The Coping Strategies of Family Caregivers of Persons With Advanced Alzheimer’s Disease

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Alzheimer’s disease (AD) is an insidious disease of unknown etiology that causes a steady, progressive deterioration of the individual’s intellectual capacity, with no signs of remission. (AA, 2010a; AA, 2010b; AA, 2009).

The progress of AD requires assistance with personal care and safety from a family caregiver, but providing care to persons with AD promote negative health outcomes for family caregivers.
Problem Statement

- Family caregivers present difficulties in handling coping with the diagnosis and the disease challenges as the disease progresses into later stages (AA, 2009; Boise, Congleton, & Shannon, 2005).

- An increment in the stressors and the burden experienced by family caregivers, result in adverse health outcomes (Cooper, Katona, Orrell, & Livingston, 2008; Donelan, et al., 2002; Paun, Farran, Perraud, & Loukissa, 2004).
Who are the Family Caregivers?

The family caregivers are:

- The persons within the family members who are responsible for the affected person’s daily care.

- Unpaid relatives who may or may not live with the persons with AD, but provide extensive hours of personal care to the affected persons.

(Brodaty & Green, 2002; Farcnik & Persyko, 2002; Nerenberg, 2002).
What is Caregiver Burden?

Caregiver burden is used to:

- Describe the “emotional, physical, social, and financial” (Brangman, 2006, p. 15) stress associated with the provision of care to a relative with AD.

- Identify the stress and strain sustained by people who provide care to a relative with AD and when they are unable to cope with caregiving demands, they experience caregiver burden (Brodaty & Green, 2002).

- Indicate that high levels of stress associated to the provision of care to a relative with AD produces an impact on the caregivers’ physical and mental health (Brodaty & Green, 2002; Savundranayagam, Hummert, & Montgomery, 2005).
Family Caregiving’ Health Outcomes

Family caregivers experience:

- Adverse health outcomes due to stress and strain of caring for their love ones for many hours a day
- Difficulties in their ability to cope with the diagnosis and the disease challenges as the disease progressed into later stages
- Stressors associated with personal characteristics, socioeconomical status, kinship, and family support, affect family caregivers’ health and the ability to provide care.
Research Methodology and Theoretical Framework

- Initially I used grounded theory to investigate the coping strategies among family caregivers of persons with stages 5 to 7 of AD.

- The theory of self-efficacy (TSE) from Bandura (1994) was used as theoretical framework.

(Bandura 2001; Creswell, 2007; Liamputtong, 2009).
Study Population and Inclusion Criterion

Study population and participation criterion included:

- Family members who were providing care at home to persons with stage 5 to 7 of AD
- Lived in Puerto Rico
- Have taken care of the affected person for 5 years or more
- Were older than 18 years
- Had no personal or professional relation with me.
Sample Size

- A sample size of 10 participants permitted me to collect sufficient data about the coping strategies of family caregivers of persons with stage 5 to 7 of AD.
Data Collection Method and Tool Used

- A questionnaire with 6 open-ended questions was used to collect data during face-to-face interviews.

- Interviews were recorded
Table 1: Demographic Characteristics of Study Participants.

Table 1 lists a summary of demographic characteristics of study participants.

<table>
<thead>
<tr>
<th>Gender</th>
<th>Number</th>
<th>Mean Age</th>
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<tbody>
<tr>
<td>Female</td>
<td>9</td>
<td>61</td>
</tr>
<tr>
<td>Male</td>
<td>1</td>
<td>75</td>
</tr>
<tr>
<td>Total</td>
<td>10</td>
<td>62.4</td>
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<table>
<thead>
<tr>
<th>Relationship to Person with AD:</th>
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<tbody>
<tr>
<td>Relationship</td>
</tr>
<tr>
<td>-------------</td>
</tr>
<tr>
<td>Daughter</td>
</tr>
<tr>
<td>Female Spouse</td>
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<tr>
<td>Male Spouse</td>
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<td>Total</td>
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Sub Question 1

“What are the coping strategies used by family caregivers of those persons with AD in stage 5 to 7?”

- Codes: Bedbound Care, routine care, mobile persons, and communication

- Sub codes: Functional dependency, combativeness, and prevention of disruptive behavior

Theme: Caregiving skills
Sub Question 2

“What difficulties do family caregivers experience during the provision of care to family members with AD in stage 5 to 7?”

- Codes: Physical problems, disruptive behavior, and lack of support

- Sub codes: Injuries during care and caregiver negligence of health

Theme: Difficulties (physical and behavioral)
Research Sub Question 3

“What stressors do family caregivers experience while taking care of persons with AD in stage 5 to 7 that may impact their health and ability to provide care?”

- Codes: Functional and cognitive deficits, mourning conjugal relationship, changes in lifestyle, and role changes

Theme: Stressors (cognitive and emotional)
Research Sub Question 4

“What strategies do family caregivers use to reduce stressors associated with caregiving of persons with AD in stage 5 to 7?”

- Codes: Use family help and paid help

Theme: Strategies to reduce stressors
Research Sub Question 5

What learning strategies are employed by family caregivers to learn about AD?

- Codes: Physical and cognitive impairments and behavioral management

Theme: Increased knowledge about AD

How to care for persons with AD?”

