



Supporting the Science of Informal Cancer Caregiving: Highlights of NCI-Funded Research

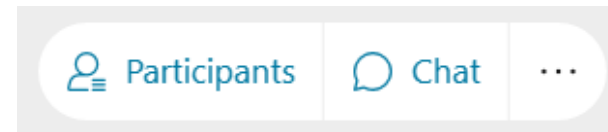
Webinar 4 – Tuesday, April 19, 2022 1 PM ET

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- All lines will be in listen-only mode
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Welcome to Webinar 4



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Webinar Outline

- **Presentation 1: Dr. Mosher**– Telephone Support Program for Adults and Their Family Caregivers Coping with Advanced Gastrointestinal Cancer
- **Presentation 2: Dr. Bradley** – Emotional and Financial Health of Caregivers of Patients with Cancer
- **Presentation 3: Dr. Kim** – A Self-Management Intervention for Lung Cancer Surgery Patients and Family Caregivers
- **Dr. Smith:** Questions and Answers

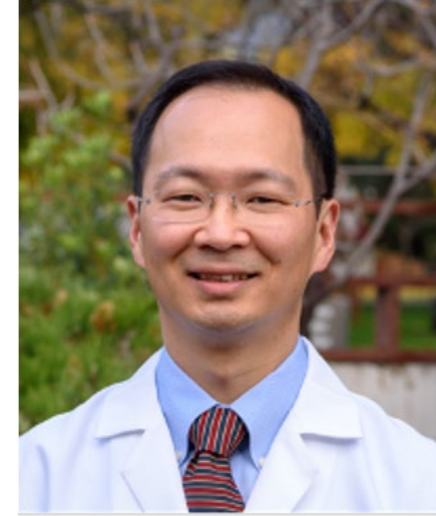
Presenters



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Catherine E. Mosher, PhD

Telephone Support Program for Adults and Their Family
Caregivers Coping with Advanced Gastrointestinal Cancer



Telephone Support Program for Adults and Their Family Caregivers Coping with Advanced Gastrointestinal Cancer

Catherine E. Mosher, Ph.D.

Department of Psychology, Indiana University-Purdue University Indianapolis



Background: Advanced Cancer

- As fatigue interferes with patient functioning, family caregivers face increased demands that impact their quality of life.
- No conclusive evidence regarding effects of medications and behavioral interventions on fatigue in patients with advanced cancer
- Small to medium effects of behavioral interventions on cancer caregivers' burden and quality of life

(Badr & Krebs, 2013; Hanly et al., 2015; Janda et al., 2017; Mucke et al., 2015; Northouse et al., 2010; O'Toole et al., 2017; Poort et al., 2017; Vardy et al., 2014; Walling et al., 2015)



Background: Acceptance and Commitment Therapy (ACT)



Aims to increase mindful awareness of present experiences and the pursuit of activities consistent with personal values.



In pilot trials, showed promise in improving functional outcomes and quality of life in patients with cancer.



Has rarely been tested in caregivers of adults with chronic illness.

(Arch et al., 2020; Han et al., 2020; Hayes et al., 2012; Li et al., 2021; Mosher et al., 2018; Rost et al., 2012)



Study Aims

1.

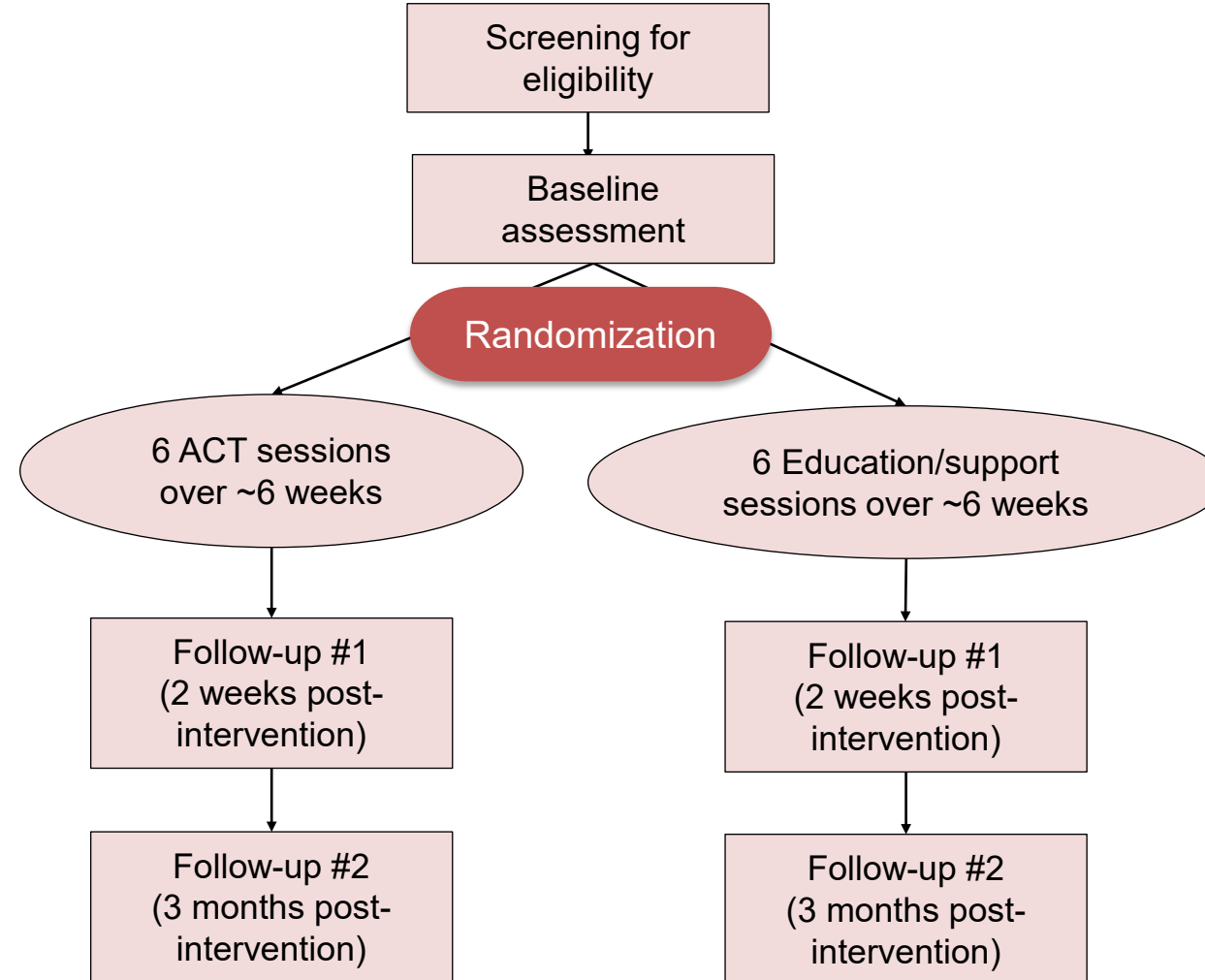
—
Evaluate the feasibility and acceptability of delivering telephone-based ACT to patients with advanced gastrointestinal cancer and their family caregivers.

2.

—
Test the effects of telephone-based ACT on patient fatigue interference and caregiver burden (primary outcomes) and patient and caregiver quality of life (secondary outcomes).
Hypothesis: ACT will lead to improved primary and secondary outcomes as compared to education/support.



Study Flow



Intervention Components

Acceptance and Commitment Therapy	Education/Support
<ul style="list-style-type: none">• Mindfulness exercises	<ul style="list-style-type: none">• Orientation to their medical center and treatment team
<ul style="list-style-type: none">• Goal-setting aligned with personal values	<ul style="list-style-type: none">• Discussion of quality-of-life concerns and resources
<ul style="list-style-type: none">• Learning adaptive coping skills (e.g., acceptance, perspective-taking)	<ul style="list-style-type: none">• Tips for evaluating health information



Feasibility and Acceptability

Feasibility:

- 54% eligibility screening rate for reached patients (96% for caregivers)
- 100% of eligible patients and caregivers consented
- 81% retention at 2 weeks and 73% retention at 3 months post-intervention

Acceptability: High helpfulness ratings for ACT

- Patient mean = 4.17/5.00, SD = .87
- Caregiver mean = 4.41/5.00, SD = .59



Mean Changes and Effect Sizes for Patient Outcomes

(Ns = 29-32)

Outcome	ACT		Education/Support		
	Mean change	Within-group ES	Mean change	Within-group ES	Between-group ES
Fatigue interference					
Baseline to 2 weeks	-4.29	-0.46	-0.67	-0.05	-0.32
Baseline to 3 months	-2.86	-0.31	3.67	0.30	-0.60
Physical quality of life					
Baseline to 2 weeks	3.14	0.71	0.61	0.11	0.49
Baseline to 3 months	-1.07	-0.18	-1.47	-0.22	0.06
Mental quality of life					
Baseline to 2 weeks	2.79	0.32	1.83	0.35	0.14
Baseline to 3 months	3.71	0.49	-1.20	-0.14	0.62

ACT = acceptance and commitment therapy. ES = effect size.



