Family Caregivers: Presence, Perspectives, Challenges, and Health

Andrew Bugajski, PhD, RN
Paula Cairns, PhD, RN
Cecile Lengacher, PhD, RN, FAAN, FAPOS
Victoria Marshall, PhD, RN
At the end of this session attendees will be able to:

• Discuss previous, current and future research that intersects with family caregivers and patients who require substantial care.
• Describe caregiver stress levels and quality of sleep in the intensive care unit (ICU) and risk of post intensive care syndrome.
• Discuss caregiver perspectives on patient symptoms.
• Identify challenges for caregivers of patients on oral anticancer agents.
• Describe effects of caregiver presence on perceived self-management adherence.
• Discuss strategies for interventions to support caregivers.
Examination of Stress and Sleep on Family Caregiver Health in the ICU

Paula Cairns, PhD, RN¹
Kevin E. Kip, PhD²
Victoria K. Marshall, PhD, RN¹
Andrew Bugajski, PhD, RN¹
Cecile A. Lengacher, PhD, RN¹
Cindy L. Munro, PhD, RN³

¹College of Nursing, University of South Florida, Tampa, FL, USA
²College of Public Health, University of South Florida, Tampa, FL, USA
³College of Nursing, USF College of Nursing, Tampa, FL, USA
PICS Model

Post Intensive Care Syndrome (SCCM, 2013)

ICU Survivor (PICS)
- Physical Impairment:
  - ICU Acquired Weakness
    - 25%-50%
- Cognitive Impairment:
  - Executive Function
  - Memory
  - Attention
    - 30%-80%
- Psychological Impairment:
  - Anxiety
  - Depression
  - PTSD
    - 10%-50%

Decreased Quality of Life
1-Year Mortality Rate: 26%-63%

Family Member (PICS-F)
- Psychological Impairment:
  - Acute Stress Disorder – 45%
  - Anxiety – 73%
  - Depression – 35%
  - PTSD – 81% (> 4 years)
  - Complicated Grief - 59%

Decreased Quality of Life
Additional Physiological & Social Consequences:
Lack of physical energy, sleep, appetite, and self-care; interruptions in routine; role and responsibilities of the family; delayed life plans; family conflicts; and stigmatization.

(Davidson, Jones, Bienvenu, 2012; Desai, Law, & Needham, 2011; Harvey & Davidson, 2011; Meert et al., 2011; Needham et al., 2012; Paparrigopoulos et al., 2006; Pochard et al., 2005; Wolters et al., 2014)
Added Risk of PICS-F in Spouses:

Surrogate Health Decision-Making

Sleep Deficiency
Methods

• Parent Randomized Feasibility Trial
• Prospective & Longitudinal
• Control Group (n = 5)
• Sample:
  • Spouses of Mechanically Ventilated, ICU Patients
  • Eligibility: >18, within 36 hours of ICU admission & intubation
  • Exclusion: present PICS condition, imminent patient death, does not understand English

• Measures:
  • Repeated - Perceived Stress Scale (study days 1, 3, 30 & 90)
  • Continuous - Wrist Actigraphy (study days 1-3)
  • Data was collected from August to December in 2017.
## Results

### Table 1. Demographic Characteristics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>(n=5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race n (%):</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>5 (100.0)</td>
</tr>
<tr>
<td>Ethnicity n (%):</td>
<td></td>
</tr>
<tr>
<td>Non-Hispanic</td>
<td>3 (60.0)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>2 (40.0)</td>
</tr>
<tr>
<td>Sex n (%):</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1 (20.0)</td>
</tr>
<tr>
<td>Female</td>
<td>4 (80.0)</td>
</tr>
<tr>
<td>Age in years, mean (SD)</td>
<td>50.8 (9.5)</td>
</tr>
</tbody>
</table>
Results

Rate of Change in Perceived Stress

(High ≥ 12)

Mean Score

PRE  POST  30 DAYS  90 DAYS

15.6  18.4  15.5  15.25
Sleep Efficiency = ratio of total time asleep to total time in bed.

