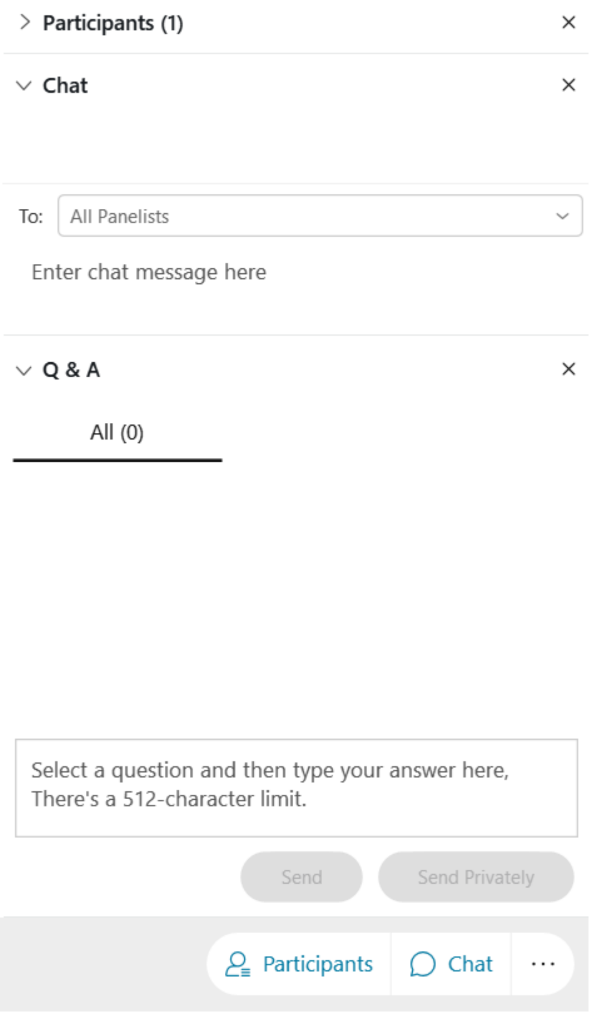
Supporting the Science of Informal Cancer Caregiving:

Highlights of NCI-Funded Research

Webinar 2 – Wednesday, February 23, 2022 1 PM ET

Using WebEx and webinar logistics



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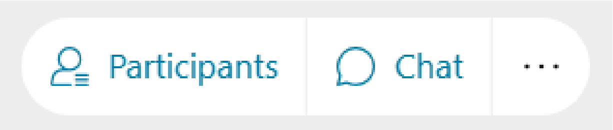

- This webinar is being recorded

Welcome from the National Cancer Institute

Ashley Wilder Smith, PhD, MPH
Chief, Outcomes Research Branch
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Division of Cancer Control and Population Sciences
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Michelle Mollica, PhD, MPH, RN, OCN
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Molly Maher, MS
Cancer Research Training Award Fellow, Outcomes Research Branch, Healthcare Delivery Research Program
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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

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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

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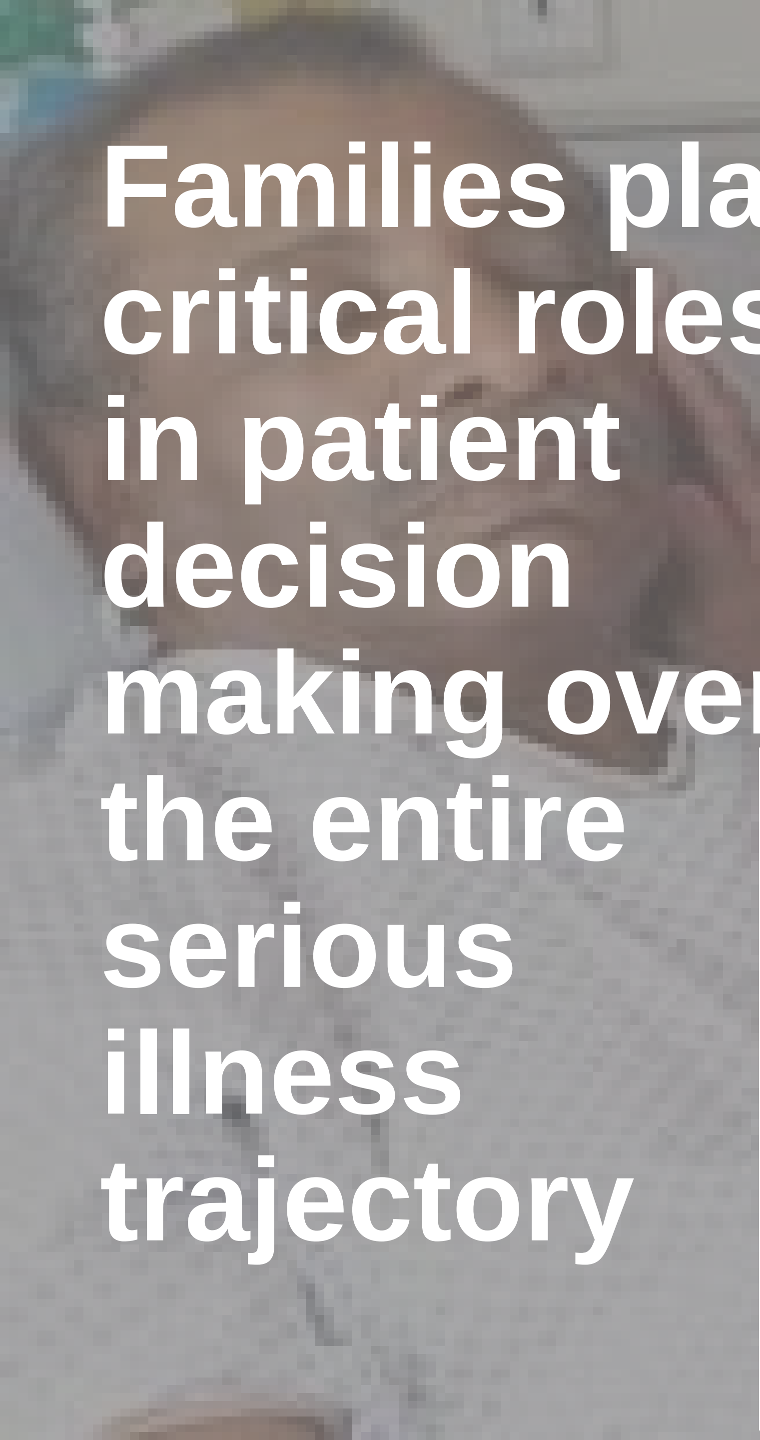
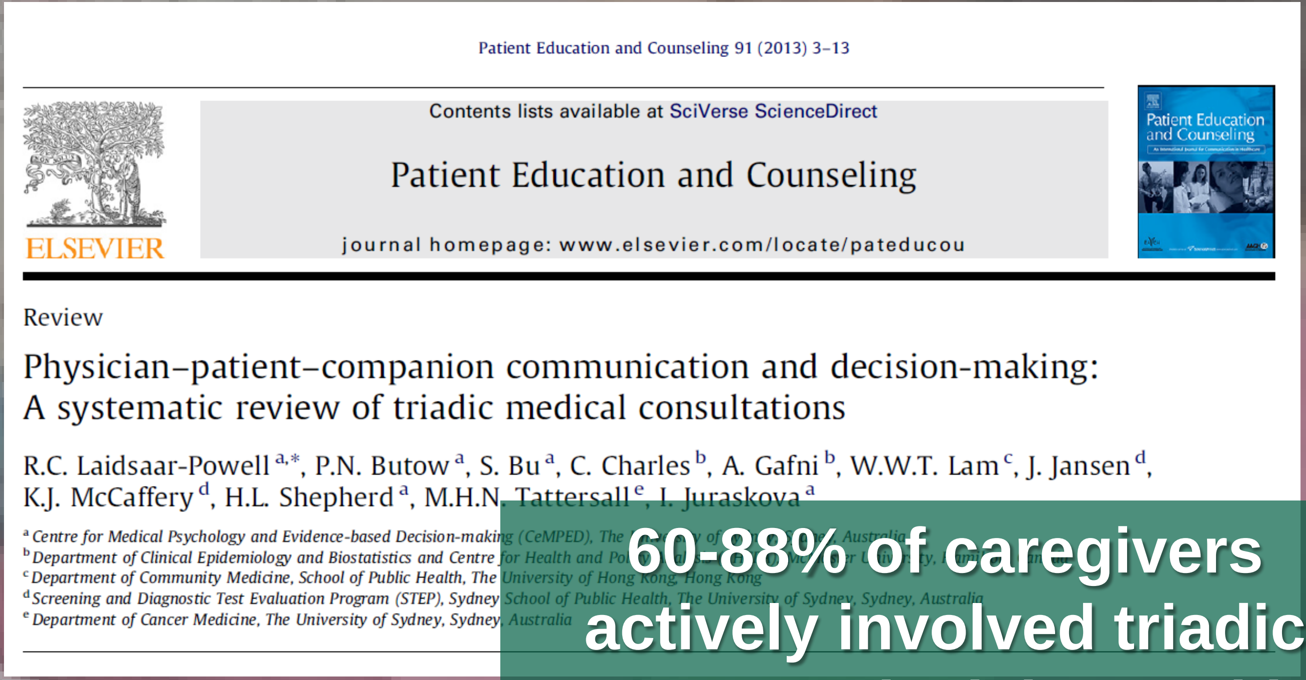