Mean Changes and Effect Sizes for Caregiver Outcomes (*Ns* = 29-32)

Outcome	ACT		Education/Support		
	Mean change	Within-group <i>ES</i>	Mean change	Within-group <i>ES</i>	Between-group <i>ES</i>
Caregiver burden					
Baseline to 2 weeks	-2.27	-0.74	-1.44	-0.24	-0.17
Baseline to 3 months	-1.36	-0.26	-0.20	-0.03	-0.18
Physical quality of life					
Baseline to 2 weeks	1.83	0.46	0.56	0.11	0.27
Baseline to 3 months	2.12	0.49	0.03	0.01	0.41
Mental quality of life					
Baseline to 2 weeks	2.85	0.47	0.97	0.25	0.37
Baseline to 3 months	2.08	0.33	1.35	0.29	0.13

ACT = acceptance and commitment therapy. *ES* = effect size.



Discussion

1. **Feasibility:** Enrollment and retention rates were above average compared to prior trials with cancer patient-caregiver dyads.
2. **Acceptability:** Average helpfulness ratings for ACT were high.
3. **Promise:** Effect sizes suggest that ACT shows promise in improving patient and caregiver functional and quality-of-life outcomes.

(Song et al., 2021)



Future Directions

- Large-scale efficacy trials of acceptance and commitment therapy for patients and caregivers coping with advanced cancer.

If found to be efficacious, ACT could be disseminated to clinicians and fulfill an unmet need in the comprehensive care of this population.



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References

Arch JJ, Fishbein JN, Ferris MC, Mitchell JL, Levin ME, Slivjak ET, Andorsky DJ, Kutner JS. Acceptability, feasibility, and efficacy potential of a multimodal acceptance and commitment therapy intervention to address psychosocial and advance care planning needs among anxious and depressed adults with metastatic cancer. *J Palliat Med.* 2020;23(10):1380-5.

Badr H, Krebs P. A systematic review and meta-analysis of psychosocial interventions for couples coping with cancer. *Psychooncology.* 2013;22(8):1688-704.

Han A, Yuen HK, Jenkins J. Acceptance and commitment therapy for family caregivers: A systematic review and meta-analysis. *J Health Psychol.* 2020;26(1):82-102.

Hanly P, Maguire R, Hyland P, Sharp L. Examining the role of subjective and objective burden in carer health-related quality of life: the case of colorectal cancer. *Support Care Cancer.* 2015;23(7):1941-9.

Hayes SC, Strosahl KD, Wilson KG. *Acceptance and Commitment Therapy, second edition: The process and practice of mindful change.* New York: Guilford Press; 2012.



References

Janda M, Neale RE, Klein K, O'Connell DL, Gooden H, Goldstein D, Merrett ND, Wyld DK, Rowlands IJ, Beesley VL. Anxiety, depression and quality of life in people with pancreatic cancer and their carers. *Pancreatology*. 2017;17(2):321-7.

Li H, Wong CL, Jin X, Chen J, Chong YY, Bai Y. Effects of Acceptance and Commitment Therapy on health-related outcomes for patients with advanced cancer: A systematic review. *Int J Nurs Stud*. 2021;115:103876.

Mosher CE, Secinti E, Li R, Hirsh AT, Bricker J, Miller KD, Schneider B, Storniolo AM, Mina L, Newton EV, Champion VL, Johns SA. Acceptance and commitment therapy for symptom interference in metastatic breast cancer patients: a pilot randomized trial. *Support Care Cancer*. 2018;26(6):1993-2004.

Mucke M, Cuhls H, Peuckmann-Post V, Minton O, Stone P, Radbruch L. Pharmacological treatments for fatigue associated with palliative care. *Cochrane Database Syst Rev*. 2015(5):CD006788.

Northouse LL, Katapodi MC, Song L, Zhang L, Mood DW. Interventions with family caregivers of cancer patients: meta-analysis of randomized trials. *CA Cancer J Clin*. 2010;60(5):317-39.



References

O'Toole MS, Zachariae R, Renna ME, Mennin DS, Applebaum A. Cognitive behavioral therapies for informal caregivers of patients with cancer and cancer survivors: a systematic review and meta-analysis. *Psychooncology*. 2017;26(4):428-37.

Poort H, Peters M, Bleijenberg G, Gielissen MF, Goedendorp MM, Jacobsen P, Verhagen S, Knoop H. Psychosocial interventions for fatigue during cancer treatment with palliative intent. *Cochrane Database Syst Rev*. 2017;7:Cd012030.

Rost AD, Wilson K, Buchanan E, Hildebrandt MJ, Mutch D. Improving psychological adjustment among late-stage ovarian cancer patients: Examining the role of avoidance in treatment. *Cogn Behav Pract*. 2012;19(4):508-17.

Song L, Qan'ir Y, Guan T, Guo P, Xu S, Jung A, Idiagbonya E, Song F, Kent EE. The challenges of enrollment and retention: A systematic review of psychosocial behavioral interventions for patients with cancer and their family caregivers. *J Pain Symptom Manage*. 2021;62(3):e279-e304.

Vardy J, Dhillon HM, Pond GR, Rourke SB, Xu W, Dodd A, Renton C, Park A, Bekele T, Ringash J, Zhang H, Burkes R, Clarke SJ, Tannock IF. Cognitive function and fatigue after diagnosis of colorectal cancer. *Ann Oncol*. 2014;25(12):2404-12.

Walling AM, Weeks JC, Kahn KL, Tisnado D, Keating NL, Dy SM, Arora NK, Mack JW, Pantoja PM, Malin JL. Symptom prevalence in lung and colorectal cancer patients. *J Pain Symptom Manage*. 2015;49(2):192-202.





Cathy J. Bradley, PhD

Emotional and Financial Health of Caregivers of
Patients with Cancer



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**Emotional and financial needs of employed caregivers
eCare: A virtual stress management intervention for
employed caregivers of solid tumor cancer patients
R01CA231387**

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Profile of a caregiver

“If society wants us to keep caring for others, it’s going to have to show a little more care for us.”
Kate Washington, the author of “Already Toast: Caregiving and Burnout in America”²

- 88% of caregivers care for a family member¹
- 39% lived with the person they cared for¹
- 50% reported high emotional stress¹
- 72% assisted with medical tasks¹
- 43% reported needing help with emotional and physical stress¹
- **50% were employed working an average of 35 hours per week¹**

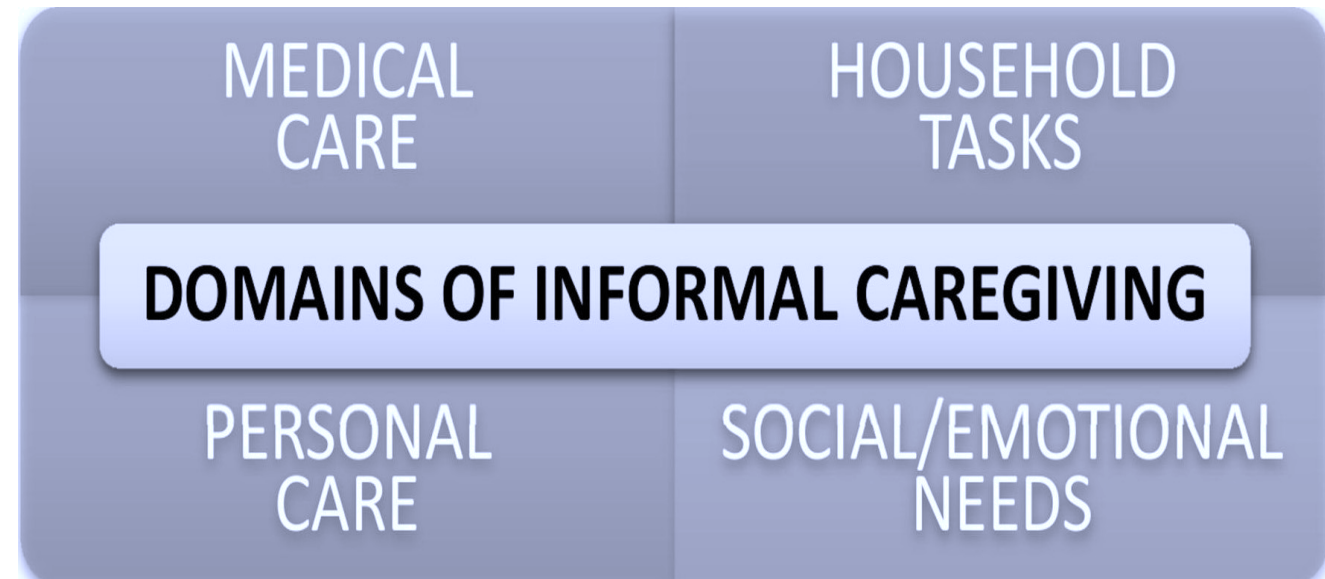


Image source: Adashek JJ, Subbiah IM. Caring for the caregiver: a systematic review characterizing the experience of caregivers of older adults with advanced cancers. *ESMO open*. 2020;5(5):e000862-e000862. doi:10.1136/esmooopen-2020-000862

