

# Impact of heart transplantation in infancy and adolescence on quality of life and compliance

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## ABSTRACT

**Introduction:** Young patients who undergo heart transplantation in their early childhood or adolescence are confronted with typical developmental problems, which affect their specific adjustment to heart transplantation. This study aims at evaluating patients' health related quality of life and at determining the degree and sources of non-compliant behavior with its somatic and psychosocial consequences.

**Methods:** The study sample consists of 38 patients, who received heart transplantation between the age of 1 and 18 and are now between 16 and 34 years old. All participants received self-rating instruments: The Short-Form Health Survey (SF-36), Giessen Subjective Complaints List (GGB), Medication Experience Scale for Immunosuppressants (MESI), and Health Questionnaire for Children and Young People (KIDSCREEN-27). Patient's scores were compared to the scores of the specific norm sample. Further assessment was done by semi-structured interviews directed at psychosocial outcome, compliance, relationship to family and peer-group and integration into the work environment.

**Results:** In comparison to healthy controls the patients showed a significantly reduced quality of life (SF-36) in all psychological and nearly all somatic domains. Patients emphasized a very close and satisfying relationship to their parents and pronounced overall social support. Almost 50 % of the patients reported some reduced medical compliance and 20 % are to be seen as a high risk group for noncompliance, simultaneously characterized by poor physical and mental status.

**Conclusion:** Young adult transplant patients are to be carefully evaluated for psychosocial risks to avoid non-compliance and reduced quality of life in long-term follow up.

**Keywords:** Heart transplantation in childhood and adolescence, psychosocial integration, quality of life, compliance.

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## INTRODUCTION

Heart transplantation affects the lives of the persons concerned in many respects. Especially in infancy and adolescence, such surgery, the exposure to it, and the corre-

sponding inner, mental handling have an extensive impact on the further mental, emotional and psychosocial development of the concerned patients. While some authors have examined the long-term postoperative quality of life of adult patients (1-3), the number of studies that deal with the quality of life of transplant recipients in infancy and adolescence is comparatively low.

Nevertheless, in spite of the heterogeneity of the research designs, the results of indi-

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vidual studies suggests that the quality of life of young transplant recipients aligns with that of the healthy norm population. For instance Petroski et al. (4) noted an equivalent quality of life in comparison with the total population, despite a multiplicity of serious complications. This applies both for the mental and for the physical dimension. Also Pollock-Barziv et al. (5) found comparable readings between those who were transplanted at a young age and the norms of healthy peers.

Contradictory results are to be found in Weissberg-Benchell (6) und Simons (7).

Here, the adolescents describe a significantly lower general quality of life than the healthy norm group. In this respect, the mental and the somatic implications of transplantation and the familial environment were identified as factors influencing the perceived quality of life of adolescents. Regarding the recording of non-compliant behavior, a multiplicity of study designs exists. In the meta-analysis by Dew (8) it was detected that reduced compliance correlates with a set of factors: higher age, pronounced stress, and lower coherence in the families, as well as the mental state of the child or the adolescent. Simons (7) identified increasing non-compliance when the adolescents were responsible for their own medication.

Lawrence and Stilley (9) noted that compliant patients are capable of incorporating the transplant into their sense of self; they showed rather successful development of their autonomy, and at the same time good integration into their psychosocial environment. Besides, they develop an awareness of problems and the capability to deal with them.

In the study at hand, the subjective health-related quality of life of young grown-ups who were heart-transplanted in their infancy and adolescence was examined. The implications of heart transplantation are

first of all related to the characteristics of the physical and mental functioning as well as the social integration.

Moreover, the psychosomatic disorders perceived by the patients that are associated with the effects of heart transplantation have been covered and compared with the data of a control group of the same age.

Another significant aspect of the study describes the reciprocity between the compliance associated with drugs and the subjectively perceived quality of life.

## METHODS

The study was conducted at the Deutsches Herzzentrum Berlin (DHZB, German Heart Institute Berlin), where a total of 169 children and adolescents have received heart transplantation between 1986 and 2010 with a survival rate of 87% after 1 year and 50% after 15 years. Patients included in this study were less than 18 years old when received heart transplantation at the DHZB and had to be at least 16 years old at the time of follow up.

These selection criteria resulted in a sample of 52 patients who were contacted between March and August 2009.

After ethical committee approval patient recruitment started and forty patients aged between 16 and 34 years, nine of them younger than 18 years, decided to participate in the study.

To cope with the complexity and the subjectiveness of the conceptions of quality of life and compliance, quantitative as well as qualitative analysis instruments were applied. Thus, the individual wellbeing, the health-related changes over the years and the handling of the medical requirements after heart transplantation were detected and examined more adequately. The application of standardized questionnaire tools allowed the data of the young heart recipi-

ents to be compared with those of control persons of the same age.

To investigate the compliance and the health-related quality of life, we conducted a semi-standardized interview and made use of a questionnaire inventory. This comprised the *SF-36 Health Survey* (SF-36) by Bullinger and Kirchberger (10), a disease overlapping method to measure the health-related quality of life, reflecting the patients' sense of self in eight different areas of life.

