

## BACKGROUND

■ To date there is not a structured interview for clinicians that provides a comprehensive and balanced assessment of what it is like to live with the early stages of Alzheimer's disease and other memory disorders.

## AIMS

The aims of this study were:

- 1) To develop an interview schedule that would:
  - Identify struggles & concerns of living with the early stages of AD and other dementias;
  - Uncover personal coping resources for living with the early stages of AD and other dementias; and
  - Identify areas of growth for individuals with early-stage AD and other dementias.

## METHODS

- **Participants** (n=54)
  - **Inclusion Criteria:**
    - a) Age 55 or older
    - b) Diagnosis of Alzheimer's Disease
    - c) Clinical Dementia Rating (CDR) = 1 (mild dementia)
    - d) Ability to complete a structured interview and other measures from a trained examiner
  - **Exclusion Criteria:**
    - a) Severe psychiatric problems such as untreated Schizophrenia
    - b) Severe auditory impairment
    - c) Severe aphasia
    - d) Not fluent in English
    - e) Unwilling to complete a structured interview and other measures with a trained examiner
- **Procedures:**
  - 2 versions of Dimensions of Living with Dementia (DLD) Interview developed by McGee & Carlson (2011), one for people with dementia and one for family members.
  - Input received from 4 clinicians with expertise in dementia care, 2 dementia researchers, and 2 people with mild AD.
  - 28 people with early stage AD and 26 family members received the DLD (n=54) by a trained interviewer.
  - Responses were recorded and analyzed.

## Dimensions of Living with Dementia Interview

### Section A: Impact of Living with Dementia

1. As you think about living with dementia what words come to mind?  
[Note to Interviewer: Try to elicit at least 8 words, record in order]
2. What does having dementia mean to you personally?
3. How do you see yourself differently, if at all?
4. What is the hardest part [or greatest challenge]?
5. What good, if any, has come to you from this experience?
6. Have you grown in any way from this experience? If so, how?
7. What keeps you going?



### Section B: Spiritual/Religious Dimensions of Living with Dementia

1. What do you hold as most sacred in your life? Has this changed at all since you were diagnosed with dementia? If so, how?
2. What are your most important spiritual/religious beliefs? Have they changed at all since you were diagnosed? If so, how?
3. How would you describe your relationship with God (e.g. use words like divine, spirit, higher power, gods if relevant)? Has this changed at all since you were diagnosed? If so, how?
4. Tell me about your current spiritual/religious practices. Have they changed at all since you were diagnosed? If so, how?
5. Tell me about your current involvement with your religious/spiritual community. Has this changed at all since you have been diagnosed? If so, how?
6. What religious/spiritual writings/teachings have been most helpful to you in dealing with dementia, if any?
7. Have there been any religious/spiritual writings/teachings that have made it more difficult for you to cope with being diagnosed with dementia? If so, which ones?
8. Have you had any religious/spiritual struggles since you were diagnosed? If so, please tell me about it?

### Section C: Positive Psychological Dimensions of Living with Dementia

1. What does *hope* mean to you? How has hope come into play in your experience?
2. What does *love* mean to you? How has love come into play in your experience?
3. What does *forgiveness* mean to you? How has forgiveness come into play in your experience?
4. What does *gratitude* mean to you? How has gratitude come into play in your experience?
5. What does *acceptance* mean to you? How has acceptance come into play in your experience?
6. What does *commitment* mean to you? How has commitment come into play in your experience?
7. What does *resilience* mean to you? How has resilience come into play in your experience?
8. What would you want other people who have dementia to know about your personal experience?

## FINDINGS

- The DLD Interview took on average 30-45 minutes for completion.
- People with AD and their family members were able to engage in rich and meaningful discussion about their core values and beliefs, resources, and concerns.
- The open-ended questions allowed for a unique opportunity to express and share participants unique personal experiences.
- Many participants viewed the interview process as meaningful and an opportunity to share their deepest thoughts.
- At least one person said that the interview had made her "feel like a person again".
- Several individuals noted that the interview was a therapeutic process for them.



## CONCLUSIONS

- The DLD interview is a potentially useful tool for assessing coping resources and strengths in this population.
- The DLD interview offers the foundation for a strengths-based clinical intervention for coping with the early stages of AD and other dementias (which the authors are developing).
- Future work should involve learning about the dimensions of living with dementia among people with different types of dementia (i.e. AD versus FTD) and across diverse social, ethnic, and religious cultures.