



CAROLINE E. STEPHENS, PHD, RN, GNP, FGSA, FAAN
Associate Professor, Helen Lowe Bamberger Colby
Presidential Endowed Chair in Gerontological Nursing

- 20+ years clinical experience as Gerontological Nurse Practitioner & Geropsychiatric Advanced Practice Nurse
- PhD Gerontological Nursing & Health Policy
- Interdisciplinary community-engaged program of research focused on improving the health and care of older adults with complex physical, cognitive and mental multi-morbidity at high risk for poor care transitions and their formal and informal and caregivers
- Employ diverse mixed methods; focus groups; quality improvement; clinical trials; implementation science; advanced quantitative analyses of population-based datasets

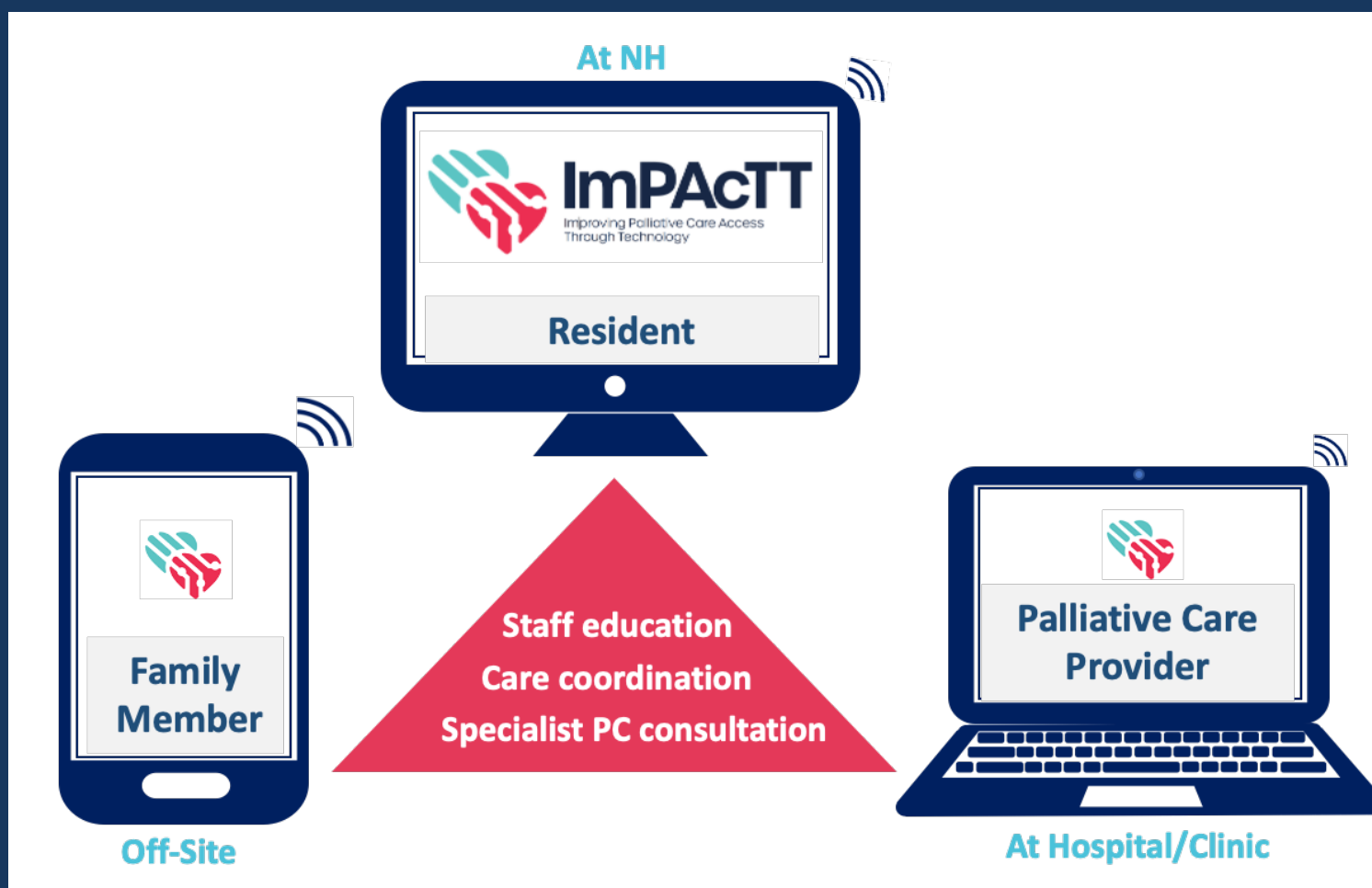
PALLIATIVE CARE ELIGIBILITY, SYMPTOM BURDEN & FAMILIES



- Over 2/3 of nursing home residents are considered eligible for palliative care services and supports
- Few residents and families recognize or recall the POLST despite nearly 100% completion
- Symptom burden is high for residents, and more so than perceived by families
- Family knowledge gaps lead to them to feeling unprepared to effectively advocate for the needs and wishes of the resident

