Transplant International

ORIGINAL ARTICLE

Quality of life and patient satisfaction with outpatient care after heart transplantation in adult and pediatric patients – room for improvement?

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SUMMARY

Reduced adherence after heart transplantation increases the risk for acute rejection. Therefore, the aim of this study was to evaluate the patient's satisfaction with outpatient care and quality of life (QOL) after pediatric and adult heart transplantation. Observational study after pediatric ($n = 22$) and adult ($n = 65$) heart transplantation and the parents of the pediatric patients ($n = 22$) to evaluate the patients' satisfaction with outpatient care and QOL. Established standardized questionnaires were used for patient satisfaction (ZAP survey) and QOL (SF36); the latter was compared with the cohort of the BGS98 survey (BGS98 cohort). ZAP score: excellent results with almost all values >80. QOL: pediatric cohort showed significantly higher values in physical functioning ($P = 0.041$) and role physical ($P = 0.003$) but significantly lower values in the sub-scale general health ($P = 0.02$) compared to adult cohort. In comparison with BGS98 cohort, children showed almost similar results, whereas adult cohort showed worse values in physical and emotional functioning, but higher values regarding general health. The QOL of patients after pediatric heart transplantation is comparable to a standardized reference population in Germany, whereas adult patients show reduced physical and emotional functioning, but better values regarding general health. The patients' satisfaction with the outpatient care is very high.

Transplant International 2021; 34: 2578–2588

Key words
adult heart transplantation, pediatric heart transplantation, quality of life, SF36, ZAP

Received: 24 July 2021; Revision requested: 16 September 2021; Accepted: 19 October 2021; Published online: 5 November 2021

Introduction

Heart transplantation is often the last treatment option for pediatric and adult patients with terminal heart failure. In the recent decades, the prognosis after heart transplantation improved significantly. While between 1982 and 1992 the 5-year survival probability was about 60% in pediatric and adult patients, the current 5-year survival probability is about 80% in pediatric and 75% in adult patients [1,2]. However, graft failure, acute rejection, cardiac allograft vasculopathy, and the side effects of the immunosuppressive therapy still remain main problems influencing the long-term survival [1–3]. Beside immunological events causing graft failure,

doi:10.1111/tri.14147

the adherence to therapy and follow-up of the patient also plays an important role for the successful outcome after heart transplantation. Several studies revealed a correlation between nonadherence and poor post-transplant outcomes including late acute rejection and graft failure [4–6]. Thus, a comparison between patients with and without nonadherence after adult heart transplantation revealed a higher rate of late acute rejection (11.8% vs. 2.4%), re-transplantation (13.3% vs. 2.5%), and a significantly shorter clinical-event-free interval of patients with nonadherence [6]. Also, after pediatric heart transplantation, nonadherence is a substantial risk factor for reduced survival. Oliva *et al.* could show that medical nonadherence occurs in 10% of pediatric patients after heart transplantation [7].

Denhaerynck *et al.* demonstrated that multiple levels, such as the patient, the family/healthcare providers, the organization, and the policy levels, must be addressed to improve the adherence to medication [4]. The influence of system factors on nonadherence seems to be responsible for the different prevalence of nonadherence between European and US patients as well as among European patients after kidney transplantation [8].

Data regarding patient's quality of life (QOL) after heart transplantation at European centers are scarce. Mantovani *et al.* could show that the transplantation has a positive impact on the QOL in comparison with patients on the waiting list [9]. Adult survivors at least ten years after pediatric heart transplantation showed a similar perception of mental and physical health in comparison with the general population [10]. Adult patients ten years after heart transplantation showed a similar mental QOL but a significantly lower physical QOL in comparison with the general population [11]. These different developments in QOL after adult and pediatric heart transplantation could also be confirmed by Cavalli *et al.* In the comparison of QOL of adult patients, who underwent heart transplantation at pediatric or adult age, the "pediatric" patients showed a significant better physical functioning ($P = 0.01$), role physical ($P = 0.03$), and general health ($P =< 0.001$) as well as significantly less bodily pain ($P = 0.01$) [12]. However, a comparison between pediatric heart transplant patients, pediatric patients after cardiac surgery and healthy children, showed a significantly reduced physical and psychosocial QOL, including emotional and social functioning, in comparison with healthy children [13]. In contrast, there was no significant difference between emotional and social mean score between the transplant patients and the children after cardiac surgery [13]. The QOL is therefore an important parameter for the clinicians. To the best of our knowledge, there are up to now just a few studies about QOL after pediatric or adult heart transplantation in Germany [14–16]. Also, the QOL of the parents is only evaluated in a few studies.

