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ORIGINAL ARTICLE

Stress, psychological distress, and coping in patients on the waiting list for lung transplantation: an exploratory study

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Summary

Little information is available in literature on quality of life, stress and coping during the period patients are waiting for lung transplantation. This study explored potential stressful events that patients experience during the waiting period assessed the level of anxiety and depression and explored the use of coping strategies. Cross sectional analysis were performed. Between 3 and 27 months the number of patients that participated varied between 70 and 21. Measurements took place every 3 months until 27 months after waiting list placement. Instruments were the State Trait Anxiety Inventory, the Self-rating Depression Scale (SDS)-Zung and questions concerning stress and coping. Feeling tension caused by 'having to wear a beeper', and 'being afraid that the transplantation will come too late' were identified as important stress factors. Patients on the waiting list experienced more anxiety and depression, compared to the general population. The longer patients had been on the waiting list, the more anxiety and depression they experienced. Positive coping strategies like 'trying to relax' were more frequently used than negative ones like 'taking sedatives'. Stress, anxiety, and depression occur frequently in waiting list patients.

Introduction

Lung transplantation is an appropriate therapeutic option for patients suffering from end-stage lung disease. Over 17 000 single and bilateral lung transplant procedures from all over the world have been reported to the International Society for Heart and Lung Transplantation [1]. No data from major international registrations were published regarding time spent on the waiting list. The mean waiting time for lung transplantation in the Dutch lung transplant program was 468 days (range 1–2207; period 1992–2002). World wide the median survival of patients transplanted between January 1998 and June 2001 was 4.7 years [1]. Apart from studies on clinical outcome after lung transplantation, in the recent years increasing attention is being paid to the effect of lung transplantation on Health Related Quality of Life (HRQL). In general, these studies report significant improvements across many domains of HRQL after lung transplantation [2–9].

Until now no studies have been performed assessing HRQL at various time points on the waiting list. With a large number of lungs transplant procedures and a relatively long waiting period it is relevant to study changes in HRQL on the waiting list.

Most workers in the field of solid organ transplantation observed that the waiting period is extremely stressful for patients. Consequently, experienced stress may affect patients' behavior and compliance and may afflict, especially if not recognized, doctors decisions and thus patients' health and survival [10]. Therefore, it is important for nurses and doctors working with pretransplant patients to understand the fears and concerns patient may have [11].

Most studies published on the subject of stress, anxiety, and depression in patients waiting for an organ transplant

focused on patients waiting for a heart. Stress factors and potential stress factors that were identified in literature in patients waiting for an organ transplantation were: 'having a terminal illness' [12–14], 'needing an organ transplant' [12–14], 'worrying family members' [11,13,14], 'undergoing prolonged hospitalization', 'fear of death' [14], 'financial burdens' [14], 'stress related to the use of a beeper' [11], 'deteriorating physical health' [11,15], and 'loss of control' [11,15]. Other potential stress factors that were suggested in studies concerning patients waiting for a heart transplantation were: 'fear that a suitable donor might not be found in time,' 'worrying that the new organ might change the person in some way,' 'feeling guilty that an other person must die before an organ becomes available,' and 'worrying that the new organ might not work' [15].

Only two studies [11,16] examined the experiences of patients waiting for lung transplantation. In these studies outcome was assessed at only one time point during the waiting period. In a German study, Huttner [10] acknowledged the importance of anxiety during the waiting period for lung transplantation. Thirty-five percent of the patients in this study appeared to have increased anxiety scores compared to the general population, and 20% suffered from clinical significant anxiety, at the moment of evaluation for lung transplantation [10]. Furthermore, Burker [16] provided a thorough baseline assessment of quality of life in patients with end-stage lung disease. She concluded that, despite impairment in physical functioning in the area's of recreation, household activities, sleep, and ambulation other indices of quality of life suggested good adaptation to having end-stage lung disease in the majority of patients, at the moment they were being evaluated for lung transplantation. However, as assumed by Burker, during the pretransplant period, the stress most likely involves gradually declining health status. Other possible stress factors Burker suggested are relocation to the transplant center, watching other patients die while waiting for an organ, and the fear that a suitable organ will not be found in time [16].

