

# Loss and Attainment of Identity for Individuals Experiencing Early-Onset Dementia

## Introduction

Dementia is a progressive neurogenic disease impacting individuals younger than 65 years old who often are working, raising families, and contributing to society. Individuals experiencing early-onset dementia (EOD) gradually lose self-perception, and others including family may no longer perceive them as the people they once were. How can caregivers and therapists protect and preserve a sense of identity that will contribute to quality of life? Narrative research claims storytelling stitches together fragments of life and is a tool for understanding oneself and negotiating this with others. Understanding the impact of narrative shifts that reflect changing identity and personhood could facilitate person-centered interventions designed to maximize quality of life along the dementia continuum.

## Objective

This study aimed to map how personal and socially attributed identity shifted as everyday life changed over the dementia continuum. The goal was to determine if common narrative and life story themes marked key indicators of perceptions of self, others and everyday life roles.

## Methods

The materials of the study were open-source video, audio, and text material submitted by individuals experiencing EOD and their family members for public use. Nine of the participants were male, two were female, all from English-speaking countries and working at the time of their dementia diagnoses. The qualitative analyses began with line-by-line transcription of textual, video, and audio materials. Descriptions of symptoms associated with the initial, middle, and late phases of dementia were used to segment each transcript. Two sets of theme analyses were then used for coding. The first focused on disease description, behavioral challenges, situational needs, and themes associated with personal identity and quality of life changes. The second identified themes that concentrated on attributed self-identity, attributed self-identity from caregivers, and attributions of identity toward others from a person experiencing EOD. The major and minor themes derived from the analysis were cross coded for interrater reliability.

