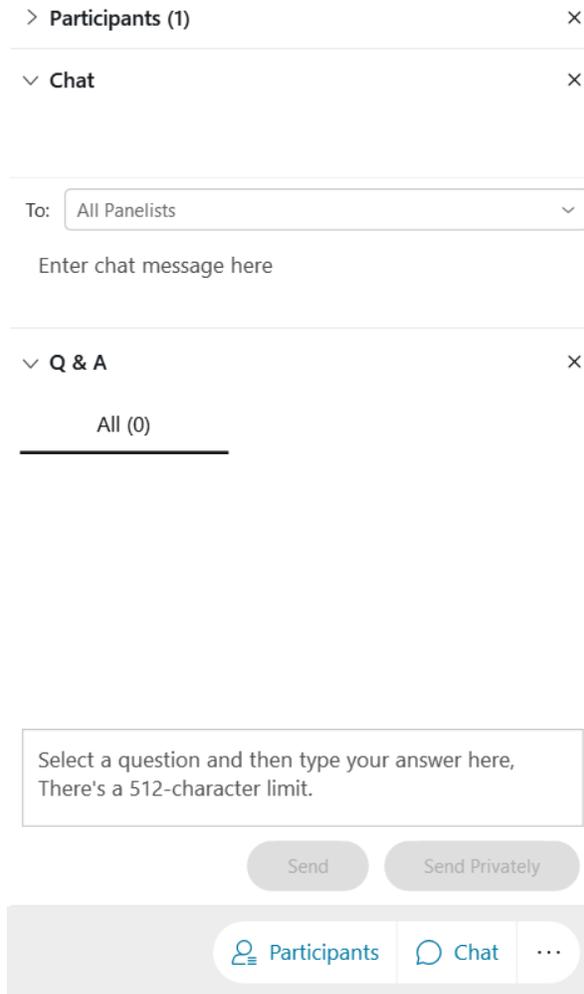




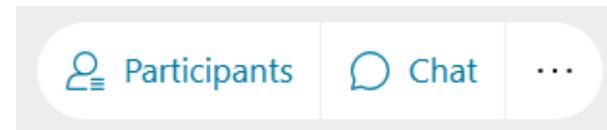
Supporting the Science of Informal Cancer Caregiving: Highlights of NCI-Funded Research

Webinar 1 – Tuesday, January 18, 2022 1 PM ET

Using WebEx and webinar logistics



- All lines will be in listen-only mode
- Submit questions at any time using the Q&A or Chat Panel and select *All Panelists*
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- This webinar is being recorded

Presenters



Ashley Wilder Smith, PhD, MPH
Chief, Outcomes Research Branch
Healthcare Delivery Research Program
Division of Cancer Control and
Population Sciences
National Cancer Institute



Christine Vinci, PhD
Assistant Member
Department of Health Outcomes
and Behavior
Moffitt Cancer Center



Maija Reblin, PhD
Associate Professor
Department of Family Medicine
Larner College of Medicine,
University of Vermont

Webinar Outline



- **Dr. Smith:** Introduction and Updates - The Need to Study Informal Cancer Caregiving and NCI Support of Research
- **Dr. Vinci:** Testing a Mindfulness-Based Intervention for Caregivers of Allogeneic Hematopoietic Stem Cell Patients
- **Dr. Reblin:** The CARING Study: Development of a Support Intervention for Neuro-Oncology Family Caregivers
- **Dr. Mollica:** Questions and Answers



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

Introduction and Updates from the National Cancer Institute

Background: Informal Caregiving



- Individuals that assist family members/friends by providing care which is:
 - typically uncompensated
 - usually in the home setting
 - involving significant efforts for extended time
- Caregiving tasks may include:
 - Supporting treatment decision-making
 - Administering medication and monitoring for side effects
 - Coordinating care and communicating with providers
 - Providing emotional support



Unique Aspects of Cancer Caregiving

- Distinguishing features:
 - Rapid deterioration of health
 - High burden of care
 - Multi-modal therapies
 - Cancer care continuum
 - Recurrence, and fear of recurrence

Research has shown that supporting cancer caregivers can improve patient outcomes

Kent et al., (2016). *Cancer*, PMID: 26991807
Litzelman et al., (2016). *JCO*, PMID: 27573657



Caring for Caregivers and Patients: *Revisiting the Research and Clinical Priorities for Informal Cancer Caregiving*

Sponsored by the National Cancer Institute and
the National Institute for Nursing Research