In sum, until now, a limited number of studies and workers in the field of solid organ transplantation have pointed out that there are specific issues like stress, anxiety, depression, and coping strategies that play an important role in the lives of patients on the waiting list for a lung transplantation. Knowledge on these aspects at different stages in the waiting period is of real importance because; it seems logical that the stressfulness of a situation might vary depending on how long the patient is on the waiting list [15]. Consequently, if problems are identified in specific periods during the waiting period for an organ, interventions can be presented to these patients. In addition, Burker has suggested that future research should follow these patients over time as they await lung transplantation, among others, to monitor psychological adaptation and to determine if there are critical periods during the pretransplant phase to implement psychological interventions [16]. However, to our knowledge, no studies assessing these aspects at different points in time during the waiting period for lung transplantation were published.

Therefore the aim of our study was to explore potential stressful events that adult patients experience during the waiting period for lung transplantation. In addition, the levels of anxiety and depression were assessed, and coping strategies were explored.

Materials and methods

Study design and patients

Adult patients suffering from end stage lung disease who were on the active waiting list for lung transplantation, and signed an informed consent received HRQL questionnaires every 3 months by mail. Data collection took place between June 2002 and January 2005. Assessments took place at 3, 6, 9, etc. months after placement on the waiting list until 27 months. At all time points, data from all available completed HRQL questionnaires were used. The numbers of patients included in these samples were: 61 at 3 months, 70 at 6 months, 54 at 9 months, 42 at 12 months, 36 at 15 months, 32 at 18 months, 29 at 21 months, 22 at 24 months, and 21 at 27 months. At all time points at least 93% of the patients who included in the Dutch lung transplant Quality of life study participated in the present study. A longitudinal design, that is, to analyze data from the same group of patients for a period of 27 months was not considered feasible because patients leave the waiting list at different points in time due to transplantation or death. To avoid the risk of selection bias, a cross-sectional design was chosen by including data from all patients who completed a questionnaire at a specific point of follow up.

Instruments

Based on the literature discussed earlier in this paper we developed three statements to assess the stress factors that are most important to patients waiting for lung transplantation. Statements were: 'I have the feeling that the transplantation hospital will forget about me,' 'I feel tense because I have to carry a beeper,' and 'I am afraid that the transplantation will come too late.' Patients could indicate to what extend they agreed with these three statements. Response categories were 'never,' 'sometimes' and 'often.' Furthermore, patients were encouraged to express their additional comments.

The State Trait Anxiety Inventory (STAI) is a 20-item questionnaire, and was used to measure general anxiety [17]. To measure depression, the Self-rating Depression Scale (SDS)-Zung was used [18]. To get insight in the use of coping strategies among waiting list patients, the following eight coping strategies were added to the questionnaire: 'looking for distractions,' 'trying to relax,' 'talking about it,' 'expressing anger,' 'thinking it could be worse,' 'taking it out on others,' 'asking for help,' and 'taking sedatives' [19]. Response categories were 'never,' 'sometimes,' and 'often' using this strategy. Furthermore, space was reserved to write down other coping strategies patients possibly used.

Statistical analysis

Descriptive statistics were performed to analyze demographic characteristics of the patients, and to explore the experienced stress, anxiety, depression, and coping. These outcome variables were analyzed in a cross-sectional manner. Data analyses were performed using the SPSS 11.0 program (SPSS 11.0; SPSS Inc., Chicago, IL, USA).

Results

Demographic characteristics of the patients at the different points of follow up are given in Table 1. At the different time points after placement on the waiting list, the percentage of male patients in the study varied between 40 and 57. The mean age in the different study periods varied between 45 and 50 years (range 20–70 years). At all different time points, the main diagnosis was emphysema.

