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Family Caregivers: Presence, Perspectives, Challenges, and Health

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Learner Objectives

(**Disclosures**: We have no financial disclosures to report.)

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.

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Examination of Stress and Sleep on Family Caregiver Health in the ICU

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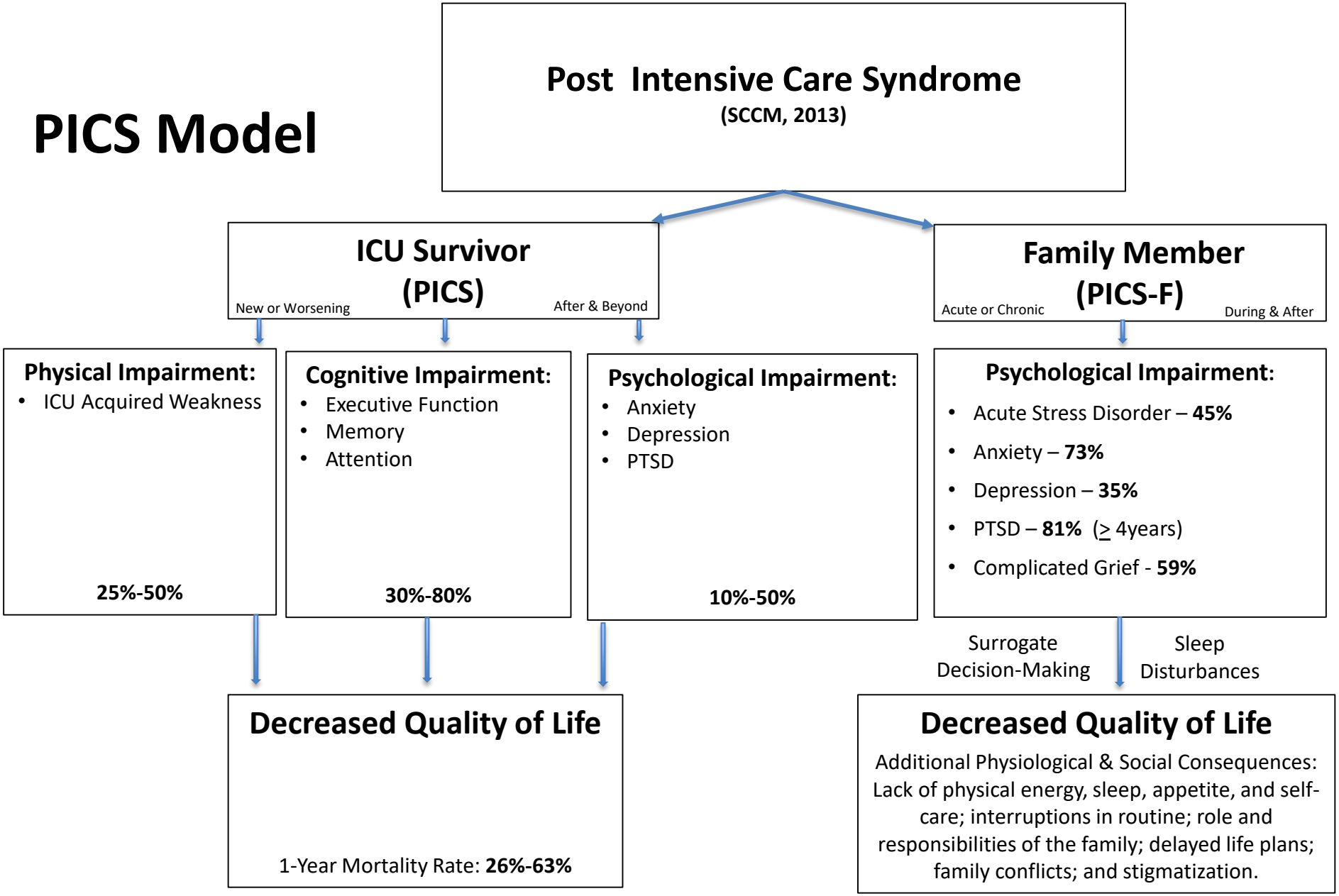
PICS Model



(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.

