Past & Current Research Studies

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Selected Studies

- Virtual Reality Dementia Empathy Study
- Caregiver Competency
- Resources Enhancing Alzheimer's Caregiver Health Program Adaptation
- Department of Health and Human Services Caregiver Stress Survey
- Healthcare Utilization and Cost for Persons with Alzheimer's Disease or a Related Dementia

Virtual Reality (VR) Dementia Study: Team

- PI: Kapil Madathil, PhD
- Co-PI: Jeff Bertrand, PhD
- Aasish Chandrika Bhanu, PhD Candidate
- McKenzie Wilson
- Caitlin Torrence, PhD Candidate

VR Dementia Study: Design

- Pilot study
- Participants: Clemson University Students
- Randomized into three conditions
  1. Story
  2. Physical
  3. Virtual Reality
- Measures
  - Preparedness for caregiving
  - Knowledge of Alzheimer's Disease
  - Dementia Attitudes Scale
  - NASA and Presence (VR simulation)
  - Semi-structured interview questions

VR Dementia Study: Design

- Research questions
  - Are the three conditions equally able to increase empathy for persons with Alzheimer's disease operationalized by caregiving preparedness, attitudes about Alzheimer's disease and knowledge of Alzheimer's disease?
- Hypothesis:
  - The three conditions do not increase empathy for persons with dementia equally.
    - Caregiver preparedness ↓
    - Caregiver attitudes ↑
    - Caregiver knowledge ↑

VR Dementia Study: Results

- Results are forthcoming

VR Dementia Study: Future Studies

- Expanding our work to the Home and Community Based Waiver (Medicaid) Community Long-Term Living case managers.
- We have focused heavily on the caregiver, which is important; however, we believe that a potentially more appropriate audience for the dementia empathy tour among this population are case managers.
  - Case manager work directly with both the participants and caregivers
  - Case managers are the “link” between the participant/caregiver and services
  - If case managers have this training, perhaps they will be more sympathetic to the caregiver role.
    - Ideally, the case manager will administer caregiver stress assessments and referrals to respites, ADHC and other services offered by the Home and Community Based Waiver to support the caregiver.
- Building on the VR simulation

Caregiver Competency

- Research Question
  - How does competency for caregiving influence institutionalization?
- Hypothesis:
  - The higher the caregiver's competency, the less likely the caregiver will be to institutionalize.
- Secondary Analysis
  - Association Between Behavioral Disturbances and Nursing Home Admissions in Patients with Alzheimer's Disease Study*
    - Case-Control study (case= institutionalized; control=non-institutionalized)
  - Maggi Miller, Research Assistant Professor at the University of South Carolina
  - Candace Porter, PhD
  - Office for the Study of Aging at the University of South Carolina
- Sample (n=352)
  - Alzheimer's disease diagnosis
  - Isolated to Cases – Institutionalized

**Porter CN, Miller MC, Lane M, Cornman C, Sarsour K, Kahle-Wrobleski K. The influence of caregivers and behavioral and psychological symptoms on nursing home placement of persons with Alzheimer's disease: A matched case–control study. SAGE Open Medicine. 2016;4:2050312116661877*

Caregiver Competency: Dependent Variable

- Caregiver's main reason for institutionalization
  - Qualitative answers coded into five categories:
    1. Challenging behaviors
    2. "Just couldn't do it anymore" (lack of social support)
    3. "Dementia" (because they have the diagnosis)
    4. Medical reasons/recommendation by the doctor
    5. Better quality of care provided at the nursing home

Caregiver Competency: Independent Variable

- Caregiver competency scale (validated, continuous measure)
  - Caregiver self-efficacy
  - Confidence with caregiving
  - Ability to manage difficult situations
  - Feelings of success as a caregiver

Caregiver Competency: Covariates

- Caregiver gender
- Caregiver age
- Relationship to care receiver (spouse/non-spouse)
- Caregiver educational achievement
- Caregiver employment status
- Center for Epidemiologic Studies Depression Scale Revised
- Neuropsychiatric Inventory Scale (NPI-4)
- Zarit Burden Scale (4-item)

Caregiver Competency: Descriptive Statistics

Descriptive	%(n) or x(sd)
Main reason for institutionalization	
Challenging behaviors	10% (34)
"Unable to do it anymore"	34% (118)
Dementia as a diagnosis	6% (22)
Medical needs	33% (116)
Better care in nursing home	17% (57)
Caregiver age	60.0 (11.4)
Female	77% (270)*
Education	
Less than high school diploma	30% (121)
High school diploma	24% (73)
More than high school diploma	36% (113)
Employment Status	*
Retired	34% (120)
Employed	48% (168)
Not employed	18% (63)
Spouse	54% (189)
Validated Scales	
Depressed (CESD-10)	59% (204)
High burden (Zarit Burden)	51% (179)
Caregiver competency	14.8 (1.61)
NPI-4	14 (11.1)

