Perspectives of Caregivers on Early Onset Dementia: an investigation of the role of attachment and shifts in identity

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Introduction

Early onset dementia (EOD), diagnosed earlier than 65, is an incurable, neurogenic disease that impacts every aspect of individual and family life as it progresses through three stages. The scope of caregiving broadens from initially helping with the instrumental activities of daily living (IADL) and progressing to assistance with essential activities of daily living (ADL) as dementia deepens. The physical demands of caregiving and emotional demands of caring about a loved one who is losing themselves are challenges that impact quality of life. Understanding the role that identity preservation plays as dementia deepens becomes a quality-of-life priority for caregivers and partners with dementia (PWD).

Objective

The goal of this qualitative study was to investigate changes in caregiver perceptions of themselves in the caregiving process and how their quality of life and that of the affected partner shifted in this process.

Methods

This research focused on two dynamics of relationships: attachment and socially situated self-other identity. The materials were open source, archived video, audio, and text material collected from partners of individuals living with EOD (see Figure 1). Analyses began with line-by-line transcripts of the video and audio material added to textual materials from books, articles, and dementia data banks organized in a spreadsheet document. Entries were read for attachment themes using Bartholomew and Horowitz's (1991) four-category model. Narrative analysis was used to identify themes related to self-identity of the caregivers as well as their attributions of identity to the partner with EOD. These two parameters were coded and cross coded (IRR) for patterns between attachment and social identity across the stages of dementia.

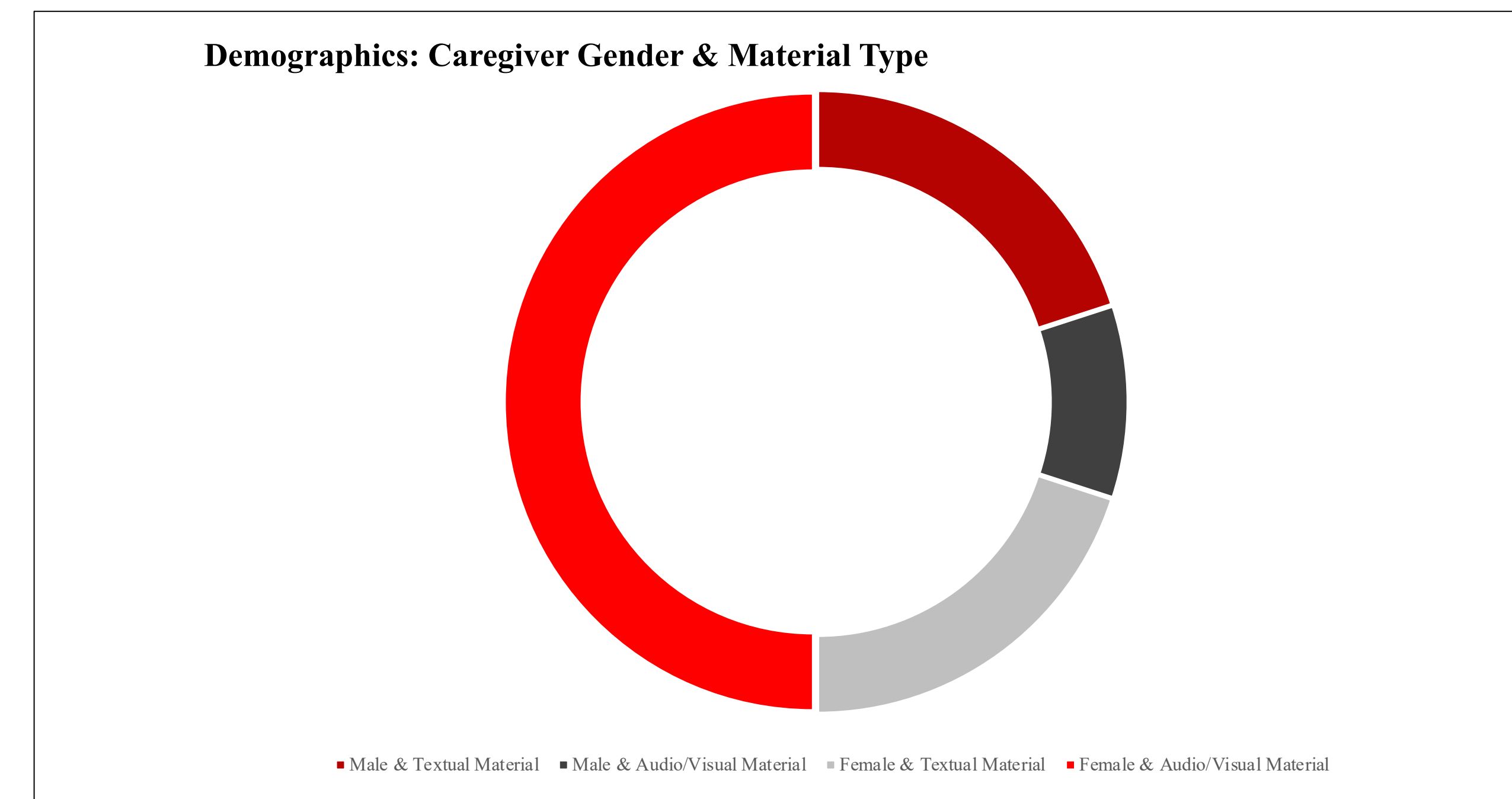### Figure 1. Demographics & Material Type