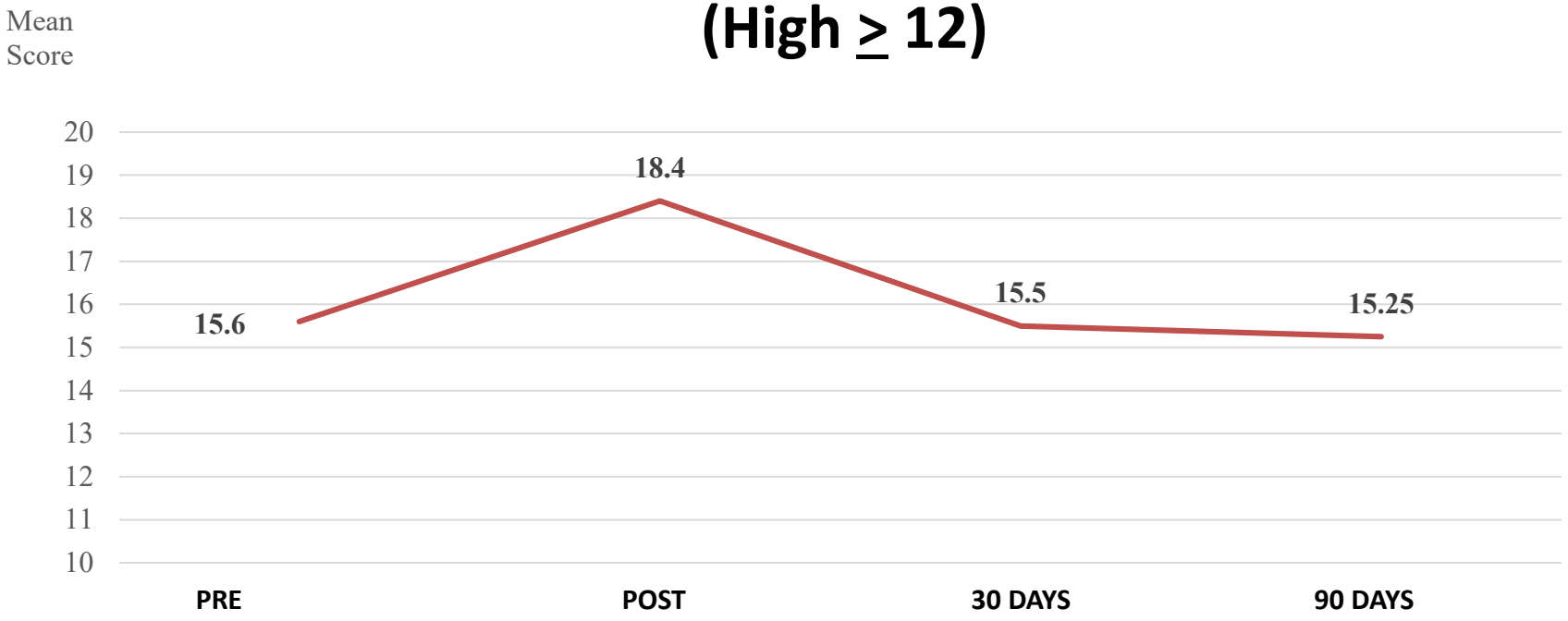
Results

Table 1. Demographic Characteristics

Characteristics	(n=5)
Race n (%):	
White	5 (100.0)
Ethnicity n (%):	
Non-Hispanic	3 (60.0)
Hispanic	2 (40.0)
Sex n (%):	
Male	1 (20.0)
Female	4 (80.0)
Age in years, mean (SD)	50.8 (9.5)

Results

Rate of Change in Perceived Stress
(High ≥ 12)