- >90% = very good
- >85% = normal
- <85% = poor
- <75% = insomnia

Mean = 64% (17.8%)
Range = 40% to 90%
Median = 66%
Results

ACUTE STRESS
(High > 25)

ANXIETY
(High > 7)

DEPRESSION
(High > 12)

PTSD
(High > 9)
Stress, depressive symptoms, and sleep disorders are the most frequent negative influences on caregiver health.\textsuperscript{26}

Elevated perceived stress levels, along with the added stress of poor sleep efficiency during the ICU stay of a loved one, place family caregiver health at risk for post intensive care syndrome:

- Acute Stress Disorder
- Ongoing Anxiety
- Depression
- Posttraumatic Stress Disorder

Caregivers who provide substantial care are more likely to have physical and emotional health problems.\textsuperscript{27}

Interventions are warranted that reduce stress and enhance sleep during the ICU stay to lower risk of PICS-F and promote caregiver health (R34).
References


Questions?
Patients With Advanced-Stage Cancer: Caregivers Perspective on Patient Symptoms, Treatment Sessions, and Coping

Cecile A. Lengacher, PhD, RN, FAAN, FAPOS
Paula Cairns, PhD, RN
Andrew Bugajski, PhD, RN
Victoria K. Marshall, PhD, RN
Trudy Wittenberg, BS

(1)College of Nursing, University of South Florida
(2)Research Enterprise, University of South Florida College of Nursing
Goals of the Study

– Obtain caregiver perspectives on patient symptoms, difficulties during treatment, and their coping needs when caring for advanced-stage cancer patients (ASCP).

– Obtain caregiver perspectives on the design of an effective, self-management web based/mobile intervention for caregivers of ASCP.
• An estimated **39.8 million** Americans provide unpaid care to adults (7% for cancer patients).\(^1\)

• Cancer caregivers report higher levels of stress, depression and anxiety compared to the normal population affecting their QOL.\(^2,\ 3\)
• Caregivers providing higher levels of care report negative outcomes often postponing their health care needs, leading to lower QOL. ⁴

• Cancer caregivers who are younger and female often report higher levels of distress. ⁵,⁶

• Prevalence of emotional distress among caregivers of advanced stage patients ranges between 20 and 50%.
Caregiver distress is also related to physical problems:

- Increased fatigue,
- Decreased sleep,
- Unhealthy behaviors.\(^8\)

High levels of caregiver fatigue leads to:

- High symptom burden.\(^9\)
• Poor QOL is associated with
  – Caregiver burden and
    • Deterioration in psychological well-being, \(^{10}\)
  – Worse mental health,
    • Being female and number hours of caregiving. \(^{11}\)
Recruitment

- 7 Caregivers (2 lung, 3 breast and 2 colon female caregivers of advanced stage cancer patients) were recruited from the outpatient infusion clinic at Moffitt Cancer Center in Tampa Florida.

- Eligible caregivers were:
  - English speaking
  - Caregivers of advanced stage breast, lung, and colon cancer patients
  - 18 years and older
  - Providing care at least 5 hours per week
Focus group: Semi structured interviews were conducted with caregivers by a Master’s prepared Research Assistant.

