A QUALITATIVE STUDY OF CAREGIVER STRESS AND COPING FOLLOWING THE PLACEMENT OF A FAMILY MEMBER IN A DEMENTIA CARE FACILITY

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MAY 2016
INTRODUCTION

There is a range of taxing demands on a familial caregiver of those with AD, including assisting with ADLs, managing problems related to behavior symptoms and cognitive impairment, as well as coping with ambiguous loss and the relationship that he or she used to have with his or her family member (Papastavrou, 2011).

1. What were the motivating factors or life circumstances that compelled a caregiver family member to place a loved one with Alzheimer's disease into a long-term dementia care facility?

In a longitudinal study, Gaugler (2007) states that even after placement family members do not lose their caregiver role as they visit the facility, provide emotional support, and sometimes continue to assist with activities of daily living.

2. How have family members caregiver role changed during the transitional period of moving a loved one to a long-term dementia care facility?

According to Spruytte (2011) early nursing home placement of a family member with AD has been linked to caregiver burden.

3. What coping strategies were the most helpful to caregivers after placement of a loved one with AD?

Research shows that dementia caregivers tend to overuse healthcare resources and underutilize support services, such as support groups or respite care (Tremont, 2014).

4. What support services or resources were most helpful to families experiencing placement of a loved one with AD?
Social workers are a significant support service for dementia caregivers, as they help navigate through the transitions of dementia caregiving and placement of a family member (Pearce, 2012). Social workers facilitate effective clinical interventions as they tend to run support groups and provide individualized therapy for caregivers (Pearce, 2012). Data show that participation in group therapy or one on one therapy generally has positive influences on easing caregiver burden (Yoo, 2010). Participants reported decreased feelings of isolation, increased self-esteem and personal strength, and improved coping skills (Yoo, 2010).

Paun et al. (2015) completed a study on a grief management intervention for dementia caregivers who placed their family members in a long-term care facility. Paun et al. (2015) revealed that follow up calls to caregivers proved to decrease chronic grief and feelings of guilt after 6 months of placement. Social workers can play a crucial role in these grief management interventions during that transitional 6 month period of moving a relative to a long-term dementia care facility. By reintroducing caregivers to the familial roles they used to possess before they became a caregiver, the daughter or son can return to his or her role as the adult child and the husband or wife can return to his or her role as partner.
Ethnic and socioeconomic disparities influence the level of Alzheimer's disease (AD) education, the use of dementia care and supportive services, and the decision of long-term care placement for caregivers (Cooper et al., 2010; Odenheimer, 2013). There are barriers among minority groups, and lower economic groups, when it comes to seeking dementia care or support services (Cooper et al., 2010; Odenheimer, 2013). Barriers include lower levels of accurate knowledge about AD and the need for adaptation to the disease (Cooper et al., 2010; Odenheimer, 2013).

Culturally associated beliefs about dementia, such as stigma associated with AD and the perception of memory loss as a normal part of aging, influence families (Sayegh, 2013). Cultural beliefs and values create health system barriers by discouraging families to seek the appropriate services and support they need (Sayegh, 2013). Socioeconomic disparities create barriers to available dementia care and support services, and ultimately influence the decision of placement for families (Odenheimer, 2013; Sayegh, 2013).
METHODS

- **Sample/ Sample Method:** The participants in this study were selected by purposive sampling in order to accommodate the topics of caregiver stress and coping strategies. The participants recruited were a part of various caregiver support groups that are affiliated with the Alzheimer's Association, Southland Chapter. The total sample consisted of approximately 15 participants who met the eligibility criteria of having recently, within the past 6 months, placed their family member in a long-term dementia care facility.

