



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

1. Hu Z, Yuan X, Rao K, Zheng Z, Hu S (2013). National trend in congenital heart disease mortality in China during 2003 to 2010: A population-based study. *J Thorac Cardiovasc Surg*, pii: S0022-5223 (13) 01064-7. doi: 10.1016/j.jtcvs.2013.08.067 [Epub ahead of print].
2. Tu L, Li H, Zhang H, Li X, Lin J, Xiong C (2012). Birth defects data from surveillance hospitals in hubei province, china, 2001 - 2008. *Iran J Public Health*, 41:20-5.
3. Uzark K, Jones K, Slusher J, Limbers CA, Burwinkle TM, Varni JW (2008). Quality of life in children with heart disease as perceived by children and parents. *Pediatrics*, 121:e1060-7.
4. Rubin D, Dodd M, Desai N, Pollock B, Graham-Pole J (2009). Spirituality in well and ill adolescents and their parents: the use of two assessment scales. *Pediatr Nurs*, 35:37-42.
5. Scrimin S, Axia G, Tremolada M, Pillon M, Capello F, Zanesco L (2005). Conversational strategies with parents of newly diagnosed leukaemic children: an analysis of 4880 conversational turns. *Support Care Cancer*, 13:287-94.
6. Kirpalani HM, Parkin PC, Willan AR, Fehlings DL, Rosenbaum PL, King D, Van Nie AJ (2000). Quality of life in spina bifida: importance of parental hope. *Arch Dis Child*, 83:293-7.
7. Peterman AH, Fitchett G, Brady MJ, Hernandez L, Cella D (2002). Measuring spiritual well-being in people with cancer: the functional assessment of chronic illness therapy--Spiritual Well-being Scale (FACIT-Sp). *Ann Behav Med*, 24:49-58.
8. Hasson RE, Adam TC, Pearson J, Davis JN, Spruijt-Metz D, Goran MI (2013). Sociocultural and socioeconomic influences on type 2 diabetes risk in overweight/obese African-American and Latino-American children and adolescents. *J Obes*, 2013:512914.
9. Abachizadeh K, Omidnia S, Memaryan N, Nasehi A, Rasouli M, Tayefi B, Nikfarjam A (2013). Determining dimensions of iranians' individual social health: a qualitative approach. *Iran J Public Health*, 42:88-92.