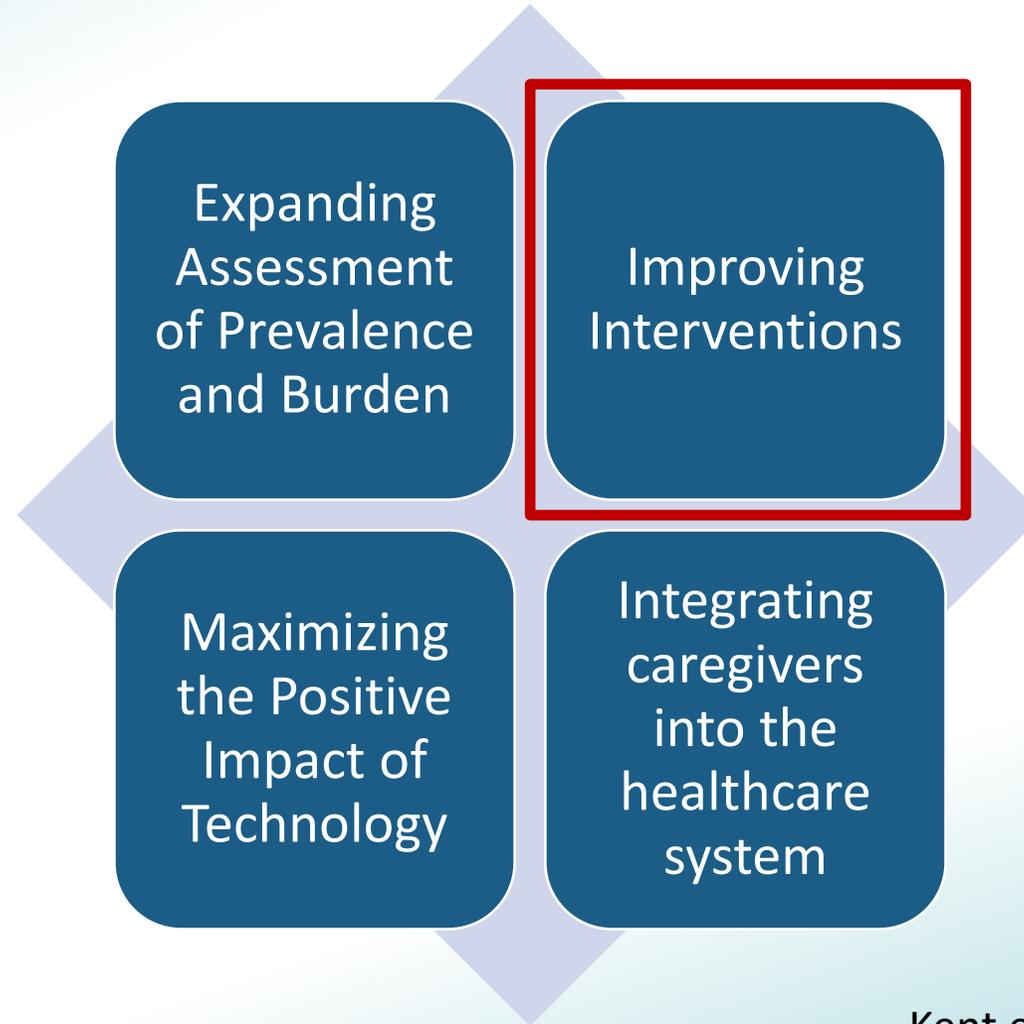
May 4-5, 2015
NCI Shady Grove TE406

NCI Planning Committee: Co-chairs Erin Kent (NCI), Julia Rowland (NCI)
Wen-Ying Sylvia Chou (NCI/DCCPS/BRP), Kristin Litzelman (NCI/DCCPS/BRP),
Ann O'Mara (NCI/DCP), Nonniekaye Shelburne (NCI/DCCPS/EGRP)

Caring for Caregivers and Patients: Research and Clinical Priorities for Informal Cancer Caregiving

Erin E. Kent, PhD, MS¹; Julia H. Rowland, PhD¹; Laurel Northouse, PhD, RN²; Kristin Litzelman, PhD¹;
Wen-Ying Sylvia Chou, PhD, MPH¹; Nonniekaye Shelburne, MS, CRNP, AOCN¹; Catherine Timura, PhD, MPhil³;
Ann O'Mara, PhD, RN, MPH⁴; and Karen Huss, PhD, RN⁵

