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# Quality of life and psychosocial situation before and after a lung, liver or an allogeneic bone marrow transplant

**Results from a prospective study**

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## Summary

*Background and objectives:* Only few comparative prospective studies have been published on psychosocial issues of organ transplant. This study investigated patient groups with various organ transplants with respect to their quality of life and psychosocial situation before and after surgery.

*Methods:* 76 patients receiving an organ transplant (lung n = 22, liver n = 26, allogeneic bone marrow n = 28) were investigated with regard to quality of life (SF-36), life satisfaction (FLZ), social support (F-SozU), and psychological symptoms (HADS-D) before (T0) as well as six (T1) and twelve (T2) months after transplant.

*Results:* In the pre-transplant period the values of the psychosocial variables were partly lower than those of the community normal sample. After transplant lung and bone marrow patients reported less anxiety and depression and a higher life satisfaction, and liver patients reported less depression, compared to the norms. Quality of life, life satisfaction and psychological symptoms of all patients improved significantly post-transplant, whereas the perceived social support decreased. Contrary to the other groups, the psychological well-being of liver transplant recipients was deteriorating between T1 and T2.

*Conclusions:* An organ transplant improved the patients' quality of life and psychosocial situation to a great extent. This effect was better in lung and bone marrow than in liver transplant patients.

*Key words: lung transplant; liver transplant; bone marrow transplant; quality of life; life satisfaction; social support; anxiety; depression; comparison between organ groups*

## Introduction

To our knowledge only a few prospective studies have been published on quality of life comparing different types of organ transplants [1, 2]. To date, most published studies on lung, liver or bone marrow transplants were either comparative cross-sectional studies [3–7], cross-sectional studies on one organ type [8–22] or prospective studies on one organ type [22–41]. Generally, organ transplants significantly improve the quality of life as well as the psychosocial situation. However, quality of life of healthy persons is rarely reached, and a persistence of psychological symptoms is found [42, 43].

The few studies, which compared organ groups by means of cross-sectional or longitudinal assessments, showed that differences between the different types of organ transplants exist. For instance, differences occured in quality of life as well as in the frequency of psychiatric disorders [1–7]. A prospective study design allows conclusions concerning general effects of transplants with respect to psychosocial variables. Furthermore, comparisons between different organ types provide the identification of typical features of particular organ groups.

The present study investigated prospectively the quality of life and psychosocial situation of different organ groups (lung, liver, and bone marrow). Quality of life was conceptualised as a multidimensional psychological construct with physi-

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cal, mental and social aspects, self-rated by the patients. Quality of life assessments are often used to evaluate the success of medical interventions [44, 45]. Further, patient's psychosocial situation before and after an organ transplantat was assessed by life satisfaction, psychiatric symptoms and social support.

The study addressed the following questions:

1. Do patients differ from community normal samples in their quality of life, life satisfaction, psychiatric symptoms and social support before, six and twelve months after the transplant?

2. How does the patients' quality of life, life satisfaction, psychiatric symptoms and social support develop from before the transplant throughout the following six and twelve months after the transplant?

3 a.) Are there differences between the three organ groups (lung, liver, bone marrow) and 3 b.) do they differ over the course of time?

## Patients and methods

### Study design and course of investigation

The design of the study was prospective, comparing three organ groups (lung, liver and bone marrow). The first inquiry period was performed between September 2000 and August 2003 at the University Hospital of Zurich. At this time, 161 lung-, liver- and bone marrow transplantation candidates were included in the study. All patients were informed verbally and in a written form about the trial and then signed a written informed consent. The study was approved by the responsible ethical committee of the University of Zurich.

The lung and liver transplant patients' *first inquiry* (T0) took place during the hospitalisation in which the evaluation for an organ transplant took place, ie before the patient had been accepted for placement on the waiting list. The bone marrow transplant candidates were questioned during the first two days of their hospitalisation planned for the transplant (T0). The investigation consisted of a 45-minute interview and a written questionnaire that was completed by the patients during the following days and returned to the study group within one week.

The *follow-up investigations* took place six (T1) and twelve (T2) months after the transplant. They consisted of a 45-minute-interview and a further questionnaire that the patient received by mail.

### Instruments

The *patient questionnaire* at the time of the first inquiry (T0) assessed global sociodemographic data (age, gender, partnership status, children, and employment status). For all three inquiries (T0–T2), the Questionnaire for Health Survey SF-36 [44, 45], the Questionnaire on Life Satisfaction FLZ [47], the Hospital Anxiety and Depression Scale HADS-D [47–49] and the Social Support Questionnaire F-SOZU [50] were administered. The normative values of these questionnaires were representative for the German population assessed in samples of 2000 to 2500 participants.

