

# Research Article

## What do patients think after a lung transplantation about their self, lung and social network? A quantitative analysis of categorical interview data

### Was denken Patienten nach einer Lungentransplantation über ihr Selbst, ihre transplantierte Lunge und ihr soziales Netzwerk? Eine quantitative Analyse kategorialer Interview-Daten

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#### Abstract

**Objective:** Psychosocial aspects have been investigated in transplant medicine mainly by the means of various structured questionnaires. To date only few interview data are available on patients thoughts about their self, the transplanted lung or the medication, and the relationship between these thoughts and compliance or gender.

**Methods:** Twenty patients were interviewed after transplantation about their perceptions on self, body, transplanted lung, medication and social network. Their compliance was rated by the attending physicians. The overall interrater-reliability for the category groups was Kappa=.8. The article presents quantitative results of the content analysis.

**Results:** Statements were made most frequently about the patients' social network and their self, and significantly less frequently about their body, lung and medication. "Closeness", "distance" and "depression" were main issues that these patients were dealing with. "Closeness" and "distance" played major roles in interpersonal relationships as well as in the relationship to the new lung. Depression mainly had to do with health burdens and the psychosocial consequences of the transplantation (e.g. financial worries). Women made significantly more statements about their social network than men; furthermore they formulate more accented emotional evaluations. Patients with low compliance were more frequently preoccupied with their self, their body as well as the experience of "dependence" and "achievement" than patients with high compliance; also low compliant patients made more critical statements.

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**Conclusions:** For lung transplant recipients social relationships are the prime topic of their daily experience. With respect to compliance behaviour, special attention should be paid to the patients' self and body perception as well as to their experience of dependence. These results should be confirmed in studies with larger sample sizes.

**Keywords:** lung transplantation, self, body, compliance, gender, content analysis

## Zusammenfassung

**Hintergrund:** Psychosoziale Aspekte der Organtransplantation werden meistens anhand verschiedener empirischer Fragebogen untersucht. Bis heute liegen allerdings wenige Interview-Daten vor, welche Vorstellungen transplantierte Patienten über ihr Selbst bzw. ihre Person, die transplantierte Lunge oder die Medikamente haben, und welche Zusammenhänge zwischen diesen Vorstellungen und dem Compliance-Verhalten oder dem Geschlecht bestehen.

**Methode:** 20 Patienten nach einer Lungentransplantation wurden zu ihren Vorstellungen über ihr Selbst, ihren Körper, die transplantierte Lunge und ihr soziales Netzwerk interviewt. Die Compliance wurde durch die behandelnden Ärzte eingeschätzt. Die Interraterreliabilität (Cohen's Kappa) über die Kategoriengruppen lag bei  $K=0.8$ . In der vorliegenden Studie werden die quantitativen Ergebnisse der Inhaltsanalyse vorgestellt.

**Ergebnisse:** Am häufigsten fanden sich Äußerungen zum Sozialen Netzwerk und der eigenen Person, wesentlich seltener zum Körper, der Lunge und den Medikamenten. Insgesamt beschäftigten sich die Patienten am meisten mit den Themen Nähe, Distanz und Depressivität. Nähe und Distanz spielten vor allem in den interpersonellen Beziehungen eine Rolle, aber auch in der Beziehung zur transplantierten Lunge. Die Depressivität bezog sich vor allem auf Gesundheitsprobleme und auf psychosoziale Folgen der Transplantation (z.B. finanzielle Belastungen). Frauen machten signifikant mehr Aussagen zum Sozialen Netzwerk als Männer, ihre Aussagen waren emotional akzentuierter. Patienten mit niedriger Compliance beschäftigten sich häufiger mit ihrer Person und ihrem Körper sowie mit den Themen Abhängigkeit und Leistung als Patienten mit hoher Compliance.

**Schlussfolgerung:** Für lungentransplantierte Patienten sind soziale Beziehungen ein zentrales Lebensthema. Hinsichtlich des Complianceverhaltens sollte darauf geachtet werden, wie transplantierte Patienten ihr Selbst und ihren Körper wahrnehmen sowie welche Rolle Abhängigkeitserfahrungen spielen. Diese Ergebnisse sollten in Untersuchungen mit grösseren Stichproben überprüft werden.

