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

Webinar 2 – Wednesday, February 23, 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
- You may need to activate the appropriate box using the floating navigation panel. Found on the bottom of your screen
- This webinar is being recorded
Welcome from the National Cancer Institute

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

Michelle Mollica, PhD, MPH, RN, OCN
Senior Advisor, Office of Cancer Survivorship
Program Director, Outcomes Research Branch
Division of Cancer Control and Population Sciences
National Cancer Institute

Molly Maher, MS
Cancer Research Training Award Fellow, Outcomes Research Branch, Healthcare Delivery Research Program
Division of Cancer Control and Population Sciences
National Cancer Institute
Webinar Outline

• **Presentation 1: Dr. Dionne-Odom** – Decision Support Training for Advanced Cancer Family Caregivers: The Project CASCADE Randomized Factorial Trial

• **Presentation 2: Drs. Trevino and Shen** – Talking About Cancer: Development and Evaluation of a Patient-Caregiver Communication Intervention to Improve Advance Care Planning Randomized Factorial Trial

• **Presentation 3: Dr. Badger** – Cancer Survivors and Caregivers: Psychological Distress, Symptom Burden and Health Care Use

• **Dr. Smith**: Questions and Answers
Presenters

J. Nicholas Dionne-Odom, PhD, RN, ACHPN, FPCN, FAAN
Assistant Professor
School of Nursing, University of Alabama at Birmingham

Kelly Trevino, PhD
Associate Attending Psychologist
Memorial Sloan Kettering Cancer Center

Megan J. Shen, PhD
Associate Professor
Fred Hutchinson Cancer Research Center

Terry A. Badger, PhD, RN, PMHCNS-BC, FAPOS, FAAN
Professor and Eleanor Bauwens Endowed Chair Chair, Community and Systems Health Science Division
University of Arizona College of Nursing
J. Nicholas Dionne-Odom, PhD, RN, ACHPN, FPCN, FAAN

Decision Support Training for Advanced Cancer Family Caregivers: The Project CASCADE Randomized Factorial Trial
Decision support training for advanced cancer family caregivers: The CASCADE factorial trial (NIH/NCI R01CA262039)

Principal Investigator:
J. Nicholas Dionne-Odom, PhD, RN, ACHPN
Assistant Professor | School of Nursing
University of Alabama at Birmingham
Co-Director | Caregiver and Bereavement Support Services
UAB Center for Palliative and Supportive Care
Email: dionneod@uab.edu Twitter: @N_DionneOdomPhD

Funded by:
NIH
THE UNIVERSITY OF ALABAMA AT BIRMINGHAM
Families play critical roles in patient decision making over the entire serious illness trajectory. 60-88% of caregivers actively involved triadic encounter decision-making. Nearly 3-in-4 patients include families in decisions.
Family influence on decisions extends to self-care management decisions in serious illness.
Qualitative study

N=20 family caregivers, 18 patients with advanced cancer

Identify/describe roles played by caregivers in supporting patients in decision making

Information seeker

Shared understanding facilitator

Values and illness understanding discussant

“What if” scenario poser

Collateral decisions (e.g., work)

Decision point identifier

Surrogate decision-making

Funding: National Palliative Care Research Center
Purpose
Test components of a decision support training intervention (CASCADE: CAre Supporters Coached to Adept DEcision partners) for family caregivers of persons with newly-diagnosed advanced cancer.

Design
$2^4$ full factorial design testing individual decision partnering training components: 1) coaching on effective decision support principles; 2) decision support communication training; 3) Ottawa Decision Guide training and 4) monthly follow-up
What is **Project CASCADE**?

**Goal** is to increase caregivers’ skills in providing effective decision support to patients.

- **1-5 coaching sessions using CASCADE Toolkit (20-30 minutes)**
- **Phone + In-person interaction**
- **Family caregivers and patients with newly diagnosed cancer**
- **Lay navigator coach-led**
There are 4 components being tested as part of the CASCADE package.

