Introduction

The term quality of life first appeared in the 1920s (Mareš et al., 2006). The term is not universally defined because it is multidimensional (Baluon and Velemínský, 2018).

“The term quality of life has been used in many areas of human activities and many scientific fields. Besides economics, political sciences and sociology (where it was first mentioned), we can find it in philosophy, theology, social work and psychology” (Mareš et al., 2006, s. 11).

Type I diabetes in children and adolescents is quite often accompanied by other immunopathological illnesses, autoimmune illness of the thyroid or celiac illnesses (Spirkova et al., 2015). If a child is diagnosed with type I diabetes mellitus, its family is in a difficult situation (Jönsson et al., 2015). Children with type I diabetes mellitus are not very physically active and are at a high risk of psychosocial morbidity including depressions, a higher level of anxiety and a lower level of quality of life (Mutlu et al., 2015).

The quality of life that is associated with health is continuously considered during the treatment of patients (Tantilipikorn et al., 2013a). The quality of life that is associated with health is now considered a necessary measurement for children with cerebral palsy (Tantilipikorn et al., 2013b). Cerebral palsy affects the quality of life of children who suffer from it, and their parents state that they must frequently decide for their children (Türkoğlu et al., 2016).

The quality of life of children and their parents can be measured by the Pediatric Quality of Life Inventory™ (PedsQL™) questionnaires. These questionnaires are useful for a scale of illnesses regarding healthy children as well.

The goal of this article is to inform experts and the wider public about the use of the validated PedsQL™ questionnaires in children who suffer from diabetes mellitus and cerebral palsy. The quality of life can be measured using many methods. We chose the PedsQL™ questionnaire, which measures the quality of life of children from birth to the age of 26, as well as the quality of life of their families.

Materials and methods

We used the method of document content analysis (Hsieh and Shannon, 2005).
In the first phase, we established where we would monitor the questionnaires (analytic category). Then, we specified what we would monitor (record unit). In the second phase, we monitored the PedsQL™ questionnaires regarding two types of illnesses.

Relevant sources were searched for in scientific databases (WOS, Pubmed, ScienceDirect, Scopus).

We use the keywords (PedsQL™, quality of life, diabetes mellitus, cerebral palsy) and the Boole operators “and” and “or”.

In the next search phase, we found 1,582 results. The filtering left us with 265 results. In the next phase of the analysis, we excluded all duplicates and studies that did not deal with the required issue. There were 26 relevant studies that we used. The collection and analysis of the results were carried out between January 2018 and December 2018.

The goal of this study is to verify the content and reliability of the questionnaires used for measuring the quality of life. We are dealing with children who suffer from diabetes mellitus and cerebral palsy.

Results

**Diabetes mellitus**

The PedsQL™ is a used construct specially designed for diabetes— the PedsQL™ module for diabetes (Hilliard et al., 2013). These tests enable clinical doctors at paediatric diabetes clinics to monitor mood swings or the behaviour of paediatric patients (Hilliard et al., 2013). The importance of the PedsQL™ regarding diabetes mellitus is confirmed by Anderson et al. (2017).

The PedsQL™ 3.0 module for diabetes can be a valuable tool for measuring the quality of life of children in studies and clinical practice (Sand et al., 2012). Studies by Sand et al. (2012) included 140 families from four diabetes centres in Sweden. The authors used the PedsQL™ 4.0 generic module and the PedsQL™ 3.0 specific module for diabetes. The questionnaires were distributed to 108 children between 5 and 18 years, and 130 parents of children between 2 and 18 years. The PedsQL™ 4.0 generic module and the PedsQL™ 3.0 module for diabetes were correlated (r = 0.76), which indicates the level of validity. The parents reported a lower level of quality of life than their children. The girls in the study stated a lower level of quality of life compared to the boys. The PedsQL™ 3.0 module for diabetes can be a valuable tool for measuring the quality of life of children who suffer from diabetes. Anderson et al. (2017) mention the use of the PedsQL™ regarding the assessment of the quality of life of people who suffer from diabetes.

