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Review article

Use of validated PedsQL™ questionnaires regarding children with ADHD and autism

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Abstract
The assessment of the quality of life of children is continuously connected to their chronic health problems. In our opinion, the optimal indicator of the quality of life of children is the Pediatric Quality of Life Inventory™ questionnaire (PedsQL™) because foreign literature is rich in its results. The validated PedsQL™ questionnaires are used to assess the quality of life of children and adolescents and their families.

The goal of this article is to broaden the knowledge of medical and social workers in using these questionnaires in the case of selected disorders (ADHD and autism). The objective of this study is to verify the content and reliability of questionnaires that are used for the assessment of the quality of life. This study focuses on children with chronic disorders of ADHD and autism. We used the method of document content analysis. We searched for relevant sources in scientific databases – WOS, Pubmed, ScienceDirect, Scopus.

PedsQL™ questionnaires are globally used for children with ADHD and autism. They are used for the assessment of the quality of life of children with the mentioned disorders and their families.

The questionnaires do not focus only on the quality of life of individuals but families in total. It is one of the few questionnaires that assess the impact of such disorders on families.

Keywords: ADHD; Autism; PedsQL™; Quality of Life

Abbreviations: DUX-25, Dutch Child TNO Quality of Life; KINDL-R, Kinder Lebensqualitat sfragebogen (Munich Quality of Life Questionnaire for Children); PedsQL™, Pediatric Quality of Life Inventory™; TACQOL, TNOAZL Child Quality of Life

Introduction

The quality of life is how a person sees their status in life regarding their cultural surroundings, lifestyle, goals, interests and expectations (Baloun and Velemínský, 2018, p. 168). The assessment of the quality of life of children is continuously connected to their chronic health problems. In our opinion, the optimal indicator of the quality of life of children is the Pediatric Quality of Life Inventory™ questionnaire (PedsQL™) because foreign literature is rich in its results. These questionnaires were designed by James W. Varni (2004; Varni et al. 2003). PedsQL™ has been developed since 1997 (Cheng et al., 2016). It includes 34 types of questionnaires. PedsQL™ has a general module (PedsQL™ 4.0 Generic Core Scales) and specific modules that specialize in individual types of illnesses, such as diabetes, asthma etc. The questionnaires are translated into several world languages and they can be found in the online database of ePROVIDE (2018).

The hyperactivity disorder (ADHD) is marked by persistent inattention. It is a developmental disorder which severely and negatively affects a child's quality of life (Lee et al., 2016). The largest problem for children with ADHD is keeping attention (Paclt et al., 2007). ADHD is the most frequent chronic mental health condition in children and adolescents (Varni and Burwinkle, 2006). It is a neurobiological condition affecting 3–7% of the child population and significantly threatens their quality of life (Marques et al., 2013). Jucovičová and Žáčková (2015) distinguish three subtypes of ADHD:

1. ADHD with the predominating motoric hyperactivity and impulsivity;
2. ADHD with the predominating persisting inattention disorder;
3. combined type.

Autism is an inborn disorder of a child's mental development. Its base is neurobiological (Autismus, 2018). The autism spectrum disorder (ASD) is a developmental disorder which is displayed with disturbed social interaction, communication and behaviour (Burke, 2014). A child with ASD wrongly assesses the incoming information. Education and autism (2018) state a triad of problematic ASD areas:

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1. Social interaction and social behaviour – i.e. disturbed ability to use and recognize non-verbal communications in different social situations.
2. Communication – it mainly includes arrested speech development or none at all.
3. Imagination, interests/hobbies, playing – the child is intrigued by one or two activities and its reaction or focus are abnormally intensive (e.g. the child is focused on means of transport, statistics, meteorology, etc.).

The goal of this article is to broaden the knowledge of medical and social workers in using these questionnaires in the case of selected disorders (ADHD and autism).

Materials and methods

We used the method of document content analysis. *"The subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns"* (Hsieh and Shannon, 2005).

In the first phase, we established where we would monitor the professional sources (analytic category). We then specified what we would monitor (recording unit). After that, we analyzed the contextual unit, i.e. the context in the documents. In the second phase, we defined the independent categories – in this case, we monitored the PedsQL™ questionnaires regarding two types of disorders.

We searched for relevant sources in scientific databases (WOS, Pubmed, ScienceDirect, Scopus).

We used the keywords (PedsQL™, quality of life, ADHD, autism) using the Boole operators "and" and "or".