Figure 1a–c show the answers to the stress factors. 'Having the feeling that the transplantation hospital would forget about them' was reported the least stressful thought at all time points. At three, 12 and 27 months after placement on the waiting list, respectively 26%, 31%, and 57% of the patients reported to have this feeling. Being afraid that the transplantation will come too late was reported to be the most important stressor for patients. At 3 months after placement on the waiting list 69% of the patients reported to be sometimes or often afraid this would happen, and this percentage was 71 at

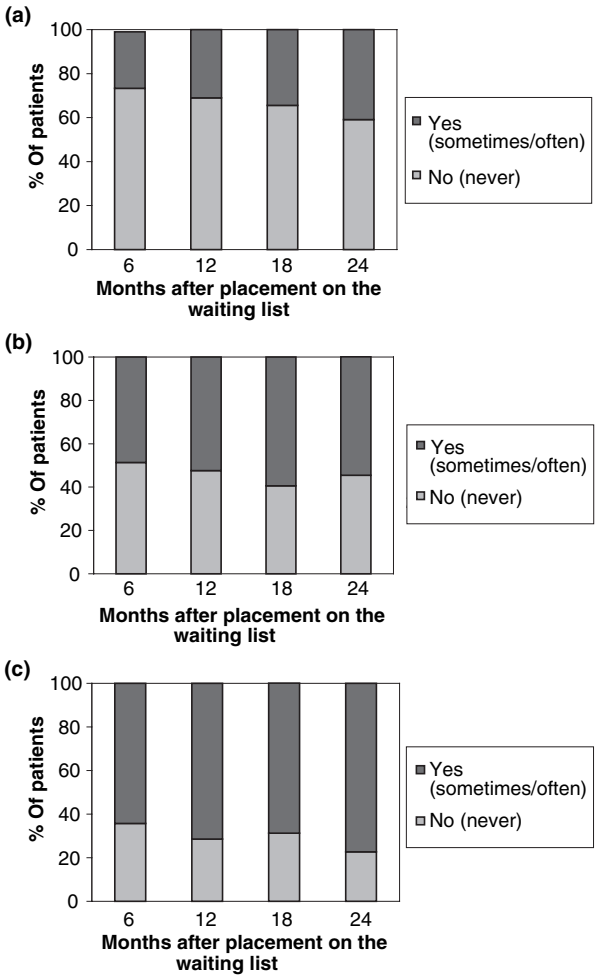

Figure 1 (a) I have the feeling that the transplantation hospital will forget about me. (b) I feel tense because I have to carry a beeper. (c) I am afraid that the transplantation will come too late.

Table 1. Demographic characteristics.

	3 months $n = 61$	6 months $n = 70$	9 months $n = 54$	12 months $n = 42$	15 months $n = 36$	18 months $n = 32$	21 months $n = 29$	24 months $n = 22$	27 months $n = 21$
Gender male *n* (%)	32 (52.5)	31 (44.3)	23 (42.6)	24 (57.1)	17 (47.2)	13 (40.6)	13 (44.8)	11 (50.0)	11 (52.4)
Age mean (range)	45 (20–70)	45 (20–70)	46 (20–70)	46 (20–70)	48 (24–68)	50 (25–70)	49 (25–71)	49 (22–66)	50 (37–66)
Diagnosis *n* (%)									
Emphysema	20 (32.8)	21 (30.0)	19 (35.2)	14 (33.3)	13 (36.1)	10 (31.3)	9 (31.0)	7 (31.8)	7 (33.3)
α_1 antitrypsin deficiency	7 (11.5)	10 (14.3)	10 (18.5)	10 (23.8)	9 (25.0)	9 (28.1)	6 (20.7)	5 (22.7)	4 (19.0)
Cystic fibrosis	15 (24.6)	15 (21.4)	9 (16.7)	9 (21.4)	6 (16.7)	5 (15.6)	4 (13.8)	2 (9.1)	3 (14.3)
Other	19 (31.1)	24 (34.3)	16 (29.6)	9 (21.4)	8 (22.2)	8 (25.0)	10 (34.5)	8 (36.4)	7 (33.4)

Table 2. The State Trait Anxiety Inventory (STAI) scores after placement on the waiting list.