Varni et al. (2009) measured the reliability and validity of the PedsQL™ 3.0 using a multidimensional scale of fatigue and the PedsQL™ 4.0 generic questionnaire in 83 paediatric patients who suffered from type I diabetes and 84 parents. The PedsQL™ questionnaire showed minimum missing responses (0.3% in children and 0.3% in parents). The resulting score of the scale of fatigue showed excellent reliability — alpha = 0.92 in children and 0.94 in adults. Children who suffered from type I diabetes showed comparable fatigue to paediatric patients who suffered from cancer (during treatment). This proves to be of relative importance regarding their fatigue symptoms — as confirmed by Sand et al. (2012).

The Italian version of the PedsQL™ 3.0 module for type I diabetes was used by D’Annunzio et al. (2014) in their research. The research included 169 Italian children and adolescents (between 5 and 18 years) and 100 parents. The validity of the questionnaire was defined using the Cronbach alpha coefficient. In the results, D’Annunzio et al. (2014) write about the reliability and validity of the Italian version of the PedsQL™ 3.0 module for type I diabetes, and the authors also support its use for measuring the quality of life of children and adolescents who suffer from type I diabetes in international clinical studies—as confirmed by Anderson et al. (2017).

Mutlu et al. (2015) used the PedsQL™ 4.0 generic module for their research. The study included 47 children and adolescents (between 8 and 12 years) who suffered from type I diabetes mellitus, and 55 healthy children as a control group. The group with type I diabetes mellitus was compared to the control group and achieved a higher score regarding depression and anxiety. The result of this study indicates that the quality of life is associated with physical activities and anxiety as well as the level of sugar in the blood—as confirmed by Sand et al. (2012).

Jönsson et al. (2015) carried out a study that included 69 children and 69 parents. The authors used the PedsQL™ 4.0 generic module and the PedsQL™ 3.0 module for diabetes. The parents filled in the PedsQL™ 4.0, and both children over 5 years and parents filled in the PedsQL™ 3.0. The mothers achieved a lower score than the fathers regarding the quality of life at the time and also a year after. Regarding the quality of life of children between 5 and 7 years, their parents showed greater concerns than the children and the parents of older children. Children between 8–12 and 13–18 achieved a higher score than their mothers. There were no differences between the children and their fathers. Spirkova et al. (2015) did not confirm these results in their study.

Varni et al. (2013) used the new version of the PedsQL™ 3.2 for diabetes in their research, which is the upgraded version of the PedsQL™ 3.0 module for diabetes. The PedsQL™ 3.2 is designed for people between 8 and 45 years who suffer from type I diabetes. The research included 31 newly diagnosed patients between 8 and 45 years old, and parents and legal guardians of children and adolescents between 8 and 18 years old. Varni et al. (2013) used the PedsQL™ 3.2 for diabetes as well as cognitive interviews. They recommend that the PedsQL™ 3.2 replace the PedsQL™ 3.0 because it is suitable for children and adolescents as well as newly diagnosed adults.

The goal of the research of Spirk et al. (2015) was to use the PedsQL™ (PedsQL™ 4.0 generic test and PedsQL™ 3.0 module for diabetes) to assess whether these conditions were associated with the changes in the quality of life because of health. The study included 332 patients between 8 and 18 years of age who suffered from type I diabetes. 248 (75%) filled in the questionnaire with their parents. After the arrangement by gender, age, diabetes duration, treatment type and diabetes check-up, this group became statistically significant only for the generic quality of life test. Celiac disease was not associated with the changes in the quality of life in the generic module or the module focused on diabetes. The parents’ score did not prove associations with celiac disease or autoimmune thyroid disease. It showed a slight decrease of the total quality of life in the group with diabetes mellitus type I in combination with autoimmune thyroid disease when compared to the group with only diabetes mellitus type I. Jönsson et al. (2015) did not confirm these results.

Yi-Frazier et al. (2016) carried out a study that included 3,755 children and adolescents between 5 and 18 years old who suffered from diabetes. 3,402 suffered from type I diabetes and 353 from type II diabetes. The authors used the PedsQL™ 4.0 generic questionnaires. There were differences between the reports from the children and adolescents and...
their parents. Better assessments came from adolescents. The parents of children between 5 and 7 years achieved a higher score. The different assessments in PedsQL™ indicate that parents can frequently underestimate the quality of life of adolescents (except in the youngest children). Spirk et al. (2015) have not totally confirmed these results.