The *SF-36 Health Survey* [44] in its validated German version [45] was used to as a questionnaire to measure the global quality of life. The SF-36 Health Survey was used to investigate the quality of life in patients who are physically ill. It contained eight sub-scales (physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, mental health). The subscales consisted of two to ten items with 2-point to 10-point Likert-type scales. Higher scores represented higher functioning.

The well-validated *Life Satisfaction Questionnaire FLZ* consisted of two 8-item modules, "General Life Satisfaction" and "Satisfaction with Health" with a 5-point Likert-type scale. The patient rated each item twice, once for the subjective importance of the aspects of life or health addressed, and once for the degree of satisfaction in that area. The two ratings were combined into a "weighted satisfaction" score. As the following weighted formula shows, importance was multiplied by satisfaction: weighted score = importance rating × [(2 × satisfaction rating) – 3]. The total score was the sum of these eight scores [46].

The *Hospital Anxiety Depression Scale HADS* [47] measured anxiety and depression, and assessed these symptoms especially in physically ill patients. The HADS is a well-known questionnaire that is used worldwide and consists of 14 items with a 4-point Likert-type scale. Seven items measure anxiety, and 7 items measure depression. The Likert-type scale values were summed for the seven anxiety or the seven depression items, respectively to create two separate scores. A total score of >10 in the anxiety scale indicated a clinical diagnosis of anxiety, a total score in the range of 8 to 10 was borderline, and values of <8 were interpreted as clinically insignificant or normal. Analogous values applied to the depression scale. Both scales could be interpreted independent of each other. The German language version HADS-D was validated [48].

The *Social Support Questionnaire* (F-SozU) consisted in a short form of 14 items with a 5-point Likert-type scale. The questionnaire measures perceived and anticipated social support, validated in the German language version [50].

In the *medical documentation form* data concerning the diagnosis of the underlying lung, liver or bone marrow disease were recorded.

### Statistical analysis

The statistical analysis was carried out with the *SPSS 12.0* software program. The descriptive data were presented in absolute frequencies, percentages, mean values and standard deviations. Assessments of the scale value developments before and after the transplant were carried out using analysis of variance with repeated measurements, followed by contrasts (repeated).

### Sample development before and after transplantation

One hundred and eighty-three transplant candidates were addressed to participate in the study. Twenty-two patients rejected to participate in the study (women n = 12; men n = 10, age mean value 46.5 years). The reasons patients mentioned were "stress of the study participation", "poor physical health status", or they did not explain their reasons for rejection. In the first assessment T0, 161 transplant candidates were included. Forty-one patients died before (n = 22) or after (n = 19) the transplantation, 18 patients dropped out of the study after the first (n = 14) or second (n = 4) assessment. Twenty-six patients showed missing data, at least at one of the inquiries.Together, 76

patients were available for all three assessments T0–T2 (lung: n = 22, liver: n = 26, and bone marrow: n = 28). The resulting response rate was 76 / 183 (42%).

Except for the age (dropouts/deceased: 49 years *vs* study participants: 44 years, p = 0.03) no significant differences were found between the study sample (n = 76) and the group of the dropouts/deceased (n = 85) with respect to the psychosocial variables that were assessed at T0 and T1. Thus, the study sample (n = 76) can be considered as comparable to the dropouts/deceased (n = 85) at the first inquiry (T0).

## Results

### Sociodemographic and medical data

The sociodemographic data of the patients as well as the sociodemographic data of the community normal samples are shown in table 1a and table 1b, and the diagnoses of the underlying diseases in table 2.

### Psychosocial data

Table 3 and 4 show mean values and standard deviations of the psychosocial variables before and after a lung, liver or bone marrow transplant. Further, differences between the mean values of the study sample and community normal samples (T0, T1 and T2) are reported. Finally, table 3 and 4 show differences over the course of time (T0/T1 and T1/T2) of the total sample, differences between the organ groups, and differences between the organ groups over time (T0/T1 and T1/T2).

### Comparisons of organ groups with community normal samples (see table 3 and 4, column A–C)

*Lung patients*: Most of the values of the pre-transplant SF-36 subscales (physical functioning, role-physical, general health, social functioning, vitality, mental health) were significantly lower than the normative data. After the transplant, lung patients came close to the community normal sample regarding these subscales, except for social functioning. The pre-transplant values of general and health-related life satisfaction (FLZ) were lower, the post-transplant values were higher or similiar, compared to the norm. The values of post-transplant depression (HADS-D) were significantly lower. Social support (F-SozU) was higher at all three inquiries (T0–T2) than the norm.

