The Experience of Unpaid Caregivers of Persons Diagnosed with Early-Stage Dementia of the Alzheimer’s Type: Embracing Unpredictability

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Abstract

Descriptive phenomenology was used in this study to explore the lived experience of unpaid caregivers of person’s recently diagnosed with dementia of the Alzheimer’s type. Twelve caregivers were interviewed about their experience at the time of diagnostic disclosure. Data were analyzed using Giorgi’s method of descriptive phenomenological research approach and the theoretical framework of Rogers’ Science of Unitary Human Beings. Three themes, desire for a diagnosis, sooner rather than later diagnosis for support, connecting with compassion. The themes were synthesized into a descriptive structure of the overall meaning as embracing unpredictability. Implications from this study is that an earlier diagnosis allows treatment to begin early, care recipients are able to participate in decision making, preparing and planning and both unpaid caregiver and care recipient can receive support services sooner.

Keywords: Early-stage dementia, Unpaid caregivers, Phenomenology, Caring

Introduction

Alzheimer’s disease (AD) is the most common form of dementia with absence of cure among older people and is the sixth leading cause of death in the United States. Unfortunately, the causes of AD are still unknown and screening for memory difficulties occurs long beyond the appearance of initial symptoms. According to Alzheimer’s Association Disease International (2010) there are 35.6 million people with dementia worldwide and this number is expected to increase to 100 million by 2050. In the United States, one in eight people aged 65 and older have (AD) and approximately 11 to 16 million Americans will have the disease by 2025. The number of family members and friends who will be providing unpaid care to people with dementia is expected to rise. Currently, 15.4 million caregivers provide 17.5 billion hours of unpaid care, valued at 216 billion dollars (Alzheimer’s Organization, 2013). AD is a type of dementia that causes problems with memory, thinking, and behavior. Symptoms usually develop slowly and get worse overtime, becoming severe enough to interfere with daily tasks. Once the disease begins to affect daily life, then the unpaid caregiver enters into the career of caregiver. The increase in number of individuals with AD will take an exceptionally high toll on those who care for them, such as negative impact on health, employment, income, and financial security.

Society is aging at an unprecedented rate, with the proportion of people 60 years and older predicted to more than double by 2050 (United Nations, 2010). There are 35.6 million people with dementia worldwide and this number is projected to increase to 100 million by 2050 (Alzheimer’s Association Disease International, 2010). In the United States, one in eight people aged 65 and older have Alzheimer’s disease (AD). According to the Alzheimer’s Association (2013), an estimated 5.4 million people are living with AD, 7.7 million Americans will have AD by 2030, and approximately 11 to 16 million Americans will have the disease by 2050. The number of family members and friends who will be providing unpaid care to people with dementia is also expected to rise. A phenomenological research design was used to describe and analyze the experience of unpaid caregivers of persons diagnosed with early-stage dementia of the Alzheimer’s type. Offering unpaid caregivers the opportunity to explore their experience of caregivin
provided information to professional caregivers for providing initial and ongoing support. Early-stage is a critical period that challenges the unpaid caregiver and care recipients coping resources as family caregivers provide up to 80 percent of care needs.

**Literature Review**

Forgettingfulness is often dismissed as a normal part of aging but, for many older people it may be a sign of Alzheimer’s disease (AD). AD is the most common form of dementia among older people. Unfortunately, the causes of AD are still unknown and screening for memory difficulties occur long beyond the appearance of initial symptoms, and there is no cure. More often, diagnosing dementia often occurs late in the disease (Vernoij-Dassen, Moniz-Cook, Woods, De Lepelieer, et al., 2005). Early detection is possible as families have report an awareness long before the diagnosis is made (Beatty, 2006). A significant number of people with early symptoms of dementia and unpaid caregivers may lack appropriate care (Jansen, van Hout, Nijpels, Rijmen, et al., 2011). It is believed that timely recognition and diagnosis of dementia is a precondition for improving care for both older adults and their unpaid caregivers. Ducharme, Levesque, Lachance, Kergoat, et al. (2011) studied 122 caregivers of an older relative diagnosed with AD within nine months. The findings revealed that the majority of caregivers receive little informal support, poor knowledge of available formal services, difficulty in planning ahead for the care recipient future needs and lack of preparedness to provide care. There are challenges associated with transition to caregiver role following diagnostic disclosure of Alzheimer’s disease. Proactive intervention to assess caregiver needs and provide support, healthy integrated balance between body, mind, emotion and spirit, as well as early psycho-educational interventions are needed to foster a positive caring-healing relationship between the unpaid caregiver and care recipient. Caregivers respond to the challenges presented by their new role, yet people begin their caregiver career when activities of daily living become an issue for the care recipient (Ducharme, et al., 2011; Stiles, 2011).

