QUALITY OF LIFE ASSESSMENT OF ELEMENTARY SCHOOL AGE CHILDREN WITH SPECIAL NEEDS

SUMMARY

Introduction. Health related quality of life is often considered to be a general informative health index. Therefore it is essential to involve children in its assessment as early as possible using measurements that are recognized world-wide. In the developed countries the indices of quality of life are used as a basis for the implementation of policies to meet children’s needs, which includes not only the needs of individuals, but are also used in the analysis of economic, social, cultural, educational and political aspects of the entire society.

The Aim of the Study. To compare self-reports of the quality of life of children with special needs aged 7–10 in Riga with the assessments of their parents and with the European normative data developed by the KIDSCREEN research group.

Materials and Methods. The theoretical aspects of the quality of life and the measurement techniques used are analyzed using KIDSCREEN. Information regarding the quality of life of children with special needs obtained by using KIDSCREEN-52 is also analyzed (questionnaires for children and parents were in Latvian).

Results. The assessments of the quality of life were analyzed by making comparisons according to the groups, parents and children (boys and girls from a comprehensive school or a specialized school, or who attended a day-care centre/lived at home). In general, self-reports of the children with special needs indicated a higher quality of life than their parents’ assessment within the KIDSCREEN dimensions 8–10.

Conclusions. Children, aged 7–10 with development disorders living in Riga, scored lower in the assessment of the quality of life in comparison with the European normative data, developed by the KIDSCREEN research group.

Keywords: quality of life, children with special needs, KIDSCREEN measurement

INTRODUCTION

Health related quality of life has often been mentioned as an essential index both in practice and in epidemiological investigations. Various authors emphasize that the term quality of life is fairly complicated as it includes psychological, social, cognitive, physical and economic factors (Bowling, 2005). The Life Quality group of the World Health Organization (WHO) states that the quality of life refers to the idea that the quality of life of an individual is linked with his perception of life within the context of his value system, as well as in connection with his personal goals, hopes, standards and interests (World Health Organization, 1993). But laws and regulations of Latvia define the quality of life as “a welfare index of a person, family, persons’ group and society, which includes physical and mental health, leisure time and its use, job as well as a link with society, the right to make and implement independent decisions and material guarantees” (Commission of Strategic Analysis, 2006). The National Development plan of Latvia for 2007–2013 envisages the commencement of the implementation of the set goal of growth for Latvia: to enhance the quality of life of its inhabitants, including children with an aim to approach the average level of the European Union (National Development Plan, 2006).
The majority of the measurements for the quality of life are created for an adult population. But they are often modified to include information obtained from children and adolescents. However, that is not right, since the assessment of children’s life quality should include such indices as the family, school, peers, etc. The latest investigations show that children are capable of an adequate and credible assessment of their welfare and functioning, provided that the questionnaire is appropriate for the child’s age and cognition level (White-Koning et al., 2007).

Already in 1993 WHO and the International Association of Children’s Psychology and Psychiatry suggested using self-reports for obtaining information about the quality of life of children as young as those attending elementary school and as often as possible (White-Koning et al., 2007). In 1995, in their survey of literature Bullinger and Ravens-Sieberer pointed out that in 90% of investigations on the children’s life quality the information had been obtained from parents or proxies (Bullinger, ravens-Sieberer et al., 1995). Eleven years later, in 2006, the Canadian researchers while analyzing reports on the investigations on children’s life quality, concluded that only 12 out of 33 measurements used in the investigations were children/adolescent self-reports (King et al., 2006).

From 2001 to 2004, a group of European investigators under the guidance of Ravens-Sieberer launched a new instrument – “KIDSCREEN” for the assessment of health related quality of life and authorized its use in 12 countries. In total, 22,110 children and adolescents have been tested and standard indices to quantify the quality of life of European children and adolescents between 8–18 years old have been determined. In addition, measurement versions were created for parents/proxies. KIDSCREEN is suitable for the acquisition of information both in clinical and epidemiological investigations (The KIDSCREEN Group Europe, 2006).

