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PALLIATIVE
CARE

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

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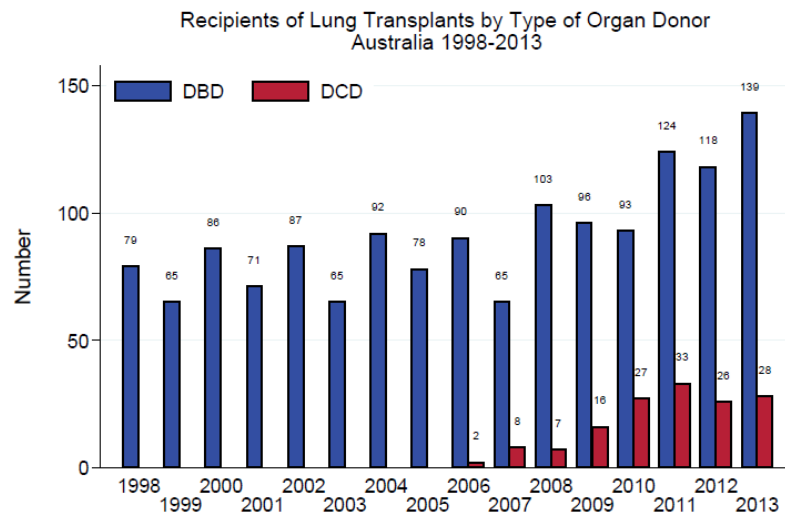
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BACKGROUND

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?



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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

