

THE EXPERIENCE OF THE SUPPORT PERSON INVOLVED IN A LUNG TRANSPLANT PROGRAMME: RESULTS OF A PILOT STUDY*

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Abstract: In contrast to the high priority most transplant programmes give to the recipient's support system there is a paucity of studies referring to the experience of the respective support persons. This study sought to focus on the subjective burden of support persons and their unmet needs.

Method: A questionnaire was designed for a cross-sectional study using numerical rating scales and fill-in-the-gap-items concerning subjective burden, stress symptoms, unmet needs, suggestions to improve the support person's situation. Participants were 39 relatives of adult transplant patients (22 cystic fibrosis transplant recipients, 17 recipients with other aetiologies) who had transplants 5 years ago (mean).

Results: The acute illness stage was rated as extremely stressful by most of the respondents. However, even during the rehabilitation period, one third described themselves as "very stressed". Stress related symptoms at or post transplant were reported by 82% of respondents (more mothers than partners). Symptoms mostly referred to depressive and anxiety states. Most support persons had to tackle organizational difficulties in order to stay with the recipient and faced financial burdens not refunded by agencies. Support persons made suggestions to improve the recipient's situation and those of other support persons. Regarding the recipient their advice referred to enhanced information giving/ aspects of communication and better access to psychosocial professionals. Regarding another support person they suggested to be well-informed beforehand and to remain optimistic.

Conclusions: Mothers in this study seemed to be particularly vulnerable as support persons and thus deserve special attention. Few resources may be needed to achieve considerable benefit for the support person, such as arranging accommodation or identifying a team member to relate to.

Key words: lung transplantation, social support, cystic fibrosis, non-medical caregiver, subjective burden, health education

INTRODUCTION

Lung transplantation has proved an effective therapy since the early 1990s for end-stage pulmonary failure caused by a variety of aetiologies, such as obstructive lung disease, cystic fibrosis, pulmonary hypertension (primary, secondary), and idiopathic pulmonary fibrosis [1]. There has been considerable success in post transplant survival [2, 3] and quality of life [4, 5, 6]. From a medical point of view, lung transplantation has become customary or at least a "viable option" [7]. However, for the vast majority of patients and for their loved ones it is a perilous and frightening experience. Not surprisingly, most lung transplantation programmes highlight the importance of personal support for the candidate [8]. Lack of support is considered a relative or even an absolute contraindication to transplantation in some programmes [9, 10]. In a study on cystic fibrosis lung transplant recipients [11] lack of family and social support was the most convincing contraindication to transplantation from the patients' point of view, too.

Saxe-Braithwaite and Chapman [12], in one of the first papers, critically reviewed the provision of personal support for the transplant candidate and recipient stating that "if the family members of these recipients are mentioned, it is only in passing" (p.69). Surprisingly, even ten years later, such a critique is still warranted: up to now, the perceptions of support persons involved in lung transplantation programmes have rarely been studied [13, 14]. If studies went beyond the patient's view, they almost exclusively focussed on the impact of transplantation on the partner and on their relationship (recently reviewed by [15]). Even though other relatives or friends may also become vitally important during the transplantation process they have mostly not been studied (with the exception of studies on the impact of paediatric transplantations on family life and on parents; e.g. [16, 17, 18]). Furthermore, studies on the impact of transplantation on couple relationship usually refer to the long lasting impact of transplantation, the support person's experience at the time of transplantation remains mostly unnoticed.

The present study focuses on the experience of the support person during the whole transplantation

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process with special emphasis on the critical inpatient period. Unlike the support persons in the study of Saxe-Braithwaite and Chapman [12], who had to be “willing to accompany and commit him- or herself to the potential transplant candidates 24 hours per day and for an indetermined period” (p. 69), the “support person” in our study was defined as the person who stayed with the patient during the critical inpatient period. The amount of time spent with the patient as well as the kind of relationship to the patient (e.g. parent, friend, partner) was unimportant in this respect.