Caregivers were asked 7 questions related to caregiving and a self-management web based/mobile intervention to assist caregivers.
Caregivers answered the following interview questions recorded by the RA:

1. What patient symptoms or problems related to cancer are most bothersome?

2. What difficulties have you experienced while the patient was on treatment?

3. In coping with your cancer patient, what specific areas would you like to improve?
Composed of 7 Caregivers
- Lung Cancer: 2
- Breast Cancer: 3
- Colon Cancer: 2

<table>
<thead>
<tr>
<th>Caregiver Response</th>
<th>Symptoms or problems of the patient that are found to be most bothersome for the caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Pain</td>
</tr>
<tr>
<td>2</td>
<td>Poor Sleep Quality</td>
</tr>
<tr>
<td>3</td>
<td>Fatigue</td>
</tr>
<tr>
<td>4</td>
<td>Exhaustion</td>
</tr>
<tr>
<td>5</td>
<td>Anxiety</td>
</tr>
<tr>
<td>6</td>
<td>Unexpected Symptoms, (diarrhea)</td>
</tr>
<tr>
<td>7</td>
<td>Unexplained Symptoms, (not being comfortable)</td>
</tr>
</tbody>
</table>
Table 1.B. Caregiver’s Response to Self-Report Interview Questions

<table>
<thead>
<tr>
<th>Caregiver Response</th>
<th>Difficulties experienced by the caregiver during patient treatment sessions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Feeling Overwhelmed</td>
</tr>
<tr>
<td>2</td>
<td>Depression</td>
</tr>
<tr>
<td>3</td>
<td>Anxiety of the Unknown</td>
</tr>
<tr>
<td>4</td>
<td>Diarrhea</td>
</tr>
<tr>
<td>5</td>
<td>Frustration</td>
</tr>
<tr>
<td>6</td>
<td>Unpreparedness</td>
</tr>
<tr>
<td>7</td>
<td>The Need to Advocate for Best Care</td>
</tr>
<tr>
<td>8</td>
<td>Guilt from Missed Symptoms or Side Effects Noted By Others</td>
</tr>
<tr>
<td>9</td>
<td>The Physical Act of Feeding Someone</td>
</tr>
<tr>
<td>10</td>
<td>Figuring Out What and How to Prepare Food to be Less Painful</td>
</tr>
<tr>
<td>11</td>
<td>Ineptitude of local physicians</td>
</tr>
</tbody>
</table>

Composed of 7 Caregivers
- Lung Cancer: 2
- Breast Cancer: 3
- Colon Cancer: 2
Table 1.C. Caregiver’s Response to Self-Report Interview Questions

<table>
<thead>
<tr>
<th>Caregiver Response</th>
<th>Coping areas in need of improvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Aggravation from Constant Schedule Changes</td>
</tr>
<tr>
<td>2</td>
<td>Easily Overwhelmed</td>
</tr>
<tr>
<td>3</td>
<td>Added Stress from Surgical Body Disfigurement</td>
</tr>
<tr>
<td>4</td>
<td>Burden of Caregiving Responsibility</td>
</tr>
<tr>
<td>5</td>
<td>Burden of Keeping Friends and Family informed</td>
</tr>
<tr>
<td>6</td>
<td>Maintaining Hope</td>
</tr>
<tr>
<td>7</td>
<td>Frustration from Process Issues at Pharmacy/Infusion Center</td>
</tr>
<tr>
<td>8</td>
<td>Routine Disruption, Need for Retuning to a Routine</td>
</tr>
<tr>
<td>9</td>
<td>Staying Informed by Providers</td>
</tr>
<tr>
<td>10</td>
<td>Debilitating Lack of Energy, to Perform Tasks</td>
</tr>
</tbody>
</table>

Composed of 7 Caregivers
- Lung Cancer: 2
- Breast Cancer: 3
- Colon Cancer: 2
Caregivers were provided with a general description of the mobile Mindfulness Based Stress Reduction (MBSR) program for caregivers mMBSR-(C) followed by 4 interview questions:

1. What would be the benefits of attending mMBSR-C program as a caregiver?
2. Would you participate in the program?
3. How often could you participate in the mMBSR-C program?
4. Do you have suggestions for additions to content in the mMBSR-C program.
Formal Meditation Practices

- Sitting Meditation
- Body Scan
- Yoga Posture
- Walking Meditation

A PREEMINENT RESEARCH UNIVERSITY
Informal techniques of mindfulness into daily activities include integrating mindfulness and attention into routine work and home activities.