Employed caregivers

- Caregiver employment is crucial
 - Financial support
 - Health insurance coverage – possibly the only coverage for the patient and family
- Nearly all report work time lost
- Increased risk of
 - leave without pay,
 - fewer work hours,
 - in lower-paying jobs
 - working from home (if possible) to manage caregiving duties⁵

Cancer caregiving is more time consuming

Hours of Care per Week (2014)

	Cancer Caregiver (n=111)	Non-Cancer Caregiver (n=1,164)
Fewer than 9 hours	32%	47%*
9 to 20 hours	24%	21%
21 to 40 hours	13%	19%
41 or more hours	32%	22%
<i>Average hours of care provided per week</i>	32.9*	23.9

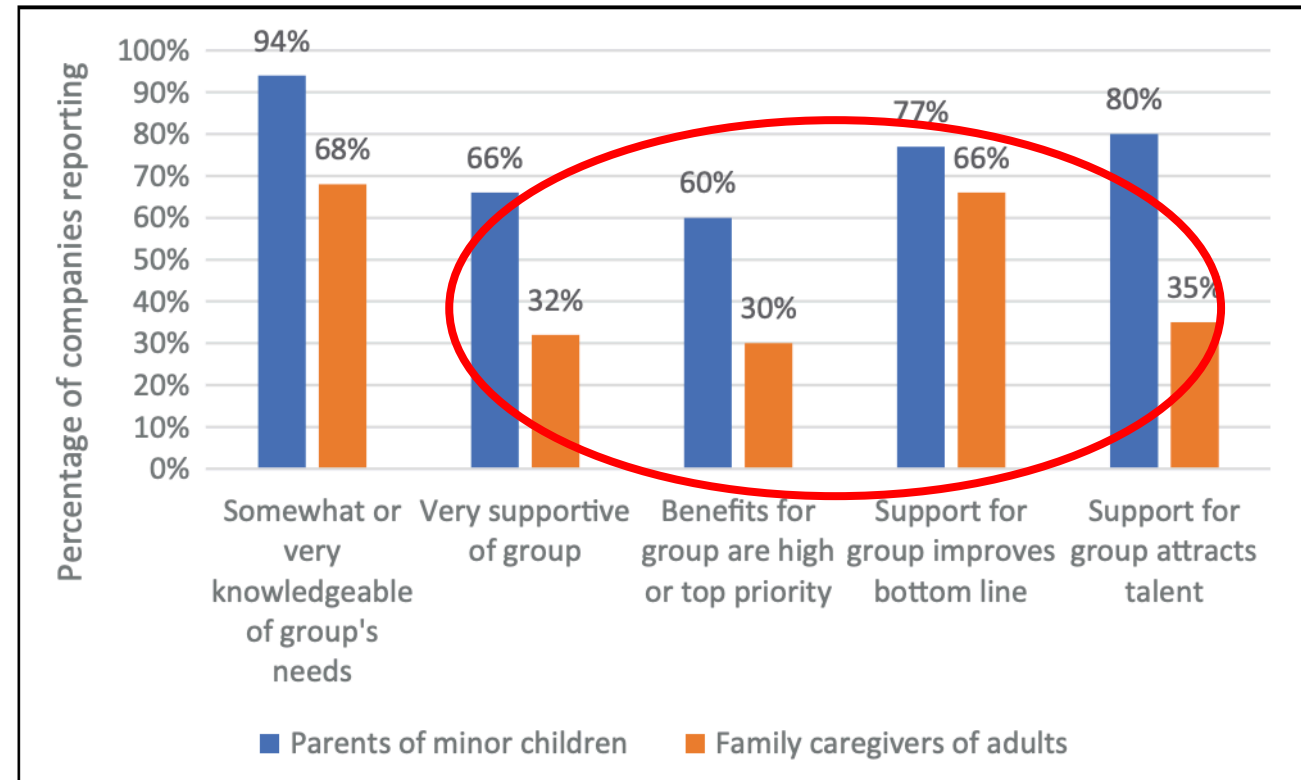
Source: National Alliance for Caregiving. Cancer Caregiving in the U.S. Accessed 2022, April 14, . https://www.caregiving.org/wp-content/uploads/2020/05/CancerCaregivingReport_FINAL_June-17-2016.pdf



In the workplace

- Most employers do not⁶:
 - Have awareness of how responsibilities differ by gender and ethnicity
 - Understand costs of caregiving on an employee
 - Understand toll caregiving has on performance
 - Believe support for caregivers improves bottom line or helps them to attract talent
- No business case to support employees who are caregivers

Largest U.S. companies' support of parents compared to family caregivers, 2020.

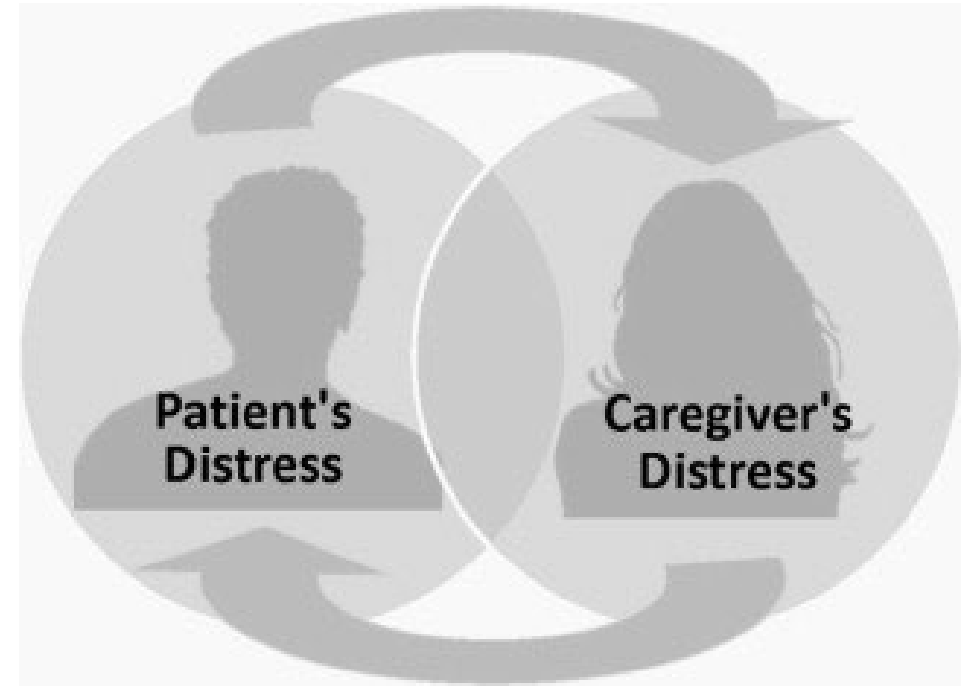


Source: AARP/S&P Global Survey of Largest U.S. Companies, July-October 2020.



Financial toxicity extends to caregivers

- Caregiver financial toxicity associated with⁵
 - Greater patient care non-adherence
 - Lifestyle altering behaviors for patients and caregivers
 - Decreased quality of life for patients and caregivers



