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Psychopathology in children: Improvement of quality of life without psychiatric symptom reduction?

Accepted: 15 March 2005

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■ **Abstract** *Objective* The aim of this study was to assess the association between change in psychopathology and Quality of Life (QoL) across time in children with high levels of psychopathology. *Methods* A referred sample of 126 seven- to 19-year-olds was studied across a 1-year follow-up period. Information concerning QoL and psychopathology was obtained from parents. *Results* Overall, 38.1 % of children showed neither psychiatric symptom reduction nor QoL improvement, 33.3 % of children showed both a clinically significant psychiatric symptom reduction and QoL improvement, and 28.6 % of children showed either psychiatric symptom reduction or QoL improvement. In 11.1 % of all children, QoL im-

proved, while the level of psychopathology remained high. Age, gender, or psychiatric diagnosis did not predict a poor outcome of persistently high psychopathology scores and poor QoL. *Conclusion* QoL in children with psychiatric problems may be improved by reducing psychiatric symptoms in a number of children, but it is also possible to improve QoL without psychiatric symptom reduction. This implicates that QoL should become an important aim and treatment outcome measure of psychiatric treatment programs, especially since psychopathology tends to persist.

■ **Key words** Quality of Life – child psychiatric disorder – follow-up

Introduction

Community and clinical studies have shown that psychopathology in children and adolescents tends to be highly persistent [6, 11, 12, 19, 20, 25]. Furthermore, treatment outcome studies in children and adolescents revealed that interventions may result in complete reduction of psychiatric symptoms in a number of patients, but, often, recovery is partial, or even absent [2, 18, 24, 29]. Hence, it might be worthwhile also focussing on minimizing the impact of symptoms on the child's functioning and on improving the child's quality of everyday life [22]. For this purpose, the construct of Quality of Life (QoL) may be useful.

QoL concerns a person's satisfaction with his/her functioning in several life domains and comprises the physical, emotional, and social functioning of the individual [30]. In this way, QoL encompasses more than simple symptom listing and can be distinguished from psychopathology measurement, because it addresses a wide range of aspects concerning a patient's functional adaptation in his or her everyday life. So far, several studies concluded that QoL of children with psychiatric disorders is considerably poorer than that of children from the general population, and as poor as or even poorer than that of physically ill children [3, 17, 21]. This underscores the need to address QoL in child psychiatric treatment [22]. Current clinical intervention trials in children and adolescents mainly focussed on psychiatric

symptoms as treatment outcome, and did not fully address QoL [2, 29, 31, 32].

It is unknown to which extent QoL improvement depends on change in psychopathology. This is especially important for children in whom psychiatric treatment does not sufficiently reduce psychiatric symptoms. The basic issue here is whether psychiatric symptom reduction is needed to achieve QoL improvement. If, during treatment, change in QoL were to be exclusively associated with change in psychopathology, this would indicate that treatment should focus on psychiatric symptoms, since this might be the only way to influence QoL. However, improvement in QoL without significant concurrent change in symptoms of psychopathology would suggest that alternative treatments, aiming more rigorously at QoL, might be needed for those in whom psychopathology is not affected by routine treatment methods.

To our knowledge, the association between psychiatric symptoms and QoL in children with psychiatric problems has not been studied longitudinally, leaving the issue of the association between change in psychopathology and change in QoL unanswered. In adults with psychiatric disorders, it has been reported that QoL may improve, even when the extent of psychopathology does not change. Browne et al. [7] studied a group of adults with schizophrenia who participated in a psychosocial rehabilitation program and found an improvement in QoL in the absence of any significant change in symptom severity. The improvement was attributed to the training in social skills and education, regarding the nature and treatment of schizophrenia. Another study assessed the effect of a pharmacological intervention on QoL in adult patients with obsessive-compulsive disorder and found that improvement in QoL was not necessarily associated with reduction of symptoms [26].

The aim of the present study was to assess the association between change in psychopathology and change in QoL across time in children with high levels of psychopathology and poor levels of QoL. These children were followed up across a 1-year period. It was chosen to focus on children with high levels of psychopathology because this group of children is most at risk for persistence of psychopathology across time and, therefore, might benefit most by improvement of QoL. The proportion of children in whom the level of psychopathology remained high across time, while QoL improved, was investigated. Furthermore, it was studied which children were at risk for persistence of both psychopathology and poor QoL, according to age, gender, and type of psychopathology. The latter might help clinicians to identify those with a poor prognosis in both domains. Since this is the first study that examined the course of QoL in a child psychiatric population, the goal was not to evaluate the effect of a specific psychi-

atric treatment program on QoL, but to perform a first explorative study.