Thus, the purpose of this study was (1) to analyze the overall patient satisfaction with the outpatient care, (2) to evaluate the QOL of patients after pediatric and adult heart transplantation in a German center in comparison with a standardized reference population in Germany (BGS98 cohort), and (3) to analyze the correlation between QOL and patient satisfaction with the outpatient care after pediatric and adult heart transplantation.

Methods

Study design

This is an observational study of patients after adult and pediatric heart transplantation as well as the parents of the pediatric cohort to evaluate their patient satisfaction with outpatient care and their QOL using the "questionnaire on satisfaction with ambulatory care – quality from the patient perspective" (ZAP, "Zufriedenheit in der ambulanten Versorgung - Qualität aus Patientenperspektive") [17] and the Medical Outcomes Study 36-Item Short form Health Survey version 2 (SF36) [18]. In addition, the results were compared with the results of the cohort of the German Federal Health Survey of 1998 (BGS98 cohort).

The study was approved by the ethical review committee of the Ludwig-Maximilians-University Munich, and all patients, or their legal representatives, gave their written consent.

Study population

The patient population is a nonrandom sample of patients after adult and pediatric heart transplantation and the parents of the pediatric cohort of the Department of Heart Surgery and Department of Pediatric Cardiology and Intensive Care Medicine at the University hospital of the Ludwig-Maximilians-University Munich, Großhadern. All patients having undergone heart transplantation between January 2008 and April 2018 and being under medical treatment of one of the two outpatient departments were included in the study. For the pediatric cohort, patients with transplantation age < 18 years were included independent of the age at time of the study. Patients with insufficient knowledge

of the German language, inability of understanding the questions, or missing consent to the study were excluded from the study. According to these criteria, 170 patients of the Department of Heart Surgery (adult cohort) and 35 patients of the Department of Pediatric Cardiology and Intensive Care Medicine (pediatric cohort), respectively, their parents (parents cohort) were included. The response rate of the questionnaires was 38% in the adult cohort ($n = 65$) and 62.9% in pediatric/parents cohort ($n = 22$ in pediatric and parents cohort, respectively). All together 109 of 240 conveyed questionnaires could be analyzed.

Analyses of the questionnaires

A correlation between the SF36 and the ZAP survey was calculated. For identification of the same cases, several items were use (gender, age, kind of insurance and department of the outpatient care). For evaluation of SF36 and ZAP, all completed questionnaires could be used (SF36: $n = 103$, pediatric cohort: $n = 22$, parent cohort: $n = 22$, adult cohort: $n = 59$; ZAP: $n = 87$, pediatric cohort: $n = 16$, parent cohort: $n = 19$, adult cohort: $n = 52$). For the analyses of the correlation between SF36 and ZAP, only the cases with clear identification of both questionnaires could be used ($n = 87$, pediatric cohort: $n = 16$; parent cohort: $n = 19$; adult cohort: $n = 52$).

SF36

The QOL was assessed by the valid and reliable SF36 questionnaire [18]. This survey consists of 36 questions that can be categorized into 8 sub-scales: physical functioning, role physical, bodily pain, general health, vitality, social functioning, role emotional, and mental health. Polar questions as well as questions with up to six possible answers are included in the questionnaire. In each sub-scale, a value between 0 and 100 is possible, whereas 100 represents the greatest possible QOL [18].

