

Applying a Developmental Approach to Quality of Life Assessment in Children and Adolescents with Psychological Disorders: Challenges and Guidelines

Abstract

Research on the quality of life (QL) of children/adolescents with psychological disorders has flourished over the last few decades. Given the developmental challenges of QL measurements in pediatric populations, the aim of this study was to ascertain the extent to which a developmental approach to QL assessment has been applied to pedopsychiatric QL research. A systematic literature search was conducted in three electronic databases (PubMed, PsycINFO, SocINDEX) from 1994 to May 2014. Quantitative studies were included if they assessed the self or proxy-reported QL of children/adolescents with a psychological disorder. Data were extracted for study design, participants, QL instruments and informants, and statistical approach to age-related specificities. The systematic review revealed widespread utilization of developmentally appropriate QL instruments but less frequent use of both self and proxy reports and an inconsistent approach to age group specificities. Methodological guidelines are discussed to improve the developmental validity of QL research for children/adolescents with mental disorders.

Keywords: Children and adolescents, Developmental approach, Pedopsychiatry, Patient- and proxy-reported outcomes, Pediatric psychological disorders, Quality of life assessment.

Introduction

In clinical and research settings, the assessment of quality of life (QL) in children and adolescents has progressed more slowly than in adult populations due to a number of conceptual and methodological considerations, such as the inclusion of developmental specificities, the ascertainment of children's cognitive abilities and the selection of respondents (self or proxy sources of information) [1]. These considerations have become particularly prominent for the measurement of QL in children and adolescents with psychological disorders. First, the prevalence of childhood psychiatric disorders may be considerably underestimated [2]; thus, it may receive less attention in clinical research and practice. Second, given the homotypic and heterotypic continuity of psychological disorders from childhood to adolescence [3], the appraisal of common QL markers is particularly warranted to enable comparisons in longitudinal assessments across both developmental periods. Third, cognitive abilities, such as perception, attention and memory, are inherently affected during emotional disturbance states. Hence, there is a distinctive need to adopt multi-respondent designs in QL assessments. This approach has been cited as a central methodological tenet in developmental psychopathology [4]. In fact, when establishing general guidelines for conducting QL assessments in children, the World Health Organization (WHO) stated that the assessments should be age-related or at least developmentally appropriate [5]. Since then, a developmental approach to QL assessment has been reiterated and gradually refined [6-9]. Two core recommendations have been maintained: the first relates to the acknowledgement of specificities and commonalties in the assessment of children's and adolescents' QL, and the second suggests selective or complementary use of self-reports and proxy reports. Given the aforementioned challenges for QL assessment in pediatric patients with psychological disorders, there is renewed interest in examining the extent to which the operationalization of a developmental approach has been successfully applied to QL assessments in this specific pediatric population. Such an examination is likely to identify current research strengths and gaps and provide crucial insight on how to improve the developmental validity of QL assessments in children and adolescents with psychological disorders.

QL has been defined by the WHO as "an individual's perception of their position in life in the context of the cultural and values systems in which they live, and in relation to their goals,

expectations, standards and concerns” [10, p.153]. QL can be seen as a multidimensional construct encompassing a variety of core domains, such as physical health, functional status, emotional well-being, social relationships, and material living conditions [11]. Despite the fact that research on the QL of pedopsychiatric patients is still in its infancy [12], available evidence indicates that children and adolescents with psychological disorders not only have more impaired QL than their peers from the general population but also that their QL is comparable to or even poorer than pediatric patients with physical conditions [13-14].

Psychological (or mental) disorders are defined as a “clinically recognizable set of symptoms or behaviors associated in most cases with distress and interference with personal functions” [15, p.11]. Although these disorders tend to be underdiagnosed in younger populations, most of them typically begin during youth, and they account for a large proportion of the disease burden in children and adolescents worldwide [16]. Moreover, inadequate appreciation of the interplay between mental disorders and other health conditions has motivated the WHO’s claim that there can be “no health without mental health” [17, p.859]. Nevertheless, although the aims of treatment for psychological disorders are to reduce symptoms, increase functionality, and improve well-being for the child/adolescent and his/her close relationships, the measurement of health outcomes in this context is often limited to monitoring symptom reduction. This measurement often neglects a more comprehensive assessment of children/adolescents’ health, which should encompass broad, positive and multidimensional outcomes, such as QL [18]. In fact, psychiatric symptom reduction and QL improvement are distinct dimensions of treatment for child/adolescent psychopathology because the latter may be achieved without necessarily implying the former [19]. That is, interventions that target psychiatric symptom reduction but overlook other factors related to pediatric QL may result in poor treatment outcomes [20]. Therefore, QL improvement should be assumed as a major goal of psychotherapeutic and psychiatric interventions in pediatric settings [21], encouraging greater sensitivity to patients’ well-being and extending the outcome measures from mere psychopathology to the more overarching construct of QL [12].

In recent decades, QL has emerged as a primary health outcome in pediatric research and clinical practice as a means of facilitating patient-physician communication, improving patient and

parent satisfaction, identifying hidden morbidities, and assisting in clinical decision making [22]. QL assessment in pedopsychiatric settings is not necessarily aimed at identifying causes of patients' mental disorders but instead focuses on children's and adolescents' broader functioning and the interference of disorders in their daily lives [14]. Generally, QL measurements can expand our knowledge of the impact of particular psychological disorders and can improve clinical and public healthcare services by integrating patients' perspectives into treatment plans and allocating resources according to the degree and complexity of QL impairments implied by different disorders [23]. Additionally, QL assessment may assume distinct relevance for the assessment and treatment of children and adolescents suffering from psychological disorders in several ways. First, it provides an overall assessment of functioning across multiple domains, thereby facilitating the adaptation of programs of care to the child's development and therapeutic progress. Second, it encourages children and adolescents to express their feelings regarding their own well-being and satisfaction with life to promote their autonomy and participation. Third, bearing in mind that symptom reduction does not necessarily mean improved day-to-day functioning, QL assessment broadens the scope of treatment progress monitoring in terms of patients' acquisition of new cognitive or social skills over a period of time and serves as an indicator of the impact of specific interventions on the child's or adolescent's environment [11, 24].

The core assumption of a developmental approach to QL assessment is that adult measures are inadequate for use in children and adolescents because of the level of abstraction required for decision making, the lack of developmental considerations, and the inclusion of areas that may be irrelevant or the exclusion of areas that may be important [8]. Moreover, school-aged children and adolescents have different cognitive abilities and face distinctive developmental tasks and challenges [7]. Therefore, an instrument is generally considered "developmentally appropriate" if the content of physical, psychological and social QL domains is related to the developmental contexts of children and adolescents and if its wording and format are adequate for children's and adolescents' language and cognitive skills [6]. Two methodological considerations have been consistently reiterated within a developmental approach to pediatric QL assessment: first, school-aged children and adolescents, despite experiencing age-specific tasks and contexts, share similar dimensions of the

operationalization of their QL; second, self-reports and proxy reports may be assumed to be complementary, rather than mutually exclusive, sources of information [6-7, 9].

Although the most general domains of physical, psychological and social QL are developmentally universal, certain aspects of their content are age specific, such as the importance of play for children or dating for adolescents [25]. Nevertheless, the focus on age-universal QL markers, though likely to miss age-specific information, enables the comparison of information across childhood and adolescence [9], which is crucial for comparing or longitudinally examining pediatric health outcomes. In fact, one way to endorse a developmental approach in these situations is to approach age-group effects in statistical analyses [7] because it may be imprecise to study pediatric QL data covering wide age ranges without stratifying the results by age group [26]. For pedopsychiatric conditions, Dey and her colleagues [23] noted that children should be studied separately from adults because of age-specific issues for the former group, such as the distinctive progression of their physical and psychosocial development, their greater dependence upon adults, and different rates and clinical manifestations of mental disorders. A developmental approach to QL assessment asserts the same recommendation for studies involving school-aged children and adolescents to avoid the inaccuracy of assuming the former group to be “small adolescents” or the latter to merely be “grown up children” [7]. In fact, it has been suggested that the incorporation of QL assessments in the therapeutic process might increase in importance from childhood to adolescence because psychopathology may persist, and its impact on QL tends to increase with age [12].