*Liver patients*: The values of physical functioning, role-physical, bodily pain, social functioning and role-emotional (SF-36) were significantly lower than in the community normal sample at all three inquiries (T0–T2). Health-related life satisfaction (FLZ) and social support (F-SozU) were lower before the transplant; the post-transplant values were similiar to the norm. Post-transplant depression was significantly lower than the norm.

*Bone marrow patients*: Before the transplant, all SF-36 subscales except bodily pain were significantly lower than the norm. Six months after the

**Table 1a**

Sociodemographic data at the time of the first inquiry T0 (total sample, N = 161).

| Sociodemographic data | | dropouts/ deceased (n = 85) n (%) | study sample (n = 76) n (%) | lung (n = 22) n (%) | liver (n = 26) n (%) | bone marrow (n = 28) n (%) |
|---|---|---|---|---|---|---|
| Sex | Women | 29 (34) | 27 (36) | 7 (32) | 9 (35) | 11 (39) |
| | Men | 56 (66) | 49 (65) | 15 (68) | 17 (65) | 17 (61) |
| Age | Mean in years | 49.4 | 44.8 | 45.0 | 49.4 | 40.5 |
| | Minimum – Maximum | 18–69 | 18–67 | 18–62 | 27–67 | 18–57 |
| Civil status | Single | 17 (20) | 16 (21) | 5 (23) | 3 (12) | 8 (29) |
| | Married | 54 (64) | 50 (66) | 15 (68) | 17 (65) | 18 (64) |
| | Divorced | 12 (14) | 8 (11) | 2 (9) | 4 (16) | 2 (7) |
| | Widowed | 2 (2) | 2 (3) | 0 | 2 (8) | 0 |
| Highest educational qualification | | | | | | |
| | Obligatory schooling | | | | | |
| | Apprenticeship | 22 (26) | 12 (16) | 4 (19) | 3 (12) | 5 (19) |
| | Maturity, higher professional school | 49 (58) | 47 (64) | 14 (67) | 19 (73) | 14 (52) |
| | University/college | 9 (11) | 9 (12) | 1 (5) | 2 (8) | 6 (22) |
| | | 5 (6) | 6 (8) missing = 2 | 2 (10) missing = 1 | 2 (8) | 2 (7) missing = 1 |
| Present occupational employment | | | | | | |
| | Full time | 16 (19) | 16 (22) | 0 | 5 (19) | 11 (42) |
| | Part time | 21 (25) | 22 (30) | 6 (29) | 8 (31) | 8 (31) |
| | Not gainfully employed | 48 (57) | 35 (48) missing = 3 | 15 (71) missing = 1 | 13 (50) | 7 (27) missing = 2 |

**Table 1b**

Sociodemographic data of the community normal samples regarding the psychometric questionnaires that are administered in this study [45, 46, 49, 50].

| Sociodemographic data | | SF-36 N = 2914 | HADS-D N = 2037 | FLZ N = 7716 | F-SozU N = 2507 |
|---|---|---|---|---|---|
| Sex | Women | 55.6% | 56.1% | 53% | 55% |
| | Men | 44.4% | 43.9% | 47% | 45% |
| Age | Mean in years | 47.7 | 49.2 | 46.0 | 48.8 |
| | Minimum – Maximum | x | 14–92 | min = 18<br>SD = 17.6 | 14–92<br>SD = 17.9 |
| Civil status | Single | x | x | x | 24.5% |
| | Married | x | x | 62.4% | 53.7% |
| | Divorced | x | x | x | 9.0% |
| | Widowed | x | x | x | 12.8% |
| Highest educational qualification | | | | | |
| | Obligatory schooling | x | 48.6% | x | x |
| | Apprenticeship | x | x | x | x |
| | Maturity, higher professional school | x | 9.6% | x | x |
| | University/college | x | 8.2% | x | x |
| Present occupational employment | | | | | |
| | Full time | 33% | x | 40.6% | x |
| | Part time | x | x | x | x |
| | Not gainfully employed | x | x | x | x |

x information not available

**Table 2**

Diagnoses of the lung, liver and bone marrow patients at the first inquiry T0 (n = 76).