In the next search phase, we found 1064 studies. We used filtering, which resulted in 157 studies. In the following phase, we removed all duplicates and non-relevant studies. The search resulted in the final 30 relevant studies, which we used in this article. The collection of the results and their analysis was carried out between September 2017 and May 2018.

The objective of this study is to verify the content and reliability of questionnaires used for the assessment of the quality of life. This study focuses on children with chronic disorders of ADHD and autism.

The limitation of this study is that we do not know whether all our source articles can be found in the mentioned databases.

Results

PedsQL™ in ADHD

Lee et al. (2016) carried out a meta-analysis of nine ADHD assessments. In seven cases, they used the PedsQL™ for the assessment of the quality of life, in one case the DUX-25STACQOL and in one case the KINDL-R. The assessment of the quality of life and modules was carried out according to the criteria of Solans et al. (2008). The authors used a 23-degree scale to assess the quality of the studies which were focused on the quality of life of children with ADHD and the control group. The results can be found in Table 1.

Table 1. The comparison of studies according to the criteria (Solans et al., 2008)

Authors	Country	The quality of life questionnaires	Assessment by Solans et al. (2008)
Bastiaansen et al. (2004)	Netherlands	PedsQL™	13
Becker et al. (2011); Ravens-Sieberer et al. (2008)	Germany	KINDL-R	10
Flapper and Schoemaker (2008)	Netherlands	DUX-25TACQOL	17
Jafari et al. (2011)	Iran	PedsQL™	17
Limbers et al. (2011)	USA	PedsQL™	17
Pongwilairat et al. (2005)	Thailand	PedsQL™	11
Varni and Burwinkle (2006)	USA	PedsQL™	18
Xin et al. (2009)	China	PedsQL™	16
Yürümez and Kılıç (2013)	Turkey	PedsQL™	14

Source: Lee et al. (2016), our own layout.

Coghill and Hodgkins (2016) claim that the impact of ADHD on the quality of life is similar to other mental and physical disorders. The mentioned authors compared the quality of life of children with ADHD and type 1 diabetes mellitus. Coghill and Hodkins (2016) presumed a significantly worse quality of life in children with ADHD and type 1 diabetes mellitus than healthy children. The total research was carried out with 213 children with ADHD, 58 children with type 1 diabetes mellitus and 117 healthy children between 6 and 16 years in three outpatient facilities in Scotland. They used the following tools: PedsQL™, Child Health and Illness Profile – child edition (CHIP-CE). Both tests showed that ADHD has a larger impact on children's quality of life than type 1 diabetes mellitus. There was no test that contracted this.

Thomas et al. (2015) studied the quality of life of children with ADHD and autism spectrum disorder and compared it with children with only ADHD. This research was carried out with 392 children. 93 had ADHD combined with autism spectrum disorder and 299 had ADHD. The authors used the generic PedsQL™ 4.0. Children with ADHD combined with autism spectrum disorder had a worse quality of life in all areas in comparison to children with only ADHD. The results were practically verified.

Marques et al. (2013) studied 95 children with a combined type of ADHD between 8 and 12 years and their parents. They used the generic PedsQL™ 4.0. Children with ADHD had a significantly lower score in all groups (physical, emotional, social and at school). The children's results in the questionnaires were

significantly similar to their parents'. The results showed that children with ADHD and their parents understood the limitations because of the disorder. Limbers et al. (2011) achieved similar results, i.e. that children with ADHD had a significantly lower level of quality of life than healthy children.

The characteristics and comparison by Solans et al. (2008)

Solans et al. (2008) compared the tools for assessing the quality of life of children and adolescents up to 19 years. In the beginning, they identified all tools which were designed or published between 1980 and 2000 and between 2001 and 2006. They assessed the quality of the study on a 23-point scale. Table 1 shows the assessment of questionnaires in points (Lee et al., 2016; Solans et al., 2008).

The best assessment by Solans et al. (2008) was gained by the study of Varni and Burwinkle (2006). The lowest number of points was gained by the studies of Becker et al. (2011), Ravens-Sieberer et al. (2008) and Pongwilairat et al. (2005), who used the PedsQL™ for their study.

We quote the authors who used the PedsQL™ questionnaires.