<table>
<thead>
<tr>
<th>Component</th>
<th>1 session vs</th>
<th>3 sessions vs</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Decision support communication skills training</td>
<td>1 session vs No sessions</td>
</tr>
<tr>
<td>2</td>
<td>Ottawa Decision Guide training</td>
<td>1 session vs No sessions</td>
</tr>
<tr>
<td>3</td>
<td>Monthly follow-up calls</td>
<td>1 monthly f/u call vs Monthly calls for 24 weeks</td>
</tr>
</tbody>
</table>
Coaching on Providing Decision Support: Single Session

- Express appreciation, orient to the program
- Decision making in serious illness and the role of family
- Delivering effective social support
Session 1
- Express appreciation, orient to program
- Decision making in serious illness and the role of family
- Making decisions about cancer treatment

Session 2
- Principles of social support effectiveness
- Delivering effective social support

Session 3
- Recognizing the role of values
- Advance directives/being a health care proxy
Decision support communication training

- Why communication is hard when facing decisions in cancer
- Listening skills
- Expressing oneself effectively
Decision aids

How to use the Ottawa Decision Guide
Monthly Follow up calls

- Ask how last month has been, any new decisions faced, provide action planning support
- Reinforce prior session content
- Follow up on prior action plans
Sessions conclude with an action planning activity.

Improving my Decision Support Skills

One thing I want to get better at is:

Why does getting better at this goal matter?

What would happen if you didn’t reach this goal?

On a scale of 1 to 10, with 1 being “not confident” and 10 being “highly confident,” how confident are you that you will reach your goal? _________

What are the biggest challenges to reaching this goal?

Over the next week, I will:
What needs to happen this week to work towards your goal? Ask yourself: what, when, who, where, how? How will you remind yourself of what needs to happen?
2^4 factorial trial design

<table>
<thead>
<tr>
<th>Condition</th>
<th>Decision support effectiveness coaching (1 session vs. 3 sessions)</th>
<th>Decision support communication training (Yes vs. No)</th>
<th>Ottawa Decision Guide training (Yes vs. No)</th>
<th>Monthly Follow-up calls (1 call vs. monthly for the 24 week timeframe)</th>
<th>n per condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1 session</td>
<td>Y</td>
<td>Y</td>
<td>1 call</td>
<td>n=22</td>
</tr>
<tr>
<td>2</td>
<td>1 session</td>
<td>Y</td>
<td>Y</td>
<td>monthly</td>
<td>n=22</td>
</tr>
<tr>
<td>3</td>
<td>1 session</td>
<td>Y</td>
<td>N</td>
<td>1 call</td>
<td>n=22</td>
</tr>
<tr>
<td>4</td>
<td>1 session</td>
<td>Y</td>
<td>N</td>
<td>monthly</td>
<td>n=22</td>
</tr>
<tr>
<td>5</td>
<td>1 session</td>
<td>N</td>
<td>Y</td>
<td>1 call</td>
<td>n=22</td>
</tr>
<tr>
<td>6</td>
<td>1 session</td>
<td>N</td>
<td>Y</td>
<td>monthly</td>
<td>n=22</td>
</tr>
<tr>
<td>7</td>
<td>1 session</td>
<td>N</td>
<td>N</td>
<td>1 call</td>
<td>n=22</td>
</tr>
<tr>
<td>8</td>
<td>1 session</td>
<td>N</td>
<td>N</td>
<td>monthly</td>
<td>n=22</td>
</tr>
<tr>
<td>9</td>
<td>3 sessions</td>
<td>Y</td>
<td>Y</td>
<td>1 call</td>
<td>n=22</td>
</tr>
<tr>
<td>10</td>
<td>3 sessions</td>
<td>Y</td>
<td>Y</td>
<td>monthly</td>
<td>n=22</td>
</tr>
<tr>
<td>11</td>
<td>3 sessions</td>
<td>Y</td>
<td>N</td>
<td>1 call</td>
<td>n=22</td>
</tr>
<tr>
<td>12</td>
<td>3 sessions</td>
<td>Y</td>
<td>N</td>
<td>monthly</td>
<td>n=22</td>
</tr>
<tr>
<td>13</td>
<td>3 sessions</td>
<td>N</td>
<td>Y</td>
<td>1 call</td>
<td>n=22</td>
</tr>
<tr>
<td>14</td>
<td>3 sessions</td>
<td>N</td>
<td>Y</td>
<td>monthly</td>
<td>n=22</td>
</tr>
<tr>
<td>15</td>
<td>3 sessions</td>
<td>N</td>
<td>N</td>
<td>1 call</td>
<td>n=22</td>
</tr>
<tr>
<td>16</td>
<td>3 sessions</td>
<td>N</td>
<td>N</td>
<td>monthly</td>
<td>n=22</td>
</tr>
</tbody>
</table>
Overall study flow