STAI*	Reference value	3 months $n = 55$	6 months $n = 68$	9 months $n = 51$	12 months $n = 41$	15 months $n = 32$	18 months $n = 31$	21 months $n = 28$	24 months $n = 21$	27 months $n = 18$
Mean	≤37	41.4	42.8	42.9	44.4	46.6	44.8	48.07	48.2	47.5
Median		40.0	43.0	42.0	45.0	49.0	46	47.5	48	47.0
SD		10.9	11.9	11.7	11.5	11.2	10.7	10.6	12.0	11.4

*Range of possible scores 20–80. Best possible score 20.

Table 3. Depression scores (Zung) after placement on the waiting list.

Zung*	Reference value	3 months $n = 53$	6 months $n = 61$	9 months $n = 46$	12 months $n = 36$	15 months $n = 30$	18 months $n = 27$	21 months $n = 24$	24 months $n = 19$	27 months $n = 19$
Mean	≤33	54.7	56.3	57.7	57.2	59.8	58.4	59.5	58.3	59.1
Median		56.3	57.5	56.3	57.5	61.9	57.5	58.8	57.5	61.3
SD		10.6	9.4	10.0	10.5	8.9	10.0	8.7	13.9	11.0

*Range of possible scores 25–100. Best possible score 25.

12 months, and 62 at 27 months after placement on the waiting list.

In general, STAI scores, measuring anxiety, showed that at all time-points patients on the waiting list for a lung transplantation experienced significantly more anxiety than the general population (P values 0.009, <0.001, 0.001, <0.001, <0.001, 0.001 <0.001, 0.002, and 0.004 at the succeeding time points). Mean anxiety scores varied between 41.4 at 3 months, 44.4 at 12 months and 47.5 at 27 months after placement on the waiting list (reference value for the general population is below 37). Furthermore, the longer patients had been on the waiting list the higher the level of experienced anxiety was (Table 2).

Zung scores indicated that patients waiting for lung transplantation experienced significantly more depression than the general population ($P < 0.001$ at all succeeding time points) (Table 3). Scores varied between 54.7 at 3 months, 57.2 at 12 months and 65.1 at 27 months, while the reference value for the general population is below 33. Like anxiety, the experienced level of depression was also higher in patients that had been on the waiting list for a longer time.

With regard to the use of specific coping strategies, at most points in time, 'trying to relax,' and 'thinking it could be worse' were reported to be the most frequently used coping strategies. Three months after placement on the waiting list 87.8% of the patients reported to 'try to relax' sometimes or often, at 12 months this was 92.3% and 27 months 55.6% of the patients reported to use this strategy sometimes or often. Percentages of patients reporting to use 'thinking it could be worse' as a strategy were 82.5, 79.5, and 83.3 at 3, 12, and 27 months, respectively. Strategies like 'looking for distractions' and 'talking about it' were also often reported. In contrast, 'taking sedatives' and 'taking it out on others' were the least used strategies, as reported by the patients. Three months after placement on the waiting list, 78.6% of the patients reported that they never took sedatives. At 12 and 27 months these percentages were 81.6 and 61.1, respectively. At 3, 12, and 27 months, 'taking it out on others' was a strategy reported to be never used by 58.9%, 41.0%, and 38.9% of the patients, respectively.

Discussion

Findings from the present study confirmed what had already been observed by workers in the field of lung transplantation, that is, apart from the physical limitations, the waiting period is a stressful and psychologically difficult period for patients. Being afraid that the transplantation would come too late, and tension caused by having to wear a beeper were identified in our study as big stress factors. Moreover, patients experienced significantly more anxiety and depression compared to the general population. Finally, the level of experienced well being was significantly lower in patients waiting for a lung transplantation than in the general population. Positive coping strategies like 'trying to relax' were more frequently reported than negative strategies like 'taking it out on others.' Thus, stress, anxiety, and depression are important problems for patients waiting for lung transplantation.