ZAP survey

The ZAP survey was first published by Bitzer et al [17]. It evaluates the patient satisfaction with outpatient care on four dimensions (patient–physician interaction, information, office organization, and professional competence). The survey was evaluated with two samples with over 2300 patients from outpatient clinics and showed good construct validity and high internal consistency [17,20]. Each dimension is evaluated using three to eight questions. All questions have four graded answer possibilities (very dissatisfied, rather dissatisfied, rather satisfied, and very satisfied). We modified the ZAP survey and expanded it with a fifth dimension, the patient–nurse interaction.

BGS98 survey

The German Federal Health Survey of 1998 was performed from October 1997 to March 1999 and included more than 7000 subjects of a representative sample of residents aged 18 to 79 years [19,21]. The survey included answering of questionnaires, interviews with physicians, physical examination, and blood sampling [22]. For the comparison of the results of our study with the cohort of the BGS98, the Robert Koch Institute provided us the data record of the BGS98 on March first 2018. Table 1 shows of the age and gender distribution of the BGS98 cohort.

Statistics

General statistics

Continuous data are expressed as mean ($\pm$ standard deviation, SD) and compared with the unpaired Student's t-test or Mann–Whitney U-test, respectively. The normal distribution was calculated using Shapiro and Kolmogorov test. A two sided P-value < 0.05 was considered statistical significant.

Statistics SF36

The analyses of the SF36 data were performed according to the manual [18]. The crude data were transformed to a scale from 0 to 100. The division into sub-scales was performed according to the manual and algorithm.

Statistics ZAP

Analyses of differences between the groups were performed by use of ANOVA, Welch test, and Kruskal–Wallis test.

Statistic for the comparison of ZAP with SF36

A correlation between the results of ZAP and SF36 was evaluated by Spearman's correlation. The strength of the correlation was interpreted according to Cohen (1988) [23].

Table 1. Age and gender distribution of the BGS98 cohort [19].

		18–29 years	30–39 years	40–49 years	50–59 years	60–69 years	70–79 years	Total
Gender	Male *N* (%)	646 (18.7)	767 (22.2)	630 (18.3)	676 (19.6)	496 (14.4)	235 (6.8)	3450 (100)
	Female *N* (%)	638 (17.4)	788 (21.4)	681 (18.5)	683 (18.6)	541 (14.7)	343 (9.3)	3674 (100)
Total	*N* (%)	1284 (18.0)	1555 (21.8)	1311 (18.4)	1359 (19.1)	1037 (14.6)	578 (8.1)	7124 (100)

N, Number.

Statistic for the comparison of QOL of our patients with BGS98 cohort

Comparisons of QOL of our three cohorts with the BGS98 cohort were performed by the use of ANOVA with bootstrapping, Welch test, and unpaired t-test. The paired comparison was performed with the Games-Howell and Tukey post hoc tests.

Results

Demographic characteristics

In the pediatric cohort (n = 22, male 10), the mean age was 19.27 ± 5.46 years. 18.2% (n = 4) of the patients after pediatric heart transplantation were in a private health insurance. In the adult cohort (n = 65, male 46), the mean age was 55.26 ± 11.92 years. 10.8% (n = 7) of the adult patients were in a private health insurance.

Patient satisfaction (ZAP survey) (n = 87)

In all five dimensions (office organization, professional competence, information, patient–physician interaction, and patient–nurse interaction), there was an excellent rating of the patients and parents with only two results < 80 (adult cohort: office organization; pediatric cohort: information). There were no significant differences between the three groups (Table 2). The pediatric cohort showed the highest satisfaction in four of the five dimensions in comparison with the adults and the parents. Only in terms of information, the pediatric cohort gave the lowest rating (not significant). Adult patients showed the lowest rating regarding the organization of the outpatient department (not significant).

QOL (SF36 survey) (n = 103)

The mean scores of each group and of the BGS98 cohort of all eight dimensions are shown in Table 3. In general, the adult cohort showed several significant worse results regarding the single sub-scales of QOL compared to a standardized reference population in Germany, whereas pediatric patients after heart transplantation as well as the parents showed only similar or even significant better results.