THE AIM OF THE STUDY
To compare self-reports of Riga children with special needs aged 7–10 with the assessment of their parents and the European Laws and Regulations of KIDSCREEN investigation group.

MATERIALS AND METHODS
Quality of life is an essential part of any health investigation and should be one of the indicators. An objective assessment of the quality of life and its regular analysis can affect health policy and legislation.

The quality of life of elementary school age children has been little investigated. School plays a major role in the intellectual, social and emotional development of elementary school age children. According to research data, in Latvia in a list of 11 basic values prepared by children and adolescents, school took 7th place (Vāsiļjevska, 2006). Children’s health affects their learning abilities. Research also points out that children’s association with school affects the assessment of their quality of life (Mansour et al., 2003). The population of elementary school age children is of interest also because these children are already able to assess their quality of life. But fellow-citizens’ or parents’ assessment is essential for the child’s functioning in society, e. g. school (Mugno et al., 2007). In the recent years many investigations have been carried out with an aim of comparing the children’s self-reports on their quality of life with the assessment of their parents/proxies. Many researchers point out that parents have a lower assessment on the quality of life of their children with special needs than the children indicate (White-Koning et al., 2007).

It should be noted that it is better to assess an effect of disease on man by using a measurement that is envisaged for healthy people, since the obtained data will show the differences between the feelings and functioning of a healthy and ill person (Arnaud et al., 2008). Therefore, at present there is no tendency to develop special quality of life instruments for a particular target group with a certain disease. To create instruments for assessing children’s quality of life is especially hard. Throughout childhood, physical and social abilities change, new interests emerge from communication with peers and the desire to become independent grows. Children are not little adults, so they need special instruments suitable to their understanding and experience (Jozefiak et al., 2008).
KIDSCREEN consists of three separate instruments: KIDSCREEN-52, KIDSCREEN-27 and KIDSCREEN-10. Using them it is possible to obtain self-reports regarding quality of life from healthy children and chronically ill children aged 8–18 according to 10 indices.

A more precise description of these life quality dimensions follows:

- Physical well-being – clarifies a child’s or adolescent’s physical activity, energy and fitness;
- Psychological well-being – checks a child’s or adolescent’s psychological satisfaction with life, including positive emotions;
- Moods, emotions – show to what extent a child or adolescent experiences depression and stress;
- Self-perception – clarifies how a respondent perceives his outer appearance and body image;
- Autonomy – assesses a respondent’s possibilities of spending his free time and being in society;
- Family, home-life – assesses the relationship with the parents and the atmosphere at home;
- Social support, peers – checks a respondent’s relations with other children or adolescents;
- Financial resources – assesses a respondent’s understanding of his family’s financial situation;
- School environment – clarifies a child’s or adolescent’s perception and cognitive abilities and his assessment of school life;
- Social acceptance – shows the degree of rejection a child or adolescent feels at school among his peers (Ravens-Sieberer et al., 2005).

A satisfactory assessment of the quality of life can be obtained by using KIDSCREEN-52 survey which yields the following data: physical well-being (5 questions), psychological well-being (6 questions), moods, emotions (7 questions), self-perception (5 questions), autonomy (5 questions), family, home-life (6 questions), social support, peers (3 questions), school environment/learning (6 questions), social acceptance (3 questions) and financial resources (3 questions) (The KIDSCREEN Group Europe, 2006).

RESULTS

The investigation of the quality of life of children with special needs involved 34 families, each having a child aged 7–10 (mean age 8.1 ± 0.9 years) with development disorders. The questionnaires were completed by 32 mothers and 2 fathers. Self-reports on the quality of life were submitted by 27 children with development disorders. 19 children came from full families, but 15 from single parent families where the bread winner was mother. 17 children of those involved in the investigation attended comprehensive schools and 8 special boarding schools. Five children attended day-care centres and four lived at home.

