



Decision-making among Black caregivers throughout their dementia care journey

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Dementia Detection and Caregiving Challenges in the Black and African American Communities
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Disclosures

- No disclosures or conflicts to declare



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Positionality Matters



Milwaukee, Wisconsin 53216 ZIP Code



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Cotton's Program of Research

Person and Environment

- Understand influence of life events
- Understand influence of Social Isms

Intervention Supports

- Examine Service Utilization Experiences
- Design and Test Interventions



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Session Objectives

- Describe a decision-making process employed by informal Black dementia caregivers
- Identify dominant factors that influence decision-making among informal Black dementia caregivers
- Describe different types of decisions made by informal Black dementia caregivers
- Identify promising strategies informal dementia caregivers utilize to navigate decisional processes



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Dementia is common among African Americans

- High prevalence of dementia among African Americans, two times greater risk and growing demographic
- Disparities in disease management, care, and caregiving
- African American women shoulder caregiving responsibilities
 - Full-Time Work
 - Care Hours
 - Care for Multiple Individuals



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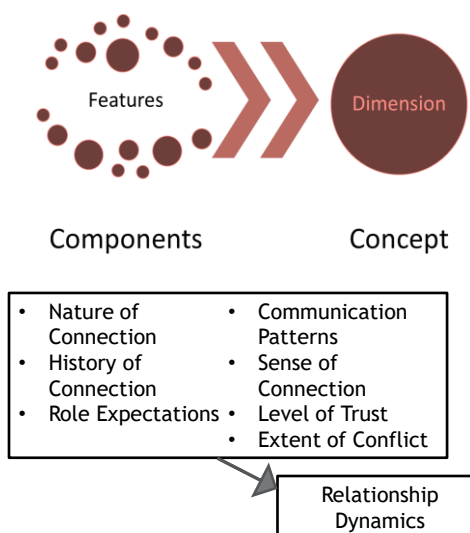
Research Gap and Study Focus

- African American dementia caregivers' experiences and perspectives under-represented
- Interest in understanding social processes caregivers engage in responding to challenges
- Original interest in crisis expanded to focus on caregiver response to challenges that present as new, emergent, and expected events
- Conducted Grounded Dimensional Analysis study to examine precipitating, mitigating, and modifiable features of new, emergent, and unexpected events among African American caregivers to generate framework for future intervention design and testing



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Grounded Dimensional Analysis



Strengths

- Places value in evaluating the voices and context of stakeholders
- Captures complexity of social phenomenon
- Useful for exploring new points of view
- Research process drives future action by identifying social process and how you might intervene
- **Key Question: what all is happening?**



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Components of a Social Process

Context	Conditions	Actions	Consequences
<ul style="list-style-type: none"> • Low resource environment 	<ul style="list-style-type: none"> • Caregiver has health challenge • Caregiver prioritizes self care 	<ul style="list-style-type: none"> • Caregiver learns about formal respite care options • Caregiver asks family member to help out 	<ul style="list-style-type: none"> • Caregiver takes time off • Caregiver aware of resources • Family member helps out



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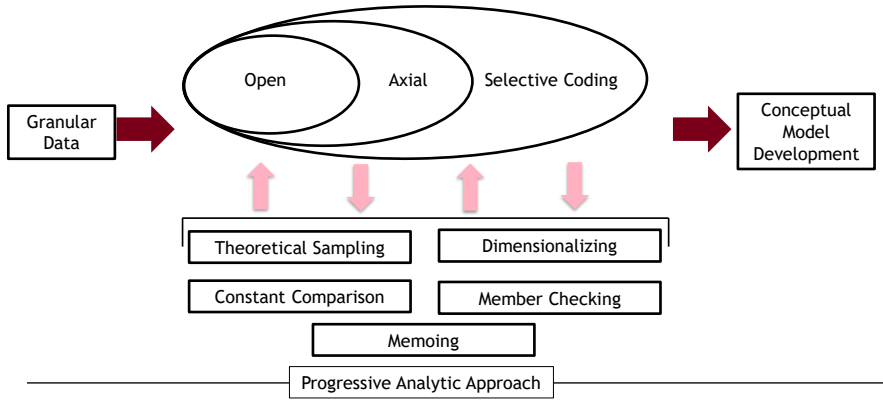
Data Collection and Analytic Process

- **Format:** Telephone Interviews
- **Average Duration:** 50 minutes
- All interviews audio recorded and transcribed verbatim
- Use of analytic team to guide analysis
- Two members of the analytic team independently reviewed the first three transcripts (line by line) followed by review of the full team
- Transcript review informed development of initial matrices and subsequent interviews focuses on filling in gaps in the summary matrix
- A final conceptual model was iteratively defined through member checking



