



UNIVERSITY OF GEORGIA SCHOOL OF SOCIAL WORK

Respite Research: Using the Expert Panel Framework

Tiffany Washington, PhD, MSW

John A. Hartford Geriatric Social Work Scholar

Associate Professor

University of Georgia School of Social Work



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Project Title: Building Evidence for Respite

Presentation Agenda

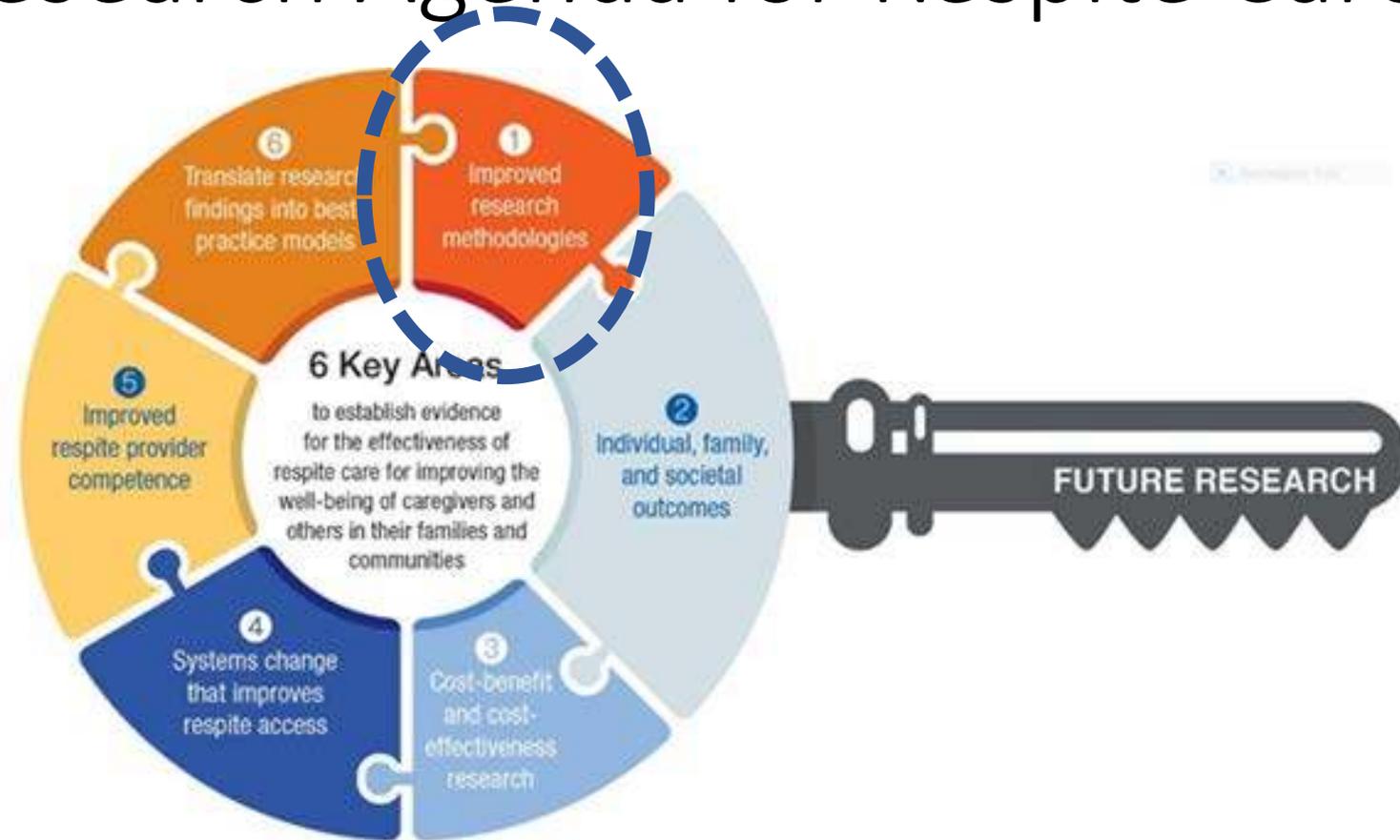
- Link the expert panel findings to this project's aims
- Describe methodological approach and challenges
- Present emerging themes*
- Next steps

*Preliminary findings only. This project is ongoing.





