷. They defined MCID as the smallest difference in score in the domain of interest that patients perceive as beneficial and that would mandate a change in the patient's management⁷. Many methods have been advocated to determine different aspects of MCID^{8,9}. We chose to use a method we had previously developed in which patients determine their own MCID under hypothetical situations 10. The knowledge of the MCID for a particular instrument could guide clinical decision-making.

There is growing interest in using QOL and HRQOL as primary outcome measures in children. However, measurement of QOL and HRQOL in children is challenging; younger children may not have the cognitive maturity to provide reliable responses for QOL instruments. Parents are often used as proxy respondents in these instances. It has been found that parents and children agree upon more observable phenomena, but there is poor agreement in more subjective areas, such as social or emotional domains⁶. For example, Vogels, *et al* noted some agreement between parents and children on pain

and symptoms, and motor and cognitive functioning, but poor agreement on autonomy, and social and global emotional functioning¹¹. Whether parents over- or underestimate their child's QOL must be considered in the context of the particular instrument used; results have differed according to which domains of interest were studied^{12,13}. Because QOL is a subjective construct that by definition⁴ is specific to the perceptions of an individual, the usefulness of proxy reporting in QOL requires investigation¹⁴.

The research questions we considered were the following: (1) Do parents and their children agree on their perceptions of the child's QOL and HRQOL as measured by the QoML questionnaire? (2) Is the QoML questionnaire valid for children with juvenile arthritis? (3) What is the MCID for QOL and HRQOL as measured by the QoML questionnaire?

MATERIALS AND METHODS

Study sample. All children with inflammatory arthritis were eligible for inclusion in this study. Inflammatory arthritis encompasses a group of conditions that include juvenile idiopathic arthritis, reactive arthritis, and arthritis associated with inflammatory bowel disease. Eligible participants were identified consecutively from the rheumatology clinics at The Hospital for Sick Children and the Bloorview MacMillan Children's Centre in Toronto. One parent representative was chosen to act as a proxy respondent for each child. Children who were 10 years of age or older (n = 58) also provided self-report independently, without knowledge of their parent's responses.

A trained interviewer enrolled the families and administered the study questionnaires as the families waited for their child's appointment. The Research Ethics Board at Hospital for Sick Children approved the study and all participants gave their signed informed consent or verbal assent as appropriate.

Measures. This study used information from parents and children reported on the Quality of My Life questionnaire (Appendix), and a series of related measures.

QoML questionnaire. The questionnaire is composed of 2 visual analog scales (VAS): one asks "Overall, my life is..." and measures overall QOL; and the other asks "Considering my health, my life is..." and measures HRQOL. Scores can range from 0 ("the worst") to 100 ("the best") on double-anchored 100 mm VAS for each question stem. Additionally, a categorical scale elicits responses about change in QOL between visits².

Each respondent was asked to rate the QOL and HRQOL under 3 distinct scenarios, as follows. All answers were recorded on a common set of VAS. (1) The child's current QOL and HRQOL were recorded using a black pen. (2) The child's QOL and HRQOL were recorded under a hypothetical situation in which the child is given a new medication that improves the arthritis by "just enough to make a difference," using a green marker. (3) The child's QOL and HRQOL were recorded under a hypothetical situation in which the child's arthritis was worse by "just enough to make a difference," using a red marker. Thus, at the end of the exercise, the QOL VAS had 3 marks (one black, one green, one red), as did the HRQOL VAS.

Other measures. Traditional measurements of health status were also collected. These included the number of joints with active arthritis (defined as demonstrating effusion, or at least 2 of limited range of motion, heat, or pain/tenderness); number of effused joints; and duration of morning stiffness. The revised American College of Rheumatology functional assessment scale (Steinbrocker)¹⁵ responses as well as both parent- and child-rated responses for the Child Health Assessment Questionnaire (CHAQ) disability index, CHAQ pain scale, and the CHAQ disease severity scale were also collected¹⁶. Statistical analysis. DataDesk (v. 6.2; Data Description Inc., Ithaca, NY, USA) was used for the statistical analysis.

