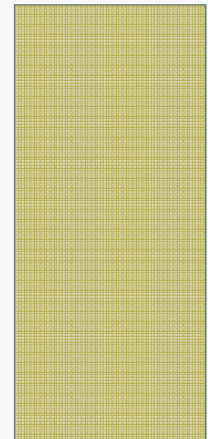


DOES GENDER AND TIME SINCE  
LUNG TRANSPLANT AFFECT  
CAREGIVER STRESS AND ANXIETY?

HAINES, J., GILES, A., SIMON, M., & CHOI, J.  
UNIVERSITY OF PITTSBURGH SCHOOL OF  
NURSING



This study was made possible by a grant from the International Society of Heart and Lung Transplantation (ISHLT)

# INTRODUCTION

65.7 million Americans serve as caregivers – 29% of the population ( National Alliance for Caregiving and AARP, 2012)

Estimated value of care provided \$450 billion a year. Exceeds total Medicaid spending and approaches 90% of Medicare expenditures.

(Economic Value of Caregiving, AARP, 2012)

# WHO IS THE AVERAGE CAREGIVER?

66% female

Average age 48

Average care provided per week 20.4 hours

72% white in US

50% employed full time

(National Caregiver Alliance and AARP, 2012)

# CONSEQUENCES OF CAREGIVING

- **HTN, CVA** (Capistrant & King, 2012, Haley et. Al, 2010)
- **Arthritis, decreased pain tolerance**  
(Pinquart, 2007, Mannion, 2008)
- **Endocrine disorders** (Hoffman, et. Al, 2012)
- **Lowered Immune Function** (Legg et al, 2013, Vitaliano et. al, 2003)
- **Early death** (Christakis & Allison, 2006, Schultz & Beach, 1999)



# CONSEQUENCES OF CAREGIVING

- **Mental Health Issues**
  - **Sleep problems** (Mannion, 2008)
  - **Depression, Anxiety** (Van der Veld, et al, 2010, Li & Loke, 2013)
  - **Suicide** (Wu, et al., 2012)
  - **Abuse of the Care Recipient** (Beach, et. al, 2006)
  - **Increased release of stress hormones** (Pinquart and Sorenson, 2007)
  - **Risky behaviors** (Beach, et. al, 2005, Hoffman et al., 2012)

# GENDER AND CAREGIVING

Two theories

## 1) Gender Role Theory

Gender roles are taught and internalized early - Reinforced

Girls: Nurturing, focus on relationships.  
Emotional and avoidance coping

Boys: autonomy, task orientation, problem solving, masking emotions and feelings

# GENDER AND CAREGIVING

Calasanti & King (2007) *Taking Women's Work Like a Man* Identified 6 coping strategies used by men in the study

- 1) Focus on tasks: "Do what you have to do. Pick it up like a trade."
- 2) Forced Compliance
- 3) Blocking Emotion: "Just keep my cool and go on."
- 4) Minimize Disruption
- 5) Distracting Attention: "Get your mind off things."
- 6) Self medicating: "Grab another beer."



# GENDER AND CAREGIVING

## 2) Role Socialization Theory:

Focuses on current social role and demands of current situation as primary explanation for gender differences in emotional distress.

In retirement, roles reversed – men more nurturing, women want more autonomy – children grown and gone so want to be done with caregiving. Can feel restrained and resentful if asked to care again.

Women more stressed – more stressful experiences and role demands.

# BACKGROUND

- Lung transplant a frequent option
  - 29,962 transplants performed between January 1, 1988 and June 30, 2015
  - Average age 50-64
  - Indications: COPD, IPF, CF, Alpha 1 Anti-trypsin Deficiency (UNOS, 2015)

# TRANSPLANT PROCESS STRESSFUL

- **Pre-transplant**

- Travel, financial costs, caregiver may remain at site

- **Post-transplant:**

- Costly medications with numerous side effects
- Highest rejection rate of all solid organ transplants and highest doses of immunosuppression needed (Carlin, 2009, Floreth, 2010, Rosenberger, et. al, 2012)
- Lowest rate of return to work (De Baere, et. al, 2010)

**5 year survival 55%** (ISHLT, 2015)

# STRESS OF CAREGIVING

- Caregivers of Lung Transplant Candidates (n=73)
  - Low quality of life
  - Trouble sleeping
  - Feeling inconvenienced
  - Angry that the patient changed so much
  - Mood disturbances
  - Decreased intimacy with patient

(Rodrigue & Baz, 2007)

# CAREGIVERS OF LUNG TRANSPLANT CANDIDATES

- Caregivers of lung transplant candidates reported fatigue, depression, financial concerns pre-transplant (Lefavier et. al, 2009)
- Caregivers of lung transplant candidates who reported greater perceived burden had higher levels of depression and anxiety. (Claar, et, al, 2005)



# CAREGIVERS OF LUNG TRANSPLANT RECIPIENTS

Greater caregiver burden predicted poor HRQOL in several physical domains at 12 months post transplant.

