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Parents' perception of health-related quality of life in healthy children and adolescents

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The purpose of the study was to evaluate current health-related quality of life of healthy children and adolescents by parent proxy assessment. A total of 278 parents of healthy children (mean age 10.79±1.03 years) and adolescents (mean age 14.15±1.01 years) were invited to participate in the survey. All participants were recruited from two public schools of Ternopil city, Ukraine. Subsequently, 148 participants were excluded from the study due to incomplete data on the Child Health Questionnaire Parent Form-50 (CHQ-PF50). Therefore, the study included 130 parents of healthy children (n=55) and adolescents (n=75). Study results revealed that there were no differences in summary score of physical health and summary score of psychosocial health between children and adolescents, while comparing these summaries showed significantly worse psychosocial health than physical health in all groups of paediatric subjects (t=9.19; p=0.000000). We also identified direct correlation between summary score of physical health and summary score of psychosocial health (r=0.45; p=0.000000). Parents of healthy adolescents attributed lower scores of the CHQ-PF50 to the domains of global behaviour and emotional impact on the parent. Quality of life in healthy girls was associated with decreased global health domain when compared with healthy boys. In contrast to girls, boys were characterised by lower scores on the CHQ-PF50 for the domains of behaviour, limitations in family activities, and family cohesion. According to the parents' reports, the summary score of physical health and summary score of psychosocial health did not differ between children and adolescents. Psychosocial health of both children and adolescents was worse than their physical health.

Key words: QUALITY OF LIFE; HEALTH; CHILD; ADOLESCENTS

INTRODUCTION

Health-related quality of life (HRQOL) is considered as a multidimensional concept that incorporates experiences, beliefs and perceptions of physical, psychological and social aspects of health (1). Throughout the last decades, HRQOL has become an ever more important outcome measure not only in clinical conditions (2). In other words, better quality of life would be reflected in better maintenance of physical health and fitness, lifestyle, social support and connection, and control over emotions and conduct in a socioeconomic context (3).

Generic HRQOL measures can be useful in identifying the subgroups of children and adolescents who are at risk of health problems, and can assist in determining the burden of a particular disease or disability. This type of measure can also be used to evaluate health service needs and thereby influence public policy decisions, promote policies and legislation related to child and adolescent health, and aid in the allocation of health care resources. Furthermore, moni-

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toring population health status should allow us to track health trends and identify inequalities in health, to plan preventive strategies and, consequently, help improve population health (4, 5).

The impact of numerous factors on HRQOL of children and adolescents has been addressed previously, e.g., weight status (6), body image status (7), gender status (8), smoking status (9), physical activity status (10), negative psychological status (11), socioeconomic status and diseases of family members (12). Furthermore, chronic conditions could affect HRQOL of children and adolescents as well (13). Concerning the measurement of paediatric HRQOL, there is an ongoing debate in the literature as for who is the most appropriate informant when there is a substantial discrepancy between child and parent reports of child health problems or child HRQOL (14). It has been strongly emphasised that additional work is required to clarify the extent to which child and proxy ratings differ from each other in regard to HRQOL domain, health status, age and circumstances of the child (15).

Much of the research in this area is based on specific paediatric populations, with limited longitudinal studies conducted, and none in general Ukrainian children and adolescent populations. This study evaluated current HRQOL of healthy children and adolescents by parent proxy-assessment. Child's self-assessment of HRQOL was not provided in this study due to the age of enrolled subjects of 8-12 years, whereas only children aged 10 years and older may self-administer the Child Health Questionnaire (CHQ). As low levels of HRQOL may indicate an underlying physical and/or psychological health concern, these findings will be important in identifying what proportion of children and adolescents could be at risk of developing health problems.

SUBJECTS AND METHODS

This study was approved by the Ethics Committee of the I Horbachevsky Ternopil National Medical University of the Ministry of Health of Ukraine. All procedures performed in the studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards. All participants and their parents provided their informed consent prior to entering the research, with the understanding that its findings would be published.

