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The impact of an interstage monitoring programme on parents of children with a hypoplastic left heart syndrome before and after bidirectional cavopulmonary anastomosis

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Background:

Studies have shown the importance of home monitoring for children with a hypoplastic left heart syndrome (HLHS) to reduce the interstage mortality between stages I and II. But very little is known about the parents' experience and impact on quality of life from coping at home with the responsibility of an interstage monitoring programme including saturation measures and body weight gain.

Methods: This multidisciplinary project used a prospective sequential mixed methods study design to analyse the medical course and psychosocial impact on the parents of an interstage monitoring programme. The parents rated their quality of life with the Short Form Health Survey questionnaire (SF-36) and the German version of the Impact of Family Scale (FaBel) one and 5 weeks following discharge, both before and after bidirectional cavopulmonary anastomosis operation (BDCPA). Semi-structured interviews were conducted twice, 5 weeks after hospital discharge before and after BDCPA. The interviews were analysed using the qualitative content analysis of Mayring.

Results: Between February 2011 and December 2012 ten infants (2 female) with HLHS (7 of 10) or other types of univentricular heart malformations (3 of 10) and their parents (one single mother) were included. Prenatal cardiac diagnosis was made in seven infants. There were no interstage deaths, but one child could not be discharged after BDCPA due to severe congestive heart failure. SF-36 subscales in the mental health summary were low, especially for vitality (37.0 ± 19.46 for mothers and 43.12 ± 25.9 for fathers) before BDCPA and did not change significantly after BDCPA. FaBel values showed gender differences to the disadvantage of the mothers in most subcategories, with a significant difference in the daily and social burden ($p < 0.047$). The most important category in the interview was "Becoming a family" to cope and find a fragile emotional balance. The parents judged the interstage monitoring primarily as a protective intervention.

Conclusions: For families with HLHS the psychosocial burden before and after the interstage period remains fairly high, but being at home as a family is a crucial experience for parents and reassures them in their parenthood. Health professionals should identify overburdened parents and provide assistance and psychosocial support.