METHOD

The present survey is part of a larger retrospective study on psychological aspects of transplantation in cystic fibrosis (CF) adults versus patients with other lung diseases (non-CF), such as pulmonary hypertension (primary, secondary) or idiopathic pulmonary fibrosis. While the study on the patients’ experience gathered data from interviews as well as from questionnaires, investigation of the support persons’ perceptions relied solely on the questionnaire.

Questionnaire

The questionnaire designed for this study looked at a) perceived stress, sources of stress, stress symptoms as well as b) on the relative’s perception of professional support (data are part of a separate paper). There was no preliminary assessment of reliability or validity of the instrument.

Regarding subjective evaluation of stress the first item asked concerning the amount of feeling strained during the transplantation process. Answers had to be given on a numerical rating scale ranging from 1 (very onerous) to 5 (not at all onerous). Similarly to other authors [19, 20] we differentiated the time course of the transplantation process: the waiting period, the inpatient period (transplantation), and the time after discharge (rehabilitation period). Stress ratings were related to each of these periods.

Two fill-in-the-gap questions asked what was particularly stressful and whether the relative had experienced any stress-related bodily or psychological symptoms at the time of transplant or afterwards.

According to the common differentiation of subjective caregiver burden (e.g. perceived strain) and objective caregiver burden (e.g. disruptions in family life; cf. [21]) we also asked respondents whether they had to overcome organizational difficulties (e.g. job, household, children) in order to stay with the patient, and whether they had any expenses that were not refunded by health insurances or other agencies. Yet, the main focus of the questionnaire was on subjective caregiver burden.

The individual perception of transplant related stress was furthermore assessed with two questions: What should be done to ameliorate the support person’s situation? What would you recommend to another support person of a transplant candidate? Since the response format of both questions was open (fill-in-the-gap question) the respective answers portray the individual priorities regarding the various aspects of transplant related stress.

Even though Kurz [22], in interviewing spouses of transplant recipients, mentioned that all interviewees could recount “events of the transplant surgery and the immediate recovery period with in-depth details regardless of the number of months that had passed since the transplantation” (p. 360) our retrospective evaluation could well be biased by the relative’s perception of the (positive or disappointing) outcome of the transplantation. In order to control for such an influence we assessed the relative’s evaluation of how the recipients had changed after transplant. Three items differentiated possible changes on a 7 point numerical rating scale as either positive or negative (personality, temper, and mood), and 5 further items differentiated changes in terms of either improved or diminished functioning (initiative, physical tolerance, mental tolerance, devotion, and independence). Retrospective bias should be assumed if most if not all of the scores would be positively (or negatively) correlated with the stress-related variables in question.

Procedure

The principal study compared CF and non-CF recipients. Due to the aetiology and course of the respective diseases, non-CF recipients usually fulfil criteria for lung transplantation at a considerably older age than CF recipients. This implies that these patient groups are transplanted at remarkably different stages in their life. In a study by Lanuza et al. [23], the mean age of CF recipients was 28 whereas that of other recipients was 39. This study age-matched the non-CF group to the CF group. For ethical reasons we excluded those patients who urgently awaited re-transplantation or who had just received another organ. Patients with a post transplant period less than 12 months were excluded.

All eligible CF recipients ($n = 37$) and the pre-selected non-CF recipients ($n = 29$) were asked to participate in the study (one-time mailing). They received a letter with a detailed description of the study design. They were asked to identify the person who provided them with most support at the time of transplant. The patient, then, had to forward another letter (study information and a questionnaire as described above) to this support person, who anonymously returned the questionnaire to us.

Informed consent and approval

The study was approved by the local ethics committee. Patients and relatives were informed about the aims of the study and that participation was voluntary. Patients signed informed; for support persons, the returned questionnaire was considered equivalent to consent.

Study sample

According to the study design it was the recipient who selected the appropriate support person and who decided whether or not to participate (forwarding the questionnaire to the support person). Therefore we start with a description of the recipients even though the support persons are the true sample of this part of the study.