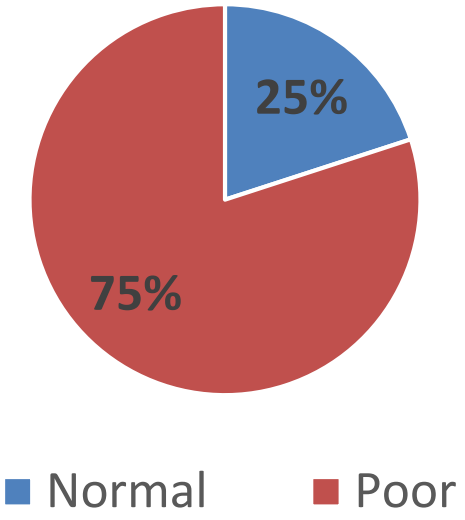


Results

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%**



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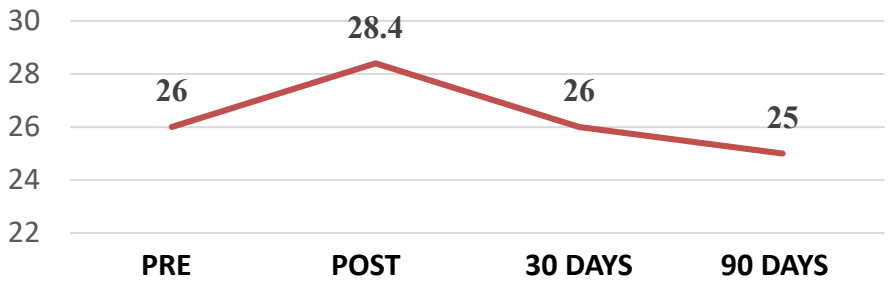
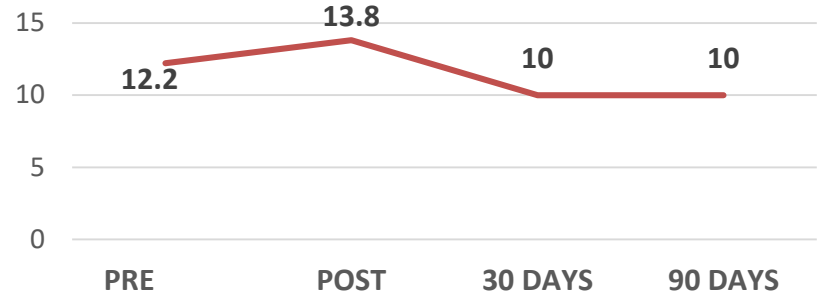
Results

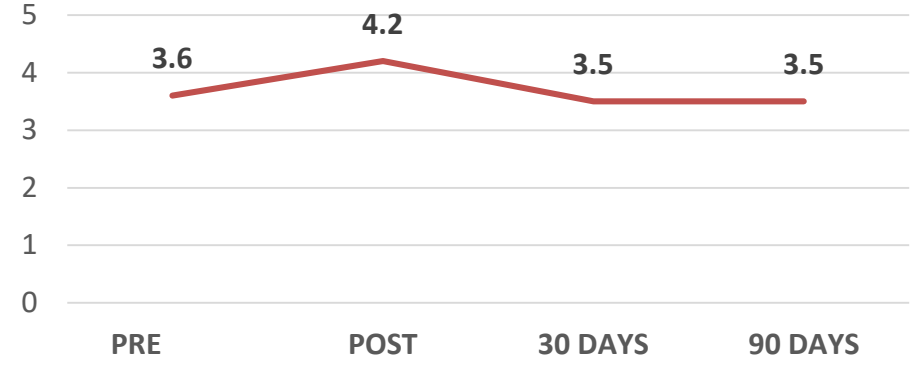
ACUTE STRESS
(High ≥ 25)



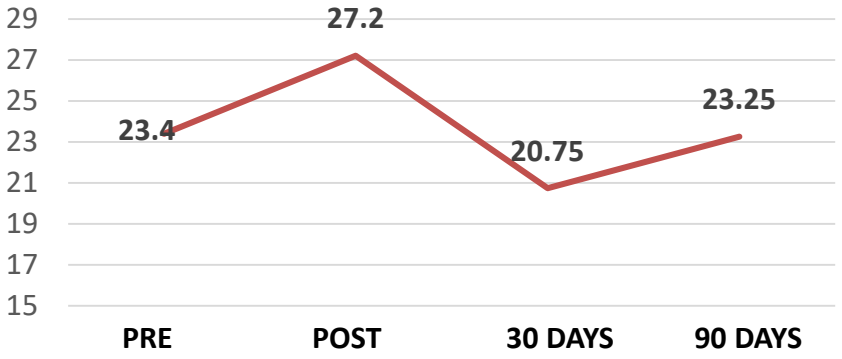
ANXIETY
(High ≥ 7)



DEPRESSION
(High ≥ 12)



PTSD
(High ≥ 9)



Conclusions

- Stress, depressive symptoms, and sleep disorders are the most frequent negative influences on caregiver health.[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.[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).