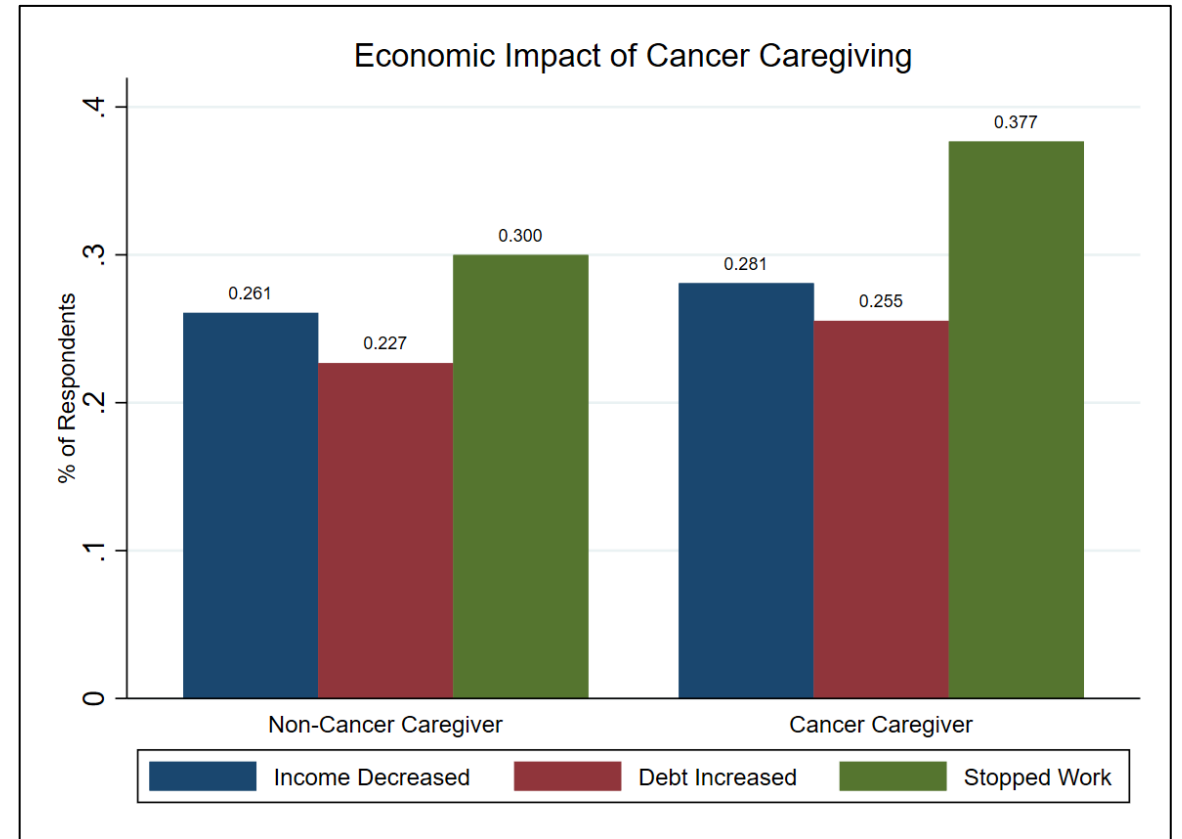
“Correlates of financial toxicity in adult cancer patients and their informal caregivers” (Sadigh et. al. 2021)



Cancer caregiving has a greater economic toll

- Using 2000-2018 Health and Retirement Study, examined impact of caregiving for a cancer spouse
- **More cancer caregivers reported**
 - Income decrease
 - Debt increase
 - Stopped working

Economic Impact of Cancer Caregiving Compared to Non-Cancer Caregiving



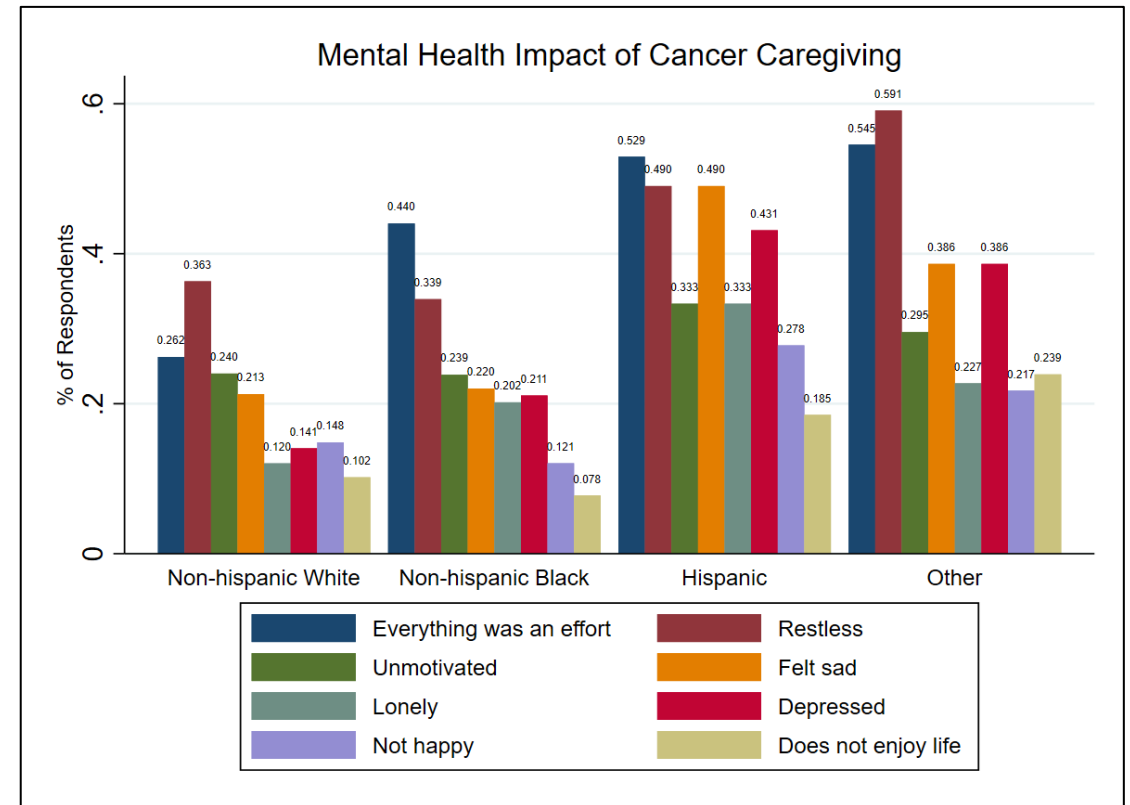
Notes: Sample includes all caregivers working prior to caregiving. N=1,488; 231 cancer caregivers.



Mental health impact on employed caregivers

- Cancer caregivers who identified as **Hispanic and Other** reported the most mental health impacts
- **Non-Hispanic White** reported the least mental health impacts

Mental Health Impact of Cancer Caregiving by Race/Ethnicity



Notes: Sample includes only cancer caregivers. N = 775 non-Hispanic White, 116 non-Hispanic Black, 54 Hispanic, 46 other race



Employed caregivers and mental health

- Association between employment change and depression and anxiety in Allo-HSCT caregivers⁷
 - 45% of employed caregivers reported a reduction in employment
 - Those who reduce employment had greater levels of anxiety and depression⁷

Unclear how to interpret:

1. Sicker patients, requiring more care
2. No support at home or the ability to hire help
3. Unsupportive work environments
4. Desire to remain employed



eCare: a Virtual Stress Management Intervention for employed caregivers

- Psycho-Education Paced Respiration and Relaxation (PEPRR) reduced distress among caregivers of adult Allo-HSCT patients in a randomized control trial (RCT)⁸
- Mobilized Psychoeducation and Skills Based Intervention (Pep-Pal) is the mobile version of PEPRR, which was an acceptable alternative to PEPRR⁹
- **Randomized controlled trial with 3 arms**
 - Virtual Psycho-Education and Paced Respiration and Relaxation (PEPRR) includes virtual sessions with a social worker and workbook
 - Web-based Pep-Pal, a self-guided, virtual workbook
 - Treatment as usual



eCare: Inclusion criteria

Caregiver Criteria

- Caregiver for a patient with a diagnosis of solid tumor cancer at any stage within 12 weeks of initiating treatment; must live with patient
- Caregiver scored 1+ on the PHQ-2 (depression) and/or GAD-2 (anxiety)
- Caregiver employed **at the time** of the patient's diagnosis for 20+ hours/week
- Age 25-64

Patient Criteria

- Primary diagnosis of solid tumor within 12 weeks of initiating treatment including chemotherapy, immunotherapy, oral targeted and/or radiation.
- Spouse or partner of the caregiver for at least a year and must live with caregiver.
- Must be able to read/speak English
- Age 18+



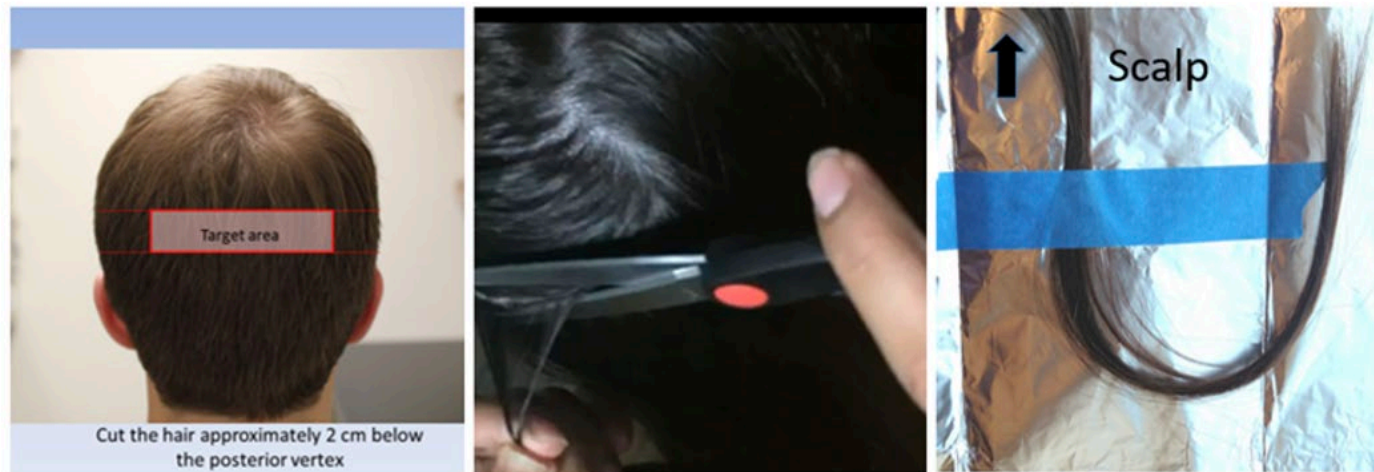
Primary & secondary endpoints

- **Primary outcomes:** Reduction in caregiver depressive symptoms
- **Secondary psychological and medical outcomes:** Reduction in caregiver baseline to 3, 6, 9, 12 months in other indicators of distress, health care utilization at 12 months
- **Employment outcome**
 - **Employed caregivers** - hours worked and job satisfaction will be positively associated with improved patient symptom management and patient psychological outcomes