Screen, approach, consent, and have participants complete baseline questionnaires by mail (Target N=352 family caregivers & 352 patients

**Intervention condition**

**Week 1**
- #1 n=22
- #2 n=22
- #3 n=22
- #4 n=22
- #5 n=22
- #6 n=22
- #7 n=22
- #8 n=22
- #9 n=22
- #10 n=22
- #11 n=22
- #12 n=22

**Week 2**
- Session 1: Basic SS
- Session 2: Commun
- Session 3: Ottawa
- Monthly f/u x 1
- Monthly f/u
- Monthly f/u
- Monthly f/u
- Monthly f/u
- Monthly f/u
- Monthly f/u

**Week 3**
- Session 4: Commun
- Session 5: Ottawa
- Monthly f/u x 1
- Monthly f/u
- Monthly f/u
- Monthly f/u
- Monthly f/u
- Monthly f/u

**Week 4**
- Session 6: Ottawa
- Monthly f/u x 1
- Monthly f/u
- Monthly f/u
- Monthly f/u
- Monthly f/u

**Week 5**
- Monthly f/u
- Monthly f/u
- Monthly f/u
- Monthly f/u
- Monthly f/u

**Week 6**
- Monthly f/u
- Monthly f/u
- Monthly f/u
- Monthly f/u
- Monthly f/u

**Week 12**
- Week 12 Questionnaires

**Week 24**
- Week 24 Questionnaires
## Timeline

### Yearly Quarter

<table>
<thead>
<tr>
<th>Year 1</th>
<th>Year 2</th>
<th>Year 3</th>
<th>Year 4</th>
<th>Year 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>July 2021-June 2022</td>
<td>July 2022-June 2023</td>
<td>July 2023-June 2024</td>
<td>July 2024-June 2025</td>
<td>July 2025-June 2026</td>
</tr>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>1</td>
</tr>
</tbody>
</table>

### Milestones

- Obtain all regulatory approvals, register trial in clinicaltrials.gov
- Hire and train staff/interventionists
- Tracking system development
- Weekly project management meeting (UAB & Emory)
- Weekly interventionist debrief and fidelity oversight meetings
- Recruitment/enrollment (cumulative recruitment goal listed in box)
- Data collection
- Data analysis
- Prepare manuscripts and confirmatory RCT R01

