

# SIGNIFICANCE OF CHILDREN’S HEALTH-RELATED QUALITY OF LIFE INDICATORS FOR FAMILY-FOCUSED PUBLIC HEALTH PRACTICE

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## Abstract

Recently, health-related quality of life has become one of the main underlying assumptions for public health practice, especially for gaining insights into highly complex health problems that are mainly determined by social factors. Children’s health is highly determined by social factors, especially those in the family environment. We follow a newly emerging trend to investigate health-related quality of life within a family-centered social system instead of individualistic approach; therefore, we chose KIDSCREEN52 questionnaire. We consider KIDSCREEN52 questionnaire significant for public health practice.

KEYWORDS: children, health-related quality of life, self-perceived health, family, public health.

## Anotacija

Su sveikata susijusi gyvenimo kokybė yra svarbi visuomenės sveikatos praktikos paradigma, ypač ieškant veiksmingų vis labiau kompleksiškomis tampančių sveikatos problemų, kurios nulemtos socialinių veiksnių, sprendimų. Vaikų sveikata veikiama įvairių socialinių veiksnių, vis dėlto ypač svarbi išlieka šeimos aplinka. Todėl pasirinktas *KINDSCREEN 52* klausimynas, kaip tyrimo strategija, įgalinanti vertinti šeimos įtaką vaikų su sveikata susijusiai gyvenimo kokybei. Straipsnyje atskleidžiama šeimos gyvenimo kokybės vertinimo rezultatų svarba visuomenės sveikatos praktikai. PAGRINDINIAI ŽODŽIAI: šeima, vaikai, visuomenės sveikata, subjektyvi sveikata, su sveikata susijusi gyvenimo kokybė.

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## Introduction

Since the 9<sup>th</sup> decade of the 20<sup>th</sup> century, health-related quality of life has been increasingly acknowledged as an important indicator of the assessment of public health service needs and a measure of intervention outcomes (Hennessy et al., 1994). This approach has gained even more power and scientific recognition in the 21<sup>st</sup> century. According to D. Vankova, improving the quality of life is considered as important as are some objective measures, such as mortality and morbidity (Vankova, 2016). Similarly, R. Leidl admits that many issues in health policy, prevention and promotion can be better understood by analyzing preference-based aggregation of quality of life (Leidl, 2009). Nowadays quality of life is considered especially important when dealing with highly complex problems. For instance, health system confronts clinically complex youth with high rates of behavioral issues, diverse mental health disorders, substance abuse, criminal behavior,

and other “at risk” behaviors (Siffman et al., 2010). According to H. Markel and J. Golden, today it is urgent to discuss children’s public health policy with a clear focus on the environment that makes children sick, rather than too much focus on sick children themselves (Markel et al., 2004).

Health-related quality of life is a pivotal concept for public health as it reveals interactions between social, economic, environmental factors and health. In general, health is considered to be one of the most important, and often the most important, dimensions of the quality of life. In 1993, the WHO proposed a definition of the quality of life that placed an emphasis on the importance of health in the social context: the quality of life is an individual’s evaluation of one’s place in life in the context of the culture and values system, in which an individual lives, as related to his or her goals, hopes, standards, and interests. That is a broad concept, immensely affected by a person’s physical health, psychological state, level of independence, social relationships, and relationships with the environment (Starkauskienė et al., 2011). Thus, health is considered to add value to the quality of life. The demand for conceptualizing health-related quality of life arises especially in cases of people with disabilities and illnesses, who tend to rate their quality of life as a good one (Furmonavičius, 2001). Thus, it implies that the relationships between health and social environment is not linear.

Even though recently the concept of health-related quality of life has been gaining prominence, still it faces two-fold problems: first, lack of theoretical conceptualization because quality of life has been frequently measured but seldom explicitly defined, and second, too much focus on the contextualization of the symptoms for individual diseases and illnesses (Lindstrom, 1992; Camfield, Ruta, 2007; Davis et al., 2006; Davis et al., 2007). Third, when we talk about research with children, we rely on questionnaires filled out by parents (Rajmil et al., 2013). We claim that KIDSCREEN52 enables to solve all three aforementioned problems. KIDSCREEN52 questionnaire encompasses the largest amount of social health indicators that have been recognized as significant for the quality of life, such as physical, emotional, and social wellbeing, satisfaction (at work or at school), interpersonal relationships (friends, family), security/social acceptance, autonomy or independence. Moreover, KIDSCREEN enables to apply a family approach instead of individual-centered approaches because the questionnaire is completed by both children and parents separately.