As is shown in Table 1, 30 out of 37 CF recipients and 20 out of 29 non-CF recipients participated in the study. At the time of transplantation most, but not all,

Table 1. Characteristics of the study sample.

	CF (n=30)	non-CF (n=20)	
Transplanted patient			
- Mean age (range)	31.5y (19-41y)	32.6y (22-42y)	
- Mean age at transplantation (range)	26y (14-35)	27y (16-35)	
- Sex ratio (male/ female)	21:9	6:14	**
- Fev1 % pred. at the time of the study (mean; range; median)	70 (13-122) 77	62 (21-107) 53	
- Fev1 % pred. at discharge (mean; standard deviation; median)	50.4 (±14) 47	50.4 (±16) 51	
- Best Fev1 % pred. after transplant (mean; standard deviation; median)	88 (±17) 88	78 (±23) 70.5	
- Living with parents at time of the study	27%	0%	*
- Living with parents at transplantation	63%	15%	**
Support person			
	CF (n=22)	non-CF (N=17)	
- Partner	32%	53%	
- Mother	36%	12%	
- Father	14%	12%	
- Other	18%	23%	

CF = cystic fibrosis; non-CF = pulmonary hypertension (primary, secondary); obstructive lung disease; idiopathic pulmonary fibrosis, other; FEV1 % pred.= Forced expiratory volume in one second given in percent predicted

* significant group difference $p < 0.05$; ** significant group difference $p < 0.01$

were adults. On average, they had had transplants five years ago.

Even though we age-matched the two groups there were still significant differences: At the time of transplant, a majority of CF recipients but only a minority of non-CF recipients was still living with their parents indicating delayed social maturation. Moreover, while CF recipients were predominantly male, the majority of non-CF recipients was female. Also, CF recipients seemed to show better improvement in lung function after transplantation (which would correspond to previous observations [24-26]: Lung function at discharge was equal, but functional improvement during the rehabilitation period seemed greater in CF recipients resulting in slightly better lung function of CF recipients at the time of the study. However, the difference did not reach statistical significance.

Since social maturation of CF recipients appeared to be delayed, it was no surprise, that support persons in the CF group were more often parents than partners or other persons (Table 1). There was no characterization of the support person other than the kind of relationship to the patient. Even though not all support persons were relatives in a literal sense we will speak of support persons and relatives as synonymous. The response rate of relatives was 73% in the CF group and 85% in the non-CF group. There were no relatives in the sample of whom the respective recipient had decided not to participate in the principal study.

Data analysis

Given the exploratory nature of the present study the perspective was to learn how relatives perceived their situation rather than testing predetermined hypothe-

ses. Open-ended questions will be analysed by grouping responses according to content. By using this approach the intention is not to make generalizations but to inform hypothesis generation.

Statistical tests on items comparing frequencies (kind of relationship; yes/no items) were performed by χ^2 -test (person), numerical items (lung function, rating scales) were analysed regarding group differences (CF versus non-CF, patient versus relatives) by t-tests for independent groups. Further statistical tests (paired t-tests) were performed regarding different evaluations during the course of the transplantation process (waiting period, at transplant, rehabilitation period). Statistical analysis was performed by using the Statistical Package for Social Sciences.

Responses on fill-in-the-gap questions were grouped according to content.

RESULTS

As regards feeling burdened during different periods of the transplantation process relatives regarded the acute illness stage significantly more stressful than the waiting period ($p < 0.01$) or the rehabilitation period ($p < 0.001$). Although the latter was significantly less stressful than the waiting period ($p < 0.01$), a considerable number of participants still rated the rehabilitation period as "very" stressful (Fig. 1).

A comment of a CF mother may illustrate possible reasons for high stress during the post transplant period: "After the transplantation you are trapped in a void. You have to learn that your child doesn't need you anymore". However, mothers did not rate respective periods different from partners.