Key Recommendations



Kent et al., (2016). *Cancer*, PMID: 26991807



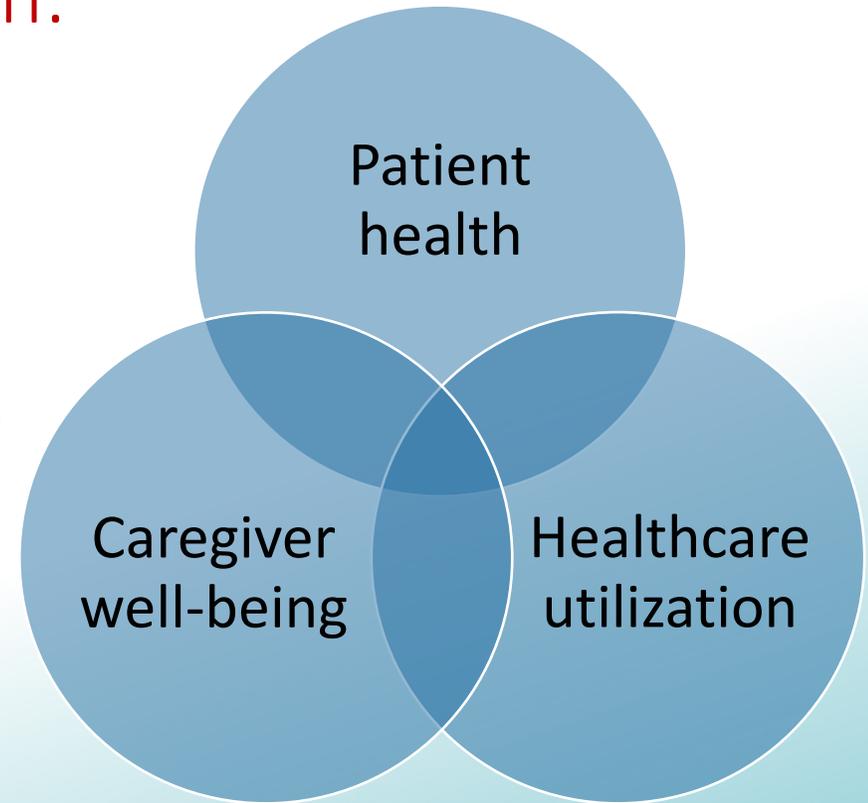
Funding Announcement:

Intervening with Cancer Caregivers to Improve Patient Health Outcomes and Optimize Health Care Utilization:
PAR-19-352 (R01), PAR-19-355 (R21)

- Fund interventions that support the success of informal cancer caregivers for adult cancer patients, as measured by the following outcomes:

<https://grants.nih.gov/grants/guide/pa-files/PAR-19-352.html>

<https://grants.nih.gov/grants/guide/pa-files/PAR-19-355.html>



Goal of webinar series

State of the
science on
informal cancer
caregiving

Highlighting
funded grantees

Discussing key
themes and future
support for cancer
caregiving research



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





Christine Vinci, PhD

Testing a Mindfulness-Based Intervention for Caregivers of Allogeneic Hematopoietic Stem Cell Patients



Testing a Mindfulness-Based Intervention for Caregivers of Allogeneic Hematopoietic Stem Cell Patients

Christine Vinci, PhD
Assistant Member
Moffitt Cancer Center
Department of Health Outcomes and Behavior



Disclosures



This study is funded by the National Cancer Institute (R01CA255265)

Background



- ▶ Allogeneic HCT caregivers
 - ▶ Significant involvement in patient care
 - ▶ High stress and burden
 - ▶ Can impact patient health outcomes (anxiety, depression, and survival)
- ▶ Existing treatment options
 - ▶ Access to support groups and social workers at hospital
 - ▶ Cognitive Behavioral Treatment
 - ▶ Delivered post-transplant
 - ▶ Issues with retention and engagement in all aspects of treatment



Mindfulness

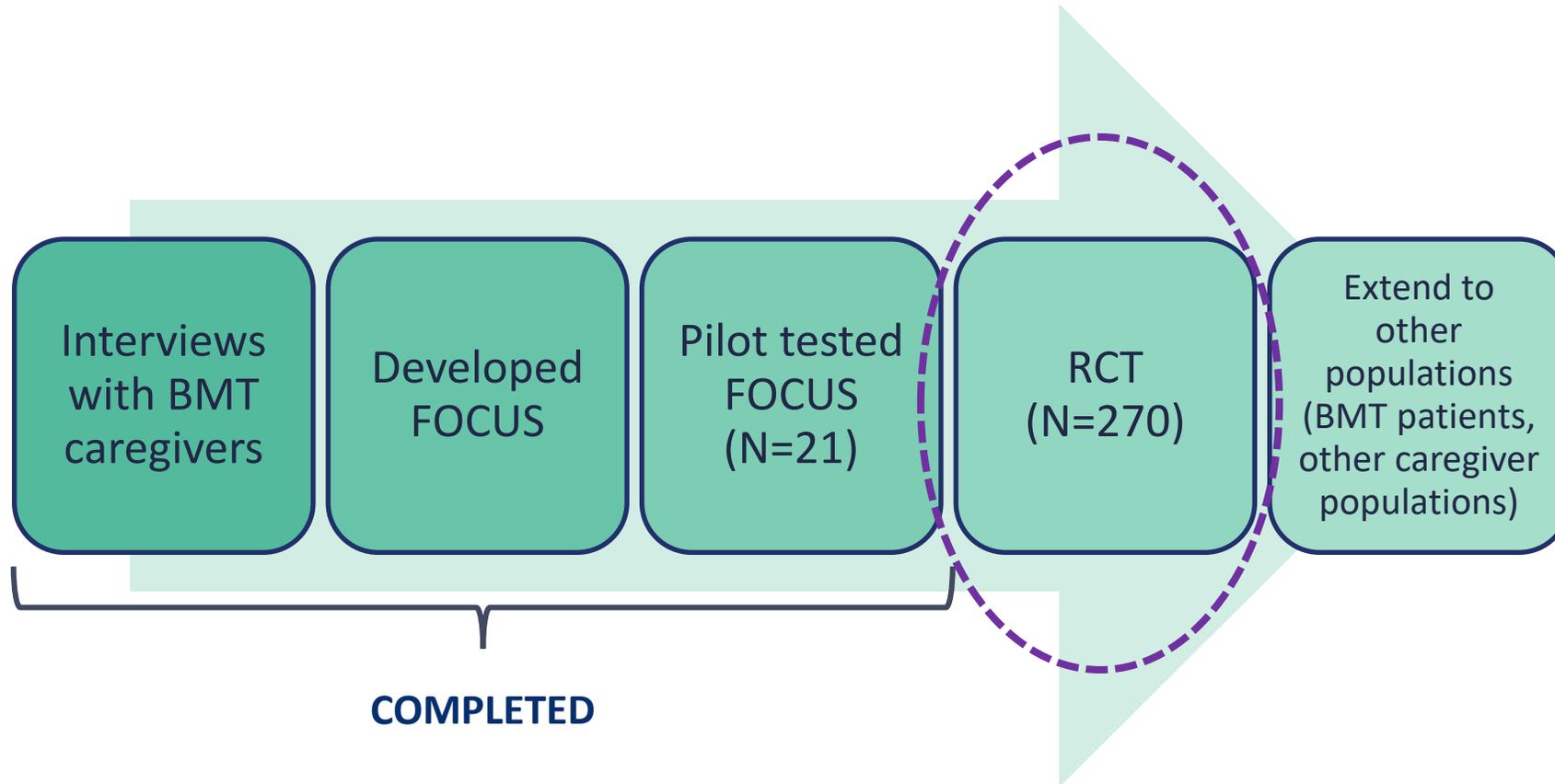
Basic human ability to pay attention purposefully, in the current moment, without judging that moment as good or bad

