Psycho-social aspects before and up to 2 years after heart or lung transplantation - experience of patients and their next of kin.

Susanna Ågren, Trygve Sjöberg, Björn Ekmehag, Maj-Britt Wiborg and Bodil Ivarsson

Journal Article

N.B.: When citing this work, cite the original article.

Original Publication:

Susanna Agren, Trygve Sjöberg, Björn Ekmehag, Maj-Britt Wiborg and Bodil Ivarsson, Psycho-social aspects before and up to 2 years after heart or lung transplantation - experience of patients and their next of kin., Clinical Transplantation, 2016.

<http://dx.doi.org/10.1111/ctr.12905>

Copyright: Wiley: 12 months

<http://eu.wiley.com/WileyCDA/>

Postprint available at: Linköping University Electronic Press

<http://urn.kb.se/resolve?urn=urn:nbn:se:liu:diva-133979>

Psycho-social aspects before and up to 2 years after heart or lung transplantation - experience of patients and their next of kin

Running head: Cardiothoracic transplantation

Susanna Ågren^{1,2}, Trygve Sjöberg^{1,3}, Björn Ekmehag⁴, Maj-Britt Wiborg⁵, Bodil Ivarsson^{1,3}

¹ Department of Cardiothoracic Surgery, Lund University

² Department of Medical and Health Sciences, Division of Nursing Science Linköping University and
Department of Cardiothoracic Surgery, Linköping, Sweden

³ Department of Cardiothoracic Surgery , Skåne University Hospital Lund, Sweden

⁴ Department of Public Health and Caring Science, Uppsala University, and Uppsala University
Hospital, Uppsala, Sweden.

⁵ Department of Cardiology, Skåne University Hospital Lund, Sweden

Address reprint requests to:

Associate Professor Bodil Ivarsson

Department of Cardiothoracic Surgery

Skåne University Hospital

SE-221 85 Lund

Sweden

Phone: +46-76-8870467

Fax: +46-46-17 60 54

Email: bodil.ivarsson@med.lu.se

Abstract:

Background: Psychosocial factors are important for patients undergoing heart (HTx) or lung (LTx) transplantation, and for their next of kin (NoK).

Aim: To describe health-related quality of life (patients only), anxiety, depression, stress, coping ability and burden (NoK only) for patients and their NoK before and up to 2 years after HTx or LTx.

Design: Adult patients (28 heart and 26 lung) and their appointed NoK were surveyed with questionnaires about specific psychosocial topics when they were accepted for the transplantation waiting list and 6 months, 1 year, and 2 years after transplantation.

Findings: Patients' coping ability and self-perceived health were low at baseline and improved over time after the transplantation. However, lung patients took longer time to recover in terms of health-related quality of life, depression, and stress than heart patients. Similarly, NoK of lung patients experienced a higher burden and more stress 1 year after transplantation than NoK of heart patients.

Conclusions: Healthcare professionals should be aware of the psychosocial challenges patients and their NoK face in daily living and provide support both before and after heart or lung transplantation. Especially, given that these patients have a serious, chronic, underlying disease.

Key words: Chronic illness; End-stage cardiac diseases; End-stage lung diseases, Family, Health-related quality of life; Longitudinal study; Psychosocial adjustment; Transplantation.

Introduction

Heart transplantation (HTx) and lung transplantation (LTx) are the ultimate treatments for end-stage heart and lung disease. As of June 30, 2014, the International Society for Heart and Lung Transplantation (ISHLT) had registered 120,992 heart transplantations and 53,760 lung transplantations worldwide (1). In Sweden, 1070 HTx and 915 LTx had been performed by the end of 2015 (2). The worldwide 10-year survival rate reported in June 2013 was 51% for HTx and 32% for LTx (1). The criteria for acceptance to the waiting list for HTx or LTx are very strict, and many patients have contraindications (3). Of patients accepted for the waiting list, approximately 10-15% dies before they receive a transplant (4,5). However, an increasing number of heart patients receive mechanical circulatory support as destination therapy (4). A factor that seriously limits the number of transplantations is the shortage of donor organs.