Bastiaansen et al. (2004) studied the relationship between paediatric psychiatric disorders and the quality of life. Their research was carried out with 310 children between 6 and 18 years. The children were hospitalized at the outpatient clinic in Rotterdam between the 1st August 2000 and the 15th September 2001. They suffered from ADHD, anxiety, mood disorders and other psychiatric disorders. The authors used the generic PedsQL™ 4.0 questionnaire. Regarding the total score, they did not find any differences between diagnostic categories. Children with ADHD had a lower score regarding school and social condition, children with anxiety had a lower score regarding emotional condition, children with pervasive developmental disorders had a lower score regarding social condition – Table 1 (Solans et al., 2008)

Jafari et al. (2011) studied psychometric properties of the Persian version of the generic PedsQL™ 4.0 in 72 Iranian children with ADHD aged between 8 and 17 years and their parents. The control group included 140 healthy children. The authors had the English version of the generic PedsQL™ 4.0 module translated into Persian. The results showed that children with ADHD had a statistically lower quality of life than children from the control group. The Persian version of the questionnaire is reliable and valid.

Limbers et al. (2011) studied the influence of ADHD on the quality of life from the point of view of children and their parents. The participants in the research were children with ADHD between 5 and 18 years and their parents. They filled in the general PedsQL™ 4.0 questionnaire and the PedsQL™ module for ADHD. The paediatric patients with ADHD showed a significantly lower level of quality of life in comparison to the responding sample group of a healthy population and a significantly higher level than children with ADHD at a psychiatric clinic.

Pongwilairat et al. (2005) studied the influence of ADHD on children and families regarding health at school age and the difference between children with ADHD and healthy children. The authors used the generic PedsQL™ 4.0 questionnaire. The research included 46 children with ADHD and 94 healthy children. 17 children with ADHD were treated with pills. The children and their parents showed a lower level of quality of life than healthy children and their parents. The children with ADHD achieved a lower score regarding physical functions despite the fact that they were physically healthy. The authors suggest including the improvement of quality of life in the total planning of treatment goals.

Varni and Burwinkle (2006) studied the generic PedsQL™ 4.0 test and their research included 3,260 healthy children and adolescents aged between 5 and 16 years. The result was that children with ADHD function much worse at school ($p < 0.001$) than healthy children. The results of these authors were practically verified.

Xin et al. (2009) studied the quality of life of children with ADHD using the generic PedsQL™ 4.0 questionnaire (Chinese version). The research included 73 children with ADHD and 98 healthy children. The research included their parents, who filled in the Conners questionnaire for parents (scale questionnaire). The questionnaires were filled in by 169 families out of the total of 171 (98.8%). The conclusion of the study was that children with ADHD had a lower level of quality of life and larger learning problems than healthy children.

Yürümez and Kılıç (2016) studied the influence of ADHD on sleep. The authors used the generic PedsQL™ 4.0 questionnaire in 16 boys between 7 and 13 years with a combined type of ADHD and 31 healthy boys. The children with ADHD had never been treated for sleep disorders or psychiatric disorders. Their IQ was at least 80, BMI was normal and they did not have any health problems. The results showed that the frequency of sleeping problems in children with ADHD was higher by 84.8% and the score showed that their quality of life is worse regarding physical and psychosocial health and the total quality of life. The correct assessment and the treatment of sleeping problems increase the quality of life of children and their families and also decrease the severity of ADHD symptoms.

PedsQL™ in autism

Ikeda et al. (2014) studied the use of the measures of quality of life regarding children with ASD. Relevant articles were searched for in expert databases, such as MEDLINE, CINAHL Plus (full text) and SPORTDiscus (full text), EBSCO, PsycINFO and ProQuest Health and Medicine between 2000 and May 2013. We included the original research articles that assessed the quality of life of children and adolescents aged between 5 and 20 years with ASD. We found 1,165 works and 13 that followed the established criteria were included. We found a number of measures for the quality of life. They were used for children and adolescents with ASD and the most frequently used was the PedsQL™. The measures of the quality of life with the use of one's own reports were unusual and their reliability and validity were not sufficiently reported for this population. Despite the differences in the studies, the results were consistent: children and adolescents with ASD had a lower score regarding the quality of life than their healthy peers, especially in the social area (Ikeda et al., 2014).