**Schlüsselwörter:** Lungentransplantation, Selbst, Körper, Compliance, Geschlecht, Inhaltsanalyse

## Introduction

Since the first lung transplantation in 1983, thousands of seriously ill lung patients have had a new chance of survival. Previous psychosocial research has dealt primarily with issues such as quality of life, psychological morbidity or the risk factors for non-compliance, e.g. medication costs, side effects, lack of information, lack of understanding with respect to the taking of medication, doctors under time pressure [1], [2], [3], [4], life crises, alcohol addiction or a psychiatric disorder [2], [3], [5], [6]. To date, however, there has been little investigation of the immediate perception organ-transplant recipients have concerning themselves, the lung or the medication, and what relationship exists between the patients' perception and their compliance behaviour.

The use of immunosuppressive medication following a lung transplant is among the most important prerequisites for enabling patient's survival. Non-compliance results in acute rejection, loss of organ and subsequently leads to the death of the patients; about 20% of organ transplant recipients, however, show a non-compliant behaviour [7], [8]. In recent studies, there is a distinction made between "compliance" and "adherence". Compliance is the historically older and more popular term. It means that the doctor's instructions are closely followed, adherence implies a more active, voluntary and cooperative role of the patient in the doctor-patient relationship [9]. For practical reasons of clinical popularity, we used the term "compliance" in the doctor's questionnaire as well as consequently in this article.

In this study, the perceptions of lung-transplant patients are examined content-analytically. Following the questions of a semi-standardized interview, five main categories ("self", "body", "lung", "medication", "social network") and two value categories ("high & positive", "high & negative") were

defined. Further, 24 attribute categories were developed inductively. The article reports the quantitative results of the categorical data analysis (i.e. the frequencies of the main, value and attribute categories as well as statistical differences between patients with high, moderate and low compliance or men and women, respectively).

The study addresses the following questions:

1. What issues are patients dealing with after a lung transplant regarding their self, the new lung and the social network?
2. To what extent do subgroups (men and women, patients with high, moderate and low compliance) differ with respect to transplantation-specific issues?

## Methods

### Sample and sampling procedures

Participating in the study were 20 patients who had undergone a lung transplant at least 12 months previously, and who had a good knowledge of German. These patients had already taken part in a questionnaire enquiry that had been carried out with 50 of 53 invited patients following a lung transplant. The patients' questionnaire contained various standardized test instruments to assess the degree of anxiety and depression, self-esteem, health perceptions and personality factors [10], [11]. As part of the questionnaire study, the attending doctors evaluated patients' global compliance on a 3-point Likert-scale ("high" - "moderate" - "low"). Based on this external rating, all patients judged as "highly" (n=10), "low" (n=5) and additionally a group of "moderate" compliant patients (n=6) were selected for interviews; one low compliant patient refused to participate in the interview study. The interviews took place four to twelve weeks after the questionnaire study. They were recorded with a mini-disc recorder and transcribed according to the standard procedure for interview transcripts in psychology [12]. The patients were informed about the study, both orally and in writing. At the moment of the interview, the interviewer was not informed about the professional compliance-rating. The Ethics Board of the University Hospital Zurich approved the study.

### Structure of the interview manual

The semi-standardized interviews were carried out on the basis of a manual containing nine questions in total. The questions referred to the patients' perception concerning their self, their body, the transplanted lung, their medication, and their social network (such as significant people). Patients were asked to describe themselves and their body, including the transplanted lung, and their subjective experience of the medication. Further, they were asked, which people were currently the most significant in their life. They were requested to describe these people and their attitude and feelings towards them.

### Qualitative data analysis

The entire interviews are analysed by content analysis [13], [14], supported by the atlas/ti software programme [15]. Following the interview questions in a first step, five main categories were defined: "self", "body", "lung", "medication", "social network", and a residual category "other statements". The residual category contained statements unrelated to the questioning in the study. In a second step further categories were developed inductively. By this scheme procedure, 1. every statement (i.e. a linguistic unit related to a certain sense, grammatically varying between half of a sentence and several sentences) from the text was encoded with a deductive main category ("self", "body", "lung", "medication", "social network") or with the residual category; 2. two value categories were defined ("high & positive", "high & negative"); these categories were assigned when patients made an value statement (e.g. "indescribably beautiful" = "high & positive"), and 3. every statement in the text was further coded with an inductively developed attribute category. The second step of content analysis led to a list of 31 main (n=5), attribute (n=24) and value (n=2) categories. For interrater analysis, the categories were provided with definitions and illustrated by anchor examples.

For example, the attribute category "closeness" was defined as follows: "All statements that describe an emotional as well as cognitive relationship with following possible characteristics: trustfulness, empathy, openness, understanding, love, intimacy, contact. Closeness can be experienced between two or several persons, or between a person and an object, for example the body."