Methods

■ Procedure and participants

The present study is part of a 1-year follow-up study of a child psychiatric outpatient sample. At the first assessment (Time 1), a sample was assessed of 310 children (response rate 73.1%; mean age 11.3 years; range 6–18 years), who had been referred between August 1, 2000 and September 15, 2001 to a general or a university child psychiatric outpatient department in Rotterdam, The Netherlands. By recruiting patients from these two clinics, children with a broad range of problems, varying from mild to severe, were included [3, 5]. At the second assessment (Time 2; mean follow-up time 389 days; SD = 66 days), 231 children and their parents participated (response rate 74.5%; mean age 12.2 years; range 7–19 years).

In the present study, the aim was to investigate changes in QoL scores across time in children with high levels of psychopathology. Therefore, children were selected with a Time 1 score in the clinical range of the psychopathology measure (Child Behavior Checklist, CBCL [1]) and in the clinical range of the QoL measure (Pediatric Quality of Life Inventory™ Version 4.0, PedsQL [27]). This yielded 126 children; 67 boys (53.2%) and 59 girls (46.8%) with a mean age of 12.3 years (SD = 3.2). Family socio-economic status (SES) was determined through parental occupational level [9]; 27.8% of the children came from families with low and 72.2% from families with middle to high SES. Based on the main clinical diagnosis, which was obtained with the DSM-IV Checklist Interview in a standardized way at Time 1 [13], each child was assigned to one of six diagnostic groups: (1) Attention Deficit and Disruptive Behavior Disorders (n = 48, 38.1%), (2) Anxiety Disorders (n = 25, 19.8%), (3) Mood Disorders (n = 16, 12.7%), (4) Pervasive Developmental Disorders (n = 16, 12.7%), (5) Other Disorders (n = 2, 1.6%; including Somatoform Disorder and Enuresis/Encopresis), and (6) No Diagnosis (n = 19, 15.1%). The validity of the DSM-IV Checklist Interview, as applied in this study, was supported by Bastiaansen et al. [5].

The study was approved by the Erasmus-MC university hospital medical ethical committee. All children and parents provided written informed consent at both Time 1 and Time 2.

■ Instruments

Child Behavior Checklist/4–18 (CBCL)

The CBCL [1] was used to obtain standardized parent reports of children's problem behaviors. The second part of the CBCL, which was used in the present study, consists of 120 items on behavioral or emotional problems in the past 6 months. The response format is 0 = not true, 1 = somewhat or sometimes true, and 2 = very or often true. Good reliability and validity of the CBCL [1] were confirmed for the Dutch translation [28].

In this study, the Internalizing (including withdrawn and anxious/depressed behaviors and somatic complaints), Externalizing (including aggressive and delinquent behaviors), and Total Problem scales of the CBCL were used. The Internalizing scale reflects problems related to internal distress, while the Externalizing scale reflects conflicts with other people and with their expectations of the individual. Summing the scores for each problem item yields the Total Problem score. A Total Problem score in the clinical range was defined as a *T* score of ≥ 63 (90th percentile [1]); the *T* distribution was based on the scoring distribution in the Dutch normative sample [28].

Pediatric Quality of Life Inventory™ Version 4.0 (PedsQL)

To measure the child's QoL, the parent version of the 23-item PedsQL [27] was used, which has versions for ages 5–7, 8–12 and 13–18 years. Parents are asked to indicate how much of a problem an item has been for the child during the past month. By formulating the instruction in this way, the parent is not asked to rate the presence of a certain behavior, but, if present, its impact on the child's everyday functioning. The items are scored on a 5-point-Likert scale (0, 25, 50, 75, 100). Scores may range from 0 to 100, from 'almost always a problem' to 'never a problem'; higher scores indicate better QoL.

Four subscales and a Total score can be computed, covering the following dimensions of QoL: (1) physical functioning (8 items; e. g., 'hard to do sports' or 'having hurts'), (2) emotional functioning (5 items; e. g., problems with 'feeling angry' or 'feeling afraid'), (3) social functioning (5 items; e. g., 'trouble getting along with peers'), and (4) school functioning (5 items; e. g., 'trouble keeping up with schoolwork'). Good reliability and validity were reported for the American [27] and Dutch version [3] of the PedsQL. In this study, the Total score was used; this score is computed by summing the scores for each item. Corresponding with the cut-off point of the CBCL, a PedsQL Total score of $\leq 10^{\text{th}}$ percentile was used as a cut-off point to define the clinical range. The cut-off point was based on the scoring distribution in a Dutch general population sample [3]. This group consisted of 74 children from the general population (re-

sponse 66.1%), who had not visited mental health services in the past year (56.8% boys; mean age 12.1 years; range 7–18 years). The scoring distribution in this Dutch sample matched the scoring distribution in a large American sample [27].