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

* Medical record review: demographics & clinical characteristics



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PRELIMINARY RESULTS

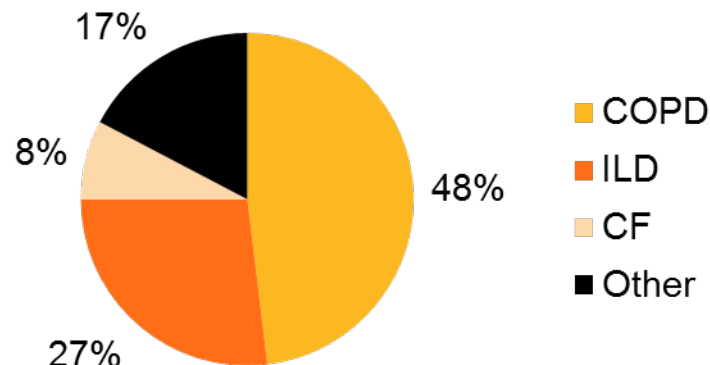
The first hundred responses

- Patients = 52
- Carers = 48

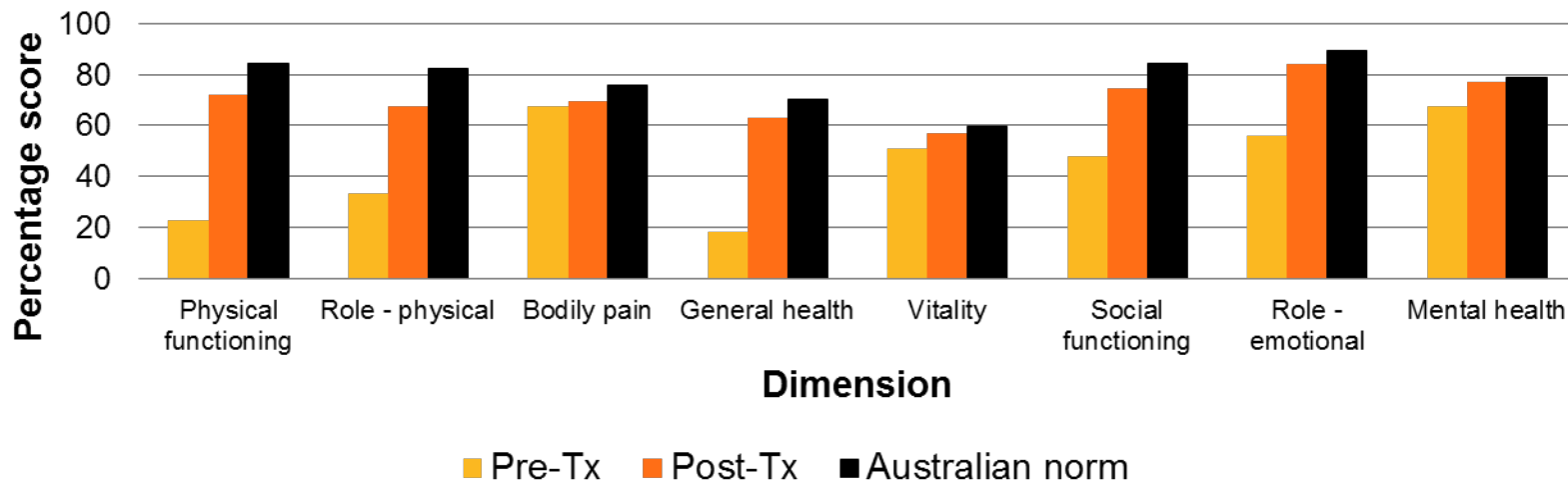
- Lives ≤ 100 km of The Alfred: 75%

- Transplanted: 88%
- Type
 - Bilateral: 85%
 - Single: 9%
 - Heart-lung: 6%

Primary diagnosis

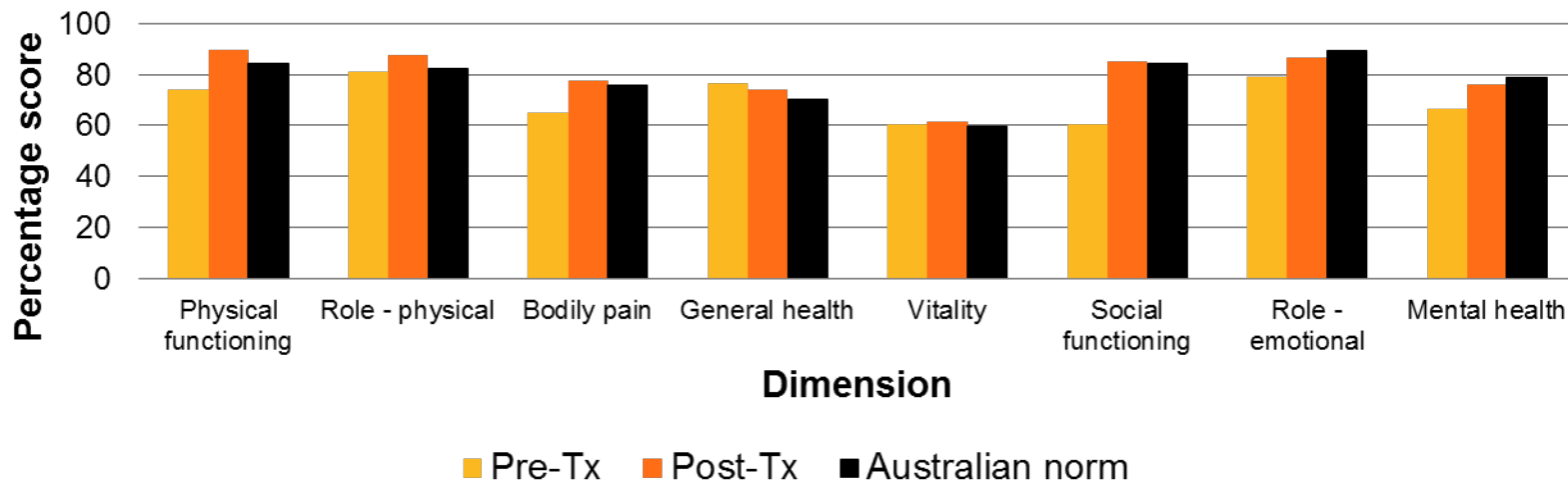


Quality of life (SF-36v2): patient



(N = 52; Pre-Tx = 6, Post-Tx = 46)

