

Quality of life in children with psychiatric disorders

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Quality of Life in Children with Psychiatric Disorders

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1 | Introduction

Chapter 1

Introduction

During the past decade quality of life (QoL) has emerged as an outcome measure of clinical research and patient care in patients with physical diseases (Katschnig, 1997; Koot, 2001). Major progress in the diagnostic process and treatment of a number of severe and chronic physical diseases has considerably increased the rate of survivors (Newacheck and Taylor, 1992) and as a result, morbidity, health status, and the psychological and social consequences of a disease have become more important. Consequently, emphasis of patient care has shifted from maintaining life to enhancing patients' QoL. With the QoL construct, a method of formulating a patient's satisfaction with life as a quantifiable variable has become available. After the introduction of the QoL construct in patients with physical diseases, QoL has also been studied in adults with psychiatric disorders. QoL was introduced in psychiatry when deinstitutionalization of the chronically mentally ill took place (Baker and Intagliata, 1982; Lehman et al., 1982; Malm et al., 1981). So far, only a few studies addressed QoL in children and adolescents with psychiatric disorders (Clark and Kirisci, 1996; Landgraf et al., 2002; Sawyer et al., 2002). The aim of the present dissertation therefore was to study several aspects of the QoL of children and adolescents with psychiatric disorders.

In the current chapter, the concept of QoL will be addressed first. Subsequently, findings and conclusions of the present literature on QoL measurement in adults and children with psychiatric disorders will be summarized. Finally, the aims and methods of the present study will be described.

The concept of quality of life

Definition of quality of life

Most current attempts to define QoL have been guided by the definition of health by the World Health Organization (World Health Organization, 1948), that described health as "a state of complete physical, mental and social well-being". Despite this definition, in today's literature QoL is not yet defined in a uniform way and lacks clarity, and large discrepancies exist between operational definitions of QoL and in the identification of different areas of QoL (Katschnig, 1997; Koot, 2001). All current definitions have in common that QoL is described as a multidimensional construct that primarily concerns the patient's personal evaluation of his/ her life with regard to functional impairment, handicaps, and living

conditions. An important distinction can be made between health-related QoL and overall QoL (Lehman, 1997). Health-related QoL comprises disease and treatment related aspects of functioning of the individual, such as pain, limitations in motor ability, or nausea, whereas overall QoL encompasses also non medical aspects of a person's life, like social, educational, and occupational functioning.

Subjective versus objective QoL

Besides the differentiation between health-related QoL and overall QoL, another conceptual differentiation of QoL is the one between subjective and objective QoL markers. Originally, it was argued that assessment of QoL is essentially subjective and that an individual him or herself should be the primary source of information regarding QoL. However, today there is general consensus that QoL measurement should also encompass objective QoL indicators (Katschnig, 1997; Lehman, 1988). Objective QoL indicators include life circumstances, like having a job or the number of friends (Lehman, 1988; Mogotsi et al., 2000) and aims to describe life conditions that are associated with well-being.

Multiple informants

In patients with chronic physical diseases, low concordance has been found between QoL ratings by patients themselves versus ratings by significant others and health care providers (Sprangers and Aaronson, 1992). This discrepancy has also been reported in adults with psychiatric disorders (Browne et al., 1996a; Sainfort et al., 1996). This indicates that the perspective of significant others is very important in QoL measurement (Sprangers and Aaronson, 1992; Wallander et al., 2001), especially in psychiatry, where the patient's view may be distorted by psychiatric symptoms (Barry and Crosby, 1996; Becker et al., 1993; Sainfort et al., 1996).

QoL in adult psychiatric patients

Initially, most studies on QoL in psychiatric populations concerned patients with schizophrenia, but more recently patients with depressive or anxiety disorders have also been studied (Lehman, 1997). Most studies that focused on patients with schizophrenia concluded that their QoL is poorer than that of individuals from the general population without a disorder, and poorer than that of physically ill patients (Duno et al., 2001; Ritsner et al., 2000; Sainfort et al., 1996). Pyne et al. (1997) studied the QoL of patients with mood disorders and

reported that QoL in patients with a major depressive disorder was as poor as in patients with chronic physical illnesses. Bonicatto et al. (2001) reported that the QoL of patients with a depressive disorder was even poorer than the QoL of patients with chronic physical conditions. QoL in patients with anxiety disorders is also significantly reduced (Mogotsi et al., 2000). One study investigated QoL in adult patients with a pervasive developmental disorder (Persson, 2000). A treatment program was evaluated and it was concluded that it was possible to improve the QoL of patients with a pervasive developmental disorder.

Although several studies described QoL of patients with a specific psychiatric disorder, few studies compared QoL of patients with different psychiatric disorders. Warshaw et al. (1993) showed that QoL was lower in patients with a posttraumatic stress disorder than in patients with another anxiety disorder. Schneier (1997) studied QoL in patients with different anxiety disorders and concluded that all of the anxiety disorders seem to impair QoL through the distress of the anxiety experience itself, the avoidance behavior which often accompanies the anxiety, and the stigma attached to having emotional problems. Besides, he concluded that the nature of the impairment in QoL shows variation between anxiety disorders depending on the particular disorder. In the study of Wittchen et al. (2000) patients with a generalized anxiety disorder had lower QoL scores than patients with major depressive disorder. Ritsner et al. (2000) reported that patients with schizophrenia were less satisfied with social relationships than patients with mood disorders. In contrast with these previously mentioned studies, another study reported no differences in experienced physical and emotional health between patients with panic disorder, major depression, and other psychiatric disorders (Klerman et al., 1991).

From the current literature on QoL measurement in adults with psychiatric disorders it can be concluded that it is possible to distinguish and measure QoL separately from psychiatric symptoms. However, there is a risk of measurement redundancy (Katschnig, 1997). This might be the case if the item content of a quality of life instrument overlaps considerably with the items of a psychopathology measure (Katschnig and Angermeyer, 1997). Another conclusion can be that the impact of a psychiatric disorder on a person's life is huge since QoL of patients with psychiatric disorders is not only poorer than in healthy individuals, but also similar to, or even lower than in patients with chronic physical conditions. This implicates a high disease burden and stresses the need to treat psychiatric disorders adequately. Finally, the current literature shows that differences in QoL exist between patients with different psychiatric disorders, although this is not demonstrated in all studies.

QoL in child psychiatric patients

So far, little attention has been paid to QoL in children and adolescents with psychiatric disorders (Kazdin, 2001). However, the few studies that have been done, generally showed that QoL in children with psychiatric problems is at least as poor as in children with physical illnesses. Graham et al. (1997) found that children with psychiatric disorders had a poorer QoL than children with chronic physical disorders or children from the general population without an illness. Sawyer et al. (2002) studied an epidemiological sample and found a poorer physical and emotional QoL for children with mental disorders than for children without a disorder. Furthermore, children with mental disorders had a poorer QoL than children with physical disorders. Landgraf et al. (1996) reported a poorer QoL for children with Attention Deficit Hyperactivity Disorder (ADHD) than for children with asthma, juvenile rheumatoid arthritis, and healthy children. However, the relatively poor QoL of children with ADHD may depend on the comparison group, since Landgraf et al. (1997) found that children with ADHD had a better overall QoL than children with end stage renal disease.

Just a few studies compared QoL of children and adolescents with different psychiatric disorders. Clark and Kirisci (1996) reported differences in self-reported QoL between adolescents with Posttraumatic Stress Disorder (PTSD), Major Depressive Disorder (MDD), and Alcohol Use Disorder. In adolescents with MDD, emotional functioning, social competence and school functioning were more impaired than in adolescents with PTSD and Alcohol Use Disorder. In the study of Sawyer et al. (2002) children with MDD had more pain and discomfort than those with Conduct Disorder (CD) or ADHD, while those with CD or ADHD were more impaired in their QoL than children with MDD due to behavioral problems. Landgraf et al. (2002) measured the effect of ADHD on QoL and found that children with ADHD combined type had a poorer QoL than children with ADHD inattentive type, both in the area of emotional-social well-being and in functioning at home.

The results of the above-mentioned studies (Clark and Kirisci, 1996; Graham et al., 1997; Landgraf et al., 1996; Landgraf and Abetz, 1997; Landgraf et al., 2002; Sawyer et al., 2002) suggest that QoL of children with psychiatric problems is poorer than in healthy and physically ill children and that some psychiatric disorders have a stronger effect on QoL than others. However, the results of these studies have to be interpreted carefully since they had several limitations concerning samples (mainly community based which implies that results may be less applicable to clinical practice), age distribution, sample size, number of informants providing information, and types of psychiatric diagnoses included. Clark and

Kirisci (1996), for instance, included only children aged 12 years and older and only used the child's self-report information. Sawyer et al. (2002) studied a community sample, relied on information from parents only, and only concerned ADHD, CD, and MDD. The study of Graham et al. (1997) had a small sample size of 25 children and the studies of Landgraf et al. (1996; 1997, 2002) focussed on children with ADHD and did not include children with other child psychiatric disorders. Furthermore, the current literature shows that, as in QoL measurement in adults, a risk of measurement redundancy between QoL instruments and psychopathology measures exists (Schmeck and Poustka, 1997). This might be the case if the item content of the quality of life instrument overlaps with the items of a psychopathology measure.

The present study

The current literature on QoL in children with psychiatric disorders describes some aspects of the QoL of these patients, but a study that assessed QoL in a large sample that included all most prevalent child psychiatric diagnoses is lacking. By consequence, our knowledge of the impact of different child psychiatric problems on QoL, the relation between change in psychiatric symptoms and change in QoL, and the impact of modifiable child, parent, and family factors on this change is largely lacking. To compare the impact of different psychiatric disorders on QoL, it is preferable to incorporate all different psychiatric disorders in one study and use a multiple informant view, in a sample with a broad age distribution.

A very important issue in measurement of QoL in children and adolescents, is the use of a well validated QoL instrument (Wallander et al., 2001). In our search for an instrument to measure QoL in children and adolescents with psychiatric disorders, the Pediatric Quality of Life InventoryTM version 4.0 (PedsQL; Varni et al., 2001) seemed a suitable instrument, because its generic part encompasses the core health dimensions formulated by the World Health Organization (1948), it is well validated, and has proven its usefulness for measuring QoL in children with different diseases (Varni et al., 2002a; Varni et al., 2002b). Furthermore, it has parallel child and parent report forms, which is necessary for the multiple informant view on QoL, and it can be completed quickly, since it has only 23 items. However, the psychometric properties and usefulness of the PedsQL in measuring QoL in children and adolescents with psychiatric problems are not studied yet.

Once it is known which specific limitations in QoL children with different psychiatric disorders experience, it is possible to aim psychiatric treatment at improving children's QoL.

To improve QoL, it is also needed to know which factors correlate with, or may influence QoL. To identify these factors, the Bronfenbrenner model can be used (Bronfenbrenner, 1979). According to this model, factors influencing a child's development may be classified from more proximal to more distal, i.e. at the child level, parent level, and family/ social network level. Proximal factors are hypothesized to be more influential than distal ones, and distal factors are assumed to exert their influence mainly through more proximal ones. Factors possibly influencing a child's QoL can be ordered similarly.

To enable adequate treatment, knowledge should also be obtained about the course of QoL in children with psychiatric disorders. 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 would be exclusively associated with change in psychopathology, this would indicate that treatment should only 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.

Aims

The aims of the present study were:

1. To assess the usefulness of the Pediatric Quality of Life Inventory (PedsQL) to measure QoL in children with psychiatric problems.
2. To compare the QoL of children with psychiatric problems with the QoL of children from the general population without psychiatric problems.
3. To compare the QoL of children with different psychiatric disorders.
4. To identify factors that are associated with QoL in children with psychiatric problems.
5. To determine the course of QoL across time in children with psychiatric problems.
6. To identify predictors of future QoL in children with psychiatric problems.

To address these aims, a sample of children who had been referred to outpatient mental health agencies was selected. In this sample the most prevalent child psychiatric diagnoses were studied and QoL was reported by the child him/ herself, parents, and the attending clinician. The QoL of these children was compared to QoL of children from the general population

without psychiatric problems and the impact on QoL of different child psychiatric disorders was studied. Besides, factors that were associated with QoL were assessed. These factors were grouped into child, parent, and family/ social network factors according to the Bronfenbrenner model. Furthermore, QoL of the children was studied across a one-year follow-up period and predictors of change across the follow-up period were assessed. In the following sections an overview will be given of the study design.

Design of the study

The study included two samples of children: a clinical sample that consisted of children who had been referred to mental health agencies, and a non-referred sample of children from the general population. The clinical sample was assessed twice across a one-year interval (Time 1, Time 2), and the non-referred sample was assessed once.

Clinical sample

At the first assessment (Time 1), the clinical sample consisted of children and adolescents aged 6-18 years who had been referred between August 1, 2000 and September 15, 2001 to a general (56%) or a university (44%) outpatient child psychiatric clinic in the city of Rotterdam, The Netherlands. By recruiting patients from these two clinics, children with a broad range of psychiatric problems, ranging from mild to severe, were included. After informed consent had been obtained, questionnaires were sent to the homes of the children for completion and an appointment was made for a home visit. During this visit the completed questionnaires were checked for missing data, the child and parents filled in additional questionnaires in the presence of an interviewer, and an intelligence test was taken from the child. After the diagnostic assessment in the clinic had been completed, standardized information was obtained from the child's clinician about the psychiatric diagnosis and functional impairment. Finally, questionnaires concerning psychopathology and school results were completed by the teacher of the child.

Of the 452 children and their parents who were asked to participate, 310 (68.6%) agreed, 114 (25.2%) refused, and 28 (6.2%) were excluded because of language problems or because they could not be reached, which yielded a final response rate of 73.1%. The mean age in the sample of 185 boys (59.7%) and 125 girls (40.3%) was 11.3 years (SD=3.2; range 6-18 years).

At the second assessment (Time 2), approximately one year after Time 1, children and parents were asked to participate again, and after they had provided written informed consent,

they were sent questionnaires via mail, with the request to return these once completed. Home visits were conducted if children or parents were not capable to answer questionnaires themselves, because of reading difficulties or language problems. After consent of parents and children, a questionnaire regarding the child's psychopathology was completed by the teacher. At Time 2 clinicians were not asked to provide information since many children were not being treated at that time.

Of the 310 children and parents who participated at Time 1, 231 children and their parents participated again at Time 2 (mean follow-up time 389 days; SD=66 days; response rate 74.5%). The mean age of the follow-up sample of 134 boys (58.0%) and 97 girls (42.0%) was 12.2 years (SD=3.2; range 7-19 years).

Community sample

To compare QoL of children with psychiatric problems with QoL of healthy children, a community sample was collected of children who were not referred to mental health services. A random sample of 6- to 18-year-olds was drawn from the birth registers of three municipalities with different levels of urbanization in the Dutch province of Zuid-Holland. Children who had visited or were visiting a mental health agency in the past year or who had insufficient knowledge of the Dutch language to complete questionnaires were excluded. After informed consent had been obtained, questionnaires were sent to the homes of the children and an appointment was made for a home visit. During this visit the completed questionnaires were checked for missing data, the child and parents completed additional questionnaires in the presence of an interviewer, and an intelligence test was conducted. Questionnaires concerning psychopathology and school results were completed by the teacher of the child.

Of the 130 children and their parents who were asked to participate, 74 (57.0%) agreed, 38 (29.2%) refused, and 18 (13.8%) were excluded because of language problems or because they could not be reached (response rate = 66.1%). The average age of the 42 boys (56.8%) and 32 girls (43.2%) in the community sample was 12.1 years (SD=3.2; range 7-18 years).

Instruments

Psychopathology measures

The *Child Behavior Checklist/ 4-18* (CBCL; Achenbach, 1991a), *Youth Self-Report* (YSR; Achenbach, 1991c), and *Teacher's Report Form* (TRF; Achenbach, 1991b) were used to

measure the child's psychopathology. To assess the DSM-IV diagnosis of the child, the *DSM-IV Checklist Interview* (Hudziak et al., 1993) was rated by the clinician of the child.

QoL measures

The self-report and parent proxy-report versions of the *Pediatric Quality of Life Inventory™ Version 4.0* (PedsQL; Varni et al., 2001) and the clinician-completed *Child and Adolescent Functional Assessment Scale* (CAFAS; Hodges, 1997) were used to measure the child's QoL.

Child factors

The *Wechsler Intelligence Scale for Children – Revised* (WISC-R; Wechsler, 1974) was used to measure the intelligence of the child. The *Questionnaire for Identifying Children with Chronic Conditions* (QuiCCC; Stein et al., 1997) was used to assess the presence of a chronic physical disease. The level of self-esteem of the child was measured with the Global Self-Worth Scale of either the *Self-Perception Profile for Children* (SPPC; ages 8-12; Harter, 1985a) or the *Self-Perception Profile for Adolescents* (SPPA; ages 13-18; Harter, 1988). The parent and teacher versions of the *Social Skills Rating System* (SSRS; Gresham and Elliot, 1990) were used to measure the child's social skills.

Parent factors

The *Young Adult Self-Report* (YASR; Achenbach, 1997) was used to assess psychopathology of the mother. The *Nijmegen Parenting Stress Index* (NPSI; De Brock et al., 1990a), which is a modified Dutch version of *Abidin's Parenting Stress Index* (Abidin, 1983) was used to measure the level of perceived parenting stress.

Family/ social network factors

Family functioning was assessed with the *McMaster Family Assessment Device* (FAD; Byles et al., 1988). The *Health Insurance Experiment Social Support Questionnaire* (HIESSQ; Donald and Ware, 1984) was used to measure social contacts and social resources of the family. To assess child-perceived support from significant others, the *Social Support Scale for Children* (SSSC; ages 8-12; Harter, 1985b) or the *Social Support Scale for Adolescents* (SSSA; ages 13-18; Harter, 1989) was employed. The incidence of stressful life events was assessed with the *Life Events Questionnaire* (LEQ; Berden et al., 1990).

A detailed description of all instruments can be found in the Chapters 2 to 6 of this dissertation. Table 1.1. shows the variables and instruments that were used and the number of informants for each of the instruments for the clinical and community sample separately. For some questionnaires, the response rate was somewhat lower because some questionnaires could not be used due to incomplete information, or because questionnaires were not returned by mail, mainly by teachers.

Structure of this dissertation

Chapter 2 provides information on the psychometric properties of the Dutch translation of the Pediatric Quality of Life InventoryTM (PedsQLTM 4.0) Generic Core Scales and on its usefulness to measure QoL in children who have been referred to mental health agencies. Besides, QoL of children with psychiatric problems was compared to QoL of children from the general population who had not been referred to a mental health agency, and to QoL of children with chronic physical conditions. In *Chapter 3*, levels of QoL in children with different psychiatric disorders were compared in the Time 1 clinical sample. Children, parents, and clinicians reported on QoL and both subjective and objective QoL indicators were investigated. Six diagnostic categories were distinguished: Attention-Deficit and Disruptive Behavior Disorders, Anxiety Disorders, Pervasive Developmental Disorders, Mood Disorders, Other Disorders, and No Diagnosis. In *Chapter 4*, the Time 1 clinical sample was used to assess factors that, in addition to childhood psychopathology, were associated with QoL. To identify these factors, the Bronfenbrenner model was used. In *Chapter 5*, the association was assessed between change in psychopathology and change in QoL scores across the one-year follow-up period from Time 1 to Time 2. It was investigated to which extent QoL improvement depends on change in psychopathology. In *Chapter 6* factors were studied that predicted QoL across the one-year follow-up period, over and above potential improvements in QoL related to a decrease in psychopathology. Candidate predictors were classified into the three levels of the Bronfenbrenner model, i.e. child, parent, and family/ social network factors. Finally, in *Chapter 7* the main findings and conclusions of Chapters 2-6 are presented and discussed. Implications and recommendations for clinical practice are given.

Table 1.1 Design of the study: used variables, instruments and number of respondents

Variables	Instruments	Clinical sample		Community sample
		Time 1 n	Time 2 n	n
Psychopathology measures				
Child psychopathology (parent report)	CBCL	305	227	72
Child psychopathology (teacher report)	TRF	254	154	46
Child psychopathology (child report)	YSR	138	117	39
Psychiatric diagnosis (clinician report)	DSM-IV Checklist Interview	310	-	-
QoL measures				
QoL - child report	PedsQL	296	206	70
QoL - parent report	PedsQL	307	226	73
QoL - clinician report	CAFAS	295	-	-
Child factors				
Intelligence	WISC-R	271	-	53
Chronic physical disease	QuiCCC	305	-	73
Self-esteem	SPPC/ SPPA	240	-	60
Social skills (parent report)	SSRS	303	226	71
Social skills (teacher report)	SSRS	236	151	48
Parent factors				
Psychopathology mother	YASR	290	225	71
Parenting stress mother	NPSI	297	225	-
Family/ social network factors				
Family functioning	FAD	300	225	71
Social contacts family	HISSQ	301	225	71
Social support	SSSC/ SSSA	240	-	60
Stressful life events	LEQ	305	227	72

Note. CBCL = Child Behavior Checklist/ 4-18; TRF = Teacher's Report Form; PedsQL = Pediatric Quality of Life Inventory; CAFAS = Child and Adolescent Functional Assessment Scale; WISC-R = Wechsler Intelligence Scale for Children – Revised; QuiCCC = Questionnaire for Identifying Children with Chronic Conditions; SPPC = Self-Perception Profile for Children; SPPA = Self-Perception Profile for Adolescents; SSRS = Social Skills Rating System; YASR = Young Adult Self-Report; NPSI = Nijmegen Parenting Stress Index; FAD = Family Assessment Device; HISSQ = Health Insurance Experiment Social Support Questionnaire; SSSC = Social Support Scale for Children; SSSA = Social Support Scale for Adolescents; LEQ = Life Events Questionnaire.