A total of 278 parents of children and adolescents were invited to participate. All participants were recruited from two public schools of Ternopil city, Ukraine. Paediatric subjects enrolled in the study had to meet the following inclusion criteria: 1) normal office blood pressure; 2) normal body mass index (BMI, 5-85 percentiles); 3) absence of any chronic diseases; 4) absence of acute diseases during the last 4 weeks; and 5) absence of any known cognitive and mental disabilities in parents and children. Office blood pressure was determined by auscultatory method according to the European Society of Hypertension Guidelines for the Management of High Blood Pressure in Children and Adolescents, 2016 (16). Subsequently, 148 participants were excluded from the study due to incomplete data on the Child Health Questionnaire Parent Form-50 (CHQ-PF50). Therefore, the study included 130 parents of healthy children (n=55) and adolescents (n=75). Most caregivers were mothers with complete secondary school level and higher. Parents who do not speak and write in Ukrainian language were excluded from the study. The age range of the children was 8-12 years and of the adolescents 13-17 years. The main demographic and clinical characteristics of enrolled subjects are presented in Table 1. Initially, all combinations were designed by gender and age set for children and adolescents.

TABLE 1. General characteristics of paediatric subjects enrolled

Characteristics	All (N=130)	Children (n=55)	Adolescents (n=75)
Age, years	12.72±1.97	10.79±1.03	14.15±1.01
Gender, male/female	67/63	26/29	42/33
Weight, kg	47,58±11.25	39.33±9.44	53.20±8.72
Height, m	1.58±0.12	1.47±1.10	1.65±0.08
Body mass index	18.89±2.62	18.01±2.93	19.38±2.13
Systolic blood pressure, mm Hg	106.40±12.76	98.74±11.42	111.87±10.69
Diastolic blood pressure, mm Hg	65.98±9.18*	60.74±7.52	69.34±8.68

Values are presented as mean ± standard deviation for all data except for gender.

The CHQ-PF50 is a generic tool for assessing HRQOL, which has been translated, culturally adapted, and validated for the Ukrainian population, aiming at children older than 5 years and adolescents (17, 18). The CHQ-PF50 has a multidimensional characteristic and determines physical, emotional and social well-being from the perspective of parents or guardians. It is estimated that the CHQ-PF50 can be completed in 10-15 minutes. The questionnaire consists of 50 items that constitute 15 domains: global health, physical functioning, limitations due to emotional aspects, limitations due to physical function, bodily pain, behaviour, global behaviour, mental health, self-esteem, health perception, change in health, emotional impact on parent, time impact on parent, limitation in family activities, and family cohesion. The evaluation of each item uses the method of summed scores (Likert method). The final score of each domain ranges from 0 to 100. Higher scores indicate better

function or sensation and, consequently, better quality of life. The scores are used to compare groups, and there is no cut-off value. Most domains refer to the experiences in the last four weeks, except for the change in health domain, which refers to the experiences in the last 12 months. Ten domains are used to compose two summaries: physical and psychosocial. All parents were well informed by the administrator on how to properly complete the questionnaire. The baseline data and outcome measures were assessed by independent researcher to reduce misunderstanding and mistakes.

Below is the item content for the CHQ-PF50:

- In general, how would you rate your child's health?
- Has your child been limited in any of the following activities due to health problems: doing things that take a lot of energy such as playing soccer or running; doing things that take some energy such as riding a bike or skating; ability (physically) to get around the neighbourhood, playground, or school; walking one block or climbing one flight of stairs; bending, lifting/stooping; taking care of him/herself?
- Has your child's schoolwork or activities with friends been limited in any of the following ways due to emotional difficulties or problems with his/her behaviour: limited in the kind of schoolwork or activities with friends he/she could do; limited in the amount of time he/she could spend on schoolwork or activities with friends; limited in performing schoolwork or activities with friends?
- Has your child's schoolwork or activities with friends been limited in any of the following ways due to problems with his/her physical health: limited in the kind of schoolwork or activities with friends he/she could do; limited in the amount of time he/she could spend on schoolwork or activities with friends?
- How much bodily pain or discomfort has your child had?
- How often has your child had bodily pain or discomfort?
- How often did each of the following statements describe your child: argued a lot; had difficulty concentrating or paying attention; lied/cheated; stole things; had tantrums?
- Compared to other children of your child's age, in general how would you rate his/her behaviour?
- How much of the time do you think your child felt like crying; felt lonely; acted nervous; bothered or upset; cheerful?
- How satisfied do you think your child has felt about his/her school ability; athletic ability; friendships; looks/appearance; family relationships; life overall?
- My child seems to be less healthy than other children I know; My child has never been seriously ill; When there is something going around my child usually catches it; I expect my child will have a very healthy life; I worry more about my child's health than other people.
- Compared to one year ago, how would you rate your child's health now?
- How much emotional worry or concern did each of the following cause you: your child's physical health; emotional well-being or behaviour; attention or learning abilities?
- Were you limited in the amount of time you had for your own needs because of your child's physical health; emotional well-being or behaviour; attention or learning abilities?
- How often has your child's health or behaviour limited the types of activities you could do as a family; interrupted various everyday family activities; limited your ability as a family to 'pick up and go'; caused tension or conflict; been a source of disagreements or arguments in your family; caused you to cancel or change plans (personal or work) in the last minute?
- In general, how would you rate your family's ability to get along with one another?