Caregiver Competency: Multinomial Logistic Regression

Variables		RRR	95% CI
Reference: "Just couldn't do it anymore"			
Reason: Challenging Behaviors			
	Competency score	0.77	(.60-1.02)
	Female	1.18	(.38-3.70)
	< High school		---
	High school diploma	4.06	(1.12-14.8)
	> High school	5.33	(1.67-17.0)
	Caregiver age	1.03	(.99-1.09)
	Retired		---
	Employed	3.08	(.84-11.26)
	Not employed	6.18	(1.65-23.16)
	NPI-4 score	1.04	(1.00-1.09)
	High burden	0.41	(.15-1.11)
	Depressed	0.51	(.52-3.69)
	Spouse	1.38	(.52-3.69)
Reason: "Diagnosis of dementia"			
	Competency score	0.67	(.49-.91)
	Female	0.51	(.16-1.61)
	< High school		
	High school diploma	0.76	(.20-2.82)
	> High school	0.41	(.11-1.54)
	Caregiver age	1.03	(.96-1.09)
	Retired		
	Employed	1.59	(.38-6.57)
	Not employed	0.72	(.11-4.81)
	NPI-4 score	1.06	(1.00-1.11)
	High burden	0.31	(.86-1.15)
	Depressed	0.35	(1.0-1.18)
	Spouse	1.96	(.61-6.33)
Reason: Medical concerns			
	Competency score	0.76	(.62-.93)
	Female	1.31	(.61-2.82)
	< High school		
	High school diploma	1.11	(.50-2.46)
	> High school	1.36	(.68-2.72)
	Caregiver age	1.1	(.98-1.05)
	Retired		
	Employed	2.3	(.98-5.42)
	Not employed	1.59	(.59-4.21)
	NPI-4 score	0.99	(.97-1.02)
	High burden	1.11	(.55-2.3)
	Depressed	0.47	(.23-.97)
	Spouse	1.03	(.53-1.98)
Reason: Better quality of care			
	Competency score	0.99	(.75-1.31)
	Female	1	(.42-2.37)
	< High school		
	High school diploma	1.75	(.72-4.23)
	> High school	1.21	(.50-2.91)
	Caregiver age	0.99	(.95-1.03)
	Retired		
	Employed	1.31	(.48-3.60)
	Not employed	0.53	(.14-2.06)
	NPI-4 score	0.99	(.95-1.03)
	High burden	0.45	(.19-1.04)
	Depressed	1.09	(.47-2.53)
	Spouse	1.25	(.58-2.71)

Caregiver Competency: Discussion

- As competency increases, caregivers are more likely to report that the main reason for institutionalizing is due to lack of support.
- With lower competency, caregivers are more likely to institutionalize for medical reasons or behavioral challenges.
- While a more competent caregiver may be better able to assess when institutionalization is appropriate, many of the comments provided by respondents illuminated that the caregivers felt that they could keep their loved ones at home longer if they had received more help from family and friends.
- A poignant reason for institutionalizing a loved one due to lack of help was, “It was too much too handle. I am a single mom, and I have to work.”

Resources Enhancing Alzheimer's Caregiver Health "REACH" Adaptation: Team

- GHS (now Prisma) awarded Administration for Community Living – Administration On Aging Grant (2015 – 2018)
- Grant supported providing Rosalynn Carter Institute REACH (RCI-REACH) in Upstate South Carolina
- PI: James Davis, MD (Prisma Health)
- PI for Evaluation: Maggi Miller, PhD (University of South Carolina)

REACH Adaptation: What is RCI-REACH?

- Trained/certified “Care Coach”
- Structured and scripted sessions
- Targeted interventions for recipient behaviors and/or issues related to communication and social support
- Dealing with Dementia Guide
- Topics covered:
  - Education about dementia
  - Behavior management
  - Problem solving
  - Stress and mood management

REACH Adaptation: Delivery

	GHS RCI-REACH
Caregiver Participants	1
Number of Sessions	10 - 12
Session Format	9 (no fewer than 5) in person; 3 (up to 7) telephone sessions
Session Length	1 hour
Session Duration	6 months

REACH Adaptation: RCI REACH Results

- Improved quality of life for caregiver and care receiver
- Reduced caregiver depression
- Reduced caregiver burden
- Improved caregiver health