Demographics: Caregiver Gender & Material Type

- Male & Textual Material
- Male & Audio/Visual Material
- Female & Textual Material
- Female & Audio/Visual Material

Table 1. Themes Presented throughout Caregiving for PWD

Fluid Themes	Flexible Themes
Denial	Adjustment
Sacrifice	Reflection
Mental Reframing	

Figure 2. Caregiver Attachment & Identity Attributed to PWD

Caregiver Attachment & Identity Attributed to PWD

- Securely Attached, Caregiver Works to Maintain PWD Identity
- Insecurely Attached, No Caregiver Acknowledgment of PWD Identity
- Securely Attached, Caregiver Acknowledge's Current PWD Identity as a Stranger
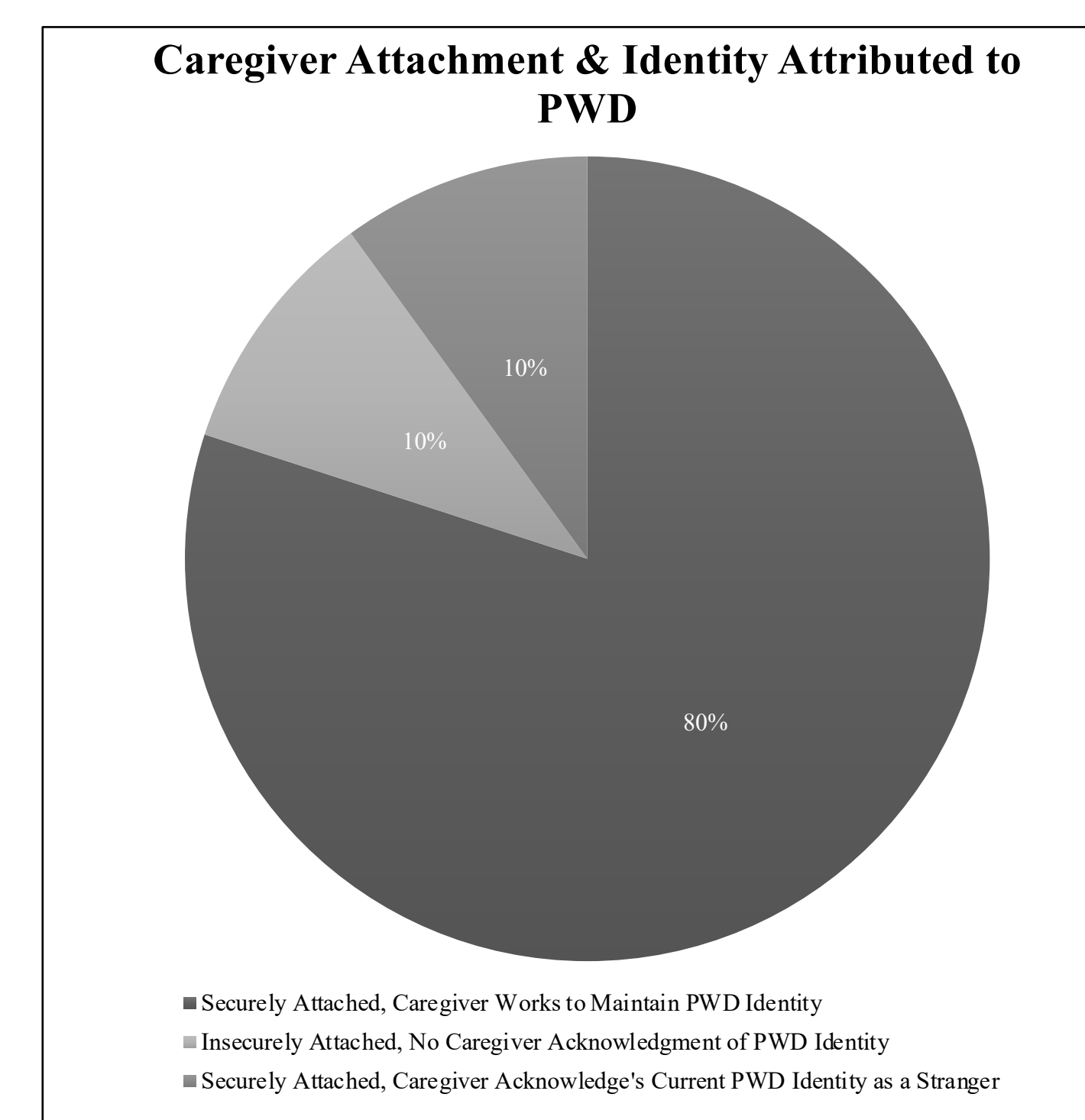
Figure 3. Secure Attachment & Higher Quality of Life Outcomes

Ways Securely Attached Caregivers Were Found to Maintain Higher Qualities of Life