Families play critical roles in patient decision making over the entire serious illness trajectory



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Review

Physician–patient–companion communication and decision-making: A systematic review of triadic medical consultations

R.C. Laidsaar-Powell [a,*], P.N. Butow [a], S. Bu [a], C. Charles [b], A. Gafni [b], W.W.T. Lam [c], J. Jansen [d], K.J. McCaffery [d], H.L. Shepherd [a], M.H.N. Tattersall [e], I. Juraskova [a]

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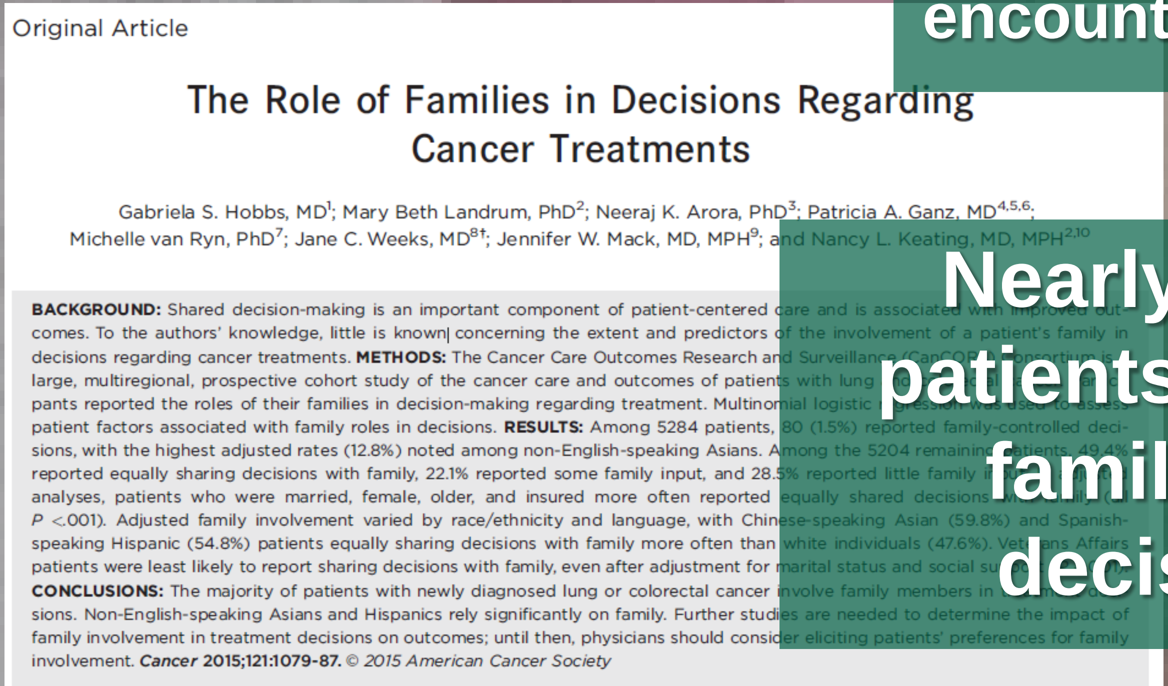
60-88% of caregivers actively involved triadic encounter decision-making



Original Article

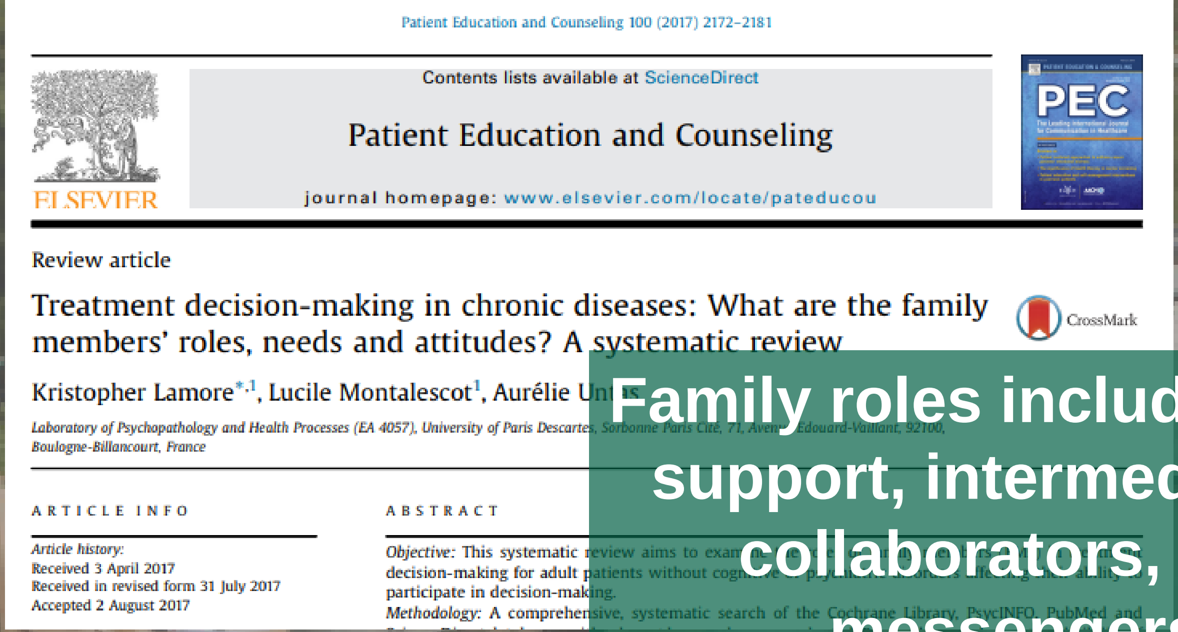
The Role of Families in Decisions Regarding Cancer Treatments

Gabriela S. Hobbs, MD[1]; Mary Beth Landrum, PhD[2]; Neeraj K. Arora, PhD[3]; Patricia A. Ganz, MD[4,5,6]; Michelle van Ryn, PhD[7]; Jane C. Weeks, MD[8†]; Jennifer W. Mack, MD, MPH[9]; and Nancy L. Keating, MD, MPH[2,10]

BACKGROUND: Shared decision-making is an important component of patient-centered care and is associated with improved outcomes. To the authors' knowledge, little is known concerning the extent and predictors of the involvement of a patient's family in decisions regarding cancer treatments. **METHODS:** The Cancer Care Outcomes Research and Surveillance (CanCORS) consortium is a large, multiregional, prospective cohort study of the cancer care and outcomes of patients with lung [illegible] pants reported the roles of their families in decision-making regarding treatment. Multinomial logistic regression was used to assess patient factors associated with family roles in decisions. **RESULTS:** Among 5284 patients, 80 (1.5%) reported family-controlled decisions, with the highest adjusted rates (12.8%) noted among non-English-speaking Asians. Among the 5204 remaining patients, 49.4% reported equally sharing decisions with family, 22.1% reported some family input, and 28.5% reported little family [illegible] analyses, patients who were married, female, older, and insured more often reported equally shared decisions [illegible] $P <.001$). Adjusted family involvement varied by race/ethnicity and language, with Chinese-speaking Asian (59.8%) and Spanish-speaking Hispanic (54.8%) patients equally sharing decisions with family more often than white individuals (47.6%). Veterans Affairs patients were least likely to report sharing decisions with family, even after adjustment for marital status and social su[illegible] **CONCLUSIONS:** The majority of patients with newly diagnosed lung or colorectal cancer involve family members in [illegible] sions. Non-English-speaking Asians and Hispanics rely significantly on family. Further studies are needed to determine the impact of family involvement in treatment decisions on outcomes; until then, physicians should consider eliciting patients' preferences for family involvement. ***Cancer* 2015;121:1079-87.** *© 2015 American Cancer Society*