Quality of life is difficult to evaluate because when doing so, we need to simultaneously tap into both broad and unique complexities of the phenomenon. Recently new trends have risen in investigating the quality of life as a purposeful social system, where results are produced by the interaction between human health and social development (Butikis, 2009). We claim that KIDSCREEN52 enables

us to uncover the complexity and uniqueness of the variable, because it is family-focused and not solely an individual approach. Family-focused approach in public health is gaining more importance. It suggests that the family should be considered as the basic unit of health promotion at the individual and societal level, a valuable context in public health practice, and an essential part of public health policy, research, and teaching (Hanson et al., 2019). In order to investigate health-related quality of life as a purposeful social system, we need an instrument that allows us to study people of different ages and with a wide variety of other characteristics. KIDSCREEN52 is suitable for studying children from 8 to 18 years old. New research-based data allows us to assume that we can get coherent survey data that includes children of different ages. Some research studies conclude that children from 8 years old are capable of evaluating their self-perceived health, relating it to a wide scope of social factors, such as friends, environment, happiness, sport, sleeping, good food, etc. (Knighting et al., 2011; Kostmann et al., 2012).

Our study results are consistent with the new optimistic trends in children's capabilities to assess self-perceived health in relation to social factors. In this research 1763 children completed KIDSCREEN52 questionnaire. The results show that even though more than two thirds of the children indicate they do not have health disorders, less than two thirds of them evaluate their health as excellent and very good. This has implications for public health practice, namely, the self-perceived health of children (within the age range of 8–18) is more related to social and psychological factors than to health disorders or illness.

**The Aim of the Study.** We aim to investigate health-related quality of life within a family-focused social system. We raise the following research questions about the most important demographic factors for the functioning of the family as a system: How children's evaluation of their quality of life is predetermined by age and gender factors? How parents' evaluations of their children's quality of life are influenced by marital status, income and education of parents? How do demographic factors affect the cohesion between children's and parents' evaluations of health-related quality of life? In addition, we raise a question about facets of perceived importance, such as children's self-perceived health and communication about health within a family in relation to the evaluations of quality of life by both parents and children.

It is evident KIDSCREEN52 questionnaire can give valuable data for different social and cultural contexts; therefore, we aim to expand the scope of validated translations into native language (The European KIDSCREEN group, 2006).

## 1. Material and Methods

### 1.1. Study design

When dealing with investigations of children's health-related quality of life, in the majority of cases questionnaires are to be filled out by parents evaluating children's quality of life. On the contrary, the KIDSCREEN52 questionnaire is completed separately by both children themselves and parents. In order to obtain data not only from children but also from parents of the same family, the questionnaires were coded by pairing, i.e., identical codes were given to questionnaires, one for children and one for parents.

The quality of life is a highly complex phenomenon, and an enquiry should be focused on a variety of factors. We chose KIDSCREEN52 as it covers a broad range of already recognized dimensions of quality of life (Table 1).

*Table 1.* Structure of KIDSCREEN 52

<b>Dimensions of child's quality of life</b>	<b>Number of statements</b>
Physical wellbeing	5
Psychological wellbeing	6
Moods and emotions	7
Self-perception	5
Independence	5
Family life	6
Financial resources	3
Social support and peers	6
School environment	3
Social acceptance (bullying)	3

Following KIDSCREEN methodology, sociodemographic indicators were identified, such as: education, field of work, income, marital status (of parents) and gender, age (for children). We included additional statements about facets of perceived importance, such as communication in the family and children's self-perceived health: How often do children and parents talk about health in a family? How do children evaluate their own health? How do parents think children evaluate their own health? We indicated facets of perceived importance that have vast recognition in scientific literature Franz et al., 2017; Cleary, 1997; Albrecht, 1996). However, there is not enough data from the children's perspective.