Mindfulness for HCT Caregivers



1. Decreases stress reactivity
2. Facilitates attention to the environment, body, and mind
3. Promotes cognitive flexibility
4. Aids in “decentering” or shifting perspectives
 -

Development Process





The COMPASSion Study



Primary Aim: To test the efficacy of a mindfulness-based intervention on caregiver burden, patient distress, and patient healthcare utilization



Participants: Eligibility

Allo caregivers

- 21 years of age or older
- Primary caregiver
- Owns smartphone and willing to download app
- Read and write in English

Patients

- 21 years of age or older
- Invited to participate if caregiver consents
- Read and write in English

Design: 3-arm RCT



6-week, individually-delivered
mindfulness-based treatment



6-week, individually-delivered
self-care treatment



Healthy Living booklet and
access to services at Moffitt as
usual

FOCUS and HL



- 6 consecutive, weekly sessions that last 45-60 minutes
 - Manualized treatment
 - Sessions 1-3: inpatient (delivered face-to-face)
 - Sessions 4-6: post-discharge (delivered via Zoom)
- Facilitators
 - BMT social workers
 - Integrative medicine staff
 - Graduate students/Postdoctoral fellows
- Phone App
 - Stores guided meditations
 - Delivers strategies unique to each condition throughout the day



FOCUS



Healthy Living

FOCUS Session Content



Session	Topic	Discussion Topics/Activities	In-Session Formal Meditation
1	Mindfulness for Caregivers	Existing coping strategies Introduction to mindfulness "Doing mode" vs "Being mode"	Raisin exercise Mindful Stretching Sitting meditation breath
2	Awareness of Stressors and the Experience of Stress	Common Challenges Stress and the body Surfing the Stress	Sitting mediation breath Body scan
3	Skillful Action	Uncontrollability vs Skillful Action Taking time to care for yourself STOP (Stop, Take a Breath, Observe, Proceed) Preparing for discharge	Sitting meditation: senses Mountain Meditation
4	Thoughts are Thoughts	Discussion of thoughts as related to emotions, physical pain Evaluation of self as caregiver	Present moment awareness Sitting meditation: Thoughts Walking meditation
5	Self-care and Balance	Pleasant activities Taking care of the self	Gratitude exercise Loving-kindness meditation
6	Planning for the Future	What to do if things change Mindfulness and daily life	Loving-kindness meditation Sitting meditation: breath

Healthy Living Session Content



Session	Topic	Discussion Topics/Activities
1	Overview of cancer	Adjusting to the diagnosis Causes of cancer Pain and physical changes in patient
2	Eating Well	Maintaining healthy weight Fruits and vegetables Meal planning
3	Financial Wellness	Cancer and health insurance Common financial issues Common legal issues
4	Sleep	Sleep hygiene Napping Minimizing distractions
5	Cancer Prevention	Limiting alcohol use Smoking cessation Protect your skin Cancer Screening
6	Exercise	Recommendations for physical activity Reducing sedentary behavior

Assessments



Caregivers and Patients

- ▶ Baseline
- ▶ End of Treatment
- ▶ Two follow-ups through 6 months post-treatment

Caregivers Only

- ▶ Daily Diary during treatment
- ▶ Hair samples for cortisol testing

Study Aims

Aim 1

Evaluate the efficacy of FOCUS when compared to HL and EC on caregiver burden.