Lawrence et al. (2012) studied sociodemographic and clinical characteristics of adolescents with diabetes type I using the PedsQL™ 3.0 module for diabetes. The research was carried out in America in four American Indian populations. The research included 2,602 adolescents whose average age was 13.6 ± 4.1 years, and the average duration of diabetes type I was 62.1 ± 47.0 months. In multivariate analyses, the total score was negatively and significantly associated with lower age, female gender, the type of insulin intake (injection vs. pump) and parents without university education. This study identified sociodemographic and clinical characteristics of adolescents with type I diabetes, where it is more probable to have a bad quality of life – as confirmed by Anderson et al. (2017).

Rhodes et al. (2012) carried out research regarding type II diabetes that included 108 adolescents. 40.7% suffered from type II diabetes, 25% had prediabetes and 34.3% were insulin resistant. They used the PedsQL™ 4.0 generic module. The total score was higher in adolescents than in children. Their parents assessed physical functions as lower than adolescents, but there were no differences in the psychosocial area. Unlike their children, parents see physical functioning as impaired. The approach of families to the treatment and prevention of diabetes type II is important.

The research, carried out by Anderson et al. (2017), focused on type I diabetes in 20 countries on 5 continents and included 5,968 children, adolescents and young adults. Children and adolescents were divided into three age categories: children between 8 and 12 years, adolescents between 13 and 18 years, and young adults between 19 and 25 years. This global study called TEEN used the PedsQL™ 3.0 module for diabetes to measure the quality of life. The study was carried out in centres where at least 100 children, adolescents and young adults were treated. Out of the total 5,968 children, adolescents and young adults, 5,887 were included in the study after examinations. In all age groups, women showed a much lower level of quality of life than men. The third age group (between 19 and 25 years) showed the lowest score regarding quality of life. All three groups showed that the quality of life was better if the level of sugar in the blood was lower. Anderson et al. (2017) found that higher food intake, regular glucose measuring, controlled sugar intake and regular physical activities led to a better quality of life. Physical activity of over 30 minutes at least 3–7× a week has a positive effect. The authors also state that the established regime for measuring food intake has a positive effect. According to the authors, keto-acidosis has a negative effect. BMI has no effect on the quality of life of diabetics, which was verified by the clinical progress in children with diabetes mellitus. Regular check-ups and interpretation of glucose levels in the blood have a positive effect. Patients who are not stressed by a full-time job have a higher level of quality of life. The type of insulin intake – using a pump or otherwise – has no effect on the quality of life.

Another significant predictor regarding the quality of life of children who suffer from diabetes mellitus is its duration (Burešković et al., 2008). A study was carried out that included 79 children and their parents (79 parents). The goal of this study was to find out the general level of the quality of life and the level of the quality of life of children with diabetes between 8 and 18 years. This study used the PedsQL™ 3.0 module for diabetes. It was proven that the duration of diabetes worsens the quality of life.

The sooner that diabetes occurs, the worse the quality of life. Girls show a worse quality of life. A higher level of blood sugar and irregular monitoring worsens the prognosis. The level of education of parents positively affects the duration of the illness. Parents do not see the prognosis of the quality of life as positively as their children. Repeated applications of insulin using the injection and not pump are negatively reflected on the quality of life of the whole family. According to the above mentioned studies, the PedsQL™ 3.0 and PedsQL™ 4 questionnaires for measuring the quality of life are valid and usable in children with diabetes mellitus.

**Cerebral palsy**

A few general tools (including the PedsQL™ 4.0 generic module) have been developed for paediatric patients in various languages, which measure the quality of life regarding health (Tantilipikorn et al., 2013a). In children with cerebral palsy, two tools are mostly used: the PedsQL™ 4.0 generic module and the PedsQL™ 3.0 module for cerebral palsy. The Thai version of the PedsQL™ 3.0 for cerebral palsy was not available, so Tantilipikorn et al. (2013b) validated it in their study. This study was focused on psychometric characteristics and the establishment of parents’ trust in the presented Thai version of the PedsQL™ 4.0 generic module and the following comparison to the PedsQL™ 3.0 module for cerebral palsy. The PedsQL™ 3.0 module for cerebral palsy was filled in by children and their parents or legal guardians. The comparison was carried out twice in 2 or 4 weeks in children, their parents and legal guardians (Tantilipikorn et al., 2013a). There were 54 children and 97 parents or legal guardians. The study supported acceptable inner consistency – except emotional, social and school functioning. The correlation coefficients for parent proxy reports were good, even excellent (the coefficient was between 0.625 and 0.849). They found low and good correlations between both modules (Tantilipikorn et al., 2013a). The authors recommend both tools for measuring the quality of life regarding the health of children with cerebral palsy.