| Diagnoses | n (%) |
|---|---|
| Lung patients (n = 22) | |
| cystic fibrosis | 6 (27) |
| emphysema (due to A-1-antitrypsin deficiency) | 4 (18) |
| pulmonary hypertension | 4 (18) |
| chronic obstructive pulmonary disease | 3 (14) |
| pulmonary fibrosis | 3 (14) |
| Cartagener's syndrome | 1 (5) |
| lymphangioleiomyomatosis | 1 (5) |
| Liver patients (n = 26) | |
| liver cirrhosis (due to chronic hepatitis C) | 7 (30) |
| post alcoholic cirrhosis | 5 (19) |
| liver cirrhosis (due to chronic hepatitis B ) | 5 (19) |
| primary biliary cirrhosis | 4 (15) |
| cryptogenic cirrhosis | 1 (4) |
| primary sclerosing cholangitis | 1 (4) |
| liver cirrhosis (due to Morbus Wilson) | 1 (4) |
| cholangiocarcinoma | 1 (4) |
| neuroendocrine tumor | 1 (4) |
| Bone marrow patients (n = 28) | |
| chronic myeloid leukemia | 9 (32) |
| acute myeloid leukemia | 6 (21) |
| acute lymphocytic leukemia | 4 (14) |
| multiple myeloma | 4 (14) |
| Hodgkin disease | 2 (7) |
| myelodysplastic syndrome | 1 (4) |
| Non-Hodgkin lymphoma | 1 (4) |
| chronic granulomatous disease | 1 (4) |

transplant, physical functioning, role-physical, vitality, social functiong and role-emotional were lower than the norm. Twelve months after the transplant, only the values of role-physical and social functioning remained lower. General life satisfaction (FLZ) was lower before and higher after the transplant, compared to the norm; health-related life satisfaction (FLZ) was significant below the norm before and similar after the transplant. The values for post- transplant depression (HADS-D) were significantly lower than the norm. Social support (F-SozU) was significantly higher than the norm at all three inquiries (T0–T2).

*To summarise*, the transplant candidates showed lower values of the physical SF-36 subscales in all three organ groups at T0. In the post-transplant measures, only the values of the lung and bone marrow patients came close to the community normal samples; liver patients remained below the norms in most of the SF-36 subscales. Social functioning in all three organ groups was reduced before as well as after the transplant.

## Development of quality of life and psychosocial situation before and after an organ transplant (see table 3 and 4, column D and E)

The results of table 3 and 4 (see column D and E) showed significant improvements between the two inquiries T0 and T1 regarding physical functioning, mental health, general health, vitality and social functioning (SF-36), as well as general and health-related life satisfaction (FLZ), anxiety and depression (HADS-D). Physical role and emotional role (SF-36) improved between T1 and T2. Social support (F-SozU) significantly decreased

**Table 3**

Mean values and standard deviations of the SF-36 subscales before and after a lung, liver or bone marrow transplant (n = 76), differences compared to the norm values [45], differences over the course of time (T0/T1 und T1/T2) of all patients, differences between the organ groups, and differences between the organ groups over time (T0/T1 and T1/T2).