- Codes: Published information, self experiences, and others’ knowledge/experiences

Theme: Strategies to learn
Research Sub Question 6

“What strategies do family caregivers use for self-care?”

- Codes: Safety measures, love and understanding as motivators

Themes: Self-care and love and understanding
Theory of Self Efficacy (TSE)

The theory of self-efficacy (TSE) from Bandura (1994) help me to:

- Understand how family caregivers assess their personal attributes to promote changes that influence their lives.

- Delineate family caregivers needs for knowledge to understand AD.

- Find the criteria used by family caregivers to make decisions that involve the care recipients’ well-being and the safeguard of their own mental and physical health.

- Define family caregivers’ coping strategies to manage the disease challenges.

- Identify interventions used to cope with caregiving responsibilities and their effectiveness

- Identify family caregivers’ personal expectations and goals when providing care to persons with AD.

(Bandura, 1994; Rabinowitz, Mausbach, Thompson, & Gallagher-Thompson).
Study Results

With the use of the theory of self-efficacy beliefs I was able to identify the strategies used by family caregivers to develop coping strategies. The strategies included:

- Social persuasion
- Vicarious experiences
- Emotional arousal
Social Persuasion

- Bandura (1994) defined social persuasion as a strategy used to verbally persuade individuals that they have capability to overcome difficulties and to succeed.

- Four caregivers (participants 3, 4, 7, 8) were convinced by friends, neighbors, health care professionals, and others that they were able to provide care and to manage difficult situations.

(Bandura, 1994)
Vicarious Experiences

- Vicarious experiences can be done through observing others and learning from their experiences (Bandura, 1994).

- Models can enhance individuals’ personal beliefs to master challenges (Bandura, 1994).

- Three caregivers (Participants 1, 3, 4) reported that they learned from family members, friends, and/or neighbors how to provide care.

- Two caregivers (1, 2) reported that they observed other family members and paid help while providing care to relatives and learned from their experiences (modeling), which equipped them better to take care of their health.

- Five family caregivers (5, 6, 7, 8, 9) reported to persevere in what they believed can be mastered through trial and errors.

(Bandura, 1994)
Emotional Arousal

- People judged their capabilities to overcome difficult situations based on emotional and somatic reactions (Bandura, 1994).

- Family caregivers (2, 5, 7, 8, 9, 10) expressed that their love for the person with AD served as motivators for care.

- They indicated to be willing to go through difficulties to keep their love ones at home and to be motivated to take care of their health in order to be able to provide care.

(Bandura, 1994)
Coping Strategies

- The results indicated that caregivers used social persuasion, vicarious experiences, and emotional arousal to develop caregiving skills, which resulted in better health outcomes.

- Five caregivers who took care of their health reported to have better health.

- Five caregivers who did not took care of their health indicated to have medical conditions that have affected their health, which agreed with Bruce et al. (2005). Bruce et al. found that spending many hours for care affected caregivers’ physical and mental health.
Family Caregivers’ Modified Theory (Enna’s Theory)

**Vicarious Experiences**
- Strategies to learn about AD
- Strategies to increase knowledge about AD

**Verbal Persuasion**
- Strategies to reduce stressors
- Love and understanding
- Self-care

**Emotional Arousal**
- Stressors
- Physical problems
- Disruptive behavior

**Coping Strategies**
(Developed over time)
- Caregiver skills

**Successful Performance**
- Positive health outcomes
- Positive caregiving experience
- Reduced disruptive behavior
Research Findings

Research findings revealed that family caregivers needed to:

- Learn information about AD and how to manage associated signs and symptoms in order to provide care.

- Develop skills to provide care to mobile and nonmobile persons with AD, to reduce difficulties during care.

- Learn strategies to prevent injuries and falls that might affect the person with AD and/or them.

- Search for family and/or social support in order to take care of their health.
Recommendations for Action

This study confirmed that family caregivers experience many challenges at home and the lack of knowledge, support, and caregiving skills, make it difficult to cope. The recommendations for action include:

- The development of educational programs and skills’ development workshops to improve family caregivers’ knowledge about AD, its challenges, and what is expected from them during the provision of care.

- A plan to help family members to understand caregivers’ need for support and understanding.

- The development of policies and government support services’ programs that will benefit studied population.

- The publication and dissemination of the study results through different media sources.
Implications for Social Change

The implications for social change include the need to:

- Develop community-based responses to address family caregivers’ challenges at home.

- Advocate for family caregivers and change of attitudes towards them as persons that require family and social support to manage the persons with advanced AD at home.

- Disclose findings from this research at different groups, institutions, and politicians, to raise awareness about stressors that affect family caregivers of persons with advanced AD and their needs for support.

- Develop educational modules based on research findings with different Alzheimer’s associations and universities, to educate families and family caregivers of persons with AD about the disease signs, symptoms, associated challenges and strategies to address them.
Conclusion

- The results from this study revealed that lack of knowledge about AD and caregiving skills affected family caregivers of persons with advanced AD.

- The research findings exposed how family caregivers were subjected to daily stressors related to caregiving, which deteriorated their physical and mental health.

- Research participants revealed how they searched different sources for information and were able to develop coping strategies to overcome challenges associated with AD.

- The presented results from those experiences through this research will serve other caregivers in the same situation to learn that no matter how difficult is to take care of a person with AD, there is always hope to learn and to develop skills for care.
References