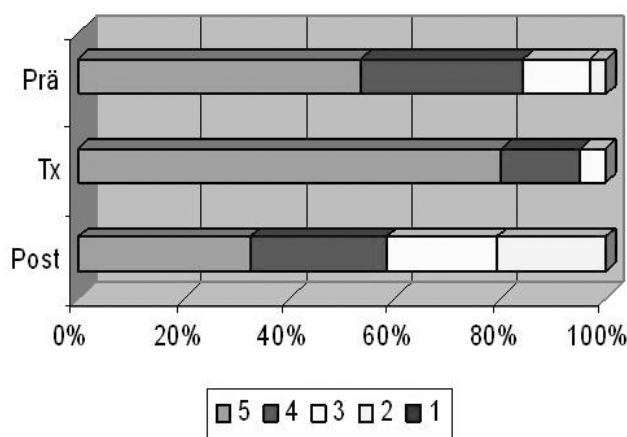


Fig. 1. Relatives' (n = 39) rating of being stressed during the waiting period (pre), at the time of transplantation (at Tx), and during the rehabilitation period (post). Maximum stress = 5, Minimum stress = 1

Relatives should also comment on the kind of events that were "particularly stressful". These covered the whole time period and a wide range (Table 2)

Both groups of relatives were particularly concerned about the post-operative health status of their child or spouse and the impact of lung transplantation on daily life. This included worries about the threat of rejection or the "loss of security". Fears of a premature death of the patient (on the waiting list) were more prevalent in relatives of CF recipients. Also, they more often mentioned loneliness during the acute illness stage (especially during the hours of surgery and during the subsequent intensive care period). In contrast, CF relatives were more optimistic concerning a positive outcome of the transplantation procedure.

Not surprisingly, the majority of respondents (82%) experienced stress related symptoms at or post transplantation. Relatives of CF recipients expressed more somatic complaints. However, these complaints mostly indicated anxiety and depressive states, such as sleep disturbances, nightmares, loss of appetite, or agitation. Tension, anxiety, and depression were also the leading

psychological/behavioural symptoms. Interestingly, transplant related stress symptoms was the only variable that clearly differed between mothers and partners: while 16 of 16 mothers mentioned these symptoms, only 7 of 16 partners did ($p < 0.01$). The comparisons concerning psychological symptoms showed a similar trend ($p = 0.054$).

Objective burden

To assess the objective burden of caregivers, we searched for disruptions in family life, organizational difficulties and expenses that were not covered by insurances. At the time of transplantation and during the subsequent inpatient period 92% of all relatives stayed with the patient each day of the week. To be able to do so, 89% of respondents had to tackle organizational difficulties such as: consumption of vacation (36%), loss of income (33%), travels between hospital and home (36%) or arranging accommodation (36%). Special arrangements concerning housekeeping and concerning care of children at home were mentioned by 18% of respondents. The financial burden of these organizational difficulties (mostly due to transport and accommodation) was quite high: the median costs not refunded by insurances or other agencies were 500 € (up to 5,000 €).

Suggestions and recommendations

As outlined above, we used an open response format (fill-in-the-gap question) to assess the relatives' priorities regarding transplant related stress and burden. We asked what relatives would suggest to improve the situation of support persons, and what they would recommend to other support persons of transplant candidates.

There were many different suggestions on how to improve the support person's situation. Most referred to the following topics (Table 3, part I): 1. improve communication with medical staff, 2. give access to non-medical staff (e.g. social worker, psychologist), 3. improve accommodation of the support person, and 4. improve other aspects such as a better liaison between the GP or local hospital and the transplant team.

Twelve of the 39 relatives (of whom 9 were CF relatives) did not mention any suggestions. These non-re-

Table 2. Main stressors for the support person.

	CF (n = 22)*	Non-CF (n = 17)*
Uncertainty about post-Tx health status and about the rehabilitation process (including fear of rejection)	7 (32%)	9 (53%)
Fear of death on waiting list (incl. being faced with patient's ambivalence towards Tx or patient's pessimism)	10 (45%)	5 (29%)
Feeling helpless and lonely (incl. lack of professional support and feeling detached on the ICU)	10 (45%)	5 (29%)
Fear of fatal outcome of Tx	1 (5%)	9 (53%)
Stressed by post-operative complications (including rejection and ICU)	4 (18%)	4 (24%)
Other (including organizational problems)	7 (32%)	8 (47%)

* raw figures; since multiple responses could be given the figures in the lines outnumber the total number of patients

Table 3. Suggestions and recommendations of support persons.

