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## Well-Being of Adult Daughters Who Care for Their Cognitively Impaired Mothers

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### Abstract

*Among the challenges in dementia care is providing assistance to caregivers so that they can remain healthy and able to care for their family member and take the time to care for self. Adult daughters can exert a significant degree of control over their own health and are inclined to do so if self-care and self-efficacy are perceived as of greater importance than perceived barriers and burden. The purpose of this qualitative study was to explore the factors that may assist adult daughters in taking care of self while taking care of their cognitively impaired mothers. This study used Heideggerian hermeneutic phenomenology as the method for interpreting the research question, do adult daughters who care for their cognitively impaired mothers care for self. The constitutive pattern identified was Doing-while-waiting from the three interpreted themes: Doing things-doing something, Place and space, and Waiting on-holding-on. By experiencing waiting the adults daughters experienced compassion energy by being present with compassion, identifying patterns to intentionally know what needs to be done to care for their mothers and this is how they expressed caring for self.*

**Key Words:** Adult daughters, Caregivers, Dementia, Compassion Energy.

### Background

The United States population is rapidly aging. The Census Bureau state that persons over age 65 in 2013 is 14.1% (U.S. Census, 2014). The number of Americans aged 65 and older will more than double to 71 million, which means that older adults will comprise roughly 20 percent of the United States population (CDC, 2012). The cost of providing health care for an older American will be three to five times greater than the cost for someone younger than 65. In part, because of this increase in the numbers of older adults and the increased healthcare costs. By 2030, the nation's health care spending is projected to increase by 25 percent due to demographic shifts (CDC, 2012). Older adults with dementia require large amounts of care to meet basic needs. On average caregivers spend 20 hours a week providing care. They provide

care on average five years or longer (NAC, 2012). This care is often provided by family members. According to the National Alliance for Caregiving (NAC, 2012) in the United States, an estimated 66% of caregivers are female and their average age is 48 years. These women provide the majority of informal care to spouses, parents, parents-in-law, friends, and neighbors, and they play many roles of caregiving framework, including those of hands-on-healthcare provider, care manager, friend, companion, surrogate decision maker and advocate (Family Caregiver Alliance, 2012). A person in the early stages of dementia may experience mild changes in ability to think and learn but still be able to perform activities of daily living (Alzheimer Association, 2014). Adult daughter caregivers play an important role in providing support, love, and companionship for these persons, and helping with keeping appointments, recalling names or places, managing money and medications, and planning for the future. A major challenge in dementia care is providing assistance to caregivers so that they can remain healthy and able to care for their family member. Adult daughters who care for their mothers with dementia must integrate feelings of loss, sorrow, and anxiety while processing daily life concerns. They experience the emotional, mental, and physical burden of caring and caring for self may not be a priority.

It is well documented that daughters experience fatigue from the physical and emotional constancy of caregiving (Alzheimer's Association, 2014). Daughters often have multiple family and work demands as well as caregiver role demands (Touhy & Jett, 2014). Caregiver stress is defined as the emotional and physical strain of caregiving and can take the form of frustration, anger, guilt, feeling lonely, or exhaustion (HHS, 2012). Also, high levels of depression, anxiety, and physical stress are prevalent among women who care for their parents (FCA, 2012). A quantitative research study of 99 caregivers from an Alzheimer Center in a Midwest City in the United States found that caregivers who reported high levels of caregiving stress also had poorer physical function and more depressed mood, and they informed fewer self-care behaviors (Lu & Wykle, 2007). This caregiving stress was indirectly related to self-care behaviors. The researchers pointed to the need for early interventions to enhance functional ability and self-care behaviors.

## **Purpose of the Study**

It is difficult to be present with others when the caregiver's vessel is empty of emotional, physical, and compassion energy. When caregivers do not replenish their own resources, the quality of care and relationships become depleted rather than enriched. Thus caring for self is an essential component of caring for others. This study of three adult daughters taking care of their cognitively impaired mothers explores their experiences in caring for their mother and caring for self.

## **Conceptual Framework**

The conceptual framework for this study is the theory of compassion energy. Compassion energy is revealed when the adult daughter cares with compassionate presence (Dunn, 2009). Dementia care recipients exhibit patterns of behavior that the caregiver and intentional know what the behaviors or concerns or issues from the dementia care recipient through a patterned

nurturance in caring. The patterns can give meaning to the caregiver of what the care recipient may desire. This meaning provides a better understanding of the care recipient and minimizes frustration, anger, and enhances vigor and understanding where caregiver stress is decreased or not experienced and optimum health occurs. Adult daughters can exert a significant degree of control over their own health and are inclined to do so if self care and self efficacy are perceived as of greater importance than perceived barriers. Adult daughter caregivers have the capacity for reflective self-awareness, value growth in direction viewed as positive and can attempt to achieve a personally acceptable balance between change and stability/ They may seek to create conditions of living through which they can express their unique human health potential.

