MEASURING THE QUALITY OF LIFE IN CHILDREN

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ABSTRACT
Quality of life measurements have been using mostly in the evaluation of medical care for chronic illnesses in recent years. Although various numbers of health-related quality of life scales have been developed for adults, quality of life measurement for children is one of the new working fields. Multi-dimensional effects of the illnesses on children and families will be understood with the measurement of health-related quality of life for children who have a chronic illness, so planning, applying and evaluating the results of nursing care will guide. Despite children are in the process of continuous growth/development and they spend their time in different leisure facilities instead of adults, health-related quality of life scales developed for adults are not appropriate for children. Therefore, specialized scales should be developed for children.

Introduction
Everybody can meet such a child like her. Two-year old S.T. has cerebral palsy. She has serious limitations in her physical functions. She is a smart child. Whenever you look at her, she looks smiling and happy. Moreover, she spends good time with his family. But can it be really understood how she really feels? Is her life acceptable as it is seen? How can it be defined her quality of life? (1)

There are various problems in measuring the quality of life for children (1, 2, 3). Children are generally the silent participants of the health care system. They mostly communicate via their parents and the ones who take care of them about their state of health (4). Furthermore, it can not be possible to define their quality of life from their perspective although little children can not express themselves (1, 2).

What is quality of life?
Quality of life is a complex wide-ranging concept that involves the multi-dimensions of life (1, 5, 6). It is a subjective perception about how individual feels about his/her related and non-related state of health (1, 2, 7). The concept of quality of life, in other words: from an individual perspective includes individual’s feelings about his/her life, the values related health or vice versa, emotional and social functions, and the relations with family and friends (5, 6, 7, 8).

The evaluation of the quality of life and the understanding of the effects of health on individual’s quality of life inside the concept of health-care have to be realized (1). Hence the concept of health-related quality of life is also a multi-dimensional concept. Additionally, it requires physical symptoms of an illness, its physiological effects, functional condition of the individual and its social functions (5, 8). World Health Organization (1948) defines health not only as a non-existence of an illness and/or a disability but also a condition of good health physically, mentally and socially. The concept of health-related quality of life also includes this definition. Individual’s health-related quality of life is influenced by the one’s physically good health, mental condition, social and emotional functions, cultural values, social support systems, the effects and the side-effects of the illness and its treatment (5, 7).
Quality of life in children

Quality of life in children is defined as a multi-dimensional situation that is composed of social, emotional and physical functions of the child, adolescent and the family (1, 9). Defining the quality of life in children is quite hard due to the regular process of their development and developmental differences in children (1, 6). Quality of life is a concept that is sensitive to the developmental changes (1, 4, 9). As a result of physical and intellectual development following child’s growth, his/her perception of health and being healthy also change. Thus, this effects child’s perception of health-related quality of life in different phases of his/her life. His/her definition of quality of life changes from childhood to adulthood in time (1). Even the change rate in children of the same ages is different. Therefore, the improved measurement tools should have the quality of responding these changes and variations (1, 6).

When compared with adults, there are a lot of theoretical and practical differences in defining quality of life in children (2, 7, 8, 9). The environment plays an important role on children compared with adults. Environmental factors have profound and long-lasting effects in social and physiological development of children. Quality of life in children depends on the complex connections between the children themselves and their social environment. Functions and behaviors of children are closely related to their social environmental that they take part in. Development theorists have propounded that the child and his/her environment are complicated owing to the mutual relations that are naturally developed between the children themselves and their peers. Children are the active agents who are shaped by the environment, and the ones who shaped their own environment from this theoretical perspective. Thus, researchers have proposed that the environmental factors such as families, peer relationships, neighbors and health organizations should be discussed in defining quality of life in children (2).

Children grow and mature in time. Great developmental differences are matters of childhood as well as normal behavioral changes in each age group. Chronic illnesses in childhood may influence normal growth and development of children conversely (5, 7, 8, 9). Therefore, all the needs for each age group should be taken into consideration while improving measurement tools (7, 8, 9).

One of the major differences in defining quality of life in children is the activities and the relationships of the child. Adults have various kinds of social relationships (husband-wife, family and friends), responsibilities (home and work) and hobbies as well as a job and a career, and they also take part in social events. Children go to school, play games, improve their relationships with family and friends, and participate in sports activities and social events. The children who have chronic illnesses may have some difficulties in cases such as family and friends relationships, choice of school and occupation, participation in daily activities (school, games, sports, domestic work, ride a bicycle, go shopping with friends, learn how to drive a car etc). Chronic illnesses may play a great role on the development of independence during the adolescent period. In this period, the development of the body image is as important as ego development. The concept of ego in adolescents may be damaged due to the effects of an illness or a treatment on body image (8).

Another major different between children and adults is the important role of families on providing and improving the care of healthy and/or unhealthy children (3, 8). This case arouse this question in mind; “Should health-related quality of life be evaluated as family based?”. According to the application results, little children can not define health-related quality of their lives, so the need of their families is needed.
However, the evaluation of family in children at school age and adolescents are different from the children’s own definitions. The quality of life measurements should be done from the child’s perspective (1, 7, 8). For instance; if the child is ill or he/she cannot give information about his/her state of health (whether the child is too little or has a learning disorder), information about the child can be taken from a proxy respondent (usually parents). However, the view of the parents may be influenced by some beliefs such as; their stress in life, their expectations from the child, their mental health and their attitudes towards health professionals. Therefore, both the parents and the child can be evaluated by the knowledge that is taken from the proxy respondent. The choice of the proxy respondent can change according to the age of the child. For instance, parents are generally chosen for little children as a proxy respondent, a sister/brother or a friend (the ones who share something together or understand the view of the child or adolescent) can be chosen for adolescents. Besides, including the views of the teachers in defining cognitive competence and relationships with the friends may be helpful (1).

### Measuring the quality of life in children

Standardized forms are used in measuring the quality of life. 4 methods are frequently used in the application of the forms. Each of these methods has its own advantages and disadvantages (1).

1. **Question forms that are answered individually:** It is generally suitable for older children and adolescents. Respondents choose the best appropriate choice for themselves. There is a possibility for false response. It is a cost-affected method.

2. **Face-to-face Interview:** Question forms are generally filled by the interviewer for little children. The child can be influenced by the interviewer, so incorrect answers may be given. Though it needs time, the cost is high.

3. **Telephone Conversation:** It is a rarely used method. It is quite hard to expect children to accomplish. They may have difficulties in understanding the instructions. Thus, it is not appropriate to use this method on children.

4. **Via Computers:** This method is mostly applicable for older children. However, it is a costly method.

It is not adequate to use only forms in defining health-related life of quality of children. Various kinds of games, figures, videos and images are advised to use as a part of the measurement (1).

As a result, family functions, peer-relationships and social functions are taken into consideration in defining health-related life of quality of children, but it must not be forgotten that the effects of the illnesses and the treatments can be different for each child. In the measurement tools that will be developed for children, childhood activities must be well-defined, and developmental and behavioral differences should be taken into consideration. The definitions of quality of life must not be restricted in systematic or quantitative questions, the limitations of it must be discussed, and objective clinical assessments and quantitative interviews should also be included (1, 2, 8).

### REFERENCES