Psychosocial factors affect these seriously ill patients and their next of kin (NoK) before patients are accepted for transplantation, during the time that they are on the waiting list, after the transplantation, and throughout their remaining lives (6-9). The majority of patients undergoing HTx and LTx have a severely reduced physical capacity (8,10,11). Before transplantation, the patients often go through a denial stage in which they do not realize that transplantation is the only option for survival (8, 12). Patients in need of a donor heart or donor lungs have been reported to say that the most stressful parts of the situation are to knowing that their illness is incurable, that they have to undergo transplantation, and that they worry about their NoK (8, 10). Many of the patients live in a complex situation, with a deteriorating economy, possibly with dependent children at home or, in some cases, in a relationship with a life partner that has become fragile due to the illness. These very vulnerable patients and their NoK need support both before and after HTx or LTx (7-9, 13).

Goetzmann et al. stated that HTx or LTx patients and NoK had experienced something unique together (14) and few studies have highlighted their experiences over time. The aim of this study was to describe health-related quality of life (patients only), anxiety, depression, stress, coping and burden (NoK only) for patients and their NoK before and up to 2 years after HTx or LTx.

Materials and methods

This consecutive, quantitative, longitudinal study was performed at the Transplantation Center at Skåne University Hospital, Sweden. The inclusion criteria were as follows: the ability to communicate in Swedish, age >18 years, and having been on the waiting list for HTx or LTx for at least 2 weeks.

Between January 2009 and June 2011, 62 patients met the inclusion criteria, of whom 3 were too weak to respond and 5 did not want to participate, without stating a reason. Thus, 54 patients and 40 NoK were enrolled in the study. (NoK were defined as a constellation of people, with or without blood ties, who have strong emotional connections and mutual participation in each other's lives (15)). Two to four weeks after patients had been admitted to the waiting list for a HTx or LTx, each person was asked to complete a series of widely used and psychometrically tested questionnaires (see below). The same questionnaires were to be completed again 6 months, 1 year, and 2 years after transplantation.

Instruments

The EuroQol 5-dimensional (EQ-5D) questionnaire (16) measures a patient's health-related quality of life (HRQoL) and in this study was only to be completed by the patients. The EQ-5D is based on 5 different health dimensions (mobility, self-care, usual activities, pain/discomfort, anxiety/depression), where each dimension can be rated from 1 to 3 and creating a total measure of an individual's HRQoL. The EQ-5D also captures a self-rating of health status on a 20-cm vertical visual analog scale (VAS) anchored at 100 (best imaginable health state) and 0 (worst imaginable health state). This frequently used instrument is well-established and has been found to have good reliability and validity (16). In this study, the coefficient alpha reliability value was 0.58.

The Hospital Anxiety and Depression Scale (HADS) (17) measures symptoms of a person's emotional state and in this study was to be used by both patients and NoK. The HADS is a self-reported instrument for patients with physical diseases consisting of 14 items, 7 relating to anxiety and 7 to depression. Each multiple-choice question has 4 response categories, each with a possible score of 0-3. The responses reflect the person's emotional state during the preceding week. A score of 8-10 points indicates doubtful cases, and ≥ 11 points reflects clinical anxiety or depression (17). The Cronbach's alpha reliability values for this study were 0.80 for patients and 0.86 for NoK.

The Impact of Event Scale (IES) (18) is a self-rated measure of current subjective distress related to a specific event, divided into symptoms of intrusion (7 items) and symptoms of avoidance (8 items); in this study it was to be completed by both patients and their NoK. The scale has 4 response categories: 0 (not at all), 10 (rarely), 30 (sometimes), and 50 (often). The scale has a useful degree of significance and homogeneity. The level of distress is considered to be low if the total score is ≤ 8 , medium if 9 to 19, and high if ≥ 20 (18). The Cronbach's alpha reliability values for this study were 0.83 for patients and 0.66 for next of kin.

The Mastery scale (19) measures self-concept and individual feelings about control over life outcomes; in this study it was to be completed by both patients and their NoK. The scale has 7 items with 4 response categories. Possible scores range from 7 to 28, with 28 indicating a high coping capacity (19). The Cronbach's alpha reliability values for this study were 0.79 for patients and 0.76 for next of kin.