2 | **Measuring quality of life in children referred for psychiatric problems: Psychometric properties of the PedsQL™ 4.0 generic core scales**

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2004, 13: 489-495

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Chapter 2

Measuring quality of life in children referred for psychiatric problems: Psychometric properties of the PedsQL™ 4.0 generic core scales

Abstract

Objective: The aim of this study was to assess the psychometric properties of the Dutch translation of the Pediatric Quality of Life Inventory™ (PedsQL™ 4.0) generic core scales and assess its usefulness in measuring quality of life (QoL) in a child psychiatric population.

Methods: Reliability and validity of the PedsQL were assessed in 310 referred children (ages 6-18 years) and a comparison group consisting of 74 non-referred children (ages 7-18 years), and the parents in both groups. **Results:** Confirmatory factor analysis resulted in a four-factor solution. Internal consistency reliability for the PedsQL Total Scale Score (alpha=0.84 child self-report, alpha=0.87 parent proxy-report), Psychosocial Health Score (alpha=0.70 child self-report, alpha=0.81 parent proxy-report), and most subscale scores were acceptable for group comparisons. Correlations between scores of fathers and mothers were large. Criterion-related validity was demonstrated by significantly lower PedsQL scores for referred versus non-referred children. Significant correlations between PedsQL scales and measures of psychopathology showed convergent validity. Small correlations between PedsQL scales and intelligence of the child evidenced discriminant validity. **Conclusion:** The PedsQL seems a valid instrument in measuring QoL in children referred for psychiatric problems.

Introduction

The quality of life (QoL) construct enables translating a person's experience of illness into a quantifiable outcome. Until now most research in child and adolescent populations has focused on chronic physical diseases (Bradlyn et al., 1996; Juniper et al., 1996). The few studies that have focussed on QoL of children with psychiatric disorders (Clark and Kirisci, 1996; Graham et al., 1997; Landgraf et al., 1996) found a poorer QoL in this patient group compared to children with chronic physical disorders or healthy child populations.

In our search for an instrument to measure QoL in children with psychiatric disorders the Pediatric Quality of Life Inventory™ version 4.0 (PedsQL; Varni et al., 2001) seemed most suitable. Its generic part encompasses the core health dimensions formulated by the

WHO (World Health Organization, 1948), it is well validated, and has proven its usefulness for measuring QoL of children with different diseases. The aim of this study was to assess the psychometric properties of the Dutch translation of the PedsQL and assess its usefulness in measuring QoL in a child psychiatric population. We focussed on the parent and child forms for ages 5-7, 8-12, and 13-18 years.

Methods

Procedure and participants

The patient sample consisted of 310 children who had been referred to an outpatient mental health clinic (response 73.1%; mean age 11.3 years (SD=3.18; range 6-18.2 years); boys 59.7%; 33.2% low, 30.0% medium, and 36.8% high socio economic status (SES) families). For 293 (94.5%) children both child and parent reports were available. For 3 (1.0%) only child self-report, and for 14 (4.5%) only parent proxy-report was available. For all analyses except the interparent agreement, information of one parent was used (89.9% mothers).

The comparison group consisted of 74 children from the general population (response 66.1%), who had not visited mental health services in the past year (mean age 12.1 years (SD=3.18; range 7.4-18.2 years); 56.8% boys; 17.6% low, 51.3% medium, and 31.1% high SES families). For 69 (93.2%) children both child and parent report were available, for one (1.4%) child only child self-report, and for four (5.4%) children only parent proxy-report. Mother was main parental informant (91.8%).

Instruments

The *PedsQL* (Varni et al., 2001; Varni et al., 1999) generic core scale consists of 23 items and has a child self-report and parallel parent proxy-report format for ages 5-7, 8-12, and 13-18 years, which can be self-administered except the ages 5-7-child self-report, which has an interview format. The items are scored on a five-point Likert-scale, ranging from 'never a problem' to 'almost always a problem' (corresponding scores 100, 75, 50, 25 or 0). The child self-report ages 5-7 is simplified into a three-point scale (100, 50 or 0). A higher PedsQL score indicates a better QoL. Four subscales can be computed: (1) physical (eight items), (2) emotional (five items), (3) social (five items), and (4) school functioning (five items), as well as a psychosocial health summary score (15 items; composed of the emotional, social and school functioning subscales) and a total scale score. Scale scores are computed as the sum of the itemscores divided by the number of items answered. Good validity has been documented

(Varni et al., 2001; Varni et al., 1999). The PedsQL was translated into Dutch by two authors (DB, HMK) independently and translated back into English by two bilingual translators. After review and comments by the PedsQL Project team this resulted in the final Dutch version.

The *Child Behavior Checklist/4-18* (CBCL; Achenbach, 1991a) and the *Youth Self-Report* (YSR; Achenbach, 1991c) were used to obtain standardized parent and child reports of children's problem behavior. A Total Problem, Internalizing and Externalizing score can be computed: the higher the score, the greater the problems. Intelligence was measured using the Wechsler Intelligence Scale for Children – Revised (WISC-R; Van Haasen et al., 1986; Wechsler, 1974). In 13.9% of the children this was not possible.

Statistical analyses

Internal consistency was determined by means of Cronbach's alpha coefficients (Cronbach, 1951). Factor structure was examined by multitrait-multimethod (MTMM) analysis of subscales and a confirmatory factor analysis (CFA) of items, using the M-plus software (Muthén and Muthén, 1998). We tested Varni's four-factor model (Varni et al., 2001), consisting of a physical, emotional, social, and school functioning factor, and included the higher-order psychosocial health factor. As fit indices were used: Root Mean Square Error of Approximation (RMSEA; Steiger, 1998), Tucker Lewis Index (TLI) and the Comparative Fit Index (CFI; Bentler, 1990). Values indicating adequate fit are RMSEA 0.03-0.08, TLI 0.90-1.00, and CFI 0.90-1.00. Interparent agreement was assessed using intra-class correlations (ICC). To test criterion-related validity, scores of patient and comparison group were compared in an Analysis of Covariance (ANCOVA) using age, sex and SES as covariates. Construct validity was assessed through PedsQL correlations with indicators of psychopathology and intelligence.

Results

Mean scale scores and Cronbach's alphas are shown in Table 2.1. Child self-report ages 6-7 years had low alphas for subscales (0.40-0.63); versions 8-12 and 13-18 years had much better alphas. Parent versions for different age groups had alphas >0.70 for almost all subscales.

Table 2.1. Scale descriptives and internal consistency reliability for PedsQL child self-report and parent proxy-report (patient sample only)

Scale	Scale descriptives						Internal consistency reliability			
	Number of items	N	Mean	SD	Minimum	Maximum	Total sample	Ages 6-7	Ages 8-12	Ages 13-18
Child self-report										
Total score	23	296	72.2	12.7	35.8	100.0	0.84	0.73	0.85	0.87
Physical functioning	8	296	81.2	14.2	31.2	100.0	0.70	0.44	0.73	0.79
Psychosocial health	15	296	67.4	14.7	23.3	100.0	0.81	0.70	0.82	0.84
Emotional functioning	5	296	61.3	19.5	15.0	100.0	0.66	0.43	0.63	0.80
Social functioning	5	296	73.0	20.4	0.0	100.0	0.75	0.63	0.72	0.78
School functioning	5	296	67.9	16.7	15.0	100.0	0.59	0.40	0.66	0.57
Parent proxy-report										
Total score	23	307	66.9	14.0	27.1	97.8	0.87	0.86	0.84	0.91
Physical functioning	8	307	80.0	17.7	21.8	100.0	0.81	0.82	0.78	0.85
Psychosocial health	15	307	59.9	15.3	21.6	96.6	0.83	0.83	0.80	0.87
Emotional functioning	5	306	54.4	18.7	5.0	100.0	0.73	0.76	0.67	0.78
Social functioning	5	307	63.3	22.9	5.0	100.0	0.85	0.81	0.84	0.86
School functioning	5	301	62.4	18.2	15.0	100.0	0.69	0.69	0.63	0.78

The factor structure was strongly replicated (Table 2.2), and explained for the total sample 44% of the variance in child and 58% in parent report. All fit indices of child report fell in the acceptable range (Bentler, 1990; Steiger, 1998) except for children ages 6-7 years; in parent report RMSEA was slightly too high.

In the MTMM analysis all monotrait-multimethod correlations were significant ($p < 0.01$; Table 2.3) and all multitrait-multimethod correlations were smaller than the monotrait-multimethod correlations. Of the correlation coefficients between dissimilar scales within the same informant (multitrait-monomethod) 46% exceeded the monotrait-multimethod correlations. Child and parent report total scores correlated 0.38 for ages 6-12 and 0.51 for ages 13-18 years.

Father and mother completed the PedsQL independently for 190 (61.3%) children (mean interval 8.9 days). All ICC's were > 0.70 and significant ($p < 0.01$; Table 2.4). Mothers' and fathers' scores differed significantly on psychosocial health and social functioning in age group 6-7 years (t -test; $p < 0.05$).

Corrected for SES, sex, and age effects, all scale scores were higher for non-referred than referred children at $p < 0.001$ in both child and parent report (Table 2.5). All effect sizes for referral were small to medium in child self-report (range 4-12%; cf. Cohen, 1988) and large in parent proxy-report (range 9-27%) except for physical functioning. Just one two-way interaction was statistically significant (referral status \times age; $p < 0.05$) with younger referred children scoring lower on the social functioning scale of the child self-report (effect size 2%).

Table 2.2. Factor loadings of items on subscales and of subscales on Psychosocial Health, percentage explained variance and fit indices reported for child and parent report

Scale/ item	Child self-report				Parent proxy-report			
	Total sample N=343	Ages 6-7 N=57	Ages 8-12 N=174	Ages 13-18 N=112	Total sample N=339	Ages 6-7 N=56	Ages 8-12 N=176	Ages 13-18 N=107
Physical functioning								
Hard to walk more than a block	0.643	0.644	0.710	0.660	0.832	0.780	0.865	0.951
Hard to run	0.574	0.726	0.565	0.710	0.803	0.663	0.838	0.824
Hard to do sports or exercises	0.659	0.341	0.645	0.865	0.796	0.645	0.810	0.855
Hard to lift something heavy	0.588	0.313	0.665	0.627	0.772	0.797	0.743	0.842
Hard to take a bath or shower	0.441	0.349	0.517	0.112	0.615	0.686	0.610	0.585
Hard to do chores around house	0.513	0.084	0.603	0.453	0.630	0.659	0.616	0.631
Hurt or ache	0.614	0.388	0.576	0.773	0.714	0.638	0.629	0.861
Low energy	0.659	0.407	0.644	0.832	0.768	0.717	0.760	0.882
Emotional functioning								
	<i>0.868*</i>	<i>0.563*</i>	<i>0.929*</i>	<i>0.840*</i>	<i>0.810*</i>	<i>0.751*</i>	<i>0.800*</i>	<i>0.861*</i>
Feel afraid or scared	0.690	0.840	0.639	0.877	0.711	0.589	0.685	0.782
Feel sad or blue	0.692	0.502	0.636	0.852	0.816	0.835	0.786	0.855
Feel angry	0.635	0.739	0.565	0.736	0.750	0.752	0.753	0.709
Trouble sleeping	0.596	0.098	0.567	0.799	0.652	0.662	0.561	0.814
Worry about what will happen	0.560	0.439	0.603	0.615	0.803	0.906	0.801	0.791
Social functioning								
	<i>0.781*</i>	<i>0.919*</i>	<i>0.840*</i>	<i>0.728*</i>	<i>0.762*</i>	<i>0.900*</i>	<i>0.738*</i>	<i>0.765*</i>
Trouble getting along with peers	0.717	0.762	0.658	0.801	0.889	0.841	0.901	0.878
Other kids not wanting to be friends	0.694	0.597	0.629	0.765	0.888	0.893	0.912	0.856
Teased	0.713	0.467	0.707	0.804	0.777	0.792	0.755	0.789
Doing things other peers do	0.602	0.462	0.643	0.554	0.724	0.595	0.660	0.855
Hard to keep up when play with others	0.772	0.772	0.706	0.881	0.874	0.772	0.855	0.923
School functioning								
	<i>0.816*</i>	<i>0.801*</i>	<i>0.866*</i>	<i>0.810*</i>	<i>0.784*</i>	<i>0.703*</i>	<i>0.774*</i>	<i>0.833*</i>
Hard to concentrate	0.620	0.733	0.593	0.751	0.798	0.836	0.814	0.753
Forget things	0.622	0.413	0.718	0.538	0.712	0.811	0.634	0.728
Trouble keeping up with schoolwork	0.647	0.781	0.593	0.650	0.770	0.696	0.770	0.873
Miss school – not well	0.475	0.160	0.537	0.678	0.670	0.689	0.622	0.819
Miss school – doctor appointment	0.481	0.447	0.558	0.312	0.651	0.541	0.714	0.685
Percentage explained variance	43.85	29.64	38.83	49.70	58.38	53.00	56.22	65.74
RMSEA	0.075	0.154	0.083	0.091	0.116	0.125	0.115	0.116
CFI	0.891	0.535	0.894	0.937	0.887	0.916	0.883	0.944
TLI	0.927	0.550	0.923	0.952	0.945	0.929	0.926	0.971

Note. Analyses were performed on the combined patient and comparison samples.

* Factor loading of subscale on higher-order factor psychosocial health.

Table 2.3. Multitrait-multimethod intercorrelations between and among PedsQL subscales (patient sample only)

Scale	Child self-report				Parent proxy-report			
	Physical	Emotional	Social	School	Physical	Emotional	Social	School
Child report								
Physical functioning		0.38*	0.33*	0.33*	<i>0.34*</i>	0.12	0.14	0.13
Emotional functioning	0.41*		0.41*	0.39*	0.11	<i>0.32*</i>	0.09	0.11
Social functioning	0.51*	0.42*		0.48*	0.21*	0.12	<i>0.41*</i>	0.10
School functioning	0.34*	0.52*	0.30*		0.17**	0.14**	0.20*	<i>0.35*</i>
Parent report								
Physical functioning	<i>0.42*</i>	0.32*	0.28*	0.32*		0.24*	0.31*	0.33*
Emotional functioning	0.29*	<i>0.53*</i>	0.26**	0.37*	<i>0.57*</i>		0.31*	0.30*
Social functioning	0.29*	0.10	<i>0.45*</i>	0.24**	0.50*	0.42*		0.36**
School functioning	0.17	0.28*	0.13	<i>0.44*</i>	0.57*	0.50*	0.49*	

Note. Age group 6-12 years above and age group 13-18 years below diagonal. Monotrait-multimethod correlations are in italics. * Correlation significant at $p < 0.01$; ** Correlation significant at $p < 0.05$.

Table 2.4. Interparent agreement on PedsQL scale scores (patient sample only)

Scale	Ages 6-7 (N = 37)	Ages 8-12 (N = 98)	Ages 13-18 (N = 55)
Total score	0.88	0.78	0.88
Physical functioning	0.80	0.80	0.82
Psychosocial health	0.89 ^a	0.77	0.86
Emotional functioning	0.86	0.77	0.85
Social functioning	0.91 ^b	0.88	0.82
School functioning	0.84	0.80	0.89

Note. All intra class correlation coefficients were significant at $p < 0.01$.

^a Mothers scored lower than fathers at $p < 0.05$.

^b Mothers scored lower than fathers at $p < 0.01$.

Table 2.5. Mean scale scores and percentages of explained variance accounted for by significant effects of referral status, sex and age in scale scores for referred and non-referred children

Scale	Mean (SD)				Percentage of explained variance		
	Referred	Non-referred		Referral ^a	Sex ^b	Age ^c	Ses ^d
Child self-report							
Total score	72.2	(12.7)	84.2	(10.4)	11	1	1
Physical functioning	81.2	(14.2)	88.8	(9.7)	4		
Psychosocial health	67.4	(14.7)	81.7	(12.1)	12		1
Emotional functioning	61.3	(19.5)	78.0	(17.3)	10	3	2
Social functioning	73.0	(20.4)	86.0	(13.4)	5		2
School functioning	67.9	(16.7)	81.4	(13.0)	9		1
Parent proxy-report							
Total score	66.9	(14.0)	87.6	(11.0)	24		1
Physical functioning	80.0	(17.7)	93.2	(9.1)	9		
Psychosocial health	59.9	(15.3)	84.6	(13.2)	27		2
Emotional functioning	54.4	(18.7)	81.1	(17.4)	23		2
Social functioning	63.3	(22.9)	90.3	(14.0)	16		2
School functioning	62.4	(18.2)	82.5	(16.3)	16		

^a All scores were higher for non-referred than referred children at $p < 0.001$.

^b Boys scored higher than girls on total score at $p < 0.05$ and on emotional functioning at $p < 0.01$.

^c Older children scored higher than younger children at $p < 0.05$; except emotional functioning on child report and social functioning on both child and parent report, where scores differed at $p < 0.01$.

^d Children with a high SES scored higher than children with a low SES at $p < 0.05$.

Convergent validity was assessed by computing Pearson correlations between PedsQL child and parent report and indicators of psychopathology (Table 2.6). All PedsQL child self-report scales except school functioning had significantly larger correlations with YSR internalizing than externalizing scores (p at least <0.05 ; Williams' formula; Steiger, 1980). In parent questionnaires, physical and emotional functioning of the PedsQL had significantly larger correlations with CBCL internalizing than externalizing scores ($p < 0.05$; Williams' formula; Steiger, 1980). All correlations between PedsQL child self-report scales and CBCL parent proxy-report scales were small (Cohen, 1988); correlations between PedsQL parent proxy-report scales and YSR child self-report scales were small to medium (Cohen, 1988). The assessment of discriminant validity showed no significant correlation between PedsQL child and parent report and the child's intelligence, except for school functioning in child self-report ($r = 0.17$; $p < 0.01$).

Table 2.6. Pearson correlations between PedsQL child and parent report and indicators of psychopathology, and intelligence (patient sample only)

PedsQL scale	YSR (N= 136)			CBCL (N= 305)			Intelligence (N= 265)
	Total score	Externalizing	Internalizing	Total score	Externalizing	Internalizing	
Total score							
Child	-0.73	-0.42	-0.68	-0.24	-0.11 ^b	-0.23	0.09 ^b
Parent	-0.39	-0.29	-0.40	-0.62	-0.43	-0.51	0.05 ^b
Physical functioning							
Child	-0.42	-0.22 ^a	-0.40	-0.14 ^a	-0.02 ^b	-0.21	0.01 ^b
Parent	-0.27	-0.18 ^a	-0.34	-0.39	-0.26	-0.38	0.02 ^b
Psychosocial health							
Child	-0.76	-0.45	-0.71	-0.24	-0.16	-0.19	0.12 ^b
Parent	-0.40	-0.31	-0.36	-0.63	-0.45	-0.49	0.06 ^b
Emotional functioning							
Child	-0.68	-0.36	-0.72	-0.14 ^a	-0.03 ^b	-0.20	0.05 ^b
Parent	-0.42	-0.27	-0.43	-0.51	-0.28	-0.56	-0.03 ^b
Social functioning							
Child	-0.53	-0.28	-0.46	-0.21	-0.17	-0.11 ^b	0.07 ^b
Parent	-0.29	-0.20 ^a	-0.23	-0.52	-0.42	-0.31	0.06 ^b
School functioning							
Child	-0.53	-0.40	-0.43	-0.20	-0.16	-0.13 ^a	0.17
Parent	-0.27	-0.29	-0.23	-0.40	-0.32	-0.26	0.11 ^b

Note. All correlations were significant at $p < 0.01$ except those marked with ^a or ^b.

^a Correlation significant at $p < 0.05$.

^b Correlation not significant.

Discussion

This article described the psychometric properties of the Dutch translation of the PedsQL when applied to children referred for psychiatric problems. Since no fit indices were found for improvement of the model, we accept the four-factor model as the measurement model of the

Dutch PedsQL at least for 8-18 year olds. Almost all scales had Cronbach's alphas sufficient for group comparisons (>0.70 ; Hays et al., 1993), except child report for ages 6-7 years. Varni et al. (2001) found similar alpha values, but higher alpha values for the younger age group. The findings of the CFA and MTMM analyses support the use of the same scale constructs for both child and parent informants. All correlations between PedsQL scale scores of fathers and mothers exceeded the mean correlation of 0.60 found in a large meta-analysis on cross-informant agreement (Achenbach et al., 1987).

Significantly lower mean PedsQL scores for referred versus non-referred children evidenced criterion-related validity. Compared to the healthy sample of Varni et al. (2001) our psychiatric group also had lower scores on all PedsQL scales, but a similar level of QoL compared to children with cancer (Varni et al., 2002a) or rheumatic diseases (Varni et al., 2002b). These findings suggest that the impact of having a psychiatric problem on QoL is at least as large as the impact of having a chronic physical disorder. Significant correlations between PedsQL scales and measures of psychopathology showed convergent validity. Small and mostly non-significant correlations between PedsQL scales and intelligence of the child evidenced discriminant validity.

Based on the results from this study we conclude that the PedsQL is a useful instrument in measuring QoL in children referred for psychiatric problems. Its reliability and validity are satisfactory, although the use in younger children (ages 6-7) with psychiatric problems needs further research. Since we were not able to include children aged 5 years, the Dutch PedsQL is only validated for children aged 6 years and older.

3 | **Quality of life in children with psychiatric disorders: Self-, parent, and clinician report**

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Chapter 3

Quality of life in children with psychiatric disorders: Self-, parent, and clinician report

Abstract

Objective: To study the relationship between child psychiatric disorders and Quality of Life (QoL). **Method:** In a sample of 310 children (ages 6-18 years) referred for psychiatric problems, children, parents, and clinicians reported on psychopathology and subjective and objective QoL indicators. **Results:** Six diagnostic categories were distinguished: attention-deficit and disruptive behavior disorders, anxiety disorders, pervasive developmental disorders, mood disorders, other disorders, and no diagnosis. In overall QoL, no differences were found between the diagnostic categories, except in clinician's ratings, who rated children with pervasive developmental disorder as having a poorer QoL than children with other diagnoses. In each diagnostic category specific QoL subdomains were affected: for children with attention-deficit and disruptive behavior disorder, school functioning and social functioning; for children with anxiety disorder, emotional functioning; for children with pervasive developmental disorder, social functioning; and for children with mood disorder, emotional functioning. **Conclusions:** Across multiple raters, the distinguished child psychiatric disorders had a different impact on QoL. Knowledge about domains of QoL that are affected in specific child psychiatric disorders can help clinicians to focus on particular QoL domains during the diagnostic process and to define adequate treatment goals.