The mean indices of the self-reports on the quality of life by the children in all the dimensions of KIDSCREEN indicate that the highest assessments were in the dimensions of self-perception (51.3), school environment (50) and parent relations, home-life (49.2). Lower self-assessments were present in the dimensions that deal with social acceptance (40.1), physical well-being (40.5) and social support (41.0) (see Picture 1).
Assessment of the parents involved in the investigation of their children’s quality of life differed markedly (indices from 24.0 to 50.7) in various dimensions. Higher mean indices, similarly to those indicated by the children, were obtained in the dimension of parent relations, home life (50.7), the second highest index was in the dimension of school environment and learning (48.7). But the lowest assessment, as also indicated by the children, was obtained in the dimensions of social acceptance (24.6) and moods, emotions (28.3) (see Picture 1).

Comparing self-reports on the quality of life of children with development disorders with their parents’ assessment, it was stated that children assess their life quality higher in six dimensions out of ten according to the KIDSCREEN-52 measurement. Statistically feasible difference in the assessments is possible in four spheres: social acceptance, self-perception, moods, emotions. Parents assess psychological well-being higher than children themselves do, but the difference is not statistically feasible. It should be noted that both parents and children identically assess the quality of life regarding the level of an everyday autonomy.
Picture 2. Self-reports on the quality of life of the girls involved in the investigation in comparison with the European laws and regulations according to KIDSCREEN

The results of the investigation show that children with development disorders aged 7–10, living in Riga, present lower assessment of their life quality in comparison with the European laws and regulations of the children’s quality of life assessment developed by the KIDSCREEN research group (age group of 8‒11 years) (The KIDSCREEN Group Europe, 2006).

Picture 3. Self-reports on the quality of life of the boys involved in the investigation in comparison with the European laws and regulations according to KIDSCREEN

It should be noted that, comparing self-reports on the quality of life of Riga children involved in the investigation, with European laws and regulations according to gender, the participants of investigation – boys showed lower indices in all dimensions of the quality of life. The mean indices of the quality of life of the girls involved in the investigation were similar to the European laws and regulations in the dimensions of self-perception and parent relation, home life...
(see Pictures 2 and 3). The parents involved in the investigation also show lower assessment of their children’s life quality in all dimensions of KIDSCREEN in comparison with the European laws and regulations, but of a particular difference is the assessment in the dimension which describes social acceptance; the parents’ assessment is 24.6 points, but according to KIDSCREEN laws and regulations – 47.9 points (The KIDSCREEN Group Europe, 2006).

Comparison of the quality of life was made in three children’s groups in correspondence with educational institutions that children attend: children from a comprehensive school, children from a special school and children who attend day-care centre/live at home (see Picture 4). Children with development disorders who attend special schools show higher life quality indices more often than children from some other educational institution. However, a statistically feasible difference between assessments of these three children’s groups was found only in two out of ten KIDSCREEN-52 dimensions: self-perception (r=-0.558, p<0.05) and school environment/learning (r=0.604, p < 0.05).

Picture 4. Self-reports on the quality of life of children from different educational institutions according to KIDSCREEN-52

Quality of life assessments in two dimensions that describe the factors associated with school life: school environment/learning and social acceptance/bullying) were analyzed separately. The results show that girls and boys have different assessments of their experience at school. Statistically feasible difference was found in the answers to the following questions: Do you enjoy going to school? Are you satisfied with your teachers? Are you afraid of other boys and girls?
CONCLUSIONS

- This investigation is the first attempt to obtain self-reports on the quality of life of the children with development disorders who live in big cities and are of the elementary school age. The results of the investigation show that the research participants — children with development disorders aged 7–10, living in Riga, show lower results when assessing quality of life in comparison with the European laws and regulations (age group 8–11 years) developed by KIDSCREEN research group.
- When comparing self-reports on the quality of life of children with development disorders with the assessment of their parents, it was found that children assess their life quality higher in six spheres out of ten according to the KIDSCREEN-52 measurement. Statistically feasible difference in the assessments was found in three spheres: social acceptance, self-perception, moods, emotions.
- Children with development disorders who attend special schools, show higher life quality indices in six spheres out of ten according to the KIDSCREEN-52 measurement. Statistically significant difference in the assessments was found in two spheres: self-perception and school environment/learning.
- The low quality of life assessment of the children with special needs indicates that there is an urgent need for special programs and services at schools and residences.

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