A Research Agenda for Respite Care





Issue 1: Improved Research Methods

- Consistent with the Panel's definition of respite as a service or support designed to benefit the family caregiver, the caregiver should be the portal of entry and an important focus of any research study or evaluation of respite services. Benefits accruing to the caregiver, the family unit, or to others are also important, but the caregiver should be the focus of at least one independent variable/dependent variable relationship.





Issue 1: Improved Research Methods

- Qualitative methods should be employed to capture contextual information. This information is critical to data interpretation; for example, to determine why cultural differences, or study site differences, may have occurred; or why fidelity was achieved or not achieved.





Background

- Caregiving refers to daily assistance with a child's or an adult's health and psychosocial needs.¹
- Respite programs are formal or informal services that provide short-term relief to caregivers.^{2,3}
- The relationship between respite dose to outcomes has not been examined fully.³
- The relationship of contextual factors to outcomes is not well understood.³

1. National Alliance for Caregiving and AARP (2015). Caregiving in the U.S., 2009. (Bethesda, MD: NAC, and Washington, DC: AARP)

2. Alzheimer's Association. Respite Care. Retrieved from <https://www.alz.org/care/alzheimers-dementia-caregiver-respite.asp>

3. Kagan, J., Kirk, R.S., & Kirk and Associates, R.S. Author, F.M. (2015). A Research Agenda for Respite Care: Deliberations of an Expert Panel of Researchers, Advocates and Funders. Retrieved from <https://archrespite.org/productpublications>



Research Aims and Methodology

- To examine respite dose (i.e., frequency, duration, and intensity of respite) and its relationship to caregiver burden, family well-being, and care recipient quality of life.
- To examine the relationship of contextual factors to caregivers' access to and desire for respite.
 - Mixed-methods research design
 - Telephone interviews
 - Focus groups





Variables

- Demographic characteristics
- Burden
- Family well-being
- Quality of life
- Dose frequency
- Duration of respite use
- Intensity of respite care





Qualitative Questions*

- What services do you consider to be respite services?
- How did you decide to use respite services?
- How satisfied were you with the service?
- What would you change about respite services?
- What more would you like for me to know about respite services?

*These questions do not constitute the full semi-structured interview guide.





Polling Question

What recruitment challenges have you encountered in caregiving research?

- Limited funding for participant incentives
- High advertisement costs
- Lack of culturally-tailored strategies
- Limited geographic scope
- Miscommunication with partnering organizations/stakeholders
- Other (please describe in the chat box)





Recruitment Strategies

- Letter to providers via New York State Office on Aging
- ARCH National Lifespan Conference
- Calls to social service agencies
- Social media ads
- Hartford network
- Snowball sampling





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| In the past three months, did you use... | a. In what month and year did you begin using this type of respite? | b. In the last 30 days or in a typical month, how many days per week did you/do you use this type of respite? | c. In the last 30 days or in a typical month, how many weekend days did you/do you use this type of respite? | d. In the last 30 days or in a typical month, how many hours per day did you/do you use this type of respite? | e. How is it paid for? (Possible options: out of pocket, Medicaid, health insurance, family contributions, free service) | f. (If answered "yes" to paying out of pocket) How much do you spend per month for respite? | g. Who provides the respite care? Is it A)Volunteer (non-family or friend), B)Paid person, C)Family or friend, D)Don't know | h. What types of care needs are provided during respite? A)Meals/snacks, B)Toileting, C)Showering/bathing, D)Medication assistance, E)Recreation, F)Therapy services (OT, PT), G)Doctor's visit | i. How much do you agree with the following statement: I used my respite plan to do something I enjoyed and felt that the respite was "time well spent"? 1-Completely disagree, 2-Disagree, 3-Neither disagree nor agree, 4-Agree, 5- Completely agree |
|---|---|---|--|---|--|---|---|---|--|
| Adult day health | | | | | | | | | |
| Residential care (e.g., assisted living) | | | | | | | | | |
| Community agency (such as a faith-based agency) | | | | | | | | | |
| Home-based services (companion services, personal care or home health aides, homemaker services), | | | | | | | | | |
| Veterans respite services | | | | | | | | | |
| Hospice respite | | | | | | | | | |
| Some other type (specify) | | | | | | | | | |