The study design was approved by bioethical council of Health Science Faculty, Klaipeda University (Lithuania).

### **1.2. Setting**

The survey was conducted from October 1, 2015 to February 29, 2016 in secondary schools in Lithuania. The principal investigator contacted school administration for introducing the research aim and scope. For this study, schools were randomly selected by using the random number generator of the SPSS software. Based on the data provided by the Statistics Department, on 1 January 2015, there were 1,195 schools in Lithuania. 11 Lithuanian schools, which approximately constitute 1 per cent, have been selected for the investigation.

### **1.3. Participants**

The sampling method targeted all students of the selected schools to participate in the survey. The research sample is representative and consists of 8 to 18-year-old children and their parents from Lithuania. The children's age was selected in compliance with the recommendations provided by KIDSCREEN. Having chosen the margin of error not exceeding 3 per cent, the required volume of the sample was 1,838; however, due the fact that the surveyed population were pupils and a lower return was likely to be expected because of some pupils missing lessons for one or another reason, also due to the exclusion of pupils with disability or those taught individually at home from the survey, the decision was made to distribute more, i.e., 2,500, questionnaires (Grubliauskienė, 2019). The survey questionnaire was handed out to all pupils in grades 2–12 of the selected schools and to their parents.

### **1.4. Data Analysis**

Data analysis was performed by using 21<sup>st</sup> version of IBM SPSS for Windows software (Statistical Package for Social Sciences), and MS Excel program. In order to check for data entry mistakes, frequencies of the responses were calculated. Survey data was compiled into a united database, using participant identification based on the following key characteristics: municipality code, school code, and family code. The use of a unified family code allowed to identify the families who participated in the study (one of the parents and the child) as well as perform a family data analysis. Statistical data analysis involved the following statistical methods: Mann-Whitney U test, Spearman rank-order correlation coefficient, Kruskal-Wallis H test, and Wilcoxon Signed-Rank Test.

## 2. Results

### 2.1. Participants

1,763 children from 8 to 18 years have filled out the questionnaires. An even gender-based distribution of the respondents has been obtained, i.e., 51.14 per cent of girls and 48.86 per cent of boys participated in the study. Age-wise, the numbers were the following: 8 to 10-year-olds accounted for 17.9 per cent of those in the study; 11 to 14-year-olds constituted for 40.4 per cent of participants; and 15 to 18-year-olds comprised 41.6 per cent of all the participants.

1,564 surveys were completed by both the child and his/her parents. 38.5 per cent of parents had secondary education; slightly more than one fifth of them (21.2 per cent) had university education; 17.1 per cent were graduates of high schools; similar numbers had incomplete secondary and higher non-university education (accordingly, 9.8 per cent and 9.3 per cent), and only 4.2 per cent of the respondents had primary education. The analysis of the marital status of the surveyed parents revealed that the majority of them, i.e., 72.7 per cent, were married or were unmarried but cohabited; almost one fifth (18 per cent) of the parents were divorced; 5.6 per cent were not married and did not cohabit, and 3.8 per cent were widows and widowers.

### 2.2. Main results

The internal reliability of the instrument was evaluated by Cronbach's alpha criterion. The initial reliability assessment showed that the questionnaire used for children in this study had an overall compatibility score of 0.848, with subscales ranging from 0.797 to 0.890. The questionnaire used for parents had a total compatibility score of 0.811, with subscales ranging from 0.842 to 0.907. When investigating the compatibility indices of subscales, one subscale, i.e., 'Self-awareness' was low on the questionnaire for both children and parents (0.118 and 0.196, respectively). Removing this subscale and adjusting the overall scaling index showed that the overall scalability of the child questionnaire increased to 0.946 and the parent questionnaire to 0.938.

Self-assessment of health-related quality of life depended on pupils' gender; thus, boys scored statistically significantly higher than the girls on the following dimensions: physical wellbeing, psychological wellbeing, relationships with parents and living in family, financial resources, and social support and peers. Meanwhile, girls had statistically significantly higher scores than the boys on the following dimensions: mood and emotions as well as independence.