The feasibility of CHQ-PF50 was determined from the percentage of missing values for each item and distribution of item responses. The range of measurements was further tested based on the percentage of scores at the extremes of the scaling range, that is, the maximum possible score (ceiling effect) and the minimum possible score (floor effect). Ceiling and floor effects were determined to show whether more than 15% of the participants achieved the highest or lowest score, respectively. Surveys with small floor or ceiling effects (1%-15%) are considered to meet acceptable measurement standards, whereas surveys with moderate floor or ceiling effects (more than 15%) are considered less precise in measuring latent constructs at the extremes of the scale (19). Scale internal consistency reliability was determined by calculating Cronbach's alpha coefficient. Scales with reliabilities of 0.70 or greater are recommended for comparing patient groups, while a reliability criterion of 0.90 is recommended for analysing individual patient scale scores (20). All data were expressed as mean (χ) ± standard deviation (SD). The Mann-Whitney U test was used for comparing the values of different groups. To compare summary score of physical and psychosocial health, Student's *t*-test was applied. Relationships between variables were examined using Spearman linear correlation analysis. For all analyses, a p value <0.05 was considered statistically significant. All statistics were analysed using the SPSS 12.0 package programme.

TABLE 2. Scale descriptives for CHQ-PF50 parent proxy-report sample

CHQ-PF50 domains and summaries	Total (N=130)				
	Mean	SD	% Floor	% Ceiling	α
Global health	60.70	24.00	0.77	4.61	0.88
Physical functioning	89.74	13.56	3.08	11.54	0.88
Limitations due to emotional aspects	80.69	21.10	0.77	13.08	0.88
Limitations due to physical function	85.77	21.51	0.77	10.77	0.88
Bodily pain	75.23	20.39	0.77	14.62	0.88
Behaviour	68.84	17.71	0.77	7.69	0.88
Global behaviour	59.81	22.98	1.54	13.85	0.89
Mental health	67.66	18.37	3.85	12.31	0.88
Self-esteem	75.90	18.76	3.08	8.46	0.88
Health perception	63.01	16.69	2.31	13.08	0.88
Change in health	61.15	23.10	3.08	12.31	0.90
Emotional impact on parent	65.83	21.23	4.61	3.08	0.88
Time impact on parent	69.52	17.34	5.38	1.54	0.87
Limitations in family activities	68.79	18.28	4.61	1.54	0.87
Family cohesion	70.05	23.59	3.08	2.31	0.89
Summary score of physical health	82.84	14.92	1.73	12.50	0.87
Summary score of psychosocial health	67.03	12.74	2.12	10.39	0.87

SD, standard deviation; α, Cronbach internal consistency reliability coefficient alpha.

RESULTS

The feasibility of CHQ-PF50 was evaluated by determining the percentage of missing data, ceiling and floor effects. Parents of healthy children left 0.8% of questions unanswered. Total missing item was less than 5%, yielding a satisfactory feasibility.