An example of this practice is rather than ruminating over something unpleasant (i.e. feeling pain or fear of recurrence), one focuses attention on the breath and the current activity, i.e. eating, housework, work in office.

Subsequently, one then becomes immersed in this task, and calmness occurs. This technique is referred to as “living in the moment.”
### Table 1.D. Caregiver’s Response to Self-Report Interview Questions

<table>
<thead>
<tr>
<th>Caregiver Response</th>
<th>Benefits of Participating in a Mobile MBSR program for Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Less stress</td>
</tr>
<tr>
<td>2</td>
<td>Lower anxiety</td>
</tr>
<tr>
<td>3</td>
<td>Less dwelling/ Ruminating on the circumstances</td>
</tr>
<tr>
<td>4</td>
<td>Sense of well-being</td>
</tr>
<tr>
<td>5</td>
<td>Being more “present”</td>
</tr>
<tr>
<td>6</td>
<td>Ability to process circumstances</td>
</tr>
<tr>
<td>7</td>
<td>Improved overall health</td>
</tr>
</tbody>
</table>

**Composed of 7 Caregivers**
- Lung Cancer: 2
- Breast Cancer: 3
- Colon Cancer: 2
Table 1.E. Caregiver’s Response to Self-Report Interview Questions

<table>
<thead>
<tr>
<th>Questions Asked</th>
<th>Caregivers’ Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Would you attend the Mobile MBSR program for Caregivers?</td>
<td>Out of 7 caregivers, 7 said yes they would attend</td>
</tr>
<tr>
<td>How often could you participate in the Mobile MBSR program?</td>
<td>Out of 7 caregivers, 6 stated they would attend weekly if delivered via iPad/mobile device.</td>
</tr>
<tr>
<td>Any suggestions for additions to the Mobile MBSR program for Caregivers?</td>
<td>2 caregivers suggested adding content on sleep hygiene.</td>
</tr>
</tbody>
</table>
Feedback from interviews suggest the following areas are the most important considerations in the design of an effective caregiver intervention, to improve:

• Overall Quality of Life,
• Depression, Anxiety, and Stress,
• Pain, Fatigue, and Sleep.
Caregivers agreed that the design of the intervention needs to include:

- mobile delivery of the mMBSR-C program, making it more accessible than a traditional program, considering time demands of the caregiver.
Caregiver perspectives are vital to inform the design of effective, self-management alternative therapy interventions related to:

- Patient symptoms,
- Difficulties experienced during patient treatments,
- Ways to improve coping.
Acknowledgements

Co-Authors:

Paula Cairns, PhD, RN
Andrew Bugajski, PhD, RN
Victoria Marshall, PhD, RN
Trudy Wittenberg, BS, CIP
References


Questions?
Oral Anticancer Agents: Presenting New Challenges for Family Caregivers of Patients with Cancer

Victoria Marshall, PhD, RN
Paula Cairns, PhD, RN
Cecile A. Lengacher, PhD, RN, FAAN, FAPOS
Andrew Bugajski, PhD, RN
**Acknowledgements**

- **Co-authors**
  - Paula Cairns, PhD, RN
  - Andrew Bugajski, PhD, RN
  - Cecile Lengacher, PhD, RN, FAAN, FAPOS

- **Mentor**
  - Dr. Barbara Given, PhD, RN, FAAN
Introduction

• Use of oral anticancer agents (OAAs) is increasing.\textsuperscript{1}

• OAAs now account for over half of the new cancer treatments approved by the Food and Drug Administration.\textsuperscript{1}

• Convenience of OAAs is apparent.\textsuperscript{2-4}

• However, new challenges are evident as the responsibility cancer care shifts from oncology clinics to patients and family caregivers.\textsuperscript{2,5}
Purpose