Nearly 3-in-4 patients include families in decisions

Families play critical roles in patient decision making over the entire serious illness trajectory



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Review article

Treatment decision-making in chronic diseases: What are the family members' roles, needs and attitudes? A systematic review

Kristopher Lamore*,[1], Lucile Montalescot[1], Aurélie Un[illegible]

Laboratory of Psychopathology and Health Processes (EA 4057), University of Paris Descartes, Sorbonne Paris Cité, 71, Aven[illegible] Edouard-Vaillant, 92100, Boulogne-Billancourt, France

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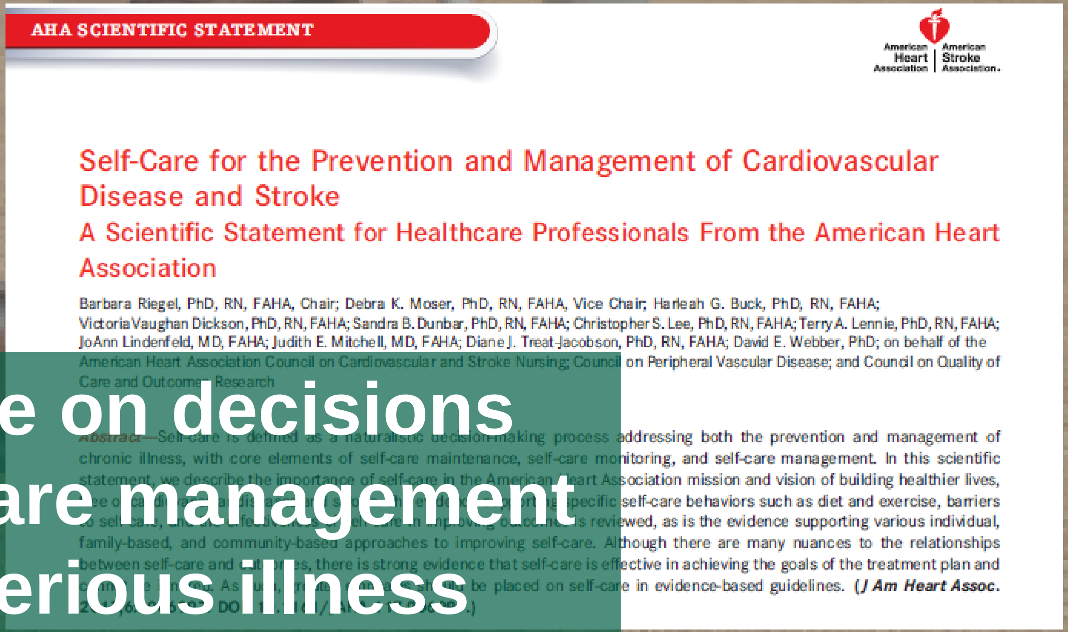
ABSTRACT

Objective: This systematic review aims to exam[illegible] decision-making for adult patients without cogn[illegible] ability to participate in decision-making.
Methodology: A comprehensive, systematic search of the Cochrane Library, PsycINFO, PubMed and

Family roles include social support, intermediaries, collaborators, and messengers



AHA SCIENTIFIC STATEMENT

Self-Care for the Prevention and Management of Cardiovascular Disease and Stroke

A Scientific Statement for Healthcare Professionals From the American Heart Association

Barbara Riegel, PhD, RN, FAHA, Chair; Debra K. Moser, PhD, RN, FAHA, Vice Chair; Harleah G. Buck, PhD, RN, FAHA; Victoria Vaughan Dickson, PhD, RN, FAHA; Sandra B. Dunbar, PhD, RN, FAHA; Christopher S. Lee, PhD, RN, FAHA; Terry A. Lennie, PhD, RN, FAHA; JoAnn Lindenfeld, MD, FAHA; Judith E. Mitchell, MD, FAHA; Diane J. Treat-Jacobson, PhD, RN, FAHA; David E. Webber, PhD; on behalf of the American Heart Association Council on Cardiovascular and Stroke Nursing; Council on Peripheral Vascular Disease; and Council on Quality of Care and Outcomes Research

[illegible] addressing both the prevention and management of chronic illness, with core elements of self-care maintenance, self-care monitoring, and self-care management. In this scientific statement, we describe the importance of self-care in the American Heart Association mission and vision of building healthier lives, [illegible] specific self-care behaviors such as diet and exercise, barriers [illegible] is reviewed, as is the evidence supporting various individual, family-based, and community-based approaches to improving self-care. Although there are many nuances to the relationships between self-care and [illegible] there is strong evidence that self-care is effective in achieving the goals of the treatment plan and [illegible] be placed on self-care in evidence-based guidelines. (*J Am Heart Assoc.* [illegible])

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

PLOS ONE

RESEARCH ARTICLE

How family caregivers of persons with advanced cancer assist with upstream healthcare decision-making: A qualitative study

J. Nicholas Dionne-Odom[1,2]*, Deborah Ejem[1], Rachel Wells[1], Amber E. Barnato[3], Richard A. Taylor[1], Gabrielle B. Rocque[2], Yasemin E. Turkman[1], Matthew Kenny[1], Nataliya V. Ivankova[1,4], Marie A. Bakitas[1,2], Michelle Y. Martin[5]

1 School of Nursing, University of Alabama at Birmingham, Birmingham, Alabama, United States of America

- 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

2^4 full factorial optimization trial design

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.

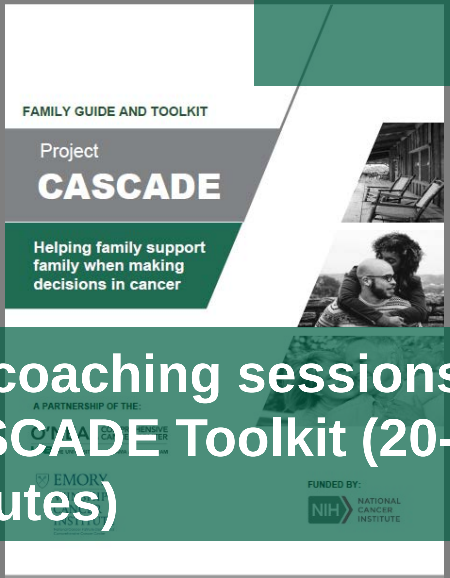
Design

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

Family caregivers and patients with newly diagnosed cancer



FAMILY GUIDE AND TOOLKIT

Project
CASCADE

Helping family support family when making decisions in cancer

A PARTNERSHIP OF THE:

EMORY

FUNDED BY:

NIH NATIONAL CANCER INSTITUTE

1-5 coaching sessions using CASCADE Toolkit (20-30 minutes)

Lay navigator coach-led

Phone + In-person interaction

There are 4 components being tested as part of the CASCADE package

1. Coaching on how to be an effective source of decision support

1 session
vs
3 sessions

PART 1

PARTNERING WITH YOUR FAMILY MEMBER IN DECISION MAKING: UNDERSTANDING YOUR MANY ROLES

It has been said that when a person gets cancer, the whole family gets cancer. Life changes suddenly and many decisions have to made involving both your loved one and yourself. Some decisions are about treatment. Other decisions arise from having to adjust work and family life. The future can be uncertain. But what is certain is that there will be more challenges to face and more decisions to be made. We want to help you provide the best support you can for your loved one when facing decisions.

2. Decision support communication skills training

1 session
vs
No sessions

PART 4

PARTNERING WITH YOUR FAMILY MEMBER IN DECISION MAKING: KEYS TO COMMUNICATION

Poor communication can be the underlying cause of misunderstandings and stress in relationships with family, friends, and healthcare professionals. But it doesn't have to be this way.