Notwithstanding the fact that pediatric QL assessment should be child-centered and should employ self-reports whenever possible [5], some pediatric patients are not able to provide useful information on their QL, such as those who are too young, acutely ill or have severe disabilities. In these situations, the use of a proxy reporter, usually a parent, is the only way to obtain information on patients’ QL [9, 27]. However, although many researchers use proxy ratings to assess QL in children/adolescents with psychological disorders even though it is advisable to employ self-reporting when the patient’s cognitive abilities and particular diagnosis permit [23], the inclusion of multiple informants has also been strongly emphasized for QL assessment in this context. First, parent-child agreement is moderate, suggesting that parents may be better informants of their children’s observable

functioning, whereas children may provide unique information on their own inner experiences [13, 20]. Second, pediatric patients' perspectives may be flawed or distorted by psychopathological symptoms [28]. Third, the utilization of parents as proxy informants is a viable alternative for the assessment of their children's QL when a psychological disorder occurs at earlier ages [23].

To provide evidence-based guidelines for improving the developmental validity and methodological quality of current research trends, the aim of this systematic review was to ascertain the extent to which the aforementioned developmental approach has been applied in studies that conducted QL assessments in children and adolescents with psychological disorders. Accordingly, this review specifically aimed to analyze the consideration of three core methodological guidelines proposed by a developmental approach in studies conducted of the QL assessment of children/adolescents with psychological disorders: the utilization of developmentally appropriate instruments, the examination of age group specificities in school-aged children and adolescents, and the inclusion of self-reports and proxy reports in QL measurement.

Methods

Search Strategy

A systematic search was conducted by two reviewers (blind for review) to identify literature published between 1994 and May 2014 in three electronic databases: PubMed (U.S. National Library of Medicine), PsycINFO (name of host: OvidSP) and SocINDEX (name of host: EBSCOhost). The search strategy was defined by the combination of the following keywords: "quality of life", "mental disorder" or "psychological disorder" or "psychological problems" or "psychiatric disorders", and "child" or "adolescent" or "youth" or "pediatric". The detailed strategy used for searching the PsycINFO database is displayed in Table 1. This search strategy was used in all three databases, with minor modifications to fit the web interfaces. The Medical Subject Headings of the U.S. National Library of Medicine (MeSH terms) were used in the PubMed search.

[Insert_Table_1]

Study Selection and Eligibility Criteria

The selection of studies was conducted in two stages. Initially, the titles and abstracts of all retrieved records were screened to identify potentially relevant articles and to decide whether to

obtain full texts. Subsequently, the selected full texts were assessed for eligibility by two reviewers (N. Silva and H. Moreira). Eligibility criteria were defined for types of studies, types of participants, and types of outcome measures [29].

Types of studies. Only empirical quantitative studies that were published in peer-reviewed journals between 1994 and May 2014 and that were written in the English language were considered. Duplicate or secondary publications on the same sample were excluded to avoid multiple-publication bias.

Types of participants. Studies were included if they assessed a sample of children/adolescents who were between 0 and 18 years of age with a clinical diagnosis of a mental disorder according to the Diagnostic and Statistical Manual of Mental Disorders (DSM) or the International Classification of Diseases (ICD) and who had no comorbidities with chronic physical conditions.

Types of outcome measures. The primary outcome for this systematic review was children/adolescents' self- or proxy-reported QL, conceptualized as a broad-ranging multidimensional construct covering the physical, psychological and social domains [9, 10]. To assess pediatric QL, both generic and disease-specific instruments were considered as long as they covered the core domains of QL, not only the child's health status.

Full texts were excluded for the following reasons: (1) type of paper (e.g., letters to editors, reviews, etc.); (2) study design (e.g., qualitative research); (3) publication date prior to 1994; (4) absence of a sample of patients diagnosed with a mental disorder according to the DSM or ICD; (5) presence of comorbidities with chronic physical conditions; (6) inclusion of patients older than 19 years of age in the sample and no data reported for different age groups; (7) no data on pediatric QL as defined by the WHOQOL group; (8) inconsistent or insufficient information; and (9) duplicate publication.

Data Extraction

Following the Data Extraction Template for Cochrane Reviews [30] as a guide, two reviewers (N. Silva and H. Moreira) extracted the following information for each included study: (1) publication information, including authors and year of publication; (2) methods, including study design, methods

and settings for the recruitment of participants, and inclusion/exclusion criteria for participation in the study; (3) participants, including sample size, country of origin, age (range, mean and standard deviation), and clinical characteristics (diagnosis and comorbidities with other health conditions); (4) outcomes, including methods and instruments used for assessing pediatric QL; and (5) statistical approach to age-related specificities. For studies reporting sociodemographic data separately for subgroups of participants (e.g., males and females or different diagnoses), data were combined into a single sample size, mean value and standard deviation [31]. Disagreements between the two reviewers were resolved by discussion to reach consensus.

Results

Description of Studies

Figure 1 presents the flow diagram summarizing the study selection process. The search identified 4438 articles containing the relevant terms. After removing the duplicates ($n = 148$), 4290 articles were screened. Of these, 4085 (95%) were excluded based on titles and abstracts. The remaining 205 (5%) articles were examined, and only those that met the inclusion criteria were included in the systematic review ($n = 66$). Therefore, 139 articles were excluded based on the following exclusion criteria: the type of paper was not an empirical quantitative study ($n = 4$); the study design was not quantitative ($n = 5$); patients were not diagnosed with a mental disorder according to the DSM or the ICD ($n = 29$); the sample included patients with a comorbid chronic physical condition ($n = 4$); the sample included patients older than 19 years old, and no data were reported for different age groups ($n = 41$); no data were reported on pediatric QL ($n = 26$); the articles provided inconsistent or insufficient information ($n = 23$); and the same sample was used in more than one study ($n = 7$). The 66 articles meeting the inclusion criteria were reviewed, and the data pertaining to the research questions were extracted (see Figure 1).

[Insert_Figure_1]

As shown in Table 2, studies examining the QL of children with the following diagnoses of mental disorder were included: attention deficit hyperactivity disorder (ADHD; $n = 27$) [18; 32-57]; autism spectrum disorder ($n = 10$) [58-67]; Gilles de la Tourette syndrome or other tic disorder ($n = 6$) [68-73]; bipolar spectrum disorders ($n = 5$) [74-78]; enuresis ($n = 3$) [79-81]; separation anxiety

disorder and anxiety disorders ($n = 3$) [82-84]; eating disorders ($n = 2$) [85-86]; major depressive disorder ($n = 2$) [87-88]; conduct disorder ($n = 1$) [89]; obsessive-compulsive disorder ($n = 1$) [24]; and learning disabilities ($n = 1$) [90]. Five studies included diverse diagnoses of a mental disorder [13-14, 23, 91-92].

The reviewed studies were conducted in several countries, including the US ($n = 26$) [24, 32-33, 37, 43, 45-47, 51, 53, 59-60, 63-64, 67-68, 72-74, 76-78, 86-87, 89, 91]; Germany ($n = 6$) [40, 44, 48, 54, 79, 92]; Switzerland ($n = 3$) [23, 82, 84]; the Netherlands ($n = 4$) [13, 38, 52, 66]; Australia ($n = 3$) [14, 49-50]; Turkey ($n = 3$) [41, 61, 80]; Brazil ($n = 2$) [39, 83]; Spain ($n = 2$) [36, 85]; Italy ($n = 2$) [70, 71]; Taiwan ($n = 2$) [55-56]; Iran ($n = 1$) [42]; UK ($n = 1$) [69]; Norway ($n = 1$) [35]; Hungary ($n = 1$) [88]; France ($n = 1$) [58]; Canada ($n = 1$) [18]; Japan ($n = 1$) [81]; Greece ($n = 1$) [90]; and Mexico ($n = 1$) [57]. Four studies were conducted in two or more countries [34, 62, 65, 75]. Thirty-two studies were cross-sectional [13-14, 18, 23-24, 36, 39, 42, 50-51, 53, 55-56, 59, 61-65, 68-70, 72-74, 79-80, 82, 86, 88, 90-91], and 34 were longitudinal [32-35, 37-38, 40-41, 43-49, 52, 54, 57-58, 60, 66-67, 71, 75-78, 81, 83-85, 87, 89, 92].

[Insert_Table_2]

Assessment Instruments

The majority of studies used age-appropriate instruments to assess children and adolescents' QL ($n = 63$; 95%). Only three (5%) studies used instruments developed to assess QL in adult populations (SF-36 and EuroQoL-5D) [66, 85-86]. Among the studies that used age-appropriate instruments, the majority assessed multiple dimensions of QL ($n = 52$; 83%) [13-14, 18, 23-24, 34-48, 50-51, 53-59, 61-65, 67-72, 74-81, 88, 90-92], nine (14%) studies only used the instruments' total scores or unidimensional scales [32-33, 49, 52, 60, 73, 84, 87, 89], and two (3%) studies did not provide information about the instruments' dimensions used in the study [82-83].