We did not show floor effects more than 5.38% for time impact on parent domain while ceiling effects were observed for a maximum of 14.62% for bodily pain domain (Table 2). This means that there was no significant floor or ceiling effect for CHQ-PF50 parent proxy-report. Table 2 also presents the internal consistency reliability alpha coefficients for CHQ-PF50 parent proxy-report sample. The total Cronbach's alpha coefficient for all CHQ-PF50 domains and summaries was 0.89.

Compared with parents of healthy children, parents of healthy adolescents attributed lower scores of the CHQ-PF50 to the domains of global behaviour and emotional impact on parent (Table 3). We found no differences in summary score of physical health and summary score of psychosocial health between children and adolescents, whereas comparing these summaries revealed significantly worse psychosocial health than physical health in all groups of paediatric subjects (t=9.19; p=0.000000). It means that healthy children and adolescents had some limitations due to emotional aspects, behavioural, mental health and self-esteem violations. We also identified direct correlation between summary score of physical health and summary score of psychosocial health (r=0.45; p=0.000000). This is due to the fact that deterioration of physical health is accompanied by deterioration in psychosocial health and *vice versa*.

Assessment of HRQOL in children and adolescents according to gender also revealed certain features. Quality of life in healthy girls was associated with decreased global health domain in comparison with healthy boys (Table 4). In contrast to girls, boys were characterised by lower scores of the CHQ-PF50 in the domains of behaviour, limitations in family activities, and family cohesion.

DISCUSSION

Healthy children and adolescents are a key resource for the future well-being of each country. Adolescents and young adults have until recently been overlooked in global health and social policy, one reason why they have had fewer health gains with economic development than other age groups. The UN Secretary-General's Global Strategy for Women's, Children's and Adolescents' Health initiated in September 2015 presents an outstanding opportunity for investment in adolescent health and wellbeing (21). However, because of limits to resources and technical capacities at both the national and global level, effective response has

TABLE 3. Quality of life scores obtained by the CHQ-PF50 in children and adolescents

CHQ-PF50 domains and summaries	Children (n=55)	Adolescents (n=75)	p
Global health	62.82±25.27	59.48±22.81	0.295767
Physical functioning	90.46±10.22	89.07±15.62	0.541877
Limitations due to emotional aspects	79.40±19.59	81.16±22.29	0.346450
Limitations due to physical function	83.74±20.56	86.42±22.39	0.333911
Bodily pain	73.07±19.15	75.80±21.05	0.338892
Behaviour	68.10±18.18	69.10±17.73	0.974401
Global behaviour	65.38±21.67	55.80±23.45	**0.025220**
Mental health	66.30±18.17	68.28±18.87	0.282241
Self-esteem	76.92±18.33	75.01±19.43	0.585260
Health perception	63.75±16.21	62.26±16.63	0.481478
Change in health	62.02±23.99	60.15±22.86	0.662104
Emotional impact on parent	69.72±19.54	60.44±20.42	**0.034821**
Time impact on parent	68.48±18.44	70.14±16.89	0.347842
Limitations in family activities	66.32±16.35	70.15±19.42	0.147676
Family cohesion	69.83±24.08	70.27±23.07	0.954726
Summary score of physical health	81.67±12.90	83.08±16.20	0.244189
Summary score of psychosocial health	67.51±11.57	66.41±13.70	0.633693

Values are presented as mean ± standard deviation; Mann-Whitney U-test was used.

TABLE 4. Quality of life scores obtained by the CHQ-PF50 in paediatric subjects according to gender

CHQ-PF50 domains and summaries	Boys (n=67)	Girls (n=63)	p
Global health	62.06±23.72	59.66±24.42	**0.000000**
Physical functioning	90.43±13.45	89.01±13.74	0.596532
Limitations due to emotional aspects	81.17±21.49	80.19±20.85	0.405613
Limitations due to physical function	84.71±23.25	86.90±19.62	0.676026
Bodily pain	75.52±21.41	74.92±19.42	0.794872
Behaviour	65.00±18.91	72.86±15.95	**0.015321**
Global behaviour	58.58±25.21	61.11±20.47	0.115576
Mental health	69.90±17.28	65.28±19.31	0.599759
Self-esteem	77.30±17.73	74.40±19.84	0.129156
Health perception	63.08±17.28	62.94±16.18	0.338401
Change in health	63.06±22.34	59.13±23.89	0.820046
Emotional impact on parent	63.82±21.13	66.91±19.82	0.457892
Time impact on parent	67.68±19.45	71.13±17.22	0.325417
Limitations in family activities	65.12±18.99	72.64±17.18	**0.024672**
Family cohesion	68.04±25.31	72.11±21.77	**0.049990**
Summary score of physical health	82.92±16.29	82.75±13.43	0.816437
Summary score of psychosocial health	64.83±13.29	67.24±12.24	0.232390