REACH Adaptation: RCI REACH Challenges

- Cost
- Compliance
- Social Support

REACH Adaptation: Group REACH

- Home safety check (-)
- Signs and symptoms of common health conditions (+)
- Environmental influence of behaviors (+)
- Social Support (+)

REACH Adaptation: Group REACH Delivery

	GHS RCI-REACH	**Group REACH**
Caregiver Participants	1	2 – 8
Number of Sessions	10 - 12	10 – 12
Session Format	9 (no fewer than 5) in person; 3 (up to 7) telephone sessions	Group sessions
Session Length	1 hour	1.5 hours
Session Duration	6 months	Approx. 3 months

REACH Adaptation: Group REACH

- 5 Groups
  - Golden Corner Respite, Seneca, SC (2 times)
  - Clemson Downs, Clemson, SC
  - Westminster Train Depot, Westminster, SC
  - PRISMA Senior Care (PACE program), Greenville, SC
- 22 participants total

REACH Adaptation: Group REACH Outcomes

- Regular attendance
  - "I wanted to garden during this class, but I just couldn't miss it!"
  - 1 drop out and 1 terminated early due to a medical condition
- Social Support
  - "[The class] has become my very close friends. I value each of you."
  - Caregivers carpool loved ones to respite programs
  - Caregivers exchange contact information at end of program
- Satisfaction
  - "I have learned so much from this class"
  - "I am so grateful for this class. Thank you."
- Self-Efficacy for Caregiving
  - "I feel so much more empathetic to my [loved one]."
  - "When I start feeling stressed, I take a signal breath and it helps!"

DHHS Community Choices Caregiver Survey: Background

- SC Department of Health and Human Services (DHHS) contracted with Clemson's Office of Research and Organizational Development (OROD) to develop a survey of caregivers of participants on the Community Choices and Home Again waivers (Medicaid).
- Waivers are for Medicaid eligible individuals who qualify for nursing home level of care but wish to live in the community.

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DHHS Community Choices Caregiver Survey: Background

- OROD carries out the annual survey of waiver participants
- In 2018 participants were asked about the help that they are receiving post-transition
  - One-year post transition
    - 73% of participants reported that family members were helping around the house
    - 8 hours/day
  - Two-years post transition
    - 4 hours/day
    - Reporting that they need more help

DHHS Community Choices Caregiver Survey: Questionnaire Topics

- Demographics
- Type of care provided (clinical and non-clinical)
- Skills and abilities
- Values and preferences
- Self-efficacy for caregiving
- Social support
- Health and wellbeing
- Supportive services
- Desire to institutionalize

DHHS Community Choices Caregiver Survey: Timeline

- Survey has been approved by DHHS
- Data collection to being in January
- Statewide sample of current caregivers of waiver participants
- Call center to collect data (staffed by Clemson students)
- Development of resource fliers and booklets for caregivers
- Recommendation of education/intervention programs

DHHS Community Choices Caregiver Survey: Goals

- Improve the current caregiver stress assessment used in the waiver assessment
- Understand the role of caregivers of participants on the Community Choices waiver
- Support the provision of services to caregivers (respite, education, etc.)

Healthcare Utilization and Cost for Persons with Alzheimer's Disease or a Related Dementia

- Data sources
  - South Carolina Patient Encounter Data
  - South Carolina Alzheimer's Disease Registry
- Longitudinal dataset
  - 2008 – 2018
- Track ADRD patient utilization of healthcare services in SC over time and across health care settings

Healthcare Utilization and Cost for Persons with Alzheimer's Disease or a Related Dementia

- All-cause emergency department (ED) and inpatient utilization
- ED visits and readmissions for conditions that caregivers should theoretically manage in an outpatient setting
- Inpatient visits that result in a hospital acquired preventable condition

Healthcare Utilization and Cost for Persons with Alzheimer's Disease or a Related Dementia

- Aim 1:
  - Describe and compare total emergency department and inpatient utilization and cost for persons with ADRD to matched controls prior to diagnosis and after diagnosis
- Aim 2:
  - 2.1 Describe ED and inpatient utilization for key complications of ADRD, specifically falls, pneumonia, and urinary tract infections
  - 2.2 Describe ED utilizations for behavioral and psychological symptoms of AD post diagnosis
  - 2.3 Explore time from first ED visit after ADRD dx to readmission to ED for a fall, pneumonia, UTI or behavioral and/or psychological symptoms associated with ADRD
- Aim 3:
  - Describe and compare the occurrence of hospital acquired preventable conditions for persons with ADRD to matched controls without ADRD.