Overview of ImPAcTT

Improving Palliative Care Access Through Technology



- ✓ Acceptable and feasible, while lowering symptom severity, facilitating GOC discussions, and improving NH residents' QOL



THE UNIVERSITY OF UTAH

Consortium for Families and Health Research



Family Caregiving Collaborative

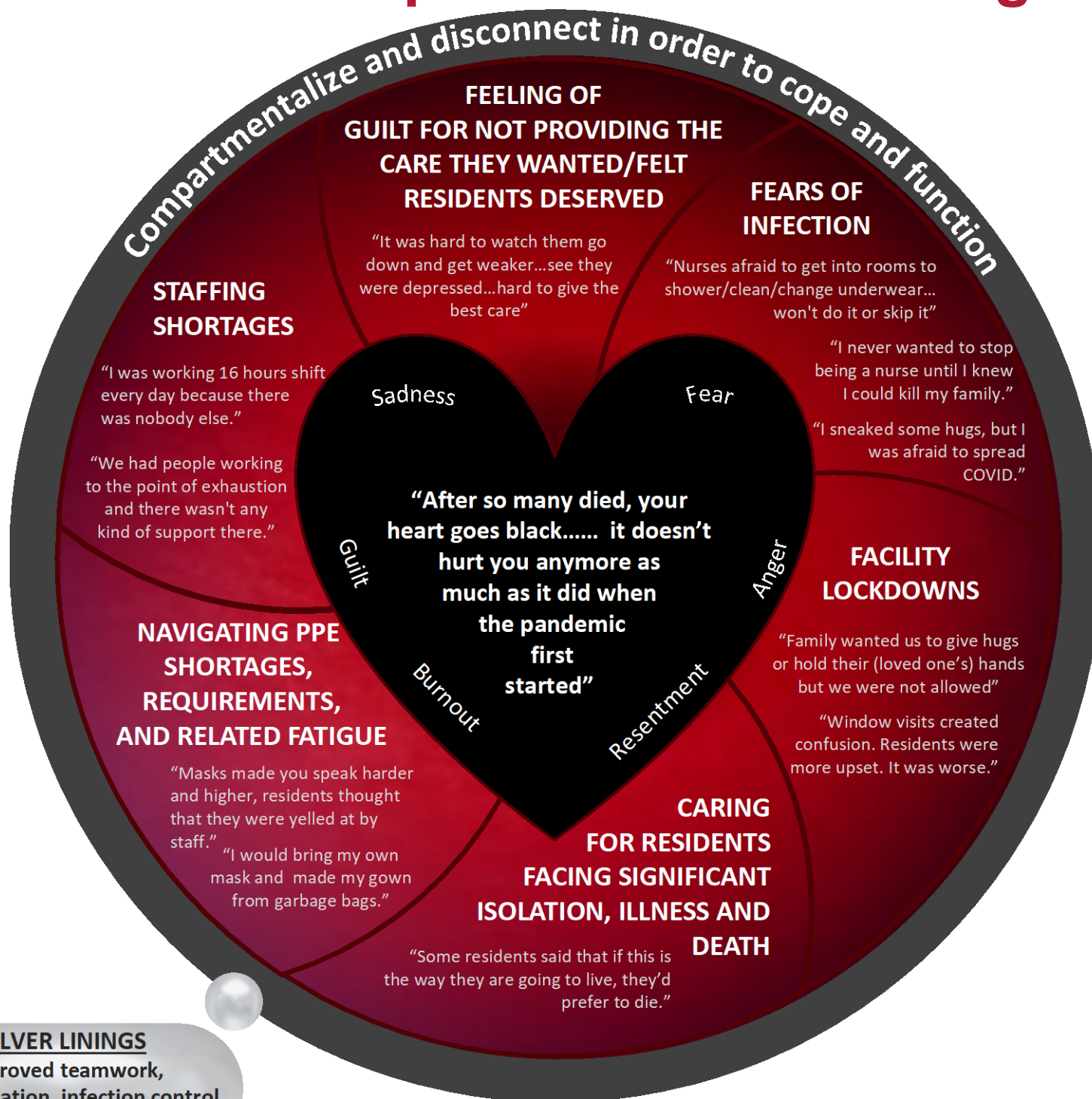


Utah C-PopS: Utah Caregiving Population Studies

- **Leveraging the Utah Population Database (UPDB) to advance family caregiving research**
- **Multiple interdisciplinary research teams, fostering new institutional collaborations and partnerships, and providing training to enhance the U's collective success in securing extramural funding for secondary data analyses related to the dynamics of caregiving within a family system, particularly at the end-of-life and across care settings**



“Your heart goes black”: The emotional toll of the COVID-19 pandemic on nursing home staff



Participant Characteristics (N=29)	
Age (years)	%
18-40	41
41-50	28
Over 50	31
Female	90
White	83
Stakeholder Role	
Staff*	66
Residents	7
Family	28
Location of 23 Facilities in 11 states	
Rural	49
Urban	51
Staff Reported COVID-19 Facility Outbreak	90
>25% Residents Infected	30
>25% Residents Died	6
>25% Staff Infected	47

*Staff Roles: 3 RNs, 3 LVNs, 8 CNAs, 3 SW, 2 Administrators

SILVER LININGS
Improved teamwork, communication, infection control, use of telehealth

PEPPER CENTER SUPPORT

- Recruitment resource for nursing home/ family caregiver interventions
- Community Advisory Board(s)
- Access to data and interdisciplinary collaborations for NIH & PCORI grants
- Link UPDB data with caregiver dyads to further identify clinical and family characteristics that influence cognitive resilience, health and health care utilization across care settings
- Grant funding for translation, dissemination, & ancillary studies
- Potential methodological core partnership with Utah C-PopS for population-based studies