The paired t test was used to compare child-rated and parent-rated QOL

and HRQOL responses. Analysis of variance (ANOVA) was used to compare demographic features between groups. Intraclass correlation coefficients (ICC) were used to assess the concordance between parent and child responses for both QOL and HRQOL. We expected only fair agreement between parent and child responses based on the premise that an individual's QOL is determined by his/her own subjective perceptions.

To assess convergent construct validity we developed a number of hypothesized relationships that should hold true if indeed the QoML scales truly measure QOL and HRQOL. We did not measure criterion validity (i.e., QoML compared to a standard HRQOL questionnaire) as we believe the information provided by each to be complementary but different^{3,10}.

Our hypotheses were: (1) Those with greatest disease severity should have the worst QOL and HRQOL scores, evident by a moderate to strong negative correlation. (2) Those with the worst pain should have the worst QOL and HRQOL scores, evident by a moderate to strong negative correlation. (3) Those with the worst disability should have the worst QOL and HRQOL scores, evident by a moderate to strong negative correlation. (4) Those with the greatest duration of morning stiffness should have the worst QOL and HRQOL scores, evident by a moderate to strong negative correlation. (5) Those with the worst QOL scores should have the worst HRQOL scores and vice versa, evident by a moderate to strong positive correlation. (6) Both the QOL and HRQOL components of the QoML should have no significant relationships with a child's sex. (7) In children aged 10 years and older, QOL and HRQOL scores should have no correlation with a child's age.

Agreement between parent proxy report and patient self-report was determined using ICC. ICC values < 0.4 were considered to indicate poor agreement, values of 0.4–0.75 fair to good agreement, and values ≥ 0.75 excellent agreement 17 . Pearson product-moment correlations were calculated where the data were normally distributed. For measures with non-normal distributions, Spearman rank correlations were calculated. Correlation values of 0.6–0.79 were considered to indicate strong correlation, values of 0.4–0.59 moderate, and 0.2–0.39 weak correlation 18 . The 2-sample t test was used to compare the child-rated QOL (cQOL) of boys versus girls, and the child-rated HRQOL (cHRQOL) of boys versus girls. The same calculations were performed for comparison of parent-rated QOL (pQOL) and HRQOL (pHRQOL) responses for boys versus girls.

MCID can be determined in a number of different ways⁸. We chose to characterize MCID as the change occurring within individuals, important at the group level, that would be observed in those estimated to have differed, using the taxonomy proposed by Beaton, *et al*⁹. We previously used the same method in determining the MCID for scores on the CHAQ¹⁰. MCID scores for each respondent were determined by calculating the difference between the scores for hypothetical improvement and deterioration and their "current" situation scores, respectively, and then using the 80th percentile as a cutoff score (i.e., 80% of respondents would agree that the cutoff score represents a real difference in QOL). The same calculations were performed to determine the MCID scores for HRQOL.

RESULTS

In total 141 consecutive families of children with inflammatory arthritis were approached. Five families declined participation. Five of the consenting families were not able to understand the questionnaire task and provide usable data; therefore our final sample consisted of 131 families. Further details of this cohort have been described¹⁰.

Descriptive characteristics of the 131 children are shown in Table 1. The mean age of the children was 9.6 years (SD 4.4, range 1–18); the majority were female. There were 58 families with children aged 10 years or older who provided independent self-report in addition to parent proxy report. Most of the children had no or mild disability, with a median Steinbrocker score of 1 [range 1–4, interquartile range (IQR)

1] and a mean parent reported CHAQ score of 0.36 (SD 0.53, range 0–2.5), which is representative of patients seen in our clinics. Overall QOL and HRQOL was good whether reported by children or their parents; neither QOL nor HRQOL differed significantly by arthritis subtype [by ANOVA: cQOL F(5,50) = 0.52, p = 0.77; cHRQOL F(5,50) = 0.51, p = 0.77; pQOL F(5,125) = 1.8, p = 0.12; and pHRQOL F(5,125) = 1.1, p = 0.4].

Parent-child agreement

QOL. The concordance between cQOL and pQOL responses was fair to good, as shown by an ICC of 0.63. However, cQOL scores were slightly but significantly higher than pQOL scores (mean of paired differences = 8.89; p = 0.0002).