Good communication skills are critical and this section will review keys to enhancing the communication process.

3. Ottawa Decision Guide training

1 session
vs
No sessions

PART 5

PARTNERING WITH YOUR FAMILY IN DECISION MAKING: THE OTTAWA DECISION GUIDE

There are many helpful tools called 'decision aids' to help you and your family to make decisions. These tools help people understand the likely outcomes of the options they face and think about their values as they relate to the risks and benefits of each option. Decision aids come in many forms: they may be videotapes, audiotapes with workbooks, booklets, CDs, or websites.

We want to introduce you to one type of paper-and-pencil decision aid: the Ottawa Decision Guide.

4. Monthly follow-up calls

1 monthly f/u call
vs
Monthly calls for 24 weeks

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

Coaching on Providing Decision Support: 3-Session Version

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

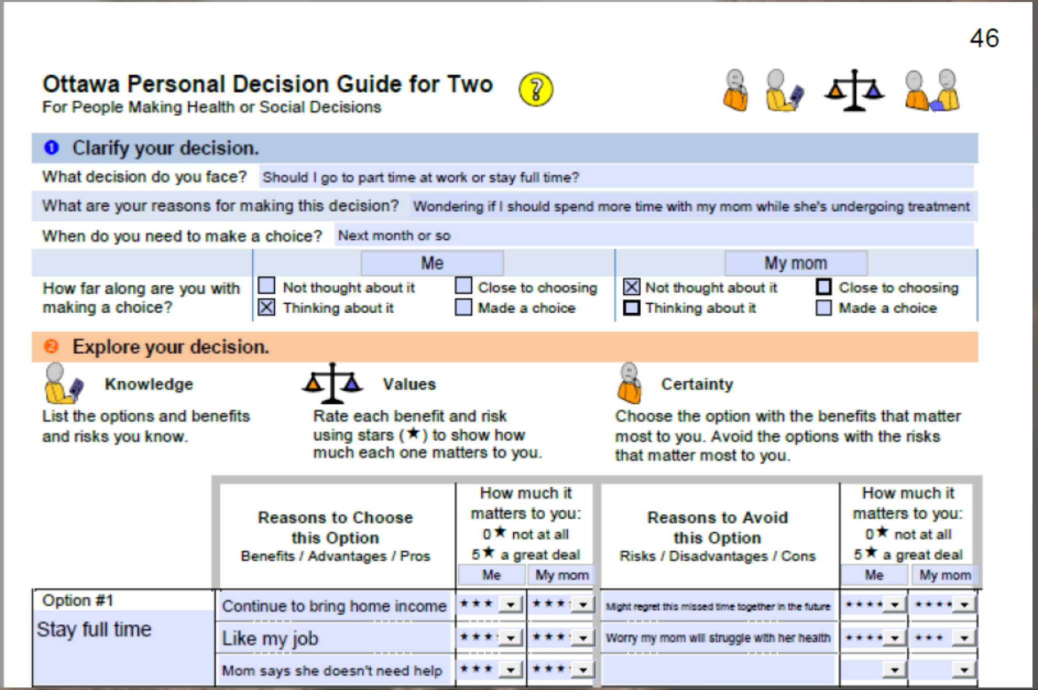
- Recognizing the role of values
- Advance directives/being a health care proxy

Decision support communication training

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

Ottawa Decision Guide training

- Decision aids
- How to use the Ottawa Decision Guide



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Ottawa Personal Decision Guide for Two
For People Making Health or Social Decisions

❶ Clarify your decision.

What decision do you face? Should I go to part time at work or stay full time?

What are your reasons for making this decision? Wondering if I should spend more time with my mom while she's undergoing treatment

When do you need to make a choice? Next month or so

	Me		My mom	
How far along are you with making a choice?	☐ Not thought about it	☐ Close to choosing	☒ Not thought about it	☐ Close to choosing
	☒ Thinking about it	☐ Made a choice	☐ Thinking about it	☐ Made a choice

❷ Explore your decision.

Knowledge
List the options and benefits and risks you know.

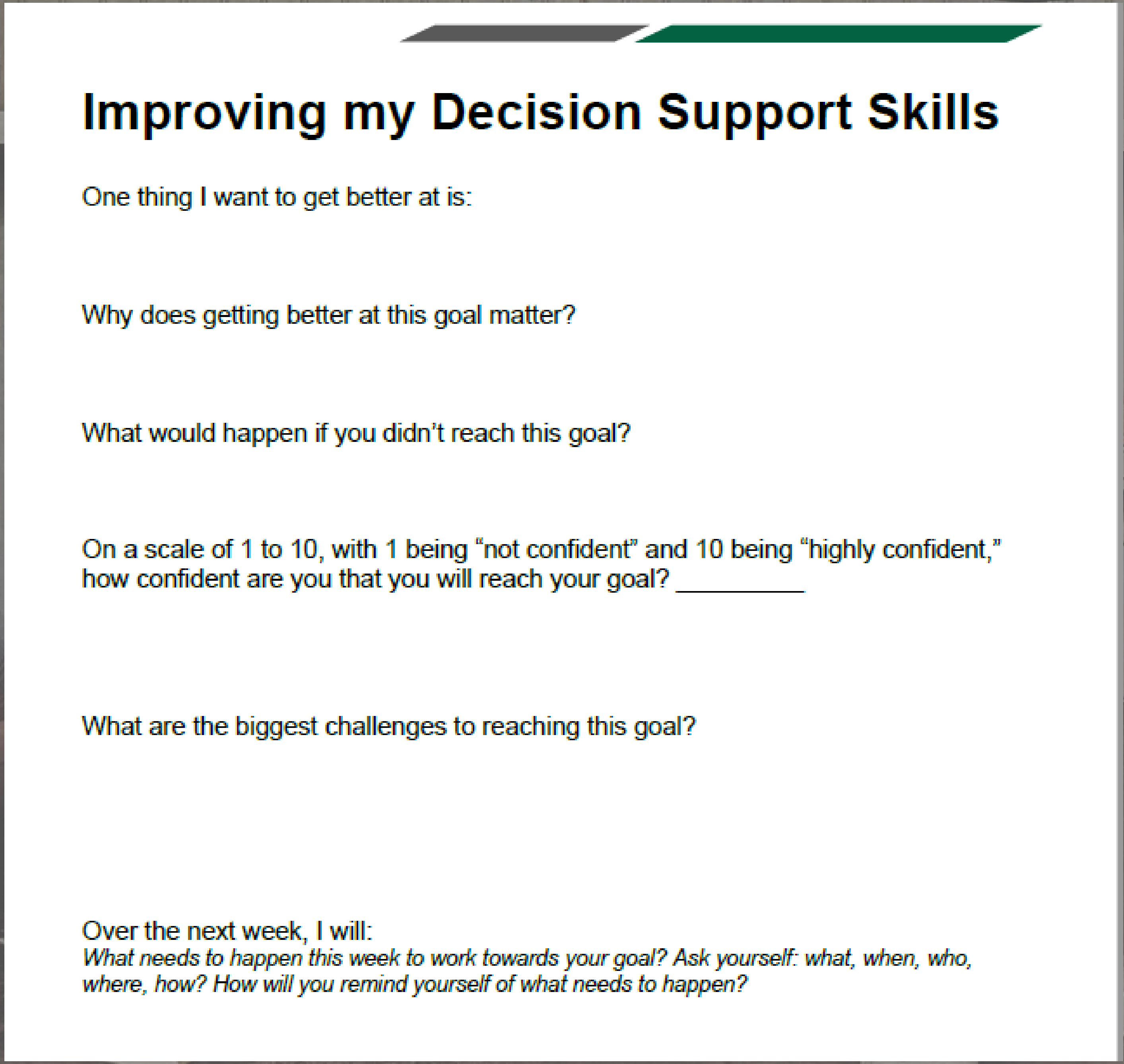
Values
Rate each benefit and risk using stars (★) to show how much each one matters to you.

Certainty
Choose the option with the benefits that matter most to you. Avoid the options with the risks that matter most to you.