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References

1. Society of Critical Care Medicine. (2015). Critical care statistics. Retrieved from http://www.sccm.org/Communications/Pages/CriticalCareStats.aspx

2. Society of Critical Care Medicine. (2013). Post intensive care syndrome: Improving the future of ICU patients. Retrieved from http://www.sccm.org/SiteCollectionDocuments/CC-Iwahyna-June-2013.pdf

3. Davidson, J. E., Jones, C., & Bienvenu, O. J. (2012). Family response to critical illness: Postintensive care syndrome-family. *Critical Care Medicine, 40*(2), 618-624. doi:10.1097/CCM.0b013e318236ebf9

4. Desai, S. V., Law, T. J., & Needham, D. M. (2011). Long-term complications of critical care. *Critical Care Medicine, 39*, 371–379. doi:10.1097/CCM.0b013e3181fd66e5

5. Harvey, M. A., & Davidson, J. (2011). Long-term consequences of critical illness: A new opportunity for high-impact critical care nurses. *Critical Care Nurse, 31*, 12–15. doi:10.4037/ccn2011597

6. Meert, K. L., Shear, K., Newth, C. J. L., Harrison, R., Berger, J., Zimmerman, J., . . . The Eunice Kennedy Shriver National Institute of Child Health and Human Development Collaborative Pediatric Critical Care Research Network (2011). Follow-up study of complicated grief among parents eighteen months after a child's death in the pediatric intensive care unit. *Journal of Palliative Medicine, 14*(2), 207-214. doi:10.1089/jpm.2010.0291

7. Needham, D. M., Davidson, J., Cohen, H., Hopkins, R. O., Weinert, C., Wunsch, H., . . .Harvey, M. A. (2012). Improving long-term outcomes after discharge from intensive care unit: Report from a stakeholders' conference. *Critical Care Medicine, 40*, 502–509. doi:10.1097/CCM.0b013e318232da75

8. Pochard, F., Darmon, M., Fassier, T., Bollaert, P., Cheval, C., Coloigner, . . .The French FAMIREA Study Group (2005). Symptoms of anxiety and depression in family members of intensive care unit patients before discharge or death: A prospective multicenter study. *Journal of Critical Care, 20*, 90–96. doi:10.1016/j.jcrc.2004.11.004

9. Wolters, A., Bouw, M., Vogelaar, J., Tjan, D., van Zanten, A., & vander Steen, M. (2014). The post intensive care syndrome of survivors of critical illness and their families. *Journal of Clinical Nursing, 24*, 876–879. doi:10.1111/jocn.12678

10. Anderson, W. G., Arnold, R. M., Angus, D. C., Bryce, C. L. (2009). Passive decision-making preference is associated with anxiety and depression in relatives of patients in the intensive care unit. *Journal of Critical Care, 24*, 249–254. doi:10.1016/j.jcrc.2007.12.010

11. Azoulay, E., Pochard, F., Kentish-Barnes, N., Chevret, S., Aboab, J., Adrie, C., . . .Schlemmer, B. (2005). Risk of post-traumatic stress symptoms in family members of intensive care unit patients. *American Journal of Respiratory Critical Care Medicine, 171*(9), 987-994. doi:10.1164/rccm.200409-1295OC

12. Gries, C. J., Engelberg, R. A., Kross, E. K., Zatick, D., Nielsen, E. L., Downey, L., Curtis, J. R. (2010). Predictors of symptoms of posttraumatic stress and depression in family members after patient death in the ICU. *CHEST, 137*(2), 280-287. doi:10.1378/chest.091291

13. Heyland, D. K., Cook, D. J., Rocker, G. M., Dodek, P. M., Kutsogiannis, D. J., Peters, S., Tranmer, J. E., O'Callaghan, C. J. (2003). Decision-making in the ICU: Perspectives of the substitute decision-maker. *Intensive Care Medicine, 29*, 75–82. doi:10.1007/s00134-002-1569-y

14. Kentish-Barnes, N., Lemiale, V., Chaize, M., Pochard, F., Azoulay, E. (2009). Assessing burden in families of critical care patients. *Critical Care Medicine,* 37, S448-456. doi:10.1097/CCM.0b013e3181b6e145

15. Kross, E. K., Engelberg, R. A., Gries, C. J., Nielsen, E. L., Zatzick, D., Curtis, J. R. (2011). ICU care associated with symptoms of depression and posttraumatic stress disorder among family members of patients who die in the ICU. *CHEST, 139*(4), 795–801. doi:10.1378/chest.10-0652

16. Lefkowitz, D. S., Baxt, C., Evans, J. R. (2010). Prevalence and correlates of posttraumatic stress and postpartum depression in parents of infants in the neonatal intensive care unit (NICU). *Journal of Clinical Psychology, 17*, 230–237. doi:10.1007/s10880-010-9202-7

17. Miles, M. S., Holditch-Davis, D., Schwartz, T. A., Scher, M. (2007). Depressive symptoms in mothers of prematurely born infants. *Journal of Developmental & Behavioral Pediatrics*, *28*, 36–44. doi:10.1097/01.DBP.0000257517.52459.7a

