QUALITY OF LIFE IN CHILDREN AND ADOLESCENTS WITH CONGENITAL HEART DISEASE

A NEW CHALLENGE FOR PARENTS, PROFESSIONALS AND COMMUNITY

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Learner objectives

- To identify and discuss the importance and implications of to assess the “Quality of Life” in children and adolescents with chronic conditions
- To identify and discuss the perception of quality of life in children and adolescents with congenital heart disease and their parents, as well to recognize some factors that could impact the “Quality of Life”
Expanded content outline

1. Introduction. The concept of “Quality of Life” and the implications for health professionals to assess it.

2. The Research design.

3. Results

4. Conclusions and implications
Introduction

- The Quality of life is, currently, a major topic discussed in our society.

- The WHO has been developing an unifying and transcultural definition of QOL.…”"the individual's perception of his or her position in life, within the cultural context and value system he or she lives in, and in relation to his or her goals, expectations, parameters and social relations. …”
Introduction

…”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.”

Introduction

- Congenital heart disease is the most prevalent congenital disease in Portugal.

- Despite the advances in cardiac treatment and an early correct diagnosis that could increase the survival of children and adolescents, it influences the quality of life of them, and their parents.
Introduction

Knowing the perception of QOL, it could help healthcare professionals, nurses in particular:

- Providing suited care to the needs of these families;
- Establishing priorities in their interventions;
- Sensing predictors of a poor quality of life;
- Promoting adherence to treatment;
- Boosting compliance with it, and fostering greater satisfaction for these children/adolescents and parents.
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Objectives

As part of a broader research the main objective was:

- To determine the quality of life in children and adolescents with congenital heart disease (CHD) and the perception of their parents, as well as the factors that influence it.
The research design

- Quantitative, descriptive and correlational research.
- The data collection tool was a questionnaire, with four parts: sociodemographic, educational and clinical characteristics.
- The quality of life instrument was the Pediatric Cardiac Quality of Life Inventory – PCQLI - (Marino, Tomlinson, Wernovsky, Drotar, Newburger, Mahony et al., 2010) translated into Portuguese.
The research design

- Data collection took place between February and July 2014, in compliance with ethical research guidelines.

- The sample comprised 59 children, 59 parents of children, 80 adolescents and 80 parents of adolescents.
Results

- They indicated that children, adolescents, and their parents have high level of perceived health. They are similar in all groups: children/parents and adolescents/parents.

- In the group of children, we observed: "Good" in 66.10%, followed by "Very Good" at 18.65% and "fair" in 15.25% of cases.
Results

- The parents of the children responded in about half the cases that the health of their children was "good" (50.85%), "very good" in 30.51% "fair" in 11.86% and "Excellent" in 6.78%.

- In turn, the group of adolescents can be seen that 46.25% rate their health as "good", 32.50% as "very good", 16.25% as "Average" and 5% as "Excellent".
Results

- Parents of teenagers classify the health of their children mostly as "good" in 42.50%, 31.25% as "very good", 20% as "fair" and 6.25% as "excellent".

- To point out that none of the respondents considered the option of a health status as "Bad".
Results

About the quality of life, in general the results indicated that children, adolescents and their parents have high levels of quality of life, and that perceptions of parents and children are similar.
Results

- Only in the children’s group (8 to 12 years old), was no influence of socio-demographic, school or clinical variables on quality of life observed.

- For adolescents (13 to 18 years old), school, special education, school retention, the age of diagnosis of congenital heart disease, cardiac catheterization and surgical intervention influenced their quality of life.
Results

- Perception of quality of life of parents of children and of adolescents was influenced by socio-demographic and clinical variables. The results partly agree with the literature in this field.
Conclusions

To analyze the quality of life of children and adolescents with CHD must be a key focus of attention in caring for this population, allowing the identification of individual differences, interests, preferences, and prevent potential problems.
Conclusions

The knowledge acquired along with clinical experience contributes to improve the quality of life of children and families, facilitating their growth, psycho-emotional development and social integration.
Conclusions

Nevertheless, the interpretation of these results must be prudent and cautious, there are limitations including:

- The use of a range of specific quality of life for the congenital heart disease in children, adolescents, and parents but whose validation process could not be completed in this study;
Conclusions ..limitations including..

- The low prevalence of severe conditions in our sample;
- The absence of national studies to enable comparison with the results obtained.

We intend to continue the process of validation of the instrument and enlarge the research to Lisbon and Oporto, other Portuguese cardiac major centers.
References


THANK YOU