Aim 2

Evaluate the impact of FOCUS on patient health and patient healthcare utilization compared to HL and EC.



Aim 3

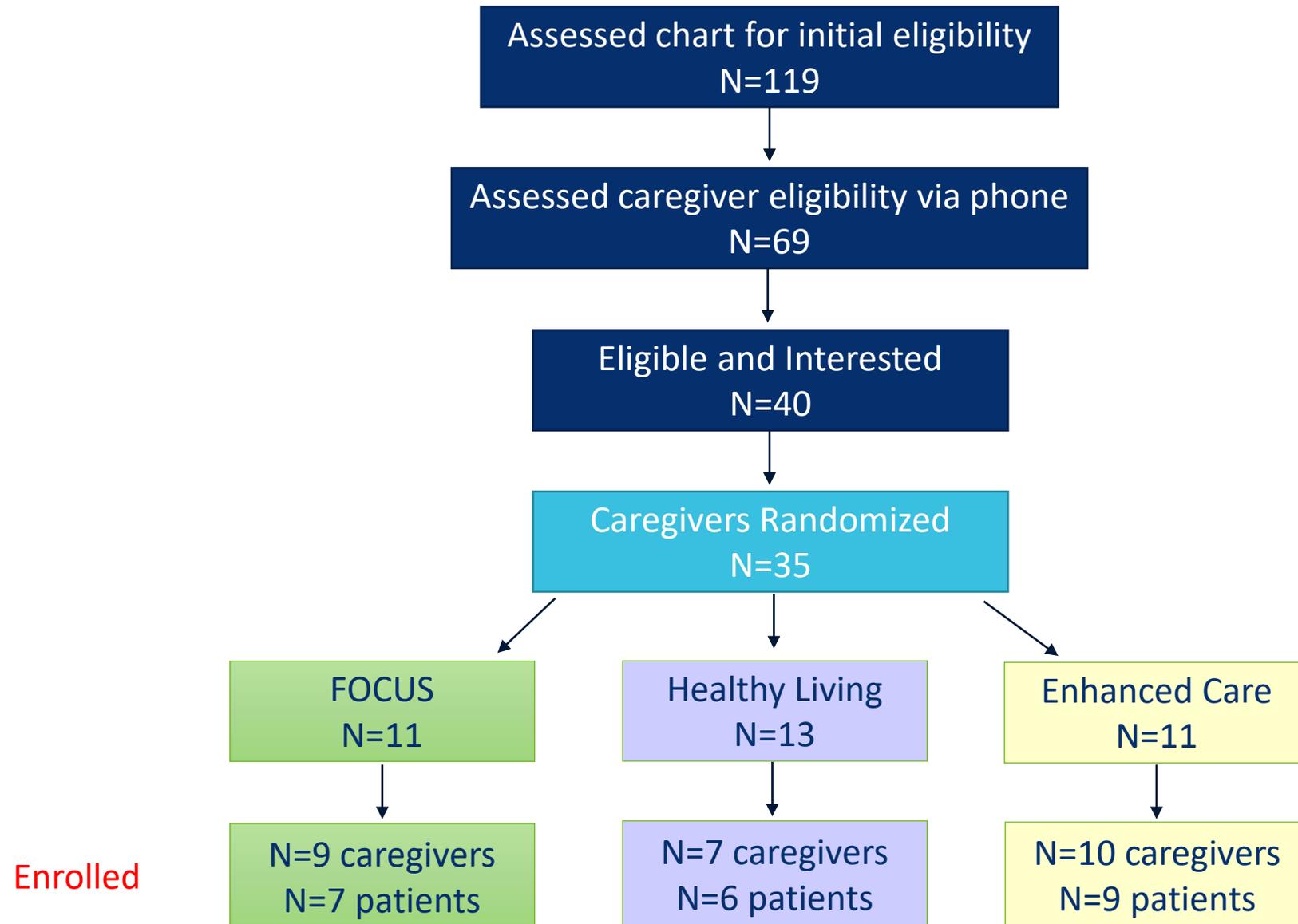
Evaluate putative mechanisms and moderators of FOCUS.

Recruitment



- ▶ Contact every allo caregiver being admitted that appears eligible via the patient chart
- ▶ Work closely with BMT social workers and transplant nurse coordinators to help bring awareness to our study
 - ▶ Send quarterly newsletter about the study to entire BMT staff
- ▶ Flyers for the study in the waiting room

Enrollment to date



COVID-19 Adjustments



- ▶ First several sessions commonly on Zoom due to BMT unit COVID-19 restrictions
 - ▶ Documenting the “planned” modality for treatment delivery, as well as the “actual” modality for treatment delivery
- ▶ Recently had to modify our consenting sessions to be <15 minutes in-person contact
 - ▶ Approval to consent over phone
 - ▶ In-person meeting only includes necessary components (hair sampling, providing study materials)
- ▶ Unclear how COVID-19 distress will impact outcomes
 - ▶ Assessing COVID-19 distress at baseline and follow-up

Thank you!