	Reasons to Choose this Option Benefits / Advantages / Pros	How much it matters to you: 0★ not at all 5★ a great deal		**Reasons to Avoid this Option** Risks / Disadvantages / Cons	How much it matters to you: 0★ not at all 5★ a great deal	
		Me	My mom		Me	My mom
Option #1 Stay full time	Continue to bring home income	★★★	★★★	Might regret this missed time together in the future	★★★★	★★★★
	Like my job	★★★	★★★	Worry my mom will struggle with her health	★★★★	★★★
	Mom says she doesn't need help	★★★	★★★			

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



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?

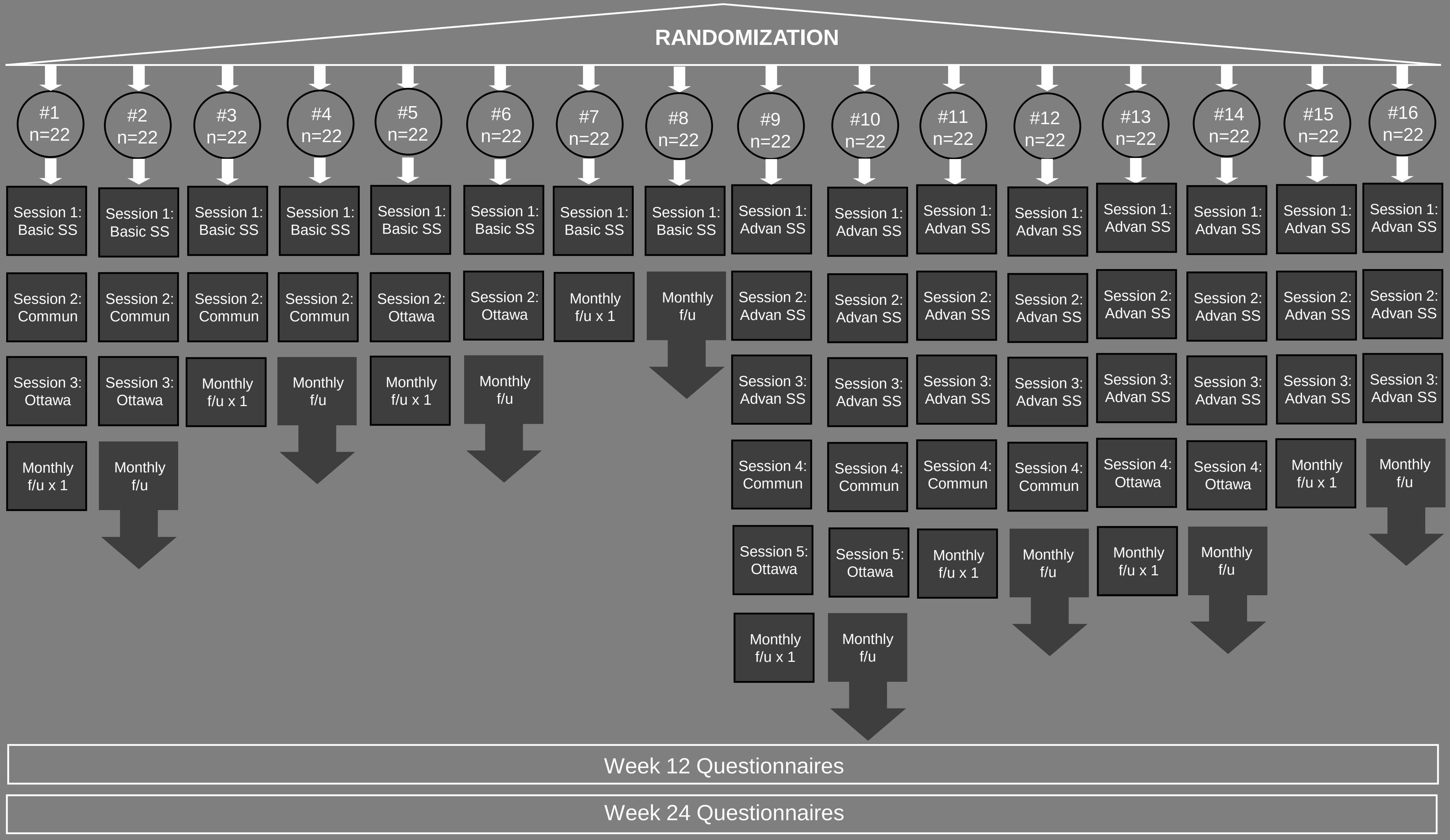
Sessions conclude with an action planning activity

2^4 factorial trial design

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

Overall study flow

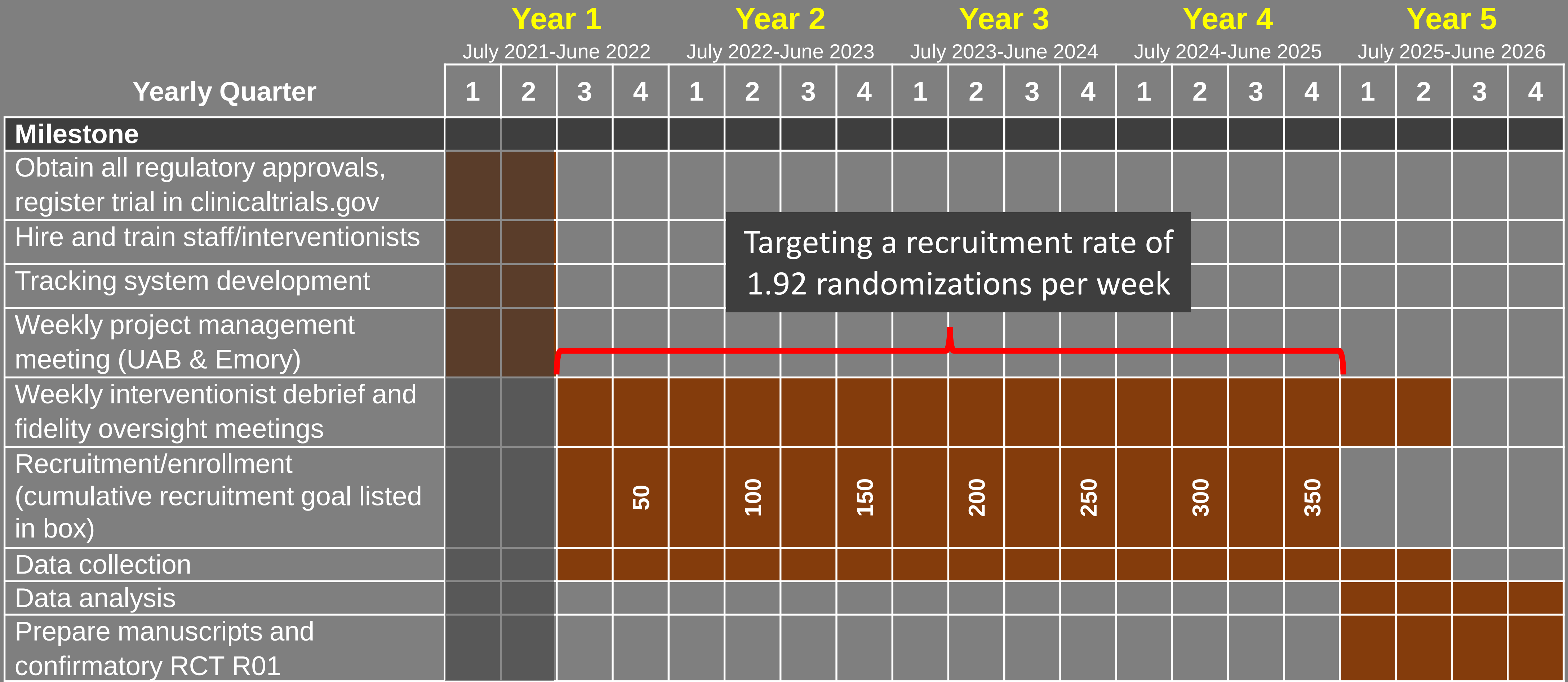
Screen, approach, consent, and have participants complete baseline questionnaires by mail (Target N=352 family caregivers & 352 patients