**Targeting a recruitment rate of 1.92 randomizations per week**

- 50
- 100
- 150
- 200
- 250
- 300
- 350
### Timeline

<table>
<thead>
<tr>
<th>Yearly Quarter</th>
<th>Year 1 (July 2021-June 2022)</th>
<th>Year 2 (July 2022-June 2023)</th>
<th>Year 3 (July 2023-June 2024)</th>
<th>Year 4 (July 2024-June 2025)</th>
<th>Year 5 (July 2025-June 2026)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1 2 3 4</td>
<td>1 2 3 4</td>
<td>1 2 3 4</td>
<td>1 2 3 4</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>Observe milestone</td>
<td>Obtain all regulatory approvals, register trial in clinicaltrials.gov</td>
<td>Hire and train staff/interventionists</td>
<td>Tracking system development</td>
<td>Weekly project management meeting (UAB &amp; Emory)</td>
<td>Weekly interventionist debrief and fidelity oversight meetings</td>
</tr>
<tr>
<td>Recruitment/enrollment (cumulative recruitment goal listed in box)</td>
<td>50 100 150 200 250 300 350</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Data collection</td>
<td>Data analysis</td>
<td>Prepare manuscripts and confirmatory RCT R01</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Total randomized as of ???: X Caregivers, X Patients
Avg. randomizations/week: ??
Thank you to...

Project CASCADE
Co-Investigators, Collaborators, Students

Dio Kavalieratos, PhD (Emory Site-PI, CASCADE)
Marie Bakitas, DNSc, NP-C
Andres Azuero, PhD, MBA
Maria Pisu, PhD
Richard Taylor, DNP
Grant Williams, MD
Abby Rosenberg, MD, MS, MA
Christine Rini, PhD
Rachel Wells, PhD, RN
Rhiannon Reed, PhD
Erin Harrell, PhD
Shena Gazaway, PhD, RN
Avery Bechthold, BSN, RN
Kyungmi Lee, BSN, RN

Research Project staff

Peg McKie, MPH (Project Manager)
Jane Lowers (Emory site project manager)
Sally Engler, MPH
Charis Smith
Kayleigh Curry MPH (Coach)
Briana McDuffie, BS (Coach)
Stephanie Ford (Coach)

The UAB SON Office of Research and Scholarship
Julie Schach, BS & the UAB Recruitment and Retention
Shared Facility (James Mapson, Beth Ruf, Diane Williams, Greg Brecht)

Funding: National Cancer Institute (R01CA262039)

O’NEAL COMPREHENSIVE CANCER CENTER
UAB THE UNIVERSITY OF ALABAMA AT BIRMINGHAM
Talking About Cancer: Development and Evaluation of a Patient-Caregiver Communication Intervention to Improve Advance Care Planning
Talking About Cancer (TAC): Development and initial pilot testing of a communication-based intervention to improve engagement in advance care planning among cancer patients and their caregivers

Supporting the Science of Informal Cancer Caregiving: Highlights of NCI-Funded Research
National Cancer Institute
Megan J. Shen, PhD & Kelly M. Trevino, PhD
(R21-CA224874z)
February 23, 2022
Introduction

- Advanced cancer patients who understand their prognosis are more likely to:
  - Engage in advance care planning
  - Prefer comfort over aggressive care
  - Receive preference-concordant care
  - Die in their preferred location (home)

- Caregivers are integral to end-of-life care decision making
  - Caregivers may have a more accurate understanding of prognosis than patients

Waite et al., 2013, JAGS; Mack et al., 2010, JCO; Sudore et al., 2010, Ann. Intern. Med.; Yun et al., 2010, JCO
Patient-caregiver dyads’ prognostic understanding and associations with DNR order completion (N=279 dyads)

<table>
<thead>
<tr>
<th>Patient-Caregiver Prognostic Understanding</th>
<th>n (%)</th>
<th>% DNR Order “Yes”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient and caregiver have prognostic understanding</td>
<td>60 (27.8%)</td>
<td>70.7%</td>
</tr>
<tr>
<td>Neither patient or caregiver have prognostic understanding</td>
<td>96 (44.4%)</td>
<td>36.3%</td>
</tr>
<tr>
<td>Only patient has prognostic understanding</td>
<td>21 (9.7%)</td>
<td>38.9%</td>
</tr>
<tr>
<td>Only caregiver has prognostic understanding</td>
<td>39 (18.1%)</td>
<td>31.6%</td>
</tr>
</tbody>
</table>