Introduction

Quality of Life (QoL) measurement in child psychiatric populations addresses a wide range of aspects concerning a patient's functional adaptation in his or her context. It encompasses more than simple symptom listing, but emphasizes the patient's subjective satisfaction with his or her functioning in everyday life. Since most psychiatric illnesses tend to persist (Hofstra et al., 2000), improvement in the quality of everyday life should be an important treatment goal (Schmeck and Poustka, 1997). The concept of QoL could also be used to

define outcome variables in treatment outcome research. To fine-tune interventions, more knowledge is needed regarding the impact of psychiatric diseases on different aspects of QoL.

QoL is defined as a multidimensional concept that taps a person's subjective functioning and objective indicators (Schmeck and Poustka, 1997). The subjective functioning comprises the physical, emotional, and social functioning of the individual (Wallander et al., 2001). The objective QoL indicators include living conditions, employment or school functioning, and social relationships (Lehman, 1988; Mogotsi et al., 2000). In QoL measurement, besides information from the patient, information from significant others may also be very important (Wallander et al., 2001), especially when the patient's perspective may be flawed or distorted by psychiatric symptoms (Sainfort et al., 1996). Significant others can provide information on both subjective and objective QoL indicators.

Most research on QoL in adult psychiatry has concerned patients with schizophrenia and, more recently, patients with depression and anxiety disorders (Bonicatto et al., 2001; Mogotsi et al., 2000). These studies concluded that the QoL of psychiatric patients is considerably poorer than that of individuals from the general population, and comparable to or even poorer than that of physically ill patients. Surprisingly, until now little attention has been paid to QoL in children and adolescents with psychiatric disorders. Bastiaansen et al. (2004a) and Sawyer et al. (2002) reported a poorer overall QoL for children with psychiatric disorders compared to children with no disorder. Landgraf et al. (1996) reported a poorer QoL for children with psychiatric disorders versus children with physical disorders in many areas. So far, only two studies have compared QoL between children and adolescents with different psychiatric diagnoses. In the study of Clark and Kirisci (1996), posttraumatic stress disorder, major depressive disorder (MDD), and alcohol use disorder in adolescents from a combined clinical and community sample had different effects on QoL. In the general population study by Sawyer et al. (2002), children with MDD showed a poorer physical and emotional functioning than children with attention-deficit/hyperactivity disorder (ADHD) or conduct disorder.

The two above-mentioned studies (Clark and Kirisci, 1996; Sawyer et al., 2002) have several limitations concerning community samples, age distribution, type of informants providing information, and type of child psychiatric diagnoses included. Clark and Kirisci (1996) included only children aged 12 years and older and used information from self-report. Sawyer et al. (2002) relied on information obtained from parents only and used a community sample. Therefore, the aim of the present study was to determine the relationship between the most prevalent child psychiatric diagnoses and QoL as reported by the child, parents, and the

attending clinician in a clinical sample of children aged 6 to 18 years. Information was collected on both subjective and objective QoL indicators. Furthermore, we studied the agreement in reported QoL between child, parent, and clinician. We expected QoL to be poorest in those areas of life that are most affected by the symptoms specific to the diagnosis: emotional functioning in children with anxiety and mood disorders, social functioning in children with pervasive developmental disorders, and social and school functioning in children with attention-deficit or disruptive disorders.

Method

Procedure and participants

The target sample consisted of consecutive referrals of children and adolescents aged 6 to 18 years who had been referred between August 1, 2000, and September 15, 2001, to a general or a university outpatient child psychiatric clinic in Rotterdam, The Netherlands. By recruiting patients from these two clinics, children with a broad range of presenting problems, ranging from mild to severe, were included. A clinician informed the children and their parents about the QoL study during their first visit to the clinic and asked for their participation. After informed consent was obtained from the child and parents, questionnaires were sent to their homes for completion and an appointment was made for a home visit. During this visit the completed questionnaires were checked for missing data and the child and parents filled in additional questionnaires in the presence of an interviewer. Following all required diagnostic procedures in the clinic, the child's clinician informed the researchers on the diagnosis and functional impairment of the child. Finally, questionnaires concerning psychopathology and school results were sent to the child's teacher. The study was conducted after approval by the university hospital medical ethical committee.

A total of 310 children and their parents were included (response 73.1% of the eligible sample). There were no significant differences between responders and nonresponders in the distribution of sex ($\chi^2_1 = 0.11, p = .74$), age ($t_{422} = 1.36, p = .17$), socioeconomic status (SES) ($\chi^2_2 = 1.39, p = .50$), or Total Problem score on the Child Behavior Checklist (CBCL) (Achenbach, 1991a) ($t_{390} = 1.67, p = .09$). SES was assessed using a 9-point scale of parental occupation, with 1 to 3 corresponding with elementary and lower occupations (low SES), 4 and 5 corresponding with middle occupations (medium SES), and 6 to 9 corresponding with higher and scientific occupations (high SES). Completed questionnaires from both child and parent were available in 293 (94.5%) cases, from the child only in 3 (1.0%) cases and from the

parent only in 14 (4.5%) cases. The parental informant was mainly the child's mother (89.9%). The mean age for the total sample of 185 boys (59.7%) and 125 girls (40.3%) was 11.3 years (SD=3.2; range 6.0-18.2 years). In terms of SES, 33.2% of the children came from low SES families, 30.0% from medium SES families, and 36.8% from high SES families.

Measures

Pediatric Quality of Life Inventory™ Version 4.0. The Pediatric Quality of Life Inventory™ Version 4.0 (PedsQL) (Varni et al., 2001) was used to measure the child's QoL from the perspective of the child and the parents. It has a child self-report and a parallel parent proxy-report format and has different versions for ages 5 to 7, 8 to 12, and 13 to 18 years. The items on each of the forms differ slightly in developmentally appropriate language or use of the first or third person. The parent proxy-report format assesses the parent's perceptions of the child's QoL. The instructions in each question ask how much of a problem an item has been for the child during the past month. By formulating the instruction in this way, the informant is not asked to rate the frequency with which a certain behavior took place, but how much the child was suffering from the behavior. The 23 items are scored on a 5-point Likert scale from 100 to 0 (100 = 'never a problem'; 0 = 'almost always a problem'; higher scores indicated a better QoL). Four subscales can be computed from the 23 items, covering different dimensions of QoL: (1) physical functioning (8 items; e.g. 'hard to do sports or exercises'); (2) emotional functioning (5 items; e.g. 'feel angry' or 'feel 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'). A scale score is computed as the sum of the items divided by the number of items answered. Also, a psychosocial health summary score and a Total Scale score can be computed. The psychosocial health summary score (15 items) is the sum of the items divided by the number of items answered in the emotional, social, and school functioning subscales. Good reliability and validity of the PedsQL have been reported (Bastiaansen et al., 2004a; Varni et al., 2001).

Child and Adolescent Functional Assessment Scale. The Child and Adolescent Functional Assessment Scale (CAFAS) (Hodges, 1997) was used to measure the child's QoL from the perspective of the clinician, working with the child and parents. It is designed to measure functional impairment across multiple domains in children and adolescents. Impairment is operationalized as the degree to which the child's problems interfere with his or her functioning in various life roles. The child's functioning is rated on eight domains: (1) Role Performance–School/Work (e.g., 'school grades are below average'); (2) Role

Performance–Home (e.g., ‘comply with rules’); (3) Role Performance–Community (e.g., ‘delinquent behavior’); (4) Behavior Toward Others (e.g., ‘difficulties in interactions with friends’); (5) Moods/Emotions (e.g., ‘fears’ or ‘sad’); (6) Self-Harmful Behavior (e.g., ‘harming self’); (7) Substance Use (e.g., ‘usage of alcohol or drugs’); and (8) Thinking (e.g., ‘thought distortions’). Each domain contains numerous behavioral descriptions, divided in four categories of impairment and scored as follows: 30, severe; 20, moderate; 10, mild; or 0, minimal or no impairment. The rater determines for each domain the category that describes the child’s most severe level of dysfunctioning during the past 3 months. The eight domain scores are summed to yield a CAFAS Total Child score, with a possible range from 0 to 240; higher scores indicate more impairment. The CAFAS is a reliable and valid instrument (Hodges and Wong, 1996).

Child Behavior Checklist 4-18 and Teacher’s Report Form. To assess the effect of the severity of the emotional and behavioral problems on experienced QoL, we used the Child Behavior Checklist 4-18 (CBCL) (Achenbach, 1991a) and the Teacher’s Report Form (TRF) (Achenbach, 1991b). The CBCL and the TRF obtain standardized parent and teacher reports of children’s problem behavior over the preceding 6 and 2 months, respectively. The problem items are scored on a 3-point Likert scale, and a Total Problem score can be obtained by summing the scores on all individual problem items. Studies have shown good reliability and validity of the Dutch CBCL and TRF (Verhulst et al., 1996; Verhulst et al., 1997).

The DSM-IV Checklist Interview. The DSM-IV Checklist Interview (Hudziak et al., 1993), a software-only interview created for the diagnostic assessment of psychiatric disorders, was used to establish subjects’ diagnoses. The interview text is written as it appears in the DSM-IV and includes the psychiatric disorders as listed in Table 3.1. Diagnoses not included were added, such as pervasive developmental disorder. The validity of the instrument was shown in an agreement of 95% between attending psychiatrists’ diagnoses and the DSM-IV Checklist Interview (Hudziak et al., 1993).

To confirm the validity of the DSM-IV Checklist Interview, we determined associations between the DSM-IV Checklist Interview diagnoses and the DSM-oriented scales of the CBCL and TRF (Achenbach and Rescorla, 2001). The DSM-oriented scales of the CBCL and TRF comprise problems that psychiatrists and psychologists from 16 cultures rated as very consistent with diagnostic categories of the DSM-IV (Achenbach and Rescorla, 2001). The following DSM-oriented scales for both CBCL and TRF can be computed by summing the scores on the individual problem items: (1) affective problems; (2) anxiety problems; (3) somatic problems; (4) attention-deficit/hyperactivity problems; (5) oppositional

defiant problems; and (6) conduct problems. We performed forward stepwise logistic regression analyses. A first logistic regression analysis was performed with all continuous DSM-oriented scales of the CBCL and TRF as predictor variables and a DSM-IV Checklist Interview diagnosis of ‘any mood disorder’ as dependent variable. Similar regression analyses were performed for the following DSM-IV Checklist Interview diagnoses that were present in more than 10 cases and for which correspondence with a DSM-oriented scale of the CBCL or TRF could be expected: ‘any anxiety disorder’, ADHD, oppositional defiant disorder, and ‘any somatoform disorder’. Logistic regressions yield odds ratios (ORs) for specific outcomes (a DSM-IV Checklist Interview diagnosis) in relation to predictor variables (DSM-oriented scales of CBCL and TRF). ORs greater than 1 indicate a positive association between the predictor and the outcome variable, while values smaller than 1 indicate a negative association. Likelihood ratio tests were used to test the significance of full regression models, and Wald tests were used to test the significance of each predictor variable. The forward stepwise logistic regression analyses were used to identify the best set of predictors, using a significance criterion of $p < 0.05$ for inclusion. In this way, DSM-oriented scales that did not contribute to the prediction of a DSM-IV Checklist Interview diagnosis, independently of other scales, were not included in the model.

The forward stepwise logistic regression analysis indicated that a DSM-IV Checklist Interview diagnosis of ‘any mood disorder’ was predicted by CBCL DSM-scale affective problems (OR=1.22, $p < 0.01$), TRF DSM-scale affective problems (OR=1.27, $p < 0.01$), CBCL DSM-scale conduct problems (OR=0.78, $p < 0.01$), and TRF DSM-scale anxiety problems (OR=0.77, $p < 0.05$). Hence, these DSM-oriented scales of CBCL and TRF predicted the presence of a DSM-IV Checklist Interview diagnosis of ‘any mood disorder’ independently of other scales.

Similar results were found for the other DSM-IV Checklist Interview diagnoses. A DSM-IV Checklist Interview diagnosis of ‘any anxiety disorder’ was predicted by CBCL DSM-scale anxiety problems (OR=1.47, $p < 0.01$), CBCL DSM-scale affective problems (OR=0.83, $p < 0.01$), and TRF DSM-scale ADHD Problems (OR=0.89, $p < 0.01$). A DSM-IV Checklist Interview diagnosis of ADHD was predicted by CBCL DSM-scale ADHD problems (OR=1.24, $p < 0.01$), TRF DSM-scale ADHD problems (OR=1.09, $p < 0.01$), and CBCL DSM-scale anxiety problems (OR=0.84, $p < 0.05$). A DSM-IV Checklist Interview diagnosis of oppositional defiant disorder was predicted by CBCL DSM-scale conduct problems (OR=1.14, $p < 0.01$). Finally, a DSM-IV Checklist Interview diagnosis of ‘any

somatoform disorder' was predicted by CBCL DSM-scale somatic problems (OR=1.45, $p<0.05$), and CBCL DSM-scale ADHD problems (OR=0.56, $p<0.05$).

In summary, the results showed that an increase in scores on a specific DSM-oriented scale of the CBCL or TRF increased the likelihood of the presence of the corresponding diagnosis on the DSM-IV Checklist Interview, and the unlikelihood of the presence of noncorresponding diagnoses.

The checklist was completed after all diagnostic information was obtained from the child, parents, and teacher. Multiple diagnoses were allowed. The diagnosis of greatest immediate clinical significance was taken as primary diagnosis.

Objective QoL indicators. Several aspects of functional status of the children were studied. From the first part of the CBCL and TRF, we obtained information on the number of sports and number of organizations the child was participating in, number of friends, academic performance, and special education. The items were scored according to the rules of the CBCL and TRF manual (Achenbach, 1991a; Achenbach, 1991b). From a questionnaire on demographic data, we registered whether the parents were divorced. Furthermore, the child reported on the number of persons inside and outside the family seen as important to himself or herself.

Data Analysis

Sex, age, and SES differences between diagnostic categories were analyzed using the χ^2 test and one-way analysis of variance (ANOVA). Mean scale scores on questionnaires for the different diagnostic categories were compared using ANOVA with a 6 (diagnostic category) x 2 (ages 6-12 versus 13-18 years) x 2 (sex) factorial design. In case of a significant F ratio for diagnostic category, a least square differences (LSD) post hoc test was carried out. To control for overall severity of problem behavior that might conceal differences between diagnostic groups, Total Problem scores on CBCL and TRF were added as covariates to the ANOVA.

Differences in objective QoL indicators between diagnostic categories were analyzed using the χ^2 test and ANOVA. In case of a significant F ratio for diagnostic category, LSD post hoc tests were carried out. To assess agreement between ratings of parents, children, and clinicians, Pearson correlations were computed. Significance was set at $p<.05$.

Results

Diagnostic categories

Six diagnostic categories were distinguished: attention-deficit and disruptive behavior disorders, anxiety disorders, pervasive developmental disorders, mood disorders, other disorders, and no diagnosis. The latter contained children who had been referred to mental health services but for whom no DSM-IV diagnosis could be made. There were no differences in CBCL and TRF Total Problem scores between this group of children and the other children ($t_{303} = 0.68$, $p = 0.50$ for CBCL Total Problem score and $t_{252} = 1.65$, $p = 0.10$ for TRF Total Problem score). The category ‘other disorders’ contained children with a diagnosis of somatoform disorder, tic disorder, or another disorder not listed above.

Table 3.1. Number of children and distribution of sex and mean age across the diagnostic categories

Diagnostic category	N	%	Sex (%)		Age (years)	
			Male	Female	Mean	SD
Attention-deficit and disruptive behavior disorders	107	35	76.6	23.4	10.4	3.0
Attention-deficit disorder	39					
Disruptive behavior disorder	28					
Attention-deficit and disruptive behavior disorder	16					
Attention-deficit/disruptive disorder and anxiety disorder	7					
Attention-deficit/disruptive disorder and mood disorder	9					
Attention-deficit/disruptive disorder and any other disorder	8					
Anxiety disorders	57	18	38.6	61.4	11.4	3.1
Specific phobia	2					
Social phobia	4					
Separation anxiety disorder	7					
Obsessive compulsive disorder	4					
Posttraumatic stress disorder	11					
Generalized anxiety disorder	8					
Panic disorder	1					
Other anxiety disorders	13					
Combination of anxiety disorders	4					
Anxiety disorder and dysthymic disorder	3					
Pervasive developmental disorders	28	9	82.1	17.9	9.7	2.4
Autistic disorder	5					
Asperger’s disorder	4					
Pervasive developmental disorder not otherwise specified	14					
Pervasive developmental disorder and any other disorder	5					
Mood disorders	29	9	31.0	69.0	11.8	3.4
Depressive disorder	6					
Dysthymic disorder	18					
Depressive disorder and any other disorder	5					
Other disorders	22	7	50.0	50.0	12.0	3.3
Somatoform disorder	6					
Communication or learning disorder	9					
Other	7					
No diagnosis	67	22	56.7	43.3	12.6	3.2

Table 3.1 shows the characteristics of each diagnostic category. Boys had significantly more attention-deficit and disruptive behavior disorders and pervasive developmental disorders; girls had more anxiety disorders and mood disorders ($\chi^2_5 = 40.17, p < 0.001$). Children with attention-deficit and disruptive behavior disorders and pervasive developmental disorders had a lower mean age than children in the other diagnostic categories ($F_5 = 6.00, p < 0.001$). No SES differences were found ($\chi^2_{10} = 12.83, p = .23$).

Child and parent report on QoL

Table 3.2 shows child and parent PedsQL scores; higher scores reflect a better QoL. There were no significant differences in Total PedsQL scores between diagnostic categories. In the PedsQL parent report, however, significant differences in subscale scores between diagnostic categories were found for satisfaction with psychosocial health ($p < 0.01$; proportion of explained variance [PEV]=6%), satisfaction with emotional functioning ($p < 0.01$; PEV=6%), and satisfaction with school functioning ($p < 0.05$; PEV= 4%). Post hoc tests were performed to determine which effects were responsible for these significant differences (see footnotes in Table 3.2). Children with attention-deficit and disruptive behavior disorder, for instance, were scored significantly higher than children with anxiety disorder ($p < 0.01$) on satisfaction with emotional functioning.

The CBCL Total Problem score was associated with the child Total PedsQL score ($p < 0.05$; PEV=3%), and the CBCL Total Problem score was associated with the parent Total PedsQL score ($p < 0.01$; PEV=38%). The TRF Total Problem score showed no significant association with the child Total PedsQL score or the parent Total PedsQL score. The CBCL Total Problem score was associated with the child PedsQL physical and school functioning score ($p < 0.05$; PEV=2-3%), and with all parent subdomain PedsQL scores ($p < 0.01$; PEV=11-28%). The TRF Total Problem score was associated only with the child and parent PedsQL social functioning score ($p < 0.01, PEV=4%$; $p < 0.05, PEV=2%$, respectively), and not with the other subdomain PedsQL scores.

To control for overall severity of problem behavior that might conceal differences between diagnostic groups, CBCL and TRF Total Problem scores were added as covariates to the ANOVA. The only difference between diagnostic categories that remained significant was the parent PedsQL report on satisfaction with emotional functioning ($p < 0.05$; PEV=5%).

There was no significant difference in child and parent Total PedsQL scores between children with one diagnosis versus those with more than one diagnosis in the category attention-deficit and disruptive behavior disorder. This was the only category in which the

number of children with multiple diagnoses was adequate for testing differences in QoL between diagnostic categories.

Clinician report on QoL

Table 3.3 shows mean CAFAS scale scores for different diagnostic categories; a higher score means more impairment. There was a significant ($p < 0.05$; PEV=5%) difference in the CAFAS Total Child score between the diagnostic categories. Significant differences in subscale scores were found for Role Performance-Home ($p < 0.01$; PEV= 8%), Behavior Toward Others ($p < 0.01$; PEV= 8%), Moods/Emotions ($p < 0.01$; PEV= 14%), and Thinking ($p < 0.01$; PEV= 11%). To determine which effects were responsible for significant differences in scale scores, post hoc tests were performed (see footnotes in Table 3.3). On the CAFAS Total Child score, for instance, children with pervasive developmental disorder were scored significantly ($p < 0.01$) higher than all other categories.