■ Statistical analyses

For the CBCL Internalizing, Externalizing and Total Problem scores, and for the PedsQL Total scale and subscale scores, means and standard deviations at Time 1 and Time 2 were computed. Besides, to assess the association between psychopathology and QoL, Pearson correlations between CBCL and PedsQL scale scores at Time 1 and between change in CBCL and change in PedsQL, Total scale scores across time were computed. The latter was performed by calculating the difference between the Time 1 and Time 2 CBCL Total scale scores and the difference between the Time 1 and Time 2 PedsQL Total scores, and by subsequently correlating these two new variables. To assess differences in average scale scores of the CBCL and the PedsQL at Time 1 vs. Time 2, paired-sample *t* tests were performed. This test regards the amount of change in scores for the total sample. However, by using *t* tests, it is not possible to determine a significant change at the level of an individual, which is important in clinical practice. Therefore, we calculated clinically significant change for each child on CBCL and PedsQL scale scores, as defined by Jacobson et al. [14, 16]. They set a twofold criterion for clinically significant change: (1) the magnitude of the change has to be statistically reliable, and (2) by the end of therapy, an individual should score in the range of normal functioning [15].

To determine if a change in an individual's score was statistically reliable, the Reliable Change Index (RCI) was calculated according to the Edwards-Nunnally method [23]. This method minimizes the influence of regression to the mean in the calculation of improvement rates. Confidence intervals around the Time 1 score were calculated. If the Time 2 score fell in this confidence interval, the change was registered as not statistically reliable; if the Time 2 score was outside the confidence interval, the change was registered as a statistically reliable change.

Secondly, it was assessed if Time 1 and Time 2 scores fell in the range of clinical or normal functioning of the CBCL and PedsQL. A *T* score of ≥ 63 ($\geq 90^{\text{th}}$ percentile) was used as a cut-off point to define the clinical range of the CBCL Total Problem scale and, corresponding with this cut-off point, a PedsQL Total score of $\leq 10^{\text{th}}$ percentile was used as a cut-off point to define the clinical range.

Based on Jacobson et al. [16], the following categories of clinically significant change were distinguished: 'recovered', 'improved', 'unchanged – still clinical', and 'de-

teriorated within the clinical range'. Children in the category 'recovered' showed statistically reliable change and moved from the clinical into the normal range. Children in the category 'improved' showed statistically reliable change, but remained in the clinical range. Children in the category 'unchanged – still clinical' had no statistically reliable change and remained in the clinical range. Children in the category 'deteriorated within the clinical range' showed a statistically reliable worse score within the clinical range.

To assess which children were at risk for persistence of psychopathology and poor QoL, a forward stepwise logistic regression analysis was performed. Age, gender, and DSM-IV Checklist Interview diagnosis were used as predictor variables. A dichotomized variable of outcome was used as dependent variable. This variable was coded as '1' if at Time 2 both CBCL Total Problem score and PedsQL Total score were in the clinical range (labeled as 'poor prognosis') and as '0' if at Time 2 either CBCL Total Problem score or PedsQL Total score or both were in the normal range ('moderate or good prognosis').

Results

Descriptive analyses

Table 1 shows the means and standard deviations of CBCL and PedsQL scale scores at Time 1 and Time 2. Across time, all scale scores improved significantly ($p < 0.001$; paired-sample t tests).

Table 2 shows the correlations between CBCL and PedsQL scale scores at Time 1. The correlation between CBCL and PedsQL Total scale scores at Time 1 was large [8] and correlations between CBCL and PedsQL subscale scores were small to medium [8], except the correlation between the CBCL Internalizing score and the PedsQL Emotional functioning score which was large. The correlation between change in CBCL and change in PedsQL Total score across time was -0.55 ($p < 0.001$).