In comparison to other conditions, there is an insufficient focus on the quality of life of children with ASD (Tavernor et al., 2013). Their pilot study was assessing the validity of current questionnaires regarding the quality of life of children with ASD aged between 8 and 12 years. The literature between 1990 and 2011 identified the PedsQL™ and Kidscreen questionnaires as the most frequently used in children with ASD. The authors use the generic PedsQL™ 4.0 questionnaires. The study was completed with 10 parents and 4 children. Children and their parents show a lower level of the quality of life in comparison to the normative sample group. The results show that a new measure of the quality of life, which is specific for the given situation, is necessary. It must be based on the children's life perspectives and it should assess the experience with special interests. According to the authors, the active in-

volvement of young people and their families is crucial for the theoretical development of the theoretical framework regarding the quality of life of children and adolescents with ASD. It is also important for the development of specific measurements and questionnaires.

Children and adolescents with ASD have a lower quality of life than their healthy peers (Stokes et al., 2017). The evidence is based on proxy reports, whose reliability was assessed using the Cronbach alpha coefficient. Stokes et al. (2017) studied the use of the PedsQL™ and whether the respondents approved of its items, which were different for every group. The research included 229 children with ASD whose IQ was higher than 70, 229 parents, as well as 74 of their healthily developed peers. The children and adolescents with ASD were aged between 6 and 20 years old. The children were from special basic and secondary schools in the Amsterdam region. The authors used the generic PedsQL™ 4.0 questionnaires. They analyzed the data on one-dimensionality and functionality of differential items regarding healthy children and adolescents and their parents. The results of the children and adolescents with ASD and their parents were compared. Stokes et al. (2017) learned that both groups did not use the PedsQL™ differently, which corresponds with the literature, although their score may be different.

Kose et al. (2013) focused on studying the quality of life regarding health which is related to clinical variables. Their research included 102 children with ASD. 46 were autistic, 38 had a pervasive developmental disorder, 18 had Asperger's syndrome and 39 were typically developed (control group). The children were 3 to 18 years old. The authors used the generic PedsQL™ 4.0 questionnaire, which was filled in by the children's mothers. The physical, psychosocial health and the total summary regarding the group with ASD were significantly lower than in the control group. The PedsQL™ score was different among the groups where psychotropic medicines were used. The PedsQL™ score negatively correlated with CARS and positively with age. The authors concluded that the severity of ASD negatively affected the quality of life.

Ayers et al. (2016) assessed the impact of the participation in Autism Moves Gymnastics programme on gross motor skills and the quality of life of children with ASD. The study included children between 5 and 10 years. The results were compared to the children who did not participate in the programme. Gross motoric skills were measured using the Test of Gross Motor Development test (TGMD-2). The measurement of the quality of life used the generic PedsQL™ questionnaire (parent reports). The authors used the generic PedsQL™ 4.0. 21 children finished the testing – 11 participants in the programme and 10 control group children. There were no significant differences regarding gross motoric skills and the quality of life between the groups (Ayers et al., 2016).

Sheldrick et al. (2012) compared two parent reports on the quality of life of adolescents with ASD. In the first reports, the parents gave their own point of view of the quality of life and their adolescent child. In the second report, the parents stated that they believed that their adolescent child responds to their opinion. Sheldrick et al. (2012) used the generic PedsQL™ 4.0: 39 adolescents with ASD and their parents, who filled in the PedsQL™. The parents filled in the questionnaire twice and the adolescents once. The three questionnaires were assessed using the Pearson correlations. The differences between the means were assessed using ANOVA. The correlations were higher among the parent proxy reports and the adolescents' own assessment reports than the parent standard reports and the adolescents' own assessment reports. The average parent proxy reports score was closer to the adolescents' own assessment reports. The result is that parents have different opinions on the quality of life of their children from their children's, and parents realize the differences (Sheldrick et al., 2012).

The quality of life as a multidimensional construct had not been proven before in children with Asperger's syndrome (Limbers et al., 2009). The goal of their research was to study the initial workability, reliability and validity of the generic PedsQL™ 4.0 and the PedsQL™ for cognitive functions for parent proxy reports regarding children with Asperger's syndrome at school age. The PedsQL™ showed the missing answers (0.0%) and gained excellent reliability in the total score (alpha = 0.82) and cognitive functional scale (alpha = 0.92).