Table 3.2. Mean scale scores (SD) on PedsQL child self-report and parent proxy-report for different diagnostic categories

Scale	Attention-deficit and disruptive behavior disorders (n=107)		Anxiety disorders (n=57)		Pervasive developmental disorders (n=28)		Mood disorders (n=29)		Other disorders (n=22)		No diagnosis (n=67)	
	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)
Child self-report												
Total score	72.4	(12.2)	71.3	(12.2)	69.6	(14.0)	69.7	(13.1)	75.4	(13.5)	73.5	(13.2)
Physical functioning	84.3	(13.2)	78.6	(15.6)	78.5	(14.3)	80.0	(13.3)	79.9	(13.1)	80.4	(14.8)
Psychosocial health	66.0	(14.7)	67.4	(13.6)	64.8	(16.6)	64.2	(15.0)	72.9	(16.0)	69.8	(14.3)
Emotional functioning	61.3	(19.5)	59.0	(17.7)	63.8	(17.4)	55.5	(21.7)	68.4	(21.5)	62.6	(19.8)
Social functioning	70.3	(21.4)	74.4	(19.5)	63.1	(23.0)	73.3	(22.0)	79.5	(17.5)	77.0	(17.7)
School functioning	66.4	(16.2)	68.9	(13.9)	67.6	(20.5)	63.9	(16.4)	71.0	(21.0)	70.2	(17.2)
Parent proxy-report												
Total score	65.8	(13.5)	66.0	(14.2)	61.5	(13.1)	65.7	(11.7)	74.3	(15.0)	70.1	(14.7)
Physical functioning	80.3	(16.2)	80.3	(17.6)	76.3	(22.0)	79.2	(17.8)	82.1	(19.7)	80.4	(17.8)
Psychosocial health	58.0 ^{a,c}	(15.4)	58.2 ^{a,b}	(15.1)	53.7 ^{a,c}	(12.4)	58.6 ^a	(12.3)	70.1	(16.8)	64.7	(15.1)
Emotional functioning	54.9 ^{a,d}	(18.7)	46.8 ^{a,c}	(16.7)	53.7 ^a	(14.0)	49.1 ^{a,b}	(16.9)	67.7	(18.7)	58.5	(20.1)
Social functioning	59.1	(22.5)	66.3	(25.7)	47.2	(20.2)	66.2	(18.4)	70.8	(21.1)	70.6	(20.2)
School functioning	59.8 ^{b,e}	(17.8)	62.0 ^e	(17.8)	61.4	(15.8)	60.6 ^e	(16.7)	72.0	(19.7)	65.5	(19.6)

^a Lower score than children in the category Other disorders at $p < 0.01$.

^b Lower score than children in the category No diagnosis at $p < 0.05$.

^c Lower score than children in the category No diagnosis at $p < 0.01$.

^d Higher score than children in the category Anxiety disorders at $p < 0.01$.

^e Lower score than children in the category Other disorders at $p < 0.05$.

Table 3.3. Mean scale scores (SD) on CAFAS for different diagnostic categories

Scale	Attention-deficit and disruptive behavior disorders (n=106)		Anxiety disorders (n=57)		Pervasive developmental disorders (n=27)		Mood disorders (n=28)		Other disorders (n=22)		No diagnosis (n=55)	
	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)	Mean	(SD)
Total child score	44.1 ^b	(23.6)	41.6	(30.2)	63.0 ^a	(33.2)	33.6	(16.4)	31.4	(21.0)	37.8	(30.7)
Role performance – school/work	12.7	(8.0)	8.8	(10.4)	11.8	(9.2)	6.8	(7.2)	10.0	(10.2)	8.5	(8.6)
Role performance – home	11.7 ^{b,c}	(8.3)	6.5 ^d	(7.2)	11.1	(8.5)	4.8 ^e	(5.8)	7.3	(8.8)	9.6	(8.4)
Role performance – community	1.5	(4.3)	1.0	(4.1)	0.7	(2.7)	0.0	(0.0)	0.0	(0.0)	0.9	(4.0)
Behavior toward others	9.5 ^c	(6.8)	6.3	(6.5)	13.3 ^a	(6.8)	5.6	(5.1)	6.8	(4.8)	7.8	(6.0)
Moods/ emotions	7.3	(5.9)	14.5 ^f	(7.1)	13.0 ^f	(6.1)	14.3 ^f	(5.7)	5.4	(5.1)	7.6	(6.9)
Self-harmful behavior	0.3	(2.1)	1.0	(3.6)	1.5	(6.0)	1.4	(4.5)	0.0	(0.0)	0.9	(4.4)
Substance use	0.5	(2.5)	0.5	(4.0)	0.4	(1.9)	0.0	(0.0)	0.5	(2.1)	0.7	(3.8)
Thinking	0.7	(2.5)	2.8 ^g	(5.6)	11.1 ^a	(10.5)	1.1	(3.2)	1.4	(4.8)	2.0	(4.9)

^a Higher score than children in all other categories at $p < 0.01$.

^b Higher score than children in the category Other disorders at $p < 0.05$.

^c Higher score than children in the categories Anxiety and Mood disorders at $p < 0.01$.

^d Lower score than children in the categories Pervasive Developmental disorders and No Diagnosis at $p < 0.05$.

^e Lower score than children in the categories Pervasive Developmental disorders and No Diagnosis at $p < 0.01$.

^f Higher score than children in the categories Attention-Deficit and Disruptive Behavior disorders, Other disorders and No Diagnosis at $p < 0.01$.

^g Higher score than children in the category Attention-Deficit and Disruptive Behavior disorders at $p < 0.05$.

Agreement between informants

Table 3.4 shows the correlations between parent Total PedsQL score, child Total PedsQL score, and clinician CAFAS Total Child score for ages 6 to 12 and 13 to 18 separately. Correlations between the child Total PedsQL score and the parent Total PedsQL score were moderate (Cohen, 1988); correlations between the child Total PedsQL score and the clinician CAFAS Total Child score were small (Cohen, 1988). Correlations were somewhat higher for older children than for younger children. Correlations between the parent Total PedsQL score and the clinician CAFAS Total Child score were moderate.

Table 3.4. Cross-informant correlations between PedsQL child and parent report and CAFAS clinician report

	PedsQL Total Score - Child report	PedsQL Total Score - Parent report	CAFAS Total Score - Clinician report
PedsQL Total Score - Child report	-	.38**	-.07
PedsQL Total Score - Parent report	.51**	-	-.39**
CAFAS Total Score - Clinician report	-.25*	-.37**	-

Note. Age group 6-12 years above and age group 13-18 years below diagonal.

* Correlation significant at $p < .05$; ** correlation significant at $p < .01$.

Objective QoL indicators

Four objective QoL indicators were significantly different between diagnostic categories: (1) children with pervasive developmental disorder had fewer friends than all other categories ($\chi^2_{15} = 48.4, p < 0.01$); (2) children with attention-deficit and disruptive behavior disorder showed a lower academic performance than children with anxiety disorders and other disorders ($F_5 = 2.7, p < 0.05$); (3) more parents of children with attention-deficit and disruptive behavior disorder, mood disorder, or no diagnosis were divorced than those of children in the other three categories ($\chi^2_5 = 17.9, p < 0.01$); (4) more children in the categories pervasive developmental disorder and other disorder received special education ($\chi^2_5 = 16.6, p < 0.01$).

Discussion

This article describes the first study that included the most prevalent child psychiatric diagnoses and assessed their impact on specific areas of QoL in a clinical sample, and the first study that relied on information obtained from three different informants. In general, we found few differences in QoL between children with different child psychiatric disorders. However, clinicians rated children with pervasive developmental disorder as having a poorer

QoL than children with other diagnoses. Although few differences in overall QoL between the child psychiatric disorders could be demonstrated, each diagnostic category influenced QoL in a different way.

Attention-deficit and disruptive behavior disorders

Children with attention-deficit and disruptive behavior disorder had, according to parent ratings, a better emotional functioning score than children with anxiety disorders. Their academic performance was significantly lower than for children with anxiety disorders and other disorders, but school functioning was reported as equal. Clinicians reported more problems in behavior toward others for this group compared to children with anxiety and mood disorders. Comorbidity of attention-deficit disorder or disruptive behavior disorder with other psychiatric diagnoses did not influence overall QoL. Landgraf et al. (1996) also found that children with ADHD were more limited in schoolwork and social functioning.

Anxiety disorders

This study was the first that studied the impact on QoL of anxiety disorders in children. Although clinicians may consider anxiety disorders less severe than other child psychiatric disorders, we saw their impact on QoL being equal to children with externalizing behavior disorders and mood disorders. They even had a poorer QoL on emotional functioning compared to other disorders on both parent and clinician report. Compared to other disorders, their functioning at home was less affected. Adverse effects on QoL were also shown for adults with anxiety disorders (Mogotsi et al., 2000).

Pervasive developmental disorders

According to clinician's ratings, children with pervasive developmental disorder had a poorer overall QoL than children in all other diagnostic categories. They received significantly more special education than children in other diagnostic categories, but surprisingly all three raters did not judge their school functioning as poorer than that of children in other categories. Apparently, raters judge school functioning against the background of special school placement.

Mood disorders

Children with mood disorder had a poorer QoL in the emotional functioning domain compared to children with attention-deficit and disruptive behavior disorder, other disorder, or

no disorder. School functioning was less affected. Sawyer et al. (2002) also observed that children with MDD had more emotional problems, but they only made a comparison with children with ADHD and conduct disorder and relied on parent information solely. Clark and Kirisci (1996) found a substantial effect of MDD on psychological functioning, and also a less severe effect on school achievement, but they only included children aged 12 years and older and used information from self-report.

Informant differences

The agreement on QoL between children and parents was moderate, the agreement between children and clinicians was small and the agreement between parents and clinicians was moderate. This is remarkable because parents agree with both children and clinicians, but children and clinician do not agree with each other. These results confirm that a multirater assessment is desirable in QoL measurement in children with psychiatric disorders, as was also concluded from QoL studies in adult psychiatric samples (Sainfort et al., 1996).

The level of agreement on QoL between children and parents was larger than the previous reported correlation of .25 between children's and parents' reports on behavioral/emotional problems (Achenbach et al., 1987). The agreement on QoL between children and clinicians for the older age group resembled the average correlation of 0.27 found by Achenbach et al. (1987). The agreement on QoL between parents and clinicians found in our sample was somewhat larger than the average of 0.24 reported by Achenbach et al. (1987).

Limitations

The instruments used to measure QoL were different for children/ parents and clinicians. Although the PedsQL and CAFAS measure approximately the same constructs, their items and scales differ. Besides, we investigated a referred sample that may represent those with the most serious impairment and may be unrepresentative of children with psychiatric disorders in general, but this is the first study that included all most prevalent child psychiatric disorders.

Clinical implications

In this article the most affected QoL domains were as follows: for children with attention-deficit and disruptive behavior disorder, school functioning and social functioning; for children with anxiety disorder, emotional functioning; for children with pervasive developmental disorder, social functioning; and for children with mood disorder, emotional

functioning. Knowing which domains of QoL are affected in specific psychiatric disorders can help clinicians focus on particular QoL domains during the diagnostic process and define adequate treatment goals. Therefore, the assessment of QoL may be an important part of the diagnostic process because it can give insight into the areas of functioning in which a child is suffering the most. This should be a multirater assessment, because each rater (child, parent, and clinician) has his or her unique point of view, as can be concluded from the relatively low agreement on QoL between children, parents and clinicians in this study.

Since few differences in overall QoL were found between different diagnostic categories, we may speculate that other factors than the psychiatric diagnosis may influence the QoL of children with psychiatric disorders, at least as experienced by themselves and their parents. The fact that in parent ratings, differences between diagnostic groups became less obvious when the severity of child problems was accounted for by adding parent and teacher ratings on psychopathology to the analyses, suggests that number of symptoms may be one of these factors. Differences in QoL may be influenced more by the magnitude of the emotional/behavioral problems than by the characteristics of the diagnosis itself. Besides, other factors, which were not measured in the present study, may influence the child's QoL, such as family functioning or the child's social skills.

4 | **Determinants of quality of life in children with psychiatric disorders**

Quality of Life Research
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Chapter 4

Determinants of quality of life in children with psychiatric disorders

Abstract

Objective: To assess factors that, in addition to childhood psychopathology, are associated with Quality of Life (QoL) in children with psychiatric problems. **Methods:** In a referred sample of 252 8-18-year olds, information concerning QoL, psychopathology and a broad range of child, parent, and family/ social network factors was obtained from children, parents, teachers and clinicians. **Results:** Poor child, parent, and clinician reported QoL was associated with child psychopathology, but given the presence of psychopathology, also with child factors, such as low self-esteem, and poor social skills, and family/ social network factors, such as poor family functioning, and poor social support. In multiple linear regression analyses the importance of parent factors, such as parenting stress, was almost negligible. **Conclusion:** To increase QoL of children with psychiatric problems, treatment of symptoms is important, but outcome might improve if treatment is also focussed on other factors that may affect QoL. Results are discussed in relation to current treatment programs.

Introduction

Several studies have shown that Quality of Life (QoL) is poor in children with psychiatric disorders (Bastiaansen et al., 2004b; Sawyer et al., 2002). It has been reported that QoL in children with psychiatric disorders is not only considerably poorer than that of children from the general population, but also comparable to or even poorer than that of physically ill children (Bastiaansen et al., 2004a; Bastiaansen et al., 2004b; Sawyer et al., 2002), indicating that there is an association between poor QoL and child psychopathology. These findings underscore the need for QoL assessment in children with psychiatric disorders. Since recent studies have shown that psychopathology is persistent from childhood into adulthood (Heijmens Visser et al., 2003; Hofstra et al., 2000), it is desirable to reveal factors that, besides child psychopathology, are associated with QoL in children with psychiatric disorders. These factors could then, along with psychiatric symptoms, be chosen as a focus of treatment. Improving possible mediating factors, such as family circumstances or the social skills of the child might provide important opportunities to improve QoL. To our knowledge,

studies that examined factors that may explain differences in QoL, over and above psychopathology, in children with psychiatric disorders, are not available.

The aim of the present study was to assess which factors, besides child psychopathology, are associated with QoL in children with psychiatric problems. To identify these factors, the Bronfenbrenner model was employed (Bronfenbrenner, 1979). According to this model, factors influencing a child's development may be ordered from more proximal to more distal, i.e. at the child level, parent level, and family/ social network level. Proximal factors are hypothesized to be more influential than distal ones, and distal factors are assumed to exert their influence mainly through more proximal ones. In this study, factors possibly influencing a child's QoL were ordered similarly. Associations between QoL and child, parent, and family/ social network factors were assessed over and above the association between QoL and child psychopathology.

At the child level, the present study assessed the association between QoL and presence of a chronic physical disease and low self-esteem, over and above the association between QoL and psychopathology, because both of these factors have previously been associated with QoL. Several studies among children reported an association between poor QoL and presence of a chronic physical disease (Koot, 2001) and studies among adults with psychiatric disorders showed an association between poor QoL and low self-esteem (Ritsner et al., 2000). However, until now, no study has examined the association between QoL and these factors in children with psychiatric problems. Further, this study examined whether other child factors - intelligence, and poor social skills – were correlated with QoL, because previous studies found an association between these factors and level of psychopathology (Einfeld and Tonge, 1996; Spence, 2003). It is likely that these factors also affect QoL, although this has not been studied previously.

At the parent level of the Bronfenbrenner model, the present study assessed the association between QoL and psychopathology in mothers, mothers' mental health service use, and parenting stress. Although their association with child QoL has not yet been addressed, several studies found an association between these factors and level of psychopathology in children (Downey and Coyne, 1990; Mesman and Koot, 2000). It could be possible that these factors also affect QoL.

At the family/ social network level, associations between QoL and family composition, family Socio-economic Status (SES), social contacts of the family, and perceived social support were assessed, because previous studies found an association between QoL and these factors. Family composition was associated with poor QoL in adults

with psychiatric disorders (Koivumaa Honkanen et al., 1996). SES has been found to affect QoL in children with asthma (Halfon and Newacheck, 1993). Studies in children with chronic physical disorders reported a positive association between QoL and social functioning of the family (Andelman, 2000). Perceived social support was correlated with better QoL in adult psychiatric patients and in children with chronic physical disorders (Koivumaa Honkanen et al., 1996; Varni et al., 1994). Further, at the family/ social network level, the association between QoL and family functioning and stressful life events was studied. Previous studies reported a correlation between these factors and level of psychopathology (Berden et al., 1990; Mathijssen et al., 1998). However, the relation between QoL and these factors is still unknown.

In summary, besides the assessment of the association between child psychopathology and QoL, factors possibly associated with QoL were assessed at three levels: child, parent, and family/ social network level. To our knowledge, studies that examined the relation between such factors and QoL in children with psychiatric problems, and that determined the importance of factors from each level, compared to factors from other levels, are not yet available. Since this is the first study that examined this relation, the goal was not to construct an elaborated theoretical framework of factors associated with QoL, but to perform explorative analyses. To assess the independent contribution of factors associated with QoL, i.e. over and above the influence of psychopathology, measures of child psychopathology were included in the analyses before other factors were entered. We hypothesized that child psychopathology would be strongly associated with poor QoL and that QoL would be poorer in children with male gender and older age. At the child level, QoL was expected to be poorer in children with chronic physical disease, low self-esteem, lower intelligence, and poor social skills. Further, at the parent level, we expected QoL to be compromised by parental psychopathology, parental mental health service use, and high levels of parenting stress. Finally, at the family/ social network level, QoL was expected to be negatively influenced by single parent family, low family SES, poor social contacts of the family, poor social support, poor family functioning and stressful life events.

Methods

Procedure and participants

The target sample of this study consisted of consecutive referrals of children and adolescents aged 8-18 years who had been referred to two outpatient child psychiatric clinics in the

Netherlands. The present sample was part of a larger study, which was described elsewhere (Bastiaansen et al., 2004a). During their first visit to the clinic, children and their parents were informed on the quality of life study by a clinician and their participation was asked. Written informed consent was obtained from both children and parents. Children and parents filled in questionnaires concerning QoL, psychopathology and a broad range of child, parent, and family/ social network factors. The child's clinician provided information on functional impairment of the child. After consent of parents and children, teachers filled in questionnaires regarding psychopathology and the child's social skills. The study was conducted after approval by the university hospital medical ethical committee.

Of the 364 children and their parents who were asked to participate, 252 (69.2%) agreed to participate, 91 (25.0%) refused, and 21 (5.8%) were excluded because of language problems or because they could not be reached, leaving a final response of 73.5%. The mean age of the total sample of 145 boys (57.5%) and 107 girls (42.5%) was 12.2 years (SD=2.8; range 8.0-18.2 years); 34.9% of the children came from families with low SES (determined through parental occupational level; Dutch Central Bureau of Statistics, 1993) and 65.1% from middle-high SES families. Based on the main clinical diagnosis, that was obtained with the DSM-IV Checklist Interview in a standardized way (Hudziak et al., 1993), each of the children was assigned to one of six diagnostic groups: (1) Attention Deficit and Disruptive Behavior Disorders (n=79, 31.4%), (2) Anxiety Disorders (n=50, 19.9%), (3) Mood Disorders (n=23, 9.1%), (4) Pervasive Developmental Disorders (n=19, 7.5%), (5) Other Disorders (n=20, 7.9%; including Somatoform Disorder and Enuresis/ Encopresis), and (6) Referred – No Diagnosis (n=61, 24.2%). Children from each of these 6 categories were included in all analyses. The validity of the DSM-IV Checklist Interview, as applied in this study, was supported by Bastiaansen et al. (2004b).

Completed questionnaires of both child and parent were available in 240 cases (95.2%), of the child only in 3 cases (1.2%) and of the parent only in 9 cases (3.6%). Ninety percent of the questionnaires were obtained from mothers, and 10% from fathers. Information concerning parental psychopathology and parenting stress was only obtained from mothers and not from fathers. Information from clinicians was available for all 252 children and teacher information for 199 out of the 252 children (79.0%).

*Instruments**QoL measures*

Pediatric Quality of Life Inventory™ Version 4.0 (PedsQL). To measure the child's QoL the 23-item PedsQL (Varni et al., 2001) was used, which has a child self-report and a parallel parent proxy-report format. Versions for ages 8-12 and 13-18 years were used. The instructions ask the respondent 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 informant 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 0-100, from 'almost always a problem' to 'never a problem'; higher scores indicating 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 'trouble sleeping'), (3) social functioning (5 items; e.g. 'trouble getting along with peers' or 'being teased'), and (4) school functioning (5 items; e.g. 'trouble keeping up with schoolwork' or 'missing school'). In the present study we only used the Total Score, computed as the sum of the 23 items divided by the number of items answered. Good reliability and validity were reported for the American (Varni et al., 2001) and Dutch version (Bastiaansen et al., 2004a) of the PedsQL.

Child and Adolescent Functional Assessment Scale (CAFAS). The CAFAS (Hodges, 1997) is a rating scale to be completed by the child's clinician and designed to measure functional impairment across multiple domains of functioning in children and adolescents. In this study it was used as an instrument to measure QoL from the perspective of the clinician. Impairment is operationalized as the degree to which the child's problems interfere with his or her functioning in various life roles. The child's functioning is rated on 8 domains: (1) role performance – school/ work (e.g. 'school grades are below average' or 'frequent absences from school'), (2) role performance – home (e.g. 'comply with rules'), (3) role performance – community (e.g. 'delinquent behavior'), (4) behavior towards others (e.g. 'difficulties in interactions with friends'), (5) moods/ emotions (e.g. 'fears' or 'sad'), (6) self-harmful behavior (e.g. 'harming self'), (7) substance use (e.g. 'usage of alcohol or drugs'), and (8) thinking (e.g. 'thought distortions'). Each domain contains numerous behavioral descriptions that are divided in four categories. Impairment scores are as follows: 30 - severe; 20 - moderate; 10 - mild; or 0 - minimal or no impairment. For each domain the category is rated that describes the child's most severe level of dysfunctioning during the past 3 months.

Clinicians were blind to all information obtained in this study except the data of the Child Behavior Checklist (CBCL; Achenbach, 1991a) and Teacher's Report Form (TRF; Achenbach, 1991b).

The Total Child Score is computed as the sum of the scores on the 8 domains. Scores were recoded so that higher scores indicated better functioning (range 0-240). Good reliability and validity of the CAFAS have been reported (Hodges and Wong, 1996). To enhance reliability in our study, raters were trained in scoring the CAFAS three times during the course of the data collection. Training sessions included instructions on how to score the CAFAS and the scoring of vignettes that were provided by Hodges in the CAFAS manual (Hodges, 1997). Each vignette contained a description of the family constellation and a detailed report of the child's behavior. Cronbach's alpha for the Total Child Score was .67.