Age Group Analyses

The studies included in the present review were analyzed in relation to their statistical approaches to the variable of pediatric patients' age. Age categories were defined according to the MeSH terms: preschoolers (2-5 years), children (6-12 years), and adolescents (13-18 years). As presented in Figure 2, no study included only preschoolers, 11 (17%) studies included children

exclusively [33, 35-36, 38-39, 52, 57-58, 63, 81, 92] and 4 (6%) studies included adolescents exclusively [37, 71, 75-76]. The majority of studies comprised participants of more than one age group ($n = 51$; 77%) [13-14, 18, 23-24, 32, 34, 40-51, 53-56, 59-62, 64-70, 72-74, 77-80, 82-91]. Of these, 19 (29%) did not report whether and/or how age was statistically treated [23, 41-44, 49, 53, 56, 60, 64, 67, 69, 73, 82, 84-86, 89-90], and 32 (48%) performed some sort of statistical analysis that involved the variable of age [13-14, 18, 24, 32, 34, 40, 45-48, 50-51, 54-55, 59, 61-62, 65-66, 68, 70, 72, 74, 77-80, 83, 87-88, 91].

[Insert_Figure_2]

Considering all studies in the present review (see Figure 3), approximately half of the studies did not report whether and/or how age was statistically treated ($n = 34$; 52%) [23, 33, 35-39, 41-44, 49, 52-53, 56-58, 60, 63-64, 67, 69, 71, 73, 75-76, 81-82, 84-86, 89-90, 92]. The remaining studies analyzed the correlations between age and QL ($n = 4$; 6%) [32, 74, 79-80], performed separate analyses for different age groups ($n = 4$; 6%) [34, 40, 48, 77], compared QL scores between age groups ($n = 6$; 9%) [13, 24, 61-62, 72, 87], introduced age as a covariate in comparison analyses ($n = 8$; 12%) [45, 47, 51, 54, 59, 65, 70, 83], or analyzed age as a predictor in regression analyses ($n = 10$; 15%) [14, 18, 46, 50, 55, 66, 68, 78, 88, 91].

[Insert_Figure_3]

Self versus Proxy Reports

As presented in Figure 4, the QL of children was self-reported in 14 (21%) studies [37, 39, 45, 51, 56-57, 69-71, 80, 83, 85-87] and assessed through parents' proxy reports in 29 (44%) studies [14, 18, 32-33, 36, 43, 46-47, 49-50, 52, 54-55, 58-59, 60-63, 65, 67-68, 74-77, 89, 91-92]. In 23 (35%) studies, self-reports and proxy reports were both used to assess children's QL [13, 23-24, 34-35, 38, 40-42, 44, 48, 53, 64, 66, 72-73, 78-79, 81-82, 84, 88, 90].

[Insert_Figure_4]

Discussion

This review aimed to operationalize a developmental approach to QL assessment in children and adolescents with psychological disorders while systematically examining the extent to which such methodological guidelines were effectively applied in the context of pedopsychiatric QL research.

This review thus represents an original contribution to the delineation of a clear-cut methodological framework that seeks to enhance the developmental appropriateness of QL assessments for children and adolescents suffering from mental disorders by proposing three core operational procedures: the administration of developmentally appropriate instruments; the study of childhood and adolescence as independent, though consecutive, age groups; and the simultaneous utilization of self-reports and proxy reports. Following a selection process of studies conducted over the last twenty years on the QL of children and adolescents with psychological disorders, the systematic review of 66 studies allowed us to obtain a straightforward picture of recent research trends to substantiate the aforementioned developmental approach for this specific pediatric population. First, the large majority of studies adopted developmentally appropriate instruments in their research assessment protocols. Second, nearly one-third of the examined studies did not perform age analyses even though the age range of their participants encompassed more than one age group. Of the remaining half of the studies that performed such analyses, only a modest proportion distinguished between the age groups of school-aged children and/or adolescents. Third, despite the fact that most studies exclusively employed proxy reports (nearly double the amount of those that used self-reports only), approximately one-third of them used self-reports and proxy reports simultaneously. These results generally portray a positive trend in applying a developmental approach to QL measurement in children and adolescents with mental disorders and, most importantly, support the identification of areas for further improvement of this methodological challenge in pedopsychiatric research.

The acknowledgement of developmental specificities in pediatric QL assessment is evident in the utilization of developmentally appropriate instruments by the large majority of the reviewed studies assessing the QL of children and adolescents with mental disorders. Although QL for people across the life span should be conceptualized in terms of similar overall domains (i.e., physical, psychological and social), developmental considerations must be taken into account when selecting the specific aspects to integrate in a QL domain [93]. Given that a number of QL instruments with sound psychometric properties have been developed over recent years and are now available in a variety of languages, it is no longer acceptable to utilize adult QL measures, such as the Medical Outcomes Study (MOS)-SF-36 or the EuroQoL-5D, to conduct these assessments in pediatric

populations. The PedsQL [94], KIDSCREEN [95], and KINDL questionnaires [96] are widespread measures that, in addition to their well-established developmental adequacy and sound psychometric properties, may facilitate cross-cultural pediatric QL studies for pediatric patients with chronic physical conditions [97], which are lacking for pedopsychiatric patients. Nevertheless, it is interesting that in a 1993 paper, the WHO stated that children's QL instruments should "be age-related or at least developmentally appropriate" (p. 3), thus revealing the subtlety of a distinction between age group specificities from common QL markers across childhood and adolescence. It seems crucial to accept that age-specific and common markers are both relevant for pediatric QL assessments in the sense that they allow greater developmental sensitivity paired with the possibility of conducting longitudinal or between-age-group comparisons, respectively. To resolve this apparent dilemma, two recommendations are advanced. One recommendation is to use different age versions of the same instrument [9], as is the case for the three forms of the KINDL questionnaires [96]: KINDL-Kiddy (4-7 years), KINDL-Kid (8-12 years) and KINDL-Kiddo (13-16 years). Another option is to complement QL measurements based on common markers with supplemental assessments that account for the most age-specific aspects [98]. Although the latter suggestion may be fairly easy to implement in clinical practice (by gathering additional information from clinical interviews, for instance), for more formal assessments, such as those required in research, the development of age-specific modules may be pertinent. In fact, although the importance of disease-specific modules has been amply acknowledged in the context of health-related QL assessments for physical conditions [99], the development of age-specific modules for school-aged children and adolescents could represent a practical way of fully endorsing a developmental approach to QL measurement by simultaneously focusing on common QL markers and age-specific aspects across both age groups. Although this has not been the dominant trend in pediatric QL research, the fact that psychopathology tends to persist from childhood into adolescence [3] may motivate the adoption and refinement of this procedure in pedopsychiatric settings, where age-specific abilities, contexts and tasks are decisive for effectively planning and implementing interventions.

Despite the fact that age is likely to be a primary developmental variable that must be considered in pediatric psychosocial research [100], nearly one-third of the studies included in this

review did not analyze the influence of age on QL outcomes and did not present results stratified by age groups. Of the remaining studies that performed specific age analyses (nearly half of the studies reviewed), there was significant variability in the ways this variable was statistically approached, including age as a covariate, correlate or predictor; QL comparisons between age groups; and separate analyses for different age groups. In this context, statistical analyses that differentiate age groups seem preferable for two main reasons. First, they are especially useful to detect differences and similarities in terms of both QL outcomes and QL predictors that could otherwise be masked or overlooked across two subgroups of pediatric patients. Second, the age clustering of school-aged children and adolescents is especially desirable to inform clinical practice because it provides a practical way of conveying knowledge that is not necessarily invariant across subgroups of pedopsychiatric patients. These subgroups pose different challenges and require distinct approaches in a variety of assessment and intervention situations in regular clinical routines. The fact that age was statistically treated as a covariate in some of the studies reviewed, although pertinent to controlling for that specific effect in variance analyses, does not provide insight into the role of age in determining QL outcomes. Likewise, the analysis of age as a correlate or predictor, though useful for examining or even discriminating its effects on QL outcomes, does not facilitate a practical translation of empirical research results into pedopsychiatric clinical practice, where age groups may be used to differentiate screening routines, the allocation of resources and service delivery. In fact, a developmental approach to QL assessment in this context would call for age-group analyses even at the level of psychometric examinations [98], which should be preliminary to any other analysis. This is particularly noteworthy not only because common QL dimensions may encompass different features in the daily life experiences of school-aged children and adolescents (e.g., family relationships, school functioning) [93] but also because the psychometric quality of broadband QL measures may differ across the two age groups [98]. However, the definition of these age groups is not straightforward. Although studies generally endorse the idea that any school-aged child can self-report his or her health [101] and despite evidence of reliable QL self-reports from children five years and older [102], in the context of the present review, it is suggested that school-aged children and adolescents with mental disorders can be clustered within the age groups of 8-12 years and 13-18 years old, respectively, as a harmonized

guideline for research. This guideline is in agreement with the methodological options of previous world-renowned pediatric QL projects, such as KIDSCREEN [103], PedsQL [94] and DISABKIDS [97].

