Quality of life in families of children with congenital heart disease

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Abstract

Within a family perspective on quality of life (QL) with congenital heart disease, the study investigates parental QL, and patients' health-related QL as reported by themselves and by their parents. We examined the hypotheses that parental QL moderates the parental proxy reports. Sixty-nine patients (7–20 years, 61% male) and their caregivers participated in a computer-assisted QL-assessment. Children’s self-rated and proxy-rated QL correlated moderately, with the highest intra-class correlation on the subscale psychological well-being/functioning ($r = 0.61; p < 0.001$), less convergence in physical well-being/functioning ($r = 0.49; p < 0.001$) and absent correlation in the evaluation of intra-family relationships. Parental QL was correlated both with the children’s self-rated QL ($r = 0.42; p < 0.05$) and children's parent-rated QL ($r = 0.60; p < 0.001$). Support for the moderator hypotheses is indicated by the results of regression analyses demonstrating a significant interaction effect of parental QL and patients’ self-reported QL in predicting parental proxy reports on their children’s QL. Post-hoc tests reveal that parents with low own QL agree significantly more with their children than parents with high QL. Parent–child agreement on the children’s QL is limited and reflects complementary subjective viewpoints. Psychosocial interventions should be family-focused and provide support for patients’ and their caregivers’ QL.

Key words: Congenital heart disease, Family aspects, Multi-informant assessment, Quality of life

Abbreviations: CHD – chronic heart disease; QL – quality of life

Introduction

In consequence of medical progress life expectancy of children with chronic heart disease is increasing. With a prevalence of 0.8%, congenital heart defects (CHD) represent one of the most frequent chronic diseases in childhood and adolescence [1, 2]. Disease- and therapy-related distress and anxiety, restrictions of physical functioning, potential expenses as well as organizational efforts affect the whole family of children with CHD [2, 3]. Therefore evaluation of health-related quality of life is becoming increasingly important. Quality of life (QL) is defined as a multi-dimensional construct integrating physical, emotional, and social well-being and functioning as perceived by the individual.

Although multi-informant strategies including self-reports are recommended for children and adolescents [4], many researchers and clinicians rely exclusively on caregivers’ perceptions of children's QL or on proxy-ratings by parents or medical staff. Children are increasingly considered as reliable informants on their QL [5–8], and recently the development of child-specific self-report measures has improved the participation of children in the evaluation of their QL [for example 9–11]. Multi-informant strategies may produce limited accordance between proxy- and self-evaluated QL of children [7, 8], and it is not clear how to interpret these differences. Eiser and Morse [12] show in their review inevitable differences between the children’s and parental perceptions of QL. The
direction of the reporter-bias varies. Some studies found that relatives underestimate pediatric patients’ QL and perceive in general more negative consequences of an illness than the children themselves [8, 13]. A recent study of self-reports of adolescents with CHD indicated less impairment of their QL than the parent-reports on the same scales [14]. In contrast, Sturms et al. [15] demonstrated that parents of traffic accident victims overestimate their child’s QL, especially regarding physical functioning. In another study on QL of children with CHD, Uzark et al. [11] reported medium correlations between child self-reports and parent proxy-reports on the pediatric quality of life inventory. Under- or over-estimation of children’s QL by their parents was not consistent between the different subscales. Thus the parent–child agreement may vary depending on the specific dimension of QL in question. It has been proposed that parents can more reliably report externalizing behaviours of their children than the children themselves, and that children and adolescents can better report on internalizing dimensions [7, 16]. In families of adolescents with very low birth weight, inter-rater agreement was generally good in observable QL-domains, and only moderate in less readily observable, and possibly less stable, domains such as mood, pain and physical symptoms [17]. Child factors such as age, developmental status and health status may trigger the parent–child accordance [4, 11, 18].

Also parent factors may contribute to the accordance of parent- and self-reports. In a study on pediatric asthma [19] parental anxiety and depression was associated with children’s parent-reported QL. Thus parental perception of their children’s QL may be biased by parental negative affect. In another study on adolescent asthma, Vila et al. [20] found an association between parental QL and adolescents’ QL. Although parental factors are considered as crucial for the effectiveness of coping with a chronic disease in childhood and adolescence [21–23], so far few studies on CHD have investigated parental QL. In a comparison with parents of healthy children and parents of children with other diseases, Lawoko and Soares [24] found that parents of children with CHD, especially mothers, reported the lowest QL of all groups. Distress, hopelessness and financial problems explained more variance of QL than disease severity. High levels of daily stress and palliative coping techniques were associated with maternal adjustment in families of children with CHD [25]. Kirschbaum [26] described in a study of parental reactions to the diagnosis of CHD more fear, anger and sadness compared with parents of healthy infants. Excessive parenting stress has been reported more frequently by parents of children with heart disease compared with parents of healthy children [27].

In spite of the overwhelming evidence for the clinical relevance of a family perspective on QL in chronic pediatric conditions, so far no studies have integrated the perspectives on parental QL and children’s QL with CHD. In our study we comply with the recommendations for a comprehensive multi-informant QL assessment and compare three perspectives on quality of life with CHD: parental QL, proxy-reported patients’ QL, and self-reported patients’ QL. In absence of former disease-specific studies with a similar approach, the following exploratory research questions are addressed:

1. To what extent do children and adolescents with CHD and their caregivers agree on the patients’ QL?
2. Is the caregivers’ own QL associated with their children’s QL?
3. Does parental QL moderate the degree of parent-child agreement on the patients’ QL?

**Method**

**Participants and procedure**

The study sample was recruited consecutively in a German outpatient pediatric university clinic for CHD. Inclusion criterion for the study was a primary cardiac disease. Patients with co-morbid diseases (e.g., cancer, Down syndrome), mental retardation (clinical judgement) or insufficient knowledge of German language were excluded. The participants were approached for the assessment after their medical appointment. Informed consent was acquired according to the principles of the local ethical committee. Patients and caregivers were instructed to fill in the computer-administered questionnaires independently of each other. If necessary they were separated to guarantee compliance with this instruction.