Psychopathology measures

The Child Behavior Checklist/ 4-18 (CBCL; Achenbach, 1991a) and Teacher's Report Form (TRF; Achenbach, 1991b) were used as standardized parent and teacher reports of child psychopathology over the preceding 6 and 2 months, respectively. The child's behavior is rated on a three point scale (0=not true, 1=somewhat true, 2=very true or often true); both questionnaires contain 120 problem items. In this study the Total Problem Score was used; higher scores indicate a higher level of psychopathology. Over the years, studies have shown good reliability and discriminative validity of the Dutch CBCL and TRF (Verhulst et al., 1996; Verhulst et al., 1997).

Child factors

Intelligence. The Wechsler Intelligence Scale for Children – Revised (WISC-R; Wechsler, 1974) was used to measure the intelligence of the child. In 13.9% of the children this was not possible, because their IQ was too low to be measured (n=12) or because their age was above the age range (>16 years) for which WISC-R norms are available (n=23). Self-report questionnaires were not obtained from the low IQ children of the first group (n=12).

Chronic physical disease. The Questionnaire for Identifying Children with Chronic Conditions (QuICCC; Stein et al., 1997) was used to assess the presence of a chronic physical disease. The QuICCC consists of 39 items and each item consists of three sequences. The first part of each question sequence asks about one or more specific consequences of having a chronic health condition; the second level asks whether the consequence is the result of a medical, behavioral, or other health condition; and the final part assesses the duration of the

condition (which has to be at least one year). To meet the definition of a chronic disease, a child must qualify in each component of at least one question sequence. Good reliability and validity of the QuICCC have been demonstrated (Stein et al., 1997).

Self-esteem. Children completed the Global Self-Worth Scale of either the Self-Perception Profile for Children (SPPC; ages 8-12; Harter, 1985a) or the Self-Perception Profile for Adolescents (SPPA; ages 13-18; Harter, 1988), consisting of 6 or 5 four-point items, respectively. High scores indicate high self-esteem. Harter (1985a, 1988) reported good reliability and validity of the Global Self-Worth Scale of the SPPC and SPPA. The Dutch translation of the SPPC was also found to be reliable and internally valid (Van Dongen Melman et al., 1993). In our sample Cronbach's alphas were .74 (SPPC) and .82 (SPPA).

Social skills. Parents and teachers rated children's social skills on separate versions of the Social Skills Rating System (SSRS; Gresham and Elliot, 1990) for children aged 6-12 or 13-18 years. Parent forms contain 38 and 40 items for ages 6-12 and 13-18 years, respectively; teacher forms contain 30 items for both age groups. In this study the Total Score was used; higher scores indicate better social skills. Good reliability and validity of the SSRS were reported (Gresham and Elliot, 1990). In this sample, Cronbach's alphas were .91 (ages 6-12) and .89 (ages 13-18) for the parent version and .93 (ages 6-12) and .90 (ages 13-18) for the teacher version.

Parent factors

Psychopathology mother. Mothers were asked to complete the Young Adult Self-Report (YASR; Achenbach, 1997) to assess psychopathology of the mother. The YASR has the same format as the CBCL and concerns the past 6 months. In order to limit the amount of time needed to fill in the questionnaire, we only used those 29 of the 110 problem items which discriminated best between referred and non-referred subjects (Wiznitzer, 1993). A Total Problem Score was computed by summing the scores on the 29 items, with higher scores indicating higher levels of psychopathology. The Dutch translation of the YASR was found to be a reliable and valid instrument (Wiznitzer et al., 1992). In this sample Cronbach's alpha was .92.

Psychiatric treatment mother. Maternal mental health use was assessed with a questionnaire on mental health use. Current and past mental health service use, both in an outpatient clinic as in a day-and-night treatment clinic, were assessed.

Parenting stress mother. Mothers completed the Nijmegen Parenting Stress Index (NPSI; De Brock et al., 1990a), which is a modified Dutch version of Abidin's Parenting

Stress Index (Abidin, 1983), measuring the level of perceived parenting stress originating from several child and parent characteristics within the caregiving context. A short form was used, including 25 items derived from scales measuring the perceived child and parent characteristics (De Brock et al., 1990b). A Total Problem Score was computed by summing the scores on the 25 items, with higher scores indicating higher parenting stress ($\alpha = .95$ in this sample).

Family/ social network factors

Family composition and family SES were assessed with a questionnaire on family composition, parental education and occupational level. To classify the parental occupational level, the classification system of the Dutch Bureau of Statistics (Dutch Central Bureau of Statistics, 1993) was used, which distinguishes 10 levels, ranging from 0-9, with '0' corresponding with unemployment and '9' with academic occupations. These levels can be recoded into three categories: low, middle, and high SES. Low SES is corresponding with levels 0-3, middle SES with 4-5, and high SES with 6-9. In the current study, the family was assigned to one of two categories based on the highest occupational level in the family (father or mother): low SES or middle-high SES.

Family functioning. The child's clinician rated the two scales of the Child and Adolescent Functional Assessment Scale (CAFAS; Hodges, 1997) indicating whether the caregiver meets the child's material needs and social support. The CAFAS caregiver scales are designed to assess functional impairment in the family. The Total Caregiver Score is computed as the sum of the scores on the two scales. Scores were recoded (ranges 0-60) so that higher scores indicate better caregiver functioning. Hodges and Wong (1996) provided evidence for the reliability and validity of the CAFAS.

Parents filled in the General Functioning Subscale of the McMaster Family Assessment Device (FAD; Byles et al., 1988). This scale measures the overall health/pathology of the family; items were scored in such a way that higher scores indicate better family functioning. Byles et al. (1988) reported good reliability and validity of the General Functioning Subscale. In the present study Cronbach's alpha was .87.

Social contacts family. Parents filled in the Health Insurance Experiment Social Support Questionnaire (Donald and Ware, 1984), concerning social contacts and social resources of the family. An Overall Social Contacts Index was computed by summing the nine items. Higher scores indicated more social contacts ($\alpha = .73$ in this sample).

Social support. Children completed either the Social Support Scale for Children (SSSC; ages 8-12; Harter, 1985b) or the Social Support Scale for Adolescents (SSSA; ages 13-18; Harter, 1989). Those two measures assess child-perceived support from significant others. Three of the four scales of the SSSC/ SSSA were used, measuring social support from family members, friends, and classmates. Each subscale consists of six items. Higher scores indicate greater perceived support. We used Harter's four-point item format for the classmates' scale; the family members and friends scales were slightly changed into a two-point format. Harter (1985b, 1989) reported good reliability and validity of these three subscales of the SSSC and SSSA. Cronbach's alphas of subscale scores in the present study were .80 and .79 for family members, .76 and .82 for friends, and .71 and .68 for classmates, for SSSC and SSSA, respectively.

Life events. Parents completed a 12-item short form of the Life Events Questionnaire (Berden et al., 1990), which is a yes-or no format self-report questionnaire assessing potentially stressful life events such as parental divorce, death of a family member, or long-term hospitalization in the past two years. The item scores are summed into a Total Life Events score; higher scores indicate more life events.

Statistical Analyses

Of all variables and QoL measures, means (or proportions), standard deviations and ranges were computed. Subsequently, simple linear regression analyses were performed between a psychopathology measure, or a child, parent, or family/ social network factor as independent variable and a QoL outcome measure as a dependent variable. Finally, multiple linear regression analyses were conducted between the psychopathology measures and all child, parent, and family/ social network factors as independent variables and each of the three QoL outcome measures as dependent variable. A forward stepwise method with variables entered in four subsequent blocks was used. Measures of child psychopathology (CBCL and TRF) and the variables sex and age were entered in the first block as control variables. The other predictors then were added in subsequent blocks to see if they incremented the prediction of QoL. According to the Bronfenbrenner model, child factors were entered in the second block (intelligence, presence of a chronic physical disease, self-esteem, and social skills), parent factors in the third block (psychopathology mother, maternal mental health service use, and parenting stress), and family/ social network factors in the fourth block (family composition, SES, family functioning, social contacts of the family, perceived social support, and stressful life events). In each of the four blocks, interaction terms between sex or age and the other

predictors were added. At each step in the regressions, the increment in variance accounted for by the set of variables added at that step was tested for significance. The presence of multicollinearity was detected by means of variance inflation factors (VIF). A maximum VIF value in excess of 10 was taken as an indicator of the presence of multicollinearity (Neter, 1996).

Results

Descriptive analyses

Descriptive information of the variables and outcome measures is presented in Table 4.1. Variables are presented in groups: biographical status, psychopathology measures, child, parent, and family/ social network factors. The present sample seems to be representative of the Dutch population, since the distribution of sex, SES, and family composition is comparable to the distribution of these variables in previous Dutch general population studies (Mesman, 2000; van Lier, 2002).

Simple Linear Regression Analyses

Table 4.2 shows the results of the simple linear regression analyses. Both significant and non significant betas are presented; betas that were significant at $p < .05$ are marked. Child psychopathology was correlated with the QoL measures of all three raters. Self-esteem was the only child factor that was significantly associated with all three QoL ratings. Parent report on social skills was significantly associated with both parent and clinician's report on QoL. Surprisingly, intelligence had no significant association with any of the QoL measures.

Regarding parent factors, parenting stress and psychopathology of the mother were associated with a poor QoL in both parent and clinician QoL report. Remarkably, no parent factors were significantly associated with child report on QoL.

Finally, no family/ social network factors were significantly associated with all three QoL measures, but several factors were associated with two QoL ratings. Family functioning (parent and clinician report) and social support from family members were associated with a better QoL, in both parent and clinician's QoL judgement. Social support from classmates and stressful life events were associated with child and parent report on QoL.

Multiple Linear Regression Analyses

Table 4.3 shows the results of the multiple linear regression analyses. Betas are standardized betas for the full model, i.e. the value of the beta when all predictors were included; both significant and non significant betas are presented and betas that were significant at $p < .05$ are marked. All three regression models were significant at $p < .001$ and no indications were found for the presence of multicollinearity since no VIF factor exceeded the value of 10.

Child psychopathology was associated with the QoL measures of all three raters. The interaction between sex and child psychopathology was correlated with child and parent QoL report and showed that the decrease in QoL with an increasing level of psychopathology (parent reported) was larger for girls than for boys. The interaction between age and child psychopathology demonstrated that a decrease in QoL with an increasing level of psychopathology was larger for older children than for younger children.

Over and above the association between child psychopathology and QoL, several child factors independently contributed to the variance in the regression model. Parent report on social skills was significantly associated with clinician and parent report on QoL. In contrast to the simple analyses, self-esteem was only associated with child report on QoL. The significant interactions between sex or age and chronic physical disease and child QoL report showed that boys with a physical disease experienced a lower QoL than girls with a physical disease and that younger children with a physical disease had a lower QoL than older children.

The interaction between sex and parenting stress of the mother was the only parent factor that made a significant improvement to the models. Of all family/ social network factors, social support from classmates, stressful life events and family functioning were significantly associated with the QoL measures. The significant interactions learned that the effect on QoL of stressful life events and social support was larger for boys than for girls.

Table 4.1. Means (proportions), standard deviations, and ranges of predictor variables and QoL measures

	Instrument	Mean/ proportion	SD	Range
Biographical status				
Sex*		57.5%		
Age*		38.5%		
Psychopathology measures				
Child psychopathology (parent report)	CBCL	63.8	28.5	7-142
Child psychopathology (teacher report)	TRF	50.9	28.1	3-147
Child factors				
Intelligence	WISC-R	96.5	16.0	48-141
Chronic physical disease	QuICCC	8.8%		
Self-esteem	SPPC/ SPPA	3.1	0.7	1.2-4.0
Social skills (parent report)	SSRS	42.9	11.9	10-73
Social skills (teacher report)	SSRS	31.2	9.3	7-57
Parent factors				
Psychopathology mother	YASR	10.1	8.6	0-48
Psychiatric treatment mother		35.0%		
Parenting stress mother	NPSI	81.3	28.5	26-139
Family/ social network factors				
Single parent family		28.2%		
SES*		65.1%		
Family functioning (clinician report)	CAFAS	52.5	9.1	0-60
Family functioning (parent report)	FAD	3.1	0.5	1.5-4.0
Social contacts family	HIESSQ	3.0	0.7	0.7-5.0
Social support – family	SSSC/ SSSA	0.7	0.2	0-1
Social support – friends	SSSC/ SSSA	0.8	0.2	0-1
Social support – classmates	SSSC/ SSSA	3.2	0.6	1-4
Stressful life events	LEQ	1.5	1.3	0-6
QoL measures				
PedsQL – child report	PedsQL	73.3	12.7	35.9-100
PedsQL – parent report	PedsQL	67.6	14.0	27.2-97.8
CAFAS total child score	CAFAS	197.1	28.3	80-240

* Dichotomized variables: sex (girl (0) versus boy (1)), age (8-12 (0) versus 13-18 (1) years) and SES (low (0) versus middle-high (1))

Table 4.2. Simple Linear Regression Analyses of factors associated with QoL

Variables	Instrument	QoL measures		
		PedsQL Total Score - Child report	PedsQL Total Score - Parent report	CAFAS Total Child Score
Biographical status				
Sex*		.15**	.09	.05
Age*		.09	.07	-.16**
Psychopathology measures				
Child psychopathology (parent report)	CBCL	-.22**	-.61**	-.43**
Child psychopathology (teacher report)	TRF	-.09	-.15**	-.28**
Child factors				
Intelligence	WISC-R	.06	.05	.08
Chronic physical disease	QuICCC	-.16**	-.10	-.02
Self-esteem	SPPC/ SPPA	.39**	.19**	.18**
Social skills (parent report)	SSRS	.11	.44**	.37**
Social skills (teacher report)	SSRS	.05	.07	.18**
Parent factors				
Psychopathology mother	YASR	-.04	-.29**	-.29**
Psychiatric treatment mother		-.10	-.19**	-.01
Parenting stress mother	NPSI	-.12	-.44**	-.42**
Family/ social network factors				
Single parent family		.10	-.05	-.10
SES*		.09	.11	.17**
Family functioning (clinician report)	CAFAS	.07	.25**	.45**
Family functioning (parent report)	FAD	.10	.28**	.28**
Social contacts family	HISSQ	.03	.07	.07
Social support – family	SSSC/ SSSA	.01	.18**	.23**
Social support – friends	SSSC/ SSSA	.05	-.04	-.04
Social support – classmates	SSSC/ SSSA	.37**	.22**	.09
Stressful life events	LEQ	-.17**	-.24**	-.09

Note. Betas are standardized betas; both significant and non significant betas are presented.

* Dichotomized variables: sex (girl (0) versus boy (1)), age (8-12 (0) versus 13-18 (1) years) and SES (low (0) versus middle-high (1))

** Significant at $p < .05$

Table 4.3. Multiple Linear Regression Analyses of factors associated with QoL

Variables	QoL measures		
	PedsQL Total Score - Child report	PedsQL Total Score - Parent report	CAFAS Total Child Score
Block 1 (Psychopathology measures)			
<i>R</i> ²	.10	.43	.22
Child psychopathology (parent report)	-.44*	-.81*	.03
Child psychopathology (teacher report)	.07	.01	-.14*
Sex [#] x child psychopathology (parent report) ^a	.40*	.37*	-
Age [#] x child psychopathology (parent report) ^b	-	-	-.21*
Block 2 (Child factors)			
<i>R</i> ² change	.13	.02	.04
Intelligence	.04	-.01	-.10
Chronic physical disease	.01	.01	.03
Self-esteem	.24*	.02	.03
Social skills (parent report)	-.06	.17*	-.03
Social skills (teacher report)	-.03	-.03	.04
Sex [#] x social skills (parent report) ^c	-	-	.17*
Sex [#] x chronic physical disease ^d	-.44*	-	-
Age [#] x chronic physical disease ^e	.21*	-	-
Block 3 (Parent factors)			
<i>R</i> ² change	-	-	.03
Psychopathology mother	.15	.02	.10
Psychiatric treatment mother	-.10	-.03	-.01
Parenting stress mother	.08	-.01	-.01
Sex [#] x parenting stress mother ^f	-	-	-.16*
Block 4 (Family/ social network factors)			
<i>R</i> ² change	.06	.02	.08
Single parent family	.12	-.01	-.03
SES	-.02	-.03	.01
Family functioning (clinician report)	-.05	.02	.31*
Family functioning (parent report)	.03	.02	-.03
Social contacts family	.01	-.06	-.03
Social support - family	-.13	.01	.06
Social support - friends	.02	-.02	-.06
Social support - classmates	.07	.07	.04
Stressful life events	-.16*	.05	.08
Sex [#] x stressful life events ^g	-	-.14*	-
Sex [#] x social support – classmates ^h	.36*	-	-
<i>Cumulative R</i> ²	.29*	.47**	.37***

Note. Betas are standardized betas for the full model; both significant and non significant betas are presented.

* Significant at $p < .05$

Dichotomized variables: sex (girl (0) versus boy (1)) and age (8-12 (0) versus 13-18 (1) years)

^a The decrease in QoL with an increase of psychopathology was larger for girls than for boys

^b The decrease in QoL with an increase of psychopathology was larger for older children than for younger children

^c The increase in QoL with an increase of social skills was larger for boys than for girls

^d Boys with a physical disease had a lower QoL than girls with a physical disease

^e Younger children with a physical disease had a lower QoL than older children

^f The decrease in QoL with an increase of parenting stress was larger for girls than for boys

^g The decrease in QoL with an increase of stressful life events was larger for boys than for girls

^h The increase in QoL with an increase of social support was larger for boys than for girls

* $F(7, 157) = 9.2, p < .001$

** $F(4, 160) = 35.7, p < .001$

*** $F(5, 158) = 18.5, p < .001$

Discussion

The present study assessed factors possibly associated with poor QoL, over and above the association between QoL and child psychopathology, in children with psychiatric problems. These factors were studied according to the levels of the Bronfenbrenner model. In this model, the first level concerns child characteristics, the second level parent characteristics, and the third level family/ social network characteristics. It is important to reveal these factors, because improvement of QoL should be a major aim of child psychiatric treatment (Schmeck and Poustka, 1997). Most treatment programs predominantly focus on psychiatric symptoms, but thus far it is not known which factors, besides psychopathology, influence QoL in children with psychiatric problems. If QoL would be correlated with other factors, besides psychopathology, it might be the case that treatment programs should not only focus on psychiatric symptom reduction, but also on factors enhancing QoL. If a child's psychiatric symptoms would be targeted, while other factors related to QoL would be neglected, this might result in a poor treatment outcome.

As expected, the present study showed a strong association between child psychopathology and QoL ratings of children, parents and clinicians. In other words, psychiatric symptoms need to be addressed to improve QoL. In accordance with our hypotheses, several child and family/ social network factors were, over and above psychopathology, also associated with QoL. However, of all factors that were studied, the influence of parent factors on QoL was almost negligible. Generally, associations were found across the three QoL raters (children, parents, and clinicians), which underscores the validity of the findings, especially because clinicians were blind to almost all information obtained in this study.

Sex and age effects

Sex and age were associated with QoL in interaction with other predictors. The interaction between sex and child psychopathology indicated that the impact of psychopathology on QoL was larger for girls than for boys. A possible explanation might be that boys exhibit significantly more externalizing behavior problems than girls (e.g. Keenan and Shaw, 1997). Children with externalizing behavior problems may not experience their symptoms as problematic, which may explain our findings. Our hypothesis regarding the association between age, psychopathology and QoL, was confirmed. When QoL was reported by the clinician the impact of psychopathology on QoL indeed increased with increasing age. This

may be explained by the fact that older children may be more aware of their problems than younger children, because they are more likely to realize that they are different from their peers. This might influence their report of QoL. The association of older age and lower QoL may also be explained by the chronicity of the child's psychiatric disorder and not solely by the mature cognitive development of older children. However, since the chronicity of the child psychiatric disorder was not measured in the present study, this hypothesis could not further be tested. Despite, it should be noted that most of the children that were included in the present study, were visiting mental health care for the first time.

Interactions between sex and child, parent, and family/ social network factors learned that the effect on QoL of prediction factors that were studied was larger for boys than for girls.

Child characteristics

As expected, poor QoL was not only associated with the child's psychopathology, but also with low self-esteem, chronic physical disease and poor social skills. Low self-esteem also co-occurred with poor QoL in studies with adults (Ritsner et al., 2000) and presence of a chronic physical disease has been associated with poor QoL in children (Juniper et al., 1996). Intelligence was not correlated with poor QoL. So, beyond the relation between low intelligence and higher levels of psychopathology (Einfeld and Tonge, 1996), level of intelligence does not seem to affect QoL directly.

Parent characteristics

Except the association between the interaction of sex and parenting stress and clinician's QoL report, parent characteristics were only associated with QoL in simple regression analyses. Parent factors were added in the analyses because of their known relation with children's psychopathology. Both mothers' psychopathology and parenting stress were correlated with poor QoL. In other words, children with poor QoL had mothers with higher levels of psychopathology and/ or mothers who experienced more parenting stress.

Family/ social network characteristics

In contrast to previous studies (Halfon and Newacheck, 1993) and to what was expected, only a small association between clinician reported QoL and SES was found and only in the simple regression analysis, indicating that QoL was higher in middle-high SES levels. This is remarkable, since low SES has been mentioned as a risk factor for psychopathology in

children (Verhulst and Koot, 1992). Apparently, SES does not affect QoL beyond its effect on psychopathology.

Poor QoL further co-occurred, as expected, with poor social support and, besides this also with poor family functioning and stressful life events. The significant association between QoL and stressful life showed that children with poor QoL were likely to have experienced more stressful life events. Apparently, stressful life events not only influence a child's QoL through their known association with child psychopathology (Berden et al., 1990), but also influence QoL more directly.

Despite the previously reported relation between family composition and poor QoL in adults with psychiatric disorders (Koivumaa Honkanen et al., 1996), poor QoL was not correlated with family composition, which was operationalized as living in a one-parent family.

Clinical implications

When factors from all levels of our model were entered in one analysis, factors from the child level and the family/ social network level explained most additional variance, over and above the variance of child psychopathology, and factors from the parent level explained hardly any additional variance. In other words, statistically, child and family/ social network factors seem more important than parent factors. These results may lead to two conclusions.