RANDOMIZATION

Intervention condition	#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	#13 n=22	#14 n=22	#15 n=22	#16 n=22
Week 1	Session 1: Basic SS	Session 1: Basic SS	Session 1: Basic SS	Session 1: Basic SS	Session 1: Basic SS	Session 1: Basic SS	Session 1: Basic SS	Session 1: Basic SS	Session 1: Advan SS	Session 1: Advan SS	Session 1: Advan SS	Session 1: Advan SS	Session 1: Advan SS	Session 1: Advan SS	Session 1: Advan SS	Session 1: Advan SS
Week 2	Session 2: Commun	Session 2: Commun	Session 2: Commun	Session 2: Commun	Session 2: Ottawa	Session 2: Ottawa	Monthly f/u x 1	Monthly f/u	Session 2: Advan SS	Session 2: Advan SS	Session 2: Advan SS	Session 2: Advan SS	Session 2: Advan SS	Session 2: Advan SS	Session 2: Advan SS	Session 2: Advan SS
Week 3	Session 3: Ottawa	Session 3: Ottawa	Monthly f/u x 1	Monthly f/u	Monthly f/u x 1	Monthly f/u			Session 3: Advan SS	Session 3: Advan SS	Session 3: Advan SS	Session 3: Advan SS	Session 3: Advan SS	Session 3: Advan SS	Session 3: Advan SS	Session 3: Advan SS
Week 4	Monthly f/u x 1	Monthly f/u							Session 4: Commun	Session 4: Commun	Session 4: Commun	Session 4: Commun	Session 4: Ottawa	Session 4: Ottawa	Monthly f/u x 1	Monthly f/u
Week 5									Session 5: Ottawa	Session 5: Ottawa	Monthly f/u x 1	Monthly f/u	Monthly f/u x 1	Monthly f/u		
Week 6									Monthly f/u x 1	Monthly f/u						
…																
Week 12	Week 12 Questionnaires															
Week 24	Week 24 Questionnaires															

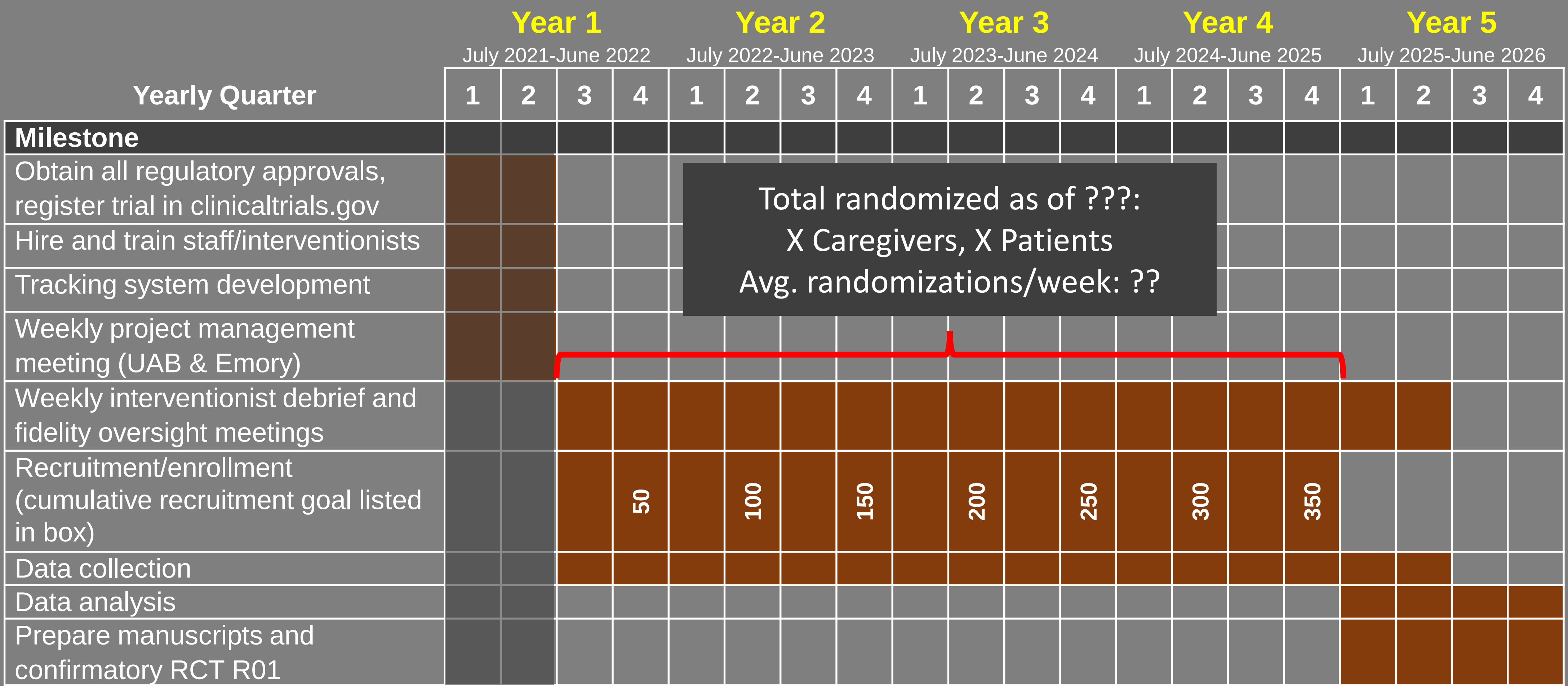
Timeline



	Year 1				Year 2				Year 3				Year 4				Year 5			
	July 2021-June 2022				July 2022-June 2023				July 2023-June 2024				July 2024-June 2025				July 2025-June 2026			
Yearly Quarter	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4	1	2	3	4
Milestone																				
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)			■	50	■	100	■	150	■	200	■	250	■	300	■	350				
Data collection			■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■		
Data analysis																	■	■	■	■
Prepare manuscripts and confirmatory RCT R01																	■	■	■	■

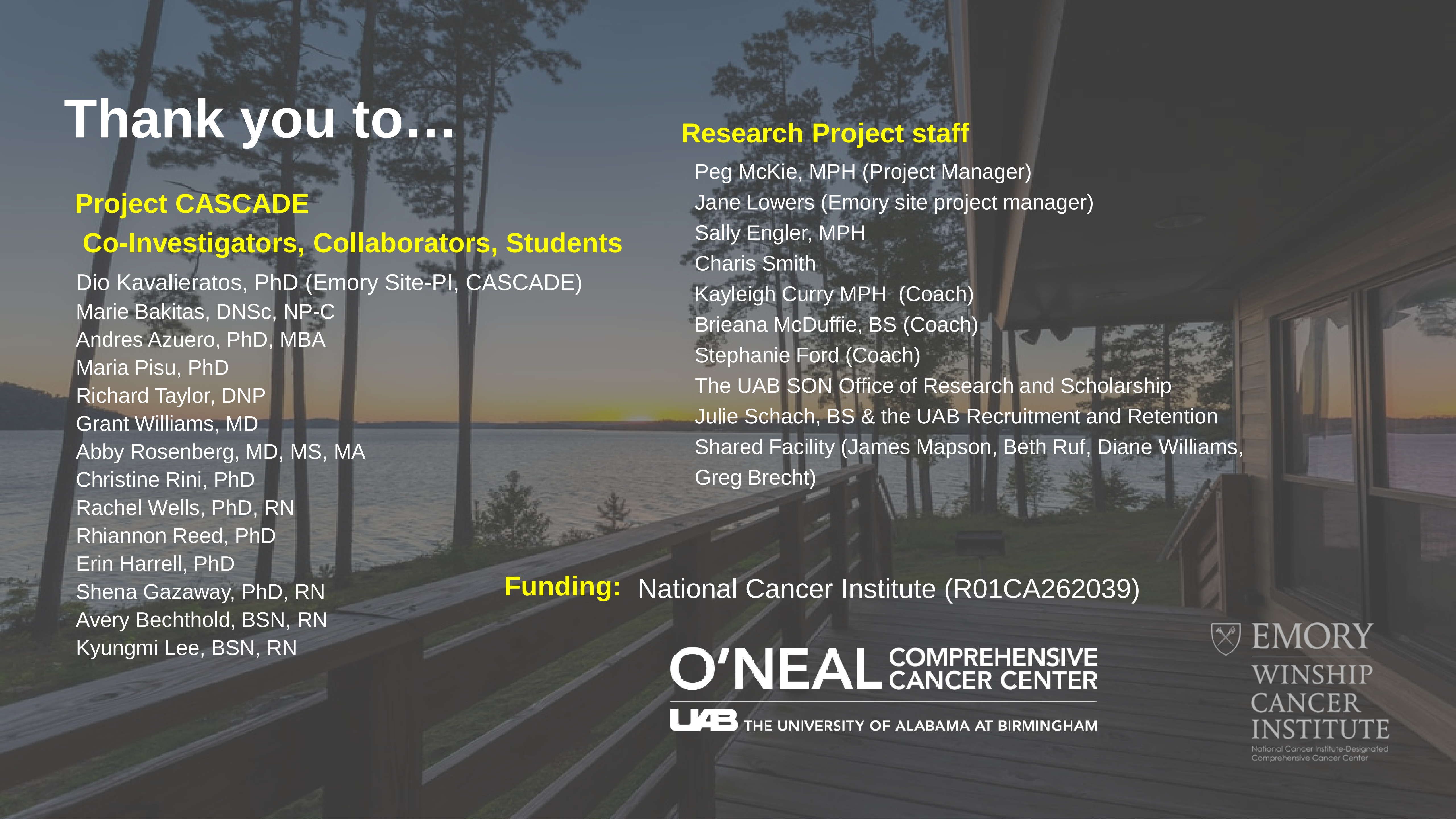
Targeting a recruitment rate of 1.92 randomizations per week