Direct statistically significant correlations have been found between the children's age and the following dimensions of self-assessed health-related quality

of life: mood and emotions ( $r = .206, p = .001$ ), financial resources ( $r = .152, p = .001$ ), and social support and peers ( $r = .062, p = .01$ ). Older children scored higher on these health-related quality of life dimensions; whereas younger children gave higher scores to: psychological wellbeing ( $r = -.182, p = .001$ ), relationships with parents and living in family ( $r = -.126, p = .001$ ), school environment ( $r = -.380, p = .001$ ) and social acceptance (bullying) ( $r = -.176, p = .001$ ) dimensions. No statistically significant correlation was found between the results of self-assessed dimensions of children's age and physical wellbeing as well as independence ( $p > .05$ ).

Statistically significant differences were found between children's self-perceived health and self-assessment of their health-related quality of life dimensions: physical wellbeing, psychological wellbeing, independence, relationships with parents and living in family, social support and peers, and school environment. To sum up, the children's health-related quality of life dimensions statistically significantly differed based on whether a child indicated he / she had or did not have long-term disability. Those children who indicated that they had no health disorders, scored higher on those dimensions. Statistically significant differences were not found in the analysis of three dimensions of children's health-related quality of life (mood and emotions, financial resources, and social acceptance (bullying)), depending on non-formal assessment of own health.

Self-assessment of children's health-related quality of life and its correlation with self-perceived health was investigated. The dimensions of physical wellbeing, psychological wellbeing, independence, relationships with parents and living in family, financial resources, social support and peers, school environment, and social acceptance (bullying) were evaluated with higher scores by those children who assessed their health as better. Statistically significant indirect correlation was found between self-perceived health and the dimension of mood and emotions ( $r = -.004, p = .001$ ). These children, who subjectively assess their health as poorer, score higher in this dimension.

The results demonstrate a trend of the children, who have conversations with parents about health, to score higher on health-related quality of life dimensions: physical wellbeing, psychological wellbeing, independence, relationships with parents and living in family, financial resources, social support and peers, and school environment.

No statistically significant differences were found in the self-assessment of the dimensions of mood and emotions as well as social acceptance (bullying), as dependent upon conversations about one's own health with parents. When analysing the data, statistically significant correlations between the four dimensions of the children's health-related quality of life and parents' education have been found.

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The findings demonstrate that the higher the level of the parents' education, the higher parents score on the dimension of financial resources ( $r = .113, p = .001$ ). The parents who have lower level education, score higher in the following dimensions: independence ( $r = -.146, p = .001$ ), relationships with parents and living in family ( $r = -.055, p = .031$ ), and social acceptance (bullying) ( $r = -.078, p = .002$ ).

Statically significant differences were found in the evaluations of the dimensions of physical wellbeing ( $p = .001$ ) and independence ( $p = .047$ ), depending on the marital status. The range means show that the assessment of the physical wellbeing dimension in terms of the range means of divorced parents (746.71) is higher than that of the parents belonging to other groups representing the marital status; thus, this group of parents evaluate the dimension of physical wellbeing as being higher. The results of the analysis of the independence dimension suggest that the mean range of married or cohabiting parents (787.68) is higher than that of those parents belonging to other marital status groups.

The analysis of the differences in the evaluations of the children's health-related quality of life, depending on objective assessment of their own child's health, indicated that the parents, who stated that their children had long-term disability, illness, or health disorder, scored higher on the following dimensions of the children's health-related quality of life: physical wellbeing, psychological wellbeing, independence, relationships with parents and living in family, financial resources, social support and peers, and school environment. The parents, who indicated that their child had no health disorders, had statistically significantly higher scores on the following dimensions of children's health-related quality of life: moods and emotions and social acceptance (bullying).

Investigation into the correlation between the evaluation of child's health-related quality of life and parents' opinion on the subjective assessment of health by their children revealed the following trend: the parents, who believed that their children evaluated their health as very good and excellent, gave higher scores to the following dimensions of children's health-related quality of life: mood and emotions as well as social acceptance (bullying). Parents, who believed that their children evaluated their health as fair and poor, had higher scores in the following dimensions: physical wellbeing, psychological wellbeing, independence, relationships with parents and living in family, financial resources, social support and peers, and school environment.