Comparison to the BGS98 cohort

Adult cohort. The adult cohort showed significant worse results in comparison with the BGS98 cohort in terms of physical functioning (adult cohort: 78.05 ± 27.35;

Table 2. Results of the patient satisfaction with the outpatient care (ZAP survey).

Dimension	Pediatric cohort	Parents cohort	Adult cohort	*P*-value*
Office organization	82.64 ± 15.70	82.28 ± 13.10	78.15 ± 13.21	0.329
Professional competence	88.89 ± 13.46	82.01 ± 18.08	84.75 ± 16.10	0.441
Information	78.94 ± 15.99	83.77 ± 15.65	82.17 ± 15.20	0.634
Patient–physician interaction	85.94 ± 14.26	83.70 ± 16.54	84.68 ± 18.27	0.927
Patient–nurse interaction	88.80 ± 9.83	81.75 ± 16.80	80.93 ± 17.58	0.064

SD, standard deviation.

The values are given as mean ± SD.

*The *P*-value was analyzed for all three groups. The pairwise analysis did not show any significant differences between the cohorts.

Table 3. Quality of life after pediatric and adult heart transplantation in comparison with the BGS98 cohort.

	Dimensions							
	Physical functioning	Social functioning	Role physical	Role emotional	Mental health	Vitality	Bodily pain	General health
(A) Pediatric cohort (n = 22)								
Mean	89.32	77.27	88.64	89.39	73.09	62.73	84.51*	37.95
SD	11.47	23.67	28.58	18.93	14.72	15.49	21.85*	8.95
(B) Parent cohort (n = 22)								
Mean	84.77	76.14	88.64	77.27	75.27	70.00*	93.51*	44.09
SD	18.22	25.85	27.52	40.35	16.91	17.66*	15.03*	13.86
(C) Adult cohort (n = 59)								
Mean	78.05*	80.08*	63.14*	74.58*	72.61	58.05	78.80*	47.03*
SD	27.35*	24.47*	42.89*	37.82*	17.27	21.09	27.85*	13.55*
(D) BGS 98 cohort								
Mean	85.76	86.76	82.83	89.36	72.62	60.26	71.24	37.72
SD	20.37	19.64	32.36	26.50	16.65	17.83	25.31	11.66
N	6948	6964	6909	6910	6945	6944	6959	6941

N, number; SD, Standard deviation.

Significant differences between values of each cohort in comparison with the BGS98 cohort are marked with *.

BGS98 cohort: 85.76 ± 20.37; P = 0.032), social functioning (adult cohort: 80.08 ± 24.47; BGS98 cohort: 86.76 ± 19.64; P = 0.031), role physical (adult cohort: 63.14 ± 42.89; BGS98 cohort: 82.83 ± 32.36; P = 0.003), and role emotional (adult cohort: 74.58 ± 37.82; BGS98 cohort: 89.36 ± 26.50; P = 0.006). Regarding bodily pain (adult cohort: 78.80 ± 27.85; BGS98 cohort: 71.24 ± 25.31; P = 0.039) and general health (adult cohort: 47.03 ± 13.55; BGS98 cohort: 37.72 ± 11.66; P = 0.001), the adult cohort showed significant higher values than the BGS98 cohort.

Pediatric cohort. The QOL of patients after pediatric heart transplantation was comparable to the BGS98 cohort. In the dimension bodily pain, the pediatric cohort even showed significantly better results (pediatric cohort: 84.51 ± 21.81; BGS98 cohort: 71.24 ± 25.31; P = 0.038).

Parents cohort. The parents cohort showed significant higher values regarding vitality (parents cohort: 70 ± 17.66; BGS98 cohort: 60.26 ± 17.83; P = 0.015) and bodily pain (parents cohort: 93.51 ± 15.03; BGS98 cohort: 71.24 ± 25.31; P = 0.001) in comparison with the BGS98 cohort. In the other dimensions, they showed similar results as the BGS98 cohort.