The WHO recommendation of employing subjective self-reports whenever possible in the context of children's QL measurement [5] appears fairly established in the reviewed literature on the QL of children and adolescents with psychological disorders. Slightly more than half of the studies obtained self-reports, and the remaining were exclusively based on proxy reports, usually obtained from parents. However, the simultaneous utilization of self-reports and proxy reports was adopted in only approximately one-third of the studies under review. This complementary use of self-reports and proxy reports is not a minor issue for the operationalization of a developmental approach to pedopsychiatric QL assessment. Although parents' reports and their children's QL reports are valid, they cannot effectively supplant each other [104]. From this perspective, the complexity and costs related to this methodological option are surpassed by a number of advantages and applications. First, although children' and adolescents' perceptions are vital to substantiate patient-centered pediatric healthcare and although these perceptions are inevitably (even if indirectly) targeted in psychological or psychiatric interventions, parents have the primary responsibility in pediatric clinical decision making, which is likely to be strongly influenced by their own perceptions of their child's functioning and well-being. Second, parents who have children with chronic conditions tend to underestimate their children's QL [27]. Hence, an exclusive focus on parents' reports may hinder the implementation of an empowering, strength-based approach to children and adolescents with mental disorders by neglecting their resiliency and their abilities to fulfill their potential [16]. Third, the replication of analyses crossing self- and proxy-reported data on pediatric QL outcomes contributes to improving the clinical validity of the observed results [98, 105]. Fourth, not only does parent-child concordance tend to be moderate in pediatric QL assessments, but, perhaps most importantly, the strength and direction of this (dis)agreement may also be linked to modifiable family factors [106] that can be targeted in the assessments performed and the interventions designed for pedopsychiatric patients. Taking this rationale into account, a developmental approach would argue for the complementary use of self-reports and proxy reports in the QL assessment of children and adolescents

with psychological disorders, which goes beyond the selective use of either source of information.

Despite its relative recency, the QL assessment of children and adolescents with mental disorders has been progressing steadily, as illustrated by the number of studies included in the present review. The challenge in research is now twofold: on the one hand, to improve the quality of research designs by systematically incorporating the aforementioned guidelines for the operationalization of a developmental approach to pedopsychiatric QL assessment; on the other hand, to move from outcome descriptions, which are important to characterize pedopsychiatric populations and their sub-groups, to outcome predictions, which enable the identification of modifiable variables and targeted links to promote the QL of children and adolescents with mental disorders. Some evidence has identified stressful life events, low self-esteem, poor social skills and poor social support as predictors of impaired QL for children and adolescents suffering from psychological disorders [13]. Nevertheless, this work could be expanded through mediation analyses that permit the development of theory from merely descriptive to a more functional understanding of the relationships between variables [107]. Additionally, the examination of mediation models could be strengthened by the assessment of their (in)variance across age groups, the inclusion of multiple informants, and the integration of developmentally appropriate and adequately validated measures. Moreover, for the adequate development and psychometric validation of QoL instruments, statistical methods such as Item Response Theory (IRT) or Rasch Analysis (RA) are currently recommended / should be considered. Moreover, the role of parents in pedopsychiatric QL research may go beyond their inclusion as proxies in obtaining child-related information. Given that pediatric clinical practice is generally expected to work with at least two patients simultaneously, a child and a parent [108], the incorporation of a parent-child dyadic perspective with the simultaneous assessment of parents' and their children's QL [109] could broaden the focus of clinical theory, case formulation and intervention. In fact, many psychotherapeutic interventions targeting children's and adolescents' psychological disorders often imply some degree of parental involvement (e.g., behavior reinforcement schedules, improvement of family routines and communication patterns, mastery and social activity monitoring, reduction of self-criticism). Hence, it is relevant to apply a parent-child perspective to foster family pediatrics in the context of child and adolescent psychopathology and

psychotherapy. Finally, although QL measures have been frequently used to describe disease impact or treatment effects, they may also be assumed to be targets for psychological intervention or mental health promotion [110]. For instance, the term “QL therapy” has been coined to describe a psychotherapeutic model that, instead of diagnosing and targeting psychopathological symptoms, focuses its action on the patient’s QL profile as a means of mapping interventions [111]. Because children and adolescents with mental disorders and their families face daily life problems that go beyond the symptoms that characterize their disorders [14], it makes sense to broaden the focus of pedopsychiatric assessment and intervention to encompass QL measures because an exclusive focus on negative outcomes and dimensions can only provide an incomplete picture [112]. Therefore, the assessment of the QL of children and adolescents with psychological disorders may contribute to the identification of relevant contexts, resources and areas of good functioning that may foster the effectiveness of intervention processes by identifying what is effective and should be used as well as what is ineffective and requires improvement.

Expert commentary:

Despite its relative recency, the measurement of the QL of children and adolescents with psychological disorders has gained increased attention in research. The quality of this research is largely dependent on the endorsement of a developmental approach to QL assessment. This developmental approach may be methodologically operationalized through the administration of developmentally appropriate instruments, the acknowledgement of age group specificities and the inclusion of both self-reports and proxy reports. Although most empirical studies conducted over the last decades have employed developmentally appropriate measures, a significant proportion have not attended to age group specificities and have only included either self-reports or proxy reports on children’s and adolescents’ QL. The incorporation of such guidelines into pedopsychiatric QL research is likely to result in increased methodological complexity as well as greater developmental validity of the observed results and their implications. These best practices in research can systematically inform pedopsychiatric clinical practice by broadening the scope of assessments and interventions and promoting their effectiveness.

Five-year view:

The importance of assessing the QL of children and adolescents with psychological disorders will increase in both research and clinical settings in the coming years. Likewise, the methodological complexity of research designs will increase toward greater developmental sensitivity, and the psychotherapeutic applications of QL assessments will receive renewed interest for improving the spectrum and quality of treatment outcomes in pedopsychiatric settings. Although the utilization of developmentally appropriate measures seems to be rather established in the field, interest in assessing common QL markers across childhood and adolescence paired with the need to complement them with QL aspects that are specifically related to either age group will likely result in greater methodological complexity and greater strength of research designs. It is also expected that greater attention will be directed toward the QL of parents who have children with mental disorders to substantiate a dyadic parent-child perspective that will contribute to the refinement of a developmental approach to pedopsychiatric QL assessment and intervention processes. The field has now reached a stage that requires a research movement from outcome descriptions to outcome predictions. Thus, it will be vital to examine mediation models linking pedopsychiatric QL outcomes with modifiable variables and mechanisms, which can be targeted in interventions aimed at promoting the QL of children and adolescents with psychological disorders.

Key issues:

- School-aged children (8-12 years) and adolescents (13-18 years) pose unique developmental challenges to the assessment of their quality of life (QL).
- Children and adolescents with psychological disorders have significant QL impairments that go beyond their psychopathological symptoms.
- QL measurements should be integrated into pedopsychiatric assessments and intervention processes along with psychopathological measures.
- A developmental approach to QL assessment implies the administration of developmentally appropriate instruments, the acknowledgement of age group specificities and the inclusion of both

self-reports and proxy reports.

- School-aged children and adolescents with psychological disorders share common QL markers, but their age group specificities should not be neglected in QL measurements.
- Self and proxy sources for pedopsychiatric QL assessment should be assumed to be complementary to each other rather than mutually exclusive.
- QL measures broaden the scope of pedopsychiatric assessments and are thus likely to improve the effectiveness of intervention processes.
- QL assessments may facilitate case formulation by mapping individual and contextual aspects that may act as predisposing, precipitating and/or perpetuating factors for child and adolescent psychopathology.
- Developmentally appropriate QL assessments are practical means of empowering children and adolescents with mental disorders as well as their parents by actively involving them in a strength-based approach to psychotherapeutic processes.

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Table 1. Strategy used for searching the PsychINFO electronic database.