Participants: A snapshot*

| Race/ Ethnicity | Gender | Age | Marital Status | Employment Status | Education | Care Receiver | Caregiver # of Chronic Conditions |
|--------------------|--------|-----|------------------------|--------------------|-------------------------------|---------------|---|
| White | Female | 68 | Married | Retired | Some college | Spouse | 4 |
| White | Female | 63 | Single | Employed part-time | Associate degree | Mother | 3 |
| White | Female | 56 | Married | Unemployed | Associate degree | Spouse | 3 |
| White | Female | 59 | Married | Retired | Bachelor's degree | Married | 0 |
| White | Female | 61 | Partnered/cohabitating | Employed full-time | High school diploma or GED | Mother | 1 |
| Latina | Female | 59 | Married | Employed part-time | Doctorate | Spouse | 0 |
| White | Female | 51 | Married | Employed full-time | High school diploma or GED | Spouse | 1 |
| White | Female | 72 | Married | Retired | Master's degree | Child | 3 |
| White | Male | 81 | Married | Retired | Associate's degree | Spouse | 3 |

*subset of sample for illustrative purposes





Benefits of Respite: Freedom

- “Being able to find rest, being able to leave my house without having to be stuck there...I am to leave the house and do what I would like to do, something enjoyable to me. And not be on call...not have to worry about someone going to call me to fix something or for information, it gives me a sense of freedom that I don't have when I'm connected and providing the caregiving responsibilities.”





Benefits of Respite: Freedom

- “It depends where would the respite service that I use, freedom can be 100% and managing my freedom is freed us in such a way that is constrained by that now, where that freedom that is with a home care aide start being more open when they have that homecare a coming for two, three months. Then she or he knows where things are, and I don't have it so the becoming familiar with the dynamic and resources at home, help me to say I know what she's doing and so forth. Who can provide me that kind of, of trust? I've had family member when it's someone from outside it's not that I don't trust but that person doesn't know everything.





Benefits of Respite: Flexibility

- I have flexibility. One staff in particular, I mean, she will work almost any hours. So that means if I want to get away with my husband overnight, she'll stay overnight. So that flexibility I appreciate that is not a set time that I have to access it.”





Barriers to Respite: Cost

- “And then the cost is impossible for me to pay, even though there was a small amount. So they told me, don't worry, we're going to give you we're going to give your husband a scholarship, scholarship. So they did so three times a day.”
- “Council on Aging called to say they can offer five free days of respite. So I put in in a nursing home for five days so I could travel. I could not have otherwise afforded to use respite.”





Motivation to Use Respite: Burden

- “For me, it was exhaustion, I was exhausted. I've never been good at asking. That was hard for me to go to somebody and say, Hey, you know what, I need a break.”
- “Every week, exhaustion, burnout, really, uh, when you get to that stage, then you become mean to the patient.”





Motivation to Use Respite: Cultural Factors

- “My father is an Italian American first generation, and he believes his daughters will take care of him. He has tried to make us all promise to never put him in a nursing home and when we refused he had his grandchildren promise. But there was a lot of resistance because he expected family to, and we did. We've been doing it for a couple of years. But it's time for more.”





Motivation to Use Respite: Nature of Social Support

- “[My daughter] she stayed with him and when I got back she was ready to run. She's like, I can't do this. I can do this a short time, but four hours, that's difficult on them. And I don't want to put them in a position.”





Future Data Analysis

- Aim 1: Bivariate and multivariate to examine the relationship between independent variables (i.e., demographic characteristics and dose) and dependent variables (i.e., caregiver burden, family well-being, and care recipient quality of life).
- Aim 2: Thematic analysis to identify the relationship of contextual factors (e.g., cultural factors, environment, care situation, nature of social support) to caregivers' access to and desire for respite.