Varni et al. (2005) carried out a study in children with cerebral palsy. The sample group included 148 families (84 men and 64 women between 5 and 18 years old). 24.3% were hemiplegics, 30.4% diplegics and 38.5% quadriplegics. Varni et al. (2005) used the PedsQL 4.0 generic questionnaire. 69 (47%) children were able to describe their condition by themselves. Children with cerebral palsy showed a significantly lower level of quality of life (65.9 on average) compared to healthy children (83.8 on average). Quadriplegic children had a lower quality of life (49.4 on average) than diplegic children (68.9 on average) and hemiplegic children (72.4 on average). Kyösti et al. (2018) used the PedsQL 4.0 generic questionnaire to measure the quality of life of Finnish children between 2009 and 2010. The questionnaire was filled in by 1,109 out of 3,682 children and adolescents.

Measuring the quality of life after intensive paediatric care is good for most children and adolescents.

Demuth et al. (2012) carried out a study with the goal to assess the quality of life regarding health after a stationary cyclic intervention (a cyclic intervention is a few-week cyclic exercise which includes strengthening and cardio-respiratory fitness phases (Siebert et al., 2010)) in children with cerebral palsy. The quality of life was assessed using the PedsQL™ 4.0 generic questionnaire and Pediatric Outcomes Data Collection Instruments (a tool used for the collection of data regarding paediatric outcomes) before and after a three-month station-
The goal of the study of Türkoğlu et al. (2016) was to study the impact of the symptoms of anxiety and depression on the quality of life of parents and monitor clinical and demographic variables that can affect the quality of life. The study included 97 patients with cerebral palsy between 7 and 18 years old. They used the PedsQL™ 2.0 parent module. They recorded all types of cerebral palsy, the level of coarse and fine brain functions, the seriousness of intellectual impairment and other necessary clinical variables. The levels of anxiety symptoms were assessed using the Beck Anxiety Inventory, and the levels of depression symptoms in all of the mothers were assessed using the Beck Depression Inventory. The PedsQL™ showed that the seriousness of mental impairment and a higher score in the Beck Anxiety Inventory had a negative effect on the physical score. Intellectual impairment and a higher score in the Beck Depression Inventory had an effect on the psychosocial score in the PedsQL™. In their conclusion, the authors show significant predictor effects of anxiety and depression symptoms in mothers, which are independent of other clinical variables.

Yun et al. (2016) developed the Korean version of the PedsQL™ 3.0 module for cerebral palsy and tested its reliability and validity. The goal of their study was to assess the quality of life of children with cerebral palsy. The study included 108 legal guardians of children with cerebral palsy (between 2 and 4 years old) and 72 legal guardians of children with cerebral palsy (between 5 and 7 years old). They were present at a number of workplaces between February and August 2015. The committee for translations did the first translation and the Mapi Research Trust Company approved of creating the Korean version of the PedsQL™. Other translations that followed were by an English native speaker who speaks fluent Korean and specializes in medical care and a native Korean speaker who speaks fluent English. For the verification of the reliability of the test, they calculated the correlation coefficient intraclass, and for the reliability of the internal consistency they used the Cronbach alpha coefficient. For the verification of the validity regarding the criteria, they used the Pearson correlation coefficient. The validity of the PedsQL™ 3.0 module for cerebral palsy was high in both groups and showed significant internal consistency in all areas. The results show that the Korean version of the PedsQL™ 3.0 for cerebral palsy is a reliable and valid tool and it is expected that it will significantly contribute to the assessment of the quality of life of children with cerebral palsy.

Yang et al. (2011) studied the reliability, validity and sensitivity of the Chinese version of the PedsQL™ 4.0 generic questionnaire and the PedsQL™ 3.0 module for cerebral palsy. The sample group included 126 parents of children with cerebral palsy between 2 and 12 years, and 5 respondents between 5 and 12 years. 69% were boys and 31% girls. The average age was 4 years and 1 month. The reliability of both modules was proven. The construction of validity was supported by the analysis of mutual relationships between the generic module score and the score of the module for cerebral palsy.