The analysis of the correlation between the assessment of children's health-related quality of life and parents' conversations with their children about health reveals that the more often parents talk with their children about health, the higher parents score on the following dimensions: physical wellbeing, psychological

wellbeing, independence, relationships with parents and living in family, financial resources, social support and peers, and school environment.

### 3. Discussion

According to S. Blue and colleagues, individualistic theories of human behavior have dominated both academic research and interventions of public health (Blue et al., 2016). On the contrary, family-focused quality of life approach reveals health as a phenomenon of collective intelligence. Our survey exposes the lack of collective understanding of health; for example, more than two thirds of the children indicate they do not have health disorders, while, on the contrary, two thirds of the parents indicate that their children have health disorders. This implies that parents and children lack comprehensive objective understanding of health. However, subjective children's health assessment of both children and parents is similarly distributed. Similarly, how parents and children evaluate social factors of health depends on communication in the family. The point of view of those parents and children, who communicate a lot about health, is more consistent. To illustrate, those parents, who have conversations with their children about health, give higher scores to the same health-related dimensions of children's quality of life as their children do. The communication between a parent and child functions as a transformative factor in health-related quality of life development. However, in present-day society, the family as a system experiences many tensions (Grigas, 2001; Juozeliūnienė, 2012) and thus needs support or interventions in order to develop fruitful communication between children and parents.

Some data from KIDSCREEN52 survey gives us insights into family support or intervention trends. Research reveals a tendency that family relationship is especially relevant for more optimistic children's evaluation of quality of life. The children, who scored high on mutual understanding, love, and honest behaviour within family, also had higher scores on the dimensions of physical and psychological wellbeing as well as mood and emotions. This implies that the evaluation of the quality of life is closely related with social awareness, which is the ability to view a situation from other people's viewpoint and to be empathic with them and to perceive similar and different notions.

KIDSCREEN52 survey results reveal that demographic characteristics, such as children's age and gender, are important for children's evaluation of health-related quality of life. The boys consider the following quality of life dimensions as the most important: physical wellbeing, psychological wellbeing, relationships with parents and living in family, financial resources, and social support and peers. The girls focus more on the following dimensions, in comparison to the boys: mood

and emotions as well as independence. Older children score higher on mood and emotions, financial resources, and social support and peers; whereas younger children give higher points to psychological wellbeing, relationships with parents and living in family, school environment, and social acceptance (bullying) dimensions. This implies the need for public health practices that are tailored to children's age and gender.

#### **4. Limitations**

Core limitation of this study is low Cronbach's alpha scores of the "Self-evaluation" subscale. For this reason, it was eliminated from the final analysis of the research results. Even though the methodology of the original instrument validation was upheld, it could be presumed that low reliability scores are due to the inaccuracies in understanding the meaning of some statements because of cultural differences, which are often difficult to predict and identify. In addition, the representativeness of the study is weakened by the fact that in the schools selected for the study every single class in the school participated in the study.

#### **Conclusions**

After carrying out the validation of the KIDSCREEN 52 instrument with a representative sample, we can conclude that the instrument is valid. Therefore, it is a reliable instrument to use in further population studies and is important for the family-focused public health practice.

Children's health-related quality of life is strongly determined by social factors. KIDSCREEN52 questionnaire results reveal that even though more than two thirds of the children indicate they do not have health disorders, less than two thirds of them evaluate their health as excellent and very good. This has important implications for public health practice: the way children (aged 8–18 years old) perceived their health was more related with social and psychological factors than with illness. That is a very important message for public health practice that should allocate social resources for health promotion.

KIDSCREEN52 survey results imply that the way parents evaluate their children's health-related quality of life is based on the importance of social and psychological factors and not solely on children's health disorders or illness. The analysis of statistically significant differences in the assessment of the children's health-related quality of life, depending on objective assessment of their own child's health, indicated that the parents who stated that their children had long-term disability, illness, or health disorder assessed the following dimensions of the

children's health-related quality of life higher: physical wellbeing, psychological wellbeing, independence, relationships with parents and living in family, financial resources, social support and peers, and school environment. Moreover, parents, who believed that their children evaluated their health as fair and poor, gave higher scores to the aforementioned dimensions. This implies a message for public health practice: social factors have a huge impact on positive children's health assessment by parents.

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