Timeline



	Year 1 July 2021-June 2022				**Year 2** July 2022-June 2023				**Year 3** July 2023-June 2024				**Year 4** July 2024-June 2025				**Year 5** July 2025-June 2026			
Yearly Quarter	**1**	**2**	**3**	**4**	**1**	**2**	**3**	**4**	**1**	**2**	**3**	**4**	**1**	**2**	**3**	**4**	**1**	**2**	**3**	**4**
Milestone																				
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)			■	50	■	100	■	150	■	200	■	250	■	300	■	350				
Data collection			■	■	■	■	■	■	■	■	■	■	■	■	■	■	■	■		
Data analysis																	■	■	■	■
Prepare manuscripts and confirmatory RCT R01																	■	■	■	■

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



Thank you to…

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UAB THE UNIVERSITY OF ALABAMA AT BIRMINGHAM

EMORY
WINSHIP CANCER INSTITUTE
National Cancer Institute-Designated Comprehensive Cancer Center

Kelly Trevino, PhD

Megan J. Shen, PhD

Talking About Cancer: Development and Evaluation of a Patient-Caregiver Communication Intervention to Improve Advance Care Planning

NIH NATIONAL CANCER INSTITUTE

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)

	n (%)	% DNR Order "Yes"
Patient-Caregiver Prognostic Understanding		**χ^2=21.27, p=.000**
Patient and caregiver have prognostic understanding	60 (27.8%)	70.7%
Neither patient or caregiver have prognostic understanding	96 (44.4%)	36.3%
Only patient has prognostic understanding	21 (9.7%)	38.9%
Only caregiver has prognostic understanding	39 (18.1%)	31.6%

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

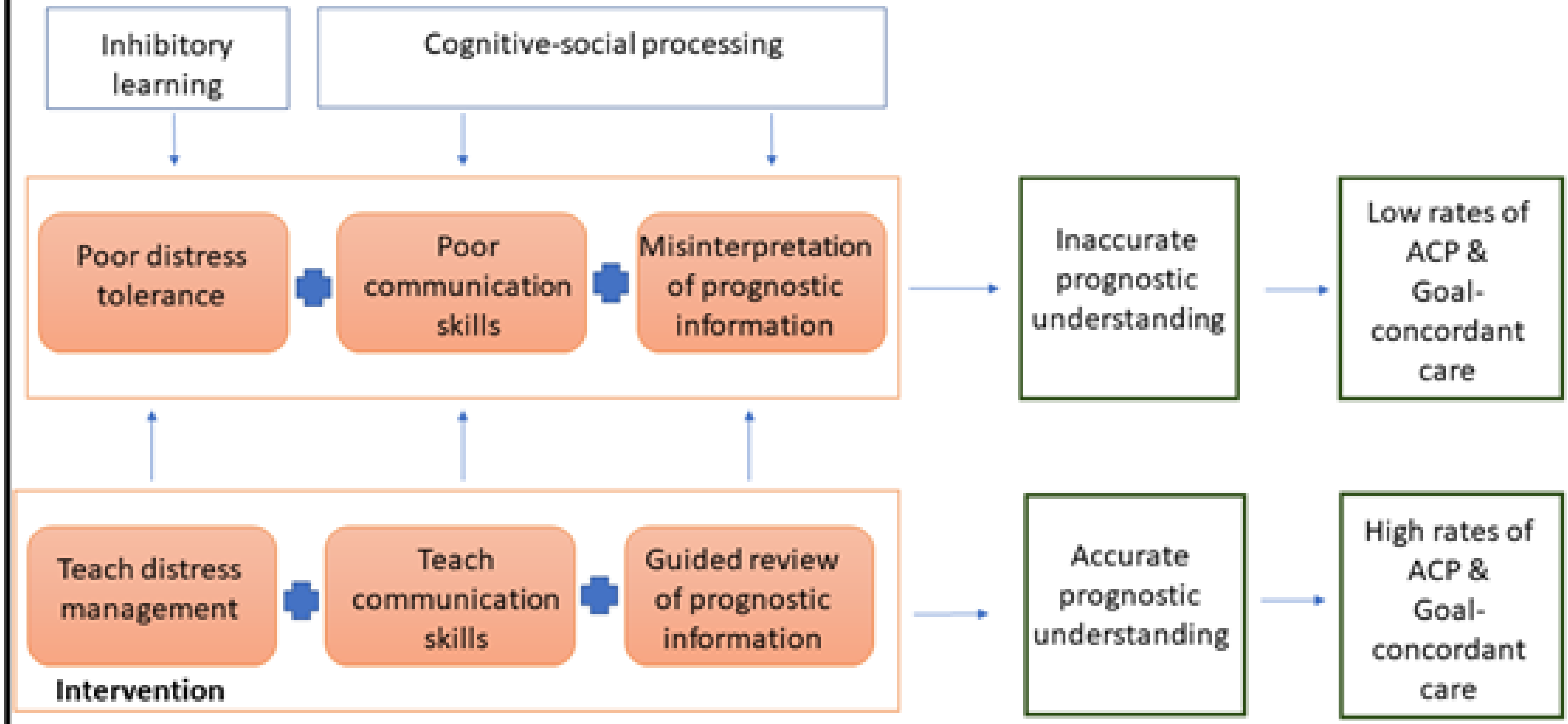

Figure 1. Theoretical framework

Craske et al., 2008, Behav. Res. Ther.; Blakey et al., 2016, Clin. Psychol. Rev.; Baike et al., 2011, JMFT; Cordova et al., 2001, J Consult Clin Psychol

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

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

Phase 1 Results: Modified TAC

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

Baseline survey

Delivery of intervention

(7 sessions, across 7-8 weeks)

Post-intervention survey

(Approximately 7 days post-intervention)

Phase 2 Methods: Overview

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

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

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

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Symptoms, Health, INnovations, Equity (SHINE)

