Exploring, recognising and preparing for palliative care needs in lung transplantation

Chi Li, Anna Collins, Greg Snell, Jennifer Philip, Michelle Gold

13th Australian Palliative Care Conference
September 2015
BACKGROUND
Lung transplantation

- Increasingly offered to selected patients dying from lung diseases
- Improves survival and quality of life
- Patients & carers endure significant symptom & treatment burden
- Not ‘cure’: median 5-year survival ~60%
Study aims

• Likely to be unmet palliative care needs in this population

• Limited data on experience and needs of those undergoing lung transplantation

• Study questions
  – What is it like for patients and their families at different stages of lung transplantation?
  – Do they have any unmet supportive and palliative care needs?
METHODS
Study design

- Prospective, cross-sectional, single-centre study

- Survey participants
  - Consecutive adult patients scheduled to attend lung transplant clinics (April to October 2015)
  - Nominated primary carers

- Recruitment & consent
  - Invitation letter & response slip
  - Follow up discussion
### Outcome measures

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Patient*</th>
<th>Carer</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Quality of life</strong></td>
<td>Medical Outcomes Study 36-item Short Form version 2 (SF36v2)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>EuroQOL-5 Dimension (EQ-5D-3L)</td>
<td></td>
</tr>
<tr>
<td><strong>Symptoms</strong></td>
<td>Edmonton Symptom Assessment System – revised (ESAS-r)</td>
<td></td>
</tr>
<tr>
<td><strong>Care burden</strong></td>
<td>-</td>
<td>Additional questions</td>
</tr>
<tr>
<td><strong>Needs</strong></td>
<td>Additional questions</td>
<td>Carer Support Needs Assessment Tool (CSNAT)</td>
</tr>
<tr>
<td></td>
<td>Palliative care Outcome Scale version 2 (POSv2) for patients</td>
<td>Palliative care Outcome Scale version 2 (POSv2) for carers</td>
</tr>
</tbody>
</table>

* Medical record review: demographics & clinical characteristics
PRELIMINARY RESULTS
The first hundred responses

- Patients = 52
- Carers = 48

- Lives ≤100km of The Alfred: 75%
- Transplanted: 88%
- Type
  - Bilateral: 85%
  - Single: 9%
  - Heart-lung: 6%

Primary diagnosis:

- COPD: 48%
- ILD: 8%
- CF: 27%
- Other: 17%
Quality of life (SF-36v2): patient

(N = 52; Pre-Tx = 6, Post-Tx = 46)
Quality of life (SF-36v2): carer

(N = 48; Pre-Tx = 6, Post-Tx = 42)
Carer burden

Number of hours per day spent caring for patient

Proportion of carers in each group

Pre-Tx

Post-Tx

- >8
- 5 to 8
- 1 to 4
- <1
- No carer
Symptoms (ESAS)
Symptoms (ESAS)
Patient needs

Do you need more support with...?

<table>
<thead>
<tr>
<th></th>
<th>Pre-Tx</th>
<th>Post-Tx</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding what</td>
<td></td>
<td></td>
</tr>
<tr>
<td>is happening</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Managing health/treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knowing what to</td>
<td></td>
<td></td>
</tr>
<tr>
<td>expect in the future</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Helping family/friends cope</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Carer needs

Do you need more support with…?

<table>
<thead>
<tr>
<th>Topic</th>
<th>Pre-Tx</th>
<th>Post-Tx</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding what is happening</td>
<td>30%</td>
<td>10%</td>
</tr>
<tr>
<td>Managing symptoms</td>
<td>40%</td>
<td>20%</td>
</tr>
<tr>
<td>Knowing what to expect in the future</td>
<td>50%</td>
<td>50%</td>
</tr>
<tr>
<td>Dealing with own feelings/worries</td>
<td>40%</td>
<td>40%</td>
</tr>
</tbody>
</table>
DISCUSSION
EXPLORING: Experience & needs

• First study in Australia to explore experience and needs as reported by lung transplant patients and carers
  – Pre-transplant patients have poor quality of life
  – Pre-transplant patients have higher symptom burden
  – Both patients and carers have unmet supportive and palliative care needs
  – Different unmet needs reported at different stages of transplantation

• Great response rate – keen to participate, particularly carers. Therapeutic?
RECOGNISING: Potential roles

• Lung transplant patients and carers are likely to benefit from palliative care
  – A complementary approach – focus on patient/family & quality of life/death
  – Symptom management
  – Psychosocial support
  – Communication, particularly around prognostication
  – End-of-life planning and terminal care
PREPARING: Integration

• Addressing these unmet needs require further integration of palliative care in the lung transplantation setting
  – Overcoming prognostic paralysis & negotiating conflicting goals of care
  – Cross-education & liaison

• Next steps
  – Complete current study recruitment/analysis
  – Qualitative & longitudinal studies
Thank you

- Anna Collins, Michelle Gold, Jenny Philip, Greg Snell
- Palliative Care & Lung Transplant Services, The Alfred
- Centre for Palliative Care, St Vincent’s Hospital Melbourne
- Victorian Palliative Medicine Training Program
- The Alfred Senior Medical Staff Association
- Lung Transplant patients and carers

- Questions? C.Li@Alfred.org.au