The Caregiver Burden Scale (CBS) (20) is a 22-item scale that measures burden as subjectively experienced by caregivers of chronically disabled persons; in this study it was only to be completed by NoK. Responses are scored on a scale of 1 to 4 (not at all, seldom, sometimes, often). The total burden index is the mean of all 22 items and the total score is divided into 3 categories: low burden (1.00-1.99), medium burden (2.00-2.99), and high burden (3.00-4.00). The CBS consists of the following subscales: general strain, isolation, disappointment, emotional involvement, and environment. Good reliability and validity have been demonstrated (20). In this study the coefficient alpha reliability value was 0.76.

The informants were also asked questions of a socio-demographic nature, such as age, education, and marital status. The study conformed to the principles outlined in the Declaration of Helsinki and the study was approved by the Regional Ethical Review Board in Lund, Sweden (LU 638/2008). Participation in the study was voluntary and informants could withdraw from the study at any time without any consequences for their care. Written informed consent was obtained from all participants and confidentiality was guaranteed.

Data analysis

Normally distributed data were analyzed by parametric methods, and non-normally distributed data by the non-parametric Kruskal-Wallis test and Dunn's Multiple Comparison Test. Informant characteristics were described using means ($\pm$ SD) for continuous variables, and percentages and numbers for categorical variables. To examine the equality of the two groups (heart and lung patients), baseline socio-demographic and clinical characteristics were compared using chi-square or Student t-tests, depending on the level of measurement. Comparisons were made between the groups for each of the variables of interest at the aggregate level using a Student t-test and one-way analysis of variance (ANOVA) to determine if the groups had significantly different mean scores at baseline or after 6 months, 1 year, and 2 years.

The level of significance for the tests was set at 0.05. The results from the quantitative data collection were analysed using SPSS release 22.0 for Windows with descriptive and analytical statistics, using univariate multi models. Due to the large amount of data generated, the description of results focuses on significant differences.

Results

A total of 28 heart patients with 21 NoK, and 26 lung patients with 19 NoK were recruited into the study between January 2009 and June 2011. The response rate at each time point is shown in Figure 1. During the follow-up period from baseline to 2 years after transplantation, mortality was higher for LTx patients than HTx patients (Figure 1). The socio-demographic and clinical characteristics of the patients and NoK are provided in Table 1.

Based on the responses for the EQ-5D questionnaire, a significant improvement in self-rated HRQoL occurred over time in both groups of patients (lung, $p<0.0001$; heart, $p=0.0001$). Compared to baseline, the number of patients with problems decreased over time for all HRQoL dimensions except for pain/discomfort in lung transplantation patients, where the number persisted and even increased over time after transplantation (Figure 2). Age, gender, education, and marital status had no effect on HRQoL (data not shown).

Based on results for the VAS module of the EQ-5D questionnaire, health status was clearly worse before transplantation in both groups of patients and improved after transplantation ($p<0.0001$ for both HTx and LTx, Table 2).

Among all patients, 29% exhibited doubtful anxiety or clinical anxiety before transplantation on the HAD anxiety subscale, compared to 5%, 6%, and 17% at 6 months, 1 year, and 2 years after transplantation, respectively. According to the HAD depression subscale, doubtful depression or a clinically significant depression disorder was exhibited by 27% of all patients before transplantation, compared to 19%, 9%, and 9% at 6 months, 1 year, and 2 years after transplantation, respectively. Patients waiting for LTx had more anxiety than HTx patients ($p=0.04$) (Figure 3A).

HAD anxiety and depression levels were quite similar in NoK to heart and lung patients (Fig 3A). The score for the HAD anxiety subscale in the entire group of NoK was 7.4% at baseline and had decreased to 1.6% after 2 years. For the depression subscale, the score was 2.1% at baseline and 0.5% after 2 years. Anxiety/depression levels were higher when NoK had a lower education ($p=0.03$). Age, gender and marital status had no statistically significant effect on anxiety/depression.