$\chi^2 = 21.27, p = .000$

Note. Prognostic understanding is defined as estimating life expectancy as ≤ 12 months

*Shen et al., 2018, Psycho-Oncology*
Introduction

- Communication may improve prognostic understanding

- Patient-caregiver communication is limited
  - Over three-quarters (77%) of patient-caregiver dyads do not discuss prognosis or treatment
  - 92% of family members thought about the patient’s death; 78% had not discussed this with the patient

- Barriers to communication
  - Distress around discussing end-of-life care topics
  - Concern about burdening loved ones

Kirchhoff et al., 2010; J Am Geriatr Soc; Van Scoy et al., 2016, AJHPM; Zhang et al., 2003, Health Communication
**Specific Aims**

- **Aim 1**: To develop a communication-based intervention (Talking About Cancer; TAC) to improve advanced cancer patients’ and caregivers’ prognostic understanding and engagement in advance care planning.

- **Aim 2**: To evaluate the feasibility and acceptability of TAC among advanced cancer patients and their caregivers.

- **Aim 3**: To test the pre-post impact of TAC on patient and caregiver prognostic understanding and completion of DNR order, living will, and health care proxy forms.
Methods:
Overview

Phase 1:
Intervention modification

Phase 2:
Single arm open trial
Methods:
Eligibility Criteria

Patient eligibility criteria:
1. Diagnosis of poor prognosis advanced cancer (i.e., locally advanced or metastatic cancer and/or disease progression following at least first line chemotherapy)
2. Identification of an informal caregiver
3. Oncologist reported discussion of prognosis with the patient and/or caregiver
4. Not currently receiving hospice

Caregiver eligibility criteria:
1. The person whom the patient indicates provides their informal (unpaid) care

Dyads in which both members had accurate understanding of prognosis (terminal status and life-expectancy) were excluded.

Provider eligibility requirements (Aim 1):
1. Current clinical practice and/or research with advanced cancer patients
2. A history of 5+ years working with advanced cancer patients.
Phase 1 Methods

- Conducted semi-structured interviews to get feedback on the intervention from key stakeholders (n=57 participants)
  - n=19 advanced cancer patients
  - n=17 caregivers
  - n=21 experts working with advanced cancer patients

- Demographics
  - Race: 1.8% Asian, 4.6% unknown race; 5.2% more than one race, 31.5% Black or African American, 53.5% White
  - Ethnicity: 29.8% Hispanic/Latinx
  - Gender: 30.9% male, 69.1% female (*No other gender identities reported)

- Modified manual based on feedback
# Phase 1 Results: Themes from Interviews

<table>
<thead>
<tr>
<th>Themes that emerged from interviews</th>
<th>Manual modifications made</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive restructuring too complex and confusing</td>
<td>Removed content</td>
</tr>
<tr>
<td>Too much information/overwhelming content</td>
<td>Reduced content and restructuring into simpler graphs and charts</td>
</tr>
<tr>
<td>Need for increasing relevance of materials for those who do not worry about cancer</td>
<td>Made case studies and material more broadly applicable to those with and without worry</td>
</tr>
<tr>
<td>Add additional information to vignettes</td>
<td>Added additional information and relevant content to vignettes</td>
</tr>
<tr>
<td>Repetition/overlap in modules</td>
<td>Removed redundancy and shortened modules</td>
</tr>
<tr>
<td>Confusing instructions for some of the exercises</td>
<td>Simplified instructions and removed irrelevant or complex exercises</td>
</tr>
<tr>
<td>Advance care planning materials were too vague/not specific enough</td>
<td>Added additional module focusing exclusively on advance care planning</td>
</tr>
</tbody>
</table>
## Phase 1 Results: Modified TAC

