• 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 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 feeling unprepared to effectively advocate for the needs and wishes of the resident

Acceptable and feasible, while lowering symptom severity, facilitating GOC discussions, and improving NH residents’ QOL
Utah C-PopS: Utah Caregiving Population Studies

- Leveraging the Utah Population Database (UPDB) to advance family caregiving research.
- Bringing together 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

FEELING OF
GUilt FOR NOT PROVIDING THE
CARE THEY WANTED/FElt
RESIDENTS DESERVED

“It was hard to watch them go
down and get weaker... see they
were depressed... hard to give the
best care”

FEARS OF INFECTION

“Nurses afraid to get into rooms to
shower/clean/change underwear...
won’t do it or skip it”

“After so many died, your
heart goes black...... it doesn’t
hurt you anymore as much as it did when
the pandemic first started”

FACILITY LOCKDOWNS

“Family wanted us to give hugs
or hold their (loved one’s) hands
but we were not allowed”

“Window visits created
confusion. Residents were
more upset. It was worse.”

CARING FOR RESIDENTS
FACING SIGNIFICANT
ISOLATION, ILLNESS AND
DEATH

“Some residents said that if this is
the way they are going to live, they’d
prefer to die.”

Compartmentalize and disconnect in order to cope and function

STAFFING SHORTAGES

“I was working 16 hours
shift every day because there
was nobody else.”

“We had people working
to the point of exhaustion
and there wasn’t any
kind of support there.”

NAVIGATING PPE SHORTAGES,
REQUIREMENTS, AND RELATED FATIGUE

“Masks made you speak harder
and higher, residents thought
that they were yelled at by
staff. I would bring my own
mask and made my gown
from garbage bags.”

Participant Characteristics (N=29)

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>%</th>
</tr>
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<tbody>
<tr>
<td>18-40</td>
<td>41</td>
</tr>
<tr>
<td>41-50</td>
<td>28</td>
</tr>
<tr>
<td>Over 50</td>
<td>31</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Gender</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>90</td>
</tr>
<tr>
<td>White</td>
<td>83</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Stakeholder Role</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff*</td>
<td>66</td>
</tr>
<tr>
<td>Residents</td>
<td>7</td>
</tr>
<tr>
<td>Family</td>
<td>28</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Location of 23 Facilities in 11 states</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rural</td>
<td>49</td>
</tr>
<tr>
<td>Urban</td>
<td>51</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Staff Reported COVID-19 Facility Outbreak</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>&gt;25% Residents Infected</td>
<td>30</td>
</tr>
<tr>
<td>&gt;25% Residents Died</td>
<td>6</td>
</tr>
<tr>
<td>&gt;25% Staff Infected</td>
<td>47</td>
</tr>
</tbody>
</table>

*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
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!

Kara.dassel@nurs.utah.edu
O: 801-646-4667
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 & Pinquart, 2020)
ENACT INTERVENTION

EnACT Intervention
Enhance Imagined Interactions

Mechanisms
- Increase Preparation
- Increase Multisensory Detail
- Decrease Discrepancy

Caregiver Stress Process

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Proximal</th>
<th>Distal</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Capacity to Adapt</td>
<td>Perceived Stress</td>
</tr>
<tr>
<td></td>
<td>Appraisal of Caregiving Demands</td>
<td>Caregiver Well-Being</td>
</tr>
</tbody>
</table>

(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
Assistant Professor
University of Utah
jacqueline.eaton@nurs.utah.edu
Pre loss Grief Support for Dementia Family Care Partners at risk for Problematic Grief

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

RCT-CGGT with bereaved caregivers

- Is CGGT efficacious with bereaved AD caregivers with CG?

Treatment Process Dismantling Study

- What elements of CGGT could be introduced into a preventive model for AD Caregivers at risk for CG?

Pre-loss Group Support Study

- Funding: National Alzheimer’s Association

Pre-loss Group Pragmatic Trial

- Funding: National Alzheimer’s Association
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>
<thead>
<tr>
<th>Table 1. PLGS Sessions</th>
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<tbody>
<tr>
<td>Session 1</td>
</tr>
<tr>
<td>• Psychoeducation</td>
</tr>
<tr>
<td>• The story of your family member—the story of the illness</td>
</tr>
<tr>
<td>• You as a caregiver</td>
</tr>
<tr>
<td>• The story of what is coming (1)group feedback</td>
</tr>
<tr>
<td>• Explanation homework, distress scoring</td>
</tr>
</tbody>
</table>

| Session 2             | Session 7 |
| • Check in You as a caregiver and homework review | • Check in You as a caregiver and homework review |
| • Developing goals, preparedness goals, and self-care goals | • Review of imaginal conversations completed |
| • Mindfulness education & practice | • Imaginal conversation for 2nd 1/4 of group-group feedback |
| | • Working with emotions, thoughts, and body sensations |
| | • Preparedness & self-care goals for next session |

| Session 3             | Session 8 |
| • Check in You as a caregiver and homework review | • Check in You as a caregiver and homework review |
| • Supportive Other visit 4(10 minutes in group) | • Review of imaginal conversations completed |
| • Working with emotions, thoughts, and body sensations | • Supportive Other visit 5(1/4 of session) |
| • Integrated preparedness description | • Supportive memories worksheet and pictures |
| • Preparedness & self-care goals for next session | • Education on integrated memory |
| | • Preparedness & self-care goals for next session |

| Session 4             | Session 9 |
| • Check in You as a caregiver and homework review | • Check in You as a caregiver and homework review |
| • The story of what is coming (2)group feedback | • The story of what is coming (4)what you want to look back on of group feedback |
| • Pleasure memory worksheet and pictures | • Integrated memories worksheet and pictures |
| • Working with emotions, thoughts, and body sensations | • Preparedness & self-care goals for next session |
| • Preparedness & self-care goals for next session | |

| Session 5             | Session 10 |
| • Check in You as a caregiver and homework review | • Check in You as a caregiver and homework review |
| • The story of what is coming (3)group feedback | • Bringing the memory of the discussed forward in your life |
| • Working with emotions, thoughts, and body sensations | • Participant accomplishments and preparedness |
| • Preparedness & self-care goals for next session | • Preparedness & self-care goals for the future |
| | • Supportive Other visit 5 (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

Life-course 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
“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

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**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

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**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