Background and aims In children with end-stage heart disease heart transplantation (HTx) offers a good therapeutic option. Patients are expected to improve in general health, but unfortunately little is known about the health-related quality of life (HRQoL) after HTx, which is also influenced by factors such as the psychosocial adaptation of children and parents. We aimed to better understand children’s HRQoL after HTx with the aim to give them adequate support.

Methods Between 2000 and January 2014 28 children underwent successful heart transplantation at our institution. All patients older than 8 years (n = 21) were asked to complete a validated and reliable questionnaire, the Child Health Questionnaire-Child Form 87 (CHQ-CF87) questionnaire themselves.

Results 76% of the patients participated; median age was 15.2 years (range: 7.0 – 19.6), median time after HTx was 31 months (range: 7 – 134). All children attended school. Even though they scored comparable to normative data on most of the subscales, their general health perception (GHP) (50.0 vs. 74.6, p < 0.0001) and physical functioning (PF) (91.7 vs. 96.8, p = 0.038) was significant lower than in healthy children.

Conclusion In children after HTx, overall HRQoL, especially on the psychosocial scales seems to be good. Only the subscales general health perception and physical functioning were significantly lower. This might be explained by their chronic need for treatment, follow-up and concomitant diseases frequently seen in HTx patients. Nevertheless, in order to learn dealing with their situation all children should be supported by a specialised multidisciplinary team, including psychologists and child life specialists.