18. Siegel, M. D., Hayes, E., Vanderwerker, L. C., Loseth, D. B., Prigerson, H. G. (2008). Psychiatric illness in the next of kin of patients who die in the intensive care unit. *Critical Care Medicine, 36*, 1722–1728. doi:10.1097/CCM.0b013e318174da72

19. Davidson, J. E., Aslakson, R. A., Long, A. C., Puntillo, K. A., Kross, E. K., Hart, J., . . .Randall, J. (2017). Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. *Critical Care Medicine, 459*(1), 103-128. doi:10.1097/CCM.0000000000002169

20. Netzer, G., & Sullivan, D. R. (2014). Recognizing, naming, and measuring a family intensive care unit syndrome. *Annals of American Thoracic Society, 11*(3), 435-441. doi:10.1513/AnnalsATS.201309-308OT

21. Verceles, A. C., Corwin, D. S., Afshar, M., Friedman, E. B., McCurdy, M. T., Shanholtz, C., . . .Netzer, G. (2014). Half of the family members of critically ill patients experience excessive daytime sleepiness. *Intensive Care Medicine, 40*(8), 1124-1131. doi:10.1007/s00134-014-3347-z

22. Cohen, S., Kamarck, T., & Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior, 24,* 386-396. PMID:6668417

23. Gironda, R. J., Lloyd, J., Clark, M. E., & Walker, R. L. (2007). Preliminary evaluation of reliability and criterion validity of Actiwatch-Score. *Journal of Rehabilitation Research Development, 44*(2), 223-230. PMID:17551874

24. Tonetti, L., Pasquini, F., Fabbri, M., Belluzzi, M., & Natale, V. (2008). Comparison of two different actigraphs with polysomnography in healthy young subjects. *Chronobiology International, 25*(1), 145-153. doi:10.1080/07420520801897228

25. Salsman, J. M., Butt, Z., Pilkonis, P. A., Cyranowski, J. M., Zill, N., Hendrie, H. C., . . . Cella, D. (2013). Emotion assessment using the NIH toolbox. *Neurology, 80*, S76–S86. doi:10.1212/WNL.0b013e3182872e11

26. Family Caregiver Alliance. *Caregiving and depression.* Available at https://www.caregiver.org/depression-and-caregiving

27. NIA. 2011. "National Health and Aging Trends Study: 2011." Report from the National Institutes of Aging. Available at https://www.nhats.org/

Questions?

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

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- 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%.** [7]

- 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]

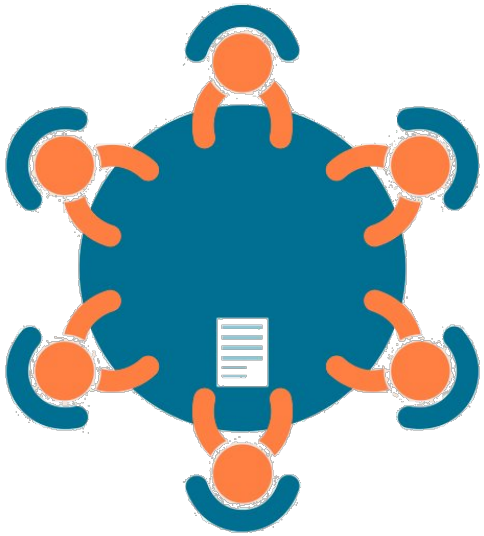
- Poor QOL is associated with
  - Caregiver burden and
    - Deterioration in psychological well-being, [10]
  - Worse mental health,
    - Being female and number hours of caregiving.[11]

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

Moffitt Cancer Center

NCI Cancer Center in the Southeast



- 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 1.A. Caregiver's Response to Self- Report Interview Questions

Caregiver Response	Symptoms or problems of the patient that are found to be most bothersome for the caregiver
1	Pain
2	Poor Sleep Quality
3	Fatigue
4	Exhaustion
5	Anxiety
6	Unexpected Symptoms, (diarrhea)
7	Unexplained Symptoms, (not being comfortable)

Composed of **7** Caregivers

- Lung Cancer: 2
- Breast Cancer: 3
- Colon Cancer: 2

Table 1.B. Caregiver's Response to Self- Report Interview Questions

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

Composed of **7** Caregivers

- Lung Cancer: 2
- Breast Cancer: 3
- Colon Cancer: 2

Table 1.C. Caregiver's Response to Self- Report Interview Questions

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

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.