With regard to the identified stress factors our findings are in line with findings from studies concerning patients waiting for a heart transplant [11,15]. In our explorative study, results suggest that the stress gradually increases. In contrast, in a study by Porter *et al.* [12] performed in

candidates for heart transplantation, no relationship was found between overall stress score measured with the Heart Transplant Stressor Scale, and time on the waiting list. The relatively small number of patients in the Porter study ($n = 39$) with a mean time on the active waiting list of only 4.25 months may have been the cause of not being able to find this relationship. Interestingly, in our study the least important stressor was 'I am afraid the transplantation hospital will forget about me.' This may be due to the very specific Dutch situation in which until recently only one lung transplant center existed, and at the moment three. Therefore, patients tend to feel very committed to the transplant team. Furthermore, two times a year, the transplant center sends a lung transplantation newsletter to the patients, and nurse practitioners contact patients on the waiting list by telephone in-between the 4 monthly outpatient visits. This may explain why the patients have little worries about the transplant center forgetting about them. Regarding the instrument used to assess coping strategies, the fact that we selected the most relevant statements from an existing questionnaire instead of using the entire coping questionnaire [19] may not seem a logical choice. However, although we recognize the advantages of using a validated questionnaire with good and defined psychometric properties, we choose to make a selection of coping strategies. Our main motivation was that we performed an exploratory study, and wanted to minimize the burden on the patients. In future research however, we plan to focus on coping strategies in more depth, and consequently will consider using the entire coping list [19].

In our study, STAI scores suggested that patients experienced more anxiety than the general population, and that the longer patients had been on the waiting list, the more anxiety they experienced. The relevance of anxiety in the therapeutic process was also identified by others [10]. They state that anxiety occurs frequently in patients who are on the waiting list for lung transplantation or who have already been transplanted.

In this context anxiety is a theme in every patient doctor interaction, which may afflict doctors' decisions and patients' health and survival. Therefore, it is necessary to recognize, and openly handle anxiety in the interaction between doctor and patient.

The relatively high levels of experienced depression found in our study are in line with findings of Zipfel *et al.* who found a notable rise in the levels of depression in patients waiting for a heart transplant in the period between placement on the waiting list and 4 months thereafter [20].

Due to the relatively small numbers of patients in the study groups. It was not possible to study associations between the use of specific coping strategies and the amount of experienced depression and anxiety. In future research, when more completed questionnaires will be available for analysis; we plan to address this issue again.

The particular importance of identifying a relation between coping strategies, and anxiety and depression is the possibility of developing and presenting an intervention, which can improve the quality of life in patients waiting for lung transplantation. After all, if specific coping strategies appear to be successful in decreasing levels of experienced depression and anxiety, the use of these strategies can be stimulated, and HRQL is likely to be increased.

Regarding the use of coping strategies, we observed that patients were inclined to use positive coping strategies like 'trying to relax,' 'thinking it could be worse,' 'looking for distractions,' and 'talking about it.' Consequently, the use of more 'negative' strategies like 'expressing anger,' 'taking it out on others,' and 'taking sedatives' is less common. This is in line with the findings from the study by Porter *et al.* [12] who also found that optimistic coping strategies were the most used, and the most effective strategies.

In our study we used a cross sectional design, and therefore, we were not able to assess changes over time. However, a cross sectional design was more feasible than a longitudinal design, because waiting list patients leave the waiting list at variable points in time due to transplantation or death. Longitudinal analysis would be based on a very specific subgroup of waiting list patients, that is, those patients that are well enough to survive on the waiting list for a longer period, and for whom a suitable organ has not yet been found. In our study, demographic statistics of all included subgroups at the distinct time points were similar, which indicates that groups are comparable (Table 1), and trends over time may be assumed.

A limitation of our study is that, due to the relatively small numbers of patients, we were not able to correlate items of the questionnaire to clinical conditions. In future research, when more patients are included, we plan to correlate responses regarding stress, anxiety depression and coping to clinical markers like FEV1 values, the use of anti-depressant drugs, or a 6 min walk test.

In future research, it would also be interesting to analyze specific subgroups of patients, for example younger patients versus older patients, men versus women, or to compare patients with different diagnoses with regard to stress, anxiety, depression, and coping strategies. However, in our study subgroups were too small to make this kind of comparisons.

In conclusion, stress, anxiety and depression occur frequently in waiting list patients and play an important role in the doctor patient interaction. Therefore, it is important to recognize and handle these problems, for example, by stimulating the use of positive coping strategies.

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