Transplant recipients whose caregivers had lower perceived general health at 12 months post-transplant showed poorer survival rates during the subsequent 7 years of follow-up.

(Myaskovsky et. al, 2012)

## CAREGIVERS OF TRANSPLANT RECIPIENTS

- Compared to spousal caregivers, overall survival was significantly worse for recipients who identified an adult child as their primary caregiver.
- Risk for long term graft failure was significantly increased among patients whose caregiver was a sibling.

(Molberg, et. al, 2015)

# CAREGIVING AND GENDER

One study (Holtzman, et al, 2011)

- Females providing care to males reported significantly higher depressive symptoms than other caregivers.
- Females also had less support from family members and a greater health impact of caregiving

## DURING HOSPITALIZATION

- Caregivers spend long hours at the bedside
- Usually due to
  - Pre-transplant deterioration
  - Post-transplant complications

## PURPOSE

Hypothesis #1: Female lung transplant caregivers will report higher levels of stress than male lung transplant caregivers.

Hypothesis #2: Female lung transplant caregivers will report greater levels of anxiety than male lung transplant caregivers.



# APPROVAL PROCESS

- IRB
- UPMC Evidence Based Practice Committee
- Medical Director, Pulmonary Transplant Program
- Chief Nursing Officer
- Clinical Director
- Unit Director

# INCLUSION CRITERIA

- 30-80 years of age
- Primary Caregiver for lung recipient
- Able to speak, read and write English

Recruited from July 2013-June 2015 during hospitalization of significant other

# INSTRUMENTS

- Perceived Stress Scale (PSS)
  - Evaluates stress experienced during past month
  - 10 item version (most reliable)
  - Rate each statement 0-4 scale
  - Score of 0-40 possible – higher numbers indicate increased stress.

(Cohen, Kazmarck, & Mermelstein, 1983)

# INSTRUMENTS

- State-Trait Anxiety Inventory (STAI)
  - State Anxiety: 20 questions – Measures how anxious someone is in the present moment with a 1-4 scale for each statement – score of 20-80 possible.
  - Trait Anxiety: 20 questions – Measures how anxious one is in general with a 1-4 scale for each statement – score of 20-80 possible
  - Higher scores = increased anxiety (Spielberger, 1983)

- Caregivers given 2 instruments at baseline, 4 and 8 weeks.
- Also completed Demographic Data Tool with first meeting
- Surveyed during hospitalization of significant other. Or if patient discharged, follow-up phone call by member of research team.



## STUDY FLOW

- 153 approached
- 95 consented
- 21 drop-outs (lost to follow-up, death of spouse)
- 74 completed study