Comparison of the three cohorts

Regarding our three cohorts, there was a significant difference in terms of physical functioning (pediatric cohort: 89.32 ± 11.47; adult cohort: 78.05 ± 27.35; P = 0.041), role physical (pediatric cohort: 88.64 ± 28.58; parent cohort: 88.64 ± 27.52; adult cohort: 63.14 ± 42.89; P = 0.003), vitality (parent cohort: 70 ± 17.66; adult cohort: 58.05 ± 21.09; P = 0.049), bodily pain (parent cohort: 93.51 ± 15.03; adult cohort: 78.80 ± 27.85; P = 0.014), and general health (pediatric cohort: 37.95 ± 8.95; adult cohort: 47.03 ± 13.55; P = 0.02). Whereas the pediatric cohort showed significant higher values regarding physical functioning and role physical in comparison with the adult cohort, the general health value was significantly lower in the pediatric cohort compared to the adult cohort.

Correlation between QOL and patient satisfaction (n = 87)

Regarding all three cohorts, there is a significant positive correlation between the patients–nurse interaction and the role physical (P = 0.014, r = 0.262), between the professional competence and the mental health (P = 0.023, r = 0.244) as well as between the professional competence and the bodily pain (P = 0.007, r = 0.285). Additionally, there is a positive correlation between all five dimensions of the patients' satisfaction and the vitality (office organization: P = 0.005, r = 0.298; professional competence: P = 0.006, r = 0.294; information: P = 0.041, r = 0.220; patient–physician interaction: P = 0.025, r = 0.241; and patient–nurse interaction: P = 0.004, r = 0.302). Regarding all three cohorts, all correlations are mild, except the

correlation between vitality and patient–nurse interaction. In contrast, the pediatric and the parents cohort show strong correlation between some dimensions of patient satisfaction and QOL.

The further correlations between patient satisfaction and QOL regarding each group are shown in Tables 4–6.

Discussion

To the best of our knowledge, there is a lack of scientific information about patient's satisfaction with outpatient care and QOL after pediatric and adult heart transplantation in Germany. The results of our study can be summarized as follows:

1. There was a high overall patient's satisfaction with the outpatient care.
2. There seems to be a need of more detailed information about their special transplantation history and management in patients after pediatric heart transplantation.
3. Regarding the estimation of QOL, the patients after pediatric heart transplantation showed less pain and otherwise similar values in comparison with the BGS98 cohort.
4. Regarding the estimation of QOL, the adult patients showed worse results in physical functioning, social functioning, role physical, and role emotional but better results in bodily pain and general health in comparison with the BGS98 cohort.
5. There are several correlations between the patient's satisfaction with the outpatient care and the QOL.

Patient satisfaction with the outpatient care

This study evaluates the patient satisfaction with the outpatient care of patients after pediatric and adult

Table 4. Correlation between patient satisfaction with the outpatient care (ZAP survey) and quality of life regarding the pediatric cohort.

SF36 Dimensions		ZAP-office organization	ZAP-professional competence	ZAP-information	ZAP-patient–physician interaction	ZAP-patient–nurse interaction
Physical functioning	rho	−0.025	0.521	0.139	0.321	−0.094
	P-value	0.926	**0.039**	0.606	0.226	0.729
	N	16	16	161	16	16
Social functioning	rho	0.179	0.688	0.045	0.535	0.177
	P-value	0.508	**0.003**	0.869	**0.033**	0.512
	N	16	16	16	16	16
Role physical	rho	−0.03	0.517	−0.135	0.227	0.115
	P-value	0.912	**0.041**	0.618	0.399	0.671
	N	16	16	16	16	16
Role emotional	rho	−0.041	0.253	−0.18	0.06	−0.245
	P-value	0.879	0.345	0.506	0.826	0.361
	N	16	16	16	16	16
Mental health	rho	0.179	0.772	0.204	0.724	0.255
	P-value	0.507	**0**	0.448	**0.002**	0.34
	N	16	16	16	16	16
Vitality	rho	0.241	0.623	0.204	0.488	0.15
	P-value	0.369	**0.01**	0.448	0.055	0.579
	N	16	16	16	16	16
Bodily pain	rho	−0.065	0.581	0.004	0.23	−0.226
	P-value	0.811	**0.018**	0.989	0.392	0.401
	N	16	16	16	16	16
General Health	rho	−0.059	−0.413	−0.205	−0.44	−0.106
	P-value	0.829	0.112	0.447	0.088	0.697
	N	16	16	16	16	16