### **Sample**

Three adult daughters caring for their cognitively impaired mothers were recruited from a memory disorder clinic at a state university in southeastern United States. All had daily contact in person or by phone.

### **Data Collection**

Participants were assured that their participation was completely voluntary. The researcher then conducted interviews that lasted up to one hour with each participant in a private room at the memory disorder clinic. The interviews were audio recorded with the consent of the participants. An interview guide was followed.

The researcher recorded the interviews and transcribed them verbatim for data analysis. Only an assigned number was used to identify the data. Field notes recorded general observations made by the researcher during the interviews and audio recording.

### **Data Analysis**

Audio-taped interviews were transcribed verbatim by the researcher. The text was then read independently and interpretations of the data were compared and consensually validated by the researcher. Heideggerian hermeneutic phenomenology was the method for interpreting the phenomenon of caring for self. Credibility of the data was established through primary investigator and researcher reviews and audit trails. Trustworthiness of the data was established by the ability to trace information from the original source via an audit trail.

### **Results**

Doing-while-waiting, became the constitutive pattern from the data analysis that shows the linkages among the three themes interpreted: Doing Things-Doing Something, Place and Space, and Waiting On-Holding On. In reading the data, the researcher found the interpretations convincing. Results of this study point toward how adult daughters do not care for self and know that they need to.

One participant did not know the definition of caring for self. After defining it for her she remarked, "Oh I see what you mean, Ok, I always eat breakfast and I try to either go to the

gym or play tennis everyday because that's necessary for me...and that's probably all I can tell ya." "I just make sure I do something". Another participant stated, "I really probably do not spend a lot of time taking care of myself and I know I really need to address that"

### Theme One: **Doing Things-Doing Something**

One participant described caring for self as. "Caring for self means, I guess, to take care...to do the things that you need to do to take care of yourself...that makes you human." Another participant said, "I know I should [care for myself], now that's the hard part." Lastly, "Doing things for her." was a consistent expression toward the mothers from all three participants.

### Theme Two: **Place and Space**

The participants expressed a non-passive understanding of waiting. According to Heidegger (1962), waiting waits upon the open-region, which is not spoken in terms of will, but rather that open place or placing that lets beings be. Waiting is ultimately identified as is thinking and looking for your place and space. One participant stated, "caring for self would mean finding your place and space...and doing things that would be self- gratifying..., that would be restful, that would be pleasurable. I don't do any of that."

### Theme Three: **Waiting On-Holding On**

Two exemplars of waiting on-holding on theme were, "If I had to wait on my kids and my mother, then I would really be in trouble" and "I had a full life, so this is a rest period. I'm on hold now because of Mom" Another exemplar was: "...make sure you have the time to do the things you need to do whether its cleaning your house or playing tennis or going food shopping, or just the regular things, just don't let everything go" The participants had their days full with things to do. If the schedule was on target, then they believed they were caring for self.

### Constitutive pattern: **Doing-While-Waiting**

Narratives in this pilot study evoke thinking consciously of the experience and the meaning of adult daughters and if they care for self and consideration of their experiences while caring for their mothers. Through understanding the lived experiences that are revealed through interpreting the participant's common meanings, caring for self while caring for their mothers can be transformative. The notion of waiting, the participants leave open what they are waiting for because waiting releases itself into openness, that open place or space that lets caring for mothers define how the adult daughter care for self. Waiting is ultimately identified as is thinking with releasing to the open-region.

Waiting in is a radical passivity for the arrival of another beginning, however while waiting the participants experience an important degree of doing. Heidegger (1962) expresses a deep significance and reference beyond being, the subjective. When we wait, we wait for something which interests us or which can provide us with what we want. Then, waiting involves our desires, goals and needs. We can wait without waiting for anything. In this

sense, we simply wait. In a human way we wait for, in a deeper sense of waiting we wait upon. In waiting upon, we leave open for what we are waiting for (Heidegger, 1962).

By waiting the adult daughters experience intentionally knowing what needs to be done to care for their mother and in effect this is how they described caring for self, if all was going well then the adult daughter participates were at peace and felt they were caring for self. However, they admitted that they know they should, but did not, and waiting for something to change or experience was the 'new normal'.

## Limitations

The limitations of this study are the small sample size of three participants who had similar characteristics. The similarities are being Caucasian, not employed, and lived close to their mothers who they were caring for. The limitations of this sample indicate repeating the study with more robust population participation in the future.

## Discussion

By better understanding and focusing on caring for self, adult daughters may make choices that support personal well-being and reinforce personal growth. Much has been written about caregiver stress and burden. The results of this study describe how adult daughters find meaning in life and relationships while caring for self while caring for their mothers. The adult daughters who take an active, problem-solving approach to caregiving issues are less likely to feel stressed than those who react by worrying or feeling helpless (HHS, 2012). Providers who are sensitive to caregiver needs can promote caring for self to those caring for a person diagnosed with dementia.

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