Factors affecting the quality of life in children with congenital heart disease

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Abstract

Congenital heart diseases are the second leading cause of death in infancy and childhood, as well as the only cause of heart disease in the pediatric population in the developing countries.
Aim : The aim of the present study was to review the literature about factors that affect the quality of life in children with congenital heart disease.
The method of this study included bibliography research from both the review and the research literature which referred to the factors that affect the quality of life in children with congenital heart disease.
Results: Although assessment of the children's quality of life began recently and more specifically during the 1980's, nowadays it is widely used in the daily clinical practice as a means for comparison of treatment options and evaluation of their effectiveness. In regard to factors affecting the quality of life in children with congenital heart disease, research studies have showed that the change in body image including the delay in physical growth exerts a negative influence on their quality of life. Furthermore, other factors that affect negatively their quality of life are the lack of social acceptance, the limitations imposed by the physical impairment, as well as the anxiety and depression that children usually experience. Other important factors that play a significant role not only on their quality of life but also on the diagnosis and the outcome of the disease are the socio-economic and educational status of the parents. In the literature is cited that quality of life in children with congenital heart diseases should be assessed according to age, growth level, severity and acceptability of the disease, as well as personality features.
Conclusions : Assessment of the quality of life by health professionals should be an integral part of the patients' treatment since it allows the identification and evaluation of personal considerations, priorities, or problems depending on the physical growth stage in regard to the severity of the disease.

Keywords: quality of life - congenital heart diseases- factors

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Introduction

Congenital heart diseases are the second leading cause of death in infancy and childhood, as well as the only cause of heart disease in the pediatric population in developing countries. The frequency is 10 per thousand, i.e. 10 infants every 1,000 births have congenital heart disease[1-4].

In the United States there are approximately 600,000 adults with congenital heart disease, while approximately 20,000 surgeries take place every year. It is estimated that only the 60% of the 25,000 infants that are born with congenital heart disease will reach adulthood. Survival of individuals with congenital heart disease is strictly associated with the type and the severity of the congenital heart disease[1-4].

Congenital heart diseases are defined as the conformation abnormalities of the heart or the blood vessels, formed during fetal life (3 to 6 weeks of pregnancy), i.e. when the heart or the major blood vessels of the heart can not develop properly before birth. The abnormalities involving the arteries, the valves, the coronary and the major vessels of the heart can be either simple or complex[1-4].

Congenital heart diseases are clinically classified depending on the existence of cyanosis in non-cyanotic, which are characterized by physiological amount of oxygen in arterial blood and normal skin color, and in cyanotic, which are characterized by reduced oxygen in arterial blood and cyan skin color[1,5-7].

The most common non-cyanotic congenital heart diseases are the interventricular septum communication (30-50%), the open ductus arteriosus (10%), the atrial septal defect (7-10%), the pulmonary valve stenosis (7%), the aortic coarctation (6%) and the aortic valve stenosis (6%). The most common cyanotic heart diseases are the Fallot's tetralogy (5%) and transposition of great vessels (5%). The rest of the congenital heart diseases are a group of rare and complex disorders of the anatomy of the heart, such as common trunk arteriosus, single ventricle, triglochinas valve atresia, total abnormal confluence of pulmonary veins[1,4-7].

Although, the etiology of these diseases in 80-90% of the cases is unknown, in the literature, it is cited that genetic and environmental factors are implicated for the incidence of congenital heart disease. More in detail, if there is a child in the family with congenital heart disease, the chance of a second child being born with congenital heart disease is 3-4 times more, compared to families that have healthy children. As to the external factors, the most frequently associated with congenital heart disease are congenital rubella, the use of various drugs by the mother during the first trimester of pregnancy, and maternal diabetes mellitus. Chromosomal abnormalities coexisting with congenital heart disease is the Down syndrome, the Turner Syndrome, the Marfan syndrome, and trisomy 18 and 13-15[1-6].

The treatment of congenital heart disease can be either conservative or surgical. Recent research data show that from 1993 to 2003, the death incidence for patients with congenital heart disease has decreased by 31% due to the improvements in the prognosis and treatment of the disease[5-7].

Health-related quality of life of children with congenital heart disease

Health-related quality of life (HRQOL) reflects the patient's perception of the impact of the illness and its treatment on their life. Though considerable advances were made during last decades in applying measurement of quality of life in daily clinical practice, only until recently its' assessment has been progressively acknowledged as an essential health outcome measure in clinical trials and health services research and evaluation. Moreover, it reflects an option for recognizing children that need support due to the severe difficulties they experience[8,9-12].