<table>
<thead>
<tr>
<th>Session</th>
<th>Content</th>
</tr>
</thead>
<tbody>
<tr>
<td>Session 1: Managing distress (Individual)</td>
<td>Intervention overview and introduction to distress management</td>
</tr>
<tr>
<td>Session 2: Managing distress together (Dyad)</td>
<td>Distress management techniques to use together (as a dyad)</td>
</tr>
<tr>
<td>Session 3: How to communicate (Individual)</td>
<td>Basic communication strategies</td>
</tr>
<tr>
<td>Session 4: Communicating with your loved one (Dyad)</td>
<td>Communication around cancer as a dyad</td>
</tr>
<tr>
<td>Session 5: Communicating about cancer (Dyad)</td>
<td>Discussion of prognostic information and distress management</td>
</tr>
<tr>
<td>Session 6: Advance care planning (Dyad)</td>
<td>Discussing prognostic information and advance care planning</td>
</tr>
<tr>
<td>Session 7: Planning for the future (Dyad)</td>
<td>Wrap up and anticipation/planning for future difficult conversations</td>
</tr>
</tbody>
</table>
Phase 2 Methods: Overview

Baseline survey

Delivery of intervention
(7 sessions, across 7-8 weeks)

Post-intervention survey
(Approximately 7 days post-intervention)
Phase 2 Measures

- Feasibility
  - Intervention session completion rates

- Acceptability
  - Ratings of helpfulness, difficulty, and overall satisfaction (liking the intervention)

- Engagement in advance care planning
  - Formally asked someone to be a medical decision maker

- Completion of advance directives (ADs)
  - Living will
  - Healthcare proxy (HCP) form
  - DNR order
Phase 2

Results

• N=21 dyads enrolled in TAC (n=42 participants)
  • n=21 dyads completed baseline measures
  • n=17 dyads started intervention (at least 1 session)
  • n=15 dyads partially completed the intervention (2+ sessions)
  • n=10 dyads completed the intervention (all 7 sessions)
  • n=12 dyads with pre/post data

• Sample characteristics
  • Race: 4.7% Asian, 33.4% white, 61.9% African American
  • Ethnicity: 28.6% Hispanic/Latinx
  • Gender: 47.6% male, 52.4% female
Phase 2 Results: Feasibility and Acceptability

- Caregivers’ ratings of the intervention (n=11 with post-intervention data):
  - Helpfulness (1 to 5 Likert-scale)
    - n=7 (63.6%) rated TAC as “5 = very helpful”
    - n=3 (27.3%) rated as “4”
    - n=1 (9.1%) rated as “3 = Moderately helpful”
  - Difficulty
    - n=10 (90.9%) rated TAC as “1 = not at all difficult” to understand
  - Satisfaction rating
    - n=10, 90.9% reported liking participating in the intervention
Phase 2 Results: Feasibility and Acceptability

- Patients’ ratings of the intervention (n=13 with post-intervention data):
  - Helpfulness (1 to 5 Likert-scale)
    - n=11 (84.6%) rated TAC as “5 = very helpful”
    - n=2 (15.4%) rated as “4”
  - Difficulty
    - n=8 (61.5%) rated TAC as “1 = not at all difficult” to understand
  - Satisfaction rating
    - n=12 (92.3%) reported liking participating in the intervention
Phase 2 Results: Pre-Post Effect

• Patient prognostic understanding (life expectancy; n=11)
  • Pre:
    • Months: n=0 (0%)
    • Years: n=11 (100%)
  • Post:
    • Months: n=1 (9.1%)
    • Years: n=10 (90.9%)

• Caregiver prognostic understanding (life expectancy; n=12)
  • Pre:
    • Months: n=0 (0%)
    • Years: n=12 (100%)
  • Post:
    • Months: n=1 (8.3%)
    • Years: n=9 (75%)
    • Don’t know: n=2 (16.7%)
Phase 2 Results: Pre-Post Effect

