Health-Related Quality of Life in Adolescents with Congenital Heart Disease: Importance of Parental Hope

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Dear Editor in Chief

From 2003 to 2010 in China, the overall mortality rate of congenital heart disease (CHD) increased from 141 per 10,000,000 person-years in 2003 to 229 per 10,000,000 person-years in 2010, a 62.4% relative increase (1, 2). Recent conceptualizations of health-related-quality-of-life (QoL) recognize the multidimensional nature of QoL, including psychological, social and family functioning (3). However, few studies have focused on QoL concerns in China. Evidence shows that adolescents who have higher levels of spirituality recover from illness more quickly, and have better QoL than their less religious peers (4). Parental hope is strongly associated with QoL in adolescents with spina bifida and cancer (5, 6). Many studies have addressed the association of low socioeconomic status with lower self-perceived health. However, there is no published literature assessing how these factors affect the QoL in adolescents with CHD.

This study evaluated QoL of Chinese adolescents with CHD and sought to determine the outcome indicator. Overall, 132 adolescents with CHD and their parents were recruited over 2 years from hospitals in Guangdong province, China. Adolescents with CHD completed questionnaires including Paediatric Quality of Life Inventory 3.0-Cardiac Module (3) and the Functional Assessment of Chronic Illness Therapy-Spirituality Scale for spirituality (7). Parents of adolescents with CHD completed questionnaires including the Hollingshead score (8) for occupation rank and occupational prestige as well as the Herth Hope Index for parental hope. A semi-structured interview with parents was used to gather information on parental education (9), sociodemographic details and family communications related to the CHD diagnosis and care.

Bivariate analyses indicated that QoL was positively associated with parental hope, spirituality, and occupational prestige, but negatively correlated with low family communications. A lower correlation between QoL and parent educational level was observed. No association was found with the heart disease severity. The stepwise multiple regressions analysis demonstrated that the significant predictor was parental hope, followed by spirituality.

Our findings suggest that greater parental hopefulness, spirituality and occupational prestige contribute to better QoL in CHD adolescents. This is the first large study of the subjective experience of adolescents with CHD in China, using a multidimensional, well-validated, and reliable instrument, across a wide range of disease severity.

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References


