The experience of the life partners during complications and hospitalisations of patients with lung transplantation

anxiety as a constant companion of everyday life

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Background

- Worldwide > 34,000 LuTx for 30 years
- In 2015 in Europe - 609 LuTx
- In 2015 in Switzerland - 52 LuTx
  - 30 at Zurich university hospital (USZ)
  - 22 at Lausanne university hospital
- In international comparison, Switzerland has a longer survival rate
- More complications due to longer survival times (medication etc.)
- A literature review reveals that medical staff mostly consider life partners to be the first point of contact
- Studies show that life partners are very stressed
- Studies on the experiences of life partners mostly come from other countries, especially America, and no comparisons with Switzerland exist

1 Inci, Schuurmans, Boehler & Weder, 2012, Swiss Med Wkly
2 Eurotransplant, 2015, Eurotransplant Statistics
3 Swisstransplant, 2015, Jahresbericht 2015
4 Boehler, 2004, Therapeutische Umschau
5 McCurry & Thomas, 2002, Western Journal of Nursing Research
Gap in the Literature

How do life partners of lung transplant patients experience the rehospitalisation occurring because of complications and what support needs do they have?
Aim of the Study

• The aim of this qualitative hermeneutical study was to gap the experience and burden of life partner from transplant patients, which are due to complications in the hospital

• Secondary aims were:
  1) build ideas for setting up a support follow-up care for life partner and
  2) to plan a quantitative pilot study of life partner support meeting their needs.
Methods

• **Design:** Qualitative, phenomenological interpretive hermeneutic approach

• **Sample:** Convenience sample of all partners of all adult lung transplant recipients, having been re-hospitalized, at the University Hospital of Zurich due to post-transplant complications (N=12)
  - **Inclusion:** able to understand, talk and fill out a questionnaire in German, aged > 18

• **Setting:** Pneumology Department of the University Hospital of Zurich

• **Recruitment:** The study information and the recruitment letter were handed over via the departmental management
Methods

• **Data collection:** Narrative interviews from February to October 2015.

• **Data analysis:** Phenomenological-interpretive analysis according to Smith et al.\textsuperscript{7}

• **Quality criteria:** Trustworthiness and credibility\textsuperscript{8}

• **Ethical aspects:** The study has received ethical approval from the Ethics Commission of the Canton of Zurich (5 February 2015)

\textsuperscript{7} Smith et al.,2009, Londen GB:SAGE Publications Ltd.
\textsuperscript{8} Lincoln & Guba, 1985, Newbury Park, CA: SAGE Publications,Inc.
Analysis

Analysis by Smith et al. (2009)

1. Reading and re-reading
2. Initial noting
3. Developing emergent themes
4. Searching for connections across emergent themes
5. Moving to the next case
6. Looking for patterns across cases
Results

Demographics of life partners

• 6 women and 6 men were interviewed
• Mean age: 47 +/- 12.46 years, Range 26 - 63 years
• All participants are either married or in a stable relationship.
• Relationship length: Median 13.5 years (25p:6.5; 75p:25); Range 4-44 years
• Time since Tx: Median 36 months (25p:8; 75p:55.5); Range 6-240 months
• Times of re-hospitalisations due to complications since LungTx:
  • 7 patient: 2-4 time
  • 3 patients: 5-10 times
  • 2 patients: >10 times
Results

Phenomenon 1
Fear of deterioration

• All 12 life partner fear the deterioration, which may even lead to death
• This was often described in connection with uncertainty about additional diagnoses or a common future.
• Complications evoke memories of the time before and after the Tx, associated with the fear of losing the life partner and perceived as very challenging.
Results

Phenomenon 2
Making sacrifices for a common life

• The life partners’ life is restricted, they are deprived of certain aspects of liberty and freedom.
• Life partners have often a guilty conscience to request liberty and freedom and consequently renounce to their need.
• Care for the partner is taken for granted. Life partners are often left aside. Nobody asks them about their experience.
Results

Phenomenon 3
Being stressed

• Being stressed physically and psychologically, when the partner (lung Tx recipient) is re-hospitalized due to complications.
• The partners feel under pressure to best meet the everyday needs.
• Different expectations at the same time: satisfying the employer, the family and the re-hospitalized partner.
Results

Phenomenon 4
Create a balance

• Life partners need time for themselves to regenerate and to process stress, in order to be a support for the partner
• Developed strategies for life balance: physical activity, meditation, find solace in spirituality, distraction with walks and talking to the partner and friends.
• Life partners punctuate the importance to obtain information about the development of the disease in order to reduce fear.
Discussion

These 4 phenomena can be summarised as shown in the figure:

- Fear of deterioration (rejection)
- Being stressed
- Making sacrifices for a common life
- Looking for a balance
Discussion

• This is the first study focusing on the experience and burden of life partners from lung Tx recipients being hospitalized due to complications
• Studies primarily looked into the life situation before and after Lung Tx
  • Especially studies from the USA
  • Comparable results are presented there
  • Partners talk about complications (such as rejection) being very stressful and associated with feelings of anxiety
• Studies on COPD and tumour diseases and other chronic diseases indicate similar phenomena with regard to family members and their experiences

10 Song et al., 2010, J Pain Symptom Manage
11 Beutel, 1988, VCH Verlagsgesellschaft, Weinheim
12 Corbin & Strauss, 2004, Hans Huber, Bern
Conclusions

Consequences for the clinical practice:

• Specifically talking about fears and taking life partners seriously
• Understanding partners as carers and including them
• Offering good information about the disease progression, identifying complications and treatment
• Including partners in the nursing assessment and integrating them in the care process
• Acknowledging their expertise, care choices and time investment

Introducing the concept of family-centred care

• "Calgary Family Assessment Model" (CFAM)\textsuperscript{13}
• "Calgary Family Intervention Model" (CFIM)\textsuperscript{13}

\textsuperscript{13} Wright L., Leahey M. (2009): Familienzentrierte Pflege. Huber Verlag, Bern
Limitations

• Phenomenological studies are not neutral and value-free
• Possible bias resulting out of the literal translation from Swiss German into standard German
• Small sample size – all living in the same region and culture
• Generalisation is only partially possible
• The results only apply to partners and cannot be transferred to other family members
• All partners were in a stable, long-term relationship; it is not clear whether this can be transferred to other relationships
Question?
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Thank you for your attention