The scientific progress in Pediatrics and especially in areas such as Neonatology and Oncology has managed life expectancy of the children-patients. Since the 1970's, the progress in surgical techniques, as well as the improved diagnostic techniques have led to significant improvements in the treatment of congenital heart disease. As a result, the rates of children' s morbidity have been decreased, whereas the number of infants and children that reach adulthood and integrate into the social environment has significantly increased. These advances in conjunction with the social changes and the new interpretation of the children's rights, make measurement of the children's quality of life obligatory[9,12-18].

Nowadays, the results of surgery are not evaluated solely driven by the increase in life expectancy, which was the highest priority before 1980's, but also take into account improvements of the quality of life. According to the literature, survival is not always synonymous to high quality of life due to the complex difficulties that these patients experience such as physical, cognitive impairment or psychological problems. More in detail, the growth of children with congenital heart disease is often characterized by relevant research as "abnormal" because of the demanding lifestyle changes imposed by the cardiac deficit, the frequent hospital admissions, abstention from pleasurable activities, isolation from the friendly environment, etc. All the above factors exert a negative impact on their quality of life[9,11-18].

Measurement of quality of life should be according to the children's development stage and growth level, the severity of the disease, their family environment, the acceptability of the disease, and the personality features. Furthermore, assessment of quality of life in children with congenital heart disease should be continuous because, as it was previously mentioned the surgery might ensure survival but it does not allow "normal life" for the reason that post-operatively are required frequent and planned reassessments of the disease, as well as implementation and compliance with the treatment guidelines[9, 12-18].

Children's perception regarding the disease differ their parents' perception. Thus, the parents may understand correctly the objective extent of the problem, but the subjective extent, as the children perceive, is the main source of information. Despite the fact that, children's' active involvement in decisions about their treatment and care, is gradually recognized in modern society, their personal considerations and views are constantly under control and / or dispute in many parts of the world. Several studies have concluded that the children's opinion should be seriously taken into consideration, as it has been shown that even children in primary school, are able to substantially assess the state of their health. According to the principles of the UN Declaration on the Child's Rights, the opinion expressed by the children-patients contributes to the improvement of their quality of life. However, assessment of both parents and children is the one that provides the complete picture of the situation, and the one that the health professionals require in order to plan individualized nursing intervention programs[9, 19-22].

Factors affecting the quality of life of children with congenital heart disease

Numerous factors may affect health-related quality of life in children with congenital heart disease accordingly to the stage of their growth. For example, during infancy, children are totally dependent on their parents, while as they are entering childhood, they have different needs such as relationships with other children, obtaining independence, knowledge, etc. Similarly, the features of their personality, which determine the degree of adaptation to the disease and the improvement of their quality of life, should be thoroughly considered[9,23].

According to the literature, the main factors affecting quality of life in children with congenital heart disease are the following:

The predominant factor that is significantly associated with the quality of life is the delay in physical growth regarding the height and the weight, which varies depending on the type and severity of the disease. Children with cyanotic congenital heart disease have the more pronounced delay in physical growth, which is visible from a very young age[9,23,24].

The change in the body image in both the pre-operative and post-operative period is the main problem experienced by children with congenital heart disease at all stages of physical growth. Post-operatively, the change in body image characterized by the large incision in the chest, is in most cases a "stigma" that reveals the disease, and gives rise to comments or questions in the child's environment, especially at the school. As a result, children become more introvert or isolated from the others for the reason that they feel shame and guilt about their body image. Taking for granted that they do not have the capacity to cope with the change in their body image, they often need psychological support by the family or a specialist[9].

Children with congenital heart disease experience anxiety and depression due to the frequent re-hospitalization, the daily medication and the limitations imposed by the disease. In the majority of cases, depression is under recognized, either because health professionals consider it inevitable or because children are not able to seek help. On the contrary, patients with complex heart diseases and those who are at the end-stage tend to express anxiety and depression, as the fear of imminent death is quite strong[25].

Poor quality of life is often attributed to the lack of social acceptance, especially in the school environment. More in detail, the physical impairment that these patients experience make them unable to fulfill their duties. As a result, they usually have to refrain from activities they used to enjoy before the onset of the disease, thus feeling loneliness, rejection, and social isolation, which make social integration even more difficult[9, 24, 26, 27].