Utah C-PopS



THE INTERSECTIONALITY OF DECISION- MAKING AND DEMENTIA ADVANCE CARE PLANNING

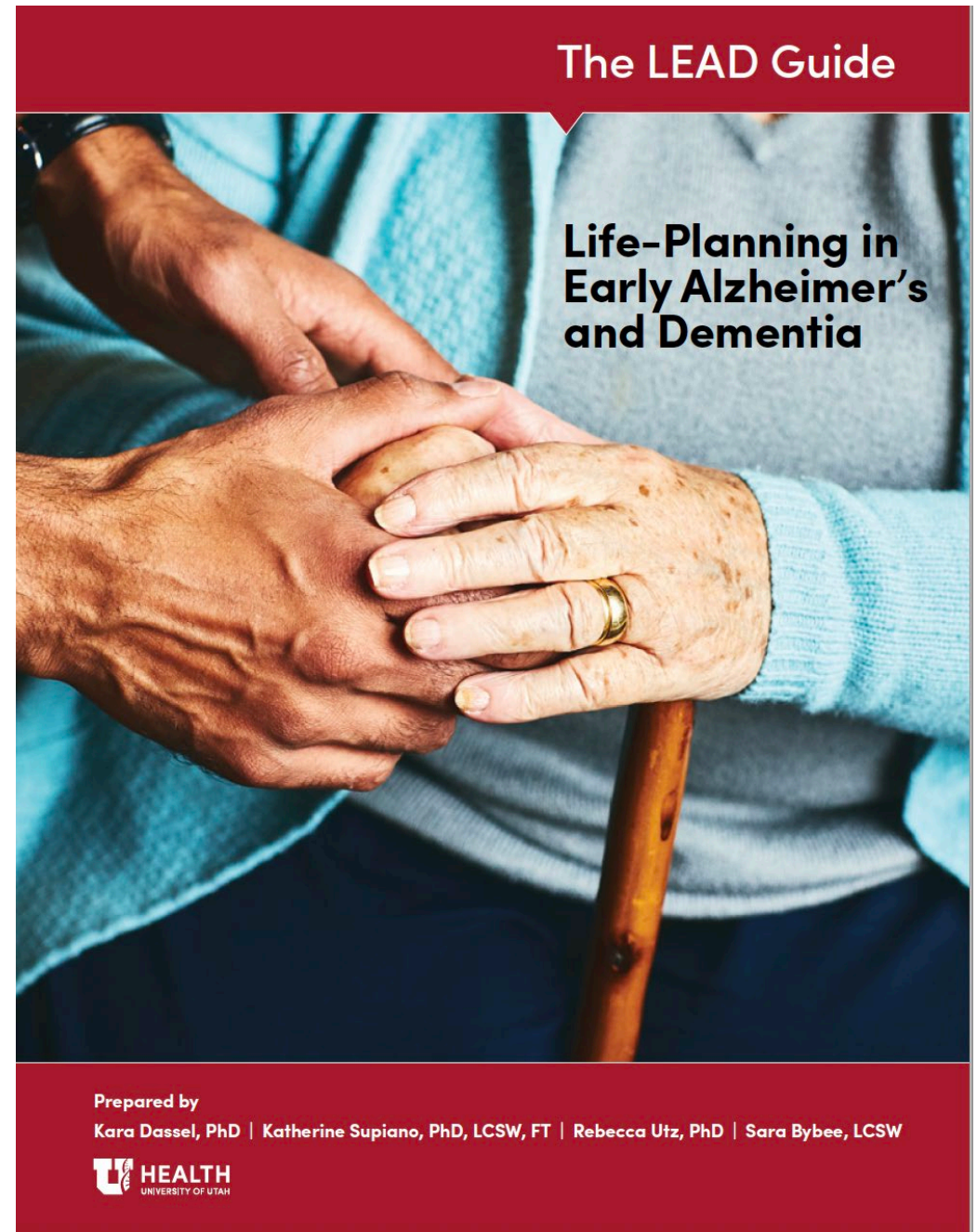
KARA DASSEL, PHD, FGSA, FAGHE

ASSOCIATE PROFESSOR

ASSISTANT DEAN, GERONTOLOGY INTERDISCIPLINARY PROGRAM