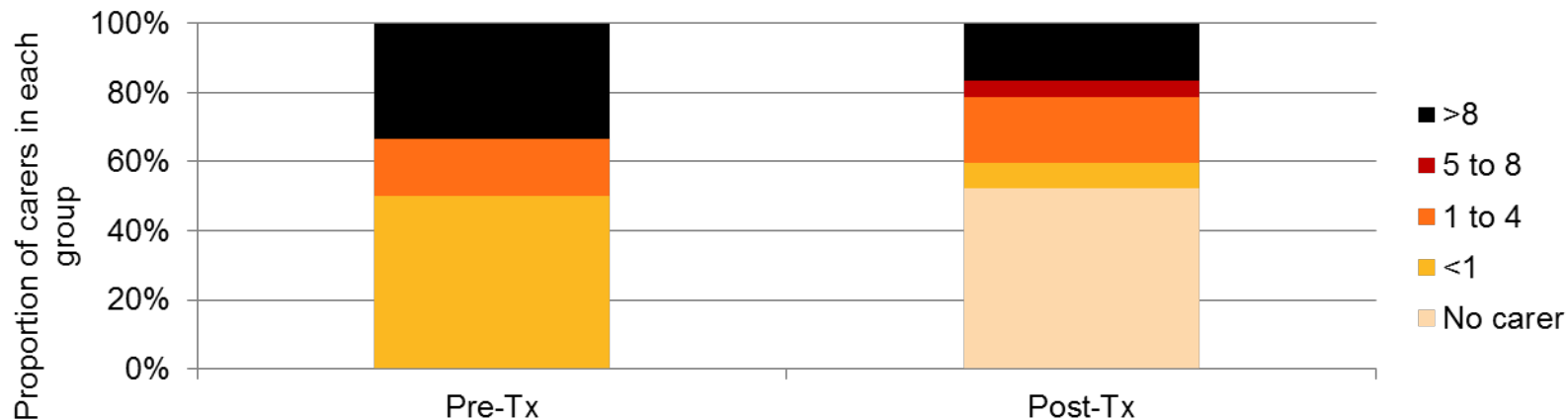
Quality of life (SF-36v2): carer



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

Carer burden

Number of hours per day spent caring for patient