- **Data Collection:** Data collection was performed by audio-recorded, in-depth, face-to-face interviews ranging from 30-60 minutes in duration. Participants were screened in person by researcher after support groups, or by telephone when participants contacted the researcher. Once eligibility was confirmed, the researcher and participant scheduled an interview date and time that was conducted in a private room provided by The Alzheimer’s Association or at the Los Angeles public library. Before the interview began each participant was presented with an Informed Consent which was signed and collected by the researcher before the interview commenced. Strict ethical considerations were applied in order to ensure the confidentiality of each participant. Participants were presented with Cathy Ladd’s, Vice President of programs at the Southland Chapter of the Alzheimer’s Association, contact information. All participants were also presented with a special promotional gift card for their choice of a free haircut or facial at Vicara Salon in El Segundo, California.
Interview Guide:
1. What resources did you use to locate this particular facility for ______? 
2. Please describe some of the circumstances that ultimately led to your decision to move ______ to this facility? 
3. How did these circumstances you described affect you and your family? 
4. What did you do to help you cope with any stressors after moving your loved one to this facility? 
5. Now that you have moved ______ into this facility, how has your caregiver role changed? 
6. How are you adjusting to this new living arrangement for your loved one? 
7. What support services have you received from the facility or others to help you with the adjustment of moving your loved one to this facility?
   a. What type of support do you receive the most? 
   b. What type of support are you lacking? 
8. If you had a friend or family member who was going through similar circumstances regarding potential dementia care placement for a loved one, what one piece of advice would you recommend to him or her? 
9. Is there anything else you would like to add regarding your situation of placing your loved one in a long-term dementia care facility?

Data Analysis: Data from the interviews, in this qualitative study, were collected and analyzed using the inductive method of grounded theory (Alberti-Alhtaybat & Al-Htaybat, 2010; Glaser & Stauss, 1967). This approach was used to identify themes and patterns related to the stress and coping of caregivers placing a relative in a long-term dementia care facility. In order to identify themes, coding paradigms were well defined and filtered from interviews. Narratives, as well as direct quotes, were used to highlight findings. Descriptive statistics were also used in order to describe the demographics of the sample, such as age, gender, ethnicity, number of dependents, and months since placement.
a) **Themes:**

- A majority of participants (66.7%) attribute behavioral changes of their loved one as the main deciding factor for long-term dementia care placement.

- Almost half (46.7%) of the participants experiencing little to no changes in their caregiver role after placement.

- All participants were emotionally affected by moving a family member to a long-term dementia care facility and these negative emotional effects influenced their coping abilities and the overall well-being.

- Due to the sample of participants all being affiliated with the Alzheimer's Association, most (66.7%) regarded the association as the most supportive resource available.
This study revealed that families struggle coping with the behavior changes of their loved one, the decision of placement, and adjusting during the transition period of moving their love one to a long-term dementia care facility. In addition, this study revealed the lack of emotional support caregivers receive from healthcare providers during this transitional, 6-month, period of long-term dementia care placement.

This exploratory study showed that Alzheimer’s disease has a particular impact on familial caregivers. Additionally, this study confirms current data on dementia caregivers experiencing high levels of caregiver burden and also that they require a higher level of emotional support. In this study, participants expressed high levels of stress caring for a loved one with a dementia diagnosis. Participants also articulated difficulty coping with the decision making process and transition period of moving a loved one to a long-term dementia care facility. Finally, participants emphasized the lack of support services received from long-term dementia care facilities during the transitional period of moving their loved one.
Paun et al. (2015) completed a study on a grief management intervention for dementia caregivers who placed their family members in a long-term care facility. Paun et al. (2015) revealed that follow-up calls to caregivers proved to decrease chronic grief and feelings of guilt after 6 months of placement. Social workers can play a crucial role in these grief management interventions during that transitional 6-month period of moving a relative to a long-term dementia care facility. By reintroducing caregivers to the familial roles they used to possess before they became a caregiver, the daughter or son can return to his or her role as the adult child and the husband or wife can return to his or her role as partner.

Caregivers in this study also credited their primary care physician or hospital doctor and facility nursing staff as being the most helpful resources when searching for placement. Only one participant in this study relied on a social worker for initial resources and not one relied on a social worker for consistent emotional support after placement. This study emphasizes a desperate need for a collaboration between primary care physicians and social workers in the early stages of placement in order to assist families in deciding what type of long-term care facility is most appropriate for their loved one. There are broader implications of a desperate need for more social work employment in long-term dementia care facilities where social workers can also continue disease and facility education as well as emotional support services.