Body Scan

Walking Meditation

Sitting Meditation

Yoga Posture

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."**

Composed of **7** Caregivers

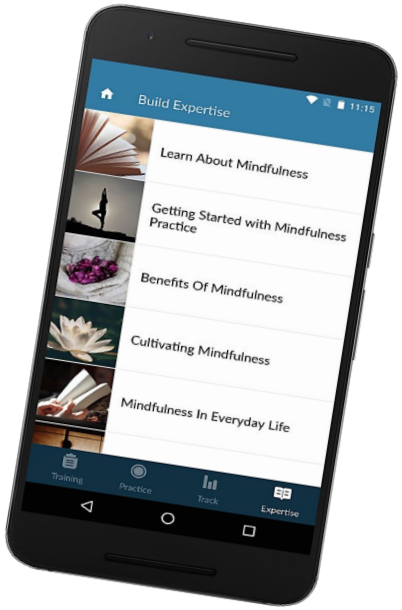
- Lung Cancer: 2
- Breast Cancer: 3
- Colon Cancer: 2

Table 1.D. Caregiver's Response to Self- Report Interview Questions

Caregiver Response	Benefits of Participating in a Mobile MBSR program for Caregivers
1	Less stress
2	Lower anxiety
3	Less dwelling/ Ruminating on the circumstances
4	Sense of well-being
5	Being more "present"
6	Ability to process circumstances
7	Improved overall health

Table 1.E. Caregiver's Response to Self- Report Interview Questions	
Questions Asked	**Caregivers' Response**
Would you attend the Mobile MBSR program for Caregivers?	Out of 7 caregivers, 7 said yes they would attend
How often could you participate in the Mobile MBSR program?	Out of 7 caregivers, 6 stated they would attend weekly if delivered via iPad/ mobile device.
Any suggestions for additions to the Mobile MBSR program for Caregivers?	2 caregivers suggested adding content on sleep hygiene.

- 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.

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References

1.National Alliance for Caregiving. *Caregiving in the U.S.*: AARP Public Policy Institute; 2015.

2. Rumpold T, Schur S, Amering M, Kirchheiner K, Masel EK, Watzke H, Schrank B. 2016. Informal carregivers of advanced stage cancer patients: Every second is at risk for psychiatric morbidity. Support Care Cancer. 2016 May;24(5):1975-1982. doi: 10.1007/s00520-015-2987-z. Epub 2015 Oct 17. PMID: 26476628

3. Karabekiroğlu A, Demir EY, Aker S, Kocamanoğlu B, Karabulut GS. Predictors of depression and anxiety among caregivers of hospitalized advanced cancer patients. Singapore Med J. 2018 Jun 7. doi: 10.11622/smedj.2018066. [Epub ahead of print] PMID: 29876580

4. Bevans M, Sternberg EM. Caregiving burden, stress, and health effects among family caregivers of adult cancer patients. *JAMA.* 2012;307(4):398-403.

5. Hagedoorn M, Sanderman R, Bolks HN, Tuinstra J, Coyne JC. Distress in couples coping with cancer: a meta-analysis and critical review of role and gender effects. *Psychol Bull.* 2008;134(1):1-30.

6.. Kim Y, Kashy DA, Spillers RL, Evans TV. Needs assessment of family caregivers of cancer survivors: three cohorts comparison. *Psychooncology.* 2010;19(6):573-582.

7. Palacio C, Krikorian A, Limonero JT. The influence of psychological factors on the burden of caregivers of patients with advanced cancer: Resiliency and caregiver burden. *Palliat Support Care.* 2018;16(3):269-277

8. Swore Fletcher BA, Dodd MJ, Schumacher KL, Miaskowski C. Symptom experience of family caregivers of patients with cancer. *Oncol Nurs Forum.* 2008;35(2):E23-44.

9.. Clark MM, Atherton PJ, Lapid MI, Rausch SM, Frost MH, Cheville AL, et al. Caregivers of patients with cancer fatigue: A high level of symptom burden. *American Journal of Hospice and Palliative Medicine.* 2014;31(2):121-125. doi: 10.1177/1049909113479153. PubMed PMID: 23434836; PubMed Central PMCID: PMC4392763

10. Grant M, Sun V, Fujinami R, et al. Family caregiver burden, skills preparedness, and quality of life in non-small-cell lung cancer. Oncol Nurs Forum. 2013;40(4):337-346.

11. Wadhwa D, Burman D, Swami N, Rodin G, Lo C, Zimmermann C. Quality of life and mental health in caregivers of outpatients with advanced cancer. *Psychooncology.* 2013;22(2):403-410.

Questions?