Table 1 Means and standard deviations of CBCL and PedsQL scale scores at Time 1 and Time 2 (N = 126)

Scale	Time 1	Time 2	t test (p)
CBCL			
Total Problem score	80.4 (21.8)	61.7 (25.9)	< 0.001
Internalizing score	23.5 (10.1)	17.9 (10.3)	< 0.001
Externalizing score	24.1 (10.7)	18.9 (10.6)	< 0.001
PedsQL			
Total score	56.8 (10.5)	67.0 (15.1)	< 0.001
Physical functioning	71.0 (18.4)	79.5 (18.3)	< 0.001
Emotional functioning	44.0 (15.6)	57.6 (18.7)	< 0.001
Social functioning	51.9 (20.6)	62.3 (24.7)	< 0.001
School functioning	52.0 (14.7)	60.9 (19.2)	< 0.001

Table 2 Pearson correlations between CBCL and PedsQL scale scores at Time 1 (N = 126)

PedsQL	CBCL		
	Total Problem score	Internalizing score	Externalizing score
Total score	-0.49^{**}	-0.37^{**}	-0.26^{**}
Physical functioning	-0.27^{**}	-0.28^{**}	-0.14
Emotional functioning	-0.37^{**}	-0.48^{**}	-0.09
Social functioning	-0.33^{**}	-0.07	-0.22^*
School functioning	-0.24^{**}	-0.08	-0.19^*

* Significant at $p < 0.05$; ** Significant at $p < 0.01$

Clinically significant change

Table 3 shows the categories of clinically significant change for the CBCL Total Problem score and PedsQL Total score. The categories 'recovered' and 'improved', and the categories 'unchanged – still clinical' and 'deteriorated within clinical range' are presented as one category.

Overall, approximately one-third of the children (33.3%) showed clinically significant change on both CBCL and PedsQL Total score, while more than one-quarter improved on either CBCL or PedsQL Total score (28.6%), and more than one-third (38.1%) showed no improvement on both CBCL and PedsQL Total score. In 11.1% of all children, the CBCL Total Problem score remained high, while the PedsQL Total score improved. In children with a persistently high CBCL Total Problem score (N = 62), 48 (77.4%) children had a continuously low PedsQL score, while in 14 (22.6%) children, the PedsQL Total score improved across time. In other words, in 22.6% of children in whom psychopathology scores remained high, QoL improved.

Children at risk

To identify children with a poor prognosis (defined as persistence of both a high level of psychopathology and

Table 3 Categories of clinically significant change for CBCL Total Problem score and PedsQL Total score (N = 126)

Categories CBCL Total Problem score	Categories PedsQL Total score		
	Recovered/ improved	Unchanged/ deteriorated within clinical range	Total
Recovered/improved	42 (33.3%)	22 (17.5%)	64 (50.8%)
Unchanged/deteriorated within clinical range	14 (11.1%)	48 (38.1%)	62 (49.2%)
Total	56 (44.4%)	70 (55.6%)	126 (100%)

% indicates the proportion of the total number of children

poor QoL), the characteristics of these children were studied, compared to children with a moderate or good prognosis (defined as a Time 2 score in the normal range on either the CBCL Total Problem scale, the PedsQL Total score or both). Table 4 shows the number of children in each diagnostic category with a poor or moderate/good prognosis. Children with a diagnosis of Pervasive Developmental disorder seemed to have a poorer prognosis, since the proportion of children in the category poor prognosis was larger than in the other three diagnostic categories, but this difference was not significant ($\chi^2(3) = 3.29, p = 0.35$). The forward stepwise logistic regression analysis with age, gender, and DSM-IV Checklist Interview diagnosis as predictor variables revealed no significant predictors of poor outcome (-2 Log Likelihood = 167.5).

Discussion

The aim of the present study was to assess the association between change in psychopathology and QoL across a 1-year follow-up period in children with high levels of psychopathology, who had been referred to a child psychiatric outpatient setting. The main question was to assess if QoL can improve without psychiatric symptom reduction. Besides, it was studied which children are at risk for persistence of psychopathology and poor QoL.

■ Association between psychopathology and QoL

The aim of this article was to assess the association between change in psychopathology and QoL. The reader may wonder whether it is possible to make a distinction between these two entities, but, as was already discussed in the introduction, the concept of QoL does not encompass psychiatric symptoms, but addresses the impact of such symptoms on a patient's everyday life. The correlations between CBCL and PedsQL scales revealed a moderate association between psychopathology and

QoL. This indicated that it can be meaningful to study changes in levels of psychopathology and QoL separately.

■ Improvement of QoL

All children that were studied had high levels of psychopathology and a poor QoL at Time 1. Of these children, 33.3% showed a clinically significant reduction in level of psychopathology, plus an improvement of QoL. However, in accordance with previous studies [6, 11, 29], in half of the children (49.2%) the level of psychopathology remained high. This group could be subdivided into children who showed persistently low levels of QoL as well (38.1%) vs. children who showed improved QoL (11.1%; $11.1\% + 38.1\% = 49.2\%$). This indicates that QoL can improve while psychopathology persists. However, unfortunately, in 38.1% of all patients with clinical levels of psychopathology, psychopathology persisted and QoL remained poor. Traditionally, most psychiatric treatment methods aim to cure psychiatric symptoms. However, the results of the present study indicate that the treatments delivered to children from the present study's sample did not only show little impact on psychopathology, but also left QoL unaffected in 38.1% of all cases. This suggests that alternative treatments, aiming more rigorously at QoL, may be a valid alternative for those children in whom psychopathology is not affected by routine treatment methods.

