

PSYCHOSOCIAL IMPACT IN FAMILY MEMBERS BEFORE AND UP TO TWO YEARS AFTER HEART OR LUNG TRANSPLANTATION

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I have nothing to declare





Introduction

- ▣ The majority of patients awaiting transplantation are very hopeful for the future
- ▣ Caregivers are essential members of the health care team who provide care
- ▣ Support from the family is important while waiting for transplantation

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.* 2012;142:w13595.

Goetzinger AM, Blumenthal JA, O'Hayer CV, Babyak MA, Hoffman BM, Ong L, et al. Stress and coping in caregivers of patients awaiting solid organ transplantation. *Clin Transplant.* 2012 26(1):97-104. .

Andershed B. Relatives in end-of-life care--part 1: a systematic review of the literature the five last years, January 1999-February 2004. *J Clin Nurs.* 2006;15(9):1158-69.



Introduction

- ▣ The families quality of life is greatly affected
- ▣ The families reported involvement in the transplantation decision, peer support, information seeking, burden and coping
- ▣ It's a gap between the information and support that families need and receive

Andershed B. Relatives in end-of-life care--part 1: a systematic review of the literature the five last years, January 1999-February 2004. J Clin Nurs. 2006;15(9):1158-69.

Lefaiver CA, Keough VA, Letizia M, Lanuza DM. Quality of life in caregivers providing care for lung transplant candidates. Prog Transplant. 2009;19(2):142-52.



Aim

- ▣ The aim was to examine the families experiences in burden, coping, anxiety, depression and stress when the patients were established on transplantation waiting list
- ▣ Was it improved or deteriorated 6 months, 1 and 2 year after heart or lung transplantation?



Method

- ▣ During the period January 2009 to June 2011,
- ▣ 54 patients responded to the transplantation center, Skåne University Hospital (SUS / Lund) and
- ▣ 40 family members in surveys 2-4 weeks after the patients have been established on the waiting list for heart or lung transplantation

Method

- ▣ Instruments:
 - HAD (Anxiety and Depression)
 - The Impact of Event Scale: A scale of current subjective distress
 - Caregiver Burden Scale: That measures caregiver burden as subjectively experienced
 - Coping Mastery scale, measures coping capacity
 - Baseline, 6 months, 1 and 2 years after transplantation

Results

- ▣ Between January 2009 to June 2011,
- ▣ 19 females and 2 men to heart patients and
- ▣ 13 females and 6 men to lung patients included
- ▣ The majority of them were spouses and 50 (mean) years
- ▣ Those who were older than 50 years had mostly high school education and the younger had mostly university education

Caregiver burden

- ▣ The family scored medium or high level of caregiver burden
- ▣ General strain was most affected
- ▣ The burden of the family was greater in lung patients
- ▣ Over time both groups decrease their burden, especially between baseline and 6 months.
- ▣ Age, gender and marital status had no effect on caregiver burden

Mastery coping

- ▣ Families of lung patients had better coping strategies at 1 year ($p = .03$) but also after 2 years ($p = .006$) compared with heart patients
- ▣ Families with higher education had a higher level of coping ability ($p = .03$)
- ▣ Age, gender and marital status had no effect on coping ability

HAD

- ▣ Existing HAD anxiety and depression levels were quite similar in families to heart and lung patients
- ▣ Anxiety/ depression showed a higher level when the family had a lower education. ($p = .03$)
- ▣ Age, gender and marital status had no effect on anxiety/ depression

Impact of event scale

- ▣ The families to lung patients experienced more stress ($P = .06$), particularly in intrusion and the greatest increase was seen after 1 year ($P = .04$)
- ▣ Stress affects burden, anxiety, depression, and if there is a lung or heart patient ($P = .05$)
- ▣ Families with less education level experienced more stress and in particular in intrusion ($p = .03$)
- ▣ Age, gender and marital status had no effect on stress

Conclusion

- ▣ Families of lung patients probably need support and information more widely
- ▣ Health - care professionals should find strategies to meet the needs of families with contacts and forums both in physical form but also via internet network
- ▣ It is probably most important with personal contact and especially when they feel lonely

Discussion

- ▣ What can be the reason why caregiver burden was reported higher in lung patients?
- ▣ Why do they have better coping?
- ▣ They experience more stress, especially in intrusion? Why?
- ▣ What support do we reach them with?

Thank you for your attention