Secondary endpoints

- **Secondary caregiver biomarker outcomes:** Stabilized or reduced biomarkers of allostatic load from baseline to 3, 6, 9, and 12 months
 - Hair cortisol and telomere length tested
 - Hair is collected by participants from the posterior vortex
 - Saliva is collected by participants
- Biomarker correlation with PROMIS, CESD, PSS and employment outcomes



eCare: Progress to date

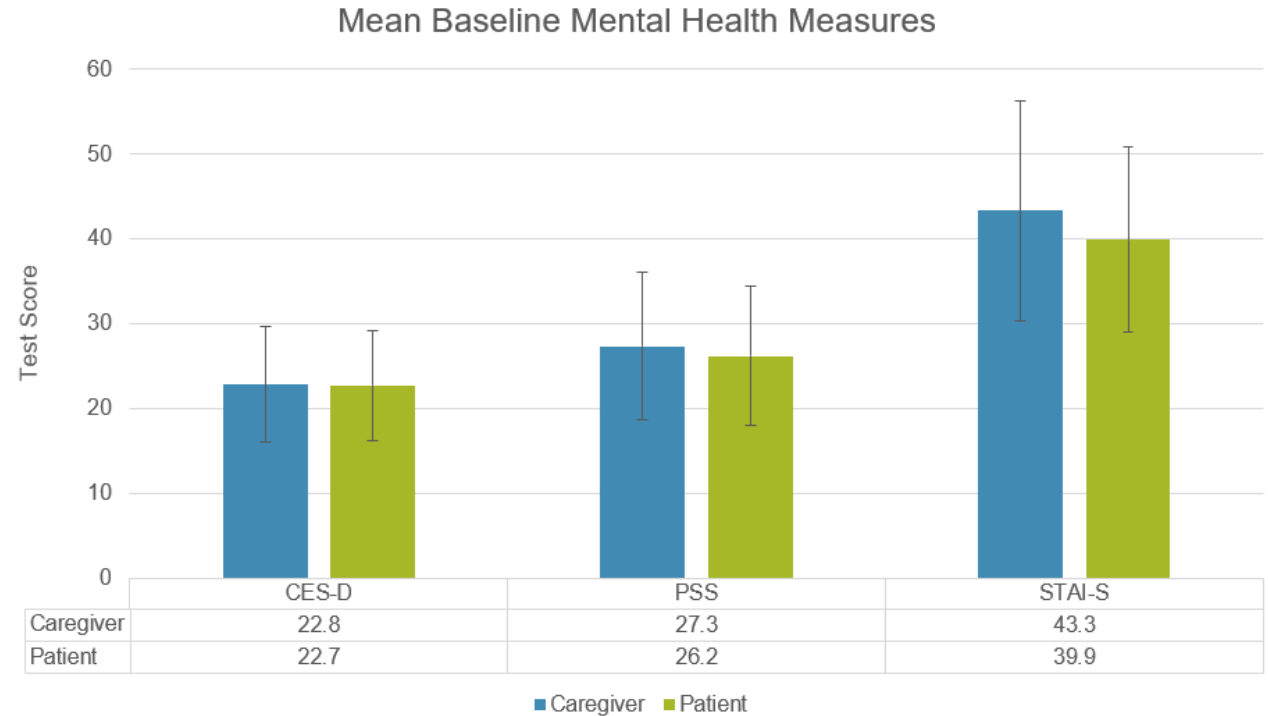
Caregivers

- Total number enrolled: 70, aiming for 300
- Mean Age: 49
- Sex:
 - Male – 55%
 - Female – 45%
- Hispanic or Latino – 10%
- College degree or greater – 92%
- Household Income above \$105,000 – 74%



eCare: Baseline symptoms

- CES-D score 16 or above signifies significant depressive symptoms
 - 87% exceeded threshold for depression
- PSS scores 27 and above is considered high perceived stress
 - 60% exceeded threshold for stress
- STAI-S scores 38-44 signify moderate anxiety, and 45-80 as high anxiety
 - 43% exceed threshold for anxiety



eCare: PROMIS depression and anxiety comparison

- **PROMIS Depression** – mean score of 54.3
 - 25% mild depression
 - 23% moderate depression
 - 2% severe depression
- **PROMIS Anxiety** – mean score of 59.4
 - 30% mild anxiety
 - 32% moderate anxiety
 - 8% severe anxiety
- Much lower levels compared to CESD, PSS, STAI-S



eCare: Continuation

- **Enrollment**
 - Enlisted Kaiser Permanente of Colorado
 - Anticipate half of the sample enrolled by fall
 - Completion by next year
- **Dissemination and implementation**
 - Health and Retirement Survey analysis
 - ASHEcon presentation June 2022



eCare: Continuation

- Inform practice and standard of care
- Inform policies such as paid sick leave by making the needs of employed caregivers known to providers, employers, and caregivers

Here's how:

- Collaboration with Center for Worker Health and Environment to inform workplaces of patients and caregiver needs
- Collaboration with Cariloop; a caregiver support organization that is developing workplace modules as part of a benefit package for caregivers
 - First evidence that an intervention improves caregiver well-being
 - Retention and job satisfaction
 - **Business case for caregiver support**





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THANK YOU & QUESTIONS
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References


1. NIH National Cancer Institute. Informal Caregivers in Cancer: Roles, Burden, and Support (PDQ®)—Health Professional Version. Accessed April 12, 2022. <https://www.cancer.gov/about-cancer/coping/family-friends/family-caregivers-hp-pdq>
2. Altman M. The Costly, Painful, Lonely Burden of Care. Accessed April 15,, 2022. <https://www.nytimes.com/2021/03/16/us/caregiving-burnout.html>
3. Applebaum A. Care for the Cancer Caregiver. <https://ascopost.com/issues/september-25-2018/care-for-the-cancer-caregiver/>
4. Family Caregiver Alliance. Caregiver statistics: Demographics. 2016. Accessed April 12, 2022. <https://www.caregiver.org/caregiver-statistics-demographics>.
5. Sadigh G, Switchenko J, Weaver KE, et al. Correlates of financial toxicity in adult cancer patients and their informal caregivers. *Supportive Care in Cancer*. 2022/01/01 2022;30(1):217-225. doi:10.1007/s00520-021-06424-1
6. Kasten J. Assessment of Family Caregivers' Needs: What Employers Need to Know. *American Journal of Health Promotion*. 2021;35(7):1038-1041. doi:10.1177/08901171211030142e
7. Natvig C, Mikulich-Gilbertson SK, Laudenslager ML, Bradley CJ. Association between employment status change and depression and anxiety in allogeneic stem cell transplant caregivers. *J Cancer Surviv*. Aug 21 2021;doi:10.1007/s11764-021-01099-3
8. Simoneau TL, Kilbourn K, Spradley J, Laudenslager ML. An evidence-based stress management intervention for allogeneic hematopoietic stem cell transplant caregivers: development, feasibility and acceptability. *Support Care Cancer*. Aug 2017;25(8):2515-2523. doi:10.1007/s00520-017-3660-5
9. Pensak NA, Joshi T, Simoneau T, et al. Development of a Web-Based Intervention for Addressing Distress in Caregivers of Patients Receiving Stem Cell Transplants: Formative Evaluation With Qualitative Interviews and Focus Groups. *JMIR Res Protoc*. Jun 22 2017;6(6):e120. doi:10.2196/resprot.7075





Jae Kim, MD

**A Self-Management Intervention for Lung Cancer Surgery
Patients and Family Caregivers**



A Multi-Media Self-Management Intervention for Lung Cancer Surgery Patients and Family Caregivers