HRQOL. The concordance between cHRQOL and pHRQOL responses was fair, as shown by an ICC of 0.40. cHRQOL scores were similar to pHRQOL scores (mean of paired differences = 2.61, p = 0.43).

Construct validity (Table 2)

As shown in Table 2, QOL and HRQOL — for both children and parents — were moderately to strongly correlated with disease severity, disability, morning stiffness, and pain in the directions predicted *a priori*. There was little correlation with age, and no differences were seen between boys and girls.

When these analyses were repeated for only those parents who were reporting for children younger than age 6, similar qualitative and quantitative results were observed (data not shown).

MCID

Child responses. The median cQOL score for the child-reported current state was 93 (IQR 15.5). The median hypothesized score for improvement in cQOL was 2 (IQR 6). The median hypothesized score for deterioration in cQOL was –13 (IQR 21.75). The MCID score (i.e., 80th percentile) for improvement in cQOL was 7. The MCID score for deterioration in cQOL was –33.

The median cHRQOL score was 89 (IQR 20.5). The median hypothesized score for improvement in cHRQOL was 6 (IQR 9). The median hypothesized score for deterioration in cHRQOL was 14 (IQR 22.75). The MCID score for improvement in cHRQOL was 11. The MCID score for deterioration in cHRQOL was –38.

Figure 1 illustrates the child-rated QOL scores under the 3 distinct scenarios.

Parent responses. The median pQOL score for the parent-reported current state was 90 (IQR 19). The median hypothesized score for improvement in pQOL was 4 (IQR 9). The median hypothesized score for deterioration in pQOL was –20 (IQR 24). The MCID score for improvement in pQOL was 11. The MCID score for deterioration in pQOL was –38.

The median pHRQOL score was 91 (IQR 16.75). The median hypothesized score for improvement in pHRQOL was 5 (IQR 10). The median hypothesized score for deterioration

Table 1. Characteristics of children in the study.

Characteristics	All Subjects, N = 131 (%)	QOL, mean (SD)	HRQOL, mean (SD)	Subgroup of Children Who Provided Self-report, N = 58 (%)	QOL, mean (SD)	HRQOL, mean (SD)
Female	90 (69)	84.2 (17.5)	83.7 (19.5)	38 (66)	87.9 (14.1)	81.3 (19.2)
Male	41 (31)	82.5 (19.7)	83.1 (21.6)	20 (34)	87.3 (18.8)	79.7 (21.3)
Types of arthritis						
JIA polyarticular (RF+ and RF-)	27 (21)	86.1 (12.5)	81.6 (21.8)	13 (22)	88.8 (15.3)	82.0 (20.1)
JIA oligoarticular	41 (31)	82.8 (18.2)	83.7 (19.6)	15 (26)	89.4 (10.5)	80.3 (20.8)
JIA systemic arthritis	17 (13)	89.6 (11.2)	91.0 (9.8)	7 (12)	93.1 (9.4)	86.7 (16.3)
JIA enthesitis related	10 (8)	70.0 (26.2)	73.6 (27.7)	8 (14)	80.8 (29.0)	71.1 (22.5)
JIA psoriatic	14 (11)	80.6 (24.4)	82.1 (22.6)	12 (21)	86.5 (15.5)	82.6 (20.3)
Other (reactive, IBD related)	22 (17)	85.7 (18.1)	85.1 (18.8)	3 (5)	86.0 (7.2)	81.7 (20.6)
Age						
≥ 10 yrs	58 (44)	79.9 (20.3)	79.4 (23.4)	58 (100)	89.0 (12.5)	81.7 (18.7)
< 10 yrs	73 (56)	86.6 (15.8)	86.8 (16.4)	0 (0)	NA	NA

JIA: juvenile idiopathic arthritis, IBD: inflammatory bowel disease, RF: rheumatoid factor, NA: not applicable.

Table 2. Validity comparisons.