First, it may be concluded that to improve children's QoL, child and family/ social network factors should, besides child psychopathology, be an important additional focus of treatment programs, especially on enhancing self-esteem and social skills, and on improving family functioning and strengthening social support. Additionally, co-morbid chronic physical diseases should be treated adequately and stressful life events should be prevented. Finally, our results showed that to focus treatment on parent factors as such seems less important.

The co-occurrence of poor QoL with low self-esteem or poor social skills may be relevant for clinical practice, because clinicians may be in a position to also address these factors, besides the child's psychopathology. In essence, it might be important to focus treatment programs on self-esteem and social skills, too. Some treatment programs for anxiety disorders already contain social skills training (e.g. Albano et al., 1995; Spence et al., 2000) or aim at enhancing self-esteem specifically (e.g. Silverman et al., 1999), while others do not (e.g. Kendall et al., 1997; Last et al., 1998). Our findings do not guarantee that treatment modules aimed at the improvement of social skills or self-esteem will result in better treatment outcome for all patients, since the present study is not a treatment outcome study.

However, they suggest that treatment including such targets may add to treatment only targeting psychiatric symptoms.

Findings regarding family functioning indicated that children with a poor QoL were more likely to live in families with poor family functioning; i.e. in families with poor problem solving, ambiguous or masked communication between family members, difficulties to reveal each other's feelings and difficulties to support each other. This may implicate that, to improve children's QoL, it might be important to focus treatment on improving these aspects of family functioning.

The relation between poor QoL and poor social support may implicate that children with a poor social network experience a worse QoL. It can be hypothesized that treatment that focuses on social support might help to improve treatment outcome. Some treatment programs already teach children skills for improvement of social support (e.g. Shortt et al., 2001; Silverman et al., 1999), but in the future it seems worthwhile to study if addition of therapy modules aimed at improving the capacity of the child to enhance social support, will improve the child's QoL.

A second conclusion from the findings of this study, concerns the analyses with parent factors only, in which associations were found between QoL and parent factors. These associations became non significant in the multiple regression analyses. Apparently, parent-related factors do not account for differences in QoL once functioning of the family as a whole is accounted for. These parent factors might be associated with child or family/ social network factors and be related to QoL through their association with child or family/ social network factors. Otherwise parent factors would have been independent predictors of QoL in the multiple regression analyses.

Informant issues

In the present study, data on the child's QoL and the different child, parent, and family/ social network characteristics were derived from four different types of informants: children themselves, parents, teachers, and clinicians. In the previous section we generalized our findings and did not focus on differences and similarities between informants in variables associated with QoL. Several associations were found across QoL raters, which enhances the generalization of findings. The association between QoL and child psychopathology was found for all raters. Overall, factors that were related to QoL ratings of parents and clinicians showed high resemblance. On the other hand, factors associated with QoL ratings of children differed from those associated with QoL ratings of parents and clinicians. Factors related to

the QoL judgement of parents and clinicians seemed to concern observable factors, like social skills of the child. Factors correlated with the child's QoL judgement seemed to represent the inner world of the child, like self-esteem and experienced social support.

In parent report on QoL most variance in QoL was explained by child psychopathology and the other predictors added little variance to the model. In child and clinician QoL report the other factors added more variance to the models.

Our findings emphasize the importance of the use of multiple informants in QoL measurement, as is suggested by others (Sainfort et al., 1996). From the results of the present study it may be hypothesized that parents and clinicians might be better informants regarding factors concerning observable characteristics of the child and parents, while children might be better informants on factors representing the child's inner world. It should be noted however, that the information on the different factors was not obtained from all informants. Children for instance did not fill in questionnaires concerning family functioning or social skills.

Limitations

A first possible limitation of the present study is the lack of child self report regarding psychopathology and social skills. Poor QoL co-occurred with teacher and parent reports on the child's psychopathology and poor social skills. The absence of child self report on psychopathology and social skills may have influenced the results, because, for instance, children themselves often disagree with parents and teachers with respect to the presence of psychopathology (e.g. Achenbach et al., 1987). Based on child information, different associations between QoL and psychopathology might have been found, because it may be possible that children with internalizing problems, for instance, suffer more from their problems than parents and teachers may expect. In these children, QoL might be associated more with self-reported symptoms, than with symptoms reported by parents or teachers. In the present study, psychopathology and social skills were not assessed via self-reports, because the majority of the participants were too young to fill in questionnaires regarding psychopathology and social skills.

The cross-sectional design of this study is a second limitation. This may limit conclusions regarding the direction of relations between QoL and each of the variables, because it is difficult to determine if QoL is influenced by a variable or vice versa. However, several factors tended to coincide with poor QoL and therefore it can be hypothesized that treatment that focuses on these factors might help to improve treatment outcome.

Longitudinal studies are needed to decide more precisely which factors are related to QoL and should be a focus of treatment programs.

A third limitation may be the present sample being a clinic sample. This is on one hand very strong, because it indicates that the findings of this study are representative and useful for clinical practice, but it cannot be assumed that the findings of the present study reflect the situation in the general population.

Conclusion

Clinicians probably aim to improve a child's QoL by treating psychiatric symptoms. In this study, indeed, poor QoL was associated with psychiatric symptoms, so, to increase a child's QoL treating these symptoms is important. Besides, poor QoL was associated with low self-esteem, poor social skills, chronic physical disease, parenting stress, poor family functioning, poor social support, and stressful life events. In multiple linear regression analyses parent factors added little variance to the models. From this it may be concluded that to improve a child's QoL, treatment programs should at least focus on diminishing the child's psychiatric symptoms, enhancing self-esteem and social skills, and on improving family functioning and strengthen social support. Aiming treatment at these factors may especially be important, because treatment programs aimed at symptoms are not always successful. In this way, treatment outcome might be improved.

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

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Chapter 5

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

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 improved, 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.

Introduction

Community and clinical studies have shown that psychopathology in children and adolescents tends to be highly persistent (Biederman et al., 1998; Heijmens Visser et al., 2003; Hofstra et al., 2000; Pine et al., 1998; Rao et al., 1995; Stanger et al., 1996). 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 (Barrett et al., 2001; MTA Cooperative Group, 1999; Spence et al., 2003; Vostanis et al., 1998). 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 (Schmeck and Poustka, 1997). 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 (Wallander et al., 2001). 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 (Bastiaansen et al., 2004a; Landgraf et al., 1996; Sawyer et al., 2002). This underscores the need to address QoL in child psychiatric treatment (Schmeck and Poustka, 1997). Current clinical intervention trials in children and adolescents mainly focussed on psychiatric symptoms as treatment outcome, and did not fully address QoL (Barrett et al., 2001; Vostanis et al., 1998; Weiss et al., 2003; Wilson et al., 2003).

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. (1996b) 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 (Tenney et al., 2003).

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 psychiatric 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 (Bastiaansen et al., 2004a; Bastiaansen et al., 2004b). 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; Achenbach, 1991a) and in the clinical range of the QoL measure (Pediatric Quality of Life InventoryTM Version 4.0, PedsQL; Varni et al., 2001). 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 (Dutch Central Bureau of Statistics, 1993); 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, that was obtained with the DSM-IV Checklist Interview in a standardized way at Time 1 (Hudziak et al., 1993), 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. (2004b).

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 (Achenbach, 1991a) 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 (Achenbach, 1991a) were confirmed for the Dutch translation (Verhulst et al., 1996).

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; Achenbach, 1991a); the *T* distribution was based on the scoring distribution in the Dutch normative sample (Verhulst et al., 1996).

Pediatric Quality of Life InventoryTM Version 4.0 (PedsQL)

To measure the child's QoL, the parent version of the 23-item PedsQL (Varni et al., 2001) 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 0-100, 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 (Varni et al., 2001) and Dutch version (Bastiaansen et al., 2004a) 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 ≤ 10 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 (Bastiaansen et al., 2004a). This group consisted of 74 children from the general population (response 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 (Varni et al., 2001).

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. (1984) and

Jacobson and Truax (1991). 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 (Jacobson et al., 1999).

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 (Speer, 1992). 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 (≥ 90 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 ≤ 10 th percentile was used as a cut-off point to define the clinical range.

Based on Jacobson and Truax (1991), the following categories of clinically significant change were distinguished: 'recovered', 'improved', 'unchanged – still clinical', and 'deteriorated 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 5.1 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 ($p < .001$; paired-sample t -tests).

Table 5.1. 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)	<.001
Internalizing score	23.5 (10.1)	17.9 (10.3)	<.001
Externalizing score	24.1 (10.7)	18.9 (10.6)	<.001
PedsQL			
Total score	56.8 (10.5)	67.0 (15.1)	<.001
Physical functioning	71.0 (18.4)	79.5 (18.3)	<.001
Emotional functioning	44.0 (15.6)	57.6 (18.7)	<.001
Social functioning	51.9 (20.6)	62.3 (24.7)	<.001
School functioning	52.0 (14.7)	60.9 (19.2)	<.001

Table 5.2 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 (Cohen, 1988) and correlations between CBCL and PedsQL subscale scores were small to medium (Cohen, 1988), 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 $-.55$ ($p < .001$).

Table 5.2. Pearson correlations between CBCL and PedsQL scale scores at Time 1 (N=126)

PedsQL	CBCL		
	Total Problem score	Internalizing score	Externalizing score
Total score	-.49**	-.37**	-.26**
Physical functioning	-.27**	-.28**	-.14
Emotional functioning	-.37**	-.48**	-.09
Social functioning	-.33**	-.07	-.22*
School functioning	-.24**	-.08	-.19*

* Significant at $p < .05$

** Significant at $p < .01$

Clinically significant change

Table 5.3 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.

Table 5.3. 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 (100.0%)

% indicates the proportion of the total number of children.

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 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 5.4 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 ($\chi^2(3)=3.29$, $p=.35$). 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).

Table 5.4. Number of children in each diagnostic category with a poor versus a moderate or good prognosis (N=126)

Diagnosis	Prognosis		Total
	Poor	Moderate or good	
Attention Deficit and Behavior Disruptive disorders	17 (35.4%)	31 (64.6%)	48 (100.0%)
Anxiety and Mood disorders	13 (31.7%)	28 (68.3%)	41 (100.0%)
Pervasive Developmental disorders	9 (56.3%)	7 (43.8%)	16 (100.0%)
Other disorders or no diagnosis	9 (42.9%)	12 (57.1%)	21 (100.0%)
Total	48 (38.1%)	78 (61.9%)	126 (100.0%)

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.

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 (Biederman et al., 1998; Heijmens Visser et al., 2003; Vostanis et al., 1998), 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 and QoL is not associated with the psychiatric diagnosis. In a previous study (Bastiaansen et al., 2004b), 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 (Bastiaansen et al., 2005a), 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 (Eiser and Morse, 2001; Wallander et al., 2001). 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.

6 | Predictors of quality of life in children and adolescents with psychiatric disorders

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Chapter 6

Predictors of quality of life in children and adolescents with psychiatric disorders

Abstract

Objective: To identify factors that predict quality of life (QoL) across a 1-year period, over and above potential improvements in QoL related to a decrease in psychopathology, in children with psychiatric problems. **Methods:** 231 referred children and adolescents, aged 7-19 years, were followed up across a one-year period. QoL and psychopathology were assessed, as were a broad range of child, parent, and family/ social network factors. Information was obtained from children, parents, and teachers. **Results:** Time 1 QoL score and change in level of psychopathology from Time 1 to Time 2 were important predictors of Time 2 QoL score. In addition, Time 2 QoL score was also predicted by the presence at Time 1 of a chronic physical disease, low self-esteem, poor social skills, and stressful life events. **Conclusion:** Findings can be useful to identify children who are at risk for lower than expected levels of QoL, even after receiving help from mental health agencies. This may help clinicians to identify children who may need additional treatment.

Introduction

All clinicians who work with children with psychiatric problems are acquainted with a group of children in which treatment sorts out little improvement in psychopathology. This is in accordance with studies that have shown that psychopathology in children tends to persist into adolescence and young adulthood (Heijmens Visser et al., 2003; Hofstra et al., 2000; Pine et al., 1998), and that clinical interventions often do not yield complete reduction of psychiatric symptoms (Barrett et al., 2001; Spence et al., 2003; Vostanis et al., 1998). Although clinicians often aim to diminish the frequency or severity of psychiatric problems, a major goal of mental health care workers is to improve the Quality of Life (QoL) of their patients (Schmeck and Poustka, 1997). Since psychopathology tends to persist, it can be hypothesized that QoL does not improve sufficiently even in those who are treated. The need to address QoL in child psychiatric treatment is also shown by recent studies that indicated that the QoL of children with psychiatric problems is considerably poorer than that of children from the general

population, and as poor or even poorer than that of physically ill children (Bastiaansen et al., 2004a; Landgraf et al., 1996; Sawyer et al., 2002). If, prior to treatment, it would be known which children have a high probability of less than optimal improvement of their QoL, this might assist clinicians with their treatment considerations.

To our knowledge, so far, no study addressed predictors of change in QoL over time in children with psychiatric problems. So, it remains unclear to what extent reduction of psychiatric symptoms leads to improvement of QoL, or which other factors are also involved in change in QoL. Bastiaansen et al. (2005b) studied the association between change in psychopathology and QoL across time in children with high levels of psychopathology at initial assessment. It was found that psychiatric symptom reduction was associated with an improvement of QoL. However, an improvement of QoL was also reported in a number of children with persistently high levels of psychopathology (Bastiaansen et al., 2005b), which suggests that QoL may improve, even if reduction of psychiatric symptoms is not achieved. This raises the question which factors are associated with significant improvement of QoL in children with psychiatric problems, over and above the potential change in QoL associated with reduction of psychiatric symptomatology. Treatment modules aiming at such factors might help to improve QoL in children with persistently high levels or only limited improvement of psychopathology across time.

Several factors may predict QoL improvement in children with psychiatric problems. To identify possible factors of influence, the Bronfenbrenner model can be used (Bronfenbrenner, 1979). According to this model, risk factors for psychopathology are grouped according to their “proximity” to the child. The first category includes child characteristics, both emotional/ behavioral and physical, that logically represent the closest and most central part of the individual. Examples of these variables are sex and age, or the child’s self-esteem and social skills. The second category includes aspects of the parents that represent contextual factors directly related to the child’s functioning and development, like parental psychopathology. The third category includes general adverse family circumstances that posit a potential influence on the child but are not necessarily directly related to or aimed at the child, such as family functioning or social network factors, like social support from friends.

Two cross-sectional studies identified factors that were associated with QoL in children with psychiatric problems (Bastiaansen et al., 2005a; Ezpeleta et al., 2000). Both studies found a strong association between psychopathology and poor QoL. Besides, QoL was predominantly associated with child factors, such as a chronic physical disease (Bastiaansen

et al., 2005a; Ezpeleta et al., 2000), low self-esteem, poor social skills (Bastiaansen et al., 2005a), temperamental characteristics, and coping style (Ezpeleta et al., 2000), and also with family/ social network factors, such as stressful life events (Bastiaansen et al., 2005a; Ezpeleta et al., 2000), poor family functioning, and poor social support (Bastiaansen et al., 2005a). These factors may also predict improvement of QoL across time.

In the present study, children with psychiatric problems were followed-up across a 1-year period. The aim of the study was to investigate which child, parent, and family/ social network factors predicted QoL at follow-up, over and above potential improvements in QoL related to a decrease in psychopathology. We hypothesized that personal and environmental sources of support, like good social skills and support from family and peers would be associated with a better QoL at follow-up, whereas factors indicating heightened levels of stress, like the presence of a chronic physical disease or the occurrence of stressful life events were hypothesized to be associated with lower QoL at follow-up.

Methods

Procedure and participants

The present sample is a one-year follow-up study of a child psychiatric outpatient sample. The first assessment (Time 1) addressed a sample of 310 children and adolescents (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 (Bastiaansen et al., 2004a; Bastiaansen et al., 2004b). Children and parents filled in questionnaires concerning QoL, psychopathology and a broad range of child, parent, and family/ social network factors. The child's clinician provided information on the DSM-IV diagnosis, family functioning and functional impairment of the child. Teachers filled in questionnaires regarding psychopathology and the child's social skills. At the second assessment (Time 2), approximately one year after Time 1, children and parents were asked for participation again and after they provided written informed consent, questionnaires were sent by mail. Home visits only took place if children or parents were not capable to answer the questionnaires themselves, because of reading difficulties or language problems. In that case, a research assistant helped them to complete the questionnaires at home (N=34). Children and parents rated questionnaires concerning QoL and psychopathology. After

consent of parents and children, teachers filled in a questionnaire regarding child psychopathology. The study was conducted after approval by the Erasmus MC university hospital medical ethical committee.

At Time 2 (mean follow-up time 389 days; SD=66 days), 231 children and their parents participated (response rate 74.5%). The mean age of the sample of 134 boys (58.0%) and 97 girls (42.0%) was 12.2 years (SD=3.2; range 7-19 years). Family socio-economic status (SES) was determined through parental occupational level (Dutch Central Bureau of Statistics, 1993); 30.7% of the children came from families with low and 69.3% from families with middle to high SES. Based on the main clinical diagnosis, obtained with the DSM-IV Checklist Interview in a standardized way during Time 1 (Hudziak et al., 1993), each child was assigned to one of six diagnostic groups: (1) Attention Deficit and Disruptive Behavior Disorders (n=74, 32.0%), (2) Anxiety Disorders (n=43, 18.6%), (3) Mood Disorders (n=25, 10.8%), (4) Pervasive Developmental Disorders (n=27, 11.7%), (5) Other Disorders (n=16, 6.9%; including Somatoform Disorder and Enuresis/ Encopresis), and (6) No Diagnosis (n=46, 19.9%). The validity of the Dutch version of the DSM-IV Checklist Interview was supported by Bastiaansen et al. (2004b).

Instruments

QoL measures

Pediatric Quality of Life InventoryTM Version 4.0 (PedsQL). The 23-item PedsQL (Varni et al., 2001) was used to measure the child's QoL. It has a child self-report and a parallel parent proxy-report format. Versions for ages 5-7, 8-12 and 13-18 years were used. The respondent is 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 informant is not asked to rate the presence of a certain behavior, but if present, its impact on the child's everyday functioning. A 5-point-Likert scale format is used and scores may range from 0-100, from 'almost always a problem' to 'never a problem'; higher scores indicate a 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 'trouble sleeping'), (3) social functioning (5 items; e.g. 'trouble getting along with peers' or 'being teased'), and (4) school functioning (5 items; e.g. 'trouble keeping up with schoolwork' or 'missing school'). In the present study only the Total Score was used, computed as the sum of the 23 items divided by

the number of items answered. Good reliability and validity were reported for the American (Varni et al., 2001) and Dutch version (Bastiaansen et al., 2004a) of the PedsQL.

Psychopathology measures

Child Behavior Checklist/ 4-18 (CBCL) and Teacher's Report Form (TRF). The CBCL (Achenbach, 1991a) and TRF (Achenbach, 1991b) were used to obtain standardized parent and teacher reports of child psychopathology. The second part of the CBCL and TRF, which were used in the present study, consists of 120 items on behavioral or emotional problems in the past 6 or 2 months for CBCL or TRF, respectively. The child's behavior is rated on a three point scale (0=not true, 1=somewhat true, 2=very or often true) and summing the scores for each problem item yields the Total Problem Score. Higher scores indicate a higher level of psychopathology. The good reliability and validity of the Dutch CBCL and TRF were supported by Verhulst et al. (1996; 1997).

Child factors

Intelligence. At Time 1 the Wechsler Intelligence Scale for Children – Revised (WISC-R; Wechsler, 1974) was used to measure the intelligence of the child. In 12.1% of the children this was not possible, because their IQ was too low to be measured (n=9) or because their age was above the age range (>16 years) for which WISC-R norms are available (n=19). Self-report questionnaires were not obtained from the low IQ children of the first group (n=9).

Chronic physical disease. The presence of a chronic physical disease at Time 1 was assessed with the Questionnaire for Identifying Children with Chronic Conditions (QuICCC; Stein et al., 1997). This questionnaire consists of 39 items and each item consists of three sequences. The first part of each question sequence asks about one or more specific consequences of having a chronic health condition; the second part asks whether the consequence is the result of a medical, behavioral, or other health condition; and the final part assesses the duration of the condition, which has to be at least one year. To meet the definition of a chronic disease, a child must qualify in each component of at least one question sequence. Good reliability and validity of the QuICCC have been demonstrated (Stein et al., 1997).

Self-esteem. To measure self-esteem of the child at Time 1, the Global Self-Worth Scale of either the Self-Perception Profile for Children (SPPC; ages 8-12; Harter, 1985a) or the Self-Perception Profile for Adolescents (SPPA; ages 13-18; Harter, 1988), was used, consisting of 6 or 5 four-point items, respectively. High scores indicate high self-esteem.

Good reliability and validity of the Global Self-Worth Scale of the SPPC and SPPA have been reported (Harter, 1985a; Harter, 1988; Van Dongen Melman et al., 1993).

Social skills. At Time 1 children's social skills were rated by parents and teachers on separate informant and age versions (6-12 or 13-18 years) of the Social Skills Rating System (SSRS; Gresham and Elliot, 1990). Parent forms contain 38 and 40 items for ages 6-12 and 13-18 years, respectively; teacher forms contain 30 items for both age groups. In the present study the Total Score was used, calculated by summing the scores of each individual item; higher scores represent better social skills. Good reliability and validity of the SSRS have been reported (Gresham and Elliot, 1990).

Parent factors

Psychopathology in mothers. The Young Adult Self-Report (YASR; Achenbach, 1997) was rated by mothers to assess psychopathology of the mother at Time 1. The YASR has the same format as the CBCL and concerns the past 6 months. Only the 29 problem items that best discriminated between referred and non-referred subjects were used (Wiznitzer, 1993). A Total Problem Score was computed by summing the scores on the 29 items. Good reliability and validity of the Dutch YASR have been demonstrated (Wiznitzer et al., 1992).