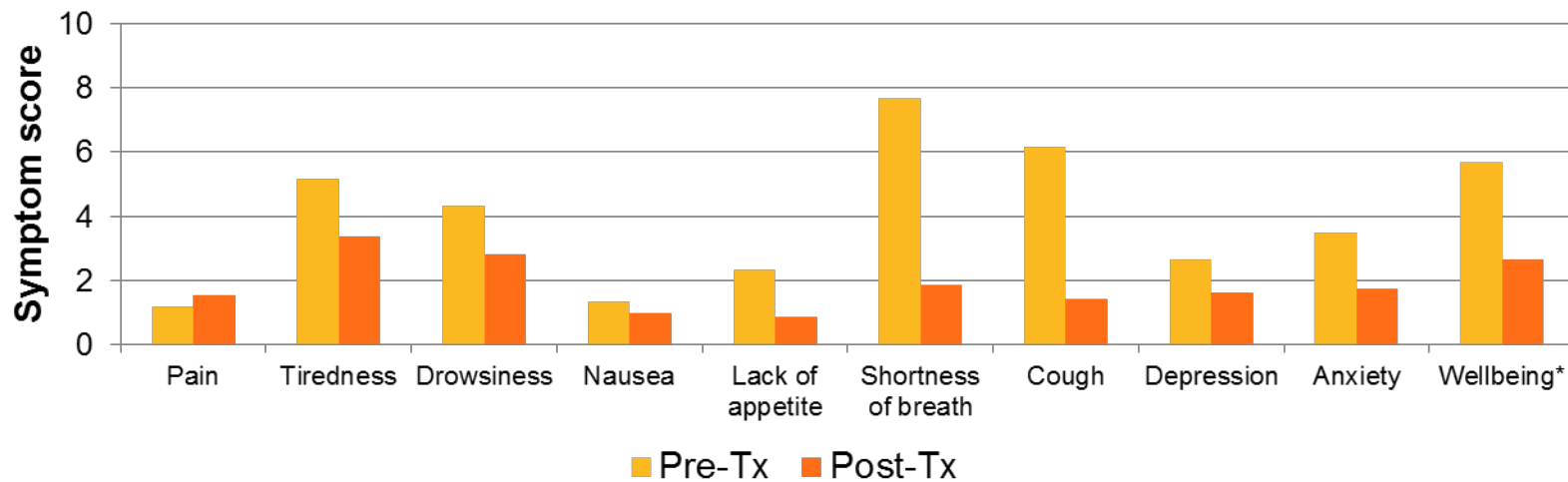




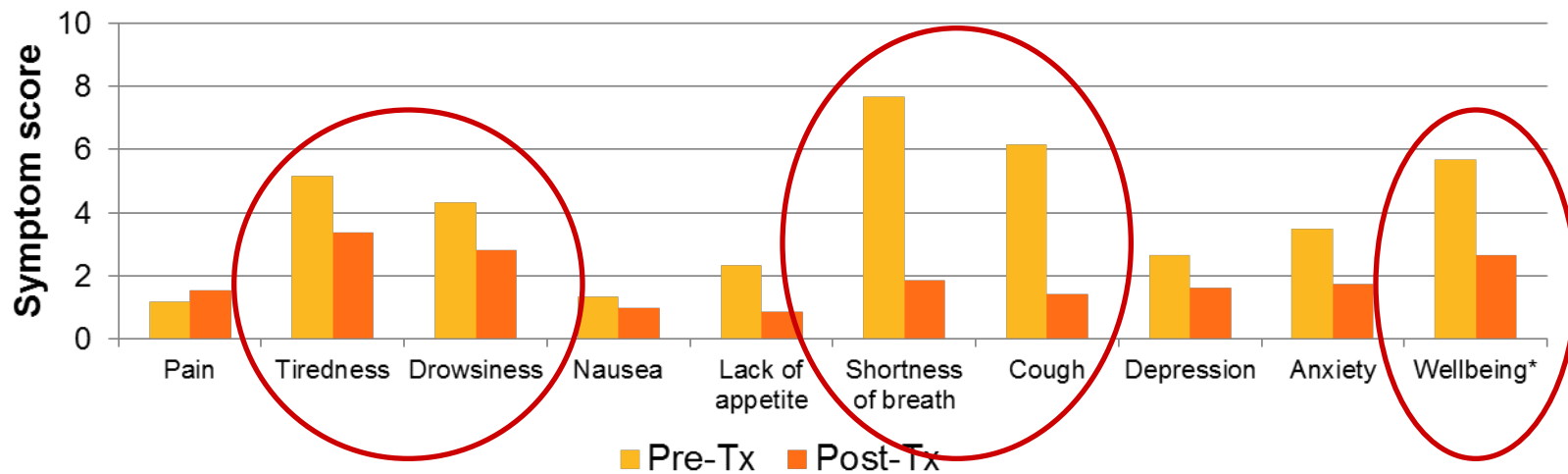
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Symptoms (ESAS)