	Child Self-report, N = 58		Parent Proxy-report, N = 58	
	QOL	HRQOL	QOL	HRQOL
Boys	87.3	79.7	82.5	83.1
Girls	87.9	81.3	84.2	83.7
p	0.90	0.77	0.63	0.87
Child's age, Pearson correlation (p)	0.077 (0.57)	0.108 (0.43)	-0.244 (0.005)	-0.25 (0.0036)
Disease severity, Spearman correlation (p)	-0.56 (< 0.0001)	-0.68 (< 0.0001)	-0.49 (< 0.0001)	-0.45 (< 0.0001)
Pain, Spearman correlation (p)	-0.55 (< 0.0001)	-0.66 (< 0.0001)	-0.50 (< 0.0001)	-0.47 (< 0.0001)
Disability, Spearman correlation (p) Duration of morning stiffness, Spearman correlation (p)	-0.46 (< 0.0001) -0.48 (0.0002)	-0.50 (< 0.0001) -0.60 (< 0.0001)	-0.39 (< 0.0001) -0.32 (0.0002)	-0.39 (< 0.0001) -0.29 (0.0009)

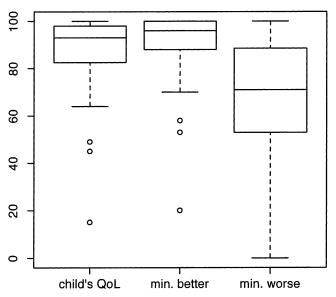


Figure 1. Child-rated QOL (cQOL) scores under 3 distinct scenarios. Child's QOL: cQOL scores in current situation; min. better: cQOL scores in hypothetically improved situation; min. worse: cQOL scores in hypothetically worsened situation.

in pHRQOL was -19 (IQR 21). The MCID score for improvement in pHRQOL was 14. The MCID score for deterioration in pHRQOL was -37.

Figure 2 illustrates the parent-rated QOL scores under the 3 distinct scenarios.

DISCUSSION

We found that the QoML questionnaire demonstrated fair parent-child agreement and good convergent construct validity, and we determined the MCID from the point of view of children and their parents, in a large cohort of children with inflammatory arthritis.

In our study, parents were fair proxy respondents for their children in completing the QoML questionnaire. However, we also observed that parents do rate their children's QOL and HRQOL lower than their children themselves. The difference was greater for QOL than for HRQOL. Because QOL is specific to an individual's perception and expectations, it is not unexpected that parents and children report different QOL scores. Bruil¹⁹ noted a similar finding for a group of children with chronic illness, where parents reported significantly

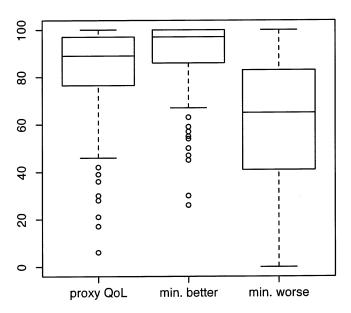


Figure 2. Parent-rated QOL (pQOL) scores under 3 distinct scenarios. Proxy QOL: pQOL scores in current situation; min. better: pQOL scores in hypothetically improved situation; min. worse: pQOL scores in hypothetically worsened situation.

lower QOL than their child. Parents were noted to report that their child participated in physical activities less often than the child reported, or less often completed school-based assignments. In addition, parents reported a lower "quality of performance" on cognitive tasks and social activities than their children¹⁹. There may be 2 reasons for this discrepancy in parent and child responses. First, parents may feel a sense of guilt when caring for their chronically ill child, which might negatively bias their perception of the influence of the disease on their child. Second, the ability of parents to assess the full psychosocial effect of the illness on their child is also limited. Good agreement between proxy and child respondents has been found for readily observable constructs, and poor agreement for more subjective constructs¹³. Ennett, et al²⁰ also demonstrated that mothers of children with juvenile arthritis consistently rated their children's perceived competence more negatively than the children themselves. Billings, et al²¹ reported agreement between parents and children 10 years of age and older on the pain and disability associated with arthritis, but differences in their reports of the psychological effects. As a result of being limited in their ability to fully understand the psychosocial impact of the illness on their child, parents may be unduly influenced by readily observable factors such as physical function when making an assessment of their child's QOL and HRQOL. This may be particularly relevant to our population of patients with inflammatory arthritis whose physical function may be impaired, but may also be pertinent to other populations of chronically ill children.