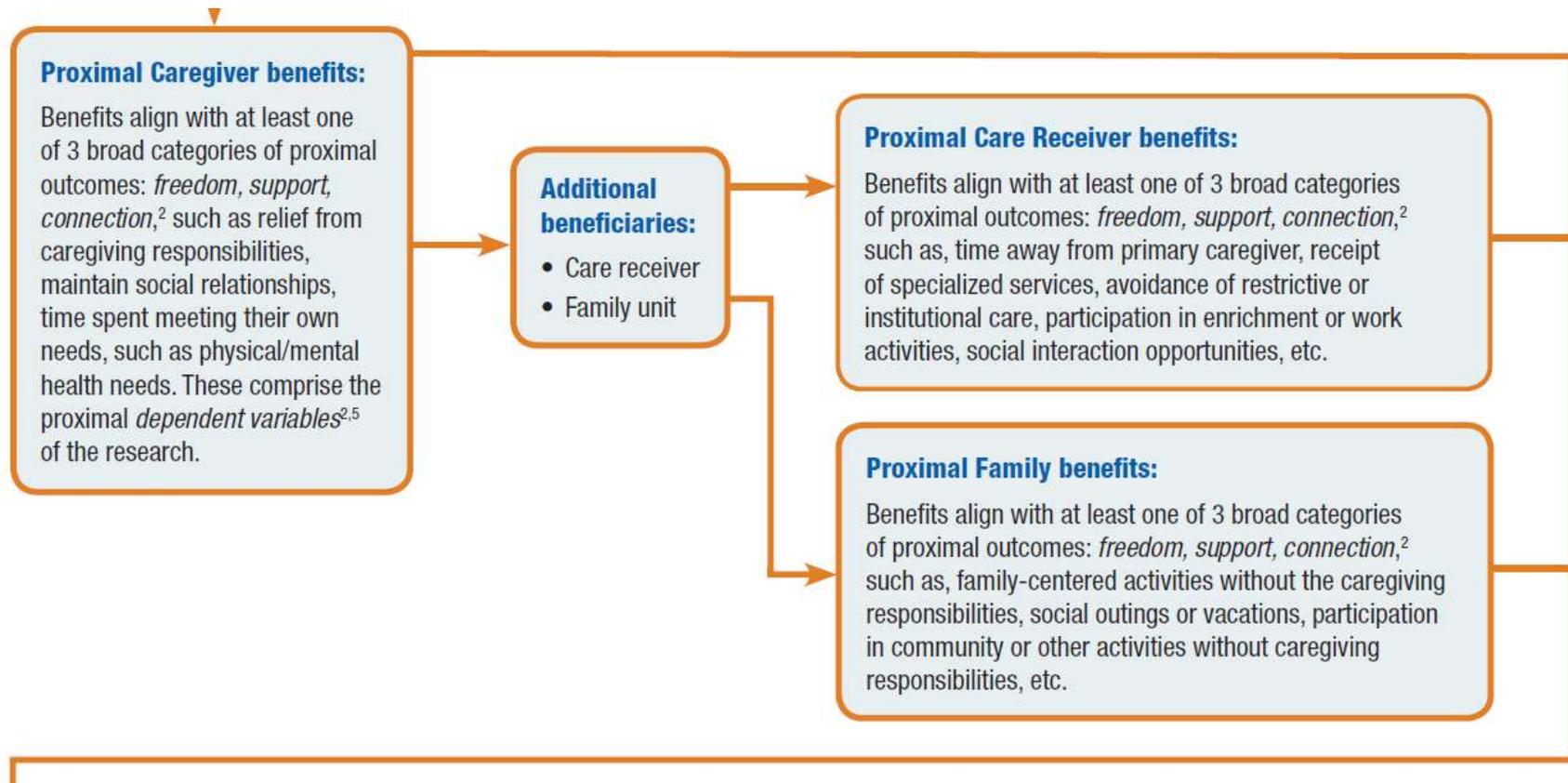
Limitations

- Cross-sectional study
- Lack of diversity
- Sample size





Next Steps, Future Research





Thank You!

Questions?

twashing@uga.edu