Values are presented as mean ± standard deviation; Mann-Whitney U-test was used.

many challenges. The question of where to make the most effective investments is now pressing for the international development community (22).

Adolescence is a significant developmental stage marked by physical, psychological and social changes. While adolescents are generally perceived to be healthy, this stage of development is also associated with the emergence of risk factors that may have long-term consequences for their wellbeing. Mental health problems in adolescents are often related to risky behaviours and the co-morbid physical health problems include obesity, diabetes, cardiovascular disease, and HIV (23). For example, a two-year longitudinal study found mood disorders to be associated with infectious disease and respiratory and weight problems, while disruptive behaviour disorders were related to higher risk-related behaviours (sexually transmitted diseases, drug overdose, suicide attempt) (24). Given the risk of psychological/mental and physical health problems that emerge in adolescents potentially continuing into adulthood, identifying and addressing early signs of HRQOL decline provides an opportunity to ensure that young people have a healthier progression through adolescence (25).

In terms of the opening questions about the measurement of HRQOL in children and adolescents, it can be stated that international instruments for measuring HRQOL in children and adolescents are now available, allowing the most important dimensions of the construct to be measured. Although no single quality of life measure can claim to cover the entire universe of HRQOL in all its possible facets, the quality of life dimensions that are relevant to a specific subject of investigation can indeed be measured (26). The CHQ-PF50 has been developed for parents of children aged 5-18 years with and without chronic health conditions using traditional item scaling analysis. It is also available in a wide range of languages for cross-cultural comparison. The CHQ-PF50 has demonstrated to be appropriate to good psychometric properties in many subject populations. The questionnaire is easy to administer, and there is minimal respondent burden (27).

In our study, the Ukrainian version of CHQ-PF50 evidenced minimal missing responses for parent proxy-report, demonstrating that parents of healthy children and adolescents are able to provide good quality data regarding their HRQOL. The range of measurement was demonstrated,

with no significant floor or ceiling effects across the CHQ-PF50 domains and summaries. Internal consistency reliability was satisfactory with Cronbach's alpha coefficient >0.70 for all scales. Results of this study are comparable with other translational researches (6, 27), and confirmed that CHQ-PF50 can be used to properly evaluate HRQOL of healthy Ukrainian children and adolescents.

In order to exclude the influence of underweight, overweight or obesity (6), as well as high blood pressure (28) on the quality of life, all subjects were included in the study only under conditions of normal BMI and office blood pressure. They did not have any chronic diseases at all, even acute diseases during the last four weeks. According to the parents' reports, the summary score of physical health and summary score of psychosocial health did not differ between children and adolescents. We found many researches studying HRQOL in children and adolescents with different chronic and acute diseases (6, 13, 18). However, studies of HRQOL in a healthy paediatric population are limited and quite controversial (5, 29).

It was estimated that physical health of children and adolescents directly depended on the psychosocial health. Moreover, children's and adolescents' psychosocial health was worse than their physical health. The results obtained highlighted the importance of a detailed study of the possible causes and ways to overcome this problem. Parents scored behaviour in adolescents worse, along with negative emotional impact on parent in the families with healthy adolescents when compared with children.

Numerous researches confirmed that girls reported lower HRQOL than boys (29, 30), but some of them report no difference in HRQOL between males and females (15, 31). We found no influence of gender on summary score of physical health and summary score of psychosocial health of healthy subjects. Healthy boys had lower scores in the behaviour, limitations in family activities, and family cohesion domains. Global health was lower in healthy girls as compared with healthy boys.