Varni, $et \ al^{22}$ suggest that the perspectives of multiple informants need to be considered when determining the

adjustment of children with newly diagnosed cancer. Crossinformant variance exists because there may be true differences in a child's behavior in multiple environments as well as differences in cross-informants' perceptions of a child's functioning²². Hence, in the area of QOL research parent report should be included, since it provides a unique perspective from someone who knows the child well and has a more extensive life experience. Moreover, if QOL information is needed for very young children, parents must be used as reporters. Our results suggest that parents can provide valid reports of QOL (in the sense that the reports are consistent with expected values based on more objective measures) for children even younger than age 6. However, parent report should not be considered as a surrogate that is interchangeable with child report. The choice of respondent is critical, and parent and child scores should not be used interchangeably on this measure.

We demonstrated that the QoML questionnaire exhibits good convergent construct validity in a large cohort of children with inflammatory arthritis. These data confirm our earlier findings in which the measured relationships between QoML responses and traditional health status measures were as predicted². The performance of the QoML questionnaire in this study provides further evidence for its use as a valid measurement tool for QOL and HRQOL in pediatric rheumatology patients.

A relatively small change, on average, in both QOL and HRQOL was clinically significant to the majority (i.e., 80%) of our subjects. We consider being able to elicit the individual's valuation of the magnitude of change and its importance a prominent attribute of the QoML questionnaire. Given knowledge of the MCID scores, healthcare professionals will also be better equipped to monitor the influence of particular treatment strategies on their patient's QOL and HRQOL.

As with any study in this area, our results should be interpreted in light of several possible limitations. OOL and HRQOL are often thought of as broad constructs influenced by many factors in a patient's life. While we measured important determinants of HRQOL (like pain, disability, and disease severity) as comparators, we did not directly measure psychosocial factors to compare with the QoML. Future studies might further test the convergent validity of the QoML when compared to differences in directly measured psychosocial domains. Regarding criterion validity, although we would expect to find complementary differences between the QoML approach and that used in traditional HRQOL questionnaires, we are currently studying this empirically by comparing a number of QOL tools (including a traditional questionnaire method, the PedsQL²³). The transferability of our results to clinical research and practice may also be limited by the innovative method we used of determining MCID using hypothetical scenarios. Finally, due to time constraints, the questionnaire was not readministered to individuals and their families in the short term, and thus no assessment of reliability was possible. We would expect reliability to be comparable to that shown for similar visual analog scales²⁴.

There may also be concerns regarding the generalizability of our results, given that the overall disease burden in our subjects was relatively mild. However, we enrolled our subjects consecutively from our clinics; this method of enrollment is likely to enroll more severely affected subjects who must be seen in the clinic more often. Therefore, the relatively high quality of life scores observed in our subjects are unlikely to have been overestimated. Our results should be applicable to pediatric rheumatology patients managed at tertiary care facilities.

We show that while the parent's answers on the QoML questionnaire may be complementary to their child's, the parent cannot be considered an identical proxy. In addition, we have shown that the QoML questionnaire is a valid measurement tool, that directly measures respondents' own values, for children with arthritis. Finally, determination of the MCID will enable clinicians to consider changes in QoML scores in a clinically meaningful context.

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Appendix. Quality Of My Life Questionnaire.

Quality of My Life								
Some of the children who come to see us feel that their life is not that great, while others think that their life is O.K. How about you?								
OVERALL, my life is								
The WORST 8	The BEST							
Considering my HEALTH , my life is								
The WORST ⊗				The BEST	,			
Since the last time I was here my life is								
•								
This is my	Much	A Little	The	A Little	Much			
FIRST visit	WORSE	WORSE	SAME	BETTER	BETTER			
Check one or both boxes. This form was filled out by		Me:	0					
		My parent:						
		Other: (please expla	ain)					
Date: DDD/DD/ (Year/Mont								

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