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

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Introduction

- Use of oral anticancer agents (OAAs) is increasing.[1]
- OAAs now account for over half of the new cancer treatments approved by the Food and Drug Administration.[1]
- Convenience of OAAs is apparent.[2-4]
- However, new challenges are evident as the responsibility cancer care shifts from oncology clinics to patients and family caregivers.[2,5]

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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.

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Methods

- Focus group methodology[2]
- An extensive review of the literature specific to caregiving and OAA were completed.

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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

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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.

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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*.

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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

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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

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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).

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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

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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

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Resources for Oncology Nurses Providing Support to Caregivers

Resource	Description
National Cancer Institute[6-8]	• Steps to prevent/manage cancer and treatment related side effects • Dealing with being a caregiver • Taking care of yourself as a caregiver • Long-distance caregiving • Caregiving in advanced cancer • Education and information • Coping skills • Counseling • Conducting family meetings • Home care help • Hospice care for the cancer patient

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Resources for Oncology Nurses Providing Support to Caregivers

Resource	Description
American Society of Clinical Oncology: Updated 2016 Chemotherapy Safety Standards[9]	• Education program to support nurses in delivering what patients need to know about oral chemotherapy.
The American Cancer Society Caregiver Resource Guide[10]	• Tool for people caring for someone with cancer
Oncology Nursing Society: ONS Center for Advocacy and Health Policy[11]	• Offers nurses information about how to support oncology health-related policy efforts (e.g. improved payment models and improving patient/caregiver education) including lobbying and meeting with Congress.

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Resources for Oncology Nurses Providing Support to Caregivers

Resource	Description
Oncology Nursing Society: Oral Adherence Toolkit[12]	• 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

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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.

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References

1. Center Watch. (2018). FDA approved drugs for oncology. Retrieved from https://www.centerwatch.com/drug-information/ fda-approved-drugs/therapeutic-area/12/oncology

2. Marshall, V. K., Vachon, E. A., Given, B. A., & Lehto, R. H. (2018). Impact of Oral Anticancer Medication From a Family Caregiver Perspective. *Oncology Nursing Forum*, *45*(5), 597-606.

3. PALOMO, A. G., Glogowska, I., Sommer, H., Malamos, N., Kilar, E., VEGA, J. M. L., ... & Finek, J. (2012). Final results of an international retrospective observational study in patients with advanced breast cancer treated with oral vinorelbine-based chemotherapy. *Anticancer Research*, *32*(10), 4539-4545.

4. Wiley, K. (September 2017). What Precautions and Recommendations Are Necessary for Patients Receiving Orla Chemotherapy in the Home? ONS Voice. Retrieved from https://voice.ons.org/news-and-views/what-precautions-and recommendations-are-necessary-for-patients-receiving-oral

5. Siden, R., Kem, R., Ostrenga, A., Nicksy, D., Bernhardt, B., & Bartholomew, J. (2014). Templates of patient brochures for the preparation, administration and safe-handling of oral chemotherapy. *Journal of Oncology Pharmacy Practice*, *20*(3), 217-224.

6. National Cancer Institute. Family caregivers in cancer (PDQ®)–patient version. https://www.cancer.gov/about-cancer/coping/family-friends/family-caregivers-pdq#section/_28. Updated 2014. Accessed January 15, 2019.

7. National Cancer Institute. Support for Caregivers of Cancer Patients. https://www.cancer.gov/about-cancer/coping/caregiver-support. Updated 2017. Accessed January 15, 2019.

8. National Cancer Institute. Side effects of cancer treatment. https://www.cancer.gov/about-cancer/treatment/side-effects. Updated 2018. Accessed January 15, 2019.

9. American Society of Clinical Oncology. Updated 2016 chemotherapy safety standards.

https://www.asco.org/practice-guidelines/quality-guidelines/standards/chemotherapy-safety-standards. Published 2016. Accessed January 15, 2019.

10. Siden, R., Kem, R., Ostrenga, A., Nicksy, D., Bernhardt, B., & Bartholomew, J. (2014). Templates of patient brochures for the preparation, administration and safe-handling of oral chemotherapy. *Journal of Oncology Pharmacy Practice*, *20*(3), 217-224.

11. National Cancer Institute. Family caregivers in cancer (PDQ®)–patient version. https://www.cancer.gov/about-cancer/coping/family-friends/family-caregivers-pdq#section/_28. Updated 2014. Accessed January 15, 2019.

12. National Cancer Institute. Support for Caregivers of Cancer Patients. https://www.cancer.gov/about-cancer/coping/caregiver-support. Updated 2017. Accessed January 15, 2019.