Jae Y. Kim, MD

Associate Professor and Chief
Division of Thoracic Surgery
Department of Surgery

Disclosures

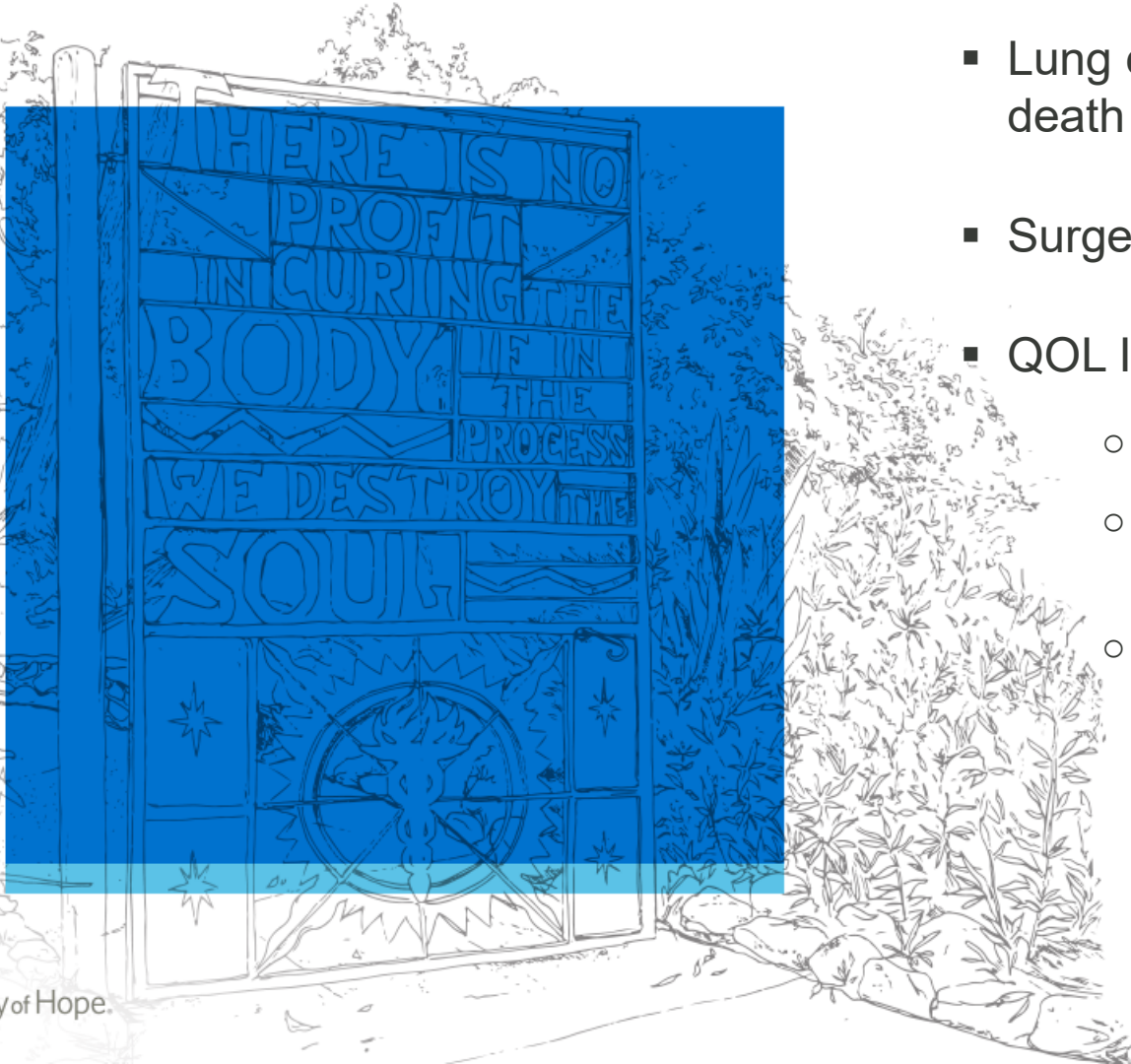


- NIH NCI R01 CA217841-A1
- Research funding from Eli Lilly (through the NCCN Oncology Research Program)
- Advisory board/speaking fees – AstraZeneca

Background



- Lung cancer is the leading cause of cancer death
- Surgery is the most common curative treatment
- QOL Impact
 - Comorbidities are common among pts and FCGs
 - Short and long term side effects of lung cancer treatments
 - High level of caregiver burden



Interdisciplinary Palliative Care for Patients with Lung Cancer (B. Ferrell PI)



- Usual care vs. interdisciplinary palliative care intervention + nurse led educational sessions.
- Early and late stage disease
- 491 patients and 354 FCGs



Betty Ferrell, MSN, PhD

Interdisciplinary Palliative Care for Patients with Lung Cancer



Table 2
Multivariate Analysis of Main Outcomes at 12 Weeks, Controlling for Baseline

Outcome	Usual Care			Intervention	Intervention			P-value	
	n	$\bar{x} \pm SD$	\bar{x}^a		$\bar{x} \pm SD$	\bar{x}^a	Main ^b	Inter ^c	
FACT-L (range = 0–140; higher = better QOL)									
Early	102	93.7 ± 20.6	97.7	129	115.4 ± 12.6	112.5			
Late	91	105.3 ± 20.1	105.2	135	105.8 ± 18.8	105.7	<0.001	<0.001	
Total	193	99.2 ± 21.1	101.4	264	110.5 ± 16.8	109.1			
Lung Cancer Subscale ^d (range = 0–32; higher = better QOL)									
Early	105	22.2 ± 4.8	23.1	129	27.1 ± 3.4	26.2			
Late	106	24.7 ± 5.1	24.8	135	25.2 ± 4.6	25.4	<0.001	0.003	
Total	211	23.4 ± 5.1	23.9	264	26.2 ± 4.2	25.8			
Trial Outcome Index (range = 0–136; higher = better QOL)									
Early	105	56.3 ± 13.1	58.4	129	70.0 ± 8.4	67.8			
Late	106	63.4 ± 14.0	63.5	135	64.1 ± 12.2	64.5	<0.001	<0.001	
Total	211	59.9 ± 14.0	60.1	264	67.0 ± 10.9	66.2			
Physical well-being ^d (range = 0–28; higher = better QOL)									
Early	105	19.5 ± 6.2	20.2	129	23.3 ± 3.3	22.4			
Late	106	21.2 ± 6.2	21.4	135	22.2 ± 4.9	22.4	<0.001	0.004	
Total	211	20.3 ± 6.2	20.8	264	22.8 ± 4.2	22.4			
Social/family well-being ^d (range = 0–28; higher = better QOL)									
Early	105	20.4 ± 6.9	21.9	129	24.5 ± 5.0	24.1			
Late	105	24.1 ± 4.3	23.8	135	22.7 ± 6.5	22.2	0.49	<0.001	
Total	211	22.3 ± 6.0	22.9	264	23.6 ± 5.8	23.1			

Interdisciplinary Palliative Care for Patients with Lung Cancer



TABLE 3. Multivariate Analysis of Family Caregiver Psychological Distress and Quality of Life by Group and Disease Stage

Outcome	Usual Care Group (N = 157)			Intervention Group (N = 197)			<i>P</i> _{Main} ^a
	Mean Score	SD	Adjusted Mean	Mean Score	SD	Adjusted Mean	
Psychological distress ^b							
Early, stages I-III	4.87	2.87	4.90	4.15	2.26	4.00	.010
Late, stage IV	4.40	2.89	4.54	4.25	2.43	4.23	
Total	4.61	2.88		4.20	2.36		
Physical QOL ^c							
Early, stages I-III	7.07	1.76	7.08	7.27	1.88	7.07	.886
Late, stage IV	7.06	1.78	7.22	7.26	1.62	7.27	
Total	7.06	1.76		7.26	1.73		
Psychological QOL ^c							
Early, stages I-III	5.38	1.69	5.43	5.79	1.28	5.39	.803
Late, stage IV	5.13	1.57	5.35	5.34	1.43	5.44	
Total	5.24	1.62		5.53	1.38		
Social QOL ^c							
Early, stages I-III	5.84	1.98	5.81	6.86	1.48	6.50	<.001
Late, stage IV	6.13	1.80	6.21	6.20	1.82	6.44	
Total	6.00	1.89		6.48	1.71		
Spiritual QOL ^c							
Early, stages I-III	6.67	1.79	6.56	6.55	1.41	6.39	.043
Late, stage IV	6.43	1.81	6.53	6.14	1.70	6.25	
Total	6.54	1.80		6.32	1.59		
Total QOL ^c							
Early, stages I-III	5.97	1.48	5.98	6.40	1.13	6.08	.484
Late, stage IV	5.90	1.38	6.07	5.97	1.34	6.09	
Total	5.93	1.42		6.16	1.27		