I. Support persons' suggestions to improve the situation of the recipient		n = 27 relatives*
Information giving including		
- better access to physician (8)		
- more medical updates during the critical stage (4)		
- broader spectrum of pre-transplant information (3)		
- more time to talk (1)		16
Access to psychosocial staff		8
Accommodation		7
Other (e.g. general plea for more intensive care/ additional staff; organizational aspects)		11
II. Recommendations to other support persons**		n = 28 relatives***
Focussing on the support person's role towards the recipient		
- stay close to the patient		9
- strengthen his or her positive attitude		6
- respect his or her decision		5
- other		5
Focussing on the support person's own situation		
- be prepared (medical information and personal experiences)		13
- maintain a positive attitude		8
- seek help for yourself		5
- other		6

* raw figures; 12 relatives made no comments/ suggestions (9 CF, 3 non-CF); relatives who gave comments did not differ with respect to recipient's diagnosis (CF, non-CF)

** since multiple responses could be given the figures in the lines outnumber the total number of patients

*** raw figures; not including missing values/ no suggestions $N_{CF} = (8)$, $N_{non-CF} = (3)$

sponders scored significantly better on a scale concerning satisfaction with information giving by medical staff and feeling involved in patient care (data will be presented in a separate paper [22]).

Recommendations to other support persons were not given by 11 participants. Three of these had the opinion that advice can only be given to an individual person and not in a general way. Albeit this, they gave specific recommendations which therefore were included to the analysis. (see Table 3, part II).

The suggestions were grouped into those that referred to the relative's best way of supporting the patient and those which focussed on the support person as such. As regards the latter, respondents recommended to seek information on the transplantation procedure and concerning the local conditions at the centre. Both, for the patient and the support person, they emphasized the importance of maintaining a positive attitude (e.g. "It is important to remain positive, not to lose hope, and to communicate this to the patient. But if you ask me how to remain positive, I can't tell it."). Relatives should also seek help for themselves (Table 3). As one mother of a CF recipient shared: "You should seek a full-scale and vigorous rope team to rely upon. The highest mountain lies right in front of you, and you must heavily rely on help, then".

Controlling for retrospective bias

As regards a bias of the retrospective evaluation according to the recipient's positive or negative outcome stress ratings at three different stages of the transplantation process (pre, during, and post) were correlated

with the relatives' perception of patient outcome (8 variables). Retrospective bias would have been suggestive if most of the outcome variables were significantly correlated with stress perception.

Three items described change as either positive or negative, and 5 items described change in terms of improved or diminished functioning. Given that a mean of or around 0 would mean no alteration at all, the overall evaluation of transplant outcome was positive (see Table 4): The mean scores of all 8 items were above the "no change" level (i.e., 0 points), and were more pronounced for behavioral than for psychological dimensions. Except for "initiative" which was significantly correlated with lung function (FEV1 at the time of the study), the scores were unrelated to the recipients' lung function results. Also, there were only few differences between support persons' perceptions whether the recipient had CF or another lung disease.

The present results do not confirm the assumption of a bias according to the positive or negative overall outcome of the recipient. For most variables there were low and non-significant correlations between the perception of transplant related stress and the perception of recipient outcome according to physical and psychosocial variables. Only 3 out of 24 correlations were statistically significant ($p < 0.05$): recipient's post-Tx initiative with relatives' rating of post-Tx stress ($r = -0.35$); recipient's post-Tx physical tolerance with relatives' rating of post-Tx stress ($r = -0.35$) and the recipient's post-Tx mental tolerance and the relatives' rating of stress at Tx ($r = 0.35$).

Table 4. Support person's views on how the recipient changed post transplant?