According to the IES subscales 44% of the patients had a medium or high level of intrusion stress and 38% had avoidance stress before the transplant. Some patients still scored for stress at 6 months (37% intrusion, 31% avoidance) and 2 years (22% intrusion, 4% avoidance). No significant differences were found based on age, gender, education level, or marital status. LTx patients reported significantly higher intrusion stress than HTx patients at baseline ($p=0.001$) (Figure 3B).

As measured by the IES, 17.7% of NoK scored medium or high levels of stress, at baseline, decreasing to 5.9% after 2 years. NoK to lung patients tended to score higher levels of stress ($p=0.06$), particularly intrusion stress. The greatest increase was seen after 1 year ($p=0.04$) and linear regression analysis showed correlations between stress and burden ($p=0.05$), anxiety ($p=0.02$), depression ($p=0.05$). NoK with a lower level of education experienced more stress, particularly intrusion stress ($p=0.03$). Age, gender and marital status had no statistically significant effect on stress levels.

At baseline, the mean total score on the Mastery scale was 19.3 for all patients and coping capacity increased after transplantation (Figure 3C). Patients below 50 years of age had greater coping capacity ($p=0.029$). Comparing patients values at baseline and 2 years, lung transplantation patients had a significantly ($p=0.04$) better coping ability than heart transplantation patients, based on total score and analyzed over time.

At baseline, the mean total score on the Mastery scale was 22.9 for the entire group of NoK, increasing to 24 after 2 years (Figure 3C). NoK to lung patients had better coping capacity than NoK to heart patients both after 1 year ($p=0.03$) and after 2 years ($p=0.006$). NoK with a higher level of education had a higher coping ability ($p=0.03$). Gender and marital status had no statistically significant effect on Mastery scores for either patients or NoK (data not shown).

A total of 22.9% of NoK scored medium or high levels of burden on the CBS, at baseline, decreasing to 9.1% after 2 years. General strain was most affected, with 22.3% recording medium or high levels of burden at baseline, decreasing to 6.9% after 2 years, followed by disappointment (17% at baseline, decreasing to 6.4% after 2 years). The burden of the NoK to lung patients was higher, both overall and

for each dimension, except emotional involvement, where scores were higher for NoK to heart patients.

The burden of NoK to both heart and lung patients decreased over time, especially between baseline and 6 months. No significant differences were found between the groups. Age, gender and marital status had no statistically significant effect on caregiver burden.

Discussion

The present study showed that when patients are waitlisted for HTx or LTx, they are exposed to an extra strain, and this also applies to their families, which also been shown by others (21, 9). Not surprisingly, both patients and NoK in this study experienced symptoms of anxiety or depression (based on the HADS) to a higher degree when waiting for HTx or LTx than after the transplantation.

Before transplantation, as measured with the HADS, the anxiety ratings, for lung patients and their NoK and the depression ratings for all patients and their NoK were higher than in a population-based Swedish reference group (642 individuals; mean anxiety score 4.55, mean depression score 3.98) (22).

In a previous study, anxiety and depression in patients after transplantation were in parity with or lower than those in the normal population (22). However, in the present study, anxiety in HTx patients moderate increased between year 1 and year 2. This may be due to feelings of uncertainty regarding survival and recovery, and the possibility of living a normal life in the future, (23).

In most cases, transplantation is seen as positive, but life after transplantation can be awkward when complications occur, such as early or late organ dysfunction or rejection, infection, respiratory problems, cardiovascular complications, or gastrointestinal problems (6,13,24). In the present study, most of the patients, especially the lung patients, were affected by pain and discomfort (based on the results for the EQ-5D). Bodily pain and other side-effects are important problems after organ transplantation, persisting in up to half of the lung patients for several years after receiving the transplant (7, 25). This in turn may affect also the NoK to lung patients, who experienced a greater

burden of care (CBS), greater anxiety (HADS) and more stress (IES) in this study than NoK to heart patients. Despite thoughts about or actual experience of complications, it is possible to experience good health without being fully recovered after lung transplantation (25). It is therefore important to promote health by supporting the patients in their daily life and not forget that also NoK may need information, support and relief.

