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

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

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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
Key Recommendations

- Expanding Assessment of Prevalence and Burden
- Improving Interventions
- Maximizing the Positive Impact of Technology
- Integrating caregivers into the healthcare system

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:


Expiration Date: September 8, 2022
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
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
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

Bishop et al., 2007; Jim et al., 2014; Laudenslager et al., 2015; Simoneau et al., 2014; 2017; El-Jawarhi et al. 2020
Mindfulness

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

Baer, Smith, Hopkins, Krietemeyer, & Toney, 2006; Kabat-Zinn, 1994
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

- Interviews with BMT caregivers
- Developed FOCUS
- Pilot tested FOCUS (N=21)
- RCT (N=270)
- Extend to other populations (BMT patients, other caregiver populations)

Vinci et al., 2018; 2019; 2020
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 Session Content

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<td>Taking time to care for yourself</td>
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<td>STOP (Stop, Take a Breath, Observe, Proceed)</td>
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<td>Discussion of thoughts as related to emotions, physical pain</td>
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<td>What to do if things change</td>
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## Healthy Living Session Content

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<td>Exercise</td>
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<td>Reducing sedentary behavior</td>
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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

- Assessed chart for initial eligibility N=119
- Assessed caregiver eligibility via phone N=69
- Eligible and Interested N=40
- Caregivers Randomized N=35

- FOCUS N=11
  - N=9 caregivers
  - N=7 patients

- Healthy Living N=13
  - N=7 caregivers
  - N=6 patients

- Enhanced Care N=11
  - N=10 caregivers
  - N=9 patients

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

R03 CA201684 PI Reblin
eSNAP: electronic Social Network Assessment Program
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
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

NCI R01CA236034 PI: Reblin/Byrne
Study Design & Aims

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