The anchor examples were:

- Closeness: "For me, my wife is a very reliable person. I know, in the case of anything, she will be there."
- Closeness: "We are on the same wavelength, we are anyhow related to another mentally; you know what the other person thinks."

## **Interrater-reliability and quantitative data analysis**

The interrater-reliability was measured by a second independent rater. Interrater-reliability was calculated firstly by the reliability index R for single categories, that is the relationship of the identical judgements to the total number of judgements; and secondly by Cohen's Kappa over all categories; this index considers supplementary the concordance that is caused by chance.

The quantitative data analysis was carried out with the statistical software program *Microsoft Excel* and *SPSS 11.0*. The descriptive data were expressed in absolute frequencies and percentages. Multiple tests have been conducted. All categories with a frequency >2% were compared. Differences between the gender subgroups were calculated as greater-than-coincidental deviations from the distribution to be expected in the individual groups  $\chi^2$  test. However, because of the small sample size significant differences between the compliance groups were not tested. There were no greater-than-coincidental differences in word frequency between the subgroups; therefore, the analyses on group level were based on the actually found frequencies of the categories.

## **Results**

### **Sociodemographic and medical data**

The sample comprised 10 women (50%) and 10 men (50%) with a mean age of 41 years (18-60 years). Thirteen patients (65%) lived with a partner. Two patients (10%) were working more than 50% of regular working time. Nineteen patients (95%) had undergone a bilateral lung transplant, and one patient (5%) had received a unilateral lung transplant. On average, the lung transplantation had been performed 3.9 years ago (minimum 1.8, maximum 9.0 years). Lung transplantation has been performed for the following diagnoses: cystic fibrosis (N=5, 25%), COPD (N=3, 15%), pulmonary fibrosis (N=2, 10%), and pulmonary hypertension (N=3, 15%), as well as other lung diseases (N=7, 35%) such as lymphangiomyomatosis, histiocytosis X, and bronchiectasis. Ten (50%) patients were rated as "high compliant", 6 patients (30%) as "moderate compliant", 4 patients (20%) as "low compliant".

### **Interrater reliability**

Interrater reliability R (ratio of the opinions in agreement to the total number of opinions) for single attribute categories is reported in Table 1. R for the single main categories was R=.69 (self), .95 (body), 1.00 (lung), 1.00 (medication), .91 (social network) and for the two value categories R=.84 (high & positive) and R=.88 (high & negative). Additionally, the overall interrater reliability Cohen's Kappa was calculated for each group of categories and was K=.79 for the group of main categories, K=.82 for the group of the attribute categories, and K=.72 for the group of the value categories.

### **Frequency distributions of the main-, attribute-, and value categories**

An interview (including interviewer's questions) contained on average 7,572 words (S=2,785, min. 3,104, max. 14,587 words). In the entire text material, 1,788 statements were assigned for the five main categories. Most frequently found were statements on the "social network" (43.6%) and on the "self" (34.8%). The categories "body" (9.8%), "lung" (5.4%) and "medication" (6.4%) occurred significantly less frequently ( $p < 0.001$ ). Further, 394 statements were encoded with the residual category. Value categories were assigned a total of 460 times. In 72.8% of statements the value was encoded as "high & positive", in 27.2% as "high & negative".

Table 1 shows the attribute categories ranked according to frequency and reliabilities for each attribute category; further the interrater reliability R for the single attribute categories.

**Table 1: Attribute categories with reliabilities ranked according to frequency and the interrater reliability R for the single attribute categories**

Rank	Category	N	%	R
1	Closeness	424	12.9	.68
2	Depression	290	8.9	.75
3	Distance	284	8.7	.78
4	Giving help	251	7.7	.82
5	Competence	229	7.0	.90
6	Happiness	205	6.3	.84
7	Incompetence	184	5.6	.67
8	Physical activity	176	5.3	.92
9	Disability	159	4.9	.94
10	Autonomy	122	3.7	.88
11	Achievement	117	3.6	.78
12	Illness	101	3.1	.95
13	Dependence	94	2.9	.84
14	Acknowledgement	94	2.9	.84
15	Aggressiveness	93	2.8	1.00
16	Codes <2%*	453	13.8	-
<b>total</b>		<b>3276</b>	<b>100.1**</b>	

\* disappointment, acceptance, uncertainty, lacking in energy, gratefulness, receiving help, responsibility, being realist, desire for security

\*\* rounded error

During the interviews, the issues most frequently talked about were "closeness", "depression" and "distance". "Closeness" and "distance" (view examples below) mainly had to do with social networks, e.g. relationships with partner, family or lung donor.