N, number; rho: correlation coefficient.

Significant correlation is shown in red.

Physical functioning, role physical, vitality. and bodily pain show a positive correlation with the professional competence. Social functioning and mental health show a positive correlation with professional competence and patient–physician interaction.

Table 5. Correlation between patient satisfaction with the outpatient care (ZAP survey) and quality of life regarding the parents cohort.

SF36 Dimensions		ZAP-office organization	ZAP-professional competence	ZAP-information	ZAP-patient–physician interaction	ZAP-patient–nurse interaction
Physical functioning	rho	0.154	0.375	0.127	0.058	−0.090
	P-value	0.528	0.113	0.605	0.812	0.715
	N	19	19	19	19	19
Social functioning	rho	0.181	0.265	0.241	0.233	−0.027
	P-value	0.458	0.274	0.321	0.336	0.914
	N	19	19	19	19	19
Role physical	rho	0.349	0.533	0.547	0.469	0.237
	P-value	0.143	**0.019**	**0.015**	**0.043**	0.328
	N	19	19	19	19	19
Role emotional	rho	0.121	0.311	0.171	0.253	0.102
	P-value	0.623	0.195	0.485	0.296	0.678
	N	19	19	19	19	19
Mental health	rho	0.335	0.445	0.231	0.314	0.229
	P-value	0.161	0.056	0.342	0.19	0.345
	N	19	19	19	19	19
Vitality	rho	0.734	0.709	0.729	0.539	0.371
	P-value	**<0.001**	**0.001**	**<0.001**	**0.017**	0.118
	N	19	19	19	19	19
Bodily pain	rho	0.36	0.551	0.553	0.473	0.247
	P-value	0.13	**0.015**	**0.014**	**0.041**	0.307
	N	19	19	19	19	19
General Health	rho	−0.166	−0.03	−0.022	−0.044	0.042
	P-value	0.498	0.902	0.929	0.858	0.865
	N	19	19	19	19	19

N, number; rho, correlation coefficient.

Significant correlation is shown in red.

Role physical and bodily pain show a positive correlation with professional competence, information, and patient–physician interaction. Vitality additionally shows a correlation with office organization.

heart transplantation. Interestingly, the pediatric cohort showed in four of the five dimensions the highest values and in the dimension "information" the lowest value in comparison with the parents and the adult patients. This may be an indication that the information flow to patients after pediatric heart transplantation needs to be improved. Whether the information about the transplantation history and the further management were not enough or not understandable enough for the pediatric patients cannot be clarified with this study. Additionally, it cannot be excluded that the information for the pediatric patients was reduced because of the parent's request. Regarding the mean age of the pediatric cohort at time of the study, it is also possible that the low values in the dimension "information" were caused by the difficult change of the patient–physician interaction from parental phase to the adolescents. In this phase, the adolescents need to learn taking care of their medical situation by themselves. Probably, special transition programs might help to improve this situation [24] Altogether, clinicians should be aware that the pediatric patients seem to require more information about their disease.

Especially the patient satisfaction with the professional competence was very high in all three groups. Also, in our departments mostly, special teams assume the care of the heart transplanted patients. Therefore, this specialization of the physicians as well as the regular contact to the same medical team could cause these good results.