Number	Search term	Number of records
1.	*"Quality of Life"/	21711
2.	(child or children or childhood or adolescent or adolescence or youth or teen or pediatric or paediatric).ti.	212242
3.	(child or children or childhood or adolescent or adolescence or youth or teen or pediatric or paediatric).ab.	427418
4.	2 or 3	451382
5.	mental disorder.mp. or exp Mental Disorders/	386242
6.	(psychological problems or psychological disorder or psychiatric disorder or mental disorder).ti.	1683
7.	(psychological problems or psychological disorder or psychiatric disorder or mental disorder).ab.	14276
8.	5 or 6 or 7	390265
9.	1 and 4 and 8	334
10.	limit 9 to (human and yr="1994 -Current")	332

Note: Searches were performed by using OvidSP, in which “.ti.” represents title, “.ab.” represents abstract, “.mp.” represents multipurpose search, “exp” represents explode to include broader terms and related terms, and “yr” represents year of publication.

Table 2. Study design and sample characteristics reported in the studies included in the systematic review.

Study	Sample characteristics				QoL assessment				
	Country	Study design; Period of data collection	Sample size	Age (years) Range; M±SD	Diagnosis	Informant	Instrument	QoL dimensions	Age group analyses
Algorta et al., 2011	USA	Cross-sectional	138	5-18 11.18 ± 3.55	Bipolar spectrum disorder	Proxy	KINDL-R	Physical wellbeing, Emotional wellbeing, Self-esteem, Family, Friends, School	Correlation coefficient between youth's age and QL
Allen et al., 2010	Switzerland	Cross-sectional;	94	7-14 10.18 ± 1.72	Separation anxiety disorder (<i>n</i> =58) and other anxiety disorders (<i>n</i> =36)	Self Proxy	Inventory for the assessment of QL in children and adolescents	NR	NR
Bachmann et al., 2010	Germany	Cross-sectional	88	6-18 9.3 ± 2.5	Enuresis	Self Proxy	PEMQOL-SF DCGM-10	Child impact, Family impact, Total score	Pearson correlation coefficient between age and QL
Baghdadli et al., 2013	France	Longitudinal;	14	8-12 11.1 ± 1.53	Autism spectrum disorder	Proxy	KIDSCREEN -27	Physical wellbeing, Psychological wellbeing, Autonomy and parents, Social support and peers, School environment	NR
Bastiaansen et al., 2004	The Netherlands	Cross-sectional;	243	6-18 10.87 ± 3.1	Six diagnostic categories	Self Proxy	PedsQL 4.0 Generic Core Scales	Physical functioning, Emotional functioning, Social functioning, School	ANOVA by age groups (6-12 vs. 13-18 years);

								functioning, Total summary score	Agreement between informants was examined separately for each age group
Bastiaens, 2008	USA	Longitudinal	84	5-18 11.1 ± 3.3	ADHD	Proxy	HALFS	Total score	Correlations coefficients between age and change in QL scores
Bastiaens, 2011	USA	Longitudinal;	75	6-12 9.0 ± 2.1	ADHD	Proxy	HALFS	Total score	NR
Becker et al., 2011	Multicentric	Longitudinal	721	6-17	ADHD	Self Proxy	KINDL	Physical wellbeing, Emotional wellbeing, Self-esteem, Family, Friends, School	Separate analyses for children aged 6-11 and adolescents aged 12-17 years
Bernard et al., 2009	USA	Cross-sectional	56	5-17 10.46 ± 2.9	Gilles de la Tourette syndrome	Proxy	TACQOL	Physical complains, Motor functioning, Autonomy, Cognitive functioning, Social functioning, Positive emotions, Negative emotions	Regression analyses with age as a predictor of QL scores
Connor et al., 2008	USA	Longitudinal;	19	12-17 14.1 ± 1.6	Conduct disorder	Proxy	PQ-LES-Q	Total score	NR
Cutler et al.,	UK	Cross-	57	8-17	Gilles de la	Self	PedsQL 4.0	Physical functioning,	NR

2009		sectional;		11.4 ± 2.36	Tourette syndrome		Generic Core Scales	Emotional functioning, Social functioning, School functioning, Total summary score	
Cuyppers et al., 2011	Norway	Longitudinal	5	10-11	ADHD	Self Proxy	KINDL-R	Physical wellbeing, Emotional wellbeing, Self-esteem, Family, Friends, School	NR
de Souza et al., 2013	Brazil	Longitudinal;	28	10-13 12 ± 0.77	Anxiety disorders	Self	YQOL-R	NR	Age as covariate in comparison analyses
del Valle et al., 2010	Spain	Longitudinal	22	12-16 14.45 ± 0.96	Restrictive Anorexia Nervosa	Self	SF-36	Physical functioning, Physical role, Pain, General health, Vitality, Social functioning, Emotional role, Mental health, Physical component scale, Mental component scale	NR
Delahaye et al., 2014	USA	Cross-sectional	86	4-12 7.18 ± NR	Autism Spectrum Disorders	Proxy	PedsQL 4.0 Generic Core Scales	Physical summary score, Psychosocial summary score, Total score	Age as covariate in regression analyses
Dey et al., 2012	Switzerland	Cross-sectional	535	9-14 11.39 ± 1.45	Multiple diagnostic categories	Self Proxy	KIDSCREEN -27	Physical wellbeing, Psychological wellbeing, Autonomy and parent relations, Social support and peers, School environment	NR

Eddy et al., 2011	Italy	Cross-sectional	50	11-17 13.26 ± 2.32	Gilles de la Tourette syndrome + comorbid obsessive-compulsive disorder or ADHD	Self	YQOL-R	Self domain, Relationship domain, Environment domain, General domain, Total score	Age as covariate in comparison analyses (ANCOVA)
Endicott et al., 2006	USA	Longitudinal	376	6-17 11.95 ± 3.10	Major depressive disorder	Self	PQ-LES-Q	Total score	QL scores were compared between age groups (6-11, 12-17); Cronbach's alphas and Pearson correlations between measures were computed separately for each age group
Ertan et al., 2009	Turkey	Cross-sectional;	44	6-15 9.9 ± 2.9	Enuresis	Self	KINDL	Physical wellbeing, Emotional wellbeing, Self-esteem, Family, Friends, School, Total score	Correlation coefficient between youth's age and QL (but comparison analysis between enuresis and control)

									groups did not include age)
Escobar et al., 2005	Spain	Cross-sectional;	120	6-12 9.3 ± 2.0	ADHD	Proxy	CHQ	Physical functioning, Role/ social limitations - emotional/behavioral, Role/social limitations -physical, Bodily pain/discomfort, Behavior, Mental health, Self-esteem, General health perceptions, Parent impact - emotional, Parent impact - time, Family activities, Family cohesion, Physical summary score, Psychosocial summary score	NR
Findling et al., 2013	USA	Longitudinal	265	13-17 14.5 ± 1.3	ADHD	Self	YQOL-R	Self, Relationship, Environment, General QOL, Total score	NR
Flapper et al., 2008	The Netherlands	Longitudinal	23	7-10 8.5 ± 0.25	ADHD and Developmental coordination disorder	Self Proxy	DUX-25 TACQOL	Physical, Home, Emotional, Social, Total Score Bodily functioning, Motor functioning, Autonomic functioning, Cognitive functioning, Social functioning, Positive moods, Negative	NR

								moods, Total score	
Freeman et al., 2009	USA	Cross-sectional	529	8-18 12.0 ± 2.6	Bipolar disorder, unipolar disorder, behavioral disorder and other diagnosis	Proxy	KINDL-R	Physical wellbeing, Emotional wellbeing, Self-esteem, Family, Friends, School, Total score	Correlation coefficient between youth's age and QL; Age as covariate in regression analyses (but comparison analysis between diagnostic groups did not include age)
Goulardins et al., 2011	Brazil	Cross-sectional;	14	7-10 9.28 ± 1.13	ADHD	Self	PedsQL 4.0 Generic Core Scales	Emotional functioning, Social functioning, School functioning, Physical health summary score, Psychosocial health summary score, Total score	NR
Görtz-Dorten et al., 2011	Germany 11/2006 – 12/2007	Longitudinal	589 parents 552 patients	6-17	ADHD	Self Proxy	KINDL (KID and KIDDO)	Physical wellbeing, Emotional wellbeing, Self-esteem, Family, Friends, School, Total score	Correlations between QL and other measures were computed separately for parents, children, and adolescents