| column | T0[1] | | T1[2] | | T2[3] | | Norm[4] | A T0–Norm[5] | B T1–Norm[6] | C T2–Norm[7] | D Time T0–T1[8] | E Time T1–T2[9] | F Organ-group[10] | G Time T0–T1 × Group[11] | H Time T1–T2 × Group[12] |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | M | SD | M | SD | M | SD | | p | p | p | p T0-T1 | p T1–T2 | p | p T0-T1 | p T1–T2 |
| SF-36 Physical Functioning | | | | | | | 84.5 | | | | <.001 | .068 | .043 | <.001 | .970 |
| Lung | 22.6 | 19.8 | 78.1 | 19.4 | 82.7 | 20.6 | | <.001 | .137 | .690 | | | | | |
| Liver | 66.7 | 27.0 | 69.0 | 20.7 | 72.5 | 24.8 | | .002 | .001 | .021 | | | | | |
| Bone Marrow | 73.4 | 26.2 | 74.1 | 23.3 | 77.6 | 20.8 | | .034 | .025 | .090 | | | | | |
| SF-36 Role Physical | | | | | | | 83.7 | | | | .095 | <.001 | .364 | .150 | .199 |
| Lung | 29.6 | 42.0 | 54.6 | 40.6 | 75.0 | 42.3 | | <.001 | .003 | .345 | | | | | |
| Liver | 35.6 | 41.9 | 38.5 | 42.0 | 44.2 | 43.8 | | <.001 | <.001 | <.001 | | | | | |
| Bone Marrow | 36.1 | 39.4 | 36.1 | 41.2 | 61.1 | 42.9 | | <.001 | <.001 | .006 | | | | | |
| SF-36 Bodily Pain | | | | | | | 79.1 | | | | .164 | .653 | .178 | .482 | .777 |
| Lung | 73.8 | 33.0 | 67.0 | 30.3 | 66.5 | 32.3 | | .461 | .075 | .082 | | | | | |
| Liver | 65.6 | 32.1 | 66.3 | 31.5 | 66.5 | 30.3 | | .042 | .048 | .045 | | | | | |
| Bone Marrow | 83.0 | 25.6 | 72.3 | 28.2 | 76.8 | 23.4 | | .428 | .213 | .599 | | | | | |
| SF-36 General Health | | | | | | | 68.1 | | | | <.001 | .691 | .033 | <.001 | .273 |
| Lung | 22.5 | 16.5 | 64.1 | 19.3 | 66.4 | 14.7 | | <.001 | .341 | .585 | | | | | |
| Liver | 50.0 | 22.2 | 68.6 | 19.8 | 65.0 | 24.5 | | <.001 | .903 | .525 | | | | | |
| Bone Marrow | 55.3 | 19.2 | 62.9 | 18.0 | 66.6 | 16.8 | | .002 | .157 | .720 | | | | | |
| SF-36 Vitality | | | | | | | 63.3 | | | | <.001 | .151 | .503 | <.001 | .373 |
| Lung | 33.0 | 17.9 | 63.0 | 13.2 | 66.5 | 12.6 | | <.001 | .904 | .247 | | | | | |
| Liver | 44.7 | 25.7 | 55.8 | 20.0 | 55.0 | 25.3 | | .001 | .066 | .107 | | | | | |
| Bone Marrow | 53.6 | 20.5 | 56.1 | 17.1 | 61.4 | 18.7 | | .018 | .033 | .600 | | | | | |
| SF-36 Social Functioning | | | | | | | 88.8 | | | | <.001 | .371 | .253 | .056 | .028 |
| Lung | 39.5 | 27.1 | 66.8 | 23.9 | 76.5 | 18.1 | | <.001 | <.001 | .004 | | | | | |
| Liver | 58.0 | 25.3 | 71.5 | 20.0 | 66.7 | 25.7 | | <.001 | <.001 | <.001 | | | | | |
| Bone Marrow | 61.5 | 21.1 | 72.3 | 15.9 | 73.1 | 15.3 | | <.001 | <.001 | <.001 | | | | | |
| SF-36 Role Emotional | | | | | | | 90.4 | | | | .446 | .024 | .120 | .666 | .039 |
| Lung | 79.4 | 34.1 | 81.0 | 34.3 | 92.1 | 23.3 | | .174 | .246 | .742 | | | | | |
| Liver | 60.0 | 44.1 | 70.6 | 42.3 | 66.7 | 39.7 | | .001 | .015 | .006 | | | | | |
| Bone Marrow | 66.7 | 41.1 | 66.7 | 45.2 | 89.8 | 24.5 | | .004 | .013 | .360 | | | | | |
| SF-36 Mental Health | | | | | | | 74.8 | | | | <.001 | .898 | .971 | .757 | .044 |
| Lung | 65.1 | 18.8 | 76.0 | 15.8 | 79.3 | 17.6 | | .025 | .725 | .247 | | | | | |
| Liver | 67.9 | 20.0 | 78.3 | 16.8 | 72.5 | 20.7 | | .090 | .297 | .577 | | | | | |
| Bone Marrow | 68.2 | 13.8 | 75.6 | 12.6 | 77.5 | 12.0 | | .017 | .748 | .245 | | | | | |

[1] pre-transplant inquiry;
[2] inquiry six months after transplant,
[3] inquiry twelve months after transplant;
[4] norm values of the representative sample [45],
[5-7] differences between study sample and norm values (T0/T1/T2);
[8] differences over the course of time between T0 and T1;
[9] differences over the course of time between T1 and T2;
[10] differences between the organ groups;
[11, 12] differences between the organ groups over the course of time (T0/T1 and T1/T2).

**Table 4**

Mean values and standard deviations of the FLZ / HADS-D subscales and F-SozU scale before and after a lung, liver or bone marrow transplant (n = 76), differences compared to the norm values [46, 49, 50], differences over the course of time (T0/T1 und T1/T2) of all patients, differences between the organ groups, and differences between the organ groups over time (T0/T1 and T1/T2).