Intrusion stress, which could include emotions related to everything around the transplantation, and avoidance stress were scored lower by patients after transplantation compared to before transplantation in this study. Comparing HTx and LTx patients in the present study, the lung patients felt worse psychosocially. Eventually the stress levels for lung patients fell to levels similar to those for heart patients, but this took up to 2 years to happen. Whether this is associated with shortness of breath due to the lung disease, which severely impacted patients' HRQoL, is debatable. Lung patients, almost all of which are prescribed long-term oxygen therapy, experience gradual deterioration of their health status (26). Significantly higher levels of anxiety and depressive symptoms have been described in patients with chronic obstructive pulmonary disease compared to healthy controls (27). Thus, higher morbidity and mortality may be associated with LTx compared to HTx (1). A small number of patients have described emotional distress after lung transplantation as being caused by fears of lifelong treatments, complications, and possible death (7).

Stress is a condition or circumstance that may be managed by the patients' ability to cope. Healthcare professionals must help patients to use coping mechanisms (28) and offer support both before and after transplantation, with interventions focused on strengthening the patient. Prior to transplantation, patients in the present study had less coping ability (Mastery scale), than their NoK, but also compared to patients with chronic heart failure (score 23.7), patients with chronic obstructive pulmonary disease (score 22.3) (29), or a normal population (score 22.2) (30). After transplantation, the coping ability scores for both heart and lung patients and their NoK were in parity with those for the normal population.

HTx and LTx patients require good medical care before transplantation and for the rest of their lives. Transplantation centres and local care providers must be aware of these patients' psychosocial condition and be able to provide different types of support to both them and their NoK (23,31). User-friendly questionnaires similar to those used in the present study could be valuable tools for healthcare professionals in clinical practice in order to provide vital information on the psychosocial status of patients and their NoK. Information and communication are important to improve psychosocial support, and information and communication technology (ICT), such as video technology, text messages, and health monitoring, can be powerful tools for communication between patients, their NoK, and healthcare professionals (32). ICT can offer increased security for transplantation patients and their NoK. ICT may also encourage patients to engage more in self-care and reduce the time that patients, and also NoK, would otherwise use in travelling to medical facilities.

Limitations

This is a single-center study with a small study group. We are fully aware that the non-response rate was relatively high, especially at 2 years after transplantation. Possible reasons for the low response rate could be poor health, being too tired to respond to the questionnaires, or that the patients and their NoK simply did not want to be reminded of the transplantation.

Conclusion

This study indicates that patients are severely affected during the time that they are waiting for a transplant, but HTx or LTx leads to positive psychosocial effects 6 months, 1 year, and 2 years after transplantation for most patients. Healthcare professionals should be aware of the challenges faced by their patients in daily living both before and after a HTx or LTx, not only the symptoms of their severe chronic disease, but also psychosocial factors. For the patient and their NoK, a continuum of care is important; therefore, a holistic approach and workforce cooperation between different health institutions are important.

Conflict of interest: none

Funding

This study was supported by Skåne University Hospital and postdoctoral grants from Region Östergötland and the Dahlbäck foundation, Lund.

Contributions

Study design: BI, BE, M-BW, SÅ, TS; Data collection: M-BW, BI;

Data analysis: SÅ, BI, TS; Drafting article. BI, SÅ, TS Critical revision and approval of article BI, BE, M-BW, SÅ TS.