- Closeness: "I can really trust my wife and I know that she will always be here for me." - "We really have a good family harmony." - "I keep thinking about the donor." - "I have a close relationship with the donor."

Feelings of closeness in connection with the transplanted lung are very common as well. Patients would say that the lung was part of them and belonged to them.

- Closeness: "The lung has actually always belonged there". - "The lung just is a part of me."

"Depression" was frequently mentioned during the interviews. Often patients would look back at the difficult time before the transplant, during which they had suffered from heavy physical symptoms. Two patients told about depressive episodes following the transplant, a further patient went through depression when her partner left her after the transplant. Furthermore, financial worries, medical complications and mainly allograft rejections were named as a cause of depression. Some patients connected doubts about the purposefulness of the transplant with their depressive mood.

- Depression: "Sometimes I think if only I hadn't agreed to this mess. Not that the transplant is a mess, of course, but sometimes I still wonder why I'm putting myself through this."

As well as "closeness", the complementary theme, "distance", plays a role in interpersonal relationships. Patients repeatedly describe having backed off from other people to a certain extent after the transplantation. This social distance is not necessarily experienced as negative. It more likely goes along with a new balance and stoic reserve when dealing with daily conflicts or problems.

- Distance: "I just have a bit more distance. When my neighbour complains about something, it does not get to me that much any more."

Where some patients feel close to the new lung, others tell of feelings of distance; the lung is being foreign, unfamiliar or imperceptible.

- Distance: *"There is something foreign inside my body."*

"Giving help" is a further topic that lung transplant receivers deal with comparatively often. They describe the readiness to help relatives and staff, their own neediness and the wish to be able to help, possibly by donating an organ. Medication also was mainly connected with the aspect of help, mainly to prevent the lung from being rejected.

When patients talked about "competence", they mostly referred to the increase of self-competence as a result of the experiences linked to the transplant. They felt more mature, self-confident, self-reflective and more life-experienced than before the transplant. Some patients talked about others - relatives, doctors - being competent. Complementing depression, several patients described "happiness" or confident, high spirits. A new attitude towards life plays an important role in this context as well; these patients emphasize that in view of the health risks they want to enjoy everyday.

- Happiness: *"I enjoy and look at life differently today. I think I enjoy going out more, I can always dust or clean tomorrow." - "I enjoy every day."*

Other patients talk about their "incompetence": They felt that they couldn't handle their life after the transplant and insecurity had grown since the operation.

- Incompetence: *"The stability I had acquired over the years was washed away with the transplant. I feel powerless."*

A further important topic was "physical activity" or "disability". Patients here often talked about previous illnesses too. Some patients looked back wistfully to the time when they were healthy and fit. Others recalled the strong health limitations during the time waiting for the transplant, mainly the difficulty in breathing. They differed in their views of their health following the transplant; some describing the function of their lung and their state of health in a very positive way.

- Physical activity: *"The lung is functioning very well." - "I am more active than I ever was." - "I can be physically more active and don't get tired as fast."*

But other patients say that their physical activity has been reduced; though often this has to do with complications, for example pulmonary infections or allograft rejections.

- Disability: *"My physical activity has been reduced." - "My body is just not as strong as before."*

Further issues that came up during the interviews were "autonomy", "dependency", "achievement", "acknowledgement" and "aggressiveness". "Autonomy" often had to do with the patients feeling more independent because of their increased physical condition. Some patients, on the other hand, expressed the need for autonomy and experienced being dependant on relatives, doctors and medication as a burden. Some patients felt pressure, having to achieve something, either self-inflicted or sensing expectations from their social environment. They wished to be respected by the staff and to be acknowledged in their worth as a private person. Or they themselves acknowledged appreciation for the staff or the relatives.

- Acknowledgment: *"The members of the staff take care of you and they treat you as a human being, not like a number."*

A few patients experienced aggressiveness coming from other people. For example, one patient told about negative and devaluating reactions from people in his hometown, when they heard about the transplant.

- Aggressiveness: *"Some guys said: 'You're only half a person anyway, you're patched together.' They said it in a contemptuous way. One gets to hear ill-considered remarks like that."*

## Group comparisons

Table 2 shows the comparison of the observed frequency with the frequency to be expected given a uniform distribution in the gender and compliance groups, with reference to the main, attribute and value categories.