Hwang et al. (2016) carried out a study whose goal was to report on the functional results of rescue procedures of patients with cerebral palsy who suffered from a chronic dislocation of the hip joint. They retrospectively assessed 37 patients. The patients were between 8 and 22 years old (the average age was 12.2). They had been monitored for between 24–114 months (the average was 56 months). The patients were divided into three groups: (1) 14 patients who underwent a proximal femoral resection arthroplasty; (2) 10 patients who underwent subtrochanteric valgus osteotomy; (3) 13 patients who underwent subtrochanteric valgus osteotomy femoral resection of the head. All patients were assessed using the priorities of Caregiver and the Index of the Health Condition of Children with a Health Disorder and the PedsQL™ 3.0 module for cerebral palsy. The statistical analysis was carried out using the SPSS software. Regarding the Index of the Health Condition of Children with a Health Disorder, the PedsQL™ showed that the size of the sample group achieved the statistical strength of 0.65 with the significance of 0.05. A significant improvement occurred in the Index of the Health Condition of Children with a Health Disorder after the hip joint surgery and the PedsQL™ after the surgery in all patients. All three methods had similar results. There were 12 post-operation complications. The authors recommend using proximal femoral resection arthroplasty because the complications are less severe.

Balemans et al. (2015) studied the associations between the changes in the physical condition and the fatigue in children with cerebral palsy. This study was the secondary analysis of the randomized controlled study with original measuring, 6 months – after the intervention period – and 12 months. The study included 24 children (between 7 and 13 years old) with bilateral spastic cerebral palsy and 22 with unilateral spastic cerebral palsy. Their physical condition was measured using aerobic capacity, anaerobic threshold and isometric and functional muscle strength. The value of the level of physical activity regarding walking was measured by monitoring the ankle activity for one week. Fatigue was measured using the PedsQL™ with a multidimensional scale of fatigue. The longitudinal association was analyzed using regression analysis with a random coefficient. There was no relevant connection between physical activity and fatigue. Although regression analysis of random coefficients can be used for studying longitudinal relationships between parameters, it is not possible to determine a causal relationship. Children with bilateral spastic cerebral palsy could have more physical strength and a higher level of physical activity. On the other hand, children with unilateral spastic cerebral palsy did not experience improvement. Interventions focused on the improvement of the level of physical activity should be focused on children with both bilateral and unilateral cerebral palsy.

Ramstad et al. (2012) wanted to spread their findings about mental health and to study the quality of life in the area of mental health regarding recidivating muscular and skeletal changes in children with cerebral palsy. The study included 83 children and adolescents between 8 and 18 years old. They were assessed in a clinical examination, using interviews and questionnaires. They used the PedsQL™ 4.0 generic module. The questionnaires were filled in by the children and later by their mothers. Repeated musculoskeletal pain was associated with a lower quality of life and many problems regarding mental health. In their conclusion, the authors mention the importance of the co-operation between a (re)habilitation and paediatric psychologist.
Conclusions

The PedsQL™ questionnaires are globally used for measuring the quality of life of children with various types of illnesses and their families. The content analysis showed that the questionnaires are suitable for our target group, i.e. children with diabetes mellitus and cerebral palsy. Special modules of the PedsQL™ are focused on diabetes as well as cerebral palsy. These modules are designed for all age categories for up to 18 years, and the generic questionnaire that is used in these two groups can be used up to 26 years (young adults). All special modules and the generic questionnaire are always filled in by a child and his or her parent. In children with diabetes mellitus, the PedsQL™ 3.0 questionnaires with the multidimensional scale of fatigue combined with the generic questionnaire were used as well. They proved that fatigue in children with diabetes was comparable with oncological paediatric patients during treatment. In children with cerebral palsy, generic questionnaires and questionnaires focused on cerebral palsy (the PedsQL™ 3.0 for cerebral palsy) are used.

The authors of the studies that we used for this article agree on the very good utilizability of the questionnaires and the validity of their results.

Conflict of interests

The authors have no conflict of interests to declare.

Acknowledgements

This publication is part of the GAJU 044/2018/S ZSF entitled: “The use of the PedsQL questionnaires for measuring the quality of life of families with children with selected diagnoses”.

References


