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# Caregiving Research Challenges & Opportunities: *Bridges, Re-builds, & Beacons*

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**My views are my own.  
I have no financial disclosures.**

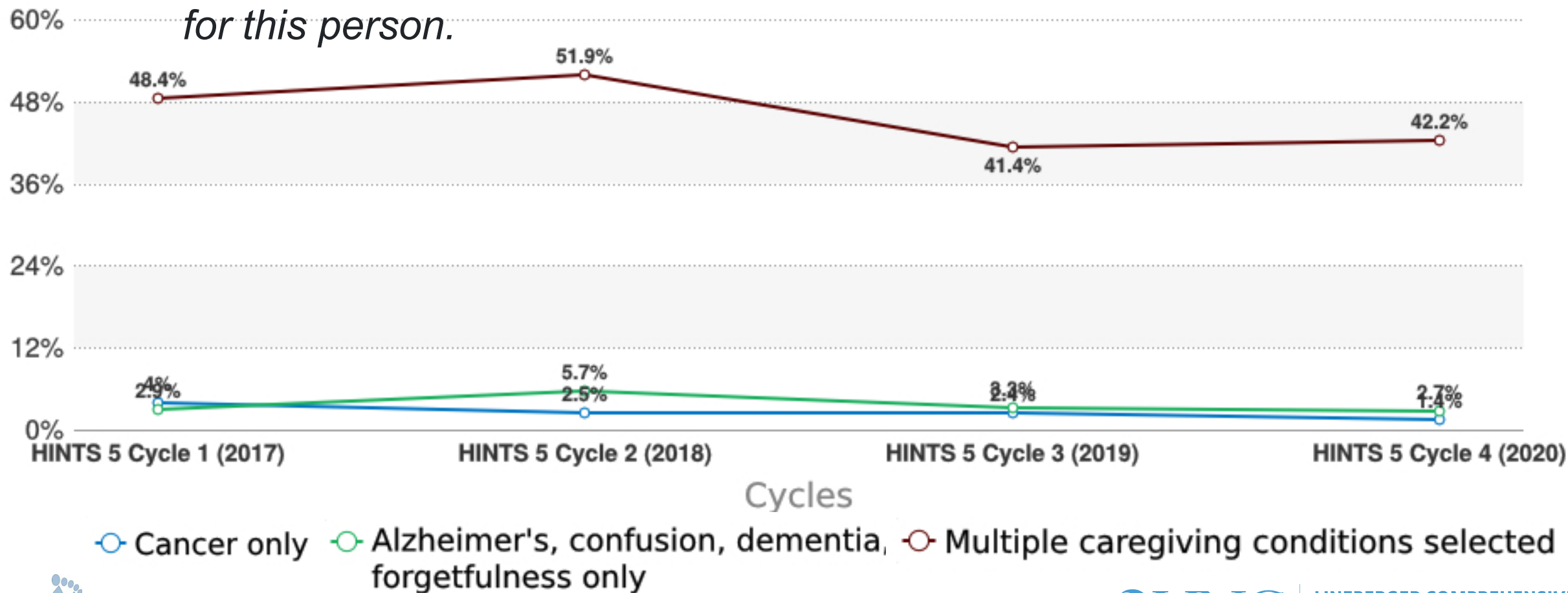




# (1) Care recipients often face multimorbidity



*Please think about the individual for whom you are currently providing the most care. Please check all conditions for which you have provided care for this person.*



... yet research funding is siloed by conditions.

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- Lack of collaboration
- More emphasis on development of new interventions, new models
- Multiple reviews and reports suggest the need for a focus on adaptation, implementation, and sustainment of caregiving interventions



## Takeaway #1: Bridges

The National Rehabilitation Research and Training Center on Family Support  
at the University of Pittsburgh presents:

### Building Bridges: Advancing Family Caregiving Research Across the Lifespan

Second Biennial Conference on Caregiving Research

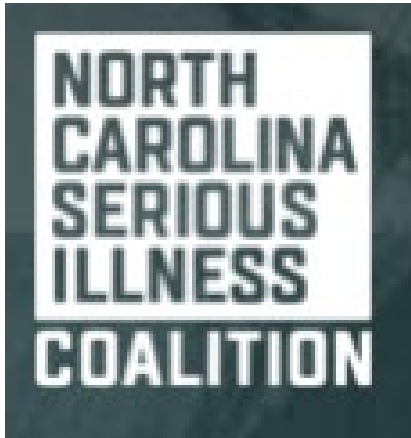
September 30 - October 1, 2022

- **Funders should consider transdisciplinary and trans-institutional funding opportunities.**
- **Foundations and societies should build deliberate bridges across these divides to share methods and practices**
- **Need for common data elements across care recipient illness context, suggesting opportunity for gerontology, palliative care, nursing, and condition specific areas to collaborate**



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# Example: North Carolina Caregiving Collaborative



Children's Complex  
Care Coalition of  
North Carolina



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## (2) Historically marginalized populations often left out of caregiving research.