**Table 2: Observed/expected frequency of the main, attribute and value categories in the gender and compliance groups**

Category	Frequency	Gender		Chi <sup>2</sup>	p	Compliance		
		women n=10	men n=10			high n=10	moderate n=6	low n=4
<b>Self</b>	observed	306	317	0.2		304	155	164
	expected	312	312			320	192	128
<b>Body</b>	observed	159	131	1.6		110	108	72
	expected	145	145			157	94	63
<b>Lung</b>	observed	52	45	0.5		37	39	21
	expected	49	49			51	31	20
<b>Medication</b>	observed	65	50	1.9		49	41	25
	expected	58	58			60	36	24
<b>Social network</b>	observed	430	350	8.2	<.01	335	289	156
	expected	390	390			402	241	161
<b>Closeness</b>	observed	223	201	1.1		206	149	69
	expected	212	212			209	125	84
<b>Depression</b>	observed	156	134	1.7		134	86	70
	expected	145	145			151	90	60
<b>Distance</b>	observed	181	103	21.4	<.001	153	87	44
	expected	142	142			136	82	54
<b>Giving help</b>	observed	158	93	16.8	<.001	134	86	31
	expected	126	126			118	71	47
<b>Competence</b>	observed	123	106	1.3		116	86	31
	expected	115	115			117	70	47
<b>Happiness</b>	observed	129	76	13.7	<.001	88	69	48
	expected	103	103			108	65	43
<b>Incompetence</b>	observed	83	101	1.7		94	46	44
	expected	92	92			93	56	37
<b>Physical activity</b>	observed	88	88	0.0		69	69	38
	expected	88	88			93	56	37
<b>Disability</b>	observed	69	90	2.8		75	46	38
	expected	80	80			82	49	33
<b>Autonomy</b>	observed	73	49	4.7	<.05	58	32	32
	expected	61	61			67	40	27
<b>Achievement</b>	observed	56	61	0.2		54	27	36
	expected	59	59			63	38	25
<b>Illness</b>	observed	56	45	1.2		40	39	22
	expected	51	51			57	68	23
<b>Dependence</b>	observed	56	38	3.5		41	24	29
	expected	47	47			51	31	20
<b>Acknowledge-ment</b>	observed	54	40	2.1		32	26	17
	expected	47	47			39	24	16
<b>Aggressive-ness</b>	observed	56	37	3.9	<.05	51	36	6
	expected	47	47			42	25	17
<b>Value: high &amp; positive</b>	observed	144	191	11.0	<.001	171	95	69
	expected	168	168			167	100	67
<b>Value: high &amp; negative</b>	observed	81	44	6.6	<.05	53	39	33
	expected	63	63			67	40	25

Significant differences between men and women were revealed in categories "social network", "distance", "giving help", "happiness", "autonomy" and "aggressiveness". These categories were assigned significantly more frequently for women than for men. With women, also significantly more frequently statements were found encoded with "high & positive value" and "high & negative value".

Women made the following statements, for example:

- Happiness: *"But I'm a cheerful person, so I am".*
- Autonomy: *"And now, uh, now it's [laughs] I do what I want".*
- High & positive value: *"There are days I am feeling absolutely well".*

The compliance groups differ in most categories, as Table 2 shows. Highly compliant patients made less statements than expected concerning their "self", "body", "lung", "physical activity", "illness", "achievement" and "dependence". Otherwise, they made more statements concerning "distance", "giving help" and "aggressiveness". Highly compliant patients make less frequently than expected statements with a negative value, low compliance patients make statements more frequently. Moderately compliant patients differ from the other groups speaking more frequently about the "social network". Apart from the categories "body" and "happiness", however, the frequency of their statements rather corresponds to the high compliance group. Furthermore, the moderate compliance group shows almost no difference between observed and expected frequency of statements with a negative value.

A low compliant patient made following statements, for example:

- Achievement: *"I can do everything, even in comparison to the others, even in terms of my job, and such, and I think to myself, now you have got to make the best of it, perhaps it's a certain pressure that you put on yourself like that".*
- Dependence: *"The fact that I now just [laughs] have to go so regularly is, simply put, a real drag".*
- High & negative value: *"Time after transplantation was a terrible comedown".*

A highly compliant patient reported:

- Giving help: *"The medical team has sometimes phoned me and asked how things are, and, yes indeed, what's more, whenever something is wrong, you can always phone".*
- Distance: *"You also probably withdraw a bit then".*
- Aggressiveness: *"But, yeah, before, until I was doing my training we were always falling out with each other, every day, I mean, not a day went by without an argument".*

## Discussion

In this study, the relationship between sociodemographic (gender) as well as medical (compliance, diagnosis) characteristics and the transplant-related thoughts of 20 patients after a lung transplantation were examined. What patients think about themselves and relevant transplant-specific topics might be essential for a successful treatment and medical counselling. The quantitative content analysis whose results are presented offers hints as to what issues particularly preoccupy lung transplant recipients, concerning for example their self and body. Moreover, it forms the data basis for further qualitative investigations.