Figure 1: Nationalities of Participants

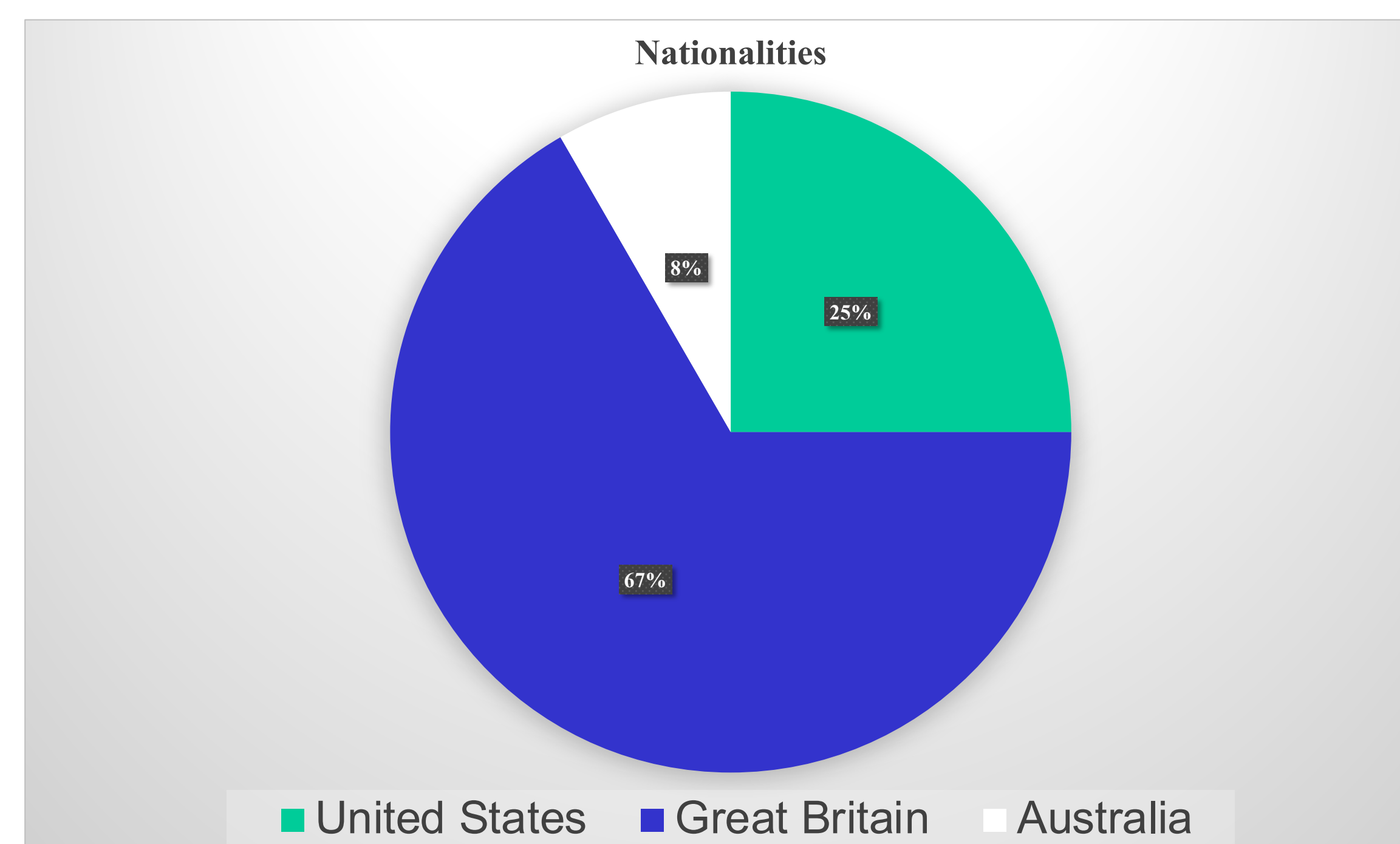


Figure 2: Types of Dementia reported by Participants

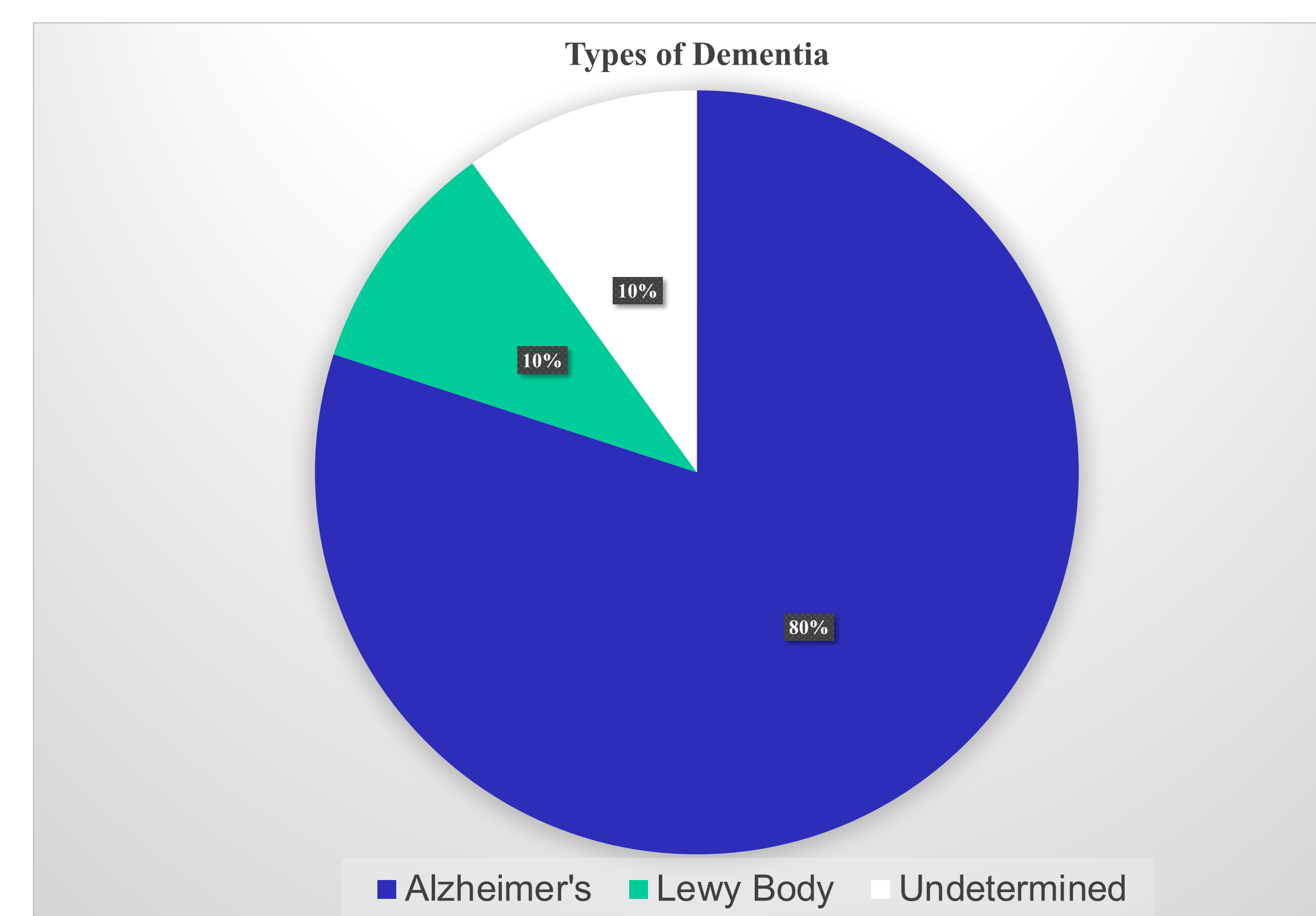


Table 1: Major & Minor Themes in Personal & Socially Attributed Identity

Major Themes	Minor Themes
Personhood Preservation	Advocacy
	Legacy-Building
	Community
Loss of Personhood	Exclusion
	Isolation
	Withdraw

## RESULTS

Participant stories in Phase-I (early) and Phase-II (middle) of the dementia continuum described how inclusion in everyday life activities, their roles, and interactions were keys to personhood preservation. Participants also expressed their negative feelings when excluded by others from everyday life participation & roles and its affect on the perceived loss of personhood as they lived with dementia. Individuals with EOD and their partners/caregivers jointly constructed late Phase-II stories while caregivers solely provided Phase-III (late) stories. As the disease progressed, the responsibility of personhood preservation and identity attribution shifted exclusively to others around the person with EOD. Identified themes reflected how both preservation and loss of identity influenced the perceived quality of life. There were no differences in narrative components across the nationalities of participants.

## CONCLUSIONS

This study's results provide clinicians with supplemental information that may assist in relevant treatment goal-setting that advances the quality of life for individuals with early-onset dementia and their families.