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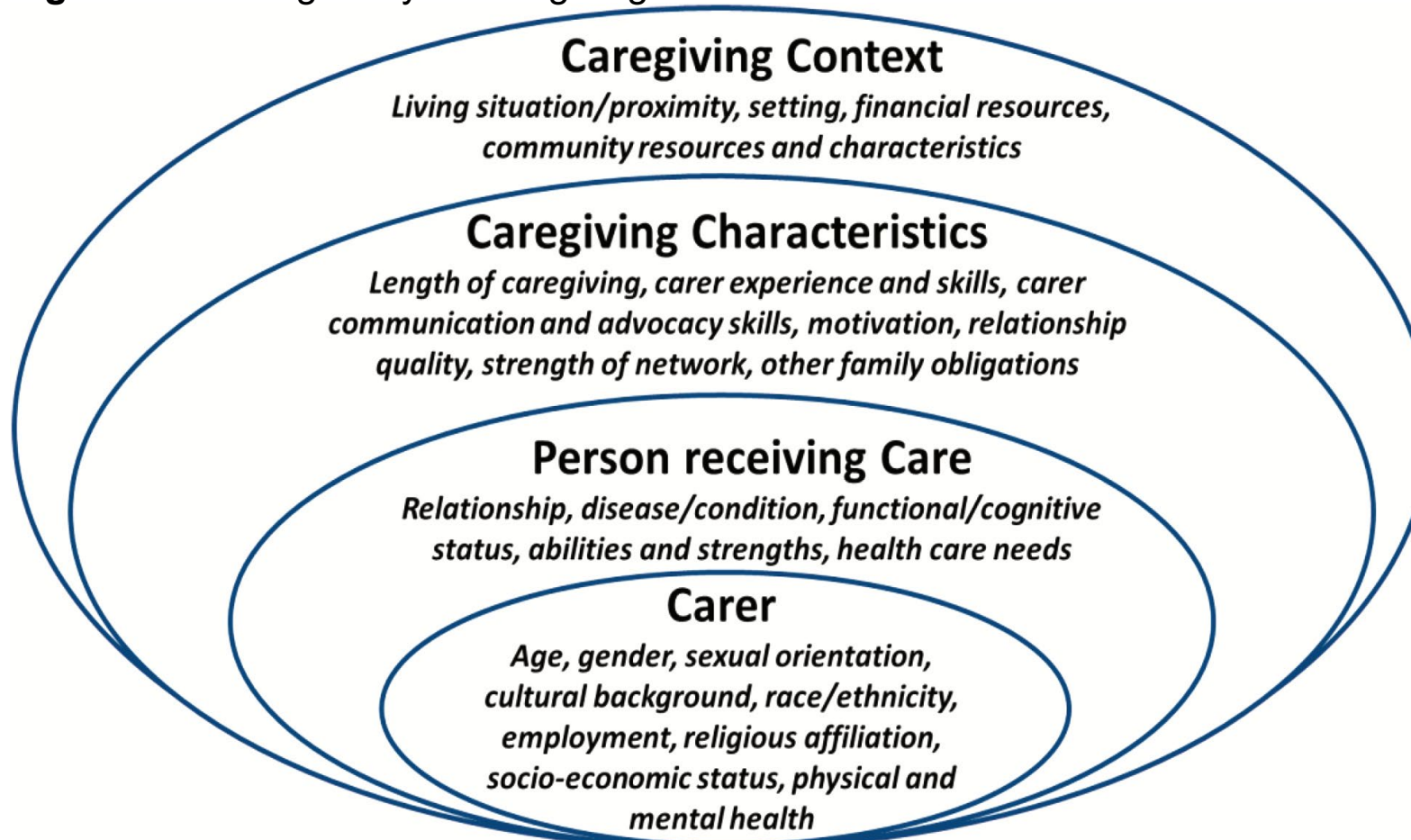
- Barriers and burdens of research on caregivers and their recipients not trivial
- Research representation *matters*.
- Northouse 2010, meta-analysis of cancer caregiving interventions, n=29, found that 84% of caregivers represented were white.
- Ferrell & Wittenberg, 2017 systematic review of cancer caregiving interventions, n=50, that 86% of caregivers represented were white.