Dimension*	Mean (SD)	Minimum	Maximum	Difference between CF and non-CF? (n = 22 vs. n = 17)
Independence	2.2 (\pm 1.0)	0	3	no
Initiative	2.2 (\pm 1.2)	-3	3	CF>non-CF (p =0.11)
Physical tolerance	2.1 (\pm 1.4)	-3	3	CF>non-CF (p <0.05)
Mood	1.8 (\pm 1.2)	-2	3	no
Temper	1.7 (\pm 1.3)	-1	3	no
Mental tolerance	1.49 (\pm 1.2)	-1	3	no
Devotion	1.49 (\pm 1.4)	-2	3	no
Personality	1.3 (\pm 1.3)	-2	3	no

* all numerical rating scales ranged from +3 (positive/ improved) to -3 (negative/ diminished)

DISCUSSION

The present study focussed on the personal experience of support persons involved in a lung transplant programme.

We found that the acute illness stage was rated as extremely stressful by most of the respondents. However, even during the rehabilitation period, one third described themselves as "very stressed". Stress related symptoms at or post transplant were reported by 82% of respondents (more mothers than partners). Symptoms mostly referred to depressive and anxiety states. Most support persons had to tackle organizational difficulties in order to stay with the recipient and faced financial burdens not refunded by agencies. Support persons made suggestions to improve the recipient's situation and those of other support persons. Regarding the recipient their advice referred to enhanced information giving/ aspects of communication and better access to psychosocial professionals. Regarding another support person they suggested to be well-informed beforehand and to remain optimistic.

Similar to Bunzel et al. [23] our focus was not purely with respect to research, but we planned to use the feedback from relatives to improve our clinical practice in the future. As mentioned earlier, the majority of studies that went beyond the patient's view referred to partners as support persons (cf. [24, 15]). The main focus in these studies was on the long-lasting impact of transplantation on the partner and on the couple relationship. The very situation of the support person during the critical pre- and post-transplant periods, however, has rarely been evaluated before. Specific features of each transplant programme as well as regional characteristics may influence the support person's situation. It may be difficult, therefore, to compare the results from different centres. A Canadian lung transplant programme, for example, required that support persons were mandatory and had to be willing to stay with the patient for 24 hours a day and an undetermined period – which eventually implied that support patients had to quit their jobs [12]. Regional aspects may also have a profound influence on the situation of relatives. If transplant centres cover very distant regions, patients (and support persons) may be

urged to relocate (cf. [30]). Not surprisingly, then, Mishel and Murdaugh [31] found that young mothers who had to relocate were amongst the relatives most profoundly stressed. Support persons involved in the Hannover lung transplant programme had to face less interfering conditions of support. However, vocational issues and accommodation problems were the most often mentioned "organizational" problems of relatives accompanying the transplanted patient.

As regards the relatives' own feelings of stress during the transplantation process our results largely correspond to those of other authors, who found that fear of loss, and uncertainty about the future (including fear of medical complications and adverse drug reactions) were most often mentioned [32, 33, 34, 14]. Contrary to expectation at first glance, stress ratings during the rehabilitation period remained on a high level for at least one third of support persons. Discrepancies between the patient's and the relative's interests may also cause high stress perception. In a prospective study on the impact of transplantation on the couple relationship, Bunzel et al., further characterized such a discrepancy: "While patients wish to discover the world, partners wait for acknowledgement to compensate for the period of self-denial during the patient's illness" ([29], p.39). Kurz [13], in summarizing her interviews with spouses of lung transplant recipients, describes a model of 5 stages of spousal adaptation.

The final stage ("settling down") in her sample was not reached before 36 months post transplant! However, the timing of the stages should not be considered normative: Some families will probably adapt more rapidly than the families interviewed by Kurz [13], while others may eventually never reach this point.

We conceived the present study as a tool to receive a feedback to improve clinical practice. However, since this is only a pilot study, conclusions must be drawn cautiously and should at least be restricted to those findings that are supported by other studies.

Practical implications of the present study could particularly be expected from the relatives' answers on the final fill-in-the-gap questions: What should be done to improve the support person's situation? What would they recommend to another support person?