Many studies have shown that caring for a person with dementia can have a negative effect on a caregiver’s physical, psychological or emotional health, social life and finances and has been defined as caregivers’ burden (Scharlach, Li & Dalvi, 2006; Alzheimer’s Association, 2011). The increase in number of individuals with AD will take a highly exceptional toll on those who care for them, such as a negative impact on the health, employment, income and financial security of caregivers. More than 60 % of unpaid caregivers report high levels of emotional stress, 43% report high levels of physical stress, and 33% report symptoms of depression. Unpaid caregivers are more likely to have reduced immune function, new onset hypertension and new coronary artery disease (Alzheimer’s Association, 2011). The majority of caregivers identify some positive aspects of their caregiving work and a caregiver who experiences satisfaction may provide better care. Acton & Wright (2000) offer that self-transcendence may be an important framework for studying caregiving experiences. Caregivers who receive information, advice and support will be more able to achieve a satisfactory outcome for their relative and for themselves (Andren & Elmstahl, 2008; Nolan, Grant & Keady, 1996).

Once the disease begins to affect daily life, then the unpaid caregiver enters into the career of caregiver. This pilot study will explore the lived experience of unpaid caregivers of persons who are diagnosed with mild or early-stage dementia syndrome of the Alzheimer’s type. Offering unpaid caregivers the opportunity to explore their experience of caregiving will provide information to professional caregivers for providing initial and ongoing support.

**Theoretical Framework**

Rogers’ (1970) Science of Unitary Human Beings (SUHB) theory guided the research process and provided the philosophical frame for the researcher’s interpretation of the data. Since humans’ lives and their energy fields are evolutionary and in constant diversity, the unpaid caregiver living through dementia caregiving experiences can be theoretically framed by the theory of SUHB. SUHB allows one to look at how nursing and caring for others are created within the person (human)-environmental process, rather than as cause and effect situations. The principles of homeodynamics, resonancy, helicy, and integrity, directly
relate to the relevance of the SUHB to nursing practice. These principles provide a foundation for nursing that reflects the nature of the human and environmental fields as ever changing, living, evolving, and becoming more complex as humans move though life’s experiences such as dementia care. Both Rogers’ SUHB and phenomenology view human beings as unique because of the person’s experience, history, and culture and the person is continuously changing and evolving with each life experience. The purpose of phenomenology is to understand the experience through discovery (Sandelowski, 1986). Phenomenological research places emphasis on the meanings of experiences in our everyday existence. Using a phenomenological approach, the experience of unpaid caregivers is described and meanings were explored. In an effort to uncover the meaning of the experience for the participant, the subjectivity enriches the authenticity of perceptions and understanding of the phenomenon. Rogers (1970) posed a unitary view of person (human) and environment as irreducible wholes. Experiences are a manifestation of person/environmental field patterning and a manifestation of the whole, all at once. As with SUHB, phenomenological research allows for understanding the whole and specifically, phenomenology, will be used to describe the experience as whole and how the unpaid caregiver lives it within the human-environment, body, mind, emotion, spirit, energy, social/cultural, relationship and context as integrated into an inseparable whole that is greater than the sum of the parts (Guzzetta, 2000, p.190; Rogers 1970).

**Research Questions**

1. What is the lived experience of unpaid caregivers of persons who are diagnosed with mild Alzheimer’s dementia?
2. How does the unpaid caregiver cope after being told of the care recipients’ diagnosis of mild Alzheimer’s disease?
3. What are the perceived benefits and challenges of the relationship between the unpaid caregiver and the person diagnosed with mild Alzheimer’s dementia as experienced by unpaid caregivers?
4. What impact does this relationship have on unpaid caregivers?

**Methodology**

A phenomenological research design was used to describe and analyze the lived experience of unpaid caregivers of persons diagnosed with dementia syndrome of the Alzheimer’s type. Phenomenology has its grounding in the life world perspective to understand, describe and analyze the world as it is experienced. The phenomenological approach and Rogers’ SUHB research methodology complement each other as both allows for describing, appreciating perceptions, expressions and experience. Therefore, the methodology will describe the experience itself as perceived by the unpaid caregiver participant experiencing it. It is a means to explore the full domain of the person’s experience, and attempts to understand the perceived lived experience (Husserl, 1967). The lived experience is the subject of phenomenology and the purpose is “to seek a fuller understanding through description, reflection, and direct awareness of a phenomenon to reveal the multiplicity of coherent and integral meanings of the phenomenon” (Ray, 190, p. 173). The interest lies in the experience itself, and not in what causes the experience. Stiles posed that in lived experience, human beings are complex and use multiple ways of knowing and multiple modes of perception to create their life world perspective (Stiles, 2011, p. 40).