Gürkan et al., 2010	Turkey	Longitudinal	45	8-14 10.09 ± 1.80	ADHD	Self Proxy	PedsQL Generic Core Scales	Physical summary score, Psychosocial summary score, Total score	NR
Jafari et al., 2010	Iran	Cross-sectional	72	8-18 11.4 ± 2.01	ADHD	Self Proxy	PedsQL 4.0 Generic Core Scales	Emotional functioning, Social functioning, School functioning, Physical health summary score, Psychosocial health summary score, Total score	NR
Jenkins et al., 2014	USA	Cross-sectional;	67	11-18 16.5 ± 2.0	Eating disorders (anorexia nervosa, bulimia nervosa, or eating disorder not otherwise specified)	Self	SF-36	Physical Health Composite Score, Mental Health Composite Score	NR
Kern et al., 2011	USA	Longitudinal	24	3-12 7.8 ± 2.9	Autism spectrum disorder	Proxy	PQ-LES-Q	General activities sub-scale	NR
Kiss et al., 2009	Hungary	Cross-sectional	248	7-14 11.45 ± 2.02	Major depressive disorder	Self Proxy	ILK	School, Family, Peer relations, Alone activities, Physical health, Mental health, Global QL	Regression analyses with age as a predictor of mother-child agreement about child's QL
Klassen et al., 2004	Canada	Cross-sectional;	131	6-17 10.0 ± 2.8	ADHD + comorbid	Proxy	CHQ	Physical functioning, Role/ social	Correlation coefficient

					diagnosis (learning disabilities, oppositional defiant disorder or conduct disorder or other)			limitations - emotional/behavioral, Role/social limitations -physical, Bodily pain/discomfort, Behavior, Mental health, Self-esteem, General health perceptions, Parent impact - emotional, Parent impact - time, Family activities, Family cohesion, Physical summary score, Psychosocial summary score	between youth's age and QL; Regression analyses with age as a predictor of QL scores
Kose et al., 2013	Turkey	Cross-sectional	102	3-18 8.2 ± 3.7	Autism spectrum disorder	Proxy	PedsQL 4.0 Generic Core Scales	Emotional functioning, Social functioning, School functioning, Physical health summary score, Psychosocial health summary score, Total score	QL scores were compared (ANOVA) between age groups (not specified)
Kuhlthau et al., 2010	USA Canada	Cross-sectional;	286	2-17	Autism spectrum disorder	Proxy	PedsQL 4.0 Generic Core Scales	Emotional functioning, Social functioning, School functioning, Physical health summary score, Psychosocial health summary score, Total score	QL scores were compared between age groups (2-4, 5-7, 8-12, ≥13)
Lack et al., 2009	USA	Cross-sectional;	62	8-17 12.56 ± 3.57	Obsessive-compulsive disorder +	Self Proxy	PedsQL 4.0 Generic Core Scales	Emotional functioning, Social functioning, School	QL scores were compared

					comorbid diagnosis (disruptive behavior disorders, generalized anxiety disorder, others)			functioning, Physical health summary score, Psychosocial health summary score, Total score	(ANOVA) between age groups (6-11, 12-17). Pearson correlations computed separately for each age group
Limbers et al., 2011	USA	Cross-sectional	22	6-12 9.25 ± 2.15	Autism spectrum disorder	Proxy	PedsQL 4.0 Generic Core Scales + Cognitive Functioning Scale	Emotional functioning, Social functioning, Psychosocial Health Summary Score, School-Related Cognitive Functioning, Missed School, School Functioning Summary Score, Physical Health Summary Score, Cognitive Functioning	NR
Naitoh et al., 2012	Japan	Longitudinal;	139	Range NR 9.7 ± 2.6	Enuresis	Self Proxy	KINDL	Physical wellbeing, Emotional wellbeing, Self-esteem, Family, Friends, School	NR
Newcorn et al., 2005	USA	Longitudinal	293	8-18 11.14 ± 2.28	ADHD (with oppositional defiant disorder, <i>n</i> = 115)	Proxy	CHQ – Parent form	Role-emotional, Behavior, Mental health, Self-esteem, Parent impact-emotional, Parent impact-time, Family	NR

								activities, Psychosocial Summary Score	
Niederkirchner et al., 2011	Germany	Longitudinal	42	6-18 11.8 ± 3.0	ADHD	Self Proxy	ILK	School performance, Family functioning, Social integration, Interests and hobbies, Physical health, Mental health, Overall HRQL, Burden of disease, Burden of treatments	NR
Olsen et al., 2012	USA and Puerto Rico	Longitudinal;	161	13-17 15.2 ± 1.3	Manic or mixed episode associated with bipolar I disorder	Proxy	CHQ – Parent form	Bodily pain, General health, Physical functioning, Role/social- physical, Family activities, Parent impact- emotional, Mental health, Self-esteem, Behavior, Role/social- emotional/behavioral, Parent impact-time, Family cohesion, Physical Summary, Psychosocial Summary	NR
Patrick et al., 2002	USA	Longitudinal	68	12-18	ADHD	Self	YQOL-R - Perceptual module KINDL	Self, Relationship, Environment, General QL, Total perceptual score Physical wellbeing, Emotional wellbeing, Self-esteem, Family,	Age was included as covariate

								Friends, School	
Perwien et al., 2006	USA	Longitudinal	728	6-17 11.1 ± 2.8	ADHD	Proxy	CHQ – Parent form	Bodily pain, General health, Physical functioning, Role/social- physical, Family activities, Parent impact- emotional, Mental health, Self-esteem, Behavior, Role/social- emotional/behavioral, Parent impact-time, Family cohesion, Physical Summary, Psychosocial Summary	Age as a predictor of long-term changes in QL scores (ANOVA models)
Rademacher et al., 2007	USA	Longitudinal	23	15.0 ± 1.1	Manic or mixed episode associated with bipolar I disorder	Proxy	CHQ – Parent form	Behavior, Bodily Pain, Change in Health, Family Activities, Family Cohesion, Global Behavior, General Health, Mental Health, Parental Impact-Emotional, Physical Functioning, Parental Impact-Time, Role/Social- Emotional/Behavioral, Role/social- Physical, Self-Esteem	NR
Remschmidt et al., 2010	Germany	Longitudinal	726	8.7 ± 3.0	Multiple diagnostic categories	Proxy	ILK	School performance, Family functioning, Social integration,	NR

								Interests and hobbies, Physical health, Mental health, Overall HRQL, Burden of disease, Burden of treatments	
Rentz et al., 2005	USA	Longitudinal	921	6-18 11.0 ± NR	ADHD	Proxy	CHQ – Parent form	Physical functioning, Role limitations-emotional/behavioral, Role limitations-physical, Bodily pain, Behavior, Mental health, Self-esteem, General health perceptions, Parental impact-emotional, Parental impact-time, Family activities, Family cohesion, Physical summary score, Psychosocial summary score	Age as covariate in ANCOVAs
Rizzo et al., 2012	Italy	Longitudinal	100	13-18 16.03 ± 1.32	Gilles de la Tourette syndrome	Self	YQOL-R	Self, Relationship, Environment, General QL, Total score	NR
Rothenberger et al., 2011	Germany	Longitudinal	822	6-17 10.1 ± 2.5	ADHD	Self Proxy	KINDL	Physical wellbeing, Emotional wellbeing, Self-esteem, Family, Friends, School	Separate analyses for children aged 6-11 and for adolescents aged 12-17 years
Rotsika et	Greece	Cross-	116	8-14	Specific	Self	KINDL	Physical wellbeing,	NR

al., 2011		sectional		10.67 ± 1.99	learning disabilities (specific reading disorder, spelling disorder)	Proxy		Emotional wellbeing, Self-esteem, Family, Friends, School	
Sawyer et al., 2002	Australia	Cross-sectional	396	6-17 10.62 ± 3.33	ADHD, major depressive disorder, or conduct disorder	Proxy	CHQ – Parent form	General health perceptions, Pain and discomfort, Self-esteem, Emotional problems, Behavioral problems, Family activities, Peer and school activities due to emotional/behavioral problems, Emotional impact on parents, Time impact on parents, Physical activities, Peer and school activities due to physical health problems	Age as covariate in ANCOVAs and regression analyses
Schneider et al., 2011	Switzerland	Longitudinal;	43	5-7 6.24 ± 0.88	Separation anxiety disorder	Self Proxy	ILK – Short version	Total score	NR
Sciberras et al., 2011	Australia	Longitudinal	27	6-15 11.52 ± 2.38	ADHD	Proxy	PedsQL 4.0 Generic Core Scales	Psychosocial health summary score	NR
Sheldrick et al., 2012	USA	Cross-sectional	39	12-18 14.8 ± NR	Autism Spectrum Disorders	Self Proxy	PedsQL 4.0 Generic Core Scales	Physical functioning, Emotional functioning, Social functioning, School	NR