| column | T0[1] | | T1[2] | | T2[3] | | Norm[4] | A T0–Norm[5] | B T1–Norm[6] | C T2–Norm[7] | D Time T0–T1[8] | E Time T1–T2[9] | F Organ-group[10] | G Time T0–T1 × Group[11] | H Time T1–T2 × Group[12] |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | M | SD | M | SD | M | SD | | p | p | p | p T0-T1 | p T1-T2 | p | p T0-T1 | p T1-T2 |
| FLZ General | | | | | | | 60.5 | | | | <.001 | .881 | .278 | .170 | .209 |
| Lung | 43.9 | 30.2 | 72.7 | 37.2 | 76.1 | 33.5 | | .017 | .140 | .040 | | | | | |
| Liver | 56.2 | 38.9 | 67.7 | 34.1 | 61.3 | 46.0 | | .574 | .290 | .933 | | | | | |
| Bone Marrow | 63.1 | 30.4 | 77.8 | 32.8 | 82.0 | 30.1 | | .658 | .010 | .001 | | | | | |
| FLZ Health | | | | | | | 74.4 | | | | <.001 | .141 | .233 | .067 | .025 |
| Lung | 22.4 | 34.6 | 60.7 | 37.2 | 75.6 | 35.3 | | <.001 | .099 | .881 | | | | | |
| Liver | 48.5 | 45.8 | 71.7 | 43.1 | 61.6 | 56.3 | | .008 | .755 | .258 | | | | | |
| Bone Marrow | 58.6 | 30.5 | 67.1 | 40.2 | 81.1 | 32.2 | | .011 | .348 | .277 | | | | | |
| HADS-D Anxiety | | | | | | | 5.0 | | | | <.001 | .904 | .596 | .627 | .605 |
| Lung | 5.5 | 3.3 | 4.4 | 3.3 | 4.0 | 3.3 | | .519 | .409 | .173 | | | | | |
| Liver | 6.7 | 4.5 | 4.7 | 3.3 | 4.9 | 3.7 | | .075 | .601 | .917 | | | | | |
| Bone Marrow | 5.7 | 3.4 | 4.2 | 2.7 | 4.5 | 3.2 | | .306 | .135 | .389 | | | | | |
| HADS-D Depression | | | | | | | 4.7 | | | | <.001 | .184 | .953 | .010 | .044 |
| Lung | 5.7 | 3.3 | 2.1 | 2.2 | 2.0 | 2.2 | | .179 | <.001 | <.001 | | | | | |
| Liver | 4.8 | 4.1 | 2.6 | 2.6 | 2.8 | 2.5 | | .894 | <.001 | .001 | | | | | |
| Bone Marrow | 4.0 | 2.6 | 3.3 | 3.0 | 2.4 | 2.6 | | .140 | .023 | <.001 | | | | | |
| F-SozU | | | | | | | | | | | .048 | .114 | .473 | .482 | .234 |
| Lung | 4.4 | .4 | 4.3 | .5 | 4.5 | .4 | 4.0 | <.001 | .010 | <.001 | | | | | |
| Liver | 4.3 | .6 | 4.2 | .6 | 4.2 | .6 | | .036 | .054 | .145 | | | | | |
| Bone Marrow | 4.5 | .5 | 4.3 | .6 | 4.4 | .6 | | <.001 | .018 | .003 | | | | | |

[1] pre-transplant inquiry;
[2] inquiry six months after transplant,
[3] inquiry twelve months after transplant;
[4] norm values of the representative sample [46, 49, 50],
[5-7] differences between study sample and norm values (T0/T1/T2);
[8] differences over the course of time between T0 and T1;
[9] differences over the course of time between T1 and T2;
[10] differences between the organ groups;
[11, 12] differences between the organ groups over the course of time (T0/T1 and T1/T2).

between T0 and T1. Except for the SF-36 subscales role-physical and role-emotional, all psychosocial parameters were stable between the post-transplant inquiries T1 and T2.

### Differences between the organ groups and between the organ groups over the course of time (see table 3 and 4, column F–H)

Table 3 and 4 (see column F) showed that the organ groups differed significantly with respect to physical functioning and general health (SF 36). The lowest values for these physical dimensions were reached by lung transplant patients before the transplant. Considering all the other psychosocial variables there were no other significant differences between the organ groups.

Looking at the differences between the organ groups over the course of time (table 3 and 4, column G and H), one can see significant differences in physical functioning (SF-36), general health (SF-36), vitality (SF-36) and depression (HADS-D) between T0 and T1. Lung transplant patients achieved the highest improvement in physical functioning, general health and vitality. Bone marrow patients showed the least differences between T0 and T1.

Significant differences between the organ groups during the course of time (T1/T2) were found on the Social Functioning and Mental Health Scales (SF-36) as well as on the Depression Scale (HADS-D). The values of mental health / social functioning of liver patients decreased whereas lung and bone marrow patients' values increased. In accordance with this, liver transplant patients' values of depression increased between the sixth and the twelfth month after the transplant, in the two other groups they decreased.

## Discussion

In the current study the quality of life and the psychosocial situation of patients before and after a lung, liver or an allogeneic bone marrow transplant were investigated. Because of the prospective study design and the investigation of three organ groups, we were able to study the development of patients' situation in general, as well as differences between the organ groups. To our knowledge this is the first prospective study that has compared these organ groups over the course of time.

### Comparisons of the study sample with community normal samples

The values for physical functioning, physical role, vitality, general health as well as the health-related life satisfaction were in all three organ groups significantly lower than those of a community normal sample. This result showed that patients, considered for an organ transplant, were physically very ill. One would expect that they also report higher anxiety and depression, but this was not the case. The results corresponded with findings of earlier studies [15, 25, 51]. Achievements in psychological adaptation, changes of their expectations, good social support and hopes for a transplant were listed as explanations for these low values in respect to anxiety and depression [15, 51]. However, these patients could belong to a selected group, as patients with severe psychiatric disorders may have been excluded as not being suitable for a transplant [52].