- “Have you formally asked someone to be your medical decision maker?” (n=12 patients)
  - Pre:
    - Yes: n=9 (75%)
    - No: n=3 (25%)
  - Post:
    - Yes: n=10 (83.4%)
    - No: n=1 (8.3%)
    - Missing: m=1 (8.3%)
Phase 2 Results: Pre-Post Effect

Completion of DNR order
- Pre:
  - Yes: $n=1$ (8.3%)
  - No: $n=10$ (83.3%)
  - Don’t know: $n=1$ (8.3%)
- Post:
  - Yes: $n=4$ (33.3%)
  - No: $n=8$ (66.6%)

Signing a living will
- Pre:
  - Yes: $n=2$ (16.7%)
  - No: $n=9$ (75.0%)
  - Don’t know: $n=1$ (8.3%)
- Post:
  - Yes: $n=3$ (25.0%)
  - No: $n=6$ (50.0%)
  - Don’t know: $n=3$ (25.0%)

Signing a health care proxy form
- Pre:
  - Yes: $n=5$ (41.7%)
  - No: $n=6$ (50.0%)
  - Don’t know: $n=1$ (8.3%)
- Post:
  - Yes: $n=7$ (58.3%)
  - No: $n=4$ (33.3%)
  - Don’t know: $n=1$ (8.3%)
Discussion

- TAC is a feasible and acceptable intervention
- TAC is associated with increased engagement in advance care planning and HCP form completion

Study strengths
- Time-limited intervention
- Remotely delivered
- Racial and ethnic minority sample

Limitations
- Pre-post design
- Unknown impact of COVID-19 pandemic

Next steps
- Multi-site randomized controlled trial
- Examination of impact of TAC on end-of-life care
Thank You

- Megan J. Shen, PhD
  - mshen2@fredhutch.org
  - @MeganJShenPhD

- Kelly M. Trevino, PhD
  - trevinok@mskcc.org
  - @KTrevino30
Terry A. Badger, PhD, RN, PMHCNS-BC, FAPOS, FAAN

Cancer Survivors and Caregivers: Psychological Distress, Symptom Burden and Health Care Use
Cancer Survivors and Caregivers: Psychological Distress, Symptom Burden and Health Care Use

Terry Badger, PhD, RN, PMHCNS-BC, FAPOS, FAAN
Eleanor Bauwens Endowed Chair and Professor

Funding: Improving Informal Caregivers' and Cancer Survivors' Psychological Distress, Symptom Management and Health Care Use (R01 CA224282), NCI.

THE UNIVERSITY OF ARIZONA
College of Nursing
Symptoms, Health, INnovations, Equity (SHINE)

Dr. Chris Segrin

Dr. Tracy Crane

Dr. Pavani Chalsani

Dr. Echo Warner

Dr. Alla Sikorskii

Dr. Jessica Rainbow
Figure 2. Conceptual framework

Mediators:
- Self-efficacy (dyad)
- Social support: informational and emotional (dyad)
- Caregiver Burden

Interventions for caregivers and survivors
- Symptom Management and Survivorship Handbook (SMSH)
- Telephone Interpersonal Counseling (TIP-C)

Survivor symptoms
- Depression
- Anxiety
- Other

Caregiver symptoms
- Depression
- Anxiety
- Other

Survivor health services use

Caregiver health services use

Moderators (to be explored in Aim 4):
- Sociodemographic & Illness Characteristics
- Intervention receipt & enactment
Sequential multiple assignment randomized trial (SMART) design

Participants are randomized into two conditions at baseline 8-week TIPC or SMSH (Handbook)

Randomized again based on depression and anxiety after 4 weeks of Handbook into TIPC+Handbook or continue with Handbook.

Allow for precision approach, better able to determine who benefits, best dose, timing
Aims

1. Determine if dyads in the TIP-C+SMSH as compared to the SMSH alone group created by the first randomization will have: a) lower depression, anxiety, and summed severity of 13 other symptoms (primary outcomes; b) lower use of healthcare services (secondary outcomes); c) greater self-efficacy, social support, and lower caregiver burden (potential mediators).