								functioning, Total score	
Sikora et al., 2012	USA and Canada	Cross-sectional	3066	2-18	Autism Spectrum Disorders	Proxy	PedsQL 4.0 Generic Core Scales	Physical functioning, Emotional functioning, Social functioning, School functioning, Psychosocial summary score, Total score	Age as covariate in generalized linear equation models
Stewart et al., 2009	USA	Longitudinal	63	10-17 13.94 ± 2.27	Bipolar I disorder (manic or mixed episode), schizophrenia or schizoaffective disorder	Proxy	CHQ – Parent form	Physical functioning, Role limitations-emotional/behavioral, Role limitations-physical, Bodily pain, Behavior, Mental health, Self-esteem, General health perceptions, Parental impact-emotional, Parental impact-time, Family activities, Family cohesion, Physical summary score, Psychosocial summary score	QL scores were examined separately for different age groups: 11-12 years, 13-15 years, and 16-18 years
Storch et al., 2007	USA	Cross-sectional	59	8-17 11.4 ± 2.6	Gilles de la Tourette syndrome or chronic tic disorder	Self Proxy	PedsQL 4.0 Generic Core Scales	Physical functioning, Emotional functioning, Social functioning, School functioning, Total score	QL scores were compared (MANOVA) between age groups (8-11 years vs. 12-17 years); Agreement

									between informants was examined separately for each age group
Sung et al., 2008	Australia	Cross-sectional;	239	5-18 11.7 ± 3.2	ADHD	Proxy	PedsQL 4.0 Generic Core Scales CHQ – Parent form	Physical summary score, Psychosocial summary score, Total score Emotional Impact, Time Impact, and Family Activities	Age as covariate in regression analyses
Topolski et al., 2004	USA	Cross-sectional	55	11-18 13.9 ± 1.6	ADHD	Self	YQOL-R	Self, Relationship, Environment, General QL, Total score	Age as covariate in comparison analyses (MANCOVA)
Van der Heijden et al., 2007	The Netherlands	Longitudinal;	105	6-12 9.20 ± 2.06	ADHD and chronic sleep-onset insomnia	Proxy	TACQOL – Parent version	Total score	NR
Van Meter et al., 2013	USA	Longitudinal	54	7-13 9.1 ± 1.59	Bipolar spectrum disorders	Self Proxy	KINDL	Physical wellbeing, Emotional wellbeing, Self-esteem, Family, Friends, School	Age as covariate in regression analyses
van Steensel et al., 2012	The Netherlands	Longitudinal	237	7-18 12.10 ± 2.77	Autism Spectrum Disorders and anxiety disorders	Self Proxy	EuroQol-5D	Mobility, Self-care, Usual activities, Pain/discomfort, Depression/ anxiety	Main effects of age (< 12 years vs. > 12 years) and interaction effects of Age X diagnostic group were entered in

									regression analyses
Varni et al., 2006	USA	Cross-sectional;	72	5-16 10.95 ± 3.13	ADHD	Self Proxy	PedsQL 4.0 Generic Core Scales	Physical functioning, Emotional functioning, Social functioning, School functioning, Total score	NR
Varni et al., 2012	USA	Longitudinal;	234	6-17 9-47 ± 3.07	Autism Spectrum Disorders	Proxy	PedsQL 4.0 Generic Core Scales	Emotional functioning, Social functioning, Cognitive functioning, Total score	NR
Wehmeier et al., 2011	Germany	Longitudinal;	180	6-17 11 ± 3	ADHD and comorbid oppositional defiant or conduct disorder	Proxy	KINDL-R	Physical wellbeing, Emotional wellbeing, Self-esteem, Family, Friends, School	Age as covariate in comparison analyses
Yang et al., 2007	Taiwan	Cross-sectional;	119	6-15	ADHD	Proxy	CHQ – Parent form	Physical functioning, Role limitations-emotional/behavioral, Role limitations-physical, Bodily pain, Behavior, Mental health, Self-esteem, General health perceptions, Parental impact-emotional, Parental impact-time, Family activities, Family cohesion, Physical summary score, Psychosocial	Age as covariate in regression analyses

								summary score	
Yang et al., 2012	Taiwan	Cross-sectional;	45	12-18 14.82 ± 2.62	ADHD	Self	TQOLQA	Family, Residential environment, Personal competence, Social relationships, Physical appearance, Psychological well-being, and Discomfort/pain	NR
Zambrano-Sánchez et al., 2012	Mexico	Longitudinal	120	7-12 9.0 ± 2.1	ADHD	Self	AUQUEI	Family life and social relationships, Leisure, Separation, Function performance	NR
Zinner et al., 2012	USA	Cross-sectional;	211	10-17 12.4 ± 2.2	Gilles de la Tourette syndrome/ Chronic tic disorder	Self Proxy	PedsQL 4.0 – Short form	Total score	NR

ADHD – Attention-deficit and hyperactivity disorder; ANCOVA – Analysis of covariance; ANOVA – Analysis of variance; AUQUEI – Auto-Questionnaire Qualité de Vie Enfant Imagé; CHQ – Child Health Questionnaire; DCGM – DISABKIDS Chronic Generic Module; DUX-25 – Dutch Child AZL-TNO Quality of Life; HALFS – Health and Life Functioning Scale; ILK – Inventar zur Untersuchung der Lebensqualität von Kindern und Jugendlichen; KINDL - Kinder Lebensqualitätsfragebogen questionnaire; MANOVA – Multivariate analysis of variance; MANCOVA – Multivariate analysis of covariance; PedsQL – Pediatric Quality of Life Inventory; PEMQOL-SF – Pediatric enuresis module to assess quality of life – short form; PQ-LES-Q – Pediatric Quality of Life Enjoyment and Satisfaction Questionnaire; RCT – Randomized Control Trial; SF-36 - Short Form-36 items; TACQOL - TNO-AZL Children’s Quality of Life scale; TQOLQA - Taiwanese Quality of Life Questionnaire for Adolescents; YQOL-R – Youth Quality of Life Instrument-Research Version.

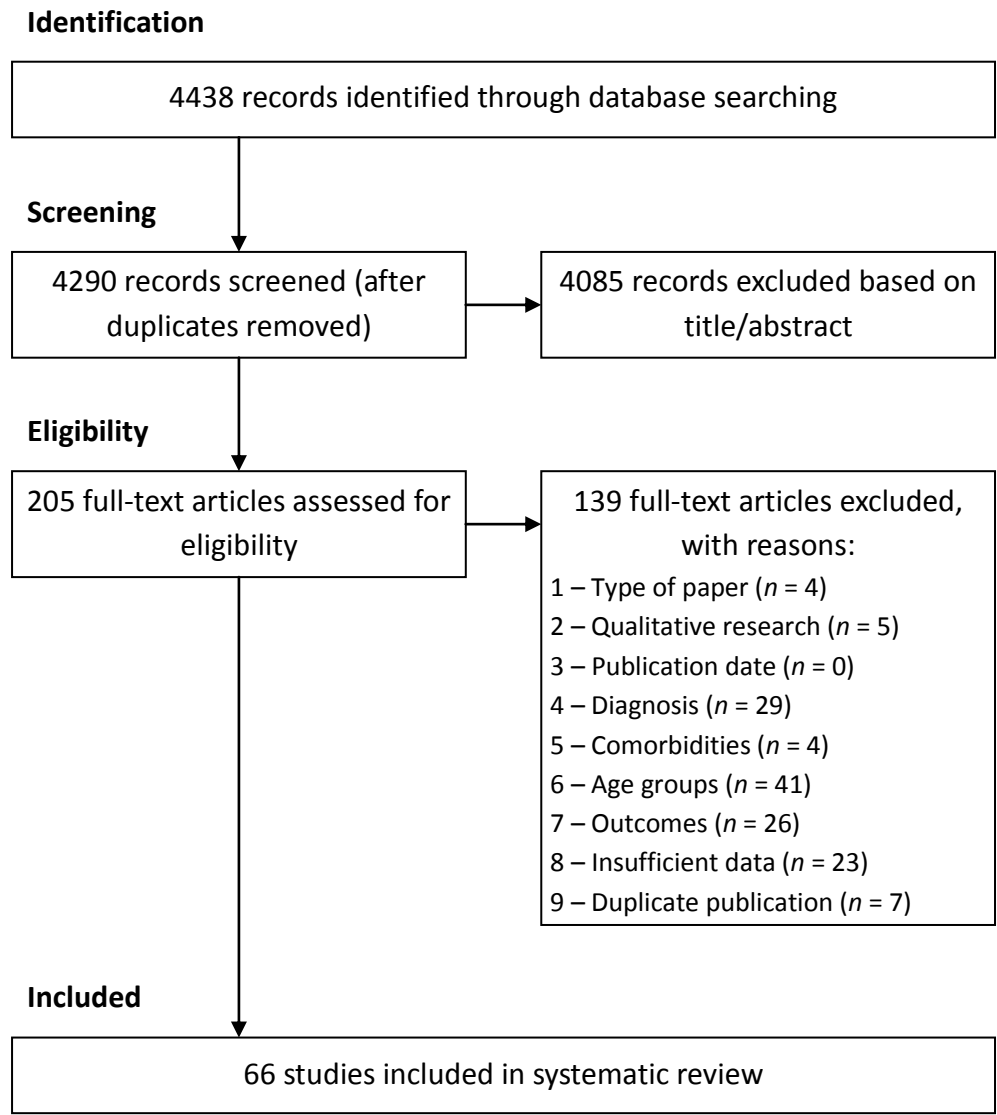


Figure 1. Flow diagram summarizing the study selection process.