There is a limited number of published data on the impact of the treatment using Aripiprazole on the quality of life regarding the health of individuals with ASD (Varni et al., 2012). The goal of this study was to assess the effect of Aripiprazole on the quality of life during the treatment of fantod in paediatric patients with ASD aged between 6 and 17 years. This post hoc analysis (regression analysis) assessed the data from two 8-week placebo-controlled studies which compared the effects of Aripiprazole (study with a fixed dosage of 5, 10 and 15 mg/day, study with a flexible dosage of 2–15 mg/day) to placebo during the treatment of fantod related to ASD. The value for the quality of life was set at the beginning and in the eighth week using the generic PedsQL™ 4.0 questionnaire scale. 316 patients were randomly divided into groups: treatment with Aripiprazole (166 children with a fixed dosage, 47 children with flexible dosage) and treatment with placebo (52 children with a fixed dosage and 51 children with flexible dosage). Aripiprazole was associated with significantly higher improvements than the placebo (total PedsQL™ score – 95% difference). The patients who were treated with Aripiprazole achieved a significantly higher probability than the patients with placebo, whose score was clinically significantly improved. The results of the contemporary post hoc analysis show that Aripiprazole was associated with the improvement of the quality of life (as it was assessed using the PedsQL™) of paediatric patients with fantod related to ASD (Varni et al., 2012).

Burke (2014) studied whether Zen Shiatsu (a kind of Japanese massage) can decrease short term and long term stress levels in a child with ASD. This longitudinal case study (focus on one group/person who is monitored for a long time) was focused on a 7-year-old boy with ASD. He underwent six 20-minute weekly sessions of Zen Shiatsu. Using a 5-point stress scale for autistic children, the client stated his stress level before and after every session. The parents were given the generic PedsQL™ 4.0 questionnaire to determine the level of the quality of life of their child before the treatment and set the initial value. The family filled in the same questionnaire after six weeks of the Zen Shiatsu sessions for comparison. The 5-point scale results showed that the stress level was decreased after the treatment. The generic PedsQL™ 4.0 questionnaire showed a higher score regarding the quality of life in all areas, which means that the total quality of life of the child improved due to the 6-week Zen Shiatsu sessions (Burke, 2014).

Conclusions

The goal of this article was to broaden the knowledge of medical and social workers in using these questionnaires in the case of selected disorders (ADHD and autism). The questionnaire began to be developed in 1997 and has been further developed since. Currently, the questionnaire has four subscales which

focus on physical, emotional, and social school functioning. PedsQL™ questionnaires are globally used in children with ADHD and autism. They are used for the assessment of the quality of life of children with the mentioned disorders and their families. The questionnaires do not focus only on the quality of life but families as a whole. It is one of the few questionnaires that assess the impact of children's disorders on families. The most convenient and most used questionnaires in this group are the generic PedsQL™ 4.0 module and the PedsQL™ 2.0 module for families. This article can contribute to a coordinated rehabilitation of people with restricted participation, as well as the healthy population of children and adolescents.

Conflict of interests

The authors have no conflict of interests to disclose.

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Využití validizovaných dotazníků PedsQL™ u dětí s ADHD a autismem

Souhrn

Hodnocení kvality života dětí je stále spojované s medicínskou problematikou dětí s chronickým onemocněním. Dle našeho názoru optimálním kontraktem pro kvalitu života dětí je dotazník Pediatric Quality of Life Inventory™ (dále jen PedsQL™), protože jeho výsledky jsou bohatě prezentovány v zahraniční literatuře. Validizované dotazníky PedsQL™ se využívají při hodnocení kvality života u dětí a dospívajících a jejich rodin.

Cílem tohoto příspěvku je rozšířit povědomí o využití dotazníků PedsQL™ u vybraných onemocnění (ADHD a autismus) u zdravotníků i sociálních pracovníků. Předmětem studie je ověřování obsahu a reliability dotazníků využívaných pro měření kvality života. Objektem studie jsou děti s chronickým onemocněním ADHD a autismem. Byla využita metoda obsahové analýzy dokumentů. Relevantní zdroje byly vyhledávány prostřednictvím vědeckých databází – WOS, Pubmed, ScienceDirect, Scopus.

Dotazníky PedsQL™ jsou celosvětově využívány u dětí s ADHD a autismem. Využívají se k hodnocení kvality života u dětí s daným onemocněním a u rodin těchto dětí.

Dotazníky se nesoustředí jen na kvalitu života jedinců, ale i rodin jako celku. Jako jeden z mála dotazníků hodnotí i dopad onemocnění dítěte na rodinu.

Klíčová slova: ADHD; Autismus; Kvalita života; PedsQL™

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