Quality of life in childhood and adolescence: from concept to practice

Kvalitet života u detinjstvu i adolescenciji: od koncepta do prakse

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The concept of quality of life
The definition of quality of life

Quality of life (QOL) is an extensive and broad ranging concept with the important position in the studies of psychology, economy, and medicine. QOL is an interdisciplinary concept resulting from numerous social, economical, health and environmental factors that cumulatively and, often in unknown ways, can interact to affect both human and social development at the level of the individual or society. However, this definition of QOL provides only the framework for genesis and participants, but does not describe the core of concept. The essence is determined to refer to the primary focus for forming the QOL conceptual models: a) economical with „not how much, but how good; not with the quantity of goods, but with the quality of lives”; b) sociological with „social utility and preference” and c) psychological with „happiness and satisfaction”. 2

Refer to health related QOL concept, the World Health Organization defined the QOL in 1991 as “the individual perception of his or her position in life, within the cultural context and value system he or she lives in, and relation to his or her goals, expectations, parameters and social relations. It is a broad ranging concept affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships and their relationship to salient features of their environment”. 3, 4

The subjective nature of QOL (“the individual perception” is crucial for understanding this concept) 3, 4. QOL is open, self-esteem concept.

At the same time, the subjective nature of QOL causes various difficulties in QOL assessment and evaluation. Health-related QOL concepts summarize those aspects of life quality or function which are impacted by one’s health status (i.e. the impact of a person’s health on his/her ability to lead full life, and “well-being” with or after the treatment). 5

The QOL concept is much broader and encompasses both medical and non medical aspects. The QOL concept is complex, multidimensional construct and actually is the holistic approach to a person.

Historical view

Is quality of life a new expression for old ideas? Yes, although the expression was introduced for the first time in 1975 as a key term in medical indexes. Despite the fact that similar theoretical (philosophical) discussions had been taking place even in ancient time (including some scientific studies), quality of life in today’s sense became a topic for research only in 1980’s. So to say, that is an old-new concept with the same essence “well-being” – for persons and their environment, but presented by a new, subjective view for the person whose QOL is evaluated.

The oncologist were the first physicians that have been confronted with the dilemma: “Should we add years to life or life to years?” 4

Since then, QOL has become a relevant factor in clinical research and patient treatment QOL is relevant how the patient feels, if she/he is satisfied with the treatment, it is important what the patient can actually expect from the treatment. At this time QOL is characterized by different approaches, thus it could be said that in a medical work term QOL does not have a single and/or distinct meaning. It ranges from a wide holistic approach to the quality of life, to more specific meaning relative to the way how the level of health of an individual would affect his/her level of life comfort. Sometimes, the term QOL is substituted with other terms such as health or functional status or simply a sum of all these as-
pects of QOL or function that affect human health. However, the widespread attitude is that: “QOL concept is much broader and encompasses both medical and non medical aspects, including physical, psychological and social functioning and also the perception of own health status, pain and, in the first place, satisfaction or dissatisfaction with the areas of life that are important to him/her” (Figure 1) 2, 4.

Clinicians base their assessment on the extent to which the disease process has been halted, i.e. their main point of reference is a disease.

It is very important to understand a matter of fact that the patients QOL assessment is more closely related to the fact how these patients feel their conditions have impacted on their lives, rather than to the presence of symptomatology.

Based on this, we could discuss additional benefits of the patient’s subjective value of its QOL to the physicians as well: it can help in prioritizing the problems, it can improve communication, provide better compliance, assist in recognizing patient’s preferences, indentify the differences, etc.

**Assessment of quality of life measurement issues**

The holistic orientation of the concept in practice suffers from various problems; within them the assessment and the measuring are prominent. Despite these facts there are numerous useful instruments (scales, inventories, questionnaires) in practice for assessment of different areas of life functioning (health, psychological, social, pleasure, satisfaction, etc.).

**Scales**

a) Relative to the population that is targeted, scales could be generic or oriented to the specific diseases. There are two different scales for assessment QOL: generic scales (developed for research and comparison between different diseases) vs disease-specific scales (developed for those individuals with particular disease or condition)

Generic scales are so-called “general scales” developed for research focused on differences between diseases and states and, in certain circumstances, for research on QOL in healthy population. These scales are the main topics in all studies.

Scales which have been developed specifically for certain diseases are much more “sensitive” and productive when come to the discovery of the problems specific for these disorders or conditions. However, they can be used only to “differentiate” relevant from irrelevant integers within one disorder or condition. It is nearly impossible to compare two disorders or conditions using these scales, therefore they are recommended only as an addition to the generic scale.

b) Relative to the estimation of capabilities and needs they can be functionalist-approach scales and needs-based approach scales.

**Functionalist approach scales** (i.e. individuals being able to perform roles that are deemed “normal” – physical mobility, socialization, employment) vs needs-based approach scales (individuals being able to satisfy their physical needs, psychological needs such as self-respect, autonomy, pleasure, socialization...)

Based on their orientation, scales could be: (so-called) functionalistic scales (one that refer to the level of function-ability/independent movement...) or on-need-bases scales (which are more accurate data and fulfill basic goal which is auto-estimate). For QOL estimating at functionalistic scales
the most important factor is if the disease or disorder has influence on the motor conditions (e.g. moving, working, etc.), on-need-bases scales offer more complex QOL estimating. These estimates target personal ability and capacity to fulfill its own needs (physical, as well as sociological, such as self-integrity, independence, social relations and content)⁵,⁶.

Commonly used instruments in pediatric practice are: Pediatric Quality of Life Inventory (PEDSQOL)⁷, and Child Health Questionnaire (CHQ)⁸. CHQ besides “typical” items, estimates family activities as well, family relationship, as well as behavioral dimensions, quality of life questionnaire for children and adolescents (KINDL)⁹.

Additional sources for estimating which could be used (are used) are estimating QOL in children by parents (parents asked as proxies about QOL of children) and physicians (which are mostly aimed towards “objective” increased of conditions – by symptoms and results)¹⁰,¹¹.

**Quality of life in practice research and implementation**

**Developmental age and quality of life assessment**

Youth and their well-being are in the first place in all national strategies.

Research on youth and especially on childhood is not easy, not only because of methodological issues, but also because of developmental specifics. This brings out most dilemmas and questions. Some interesting are the ethical questions, i.e. children rights (to understand problems, consent for participation in a research...).

The basic question for all researches on childhood is the ability for self-assessment. What is the appropriate age when children can provide realistic and valid information about their QOL?

Most interesting for QOL research on childhood and youth are the “groups at risk”. In everyday practice these groups, or more precisely the areas of research on childhood and adolescence are: children and adolescents in social welfare system, children and adolescents with disabilities or special needs and their families¹²,¹³, and children and adolescents with different chronic health conditions and their families¹⁴,¹⁵.

Research is an intermediate step between concept and real practice. In practice, QOL assessment is the basis for development, implementation and evaluation of “focus-oriented” programs and actions (QOL–related services). It is a multidisciplinary activity assembled to create better life in child and youth. The real practice is evaluation and implementation of research results in different areas of life – for improvement QOL.

**Conclusion**

The core of QOL concept is understanding of a human being and its needs, from different perspectives, keeping in mind that a human being is in constant interaction with the surrounding, according to the holistic-ecological approach.

In practice, the goal is to create a patient more comfortable (psychological, physical and social) environment from a holistic-ecological perspective.

**REFERENCES**