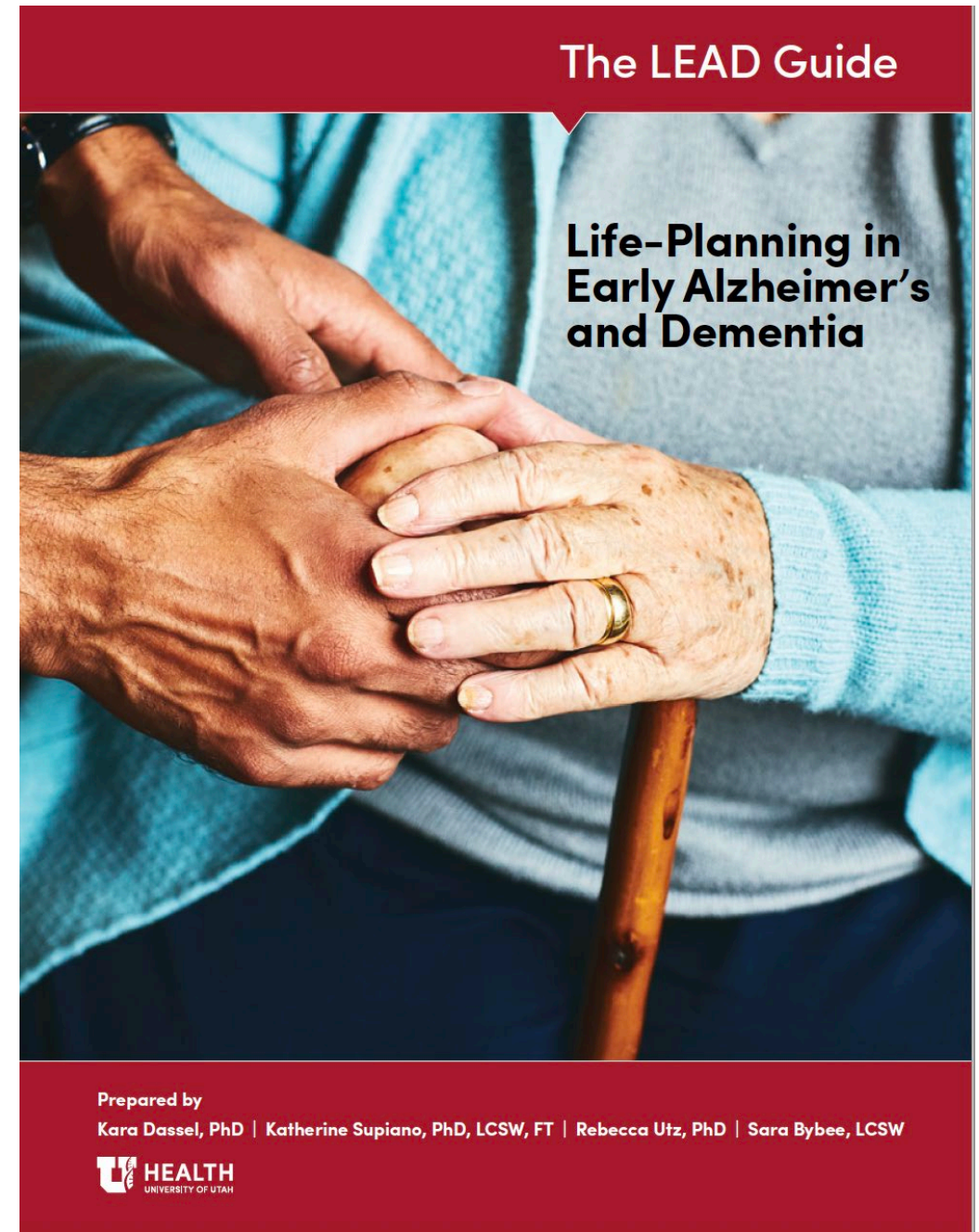
RESEARCH

- Advance care planning within the context of dementia is unique
 - There was a need for a dementia-focused ACP planning guide
 - EOL documentation
 - EOL preferences
 - EOL values
- *across the dementia trajectory