The progressive availability of an important amount of subjective indicators based on data provided by children and adolescents in more and more countries is frequently offering unexpected results, suggesting we do not know enough about the subjective well-being of the youngest generations. We need more conceptual debates, more research and more dissemination of research results to understand the perceived conditions of living of children and adolescents in different countries in the world, and in different socio-cultural contexts (32).

Our study had some limitations. The number of respondents (N=130) was inadequate to conclude about HRQOL in healthy children and adolescents at all. The reduction in the study sample size due to the loss of data may have masked the possible differences in the quality of life scores of the groups analysed. Further studies should include a greater number of healthy populations. In this research, we did not study children's and adolescents' psychosocial functioning and depression status, which may be related to their physical health, psychological health, social relationship, and overall quality of life. Future studies ought to focus more on the specific needs of children and adolescents, in order for example to be able to assess how important individual quality of life dimensions are for the further course and for the prognosis of disease development. Future studies should also take greater account of the social environment of child and adolescent when examining their HRQOL. One of the particular challenges facing HRQOL research in children and adolescents is the need to put emphasis on self-report and to take into account parent proxy-report. Further studies should focus on child self-report HRQOL and its agreement with parent proxy-report in healthy population.

CONCLUSION

According to the parents' reports, the summary score of physical health and summary score of psychosocial health did not differ between children and adolescents. Psychosocial health of both children and adolescents was found to be worse than their physical health. It means that they had some limitations due to emotional aspects, behavioural, mental health and self-esteem violations. Parents of healthy adolescents attributed lower scores of the CHQ-PF50 in the domains of global behaviour and emotional impact on parent. HRQOL in girls was associated with decreased scores in the global health domain, while in boys it was characterised by lower scores in the behaviour, limitations in family activities, and family cohesion domains.

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SAŽETAK

Kako roditelji percipiraju kvalitetu života povezanu sa zdravljem njihove zdrave djece i adolescenata

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Cilj ovoga istraživanja bio je utvrditi kako roditelji procjenjuju sadašnju kvalitetu života povezanu sa zdravljem svoje zdrave djece i adolescenata. Ukupno je 278 roditelja zdrave djece (srednja dob 10,79±1,03 godina) i adolescenata (srednja dob 14,15±1,01 godina) pozvano da sudjeluju u istraživanju. Svi sudionici izabrani su iz dvije javne škole u gradu Ternopilu, Ukrajina. Naknadno je 148 sudionika isključeno iz studije zbog nepotpunih podataka u upitniku Child Health Questionnaire Parent Form-50 (CHQ-PF50). Tako je istraživanje obuhvatilo 130 roditelja zdrave djece (n=55) i zdravih adolescenata (n=75). Rezultati studije pokazali su kako nema razlike u sumarnom zbiru za fizičko zdravlje i sumarnom zbiru za psihosocijalno zdravlje između djece i adolescenata, dok je usporedba ovih sumarnih rezultata pokazala značajno lošije psihosocijalno zdravlje u odnosu na fizičko zdravlje u svim skupinama pedijatrijskih ispitanika (t=9,19; p=0,000000). Također smo utvrdili izravnu korelaciju sumarnog zbira za fizičko zdravlje i sumarnog zbira za psihosocijalno zdravlje (r=0,45; p=0,000000). Roditelji zdravih adolescenata pridali su niži zbir na upitniku CHQ-PF50 za domene globalnog ponašanja i emocionalnog utjecaja na roditelje. Kvaliteta života kod zdravih djevojčica bila je udružena sa smanjenom domenom globalnog zdravlja u usporedbi sa zdravim dječacima. Za razliku od djevojčica, dječaci su bili obilježeni nižim zbirom na upitniku CHQ-PF50 za domene ponašanja, ograničenja u obiteljskim aktivnostima i obiteljske kohezije. Prema izvješćima roditelja sumarni zbir za fizičko zdravlje i sumarni zbir za psihosocijalno zdravlje nisu se razlikovali između djece i adolescenata. Psihosocijalno zdravlje djece i adolescenata bilo je lošije od njihova fizičkog zdravlja.

Ključne riječi: KVALITETA ŽIVOTA; ZDRAVLJE; DJECA; ADOLESCENTI