• To describe the current challenges for family caregivers of patients receiving OAAs and propose strategies for clinicians to support both patients and their family caregivers for safe care in the home environment.
Methods

- Focus group methodology\(^2\)
- An extensive review of the literature specific to caregiving and OAA were completed.
Methods: Focus Group Study

• Inclusion criteria:
  – family caregivers of patients with cancer who were prescribed an OAA
  – English speaking
  – Age 21 years or older
  – Able to hear/verbally communicate

• Recruitment:
  – Three oncology clinics in the Midwest

• Procedures:
  – Audio recorded
  – Transcribed verbatim
Methods: Focus Group Study

• Analysis:
  – Constant comparative analysis was used to evaluate data.\(^6\)
  – Independent data analysis was carried out by two nurse researchers
  – Discrepancies were discussed until an agreement was met, using a third nurse researcher as necessary.
Methods: Literature Review

- Literature obtained from PubMed, CINAHL, Medline, PsychINFO, and EMBASE

- Criteria:
  - Published between 1999 and 2018
  - Included studies of adults 18 years of age or older
  - Search terms included caregiver, oral cancer medication, oral antineoplastic, oral anticancer*, oral chemotherapy, and oral targeted agents.
Results

• Six main caregiver challenges were noted:
  – 1) overseeing the preparation, administration, and adherence of complex OAA regimens
  – 2) managing symptoms, side effects, and drug-drug or food-drug interactions
  – 3) safety concerns related to potential toxic exposure to OAAs during medication preparation and administration and from bodily fluids of the patient
Results

• Six main caregiver challenges cont’d:
  – 4) financial concerns specific to OAAs
  – 5) managing the treatment trajectory of OAAs including temporary and/or permanent interruptions to treatment
  – 6) lack of standardized OAA safety education for family caregivers during the course of treatment
Implications for Practice

- Interdisciplinary oncology professionals must advocate for the development of standardized OAA safety checklists education for family.
- Responsibility of patient and family safety related to OAAs in the home setting should remain within the collaborative efforts of the oncology healthcare team (e.g., nurses, pharmacists, and physicians).
Implications for Practice

• Family caregiver needs should be assessed upon initiation of prescribed OAAs and throughout the treatment trajectory with OAAs to ensure safe patient care in the home
  – Follow-up telephone calls/text messages
  – Emails
  – Face to face conversations during pharmacy/oncology clinic visits using standardized OAA safety checklists to ensure proper handling, administration, adherence, and monitoring of symptoms and side effects of the OAA
Recommendations for Oncology Nurses Providing Support to Caregivers

- Drug Safety Risks
- Complex Treatment Regimen & Adherence
- Symptom Management
- Financial Burden
- Coping Support Along Treatment Trajectory
- Standardized OAA Education for Caregivers
## Resources for Oncology Nurses Providing Support to Caregivers

<table>
<thead>
<tr>
<th>Resource</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Cancer Institute(^{6-8})</td>
<td>• Steps to prevent/manage cancer and treatment related side effects</td>
</tr>
<tr>
<td></td>
<td>• Dealing with being a caregiver</td>
</tr>
<tr>
<td></td>
<td>• Taking care of yourself as a caregiver</td>
</tr>
<tr>
<td></td>
<td>• Long-distance caregiving</td>
</tr>
<tr>
<td></td>
<td>• Caregiving in advanced cancer</td>
</tr>
<tr>
<td></td>
<td>• Education and information</td>
</tr>
<tr>
<td></td>
<td>• Coping skills</td>
</tr>
<tr>
<td></td>
<td>• Counseling</td>
</tr>
<tr>
<td></td>
<td>• Conducting family meetings</td>
</tr>
<tr>
<td></td>
<td>• Home care help</td>
</tr>
<tr>
<td></td>
<td>• Hospice care for the cancer patient</td>
</tr>
</tbody>
</table>
### Resources for Oncology Nurses Providing Support to Caregivers