QOL regarding the patients after pediatric heart transplantation versus the BGS98 cohort

In accordance with the results of the study of Petroski *et al*., our patients after pediatric heart transplantation

Table 6. Correlation between patient satisfaction with the outpatient care (ZAP survey) and quality of life regarding the adult cohort.

SF36 dimensions		ZAP-office organization	ZAP-professional competence	ZAP-information	ZAP-patient–physician interaction	ZAP-patient–nurse interaction
Physical functioning	R	−0.082	−0.031	0.036	0.079	0.206
	P-value	0.564	0.829	0.798	0.576	0.142
	N	52	52	52	52	52
Social functioning	*r*	0.003	0.037	0.085	0.106	0.175
	P-value	0.986	0.796	0.551	0.455	0.215
	N	52	52	52	52	52
Role physical	*r*	0.094	0.004	0.035	0.08	0.283
	P-value	0.506	0.98	0.805	0.574	**0.042**
	N	52	52	52	52	52
Role emotional	*r*	−0.259	−0.039	−0.124	−0.072	−0.013
	P-value	0.064	0.783	0.381	0.613	0.929
	N	52	52	52	52	52
Mental health	*r*	−0.027	0.036	−0.066	−0.117	0.047
	P-value	0.852	0.798	0.642	0.41	0.74
	N	52	52	52	52	52
Vitality	*r*	0.096	0.13	0.02	0.118	0.327
	P-value	0.498	0.357	0.888	0.403	**0.018**
	N	52	52	52	52	52
Bodily pain	*r*	0.049	0.188	0.122	0.107	0.213
	P-value	0.728	0.181	0.387	0.451	0.13
	N	52	52	52	52	52
General Health	*r*	0.035	0.161	0.056	0.14	−0.15
	P-value	0.808	0.255	0.694	0.322	0.29
	N	52	52	52	52	52

N, number; *r*, correlation coefficient.

Significant correlation is shown in red.

Role physical and vitality show a positive correlation with patient–nurse interaction.

showed a similar QOL in comparison with the BGS98 cohort [10]. Regarding bodily pain, the pediatric patients even showed less pain than the BGS98 cohort. This could be caused by a different sensation of pain of children and adults [25].

QOL regarding the patients after adult heart transplantation versus the BGS98 cohort

In contrast to the pediatric cohort, the adult cohort showed a reduced scale in physical functioning, social functioning, role physical, and role emotional but better results in bodily pain and general health compared to the BGS98 cohort. These results are to some extent consistent with the literature. Beilby *et al.* also showed a poorer physical functioning of the transplanted patients in comparison with the New Zealand normative data but a better mental health and vitality [26]. Politi *et al.* and Fusar-Poli *et al.* showed a reduced physical QOL but a similar mental QOL after heart transplantation in comparison with the general population [11,27]. A comparison of the QOL of adult patients after heart transplantation in UK in comparison with the general population revealed a reduced scale in all dimensions of the SF36 except mental health [28]. Physical functioning often seems to be reduced after heart transplantation in comparison with the general population [11,26,27]. However, the reduced scale of four dimensions of the adult patients in comparison with the BGS98 cohort in our study could be explained by the very heterogeneous group regarding the cohort of the BGS98 with a large age range. The better general health of the adult heart transplanted patients in comparison with the BGS98 cohort could be caused by a different perception of the QOL because of the striking contrast between life-threatening illness before transplantation and significant improvement after transplantation [26].

QOL after pediatric and adult heart transplantation

Comparing the QOL after heart transplantation at pediatric and adult ages, Cavalli *et al.* showed significant higher values in the pediatric cohort in terms of physical functioning, role physical, bodily pain, and general health [12]. In line with these results, our study showed significant higher values in the pediatric cohort regarding physical functioning and role physical in comparison with the adult cohort. These differences could be a sign for a better and faster physical regeneration after heart transplantation of the pediatric cohort in comparison with the adult cohort. Interestingly, in our study, the general health was significantly higher in the adult cohort in comparison with the pediatric cohort. Probably, the pediatric patients do not remember the life-threatening situation before transplantation and therefore they are not able to see the huge improvement of their general health after transplantation as the adult patients do.