## REFERENCES

- Alzheimer's Society (2020) *Younger Onset Dementia*. <https://www.alzheimers.org.uk/about-dementia/types-dementia/younger-people-with-dementia#content-start>
- Hagstrom, F. (2004). Including identity in clinical practices. *Topics in Language Disorders*, 24, 225-238.
- Johannessen, A., Engedal, K., Haugen, P. K., Dourado, M. C. N., & Thorsen, K. (2018). "To be, or not to be": experiencing deterioration among people with young-onset dementia living alone. *International Journal of Qualitative Studies on Health and Well-Being*, 13, 1-13. doi: 10.1080/17482631.2018.1490620
- Small, J. A., Gutman, G., Makela, S., & Hillhouse B. (2003). Effectiveness of communication strategies used by caregivers of persons with alzheimer's disease during activities of daily living. *Journal of Speech, Language, and Hearing Research*, 46, 353-367
- Taylor, Richard (2007). *Alzheimer's from the inside out*. Baltimore, MD: Health Professions Press.
- Taylor, Richard. [Alzheimer's Support Network] (2015, August 2). *Dr. Richard Taylor (April 7, 2015) -Part 1- Alzheimer's From the Inside Out* [Video]. YouTube. <https://www.youtube.com/watch?v=FxRri2gLTsY>
- WebMD. (2016, June 6). *Into the Fog: Living with Early Onset-Alzheimer's* | *WebMD* [Video]. YouTube. <https://www.youtube.com/watch?v=UxSznEI0UXA>
- Young Dementia UK. (2021). *Stories of People Living with Young Onset Dementia*. <https://www.youngdementiauk.org/stories-people-living-young-onset>