

completion of the course in the PICU, regardless the length of the hospitalisation.

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### HOW GOOD IS LIFE AFTER HEART TRANSPLANTATION, CHILDREN'S PERCEPTION

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**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 significant 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 multi-disciplinary team, including psychologists and child life specialists.

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### BLESSING OF CURSE: HOW DO PARENTS PERCEIVE THE HEALTH RELATED QUALITY OF LIFE OF THEIR CHILD AFTER PAEDIATRIC HEART TRANSPLANTATION?

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**Background and aims** For children and young adults with end-stage heart failure or other severe heart diseases paediatric heart transplantation (HTx) means a good therapeutic option. Parents have to decide for or with their children whether they want them to be transplanted. Congenital heart disease *per se* has a major influence on the child's and the family's life. Relatively little is known about the psychosocial impact of HTx. Therefore

we aimed to better understand how parents perceive the health related quality of life (HRQoL) of their child.

**Methods** Between 2000 and January 2014 28 children have received a successful heart transplantation at our institution. All parents (n = 56) were asked to complete the Child Health Questionnaire-Parent Form 50 (CHQ-PF50).

**Results** 42 parents (n = 22 female, n = 20 male) of 22 patients (median age mothers: 46 years, median age fathers: 51 years) answered the CHQ-PF50 questionnaire. Two parents were divorced. All children lived with at least one parent. On most of the CHQ-PF50 subscales parents gave significantly lower ratings on their child's HRQoL compared to parents of healthy children. Only on the subscales general behaviour and family cohesion scores were comparable to normative data. On most scales mothers gave significantly lower, thus more unfavourable ratings, than the fathers.

**Conclusion** Paediatric HTx has a major impact on the HRQoL of the affected families. In order to improve HRQoL further follow-up and more psychological support not only for the patient but also for the whole family's needs to be offered as routine care.

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### RACIAL DIFFERENCES IN PARENTAL EXPECTATIONS AND SATISFACTION REGARDING NURSING CARE IN THE NEONATAL INTENSIVE CARE UNIT (NICU)

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**Background** Nurses play a pivotal role in parental support and education in the NICU, but it is not known if parental satisfaction and expectations about nursing care differ between racial groups.

**Methods** A prospective cohort was constructed of infants born at a gestational age  $\leq 35$  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.