# STATISTICAL ANALYSIS

- 1) Descriptive statistics
- 2) Independent sample T tests

# STUDY GROUPS

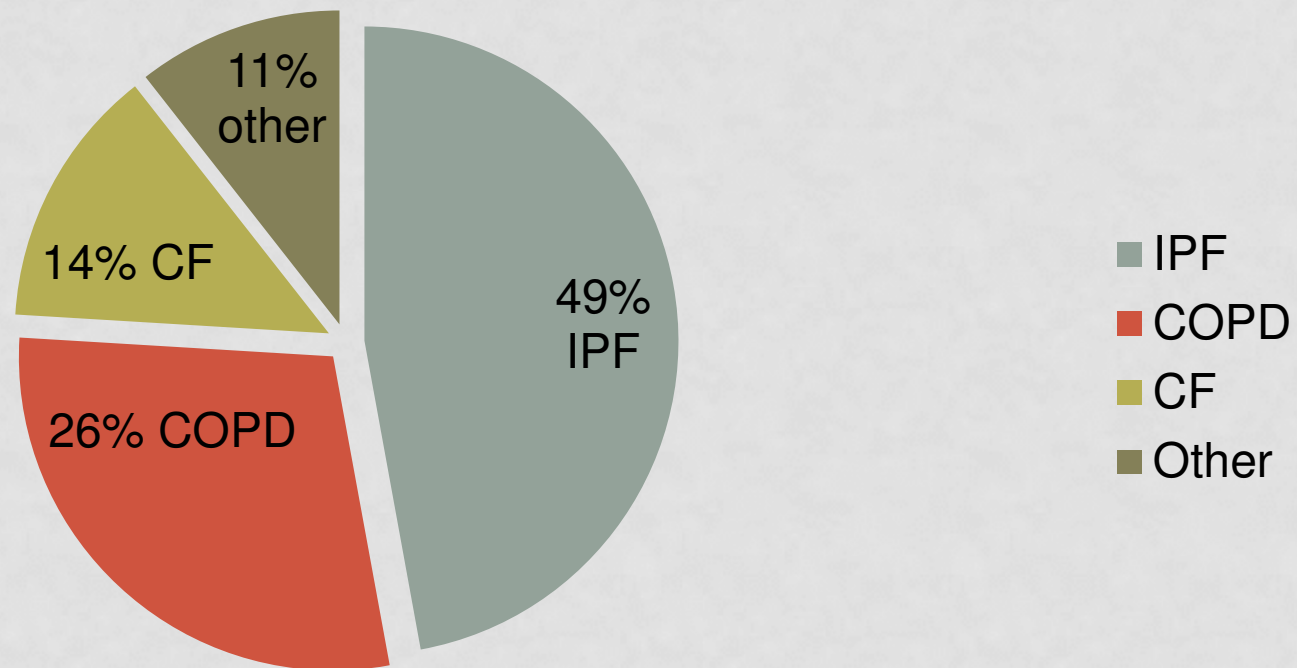
- Caregivers: 28 males, 67 females
- Age: Males: 56.2 ;Females: 54.9
- 88.3% married – 89.4% living with recipient
- 86% white
- All at least high school grads
- 40% retired; 39.4% working full time
- 54% living in temporary housing

# LUNG RECIPIENTS

- 82% double lung recipients
- Average time since transplant 26.4 months
- 56% had been admitted for complications two or more times since transplant; 25% had never been discharged,

# REASONS FOR TRANSPLANT

**Reasons for transplant**





Group	0 weeks	4 weeks	8 weeks
Male (n=28)	17.6	16.3	14.3
Female (n=67)	19.9	16.7	17.2
Sig. (two tailed)	.201	.826	.183

## PERCEIVED STRESS

NORMED SCORES: MALES 12.1, FEMALES 13.7

Group	0 weeks	4 weeks	8 weeks
Male (n=28)	43.07	39.85	37.95
Female (n=65)	42.62	38.61	40.92
Sig. (two tailed)	.876	.312	.429

## STATE ANXIETY

NORMED SCORES: MALES 50-69 (34.51); FEMALES (33.86)  
MILD (<40), MODERATE (40-59), SEVERE (> 60)

Group	0 weeks	4 weeks	8 weeks
Male (n=27)	39.96	38.11	37.05
Female (n=65)	38.42	36.20	36.73
Sig. (two tailed)	.531	.504	.913

## TRAIT ANXIETY

NORMED SCORES: MALES 50-69 (33.85); FEMALES (31.79)  
MILD (<40), MODERATE (40-59), SEVERE (> 60)

## RESULTS

All subjects had scores for the two tools that were above the normed group scores for their age and/or sex at all three data collections.

There was a significant correlation between perceived stress level and time since transplant. The longer the caregiver was involved in post-transplant care, the higher the self reported stress levels ( $P=.005$ ). State and Trait Anxiety did not show significant correlation.

# LIMITIATIONS

- Non-randomized design
- Small sample size
- Short time frame for data collection
- All subjects were from one institution and 2 nursing units
- Self-report



# SUMMARY

- Males and females in this sample were equally stressed and anxious, therefore both hypotheses were disproven.
- Both groups were more stressed and anxious than the general population, but results not statistically significant.
- Increased LOS correlated with increased stress.
- Members of the health care team need to assess stress and anxiety of patient and caregiver and provide support interventions when possible.

# FUTURE DIRECTIONS

- Support group for inpatient caregivers
- Standardized assessment tool
- Intervention to reduce caregiver stress

THANK YOU FOR YOUR ATTENTION!

**QUESTIONS???**