- Comfort In New Abilities
- Discovered New Passions
- Maintained Friendships
- Maintained Emotional Connection
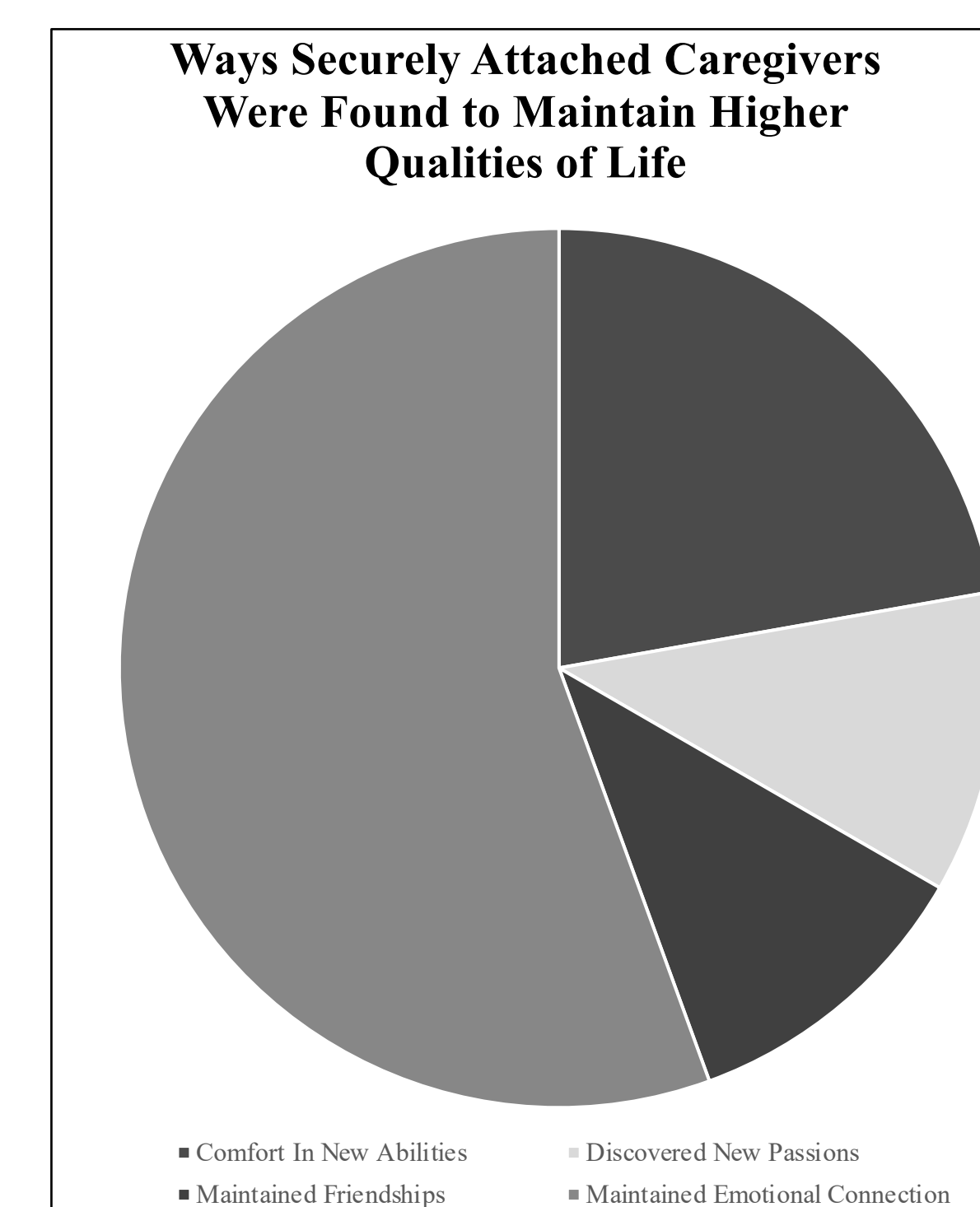
Results

As caregivers experienced the progression of each stage of dementia, caregiver strategies evolved to become more fluid and flexible due to the unpredictable shifts in behavior and inability of the partner with EOD to be flexible. Table 1 shows the themes related to the fluidity and flexibility of evolving caregiving strategies. Ninety percent of the corpus proved securely attached caregiver's self-identity moves from reliance to resilience as the scope of caregiving broadens and dementia deepens. Findings suggested that securely attached caregivers maintained a grounded sense of self throughout the deepening of dementia and worked to maintain the identity of the PWD (shown in Figure 2). Additionally, those who experienced secure attachment throughout the deepening dementia process had a greater quality of life (Figure 3). Analysis of the data also suggests that a secure attachment style provides more awareness of the PWD's experience, therefore, focusing on the PWD's quality of life.

Conclusions

The results of this study suggest that self-identity and attribution of identity to the PWD are impacted as dementia progresses. Findings of this study have the potential to provide clinicians with a model for goal setting with caregivers and partners with EOD that can advance quality of life for persons – caregiver, patient, family – living with dementia.

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