Table 5. Stages of life for well spouses after lung transplantation (adapted from Kurz [13]).

Stage	Timing*	Characteristics
1: transplant event	1. month	coping with: transplant, ICU, CMV infection, rejection
2: cocooning	2.-6. month	returning home, independently managing post Tx therapy, concerns of “doing it right”, self-restricted life with a focus on daily routines and therapy management
3: normalization	7.-18. month	starting to return to usual activities and a regular daily schedule (e.g. cleaning on Mondays, shopping on Friday); evidence of infection or rejection is no longer perceived as a crisis
4: branching out	2. year	volunteer to speak to other individuals, public groups or to become active in support groups; making plans for vacations or trips
5: settling down	3. year	being relaxed and having a rhythm of life while being aware that new problems may arise at any time; daring great plans (e.g. purchasing a house)

* “timing” should not be considered normative: The actual timing may considerably differ from it and there is no preset progression from one stage to another. In contrast, e.g. chronic rejection and the apparent need of a retransplantation may easily obstruct or even reverse this development.

Interestingly, both answers underscored the importance of being well-informed, beforehand (Table 3 and 4). “Well-informed”, in particular, included the psychosocial context of the transplantation experience, not only medical information on the procedure and on post transplant management. Therefore, seeking information from experienced patients and other relatives was explicitly recommended. This is in line with Kurz [22] who concluded from her interviews with well spouses of lung transplant candidates and recipients that the centre might arrange individual mentoring: by matching pre transplant couples with post transplant couples the vulnerability for post transplant role strain can be reduced. Busé and Pieper [32], too, stated urgent information needs of relatives. However, they cited other authors who found that patients and families on the waiting list virtually ignored preoperative teaching and information about the post transplant period. Perhaps there is the same explanation for both aspects: if the capacity to grasp information concerning the post transplant period is very limited during the most distressing waiting period, post transplant information needs will eventually be high.

In the present study, important capabilities of the support person were keeping up the patient’s hope and maintaining a positive attitude for oneself (table 4). This corresponds with results of the early study by Saxe-Braithwaite and Chapman [12] and was recently described for patients, too: Lowton [35] compared the perceptions of moderately ill cystic fibrosis patients with CF transplant candidates and transplant recipients. While predominant themes of interviews in the aforementioned group revealed “fate” and “luck “ as essentials of having a transplant, the second patient group rather emphasized one’s psychological makeup (hopefulness, optimistic attitude to facilitate endurance).

Further on practical implications, the relatives’ suggestion to facilitate access to psychosocial staff corresponds with conclusions drawn from the cross-sectional study of Busé and Pieper: “An opportunity for the spouse also to develop a therapeutic relationship with one or more transplant team members should be facilitated” ([32], p.647). Other authors have also high-

lighted the need to support the support person ([22, 12, 29]): “It seems reasonable that the lung transplant program team would make a formal effort to nurture the person who assumed the support person’s role” ([14], p. 195). Also, Laederach et al. [15] mention that the amount of extra time spent with counselling patients and relatives may be less than initially expected.

The present pilot study highlights the need to analyse the support person’s situation more thoroughly. Even though our data do not support an assumption of retrospective bias, prospective studies should be carried out. More information is needed on the influence of coping abilities and defence mechanisms on the self-perception of relatives during the transplantation process. The fact that mothers differed from partners with respect to stress perception deserves further study, too. If this result could be replicated in a future study with a more refined design, there should be a proactive counseling of mothers as support persons.

In conclusion, there is no doubt that pre transplant evaluation should carefully assess the adequacy of the patient’s support system as outlined by Bright et al. [9]. Even though this is routinely checked in many transplant programmes [10] it may be too patient-centered. Instead, the support person’s needs should also be taken into consideration. At our hospital, the most important unmet needs of the support person referred to information giving and the lack of a team member who acted as a person to relate to. Furthermore, it may be worthwhile to schedule at least one appointment during the rehabilitation period where the patient and the support person may share their prior experiences and their present feelings.

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