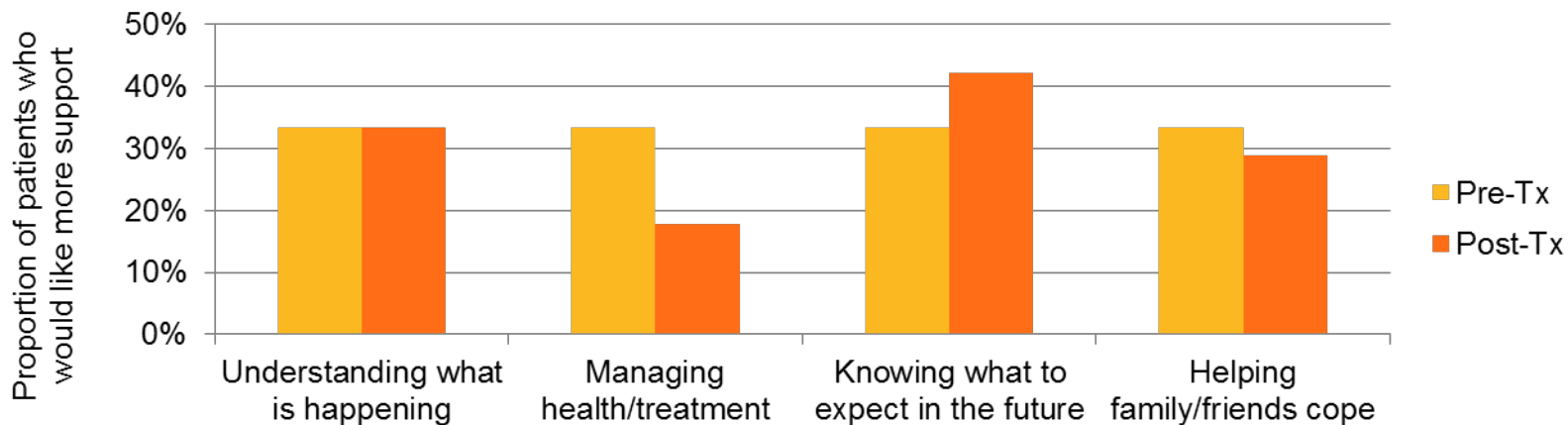


Symptoms (ESAS)



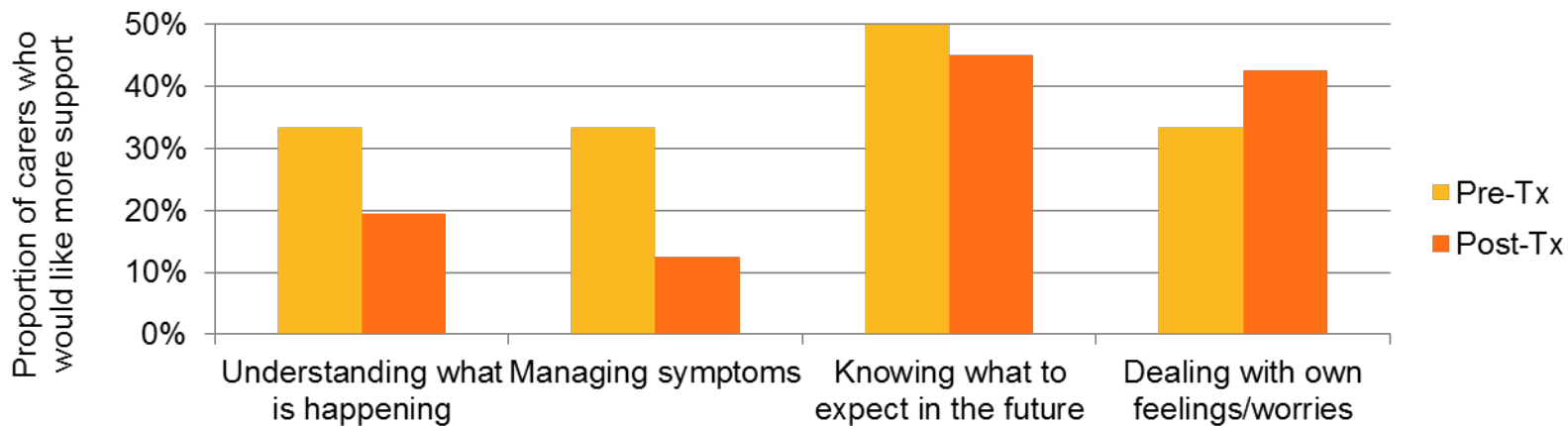
Patient needs

Do you need more support with...?



Carer needs

Do you need more support with...?





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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
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- 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