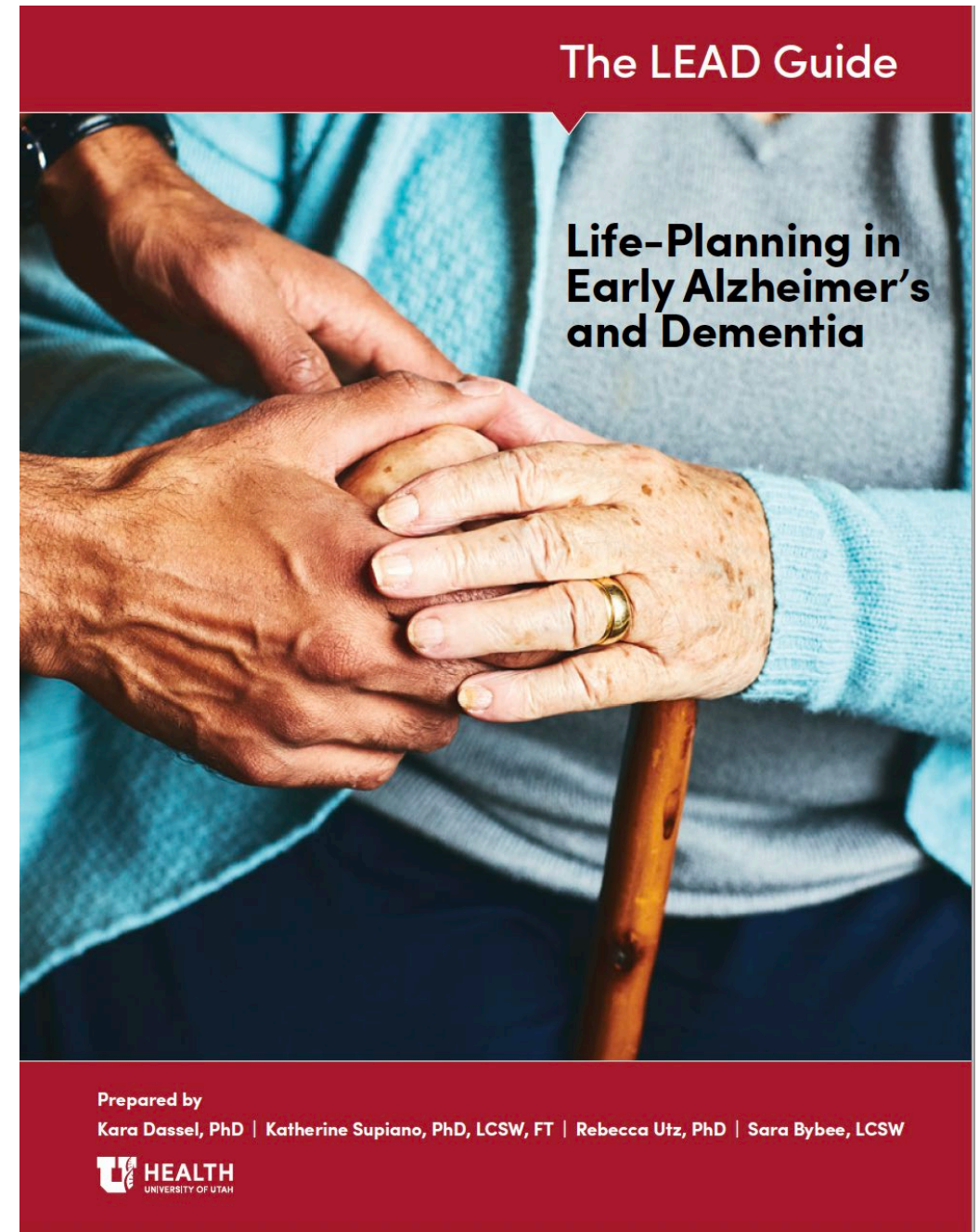
COLLABORATION

- Examine the cognitive component of decision-making of the care partner
 - Executive functioning
- Further exploration of medical aid in dying within the context of dementia
- Unbefriended older adults with dementia and ACP



PEPPER CENTER SUPPORT

- Clinical core:
 - access to CP and CR cognitive data
- Data care:
 - Study design and data storage
- Caregiver Core:
 - Recruitment of CP/CR dyads



Thank you!

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ENHANCING ACTIVE CAREGIVER TRAINING (ENACT)

JACQUELINE EATON, PHD

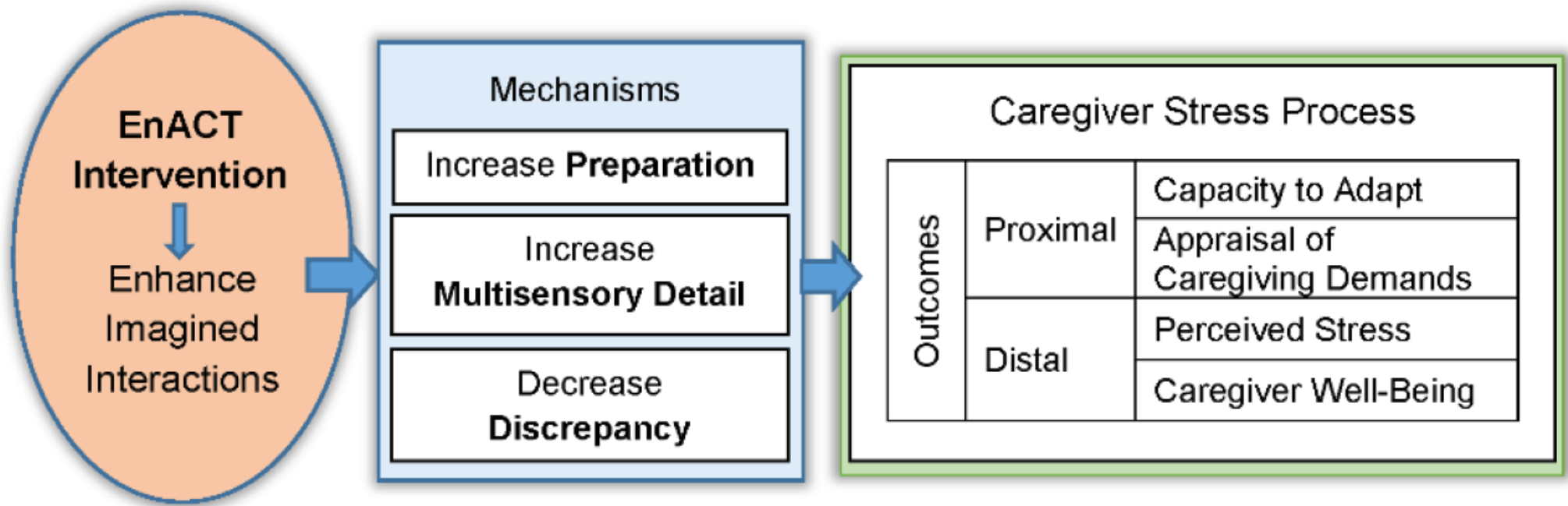
This work is supported with funding from the National Institute on Aging (Grant #K01AG065623)

BACKGROUND

- Behavioral symptoms
- Intervention limitations
 - Psychoeducational Interventions
 - Knowledge + Skills
 - Effective = active participation

(Walter & Pinguart, 2020)

ENACT INTERVENTION



(Campbell, Rowe, & Marsiske, 2011; Honeycutt, 2010)

AIMS

1. Develop and iteratively refine the EnACT intervention for dementia caregivers
2. Evaluate the feasibility and acceptability of the EnACT intervention
3. Examine potential mechanisms of change over time and their subsequent impact on proximal and distal outcomes.