QOL Trajectories After Surgery

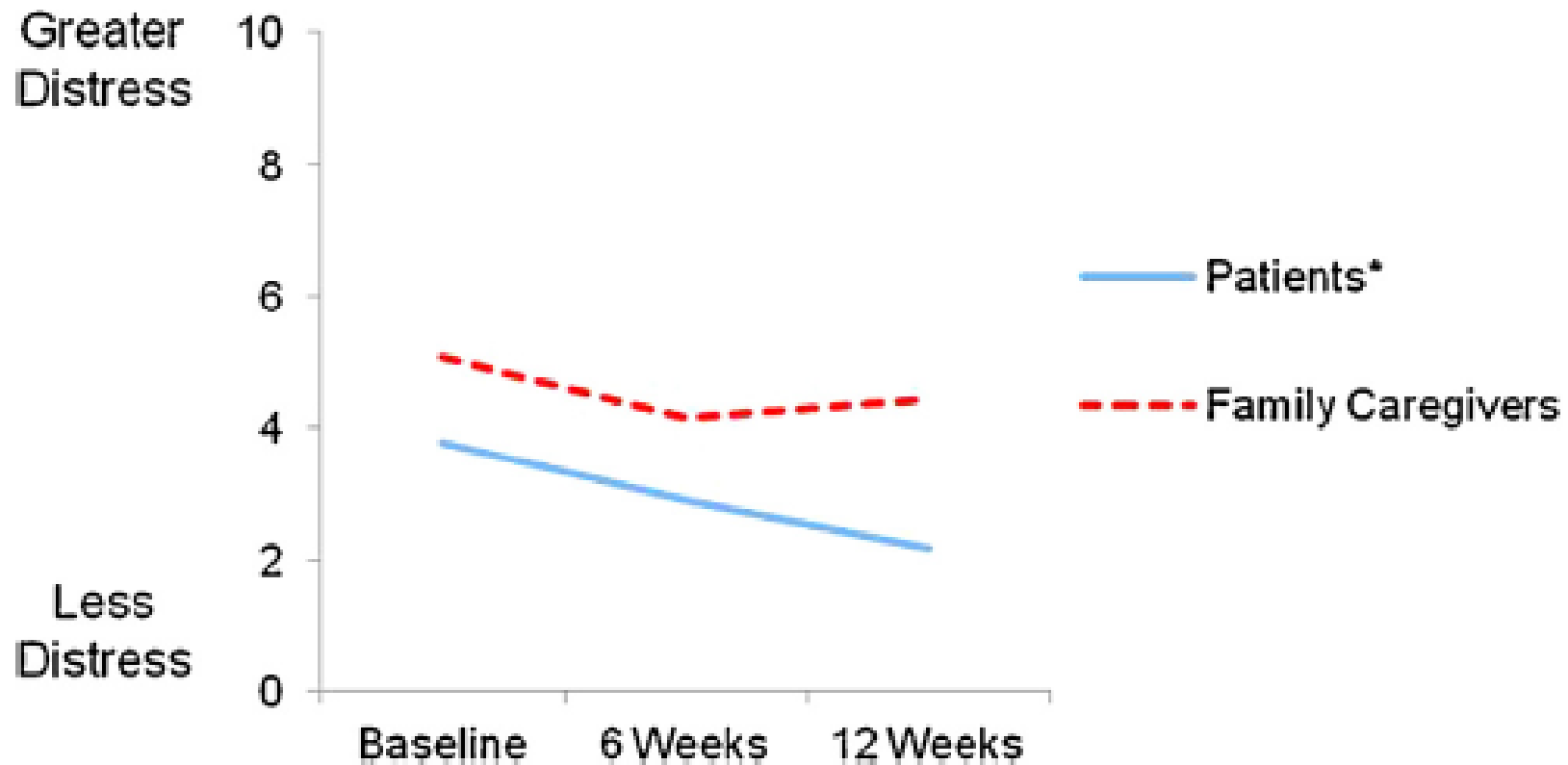
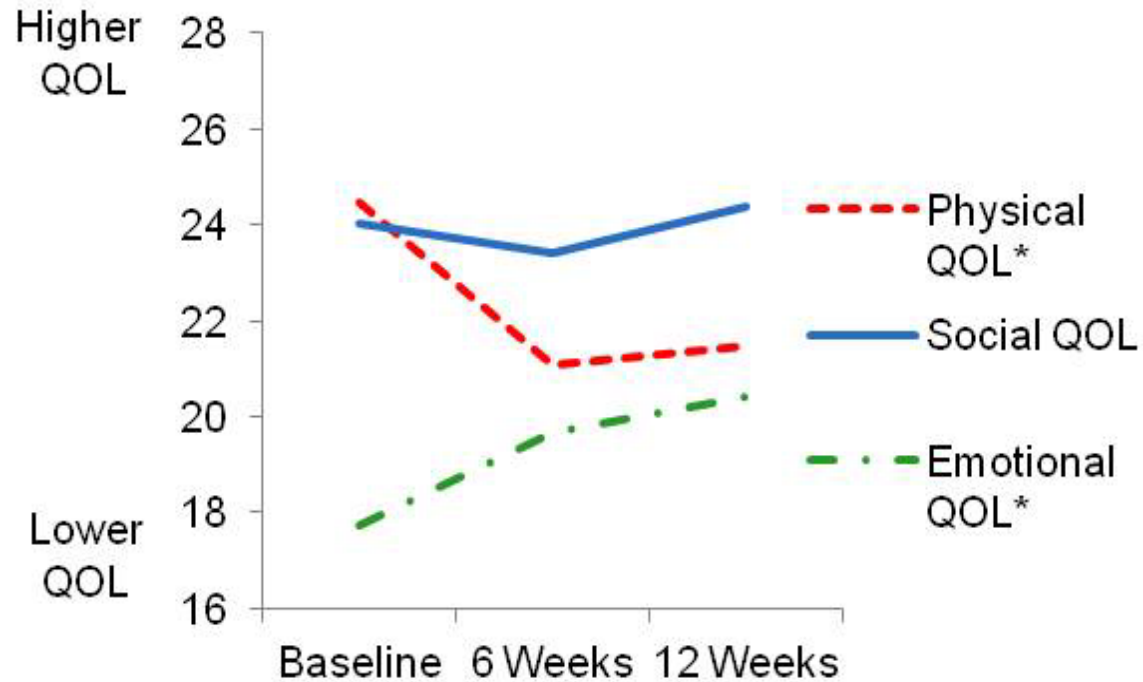


Fig. 2. Patient and Family Caregiver Psychological Distress Over Time. Possible scores range from 0 to 10. * $p < 0.05$.

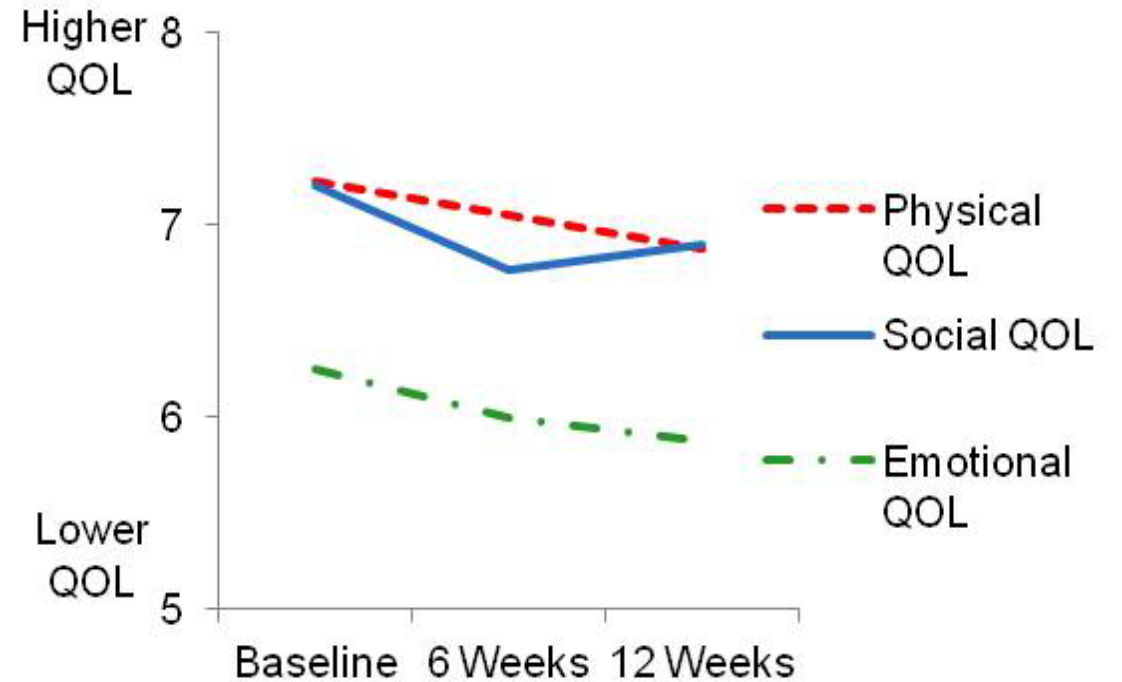
QOL Trajectories After Surgery



Patient QOL over time



FCG QOL over time



FCGs in Lung Cancer Surgery



- Palliative care intervention less effective for FCGs than patients
- High level of caregiver burden
- **Trajectory and Chronicity**
 - Multiple transitions of care
 - Opportunity for anticipatory intervention
 - Different paradigm

