The Role of Research in Examining and Understanding the Illness Experience of Individuals with Dementia

Katherine S. Judge PhD
Professor of Psychology
Director of Adult Development & Aging Doctoral Program
Department of Psychology
College of Sciences and Health Professions
Cleveland State University

Adjunct Senior Research Scientist
Center for Research and Education
Benjamin Rose Institute on Aging

RESEARCH SUMMIT ON
DEMENTIA CARE
Building Evidence for Services and Supports

#DementiaCareSummit

What is the illness experience?

- An individual's subjective appraisal and experience of their illness and the resulting impact
  - Coping abilities and resources
  - Managing primary and secondary symptoms
  - Development of mental health issues (i.e., anxiety and/or depression symptoms)
  - Overall quality of life (QOL)
  - Social and emotional well-being
  - Social support and resources
  - Engagement, purpose, and sense of self
  - Independence and autonomy
  - Roles and relationships
  - Care values and preferences
  - Expression of unmeet needs (verbally or behaviorally)

Why is it important to examine and understand the illness experience?

- Understand how individuals actively cope with and manage their symptoms and the impact of their illness

- Examine how the illness experience impacts other domains of individuals' lives and their caregivers' lives

- Intervene upon the illness experience of living with dementia to improve psychosocial, functional, and clinical outcomes for individuals with dementia

What do we know about individuals who are able to participate in research studies?

- **Research focus & cognitive level**
  - Understand the illness experience
    - Mild to moderate
  - Intervene upon the illness experience
    - Mild to moderate to severe

- **Method used and sample size**
  - Qualitative and quantitative
  - N size varies; 8 - 333

- **Inclusion criteria**
  - Cognitive screening tool

- **Data collection tools**
  - Open-ended questions
    - Impact of memory loss on activities
    - Impact of memory loss on relationships
  - Likert scales
    - Quality of life
    - Symptoms of depression
    - Role captivity
  - Behavioral/functional measures
    - Engagement
    - Strength, balance
    - Independence in completing PADLs/IADLs

Are measures reliable and valid?

- Themes extracted from qualitative data
  - Small percentage of unusable data

- Likert scales – For those who were able to complete
  - Difficulties completing PADLs ($\alpha = .76$)
  - Role captivity ($\alpha = .64$)
  - Health strain ($\alpha = .75$)
  - Relationship strain ($\alpha = .81$)
  - Embarrassment about memory loss/problems ($\alpha = .77$)
  - Anxiety ($\alpha = .72$)
  - Depression ($\alpha = .76$)
  - QOL ($\alpha = .69$)

  - All measures demonstrated structural validity with factor loadings of .40 or higher

- Behavioral/functional measures
  - Small percentage of unusable data
  - If comparison data is available, typically fall within acceptable range

How do individuals with dementia experience their illness?

- Common themes extracted from qualitative data:
  - Negative emotional experiences and stress
  - Concerns about their future and progression of the illness
  - Concerns about their memory and loss of independence
  - Positive and negative impact of their interpersonal relationships
  - Range of coping strategies used
  - No impact on their lives

How do individuals with dementia experience their illness?

- Using multiple regression analyses for predicting anxiety, depression and quality of life

- Variables included:
  - race, education, gender
  - cognitive ability and behaviors
  - difficulty with IADLs
  - role captivity
  - physical health strain, embarrassment
  - self-efficacy

- Anxiety
  - 57% of variance explained
  - Embarrassment about memory problems

- Depression
  - 56% of variance explained
  - Physical health strain and role captivity

- QOL
  - 43% of variance explained
  - Self-efficacy and difficulty with IADLs

Can we intervene upon the illness experience?

- Project *ANSWERS* (Acquiring New Skills While Enhancing Remaining Strengths)

  - RCT dyadic cognitive rehabilitation and counseling based intervention (in-person)

  - Compared to control group, individuals reported less:
    - anxiety
    - dyadic relationship strain
    - difficulty in performing personal activities of daily living
    - difficulty coping with memory related problems

- Partners in Dementia Care (PDC)

  - RCT dyadic care coordination intervention (by phone)

  - Compared to control group, individuals reported less:
    - depression
    - dyadic relationship strain
    - unmet needs
    - Isolation
    - embarrassment about memory loss

What are current research strategies & limitations?

Strategies	Limitations

• Flexible method of administration of measures and interventions
  • In-person; by phone
• Use of visual aids and cueing
• Types of questions
  • Subjective versus objective
• Wording of questions and response choices
  • Dichotomous versus full-scale
  • Unidirectional versus bidirectional
• Utilize and build on individual's cognitive and functional strengths
	• Use of cognitive screening tools for determining participation
	• Reliance on measures designed for caregivers
	• Use of appropriate strategies and for what stage
	• Lack of information for modifying data collection procedures and intervention protocols that capitalize on individual's strengths

What are the recommendations and next steps?

• Further our understanding of the illness experience and highlight areas amenable to intervention ***across all stages of the illness***

  • Determine appropriate methodology for including individuals in research studies (i.e., inclusion criteria, data collection methods)

  • Develop measures that directly capture and assess the illness experience of living with dementia and the resulting effects

  • Design data collection and intervention protocols that facilitate participation and utilize individuals' cognitive strengths/abilities

  • Develop interventions that directly address and improve psychosocial, functional, and clinical outcomes for individuals with dementia

Research examples with individuals with dementia

- Bass, et al. (2014). A Controlled Trial of "Partners in Dementia Care:" Veteran Outcomes After 6 and 12 Months. *Alzheimer's Research and Therapy, 6:9*.

- Brod, et al. (1999). Conceptualizing and measurement of quality of life in dementia: The dementia quality of life instrument (DqoL). *The Gerontologist, 39*, 25-35.

- Caddell, et al. (2011). Studying the self in people with dementia: How might we proceed? *Dementia,* 12(2), 192-209.

- Clare, et al. (2005). Perceptions of change over time in early stage Alzheimer's disease: Implications for understanding awareness and coping style. *Dementia,* 4(4), 487-520.

- Clark, et al. (2004). Outcomes for patients with dementia from the Cleveland Alzheimer's Managed Care Demonstration. *Aging and Mental Health* 8(1):40-51.

- Dawson, et al. (2013). Predictors of Self-Reported Psychosocial Outcomes in Individuals with Dementia. *The Gerontologist*, doi:10.1093/geront/gns137

- Judge, et al. (2010). Stress Process Model for Individuals With Dementia. *The Gerontologist; 50(3):294-302*.

- Krestar, et al. (2012). Including individuals with memory impairment in the research process: The importance of scales and response categories used in surveys. *Journal of Empirical Research on Human Research Ethics, 7(2):67-76*.

- Logsdon, et al. (2010) Early-stage memory loss support groups: Outcomes from a randomized controlled clinical trial. *Journal of Gerontology: Psychological Sciences* 65B(6):691-697.

- Orsulic-Jeras, et al. (2016). The SHARE program for dementia: Implementation of an early-stage dyadic care-planning intervention. *Dementia*, doi:1471301216673455.