(Onken et al., 2014)

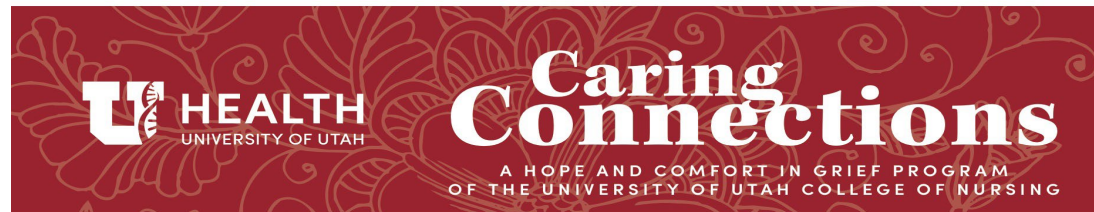
QUESTIONS?

Jackie Eaton, PhD
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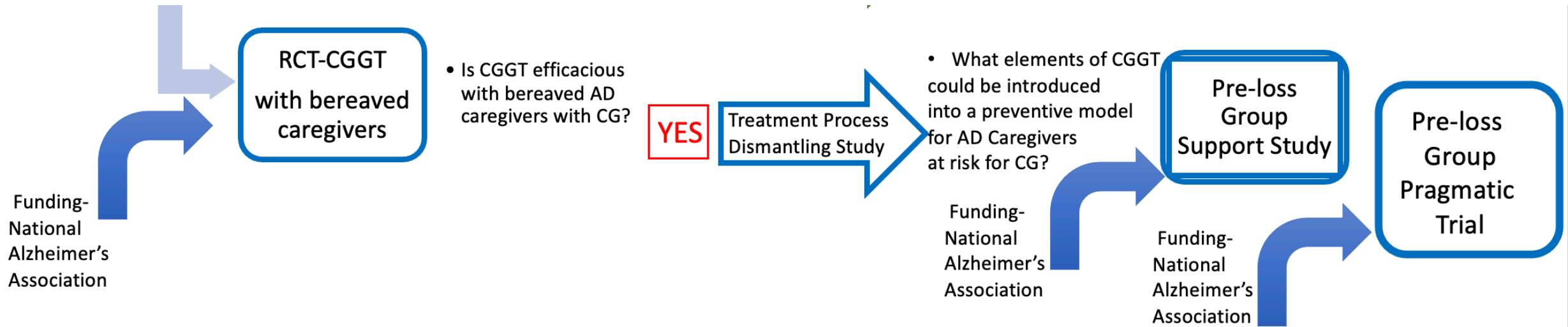
Pre loss Grief Support for Dementia Family Care Partners at risk for Problematic Grief

Katherine P. Supiano, PhD, LCSW, FGSA, FT, APHSW-C



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Research trajectory



Current study

Research Question— Does telehealth-delivered PLGS reduce CG risk in family CPs (“usual customers”) of PLWD who are at risk for CG, when telehealth-delivered by trained nursing SWs (“usual providers”), as demonstrated by lowered pre-loss grief risk and improved preparedness for death (desired clinical outcomes)?

PLGS is 10 weeks in duration with 120-minute sessions. Intervention elements focus on the relationship between CP and PLWD, how memories of life together and illness are interpreted, and strategies for creating a life without the PLWD. Intervention elements include psychoeducation, motivational interviewing, cognitive-behavioral techniques, prolonged-exposure techniques, self-care and meaning-reconstruction activities.