Psychiatric treatment of the mother. At Time 1, current and past inpatient and outpatient mental health care use by the mother was assessed with a questionnaire on mental health use.

Parenting stress mother. The Nijmegen Parenting Stress Index (NPSI; De Brock et al., 1990a) was completed by mothers at Time 1, which is a modified Dutch version of Abidin's Parenting Stress Index (Abidin, 1983). This questionnaire measures the level of perceived parenting stress of the mother originating from several child and parent characteristics within the care-giving context. A short form of 25 items, derived from scales measuring the perceived child and parent characteristics was used (De Brock et al., 1990b). A Total Problem Score was computed by summing the scores on the 25 items; higher scores indicate more parenting stress.

Family/ social network factors

Family SES at Time 1 was assessed through parental occupational level (Dutch Central Bureau of Statistics, 1993). Based on the highest occupational level in the family (father or mother), the family was assigned to one of two categories: low SES or middle-high SES.

Family functioning. The two caregiver resources scales of the Child and Adolescent Functional Assessment Scale (CAFAS; Hodges, 1997), indicating whether the caregiver meets the child's material needs and social support, were rated by the child's clinician at Time 1. These scales have been designed to assess functional impairment in the family. A Total Score is computed as the sum of the scores on the two scales. Scores were recoded (ranges 0-60) so that higher scores indicate better caregiver functioning. The CAFAS was found to be a reliable and valid instrument (Hodges and Wong, 1996).

Parents filled in the General Functioning Subscale of the McMaster Family Assessment Device (FAD; Byles et al., 1988), which measures family functioning. Higher scores indicate better family functioning. Good reliability and validity of the General Functioning Subscale have been reported (Byles et al., 1988).

Social contacts of the family. To measure the social contacts of the family at Time 1, parents filled in the Health Insurance Experiment Social Support Questionnaire (Donald and Ware, 1984), concerning social contacts and social resources of the family. It contains nine items and summing these items yields an Overall Social Contacts Index. Higher scores indicate more social contacts.

Social support. To assess child-perceived support from significant others at Time 1, children completed the Social Support Scale for Children (SSSC; ages 8-12; Harter, 1985b) or the Social Support Scale for Adolescents (SSSA; ages 13-18; Harter, 1989). These questionnaires originally consist of four scales and in this study three scales were used, measuring social support from family members, friends, and classmates. Each subscale consists of six items and Harter's four-point item format was used for the classmates' scale; the family members and friends scales were slightly changed into a two-point format. Higher scores indicate greater perceived support. Harter (1985b; 1989) reported good reliability and validity for the SSSC and SSSA.

Life events. At Time 1 parents completed a 12-item short form of the Life Events Questionnaire (Berden et al., 1990), which has a 'yes' or 'no' format and assesses potentially stressful life events such as parental divorce, death of a family member, or long-term hospitalization in the past two years. Item scores are summed into a Total Life Events score; higher scores indicate more life events. A satisfactory reliability of the LEQ has been reported (Berden et al., 1990).

Statistical analyses

To estimate possible predictors of Time 2 child and parent reported QoL scores, multiple linear regression analyses were conducted. To identify predictors of child reported QoL, Time 2 PedsQL child report Total score was entered in a regression analysis as the dependent variable, and candidate predictors were entered as independent variables in subsequent blocks (method Enter). Before each next block was added into the analysis, non significant predictors in the previous block were removed from the model, with the exception of the main factors of significant interaction terms. In the first block, the Time 1 PedsQL child report Total score, standardized residual scores of CBCL and TRF, together with sex and age and interaction terms of PedsQL, CBCL, and TRF with sex and age, were entered as independent variables. The standardized residual scores of CBCL and TRF were computed by regressing Time 2 CBCL and TRF scores on Time 1 CBCL and TRF scores, respectively, in order to assess effects of change in level of psychopathology from Time 1 to Time 2. In the second block of the analysis, the Time 1 child factors (intelligence, presence of a chronic physical disease, self-esteem, and social skills) were added, together with interaction terms between these factors and sex and age, to test if these factors improved the prediction of QoL. Parent factors were entered in the third block (psychopathology mother, maternal mental health use, and parenting stress), also together with interaction terms between these factors and sex and age. Finally, family/ social network factors were entered in the fourth block (family composition, SES, family functioning, social contacts of the family, perceived social support, and stressful life events), simultaneously with interaction terms between these factors and sex and age.

To identify predictors of parent reported QoL, a similar analysis was performed, in which Time 2 PedsQL *parent* report Total score was entered as the dependent variable and Time 1 PedsQL *parent* report Total score as independent variable.

Results*Descriptive analyses*

Table 6.1 shows the means, standard deviations, and ranges of QoL and child psychopathology measures at Time 1 and Time 2 and of predictor variables at Time 1. Total scores on child and parent versions of the PedsQL were higher at Time 2 than at Time 1 ($p < .001$ for both PedsQL child and parent report; paired-sample t -tests), which indicated improvement in QoL across time. Scores on the CBCL and TRF decreased across time

($p < .001$ for CBCL and $p < .005$ for TRF, respectively; paired-sample t -tests), also indicating improvement in psychopathology across the 1-year period.

Table 6.1. Means (percentages), standard deviations, and ranges of QoL and child psychopathology measures at Time 1 and Time 2 and of predictors at Time 1 (N=231)

	Instrument	Mean/ percentage (SD)	Range
QoL measures			
Time 1			
QoL Total score – child report	PedsQL	71.7 (12.9)	35.9-98.9
QoL Total score – parent report	PedsQL	66.1 (14.2)	27.2-97.8
Time 2			
QoL Total score – child report	PedsQL	74.8 (14.2)	25.0-100
QoL Total score – parent report	PedsQL	72.9 (15.4)	14.1-100
Psychopathology measures			
Time 1			
Child psychopathology (parent report)	CBCL	64.7 (28.1)	6-137
Child psychopathology (teacher report)	TRF	50.8 (31.9)	3-147
Time 2			
Child psychopathology (parent report)	CBCL	50.1 (28.1)	2-142
Child psychopathology (teacher report)	TRF	44.6 (29.3)	4-144
Child factors			
Intelligence	WISC-R	96.4 (15.7)	48-141
Chronic physical disease	QuICCC	9.2%	
Self-esteem	SPPC/ SPPA	3.1 (0.7)	1.3-4.0
Social skills (parent report)	SSRS	41.7 (11.9)	1-73
Social skills (teacher report)	SSRS	31.1 (11.1)	5-57
Parent factors			
Psychopathology mother	YASR	9.9 (8.6)	0-48
Psychiatric treatment mother		35.0%	
Parenting stress mother	NPSI	83.1 (26.7)	26-137
Family/ social network factors			
Single parent family		25.5%	
SES*		69.3%	
Family functioning (clinician report)	CAFAS	53.8 (8.2)	20-60
Family functioning (parent report)	FAD	3.1 (0.5)	1.5-4
Social contacts family	HIESSQ	3.0 (0.8)	0.7-5
Social support – family	SSSC/ SSSA	0.7 (0.2)	0-1
Social support – friends	SSSC/ SSSA	0.8 (0.2)	0-1
Social support – classmates	SSSC/ SSSA	3.2 (0.7)	1-4
Stressful life events	LEQ	1.5 (1.3)	0-6

* Dichotomized variable: SES (low (0) versus middle-to-high (1))

Multiple Linear Regression Analyses

Table 6.2 shows the results of the multiple linear regression analyses. Predictors are presented only if the betas were significant in the final model.

Table 6.2. Multiple linear regression of Time 2 QoL on change of psychopathology and Time 1 predictors

Predictors	Instrument	Time 2 Outcomes	
		PedsQL Total Score -Child report	PedsQL Total Score -Parent report
Block 1 (Time 1 QoL score and psychopathology change)			
R^2		.40	.58
Time 1 QoL Total score	PedsQL	.41	.50
Change in child psychopathology score (parent report)	CBCL	-.20	-.52
Block 2 (Child factors)			
R^2 change		.09	-
Chronic physical disease	QuICCC	-.29	-
Self-esteem	SPPC/A	.19	-
Social skills (parent report)	SSRS	.16	-
Sex [#] x self-esteem ^a	Sex x SPPC/A	-.26	-
Age [#] x chronic physical disease ^b	Age x QuICCC	.21	-
Block 3 (Parent factors)			
		-	-
Block 4 (Family/ social network factors)			
R^2 change		-	.05
Sex [#] x stressful life events ^c	Sex x LEQ	-	.24
R^2 for the full model		.49*	.63**

Note. Entries are standardized betas for the full model; only significant betas ($p < .05$) are shown.

[#] Dichotomized variables: sex (boy (0) versus girl (1)) and age (8-12 (0) versus 13-18 (1) years)

^a The increase in QoL with an increase of self-esteem was larger for boys than for girls

^b Younger children with a physical disease had a lower QoL than older children

^c The decrease in QoL with an increase of stressful life events was larger for boys than for girls

* $F(7, 144) = 19.4, p < .001$

** $F(5, 165) = 55.6, p < .001$

PedsQL Child report

The final model of PedsQL child report was significant at $p < .001$ ($F(7, 144) = 19.4$). The R^2 of this model was .49, which means that 49% of the variance in Time 2 PedsQL child report Total score was explained by the predictors included in the model (large effect size according to Cohen (1988)).

The Time 2 PedsQL child report Total score was predicted by the Time 1 PedsQL child report Total score and change in level of child psychopathology (CBCL). Over and above the improvement in QoL related to improvement in psychopathology, other factors also contributed independently to the variance in the regression model.

Chronic physical disease at Time 1 was an important predictor of the Time 2 PedsQL child report score; if a physical disease was present at Time 1, the PedsQL child report score at Time 2 was significantly lower. The impact of a physical disease on Time 2 QoL was larger for younger children than for older children, because younger children with a physical disease

at Time 1 had a lower QoL score at Time 2. Self-esteem and social skills (parent report) also predicted PedsQL child report scores at Time 2. The significant effect of the interaction between sex and self-esteem on Time 2 PedsQL child report indicated that the association between QoL and self-esteem was larger for boys than for girls. Higher levels of social skills at Time 1 also predicted a higher QoL score at Time 2. The child factors chronic physical disease, self-esteem and social skills together added 9% variance to the model. No parent or family/ social network factors predicted child reported QoL scores at Time 2.

Table 6.2 displays betas of the predictors. Since these are standardized regression weights, the importance of the different predictors can be compared, because they are all in the same unit of measurement. The beta of Time 1 QoL Total score was .41 and it seems to be the most important predictor of Time 2 PedsQL child report Total score. The range of the betas of the other predictors was between .16 and .29.

PedsQL Parent report

The final model for the PedsQL parent report was significant at $p < .001$ ($F(5, 165) = 55.6$) and the R^2 of this model was .63, which means that 63% of the variance in Time 2 PedsQL parent report Total score was explained by the predictors included in the model (large effect size according to Cohen (1988)). This effect size is especially large, since the model was composed of only three significant variables.

The Time 2 PedsQL parent report Total score was predicted by the Time 1 PedsQL parent report Total score and change in level of child psychopathology (CBCL). In contrast with the regression model for the PedsQL child report, no child or parent factors predicted parent reported QoL at Time 2. However, of the family/ social network factors, the interaction term of stressful life events and sex predicted Time 2 PedsQL parent report. Stressful life events at Time 1 predicted a lower Time 2 PedsQL parent report and the impact of stressful life events on QoL appeared to be larger for boys than for girls, because boys who experienced stressful life events before Time 1 had lower Time 2 PedsQL parent report scores than girls who experienced stressful life events. This predictor added 5% variance to the model, over and above the variance of Time 1 QoL score and change in level of psychopathology.

Comparison of the beta coefficients for the predictive relation between Time 2 parent reported QoL and Time 1 parent reported QoL and parent reported Time 1 - Time 2 change in psychopathology showed that both factors had a similar weight in the regression equation.

This indicates that QoL at intake and change of psychopathology are equally influential in predicting QoL 1 year later.

Discussion

In the present study, children with psychiatric problems were followed-up across a 1-year period. The aim of the study was to investigate which child, parent, and family/ social network factors predicted QoL at follow-up, over and above potential improvements in QoL related to a decrease in psychopathology. In addition to the Time 1 QoL score, change in level of psychopathology from Time 1 to Time 2 appeared to be an important predictor of Time 2 QoL score in both child and parent report on QoL. Besides, other factors also contributed independently to the variance in the regression models based on child and parent report on QoL.

PedsQL child report

Over and above the influence of earlier levels of QoL and change in psychopathology, the Time 2 PedsQL child report Total score was predicted by presence of a chronic physical disease, level of self-esteem and level of social skills at Time 1. Presence of a physical disease has previously been reported to be associated with QoL in studies with a cross-sectional design (Bastiaansen et al., 2005a; Ezpeleta et al., 2000), but not yet as a predictor of QoL over time in children with psychiatric disorders. Although several studies found that a physical disease decreases QoL of children at large (Bradlyn et al., 1996; Glasgow et al., 1999; Juniper et al., 1996), this study showed that the presence of a physical disease has an additional diminishing effect on the QoL of children with psychiatric problems. For clinical practice this implicates that extra attention should be paid to an adequate treatment of a co-current physical disease in children with psychiatric problems and that attention should be paid to the functional impairments due to the physical disease. This is especially important in younger children since our results showed that the cross-time influence of physical disease on QoL was stronger for younger than for older children.

Self-esteem was another predictor of Time 2 QoL score. It appeared that the positive effect of self-esteem on level of QoL was larger for boys than for girls. In the study of Bastiaansen et al. (2005a) self-esteem has already been reported to be associated with QoL, but the present study showed that self-esteem might also be a predictor of QoL. These findings indicate that strengthening the self-esteem of children with psychiatric problems may

help to enhance their QoL. Some treatment programs already aim at enhancing self-esteem (e.g. Silverman et al., 1999), but the effect on QoL of such interventions has not been studied yet.

Better social skills at Time 1 predicted a higher QoL one year later. No sex or age differences were found. An association between poor social skills and poor QoL has been reported previously (Bastiaansen et al., 2005a). The present study underscores the possible importance of social skills training, that is already implemented in some treatment programs (Albano et al., 1995; Spence et al., 2000).

Apparently, child characteristics reflective of competence, including self-esteem and social skills, may influence the child's well-being despite the presence of psychiatric problems and independent of the degree of improvement of these problems. This influence may work along at least two ways. First, the effect of psychopathological problems on problems experienced in major areas of functioning may be buffered by feelings of high competence as well as ascertained skills in social interactions with peers and adults. Based on these competencies these children may be more active and effective than other children with similar levels of psychopathology. Alternatively, these children may be positively biased in reporting on their QoL. However, this seems less likely given that the parents reported on social skills.

Remarkably, no parent or family/ social network factors predicted Time 2 PedsQL child report Total score. Apparently, QoL as reported by the child him/ herself, is best predicted by factors proximal to the child. This hypothesis is supported by the fact that not all child factors were reported by the child him/ herself, e.g. social skills was reported by the parent, but still was significant in the final model.

PedsQL parent report

Besides Time 1 QoL score and change in level of psychopathology, Time 2 PedsQL parent report Total score was predicted by the presence of stressful life events before Time 1. Apparently, boys are more sensitive to this influence, since the decrease in QoL with an increase of stressful life events was larger for boys than for girls. Presence of stressful life events has previously been reported as an associate of QoL in studies with a cross-sectional design (Bastiaansen et al., 2005a; Ezpeleta et al., 2000) and as a predictor of change in psychopathology (Mathijssen et al., 1999). The current results show that stressful life-events, like parental divorce or death of a family member, not only influence a child's QoL through their association with child psychopathology but also predict QoL more directly.

In contrast to our hypothesis and findings in child report on QoL, no personal or environmental sources of support, like good social skills or support from significant others, predicted Time 2 PedsQL parent report Total score. This is especially remarkably since previous studies (Bastiaansen et al., 2005a; Ezpeleta et al., 2000) reported child factors as important associates of QoL in children with psychiatric problems. It might be possible that the effect on change in QoL of other factors, like stressful life-events, is larger than the effect of child factors.

As in child report on QoL, parent factors also did not predict Time 2 PedsQL parent report Total score. Parent factors also were not associated with QoL in cross-sectional studies that identified factors associated with QoL in children with psychiatric problems (Bastiaansen et al., 2005a; Ezpeleta et al., 2000). So, from these findings it might be concluded that to improve children's QoL, to focus treatment on parent factors as such seems less important than to focus on other factors.

Limitations

This study is not without limitations. A first possible limitation might be the duration of the follow-up period. Children were followed-up across a one-year period. It might be possible that this period is too short to detect clinically significant change in level of QoL and also to identify predictors of QoL across a follow-up period. Longer follow-up periods may be needed to evaluate the potential effect of psychiatric treatment on the course of QoL for those who have been treated as well as the influence of other factors that only becomes visible after some time.

Secondly, since the nature of the present study was explorative, and treatment was unstandardized, our study gives no insight in the effects of treatment and the generalizability of the current findings across other treatment settings is hampered. Future studies might address the influence of treatment as well as of its interaction with child, family, and environmental factors on change in child QoL.

Conclusion

The present study assessed predictors of QoL across time in children with psychiatric problems, using information about different domains of functioning and from multiple informants. Change in psychopathology was clearly related to improvement in both child- and parent-rated QoL. Therefore, reduction of psychopathology seems to remain crucial to improve children's well-being. It was shown that, besides psychopathology, other factors

have their own specific contribution to future QoL. Early identification of these factors may assist in the development of early intervention of poor QoL in clinical practice. Mental health professionals must be able to intervene and follow up with children who are at high risk of poor QoL in order to provide them with adequate services and prevent the development of additional problems.

7 | **General discussion**

Chapter 7

General discussion

In the present study several aspects of quality of life (QoL) of children and adolescents with psychiatric problems were investigated. In contrast to previous studies (Graham et al., 1997; Landgraf et al., 1996; Landgraf et al., 2002; Sawyer et al., 2002), we were not only able to study all most prevalent psychiatric disorders in a large group of children (N=310) with a broad age distribution (6-18 years), but also to obtain information from multiple informants (child, parent, clinician, and teacher).

So far, it has hardly been studied to which degree children with psychiatric disorders are disabled in their everyday functioning. Besides, it was mainly unknown whether children with psychiatric disorders are equally disabled as children with chronic physical diseases. The latter is not only important for clinicians who work with these children, but also for policy makers and the distribution of resources for research and improvement of quality of care.

In the present study it was first investigated whether it is possible to measure QoL in children with psychiatric disorders. Subsequently, QoL of children with psychiatric disorders was compared to QoL of children with physical diseases. In addition, we compared the QoL of children with different psychiatric disorders, studied the association between psychopathology and QoL across time, and investigated factors that are possibly associated with QoL. In the current chapter the main findings and conclusions of the study will be presented and discussed.

Assessment of quality of life

In the present study we used the Pediatric Quality of Life Inventory version 4.0 (PedsQL; Varni et al., 2001) to assess the child's overall QoL. The psychometric properties of the PedsQL child self-report and parent proxy-report versions for ages 5-7, 8-12, and 13-18 years were studied, and the reliability and validity of the different versions of the PedsQL appeared to be satisfactory. Advantages of the PedsQL are its relatively short completion time and the existence of parallel versions for child and parent informants and different age groups, which makes results of different informants and children of different ages comparable.

However, it was also concluded that the use of the PedsQL in younger children (ages 6-7) with psychiatric problems requires further research, because of low internal consistency

reliability and a poorer factor structure in PedsQL child self-report. The use of self-report measures in children aged 4-8 years is an ongoing discussion in both the QoL (Eiser et al., 2000) and psychiatric literature (Harter, 1985a). However, as was discussed in the introduction of this thesis, the patient's personal evaluation of his/ her life is a very important aspect of QoL and in this context it is necessary to continue the development of possibilities to obtain information from young children themselves too and not only from their parents.

Despite the good psychometric properties of the PedsQL, the risk of measurement redundancy between the PedsQL as a QoL instrument and psychopathology measures, as was already discussed in Chapter 1 of this thesis, still exists. To prevent measurement redundancy in the current study, the instructions of the PedsQL asked the respondent to indicate how much of a problem an item had been for the child in the previous month. By formulating the instructions in this way, the informant was not asked to rate the presence of a certain behavior, but, if present, the impact of the problem on the child's everyday functioning. However, as expected, the results of the analysis on the convergent validity of the PedsQL in Chapter 2 showed that PedsQL scales and scales of psychopathology measures were correlated. The sizes of these correlations were small to medium according to Cohen's criteria (Cohen, 1988), which showed that the constructs of QoL and psychopathology indeed are correlated, but that the overlap is not so strong that both constructs should be regarded as similar. Further evidence for the possibility to distinguish and separate QoL from the psychopathology construct was provided by the analyses in Chapter 5. In this chapter changes in psychopathology were not always associated with changes in QoL and vice versa. Our finding that it is possible to distinguish and separate changes in level of QoL and changes in level of psychopathology across time suggests that child QoL and child psychopathology are sufficiently different to regard them as different constructs.

The results of the present study also showed that it is necessary to use multiple informants to assess QoL in children with psychiatric disorders, as has also been suggested by others (Sainfort et al., 1996; Wallander et al., 2001). Agreement between children and parents and clinicians and parents was moderate, whereas the agreement between children and clinicians was small. Likewise, factors that were associated with QoL also differed between children, parents, and clinicians. Factors associated with QoL ratings of parents and clinicians seemed to mainly concern observable factors, like social skills, while factors correlated with the child's QoL judgement seemed to mainly represent aspects of the inner world of the child, like self-esteem.

In sum, the present study showed the possibility of reliable measurement of QoL in children and adolescents with psychiatric disorders and the validity of the use of the QoL concept in the context of psychopathology. Furthermore, the data showed that it is advisable to use multiple informants in the assessment of QoL in children with psychiatric disorders.