13. National Cancer Institute. Side effects of cancer treatment. https://www.cancer.gov/about-cancer/treatment/side-effects. Updated 2018. Accessed January 15, 2019.

14. American Society of Clinical Oncology. Updated 2016 chemotherapy safety standards.

https://www.asco.org/practice-guidelines/quality-guidelines/standards/chemotherapy-safety-standards. Published 2016. Accessed January 15, 2019.

Questions?

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Caregiver Presence and Self-Management Ability Predict Perceived Self-Management Adherence in Patients with COPD

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Background

- 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

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Adherence in COPD

- Adherence mostly speaks to <u>medication adherence</u>
- 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.

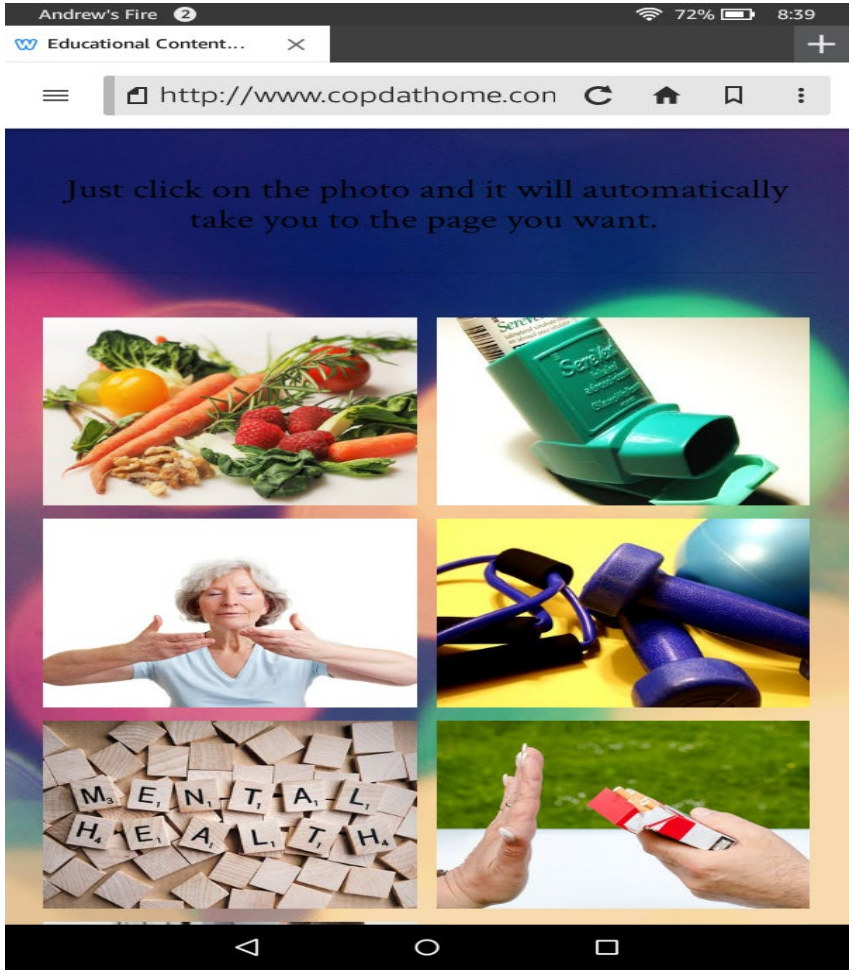
Methods

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

Characteristic	Total Sample (n = 20)
GOLD Stage	
II	9 (45%)
III	5 (25%)
IV	6 (30%)
BMI in kg/m^2	30.2 ± 7.6
Number of Comorbidities	6.6 ± 4.6
Number of Exacerbations in Previous Year	1.5 ± 1.2
Number of Medications Prescribed	12.9 ± 6.6
FEV_1	1.17 ± .43
% predicted FEV_1	43 ± 14.9
FVC	2.5 ± .73
FEV_1/FVC	48 ± 13.4

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.

	b	SE B	β	p
Constant	60.58 (11.43, 119.21)	31.02		p = .033
Self-Management Ability	0.52 (0.08, 1.03)	0.19	.60	p = .004
Caregiver Presence [yes]	-14.75 (-21.59, -6.68)	3.99	-.59	p = .007
Age	-0.22 (-0.96, 0.60)	0.35	-.12	p = .474
Biological Sex	1.36 (-8.86, 9.25)	5.52	.05	p = .791

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?