The assessment of the QOL was at different time points after transplantation as we included patients with transplantation between 2008 and 2018. Whether this different intervals to transplantation influenced the results of the QOL is uncertain. However, Kugler *et al.* showed that the QOL of patients after heart and lung transplantation remained quite stable, also 5 years after transplantation [15]. Additionally, also pediatric patients after lung transplantation showed stable QOL in average 8.7 and 24.6 years after transplantation [29].

QOL of the parents cohort

As we have outlined before, there is only sparse information regarding the parent's QOL after pediatric heart transplantation of their child. In our study, the parents QOL was comparable with the QOL of the BGS98 cohort. Only regarding bodily pain and vitality, the parents' cohort showed significant better values. In other studies of caregivers of chronic ill patients, the parents showed a reduced QOL in comparison with the general population [30,31]. Whether these good results in our study are only caused by the small patient number needs to be verified with further studies.

Correlation between QOL and patient satisfaction with the outpatient care

Up to now, there is a lack of scientific information on the patient satisfaction with outpatient care after pediatric and adult heart transplantation and the correlation with other factors in these special patients. An analysis of the ZAP survey of over 9000 patients revealed a mild correlation between gender and age and the satisfaction with the outpatient care [20]. The strongest positive effect on the patient satisfaction with the outpatient care could be seen in terms of the self-rated health [20]. In our study, the correlation analyses of the patient satisfaction with the outpatient care and the QOL especially showed a positive correlation between the vitality and all 5 dimensions of the outpatient care regarding all three cohorts. Regarding each cohort, the adult cohort was the only one with a correlation between dimensions of the QOL and the patient–nurse interaction. In the pediatric cohort, there was especially a positive correlation between several dimensions of the QOL and the professional competence. The parent cohort showed especially positive correlations between multiple dimensions of the QOL and professional competence, information, and patient–physician interaction. To what extent these findings can be used to improve the outpatient care and the QOL of these patients, must be evaluated in further studies.

Limitations of the study

Altogether, the patient number is quite small, and it is a heterogenous population, so that a generalization of the results probably is not possible. The answering of the questionnaires was anonymized, so that it is not possible to give more information about the patients (e.g. demographics, immunosuppressive therapy, incidence of rejection). This lack of information must be considered in the interpretation of QOL measurement. Additionally, the BGS98 cohort included only adult patients and an age and gender adjustment for the comparison of the heart transplant patients and the BGS98 cohort was not possible. At least, the BGS98 survey was conducted 23 years ago. Whether the evaluation of QOL of the general population changed of this timeframe and therefore influence our comparison with the transplanted population is uncertain.

Conclusion

The QOL of patients after pediatric heart transplantation is comparable to a standardized reference population in Germany. Patients after adult heart transplantation show reduced physical and emotional functioning, so that psychological care should be more included into the outpatient care and patients should be encouraged to exercise more or be included in specific

and organized exercise programs. The general health of the adult patients was even better in comparison with a standardized reference population in Germany. The patient's satisfaction with the outpatient care was very high. However, the clinicians should be aware that the pediatric patients seem to need more information about their disease and treatment plan.

Authorship

Alexander Schmithausen, Sarah M. Ulrich and Nikolaus A. Haas participated in study design and enrolling patients. Alexander Schmithausen and Sarah Ulrich participated in the performance of the research, in data collection and analysis. Alexander Schmithausen, Anja Tengler, Julia Birnbaum, Nikolaus A. Haas, Laura L. Rosenthal, Madeleine Orban, Christian Hagl, Robert Dalla Pozza, André Jakob, Marcus Fischer and Sarah M. Ulrich participated in data analysis and interpretation and the writing of the paper.

Funding

The authors declare no funding was received for this study.

Conflicts of interest

The authors declare no conflicts of interest.

Acknowledgement

Open access funding enabled and organized by ProjektDEAL.

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