Designing a QOL Intervention for FCGs

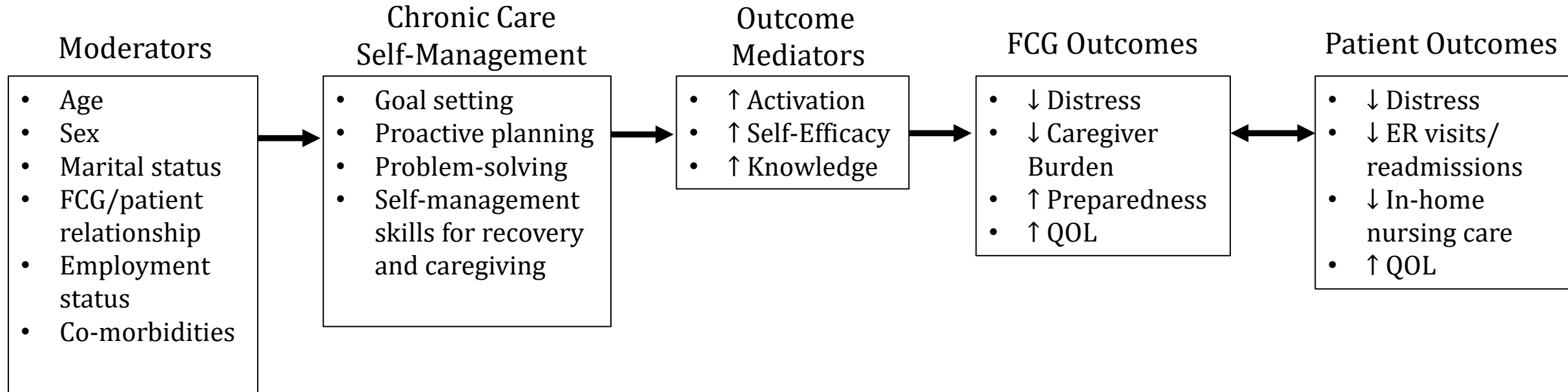


- Chronic care model of self-management
 - Reactive → Proactive
 - Social cognitive theory:
 - Goal setting
 - Skills building
 - Problem solving
- Begin intervention pre-op (anticipatory)
- Multimedia
 - Video, handbook, telephone



Virginia Sun, RN, MSN, PhD

Conceptual Framework



Pilot Study of Dyadic Intervention for LC Surgery



Component

FCG Content

Patient Content

Session 1: Pre-op

Session 2: Pre-discharge

Session 3: Post-op

Pilot Study of Dyadic Intervention for LC Surgery



Component

Session 1: Pre-op

FCG Content

- **Goal setting**
- **Self-care**
- **Problem solving**
- **Psychosocial well-being**

Patient Content

- **Tobacco cessation**
- **Breathing exercises**
- **Physical activity**
- **Coping**

Session 2: Pre-discharge

Session 3: Post-op

Pilot Study of Dyadic Intervention for LC Surgery



Component

Session 1: Pre-op

FCG Content

- Goal setting
- Self-care
- Problem solving
- Psychosocial well-being

Patient Content

- Tobacco cessation
- Breathing exercises
- Physical activity
- Coping

Session 2: Pre-discharge

- **Goal setting**
- **Support services**
- **Physical well-being**

- **Physical activity**
- **Symptom management**
- **When to call your doctor**

Session 3: Post-op

Pilot Study of Dyadic Intervention for LC Surgery



Component

FCG Content

Patient Content

Session 1: Pre-op

- Goal setting
- Self-care
- Problem solving
- Psychosocial well-being

- Tobacco cessation
- Breathing exercises
- Physical activity
- Coping

Session 2: Pre-discharge

- Goal setting
- Support services
- Physical well-being

- Physical activity
- Symptom management
- When to call your doctor

Session 3: Post-op

- **Reinforce problem solving and self-management skills**
- **Assess FCG QOL needs**
- **Review goals**

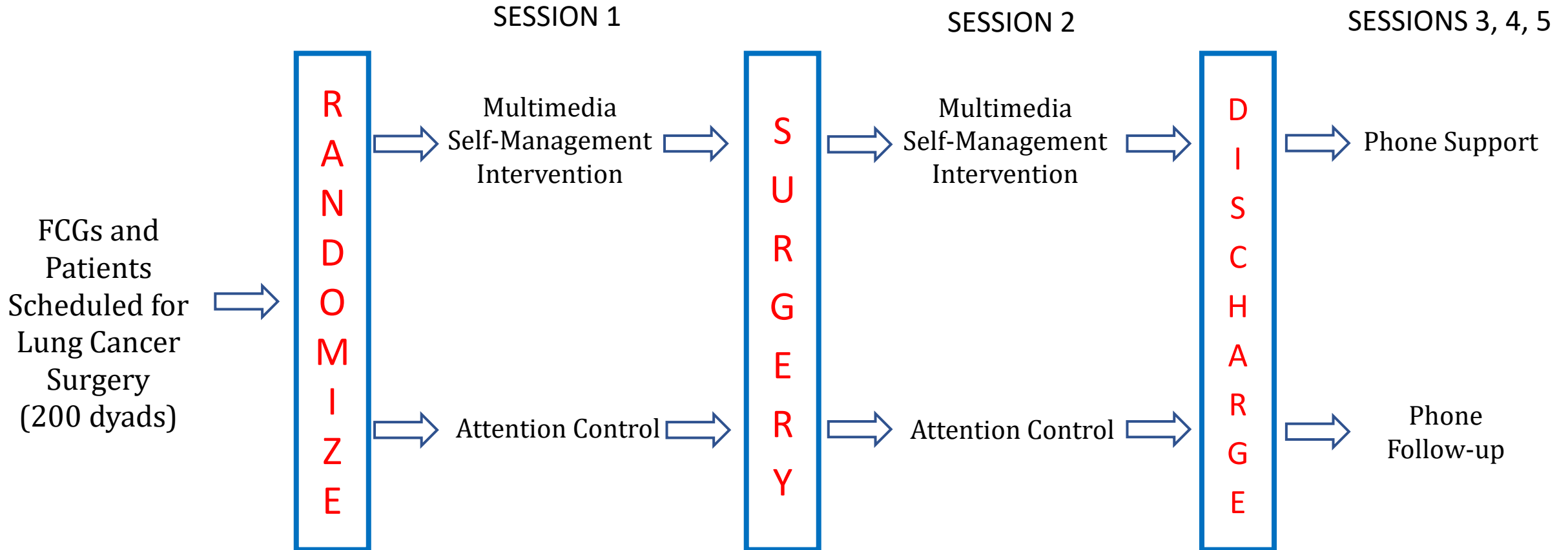
- **Reinforce problem solving and self-management skills**
- **Assess patient QOL needs**

Pilot Study of Dyadic Intervention for LC Surgery



- 38 patients and 22 FCGs
- Feasible and acceptable
- Mean patient acceptability/usability rating = 3.6-3.7/4.0
- Mean FCG acceptability/usability rating = 3.1-3.6/4.0. Desire for more content on supporting caregivers' emotional well-being and self-management.

Randomized Controlled Trial of MSM Intervention



Randomized Controlled Trial of MSM Intervention



Table 2. Outcome Measures by Aims and Assessment Time Points

	Measures	Baseline	Discharge	1 month	3 months
Family Caregivers	Distress Thermometer	x	x	x	x
	Montgomery Borgatta Caregiver Burden Scale	x	x	x	x
	Preparedness for Caregiving Scale	x	x	x	x
	COH-QOL-Family	x	x	x	x
	Family Caregiver Healthcare Use Survey		x	x	x
Patients	Distress Thermometer	x	x	x	x
	FACT-L	x	x	x	x
	Patient Healthcare Use Survey (non-COH)			x	x
	Medical Chart Audit Form				x
Outcome Mediators	Family Caregiver Activation in Transitions (FCAT) Tool	x	x	x	x
	Patient Activation Measure (PAM)	x	x	x	x
	Self-Efficacy Scale	x	x	x	x
	Surgery-Related Knowledge Tool	x	x	x	x

Progress to Date



- Month 42/54 of accrual
- 139 dyads accrued (goal = 200)
- COVID 19
 - Accrual (electronic consent, expanded cohort)
 - Impact on caregiving

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**Supporting the Science of Informal Cancer Caregiving:
Highlights of NCI-Funded Research**