Co-Investigators

- Joseph Pidala, MD, PhD
- Maija Reblin, PhD
- Heather Jim, PhD
- Bob Gore, PhD
- Jerold Meyer, PhD
- Nandita Khera, MD

Study Staff

- Karen Brandon, PhD
- Valerie Yopez, MS
- Sarah Jones, BS
- Rachel Sauls
- Sana Baban

Facilitators

- Min-Jeong Yang, PhD
- Penny Lau, MSW
- Alex Sullivan, MSW
- Sharen Lock, MS
- Libby Creagh, BSW

Other

- Study participants
- BMT staff on the unit and in the clinic
- Undergraduate interns





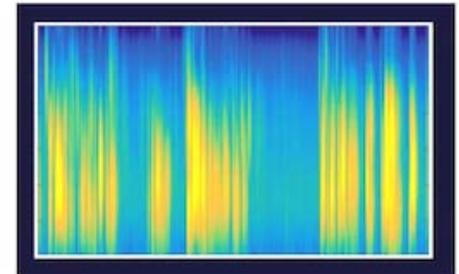
Maija Reblin, PhD

The CARING Study: Development of a Support
Intervention for Neuro-Oncology Family Caregivers

The CARING study: A social support intervention for neuro- oncology family caregivers

NCI Cancer Caregiving Webinar Series

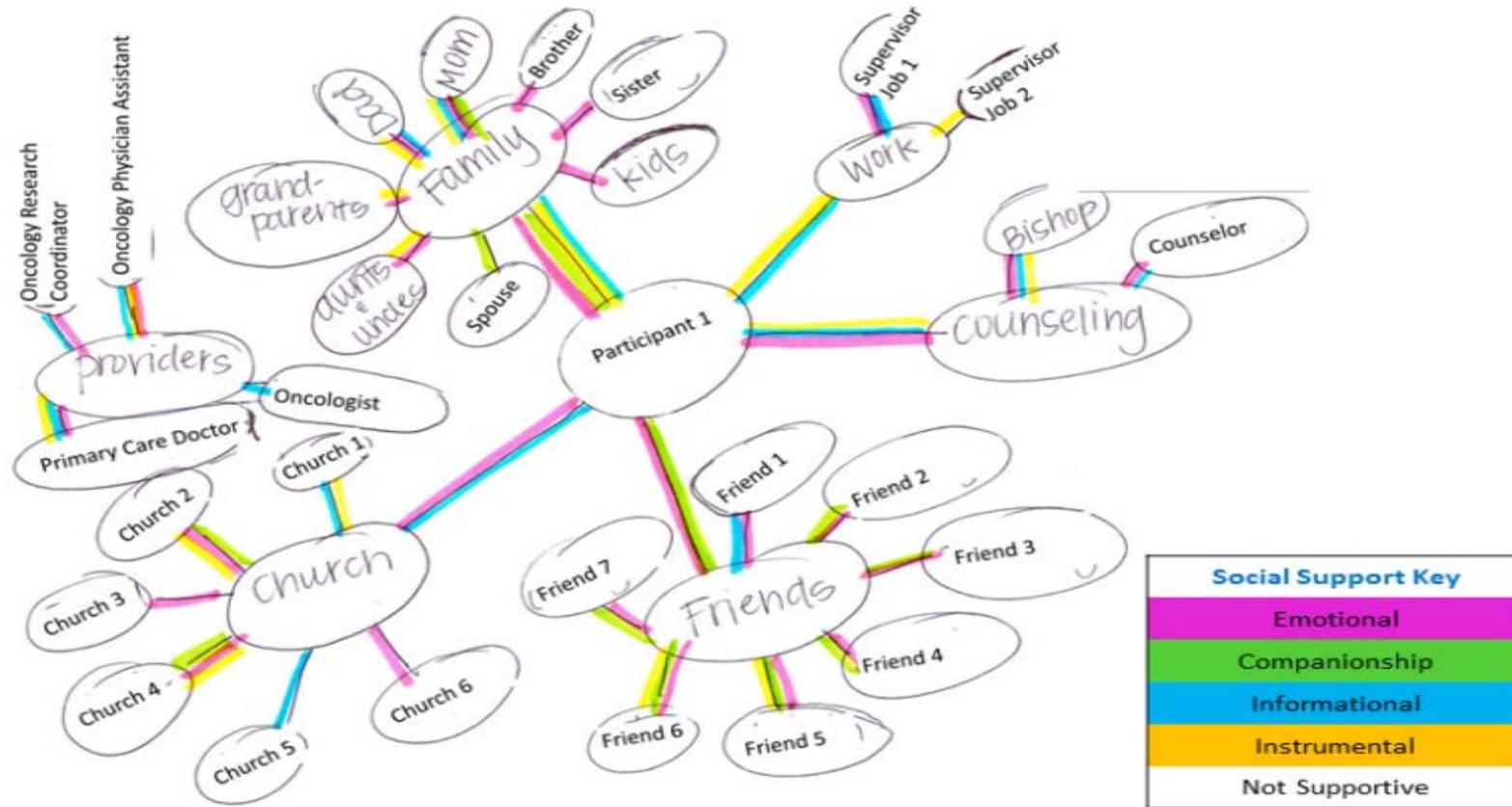
Maija Reblin, PhD
Associate Professor
Department of Family Medicine
University of Vermont