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Analytic Procedures



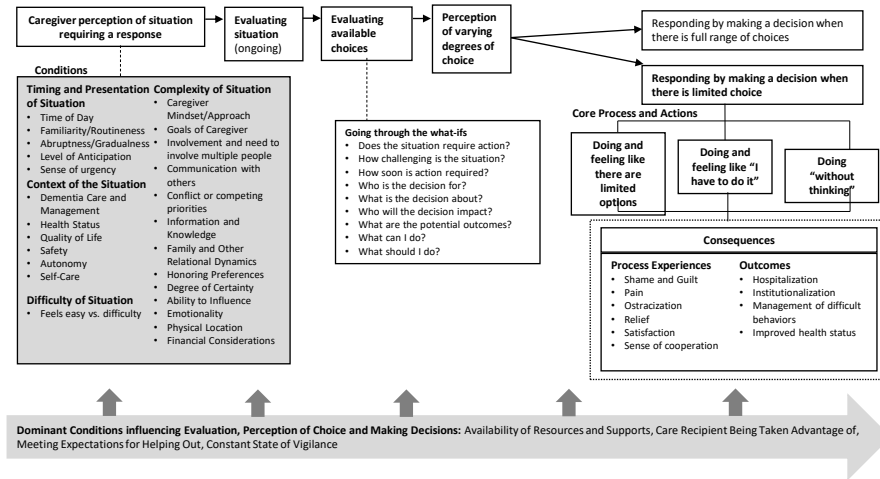
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Study Results

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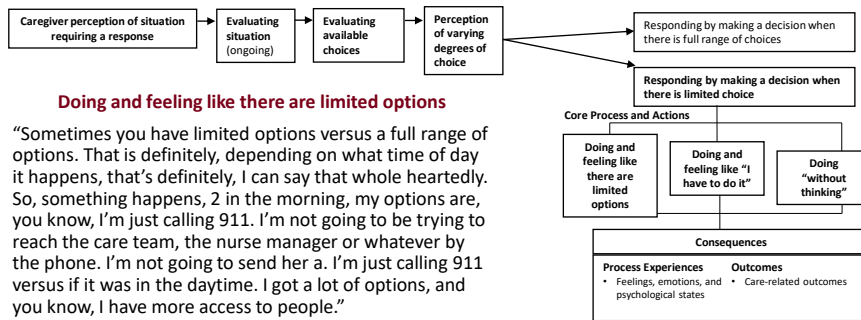
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Pathways in Responding: Dementia Caregivers' Making Decisions



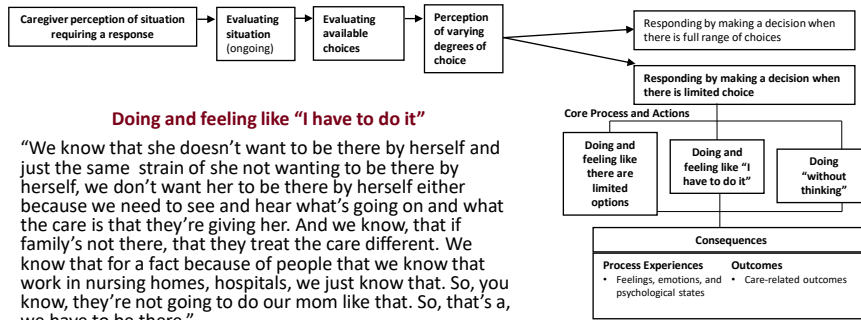
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Pathways in Responding: Dementia Caregivers' Making Decisions



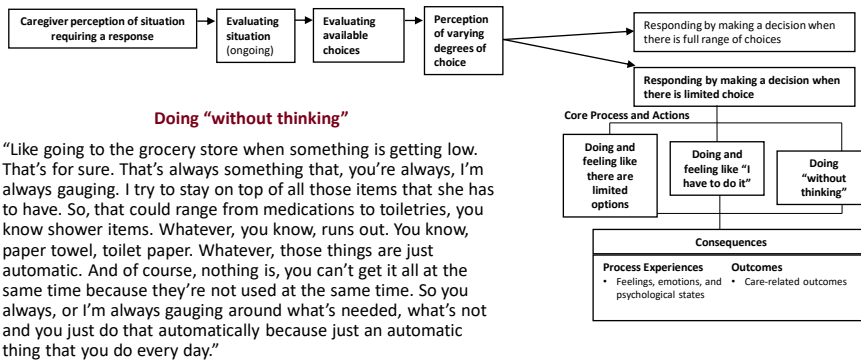
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Pathways in Responding: Dementia Caregivers' Making Decisions