References

1. ISHLT (2015). The ISHLT International Registry for Heart and Lung Transplantation in Europe. Available at:
<http://www.isHLT.org/registries/slides.asp?slides=heartLungRegistry&year=2015>
(accessed 2 October 2016).
2. Svensk transplantationsförening. Available at
<http://svensktransplantationsforening.se/wp-content/uploads/2016/06/2016-06-30-Sv-Tx-Reg-KORR.pdf> (accessed 2 October 2016).
3. Dobbels F, De Geest S, Cleemput I, Fischler B, Kesteloot K, Vanhaecke J, et al. Psychosocial and behavioral selection criteria for solid organ transplantation. *Prog Transplant* 2001;11(2):121-130.
4. Singh TP, Almond CS, Taylor DO, Graham DA. Decline in heart transplant wait list mortality in the United States following broader regional sharing of donor hearts. *Circulation: Heart Failure* 2012;5(2):249-258.
5. Gottlieb, J. Review: Update on lung transplantation. *Therapeutic advances in respiratory disease* 2008;2(4):237-247.
6. Cupples S, Dew MA, Grady KL, De Geest S, Dobbels F, Lanuza D, et al. Report of the Psychosocial Outcomes Workgroup of the Nursing and Social Sciences Council of the International Society for Heart and Lung Transplantation: present status of research on psychosocial outcomes in cardiothoracic transplantation: review and recommendations for the field. *J Heart Lung Transplant* 2006;25(6):716-725.
7. Rosenberger EM, Dew MA, DiMartini AF, DeVito Dabbs AJ, Yusem RD. Psychosocial issues facing lung transplant candidates, recipients and family caregivers. *Thorac Surg Clin* 2012;22(4):517-529.

8. Ivarsson B, Ekmehag B, Sjoberg T. Recently accepted for the waiting list for heart or lung transplantation - patients' experiences of information and support. *Clin Transplant* 2011;25(6):E664.
9. Ivarsson B, Ekmehag B, Sjoberg T. Relative's experiences before and after a heart or lung transplantation. *Heart Lung* 2014;43(3):198-203.
10. Jalowiec A, Grady KL, White-Williams C. Stressors in patients awaiting a heart transplant. *Behav Med* 1994;19(4):145-154.
11. Jha SR., Hannu MK, Chang S, Montgomery E, Harkess M, Wilhelm K et al. The prevalence and prognostic significance of frailty in patients with advanced heart failure referred for heart transplantation. *Transplantation* 2016;100(2):429-436.
12. Macdonald K. Living in limbo - patients with cystic fibrosis waiting for transplant. *Br J Nurs* 2006;15(10):566-572
13. Ivarsson B, Ekmehag B, Sjoberg T. Patients' experiences of information and support during the first six months after heart or lung transplantation. *Eur J Cardiovasc Nurs* 2013;12(4):406.
14. Goetzmann L, Scholz U, Dux R, Roellin M, Boehler A, Muellhaupt B, et al. Attitudes towards transplantation and medication among 121 heart, lung, liver and kidney recipients and their spouses: *Swiss Med Wkly*:w13595. doi: 10.4414/smw.2012.13595.; 2012.
15. Whall AL. The family as the unit of care in nursing: A historical review. *Public Health Nurs* 1986;3(4):240-249.
16. Kind P. The Euroqol instrument: An index of health-related quality of life. Philadelphia: Lippincott Williams and Wilkins; 1996.
17. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. *Acta Psychiatr Scand* 1983;67(6):361-370.

18. Horowitz M, Wilner N, Alvarez W. Impact of Event Scale: a measure of subjective stress. *Psychosom Med* 1979;41(3):209-218.
19. Pearlin LI, Schooler C. The structure of coping. *J Health Soc Behav* 1978;19(1):2-21.
20. Elmståhl S, Malmberg B, Annerstedt L. Caregiver's burden of patients 3 years after stroke assessed by a novel caregiver burden scale. *Arch Phys Med Rehabil* 1996;77(2):177-182.
21. Naef R, Bournes DA. The lived experience of waiting: a Parse method study. *Nurs Sci Q* 2009;22(2):141-153.
22. Lisspers J, Nygren A, Soderman E. Hospital Anxiety and Depression Scale (HAD): some psychometric data for a Swedish sample. *Acta Psychiatr Scand* 1997;96(4):281-286.
23. Almgren M, Lennerling A, Lundmark M, Forsberg A. The meaning of being in uncertainty after heart transplantation - an unrevealed source to distress. *Eur J Cardiovasc Nurs*. 2016 May 4. pii: 1474515116648240. [Epub ahead of print]
24. Lundmark M, Lennerling A, Almgren M, Forsberg A. Recovery after lung transplantation from a patient perspective - proposing a new framework. *J Adv Nurs*. 2016 Jun 27. doi: 10.1111/jan.13058. [Epub ahead of print]
25. Lundmark M, Erlandsson LK, Lennerling A, Almgren M, Forsberg A. Health transition after lung transplantation - a grounded theory study. *J Clin Nurs*. 2016 May 27. doi: 10.1111/jocn.13269. [Epub ahead of print]
26. Goldbart J, Yohannes AM, Woolrych R, Caton S. 'It is not going to change his life but it has picked him up': a qualitative study of perspectives on long term oxygen therapy for people with chronic obstructive pulmonary disease. *Health Qual Life Outcomes* 2013;11:124.
27. Ryu YJ, Chun EM, Lee JH, Chang JH. Prevalence of depression and anxiety in outpatients with chronic airway lung disease. *The Korean J Intern Med J* 2010;25(1):51-57.
28. Keil RM. Coping and stress: a conceptual analysis. *J Adv Nurs* 2004;45(6):659-665.