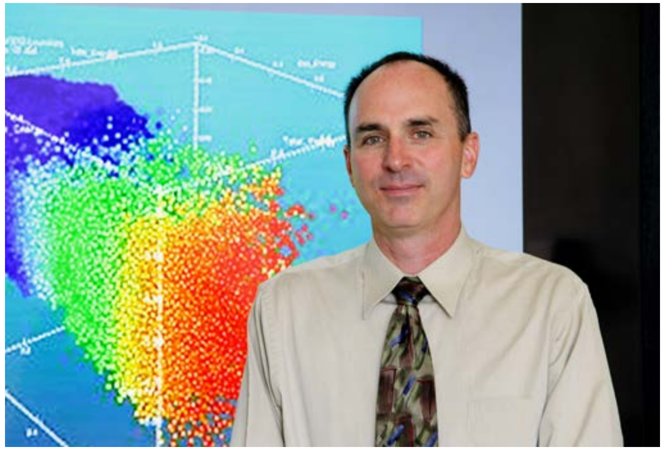
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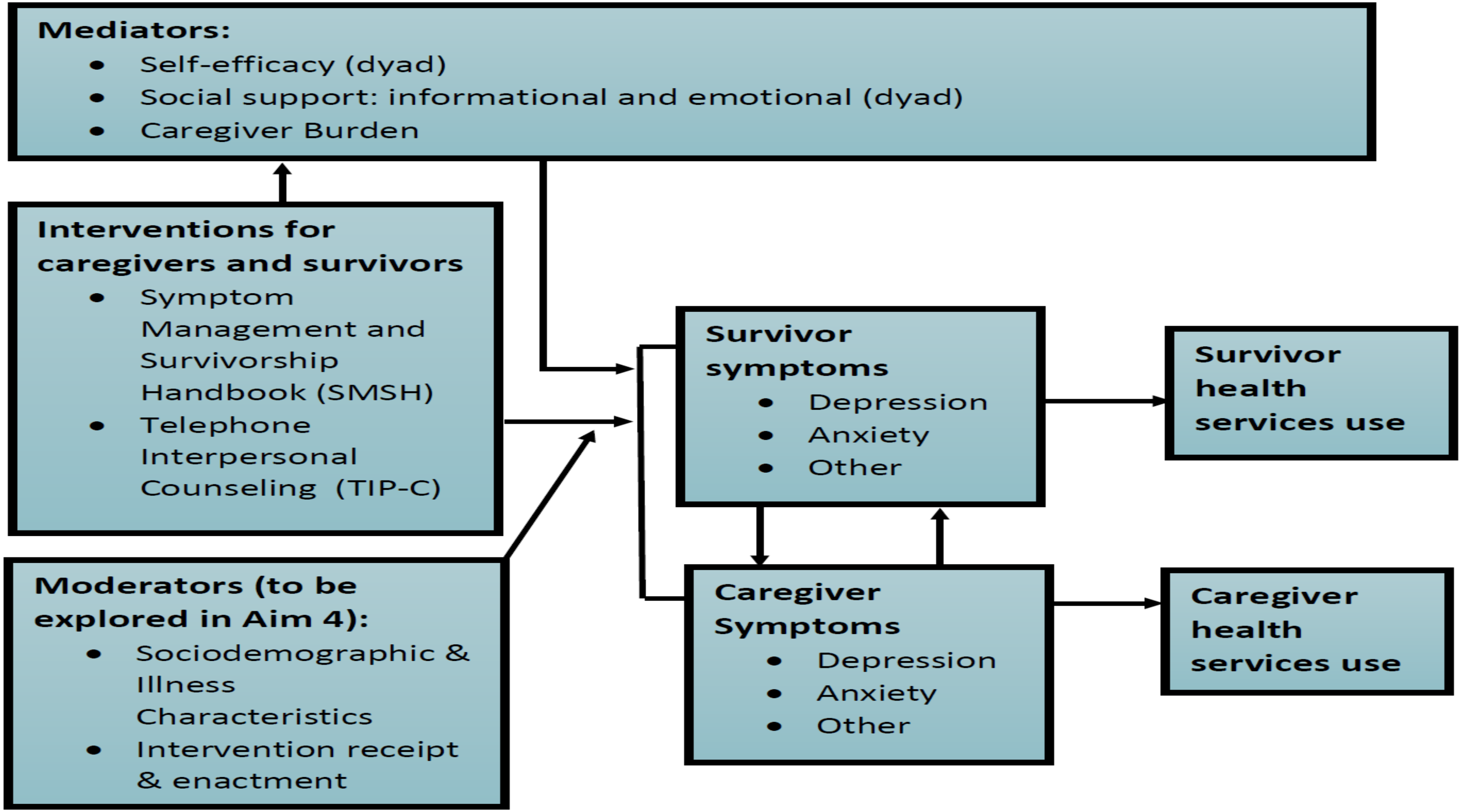
Figure 2. Conceptual framework



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)

Moderators (to be explored in Aim 4):

- Sociodemographic & Illness Characteristics
- Intervention receipt & enactment

Survivor symptoms

- Depression
- Anxiety
- Other

Caregiver Symptoms

- Depression
- Anxiety
- Other

Survivor health services use

Caregiver health services use

Sequential multiple assignment randomized trial (SMART) design

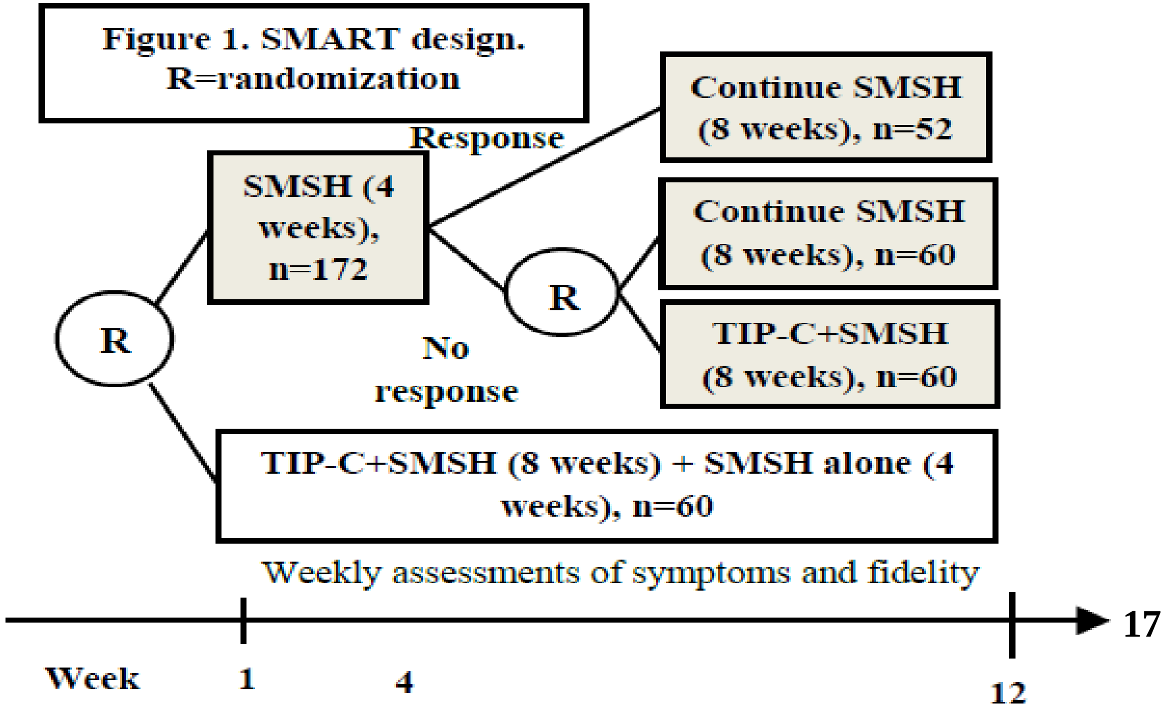


Figure 1. SMART design.
R=randomization

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.

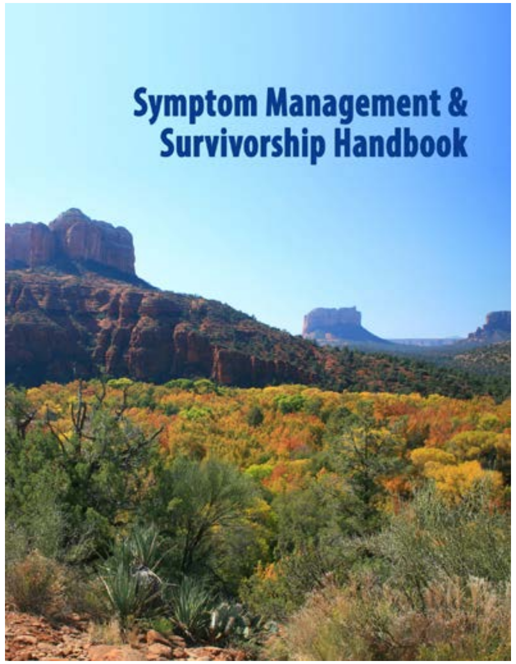
In English and Spanish based on participant preference

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

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