Table 1. PLGS Sessions

Session 1	Session 6
<ul style="list-style-type: none"> • Psychoeducation • The story of your family member—the story of the illness • <i>You as a caregiver</i> • <i>The story of what is coming</i> (1)-group feedback • Explanation homework, distress scoring 	<ul style="list-style-type: none"> • Check in <i>You as a caregiver</i>-and homework review • Imaginal conversation for ½ of group-group feedback • Working with emotions/thoughts/body sensations • Preparedness & self-care goals for next session
Session 2	Session 7
<ul style="list-style-type: none"> • Check in <i>You as a caregiver</i>- and homework review • Developing goals-preparedness goals and self-care goals • Mindfulness education & practice 	<ul style="list-style-type: none"> • Check in <i>You as a caregiver</i>-and homework review • Review of imaginal conversations completed • Imaginal conversation for 2nd ½ of group-group feedback • Working with emotions/thoughts/body sensations • Preparedness & self-care goals for next session
Session 3	Session 8
<ul style="list-style-type: none"> • Check in <i>You as a caregiver</i>-and homework review • <i>Supportive Other</i> visit #1(10 minutes in group) • Working with emotions/thoughts/body sensations • Integrated preparedness description • Preparedness & self-care goals for next session 	<ul style="list-style-type: none"> • Check in <i>You as a caregiver</i>-and homework review • Review of imaginal conversations completed • <i>Supportive Other</i> visit #2 (½ of session) • <i>Difficult</i> memories work sheet and pictures • Education on integrated memory • Preparedness & self-care goals for next session
Session 4	Session 9
<ul style="list-style-type: none"> • Check in <i>You as a caregiver</i>-and homework review • <i>The story of what is coming</i> (2)-group feedback • <i>Pleasant</i> memory worksheet and pictures • Working with emotions/thoughts/body sensations • Preparedness & self-care goals for next session 	<ul style="list-style-type: none"> • Check in <i>You as a caregiver</i>-and homework review • <i>The story of what is coming</i> (4) [emphasis-how you want to look back on it] group feedback • <i>Integrated</i> memories work sheet and pictures • Preparedness & self-care goals for next session
Session 5	Session 10
<ul style="list-style-type: none"> • Check in <i>You as a caregiver</i>-and homework review • <i>The story of what is coming</i> (3)-group feedback • Working with emotions/thoughts/body sensations • Preparedness & self-care goals for next session 	<ul style="list-style-type: none"> • Check in <i>You as a caregiver</i>-and homework review • Bringing the memory of the deceased forward in your life • Participant accomplishments and preparedness • Preparedness & self-care goals for the future • <i>Supportive Other</i> visit #3 (end of group)

PLGS can be incorporated into usual clinical care by properly trained clinicians. PLGS has potential to mitigate poor bereavement outcome in long term CPs, supporting a constructive grief process and potentially yielding a sense of caregiver accomplishment, as achieved in our prior studies.



- Family care partners prepared for the death of their PLWD are likely to be emotionally and cognitively resilient.
- Our projects align with the Family Caregiving initiatives & many CoA research activities.
- *Translation and dissemination* of PLGS would benefit from Pepper Center support.
- Team: K. Supiano, T. Andersen, C. Beynon, E. Iacob, S.E. Levitt



Rebecca L. Utz



Professor, Department of Sociology
College of Social & Behavioral Sciences

Lifecourse sociologist studying health & aging in America, particularly how end-of-life and health experiences affect family members of the patient.

Research is used provide support to family caregivers through policy and practice, and to increase public awareness of the value that family caregivers bring to health and financial well-being of our society.

Interdisciplinary Appointments & Affiliations:

- Adjunct Faculty, College of Nursing & Gerontology Interdisciplinary Program
- Director, Health Society & Policy program (undergraduate major)
- Co-Director, Consortium for Families & Health Research
- Senior Leader, Family Caregiving Collaborative

Been at Utah since 2004



TIME FOR LIVING & CARING

“Virtual Coaching to Maximize Caregivers’ Respite Time Use”

TLC provide resources, coaching, and personalized support to family caregivers, focusing on their need to take regular breaks from caregiving (respite). Technology-delivered interventions are a cost-efficient way to provide support to family caregivers

Funding: National Institute on Aging



Utah Plan for Family Caregivers

Convening many stakeholders and using evidence-informed practices to identify the goals and priorities needed to recognize, value, and support family caregivers in Utah through policy and practice.

Funding: Grantmakers in Aging

Utah C-PopS

Utah Caregiving Population Studies

This research collaborative brings together multiple research teams to develop and use the Utah Population Database (UPDB), a repository of linked administrative and health records, to understand the effect of end-of-life health experiences on the family system.

Pepper Center Core Resources

Clinical Core (caregiving focus)

- Recruitment partnerships for caregiver interventions
- UPDB linkage to clinical database to identify family-system of caregiver resources
- Community Advisory & Advocacy Boards