29. Arnold R, Ranchor AV, DeJongste MJ, Koeter GH, Ten Hacken NH, Aalbers R, et al. The relationship between self-efficacy and self-reported physical functioning in chronic obstructive pulmonary disease and chronic heart failure. *Behav Med* 2005;31(3):107-115.
30. Hollman G, Gullberg M, Ek AC, Eriksson M, Olsson AG. Quality of life in patients with familial hypercholesterolaemia. *J Intern Med* 2002;251(4):331-337.
31. Petty M. Lung and heart-lung transplantation: implications for nursing care when hospitalized outside the transplant center *Medsurg Nurs*. 2003;12(4):250-259.
32. Lindberg B, Nilsson C, Zotterman D, Söderberg S, Skär L. Using information and communication technology in home care for communication between patients, family members, and healthcare professionals: a systematic review. *Int J Telemed Appl* 2013;2013:461829. doi: 10.1155/2013/461829. Epub 2013 Apr 10.

Legends to figures

Fig 1 Flow chart of the study.

Fig 2 Distribution of the level of perceived problems in each dimension of the EQ-5D (%).

Non-problems are not shown.

Fig 3 Levels of anxiety and depression as measured by the Hospital Anxiety and Depression Scale (HADS) (A), levels of intrusion and avoidance stress as measured by the Impact of Event Scale (IES) (B), and coping scores as measured by the Mastery scale (C) before and 6, 12, and 24 months after heart or lung transplantation. Results are presented as mean $\pm$ standard error of the mean.

Table 1. Demographic data and other characteristics of patients and next of kin at baseline

Gender:	Heart patients 5 women/23 men	Lung patients 15 women/11 men	NoK to heart patients 19 women/2 men	NoK to lung patients 13 women/6 men
Age, years Mean $\pm$ SD Median (range)	52 $\pm$ 12 53 (20-69)	50 $\pm$ 14 56 (18-65)	49 $\pm$ 10 49 (range 34-68)	51 $\pm$ 13 54 (range 28-73)
Civil status: Single Married/cohabiting	13 15	13 13	2 19	3 16
Education: Elementary school High school College/university	6 15 7	5 17 4	3 11 7	5 5 9
Diagnosis: Dilated cardiomyopathy Ischemic cardiomyopathy	20 6			

Right ventricular cardiomyopathy	1			
Restrictive cardiomyopathy	1			
Chronic obstructive pulmonary disease		10		
Cystic fibrosis		4		
α 1-Antitrypsin deficiency		4		
Pulmonary fibrosis		5		
Graft-versus-host reaction		1		
Heritable pulmonary arterial hypertension		1		
Associated pulmonary arterial hypertension		1		
Relation:				
Spouses (n)			13	9
Mother (n)			2	2
Daughter (n)			4	3
Son (n)			1	2
Live-apart (n)			1	0
Brother (n)			0	2
Friend (n)			0	1
Days on waiting list before transplantation				
Mean $\pm$ SD	256 $\pm$ 235	197 $\pm$ 192		
Median (range)	217 (16-1018)	127 (3-641)		

Data are given as n unless otherwise noted

Fig 1

Fig 2

Fig 3C