The positive effect of the transplant is shown by the fact that patients experienced their physical and psychological condition after the transplant similar to the normal sample. Patients having had a lung or bone marrow transplant perceived this positive effect in respect to physical functioning, physical role, vitality, mental health, general and health related life satisfaction as well as to anxiety and depression. These patients scored even higher values on general life satisfaction and depression than the community normal samples. Similar results were also found by Littlefield et al. [1]. In this study, following a lung transplant, patients reached equal or even higher values than the normal sample. The reason of this positive post-transplant psychological condition might be, that patients compare their post-transplant health situation with the life-threatening illness before the transplant. This mental procedure is called "cognitive re-framing" or "response shift" [24]. According to Walter et al. [8] patients feel significantly happier after the transplant than before. Probably these low depression values come from the patients' increased happiness with life. In the course of psycho-traumatological research Ziegelman et al. interpreted this positive psychological development, often perceived after a transplant, as an expression of personal growth [54].

In all organ groups before and after transplantation social support was significantly higher than in the community normal sample (except in the liver group one year after surgery). Different studies have shown [55, 56] that social support plays a major role for the psychological well-being before and after a transplant. This support seemed to be particulary important because patients' social functioning, either by emotional or physical problems, was reduced during the pre-transplant as well as the post-transplant period. Thus, an important task of psychosocial counselling is to strengthen the patients' social network before and after the transplant.

A further result of our study showed that liver transplant patients, in contrast to the other two groups, did not recover physically as well. Six and twelve months after the transplant their values of physical functioning, physical role and bodily pain were significantly lower than these of the community normal sample. Our results underline the findings of other studies [2, 4] that post-transplant liver patients have higher or similar levels of psychological well-being, but poorer physical functioning, when compared with normal samples.

### Development of quality of life and psychosocial situation before and after a transplant in the study sample

The data development of the whole sample over time indicated that a transplant not only improved physical health but also added general and health-related life satisfaction and decreased anxiety and depression. Thus an organ transplant had a positive effect on the physical as well as on the psychosocial situation. The diminishing social support reflected this change, the patients were feeling better and needed less social support than during the critical state of their disease. Our results showed that these positive psychosocial changes remained stable up to a year after the transplant. Earlier studies investigating the outcome of individual organ groups have shown similar results for lung [2, 4, 12, 23, 26, 28], liver [2, 4, 33–35] and bone marrow patients [41].

### Differences between the organ groups and differences between the organ groups over time

Comparing the organ groups, the only significant differences were found in the SF-36 subscales of physical functioning, general health and vitality; lung patients suffering from an end-stage disease were physically more stressed than the others. From a medical point of view, the difficulty in breathing was mainly responsible for this strain.

Looking at the differences between the organ groups over time (interaction group × time) between the first inquiry before the transplant (T0) and the second inquiry six months after the transplant (T1), the results showed that lung patients

experienced the largest physical progress. Previous studies showed that lung patients compared with liver patients had a worse physiological performance before the transplant and made better improvements after the transplant [1, 4].

Usually this progress following surgery also had psychosocial implications. Patients were often very happy about their dramatically improved health status. Dabbs et al. [11] described this typical emotional state after lung transplant as a kind of "naivité": Later on, patients were confronted with their dependence on medication or with the risk of infections and allograft rejections; they needed to cope with these potentially disappointing realities. Often they needed professional help to "discover" the new and different bodily signals or symptoms and to develop a new "insight" regarding the strains and physical limitations of life after the transplant [11].

The second difference between the organ groups related to the decrease of depression (between T0 and T1), which was lower in bone marrow patients than in the two other groups. One must keep in mind, that the medical situation of the organ groups before and immediately after the transplant are not the same. Lung or liver transplant candidates have strong physical ailments that rapidly diminish after the transplant. Bone marrow patients on the other hand do not achieve a comparable relief. Bone marrow patients have to undergo pretransplant chemo- and in some cases radiotherapy and in the weeks following the transplant. Moreover, they receive treatment in an isolated environment. Thus, the prevalence of depressive disorders increases immediately after a bone marrow transplant [40]. In our study the psychosocial well-being of bone marrow patients improved mainly between the sixth and twelfth month after the transplant. Quality of life after a bone marrow transplantation seemed to improve with time. Chiodi et al. [20] found a delayed recovery from the bone marrow transplant. In this study, patients with an intervall <5 years from the transplant reported a significantly lower quality of life than long-term survivers. Thus, in our study we saw the tendency of a slow recovery during the first year post-transplant. In the one-year follow-up, however, most of the SF-36 scales were similar to the norm.