■ Children at risk

In 38.1% of the children, high levels of both psychopathology and poor QoL persisted. This group of children with a poor prognosis was compared to children with a moderate or good prognosis. The characteristics of these children were studied. No differences in age and gender distribution were found. Also, no differences in outcome were found between diagnostic categories. Apparently, the prognosis of psychopathology

Table 4 Number of children in each diagnostic category with a poor vs. a moderate or good prognosis (N = 126)

Diagnosis	Prognosis		
	Poor	Moderate or good	Total
Attention Deficit and Behavior Disruptive disorders	17 (35.4%)	31 (64.6%)	48 (100%)
Anxiety and Mood disorders	13 (31.7%)	28 (68.3%)	41 (100%)
Pervasive Developmental disorders	9 (56.3%)	7 (43.8%)	16 (100%)
Other disorders or no diagnosis	9 (42.9%)	12 (57.1%)	21 (100%)
Total	48 (38.1%)	78 (61.9%)	126 (100%)

Poor prognosis persistence of both a high level of psychopathology and poor QoL; *moderate or good prognosis* a Time 2 psychopathology or QoL score in the normal range or both scores in the normal range. % indicates the proportion of the number of children in the diagnostic category

and QoL is not associated with the psychiatric diagnosis. In a previous study [5], we found that average QoL was equally poor in children with different child psychiatric diagnoses. The present study indicates that differences between diagnostic categories are also of little importance for the course of QoL across time. This is remarkable since, traditionally, some child psychiatric diagnoses, such as pervasive developmental disorders, are considered to be more disabling than other disorders, such as anxiety disorders. Other factors which were not measured in the present study might influence the course of a child's QoL. In another study [4], we investigated the association between QoL and child, parent, and family/social network factors and found that several of these factors, especially child and family/social network factors, were associated with QoL. It might be these factors that need to be addressed in QoL specific interventions.

■ Limitations

This study has several limitations. First of all, to measure the child's QoL, parent reports were used, while data reported by the child were not studied. Previous studies reported differences in reports of QoL by different informants and emphasized the importance of the use of multiple informants [10, 30]. In other words, future longitudinal studies on the course of QoL should include QoL self-report.

Another limitation might be the duration of the follow-up period. Children were followed-up across a 1-year period. It might be possible that this period is too short. Symptom reduction may be needed first to subsequently achieve an increase in QoL. In children with attention deficit hyperactivity disorder (ADHD), for instance, enhanced concentration and a decrease of hyperactivity may result in improvement of social contacts and better self-esteem, but this may be a long term, rather than a short-term, effect. Longer follow-up periods may be needed to evaluate the effect of psychiatric treatment on the course of QoL.

Finally, since this was a first explorative study, specific treatment aspects were not studied, such as type of treatment and duration of treatment. This hampers the generalization of the findings across other treatment

settings, because it remains unknown if the results are applicable to all diagnosis-type of treatment combinations.

■ Clinical implications

In many children (38.1%), high levels of psychopathology and poor QoL persisted, and in only 11.1% of all children in the present sample QoL improved, while psychopathology persisted. Although no specific treatment protocols were used, it might be concluded that treatments that are aimed at improvement of QoL should be developed. Furthermore, clinicians may need to monitor psychiatric symptoms across time accurately. In case of treatment resistance, active intervention at QoL level might be warranted. QoL encompasses the impact of a disorder on everyday functioning. In this study, QoL was operationalized as the child's satisfaction with his/her physical, emotional, social, and school functioning. So, children with high levels of psychopathology across time might need to learn to deal with the impact of their psychiatric symptoms in these areas. A handicap model might be used to improve the QoL of these children, by changing some circumstances the child lives in. For instance, if a child reports an impaired QoL with respect to school functioning, it might be worthwhile identifying possibilities to adapt the class situation to the needs of the child, or referring to special education. In the meantime, it might also be useful to focus on domains in which the child's functioning is satisfactory, and try to strengthen these areas.

Conclusion

In a large proportion of referred children with instantly high levels of psychopathology, psychopathology persisted and QoL remained poor. Although the group of children who showed change in psychopathology and improvement of QoL was also considerable, the present study indicates that it may be worthwhile systematically developing treatment modules aimed at improving QoL in those children in which treatment does not diminish psychiatric symptoms.

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