Impact of child psychiatric disorders on quality of life

One of the goals of the present study was to assess the impact of the most prevalent child psychiatric diagnoses on QoL. Children were grouped into six diagnostic categories: (1) Attention Deficit and Disruptive Behavior Disorders, (2) Anxiety Disorders, (3) Mood Disorders, (4) Pervasive Developmental Disorders, (5) Other Disorders, and (6) No Diagnosis. The latter category was included to represent children with obvious behavioral and emotional problems –otherwise they would not have been referred for child psychiatric services- whose symptoms did not fulfill the criteria for a formal DSM-IV diagnosis.

In Chapter 2, a comparison was made between the QoL of children with psychiatric problems and the QoL of healthy children. It was found that children who had been referred for psychiatric problems had a poorer QoL than healthy children. Besides, children with psychiatric problems experienced an equally or sometimes even poorer QoL than children with chronic physical health conditions, like cancer or rheumatic diseases. From these results it can not only be concluded that the impact of a psychiatric disorder on a child's everyday functioning is large, but also that child psychiatric disorders are equally disabling as physical diseases. This latter finding is quite remarkable and probably a surprising finding for clinicians who work with these children. It does not only show the importance of identifying and diagnosing child psychiatric problems, but also the great need of adequate treatment. Policymakers should realize which impact child psychiatric disorders have on QoL when choices regarding funding policies are made. Besides, the current findings stress the importance of research in child psychiatry, not only because of the large impact of a psychiatric disorder on a child's life, but also because of the persistence of psychopathology from childhood into adulthood (Heijmens Visser et al., 2003; Hofstra et al., 2000).

In Chapter 3, children and parents reported no differences in overall QoL between children with different psychiatric disorders. Clinicians however, rated children with pervasive developmental disorders as having a poorer QoL than children with other diagnoses. The level of QoL of children in the other five diagnostic categories, as rated by clinicians, was approximately equal. It can be concluded that the presence of a psychiatric

disorder itself is enough to diminish a child's QoL and that the exact type of disorder is less important.

It is remarkable that children with anxiety disorders had an equally poor overall QoL as children with other disorders, especially since clinicians often seem to consider anxiety disorders as less severe than other child psychiatric disorders. Also, externalizing behavior disorders get much more media attention than other psychiatric disorders, and in scientific databases like Pubmed, studies with children with ADHD are in the majority when compared to studies with children with anxiety disorders. However, it seems that anxiety disorders deserve as much attention from clinicians and researchers as other psychiatric disorders.

Another interesting category of children is the group without a psychiatric diagnosis. These children were referred to mental health care because of emotional or behavioral problems, but no DSM-IV diagnosis could be assigned. From the perspective of the DSM-IV taxonomy, one could argue that this is a group of children with less severe problems than children with a clear psychiatric diagnosis. However, this is unlikely because in QoL ratings of all informants the QoL of children without a DSM-IV diagnosis was equal to the QoL of children who did meet the criteria for a DSM-IV diagnosis. Furthermore, children without a psychiatric diagnosis at Time 1 had an equal prognosis as children in other diagnostic categories (Chapter 5) since the presence of a DSM-IV diagnosis did not differentiate in the prediction of the course of QoL over time. Apparently, children referred for psychiatric services who do not fully meet the criteria of a specific DSM-IV diagnosis need adequate treatment as much as children with a DSM-IV diagnosis, because their prognosis is equally poor. In current clinical practice this group of children is a difficult one, because no specific treatment programs, aimed at and developed for specific symptomatology, like anxiety, can be provided. However, the present results show that further studies are needed to develop taxonomic systems in a way that these children are also addressed, because they also deserve adequate treatment.

The course of quality of life across time

Another aim of the present study was to determine the course of QoL across time in children with psychiatric problems. The relation between change in psychopathology and change in QoL was studied in children with high levels of psychopathology scores at Time 1. It was found that one third of the children showed neither psychiatric symptom reduction nor QoL improvement and one third of the children showed both a clinically significant psychiatric

symptom reduction and QoL improvement. The other children showed either psychiatric symptom reduction or QoL improvement. The relatively large number of children with no improvement of psychopathology and QoL over time stresses the importance of adequate psychiatric treatment aimed at symptom reduction. Besides, it also stresses the need to address QoL in child psychiatric treatment. The results showed that it is possible to improve QoL in children with psychiatric problems and that this is possible either with or without simultaneous reduction of psychopathology. It can be concluded that treatment of psychiatric symptoms may result in improvement of QoL in children with psychiatric problems, but that this is not always the case, and that QoL even may improve without psychiatric symptom reduction. For clinical practice it can be useful to develop screening procedures to enable clinicians to identify children in which QoL is likely to improve by treatment of psychiatric symptoms only and who will therefore not need additional treatment aimed at QoL. It is equally important to identify those children in which additional attention should be paid to QoL, either because treatment of psychiatric symptoms only will be not be enough to improve the child's QoL or because psychopathology, and as a consequence also QoL, probably will not improve.

The analyses of the course of QoL across time also showed that a poor outcome of persistently high psychopathology scores and poor QoL was not predicted by age, gender, or psychiatric diagnosis. This is remarkable because it can be expected that some psychiatric disorders diagnosed at childhood are more persistent than others, e.g. pervasive developmental disorders versus anxiety disorders. However, the results of the present study also showed that few differences existed in QoL between children with different psychiatric disorders and it is possible that the kind of psychiatric diagnosis may also not be the most important predictor of the course of a child's QoL.

Factors associated with or predictive of quality of life

To address the issue raised above, i.e. the identification of children at risk for QoL problems, another important aim of the present study was to identify factors that, besides child psychopathology, influence a child's QoL and the course of QoL. To identify such factors the Bronfenbrenner model was employed (Bronfenbrenner, 1979). This model was used to study factors that, besides psychopathology, were associated with QoL (Chapter 4) and factors that were predictive of change in QoL (Chapter 6 of this thesis). The Bronfenbrenner model was used to group factors into child, parent, and family/ social network clusters. It appeared that

some factors were only associated with QoL in cross-sectional measurements and did not predict the course of QoL, while others were both associated with QoL and predicted its course.

As could be expected, child psychopathology both was associated with level of QoL and was an important predictor of QoL. Therefore, reduction of psychopathology seems to remain crucial to improve the well-being of children with psychiatric problems. However, not all variance in statistical models was explained by level of child psychopathology, but other factors at different levels of the Bronfenbrenner model contributed independently to the models as well. Some child and family/ social network factors both were associated with QoL and predicted its course, while parent factors only were associated with QoL and did not predict its course. Apparently, parent factors have a negative effect on QoL, but this effect is not persistent across time.

Of the child factors that were studied, presence of a chronic physical disease, level of self-esteem, and level of social skills were all concurrently and predictively associated with QoL. Of the family/ social network factors that were studied, presence of stressful life events was both associated with and predictive of QoL.

In conclusion, the present findings showed that factors at the parent level of the Bronfenbrenner model seem to be not very important factors of influence on QoL of children with psychiatric problems. On the other hand, child and family/ social network factors both appeared to have a sizeable influence on QoL and this finding suggests that to improve children's QoL, child and family/ social network factors should, besides child psychopathology, be addressed in treatment programs.

Strengths and limitations of the study

The present study encompasses a large clinical sample (N=310) of children with psychiatric problems with a broad age distribution (6-18 years). The overall response was 73.1% and several aspects of QoL were studied twice across a one-year interval. Information was obtained from multiple informants (child, parent, clinician, and teacher) and all most prevalent psychiatric disorders were studied.

Besides these advantages, the study had some limitations. The instruments to measure QoL were different for children and parents (PedsQL) versus clinicians (CAFAS). Although the PedsQL and the CAFAS measure approximately the same constructs, their items and scales differ. Therefore, findings based on information on QoL from children, parents and

clinicians, respectively, may not be optimally comparable. Another limitation may be that the sample is a clinical sample. This is a strength, because findings can be easily applied to clinical practice, but also a weakness, because the sample may represent those with the most serious impairments and may not be representative of children with psychiatric disorders in general. The duration of the follow-up period may be a third limitation. It might be possible that the one-year follow-up period is too short to detect clinically significant change in level of QoL in some of the children –no standards of clinically significant change in QoL are available- and in this way to identify relevant predictors of QoL. The last limitation might be the lack of the incorporation of treatment into the analyses on factors that might predict change in QoL across time. This implicates that this study does not provide insight in the effects of treatment, and that the generalizability of the current findings across other treatment settings is hampered.

Clinical and research implications

The present study provides several important clinical and research implications:

1. The present study shows that it is possible to separately measure QoL and psychopathology in children with psychiatric problems.
2. The measurement in clinical practice of QoL in children with psychiatric problems in addition to the assessment of psychiatric symptoms is recommended, because the results of the present study show that QoL of children with psychiatric problems is impaired, both compared to healthy children and compared to chronic physically ill children.
3. Young children seem to be able to rate their QoL, but further research is needed to evaluate the validity of self-ratings of young children. However, since a child's personal evaluation is an important aspect of QoL, it can be argued that despite the uncertain validity of these ratings it is advisable to incorporate self-ratings of young children in QoL studies.
4. Multiple informants are needed for valid QoL assessments in children with psychiatric problems. This is recommended because in the present study findings on QoL and factors associated with or predictive of QoL were different between children, parents, and clinicians. Measured by the significant associations obtained, parents and clinicians appeared to be better informants on factors concerning observable characteristics of the child, while children themselves appeared to be better informants on factors representing the child's inner world.

5. To improve children's QoL, child and family/ social network factors should, besides child psychopathology, be an important additional focus of treatment programs. Treatment should especially focus on enhancing self-esteem and social skills, and on improving family functioning and strengthening social support. Additionally, co-morbid chronic physical diseases should be treated adequately and stressful life events should be prevented.
6. Treatment of psychiatric symptoms may improve QoL in children with psychiatric problems, but this is not always the case, and QoL even may improve without psychiatric symptom reduction. So, future research should be aimed at the development of screening procedures to identify children in which QoL is likely to improve by treatment of psychiatric symptoms only and who will therefore need no additional treatment aimed at QoL, and to identify those children in which additional attention should be paid to QoL.

Future research

Although the present study addressed important aspects of QoL of children with psychiatric problems, it was a first, explorative study. Several aspects of the QoL of children with psychiatric problems should be studied in the future. Especially, the long term course of QoL should be studied and a longer follow-up period should be used than the current follow-up period of one year. Besides, QoL should be measured at least three times with equal intervals between measurements to be able to more optimally study the change in level of QoL across time. As was discussed before, in these studies information on QoL and other factors should be obtained from multiple informants. Apart from these methodological issues, future foci of QoL studies might be to study the effect on QoL of different treatment modules, e.g. the use of medication versus cognitive therapy. In addition, to get a more in-depth insight into the relation between QoL and child psychopathology, studies might address the mechanisms underlying QoL improvement without obvious change in psychopathology, and vice-versa. QoL in children with psychiatric problems is a topic that has just started to be addressed seriously, and that, as this study clearly shows, deserves further attention from clinicians and researchers alike.

Conclusion

The present study showed that it is possible to measure QoL in children with psychiatric problems and that QoL of these children is impaired not only compared to healthy children, but also compared to physically ill children. Since few differences were found in overall QoL between children with different psychiatric disorders, it might be concluded that the level of QoL is more influenced by the presence of a psychiatric disorder in itself than the type of psychiatric disorder. Across time, QoL of many children did not improve, which stresses the importance of the implementation of QoL assessment and treatment in clinical practice. Factors were revealed that, besides child psychopathology, should be an important additional focus of treatment programs.



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Summary

Summary

The objective of the study described in this thesis was to examine several aspects of quality of life (QoL) of children with psychiatric disorders. In **Chapter 1**, the background and the main aims were presented. Because treatment effects for severe and chronic diseases have been improved in the last decades, QoL emerged as an important outcome measure. For the present thesis, a longitudinal study with two assessments across a one-year follow-up period was conducted among 310 children and adolescents (aged 6-18 years) who had been referred to outpatient mental health agencies. Besides, a community sample of 74 children without psychiatric problems was included. The aims of this study were: (1) to assess the usefulness of the Pediatric Quality of Life Inventory (PedsQL) as an instrument measuring QoL in children with psychiatric problems, (2) to compare QoL of children with psychiatric problems to QoL of children from the general population without psychiatric problems, (3) to compare QoL of children with different psychiatric disorders, (4) to identify factors that are associated with QoL, (5) to determine the course of QoL, and (6) to identify predictors of change in QoL across time.

In **Chapter 2**, the psychometric properties of the Dutch translation of the PedsQL were assessed. Besides, QoL of children with psychiatric problems was compared to QoL of children with chronic physical diseases and healthy children. The reliability and validity of the PedsQL were satisfactory, but need further elaboration in children aged 6-7 years. Children with psychiatric problems had a considerably lower overall QoL score than healthy children and an equal or on some areas an even lower overall QoL score compared to children with chronic physical disorders. It was concluded that the PedsQL is a useful instrument in measuring QoL in children with psychiatric problems and that having a psychiatric disorder has similar effects on children as having a physical disorder.

In **Chapter 3**, QoL of children with different psychiatric disorders was compared. Six diagnostic categories were studied: Attention-Deficit and Disruptive Behavior Disorders, Anxiety Disorders, Pervasive Developmental Disorders, Mood Disorders, Other Disorders, and No Diagnosis. No differences in overall QoL were found between the diagnostic categories, except in clinicians' ratings, that indicated lower QoL in children with Pervasive Developmental Disorder versus children with other diagnoses. Furthermore, scores for specific QoL subdomains differed per diagnostic category. Children with Attention-Deficit or Disruptive Behavior Disorder had lower scores for school functioning and social functioning.

Children with Anxiety Disorder or Mood Disorder obtained lower scores for emotional functioning, while children with Pervasive Developmental Disorder had lowest scores on social functioning. Since only subtle differences in QoL were found between children with different child psychiatric disorders, it was concluded that QoL is probably influenced more by the presence of a psychiatric disorder in itself, than by the type of psychiatric disorder. Besides, it was concluded that factors other than the psychiatric diagnosis may influence QoL of children with psychiatric disorders.

In **Chapter 4**, child, parent, and family/ social network factors were assessed that, besides child psychopathology, were expected to be associated with QoL in children with psychiatric problems. Poor child, parent, and clinician reported QoL was associated with child psychopathology, but, given the presence of psychopathology, also with child factors, such as low self-esteem, and poor social skills, and family/ social network factors, such as poor family functioning, and poor social support. The importance of parent factors, such as parenting stress, was almost negligible. It was concluded that to improve children's QoL, child and family/ social network factors should, besides child psychopathology, be an important additional focus of treatment programs.

In **Chapter 5**, the 1-year course of QoL across time and its relation with change in psychopathology in children with psychiatric problems was determined. The relation between change in psychopathology and change in QoL was studied in children with high levels of psychopathology scores at Time 1. One third of the children showed neither psychiatric symptom reduction nor QoL improvement and one third of the children showed both a clinically significant psychiatric symptom reduction and QoL improvement. The other children showed either psychiatric symptom reduction or QoL improvement. Age, gender, or psychiatric diagnosis did not predict a poor outcome of persistently high psychopathology scores and poor QoL. These results implicate that QoL in children with psychiatric problems may be improved by reducing psychiatric symptoms in a number of children, but that it is also possible to improve QoL without psychiatric symptom reduction.

In **Chapter 6**, child, parent, and family/ social network factors were identified that predicted QoL across a 1-year period, over and above potential improvements in QoL related to a decrease in psychopathology, in children with psychiatric problems. Time 1 QoL score and change in level of psychopathology from Time 1 to Time 2 were important predictors of children's Time 2 QoL score. In addition, Time 2 QoL score was also predicted by the presence at Time 1 of a chronic physical disease, low self-esteem, poor social skills, and stressful life events. It was concluded that reduction of psychopathology remains crucial to

improve children's well-being, but that clinicians should also be aware of other factors that contribute to a child's QoL.

In **Chapter 7**, the main findings and conclusions of this thesis were discussed. The present study showed that it is possible to obtain reliable and valid measures of QoL in children and adolescents with psychiatric disorders and the validity of the use of the QoL concept in the context of psychopathology. The finding of a large impact of a psychiatric disorder on a child's everyday functioning showed the importance of tracing and diagnosing child psychiatric problems and the great need of adequate treatment. Besides, it stressed the importance of research in child psychiatry and has implications for the distribution of funding across health care by governmental agencies. Since few differences were found in overall QoL between children with different psychiatric disorders, it might be concluded that the level of QoL is influenced by the mere presence of a psychiatric disorder, independently of the type of psychiatric disorder. Across time, QoL of many children did not improve, which stressed the importance of the implementation of assessment and treatment of QoL in clinical practice. Finally, the present study revealed that, to improve children's QoL, child and family/social network factors should be addressed in the treatment provided, besides child psychopathology itself.

Samenvatting

Samenvatting

De hoofddoelstelling van het in dit proefschrift beschreven onderzoek was het bestuderen van een aantal aspecten van de Kwaliteit van Leven (KvL) van kinderen met psychiatrische aandoeningen. In **hoofdstuk 1**, werden de achtergrond en de belangrijkste doelen van het onderzoek geschetst. KvL is voor behandeling en onderzoek een belangrijke uitkomstmaat geworden, aangezien de behandelresultaten voor ernstige en chronische ziekten verbeterd zijn in de afgelopen decennia. In het huidige onderzoek werd een groep van 310 kinderen en adolescenten in de leeftijd van 6-18 jaar, die verwezen waren naar poliklinieken kinder- en jeugdpsychiatrie, gedurende een jaar vervolgd. Daarnaast werd een groep onderzocht van 74 kinderen zonder psychiatrische problematiek van eveneens 6-18 jaar. De doelen van het onderzoek waren: (1) het vaststellen van de bruikbaarheid van de Pediatric Quality of Life Inventory (PedsQL) als vragenlijst om de KvL van kinderen met psychiatrische problemen te meten, (2) het vergelijken van de KvL van kinderen met psychiatrische problemen met de KvL van kinderen uit de algemene bevolking zonder psychiatrische problemen, (3) het vergelijken van de KvL van kinderen met verschillende psychiatrische aandoeningen, (4) het vaststellen van factoren die samenhangen met KvL bij kinderen met psychiatrische aandoeningen, (5) het bepalen van het beloop van KvL over de tijd en (6) het onderzoeken van factoren die de verandering van KvL over de tijd heen kunnen voorspellen.

In **hoofdstuk 2**, werden de psychometrische eigenschappen van de Nederlandse vertaling van de PedsQL bestudeerd. Daarnaast werd de KvL van kinderen met psychiatrische aandoeningen vergeleken met de KvL van kinderen met chronische lichamelijke ziekten en gezonde kinderen. De betrouwbaarheid en validiteit van de PedsQL bleken voldoende, uitgezonderd bij kinderen van 6-7 jaar. Kinderen met psychiatrische aandoeningen hadden een beduidend lagere KvL dan gezonde kinderen en een vergelijkbare en op sommige gebieden een zelfs slechtere KvL dan kinderen met chronische lichamelijke aandoeningen. Geconcludeerd werd dat de PedsQL een goed instrument is om KvL te meten bij kinderen met psychiatrische aandoeningen en dat het hebben van een psychiatrische aandoening vergelijkbare effecten heeft op het leven van een kind als een chronische lichamelijke aandoening.

In **hoofdstuk 3**, werd de KvL van kinderen met verschillende psychiatrische aandoeningen vergeleken. Zes categorieën werden bestudeerd: aandachtstekortstoornis en gedragsstoornissen, angststoornissen, pervasieve ontwikkelingsstoornissen, stemmings-

Dankwoord
Curriculum Vitae

Dankwoord

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Curriculum Vitae

Dennis Bastiaansen werd geboren op 15 juni 1975 te Rotterdam. In 1993 behaalde hij het Gymnasium- β -diploma aan de RKSG Sint-Montfort te Rotterdam. In hetzelfde jaar begon hij met de studie Geneeskunde aan de Erasmus Universiteit Rotterdam, waar het doctoraal werd behaald in september 1997. Het afstudeeronderzoek voor dit doctoraal werd gedurende een half jaar uitgevoerd op de afdeling kinder- en jeugdpsychiatrie van het Sophia Kinderziekenhuis te Rotterdam (begeleider Prof. Dr. J.M. Koot). Met dit afstudeeronderzoek won hij in november 1997 de Gerrit-Jan Mulder prijs voor de beste geneeskunde afstudeerscriptie van dat jaar. In december 1999 behaalde hij zijn artsexamen.

Vanaf oktober 1999 tot oktober 2004 was hij aangesteld als assistent geneeskundige in opleiding tot klinisch onderzoeker (AGIKO) kinder- en jeugdpsychiatrie op de afdeling kinder- en jeugdpsychiatrie van het Erasmus MC-Sophia/ Erasmus Universiteit Rotterdam (hoofd: Prof. dr. F.C. Verhulst). Van oktober 1999 tot oktober 2002 was hij fulltime werkzaam als onderzoeker; van oktober 2002 tot oktober 2004 werkte hij halftime als onderzoeker en halftime als arts-assistent geneeskundige in opleiding op de polikliniek kinder- en jeugdpsychiatrie van het Erasmus MC-Sophia. In deze gehele periode werd een onderzoek uitgevoerd naar de kwaliteit van leven van kinderen met kinderpsychiatrische aandoeningen (projectleiders Prof. Dr. F.C. Verhulst en Prof. Dr. J.M. Koot), waarvan de resultaten in dit proefschrift beschreven staan.

Sinds oktober 2004 is hij werkzaam als psychiater in opleiding op de afdeling psychiatrie van het Erasmus-MC te Rotterdam (hoofd: Prof. Dr. M.W. Hengeveld).

Hij is getrouwd met Susan Bastiaansen-van Rijen.