Background and aims In children with end-stage heart disease heart transplantation (HTx) offers a good therapeutic option with favourable outcomes. 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: 13.6–19.6), 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.

Conclusions Racial differences in satisfaction and expectations about nursing care differ between racial groups.

Methods A prospective cohort was constructed of infants born at a gestational age ≤35 weeks, who presented within 2 months after NICU discharge to The Children’s Hospital of Philadelphia primary care network between 7/1/09 and 12/31/11 (N = 249, 52% white, 42% Black). We administered a survey on trust, communication, NICU course, and expectations from the medical system. Qualitative responses about NICU nursing care were imported into ATLAS.ti to highlight key themes and relationships between race and satisfaction with NICU nursing care.

Results During the open-ended survey questioning, 120 (48%) parents commented on nursing, 58% of the comments were positive, with black parents more negative (58%) than white parents (33%). Parents of different races sought different behaviours from nurses. Black parents were dissatisfied with how nurses supported them, wanting compassionate communication and nurses that treated them “like family”. White parents were dissatisfied with inconsistent nursing care and lack of respect for parental involvement, wanting education about their child’s short and long-term needs. Both groups described a chaotic NICU environment with high nursing turnover, making it difficult to build trust and relationships.

Conclusions Racial differences in satisfaction and expectations were found with NICU nursing care. Practices to account for these differing needs will allow nurses to better support families through a premature birth and engage parents in their child’s health care.