The *Giessener Beschwerdebogen* (GBB, *Gies-sen Sheet of Complaints*) by Braehler and Scheer (11) is a method to investigate the range of physical disorders of psychosomatic patients.

The GBB is a questionnaire frequently applied in research and praxis and is regarded as a reliable tool as well as one that is sensitive to changes that can be applied from the age of 16 years onwards. The GBB allowed the researchers to cover single disorders, to collect four different sets of disorders, and also to define a total index of the disorder pressure.

The *Medikamenten-Erfahrungs-Skala für Immunsuppressiva* (MESI, *Medication Experience Scale for Immunosuppressants*) according to Götzmann (12) is a short and easily applicable screening tool for the assessment of subjective experiences and corresponding convictions of patients after organ transplantation. Clinically relevant is the correlation with the level of compliance: The MESI surveys the degree of side effects caused by immunosuppressives, and has proved to be a reliable tool to assess compliance. Above a scale value of 15, compliance disorders are significant.

The *Gesundheitsfragebogen für Kinder und Jugendliche* (KIDSCREEN-27, *Health Questionnaire for Children and young people*) by Ravens-Sieberer (13) was applied to measure the age-specific quality of life of children and adolescents. Complementary to the questionnaires, data concerning di-

agnoses, age at transplantation, course of disease and treatment from the patients' files were investigated.

Sociodemographic indications of the participants' family status, living arrangements, education and current occupational status were assessed by means of a self-designed questionnaire.

## RESULTS

Questionnaire data from 38 out of 40 recruited patients were satisfactory and were subjected to the examination. The distribution pattern between the sexes was balanced with, 50 % female patients and the mean age was 23 (range 16-34) years. Patients' average duration of living with a donor heart at the time of the assessment was 11 (range 3.1-22.6) years.

Patients living in their parents' households (66 %) were 21 (range 17-27) years old and those who did not (34 %) were 26 (range 17-35) years old. At the time of the assessment, 32 % of the patients were in a partner relationship.

Whereas 32 % of the patients finished secondary school (9<sup>th</sup> grade), 7.9 % were without a school-leaving certificate. A total of 7.9 % attained general qualifications for university entrance and 55 % held a job or an apprenticeship.

The examination of the quality of life indicated - with the exception of the vitality scale and the physical summation scale of the SF-36 - significant and highly significant differences between the patients and a healthy control group, whereas the group of patients basically scored lower values: Physical Functioning ( $p = .001$ ), Role Physical ( $p = .024$ ), Bodily Pain ( $p = .049$ ), General Health ( $p = .008$ ), Social Functioning ( $p = .008$ ), Role Emotional ( $p = .001$ ), Mental Health ( $p < 0.001$ ), and Mental Component Score ( $p = .002$ ).

The KIDSCREEN-27 application indicated a significant difference in regard to the *Autonomy and Parents* scale; here the group of patients younger than 18 years scored an average of better values than the healthy control group of the same age ( $p = .039$ ).

Regarding the psychosomatic disorders no significant differences were indicated between the control group and the patient group.

The study was able to identify three risk-groups: 51 % of the patients scored a MESI value  $\leq 15$  and thus showed a low non-compliance risk. Values 16 to 19 indicated an increased non-compliance risk, and 29 % of the patients fell into this category. 20 % of the patients scored a MESI value  $\geq 20$  and thus belonged to a non-compliance high risk group.

Compared to the other two groups with a lower to moderate non-compliance risk, the patients displaying such an increased risk were characterized by significantly reduced values on the scales Vitality ( $p = .020$ ), Mental Health ( $p = .035$ ), Mental Component Score ( $p = .048$ ), and General Health ( $p = .005$ ).

Patients belonging to the non-compliance high-risk group in addition report significantly or highly significantly more disorders on the scales cardiac disorders ( $p = .020$ ), exhaustion ( $p < 0.001$ ), epigastric pain ( $p = .002$ ), and on the total score of the GBB ( $p = .002$ ).

## CONCLUSION

Whereas the present study did not indicate significant differences between the patient group and the control group in regard to psychosomatic disorders, in nearly every dimension of the SF-36 the patient group had significantly reduced values in regard to the subjectively perceived quality of life.

The patients evaluated only the quality of the relationship to their parents on average higher than did the patients of the control group.

Furthermore, a correlation between the compliance associated with drugs on the one hand and the health-related quality of life as well as the degree of psychosomatic disorders within the patient group on the other hand was found: the higher the non-compliance risk, the more the patients perceived a reduced quality of life and the higher was the degree of psychosomatic disorders they reported.

According to the implications of heart transplantations in infancy and adolescence for the quality of life and compliance examined by the study at hand, it is a desideratum to design and to offer specific treatment for this group of patients that the study has identified as a notably burdened one, to support their mental, emotional and psychosocial development.

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