The results of our study demonstrate that lung-transplant patients are more likely to focus their thinking on their social network than on their body or their transplanted lung; they underscore the importance of social support for organ-transplant recipients, as reported in previous studies, e.g. [16]. "Closeness", "distance" and "depression" are topics that patients most often have to deal with after a transplant. "Closeness" and "distance" play major roles in interpersonal relationships as well as in their relationship to the transplanted lung. Our results show that the psychological integration of transplanted organs can take on different forms. Feelings of belonging or unfamiliarity/strangeness play major roles for the integration of the organ. Previous case studies indicate that patients shape their relationship to the new lung according to the pattern of their interpersonal object relationships [17], [18]. For counseling this means that the attitude towards the transplanted organ has to be looked at, staying in the context of a general forming of interpersonal relationships. Depression is mainly related to health limitations and psychosocial consequences of the transplant, e.g. financial worries. But, independent of the transplant experiences, issues like interpersonal conflicts were also mentioned as cause of depression. These statements show how important it is to give psychological stresses enough attention, when counseling transplant patients. On the other hand one should keep in mind



that lots of patients with the experience of a transplant feel more independent, psychologically matured and can develop more happiness.

The gender comparison shows that women speak more frequently than men about social aspects. They express more accented interpersonal positions, speaking more frequently about subjects like "distance", "autonomy", "aggressiveness", "giving help" and "happiness", furthermore they use significantly more extreme values. All these findings may refer to a stronger emotional expression, when women report about their life after lung transplantation.

Moreover, there are differences between high and low compliant patients. Low compliant patients are more frequently preoccupied with their self as well as with their body than patients with high compliance. They are also more frequently preoccupied with the subjects of "dependence". With respect to the necessity of taking medication reliably, it is not surprising that "dependence" is significant for patients after a organ transplantation. The negative perceived experience of dependence may be one factor for non-compliance behaviour. On the other hand, patients with high compliance speak more frequently on the subjects "distance", "aggressiveness" and "giving help". Both, distance and aggressiveness can be strategies to cope successfully with the experience of an organ transplantation. Distance may help to cope with somatic complications; aggressiveness with the feeling of dependence. That high compliant patients thoughts are related especially to the subject "giving help", may reflect the experience having received a new lung as well as being embedded in a good social environment. In general, however, low compliant patients made more statements with a negative value than the other patients. Probably they are more critical and perhaps more dissatisfied; this basic attitude could lead also to a non-compliance behaviour.

There are some limitations of the study results. At first we presented solely the results of the quantitative data analysis without preceding hypotheses. In our view, these findings have served primarily to indicate relevant issues in need of closer examination. For example, only a qualitative content analysis may show how patients with low compliance experience their bodies, or to what extent psychological problems are important to them. A further difficulty is that measuring compliance behaviour is in principle problematic. Neither external- nor self-assessments enable the recording of the actual compliance behaviour occurring in everyday life [9]. We opted for an external assessment, in order to avoid imbuing the interviews with an investigative quality. On the other hand, we cannot rule out the external medical rating of compliance being solely approximate in nature.

Furthermore, the sample size of 20 patients is rather small. One has to consider, however, that samples with lung transplant recipients are usually down-sized because this surgery is scarce. Additionally, the data base consists of face-to-face interviews, where transcription and text analysis require more effort and personal resources compared to a questionnaire study. Because of these limitations, our results are explorative, and further studies with larger samples and elaborated hypotheses are needed.

The results show, however, that even with the quantitative content analysis, differences between lung-transplant patients with high, moderate and low compliance, as well as between women and men are demonstrable. They are especially relevant for the medically important issue of compliance. In everyday clinical life, the medical staff should keep an eye on patients, especially on what they think about certain subjects such as the perception of the self, the body or the experience of dependence as well as if they show a basic critical attitude. Preoccupation with these subjects could be understood as an indication of low compliance behaviour, and should be afforded sufficient space in doctor-patient talks.

## Notes

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