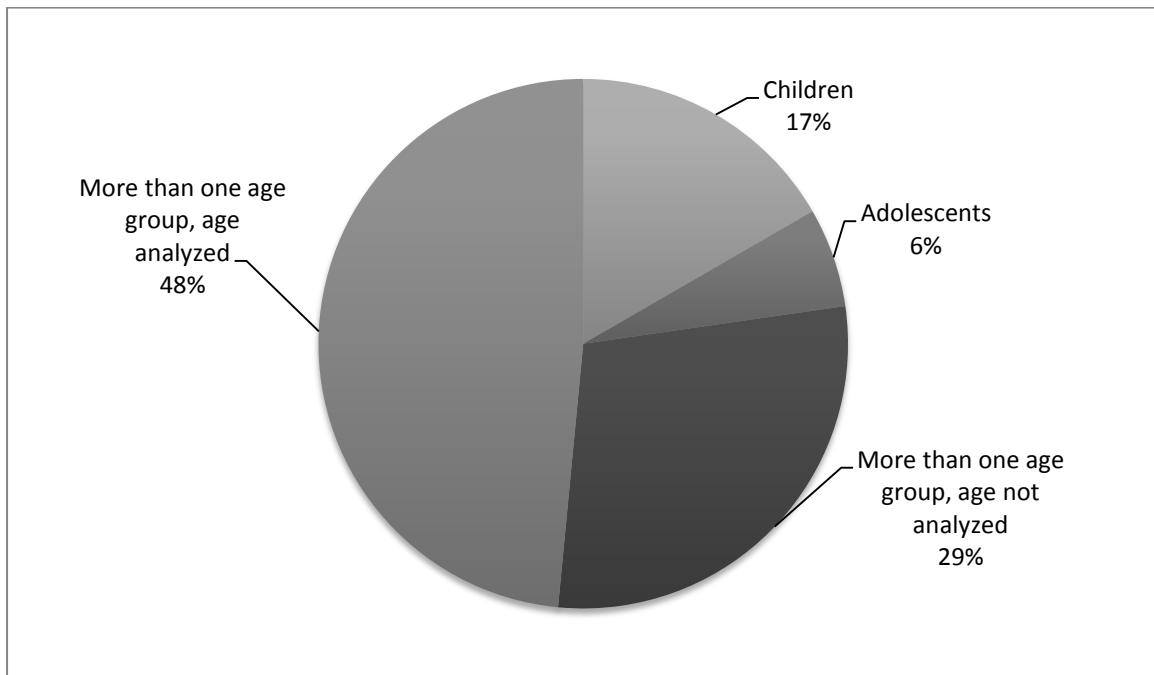


Figure 2. Distribution of participants through age categories

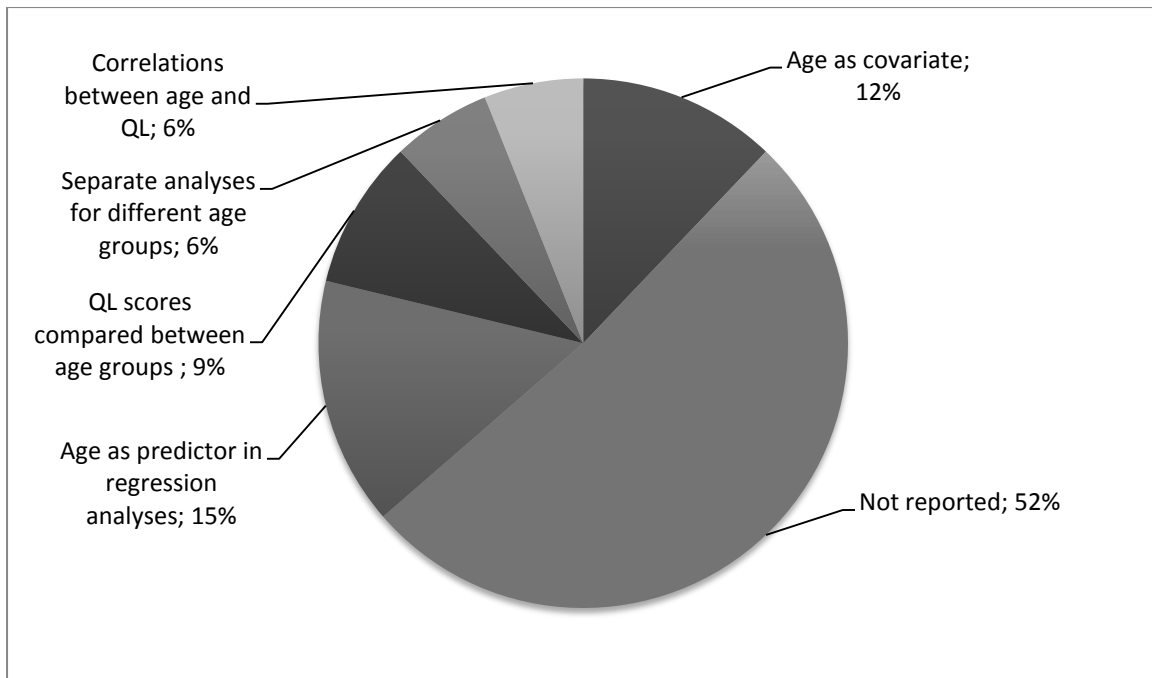


Figure 3. Statistical treatment of age in studies

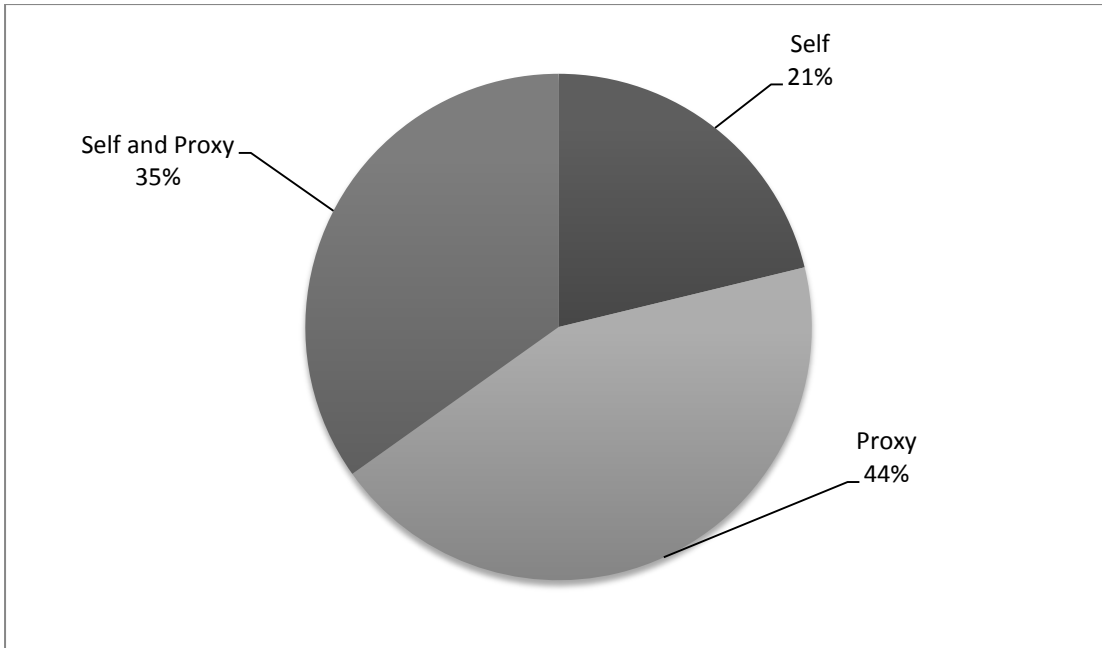


Figure 4. Frequency of the use of self-reports, proxy-reports, or both to assess QL