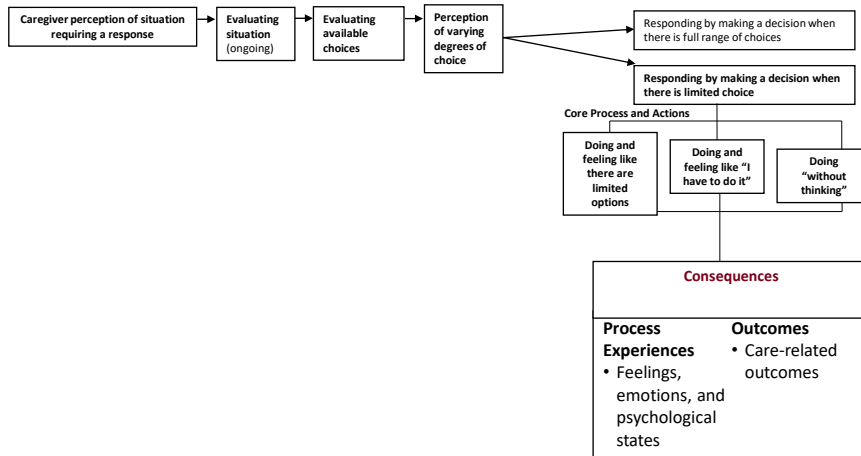
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Pathways in Responding: Dementia Caregivers' Making Decisions



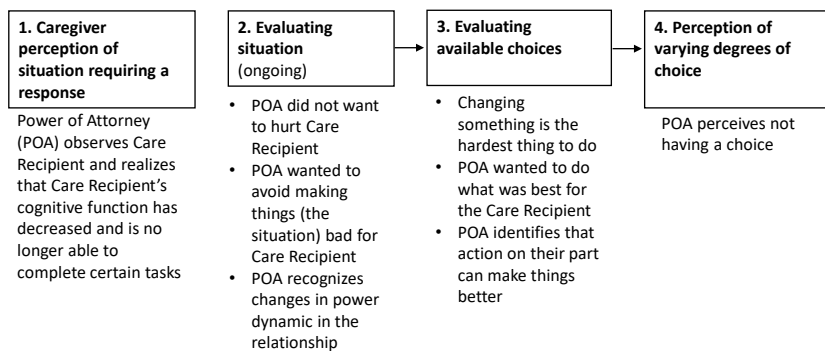
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Pathways in Responding: Dementia Caregivers' Making Decisions



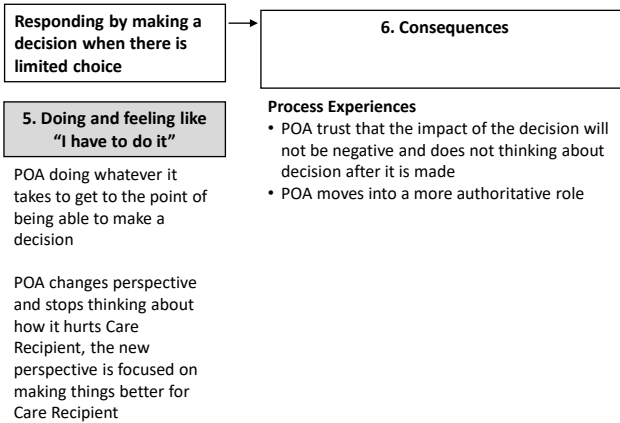
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Decision: Stepping Up



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Decision: Stepping Up (continued)



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Dominant Factors Influencing Decision-Making

Availability of Resources and Supports

Care Recipient Being Taken Advantage of

Meeting Expectations for Helping Out

Constant State of Vigilance

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Promising Strategies to Support Decision Making



Identify Power of Attorney



Activate Professionals



Activate Informal Network



Utilize Tools



Dementia-Specific Support



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Summary

- Grounded Dimensional Analysis guided examination of caregivers perspectives and experiences with new, emergent, and unexpected events
- Developed conceptual model detailing the social process of responding
- Identified dominant factors influencing decision making for African American dementia caregivers when responding to challenges
- Identified different types of decisions and strategies to support decision making



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Discussion

Implications

- Social process of responding reveals the need for individual and family supports with interpersonal skill development and the need to address longstanding relational dynamics
- Caregiver training and formal supports can prepare and support caregivers for decision making, especially when formal services are accessed

Limitations

- Researcher embeddedness
- Standards for developing categories not well defined
- Volume of data difficult to manage
- Perspectives and experiences of men not addressed

Future Directions

- Examine decision-making among caregiving networks
- Develop and pilot decision support tool



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Questions and Discussion

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