School performance is also very often impaired and the children usually fall behind the progress of their healthy schoolmates due to the fact that they have a long treatment process involving frequent hospital admissions and they are likely to have a prolonged absence from school. Moreover, the disease itself limits their learning abilities. According to the literature, the most common difficulty is the target committal, such as at the perception and the accomplishment of a task that has been assigned to them, the organization of the time and the way to accomplish the task, as well as the ability to remember which steps are required for the acquisition of the task. Relevant research has shown that the cognitive impairment experienced by children with congenital heart diseases is associated with cyanosis or the severity of the disease[9, 24, 26, 27].

A significant area related to the children's' quality of life is the restriction of their physical activities, which either the parents or their physical condition imposes. Very often, overprotective parents may require decrease of their children's physical activity, even if the disease is limited to a minor congenital failure or to a functional heart murmur. However, scientific data support that even patients with moderate heart disease should not reduce their physical activities. On the contrary, pediatric patients with severe heart disease and fatigue tend to decrease their activities themselves. Transportation to school with various means can help them maintain sufficient physical energy for activities at school and in the class. Awareness of the teachers should be of high priority throughout the school year[6, 27, 28].

Another important factor that should always be taken into account when assessing the quality of life in children with congenital heart disease is the family environment for the reason that it affects children's reaction to the disease, as well as their health progress over time. It is well established that family is a dynamic team of inter-dependent members which are in constant interaction. Therefore, family environment, as it is

developed through the relations of the family members and the parents' personality is crucial for the outcome of the disease. More specifically, the family environment, the children's role in it, and the relation with the other members such as brothers, grandfather, grandmother, form the level of acceptance of the disease, the compliance to the treatment, and the child's response to stress caused by the disease[9, 28,29].

Furthermore, "overprotective" behavior of the parents who sometimes do not allow the children to take their own initiative, and at the same time reduce their ability to take care of themselves, significantly contributes to the patients' low self-esteem. One of the most common mistakes that the parents, and especially the mother, make, is to pass their anxiety to their child. Accurate information to the parents reduces their anxiety, contributes to the treatment of the disease, and thereby to the improvement of the children's quality of life[9, 28,29].

Educational level of the parents, is significantly associated with their children's quality of life. In particular, before the diagnosis, the educational level of the parents is associated with the absence or delay in seeking medical assistance, and thereby with the worsening of the children's health. Many studies have emphasized the importance of the 'time' factor because the surgical treatment of these anatomic abnormalities is preferable before the deterioration in cardiac function or the appearance of complications in the respiratory or circulatory system. Parents with low educational and income level tend to have difficulties in recognizing that their children need advisory support, or they ignore its importance and consequently, their children show symptoms of anxiety, depression or even aggressive behavior towards the environment. Also, poor financial status of the family is positively correlated to poor assessment of quality of life in both the children's and the family. Given the fact that the disease demands frequent visits to the hospital and hospitalization cost, it is understandable that family faces financial problems which may often destroy the relationship between the parents[9, 28, 29].

Finally, maintenance of an overall good health including a balanced diet, prevention of anemia, and full vaccination against the common diseases are factors that contribute positively to the improvement of the quality of life. In particular, bacterial infections should be treated immediately, and precaution measurements against bacterial endocarditis during dental work, before an examination in urinary tract, and in lower gastrointestinal tract should always be taken. Treatment of anemia is very important, especially in patients with cyanosis, for the improvement of physical performance, their general health condition, and therefore their quality of life. Patients with cyanosis should be aware of possible dehydration. High altitude and sudden changes in environmental temperature should be avoided. Patients with severe congenital heart disease or with a history of cardiac rhythm disorders should be carefully monitored during anesthesia, even during routine surgeries[6].

In summary, the parents' personality, the socio-economic and educational status of the family, the delay in physical growth, the change in body image, anxiety and depression, lack of social acceptance, impaired school performance, and decreased physical activities are only some of social and psychological factors that play a vital role on the children's quality of life[9, 23, 28-30].

Conclusions

Assessment of the quality of life according to the physical growth stage should be an integral part of the patients' treatment because it enables health professionals to identify the children's individual differences, interests and preferences. This acquired knowledge combined with the clinical experience contributes to improvement in the quality of life in children with congestive heart

failure, their psycho-emotional development and their social integration.

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