<table>
<thead>
<tr>
<th>Resource</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>American Society of Clinical Oncology: Updated 2016 Chemotherapy Safety</td>
<td>• Education program to support nurses in delivering what patients need to</td>
</tr>
<tr>
<td>Standards</td>
<td>know about oral chemotherapy.</td>
</tr>
<tr>
<td>The American Cancer Society Caregiver Resource Guide</td>
<td>• Tool for people caring for someone with cancer</td>
</tr>
<tr>
<td>Oncology Nursing Society: ONS Center for Advocacy and Health Policy</td>
<td>• Offers nurses information about how to support oncology health-</td>
</tr>
<tr>
<td></td>
<td>related policy efforts (e.g. improved payment models and improving patient/</td>
</tr>
<tr>
<td></td>
<td>caregiver education) including lobbying and meeting with Congress.</td>
</tr>
</tbody>
</table>
## Resources for Oncology Nurses
Providing Support to Caregivers

<table>
<thead>
<tr>
<th>Resource</th>
<th>Description</th>
</tr>
</thead>
</table>
| Oncology Nursing Society: Oral Adherence Toolkit¹² | • Ability to obtain and administer OOT  
• Drug safety education  
• Benefits/concerns  
• Financial resources  
• Food, drug interactions  
• Sample treatment calendars  
• Factors and methods influencing adherence  
• Medication reconciliation and tracking  
• Patient and provider resource list |
Conclusion

• Family caregivers of patients receiving OAAs, have unmet needs that may negatively impact both patient and caregiver outcomes.

• Oncology Health Care Providers can promote strategies to support both patients and their family caregivers for safe cancer care in the home environment.
Questions?
Caregiver Presence and Self-Management Ability Predict Perceived Self-Management Adherence in Patients with COPD

Andrew Bugajski, PhD, RN
Lakeshia Cousin, MS, APRN-BC
Allyson R. Duffy, PhD, MSN, RN
Victoria K. Marshall, PhD, RN
Cecile A. Lengacher, PhD, RN, FAAN, FAPOS
Paula Cairns, PhD, RN
• Chronic obstructive pulmonary disease (COPD) affects up to 48 million people in the US and 251 million around the world.
• ≈ 80% can reduce disease burden and prevent adverse health outcomes by optimizing self-management behaviors.
• Self-management behaviors can be categorized under: medication adherence, exacerbation detection, breathing control, diet, physical activity, mental well-being and environment modification.
Adherence in COPD

- Adherence mostly speaks to medication adherence
- Adherence is estimated to be 20%-42% in people with COPD.

Caregivers in COPD

- >70% have a caregiver
- Spouse or live-in family
  - Activities of Daily Living, shopping, housework and personal care
- Caregiver assistance is associated with fewer hospitalizations, better medication adherence and smoking cessation
Purpose

• To examine if caregiver presence is predictive of perceived self-management adherence in patients with stable COPD.

  – Rationale: Understanding the effects of caregiver presence on perceived self-management adherence is critical to developing effective treatment strategies for patients with COPD.
Methods

- Secondary data analysis of 20 patients with COPD.
- Participated in a digital self-management intervention using a interrupted time-series design.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Total Sample (n = 20)</th>
</tr>
</thead>
<tbody>
<tr>
<td>GOLD Stage</td>
<td></td>
</tr>
<tr>
<td>II</td>
<td>9 (45%)</td>
</tr>
<tr>
<td>III</td>
<td>5 (25%)</td>
</tr>
<tr>
<td>IV</td>
<td>6 (30%)</td>
</tr>
<tr>
<td>BMI in kg/m²</td>
<td>30.2 ± 7.6</td>
</tr>
<tr>
<td>Number of Comorbidities</td>
<td>6.6 ± 4.6</td>
</tr>
<tr>
<td>Number of Exacerbations in Previous Year</td>
<td>1.5 ± 1.2</td>
</tr>
<tr>
<td>Number of Medications Prescribed</td>
<td>12.9 ± 6.6</td>
</tr>
<tr>
<td>FEV₁</td>
<td>1.17 ± .43</td>
</tr>
<tr>
<td>% predicted FEV₁</td>
<td>43 ± 14.9</td>
</tr>
<tr>
<td>FVC</td>
<td>2.5 ± .73</td>
</tr>
<tr>
<td>FEV₁/FVC</td>
<td>48 ± 13.4</td>
</tr>
</tbody>
</table>
3-week intervention period that targeted:

• Diet/Nutrition
• Physical activity and exercise
• Medications
• Breathing control
• Mental health
• Environment
• Exacerbation planning
Measures

- Perceived self-management ability via the Self-management ability scale, short version
- Perceived self-management adherence via an adapted Medical Outcome Study Specific Adherence Scale
  - Encompasses questions on medications, exacerbation detection, breathing control, diet, physical activity, mental well-being and environment modification
- Caregiver Presence; Yes/No via Patient Interviews
Statistical Analysis

- A multiple regression was used to examine the relationship between caregiver presence and perceived self-management adherence, with and without controlling age, gender, perceived self-management ability, and presence of a caregiver.

- Bootstrapping was conducted to generate robust bias corrected accelerated 95% confidence intervals for each predictor. Assumptions were met prior to bootstrapping.
<table>
<thead>
<tr>
<th></th>
<th>b</th>
<th>SE B</th>
<th>β</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>60.58</td>
<td>31.02</td>
<td></td>
<td>p = .033</td>
</tr>
<tr>
<td></td>
<td>(11.43, 119.21)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-Management Ability</td>
<td>0.52</td>
<td>0.19</td>
<td>.60</td>
<td>p = .004</td>
</tr>
<tr>
<td></td>
<td>(0.08, 1.03)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver Presence [yes]</td>
<td>-14.75</td>
<td>3.99</td>
<td>-.59</td>
<td>p = .007</td>
</tr>
<tr>
<td></td>
<td>(-21.59, -6.68)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>-0.22</td>
<td>0.35</td>
<td>-.12</td>
<td>p = .474</td>
</tr>
<tr>
<td></td>
<td>(-0.96, 0.60)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Biological Sex</td>
<td>1.36</td>
<td>5.52</td>
<td>.05</td>
<td>p = .791</td>
</tr>
<tr>
<td></td>
<td>(-8.86, 9.25)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Linear model of predictors of perceived self-management adherence, with 95% bias corrected and accelerated confidence intervals reported in parentheses. Confidence intervals and standard errors are based on 1000 bootstrap samples.
• Self-management ability predicts perceived self-management adherence:
  – $b = .52 \ [0.08, 1.03], \ p = .004$
  – This is an expected finding.

• Caregiver presence is inversely related to perceived self-management adherence:
  – $b = -14.75 \ [-21.59, -6.68], \ p = .007$
  – This is not consistent with current evidence in the literature.
• It is essential for patients with COPD to be adherent to complex medical and behavioral regimens to maintain optimal health.

• Surprisingly, in this small sample, we found caregiver presence was associated with decreased perceived self-management adherence in the patients with COPD.
Most measures of adherence do not encompass multifaceted behavioral regimens (diet, exercise, mental well-being, breathing control, medications, environment modification and exacerbation planning).

Decreased perceived self-management adherence scores may indicate a shift in the management or completion of tasks by the caregiver. Presence of a caregiver could also reflect an increased acuity level of the patient with COPD, who is lacking in ability to independently self-manage adherence to treatment regimens.
• Clearly more research is needed
  – Need to focus on other behavioral indicators of adherence instead of medications and smoking cessation
• This is currently an aspect in my team’s:
  – NIH R01 grant proposal as a planned data analysis
  – Local study of self-management behaviors
Questions?