Further, the organ group comparison showed that the psychological well-being (mental health, depression) during the sixth up to the twelfth month after a lung or bone marrow transplant improved. However, liver patients showed reduced psychosocial development between T1 and T2. These patients reported increasing psychological problems from six until twelve months post-transplant. To our knowledge, no other study reported this worsening development after a liver transplant.

Various explanations are possible. First, the psychosocial distress could be caused by physical symptoms, such as excess appetite, trembling, and headaches that increase after liver transplantation [8]. Second, the liver transplant group included an above-average number of patients with previous addictive disorders who generally possess less coping strategies. In our opinion, both explanations are justified. Persisting or increasing physical symptoms as well as poor coping strategies may lead to the deterioration of psychological well-being.

A further explanation could be, that liver patients of our study had had an especially poor physical outcome, leading to the increased psychological problems. However, during the first six months after surgery the incidence of an acute rejection was 26.9% and during the period between the sixth and twelfth month 11.5%. This incidence is similar to international values. In a study of Levy et al. [57] 24–26% of the patients suffered from acute rejection at 3 months post-transplant. Consequently, the negative psychosocial development of our liver patients was not associated with a particularly poor physical outcome. From this point of view the liver transplant patients presented a psychosocial risk group and should be assisted by special psychosocial and medical attention.

Some limitations of the present study have to be mentioned. First, we found a difference of age between the study sample (n = 76) and the group of deceased/dropped out patients. One could assume, that older patients show a lower level of psychosocial well-being; thus, there would be an important selection bias. On the other hand, there were no further differences between the study sample and the deceased/dropped out patients with respect to the psychosocial variables. We conclude, that the study sample and the group of deceased/dropped out patients are comparable at T0. Furthermore, the first inquiries of the organ groups (T0) were not made at the same time. Lung and liver transplant candidates were questioned before being put on the waiting list. At this point, the patients did not know how long they had to wait for an organ transplant. Bone marrow transplant candidates were questioned, after they were hospitalised for the intended transplant. This difference in the design of the investigation lies in the organ related procedure. In contrast to lung and liver transplant patients, there was no waiting list for bone marrow patients. They receive living donations that can be planned ahead. Third, in all organ groups, there was a wide range of underlying diagnoses. This implied that our patients had also different pre-transplant experiences. Patients with a chronic myeloid leukaemia, for example, may never have been in a hospital prior to the bone marrow transplant, whereas patients with acute myeloid leukaemia would already have received intensive chemotherapy. Also these different medical conditions should be considered. The relative small study sample represented a further limitation. The decrease in the number of study cases of the relatively large initial sample was due to patients dying before or after the transplant and due

to a smaller group of dropouts. This is a problem often found in prospective clinical studies in transplantation medicine.

## Conclusions

The results of this present study showed that lung and bone marrow transplant patients experienced a positive medium-term psychosocial development, ie up to one year after the transplant, probably related to the relief achieved by health related improvements of their life situation. Future investigations should be done on how long these distinct improvements are stable. Special attention should be given to patients after liver transplants, as their psychosocial well-being deteriorated during the sixth up to the twelfth month after the transplant. Obviously these patients showed greater psychological as well as social difficulties coping with a liver transplant. Prospective long-term multicentre studies with larger patient samples that compare the course of time in different organ groups are required.

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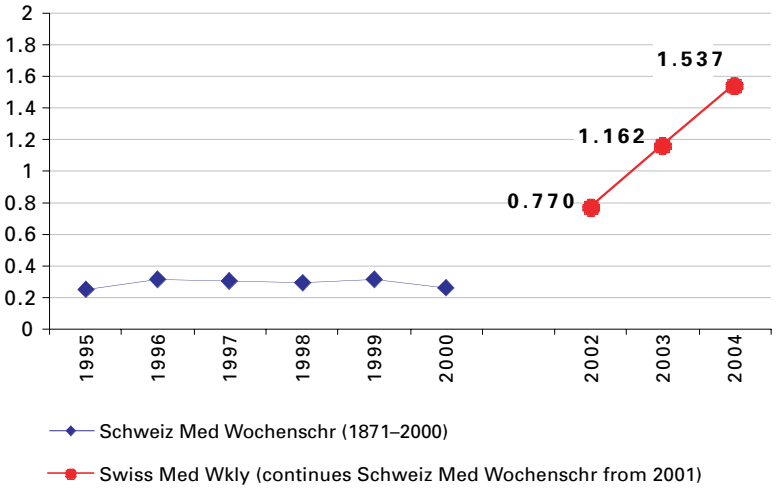


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