2. Among non-responders to the SMSH alone after 4 weeks, determine if dyads in TIPC+SMSH as compared to the SMSH alone group created by the second randomization will have better primary and secondary outcomes.

3. Test the interdependence in survivors’ and caregivers’ primary and secondary outcomes.

4. Determine which characteristics of the dyad are associated with responses to determine tailoring variables for the decision rules of individualized sequencing of interventions in the future.
Telephone Interpersonal Counseling (TIPC)

TIPC is based on interpersonal psychotherapy.

Delivered by Master’s prepared social workers who use interpersonal communication techniques to focus on depression, anxiety, and interactions between the participant and others.

In English and Spanish based on participant preference.

8-counselling sessions (one per week for about 30 minutes) address:

- mood and affect management
- emotional expression
- interpersonal communication and relationships
- social support
- follow-up, resources and referral to resources (e.g., financial)
Symptom Management & Survivorship Handbook (SMSH)

• Each symptom has its own chapter, defining the symptom, how typically the symptom is described, strategies for self management, when to talk with provider, what to report or discuss, more information, and references

• Each week, participant called in English or Spanish and symptoms assessed and referred to appropriate chapter, the following week assess use of strategies and whether successful

• About 10-15 minutes
Survivorship Guidelines

Screening and Surveillance Vaccinations.

Survivorship Care Plan

Healthy Behaviors for a Healthier Life

Maintain a Healthy Weight.

Eating Healthy

Physical Activity

Strategies for Increasing Steps

Tobacco

Alcohol

Sun
Baseline Sample: 380 Dyads plus 20 individual survivors; Total N=400 survivors

Survivors have mean age 59.87 years of age, with 5 chronic conditions (including cancer), 59% married and living with the caregiver.

78% female

42% are Hispanic

Half had a high school education or less with only 19% employed either full or part-time.

Incomes under $39,900 for 57%, incomes barely or did not meet their needs.

91% had health insurance; majority thru Medicare or Medicaid

50% of the sample had breast cancer, and 44% had metastatic disease.
Sample (Total N= 396 Caregivers)

Caregivers had mean age of 54.21 years, with 3.7 comorbid conditions, 64% married.

45% of the caregivers are Hispanic

Spouses comprised 42% of caregivers, followed by daughters (20%)

30% had a high school education or less with 47% employed either full or part time.

57% had incomes under $39,900; income barely or did not meet their needs for 48%

Majority had health insurance by Medicare and/or current employer
Next Steps

- Currently have about 40 dyads in protocol with target completion in early April
- Begun analysis of baseline data
- Longitudinal analysis after dyads complete protocol
- Future research: currently second randomization is based on response to SMSH on depression and anxiety; two consecutive weeks may be key in the future
- Testing of automated symptom management assessments and referral to Handbook
Questions?
Please type your questions in the Q & A section on WebEx

Stay connected with us!
Subscribe to our email listserv using the link on our homepage: healthcaredelivery.cancer.gov

Follow us on Twitter: @NCICareDelivRes
Join the next session on March 17, 2022

Holly G. Prigerson, PhD
Irving Sherwood Wright Professor in Geriatrics
Professor of Sociology in Medicine
Director, Cornell Center for Research on End-of-Life Care
Department of Medicine
Weill Cornell Medicine

Wendy G. Lichtenthal, PhD, FT
Director, Bereavement Clinic
Associate Attending Psychologist
Department of Psychiatry and Behavioral Sciences
Memorial Sloan Kettering Cancer Center

Kathrin Milbury, PhD
Associate Professor
Department of Behavioral Science
The University of Texas MD Anderson Cancer Center

Susan Mazanec, PhD, RN, AOCN, FAAN
Assistant Professor
Frances Payne Bolton School of Nursing, Case Western Reserve University
Nurse Scientist
University Hospitals Seidman Cancer Center

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