Social support is key for caregivers

- Social support is linked to lower levels of caregiver burden, better caregiver health and QOL
 - Can ensure patients can be cared for at home
- Neuro-oncology caregivers have high levels of burden and distress
 - Rapid, unpredictable disease progression
- Most people have friends and family that will help during hard times, but barriers exist to accessing support
- Need for a flexible tool to remind caregivers of existing support “in the moment,” change perception of support availability, get organized

Graphic Visualization: Seeing information helps identify new connections



Ecomapping helps prime availability of support, identify gaps, communicate efficiently

eSNAP: electronic Social Network Assessment Program

Introduction Add People **View My Network** Add Resources

Adeline Sherman

People Resources

Print Network

 **Hands On Support**

Rhonda McDill

Alice Sherman

Justin Sherman

McKenzie Campo

 **Financial Support**

May we recommend some helpful resources?

Add Resources

 **Informational Support**

May we recommend some helpful resources?

Add Resources

 **Emotional Support**

Alice Sherman

Allison Birmingham

McKenzie Campo

Justin Sherman

 **Communication Support**

Dr. Florsheim

Emma

Sarah

Irene Alvarez

 **Self Care Support**

Allison Birmingham

Jeffrey Sherman

Getting Started Add People View My List **Add Resources** Account

Hands On **Informational** Communication Financial Emotional Self Care

 **Informational Support Resources**

Add resources to your list to investigate later

American Cancer Society: Caregiver Resource Guide Add Resource

Provides a state-specific respite locator to find local programs and services that help caregivers to a break from caregiving.

<https://www.cancer.org/content/dam/cancer-org/cancer-control/en/booklets-flyers/american-cancer-society-caregiver-resource-guide.pdf>

American Psychological Association: Caregiver Resources Add Resource

This website is used by psychologists to provide key resources, training videos and educational handouts to family caregivers.

<https://www.apa.org/pi/about/publications/caregivers/resources>

American Society Of Clinical Oncology (ASCO) Add Resource

Discusses caregiving as a team effort, creating task lists, and communication.

<https://www.cancer.net/coping-with-cancer/caring-loved-one/tips-being-successful-caregiver>

< Back Next Category

Results

- Over 90% of participants liked eSNAP and thought it was:
 - Easy to use
 - Helpful in outlining available support
 - Provided useful information about additional resources
 - Something they'd recommend to others
- Some protective effect of eSNAP on caregiver depression
- Human engagement is still important



Development of the Electronic Social Network Assessment Program Using the Center for eHealth and Wellbeing Research Roadmap

Maija Reblin¹; Yelena P. Wu^{2,3}; Justin Pok²; Lauren Kane²; Howard Colman^{2,3}; Adam L. Cohen³; Eduardo Mendivil²; Echo L. Warner²; Miriah Meyer²; James Agutter²

Original Article | Published: 12 June 2018

Feasibility of implementing an electronic social support and resource visualization tool for caregivers in a neuro-oncology clinic

Maija Reblin, Dana Ketcher, Peter Forsyth, Eduardo Mendivil, Lauren Kane, Justin Pok, Miriah Meyer, Yelena P. Wu & Jim Agutter

Supportive Care in Cancer 26, 4199–4206(2018) | [Cite this article](#)

515 Accesses | 3 Citations | 9 Altmetric | [Metrics](#)

Clinical Study | Published: 28 May 2018

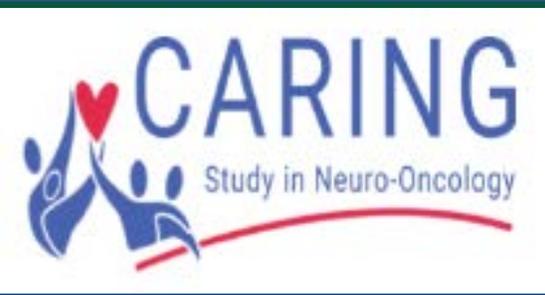
Outcomes of an electronic social network intervention with neuro-oncology patient family caregivers

Maija Reblin, Dana Ketcher, Peter Forsyth, Eduardo Mendivil, Lauren Kane, Justin Pok, Miriah Meyer, Yelena P. Wu & Jim Agutter

Journal of Neuro-Oncology 139, 643–649(2018) | [Cite this article](#)