# ... and caregiving context under-recognized

**Figure 1.** Heterogeneity of caregiving.



Young et al.'s review of 33 systematic reviews of older adult caregiving studies:

- found most interventions were low-to moderate quality
- lack of specificity on social determinants of health





## Takeaway #2: Re-build

- Along with bridges, we need new blueprints
- Inclusion criteria is a *starting* point, not the endpoint –If barriers are about time, logistical needs, or cultural divides, investment in strategies to address those are as critical as the content
- SDOH and social needs of caregivers must be studied and addressed





# Example: enCompass Carolina

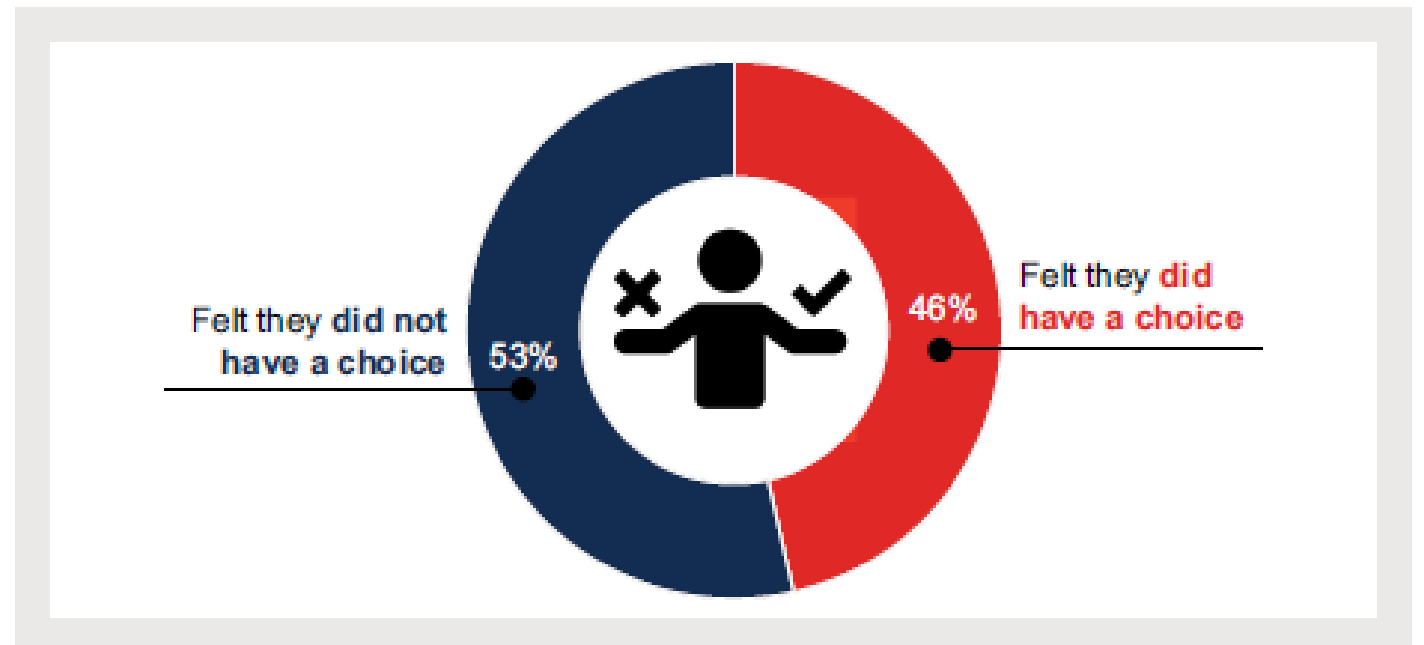


- **enCompass Carolina** is a **navigator assisted program** targeted to rural cancer caregivers and designed to help identify **social support needs** and **connect caregivers to people and resources**.
- **Adapted for the rural context** from a lay navigator-delivered social support mapping intervention called eSNAP (electronic Social Network Assessment Program) designed by Dr. Maija Reblin.
- **PIs Erin Kent & Leeza Park, Funding from The Duke Endowment**

### (3) Lack of public and professional awareness about caregiving

- Caregivers feel invisible
- Caregivers are often 'care adjacent' in healthcare delivery
- Caregiving comes as a surprise to too many

Figure 16. Choice in Taking on Caregiver Role





## Takeaway #3: Beacons

- **Communication to caregivers**
  - Where, how, and who from to seek resources
- **Public service announcements**
  - Examples: Portraits of care, #CareCantWait campaign  
AARP Billboards, National Alliance of Caregiving caregivers' spotlights
- **Pipeline educational efforts**
  - Interprofessional family caregiving competencies
  - Continuing medical and health education
  - Start much, much earlier in the pipeline
- *More data, more stories, more reach*



# Thank you



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<https://tarheels.live/caregivingcollaboratory>



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