316 Accesses | 3 Citations | 1 Altmetric | [Metrics](#)

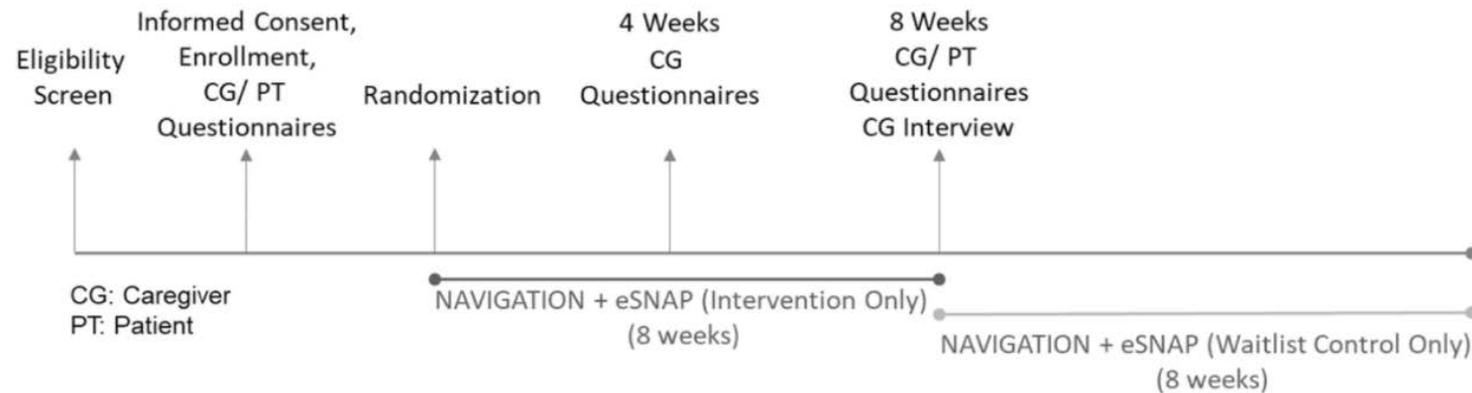
eSNAP + Caregiver Navigation



- Caregivers use eSNAP to assess & visualize existing social support
- Caregiver Navigators access eSNAP to develop a caregiver-specific plan to address social support needs through manualized sessions
 - 8 weekly sessions by phone
 - Assessment of support needs
 - Navigators may provide social support directly (e.g. emotional, informational)
 - Navigators primarily assist caregivers in obtaining support resources using motivational interviewing/problem solving
 - Informal social network
 - Formal resources
 - Activity to complete or think to practice what is discussed in the session

Study Design & Aims

- Randomized controlled trial of 225 caregiver-neuro-oncology patient dyads to compare our intervention with a wait-list control



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Study protocol | [Open Access](#) | Published: 17 April 2021

A randomized wait-list controlled trial of a social support intervention for caregivers of patients with primary malignant brain tumor

[Majja Reblin](#) [Dana Ketcher](#), [Rachael McCormick](#), [Veronica Barrios-Monroy](#), [Steven K. Sutton](#), [Bradley Zebrack](#), [Kristen J. Wells](#), [Solmaz Sahebjam](#), [Peter Forsyth](#) & [Margaret M. Byrne](#)

BMC Health Services Research **21**, Article number: 360 (2021) | [Cite this article](#)

163 Accesses | 13 Altmetric | [Metrics](#)

- Determine the efficacy of eSNAP + Caregiver Navigator support intervention on caregiver/patient well-being and health care utilization
- Identify key intervention components using mixed methods to inform future intervention implementation
 - Assess engagement with intervention components
 - Assess existing social networks and what resources get most use/referrals

Study Progress

- Recruitment opened in February, 2020
- Currently enrolled 55 (+) dyads
 - COVID has played a role in recruitment
 - Drop-outs in first wave of Covid
 - Low clinic volumes
 - Extra stress
 - ~40% only complete 1 session, but 60% complete at least 7
 - Those who complete generally have very positive feedback
 - Those who drop: too busy/too overwhelmed; patient decline

Lessons learned (so far)

- Flexibility is key
 - Meet participants where they are, when they are free, how they want to meet
- Time for the intervention: A two-sided coin
 - Navigation sessions are “me-time”
 - Better integration: Opt out vs opt in
- A great team and clinic champions are important

Thank you!

Research Team & Collaborators:

Jim Agutter, Veronica Barrios-Monroy, Margaret Byrne, Herald D'Almeida, Andrea Dombrowski, Peter Forsyth, Lauren Kane, Dana Ketcher, Rachael McCormick, Eduardo Mendivil, Miriah Meyer, Amy Otto, Justin Pok, Laura Rodriguez, Rich Roetzheim, Solmaz Sahebjam, Steve Sutton, Betsy Tiz, Kerie Walters, Echo Warner, Kristi Wells, Yelena Wu, Brad Zebrack

Extra Thanks: Research Participants

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Questions?

Please type your questions in the Q & A section on
WebEx

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Join the next session on February 23, 2022



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Highlights of NCI-Funded Research**

Questions?

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