For this study the researcher asked unpaid caregivers about their experience caring for another with a diagnosis of early-stage Alzheimer’s dementia to understand what this phenomenon of caregiving means to them. The descriptive phenomenological approach involves a complete description of the phenomena, consideration of the participants’ experiences, identification of the themes, and the identification of contextual meanings (Omery, 1983). Prior to beginning analysis, the researcher intentionally and reflectively centered self to focus on the data and to hold any previous thoughts about caregiving in abeyance in order to avoid preconceived notions about theme developments. A major characteristic of this method is bracketing which is accomplished by abstaining from or holding in abeyance an individual’s prior knowledge of the phenomenon (Husserl, 1967). The term “phenomenological reduction” has been used to describe the process of putting aside past knowledge of the phenomenon (Giorgi, 2005, p. 77).
Themes were extracted from the data. A theme is described as an expression of a lived experience containing discrete ideas or thoughts as expressed by the participant. The themes were then studied for discovery of their relevance to the phenomenon. Subsequently, a process of free imaginative variation was utilized to determine which themes were essential for identification of the phenomenon. This process resulted in creating a structure of the studied phenomenon. The general structure of the phenomenon which was developed by analysis of these themes provided insight into unpaid caregivers’ experiences. The goal was to develop an exhaustive description of the lived experience of unpaid caregivers.

Sample
People who are the primary caregiver for another person with a diagnosis of Alzheimer’s dementia were sought for individual interviews. The eligibility criteria included individuals who self-define as the primary caregiver with responsibility for care of a person 65 years of age or over with a diagnosis of early-stage Alzheimer’s dementia with the ability to speak and read English. The researcher recruited 12 participants using purposive sampling by requesting permission from gatekeepers from healthcare providers and Memory Disorder Centers in the State of Arizona. A flyer with the researchers contact information was also distributed to community libraries. Twelve caregivers contacted the researcher to schedule audiotaped interviews. Snowball sampling was also used to recruit participants.

Data Collection
The researcher obtained approval from the Institutional Review Board (IRB) of Northern Arizona University and recruitment of participants followed the IRB approved protocol. Using the informed consent process, participants were assured that their participation is voluntary and that they may withdraw at anytime without consequences. In appreciation of the participants’ time, a Starbuck’s Gift Card was given. Audiotaped interviews were conducted at a place and time identified by the participant. An interview guide with which to begin and guide the interview was utilized. The interview may trigger some mild emotional distress about their unpaid caregiver work and will be addressed by allowing the participant to process these emotions.

Another ethical consideration is the researcher’s respectful approach. Voice matters and whatever dialogue occurs during the interview will be listened to and respected. The use of silence as a technique will encourage thoughtful reflection during the interview. Lastly, field notes will be used to record general observations in the form of journaling and will be collected by the researcher. All interviews were transcribed verbatim and are kept confidential and anonymous, the transcripts were de-identified with a coded number assigned and kept locked in the researcher’s office.

Data Analysis and Findings
The data for this study was analyzed using a descriptive phenomenological research approach using the five steps adapted from Giorgi’s method by Omery as follows:
1. The researcher reads the entire description of the experience to get a sense of the whole.
2. The researcher reads the description again more slowly, identifying transitions or themes of the experience.
3. The researcher eliminates redundancies in the themes, clarifying or elaborating the meaning of the remaining themes by relating to each other and the whole.
4. The researcher reflects on the given themes, still identified in the concrete language of the subject (participant) and transforms that concrete language in to the language and concepts, using Rogers’ Science of Unitary Human Beings theoretical framework.
5. The researcher then integrates and synthesizes the themes into a descriptive structure of the meaning of that experience (Giorgi, 1997; Omery, 1983, pp. 57-58).

The audio-tapes from the individual interviews will be transcribed verbatim. Each transcribed text were read independently and description of the data was compared to the other texts. Strategies using methodological rigor were used to ensure the accuracy of data collection and analysis. Trustworthiness
Eleven women and one man aged 45 to 62 with a median age of 56.75 years were recruited. Years in caring ranged from one to five. Eleven participants were Caucasian and one woman participant was Navajo American Indian. All twelve caregivers were interviewed about their experience at the time of diagnostic disclosure. The interview questions were “tell me about a time when you first heard that your spouse/friend/partner/relative was diagnosed with mild Alzheimer’s disease.” Additional questions were asked, “Tell me about the time you realized you were in the caregiver role” and “What matters most to you right now?” Data were analyzed using Giorgi’s method of descriptive phenomenological research approach and the theoretical framework of Rogers’ Science of Unitary Human Beings. The researcher identified 121 statements from the text and developed 38 supporting categories. Further analysis guided the concrete language and three themes were discovered to be: desire for a diagnosis; sooner rather than later diagnosis for support; connecting with compassion. The themes were synthesized into a descriptive structure of the overall meaning as embracing unpredictability.

Theme One: Desire for a diagnosis. All participants stated that they wanted to have a diagnosis as they knew something was wrong, but had difficulty in having a healthcare provider provide a dementia diagnosis. One participant stated “it took me two years and three doctors to finally get a diagnoses that I knew.”

Theme Two: Sooner rather than later diagnosis for support. Most participants explained that knowing the diagnosis was helpful, but there was a long delay of four to five years before any support was suggested. Once diagnosed five participants stated that the provider did not give any education and stated that when there is a problem to make an appointment for help. The participants did not think this was a good plan and wished they became involved with a support system, one participant stated, “I wish I was given information about support groups at the time we got the diagnosis and right away for planning and knowledge of what should be taken care of first”.

Theme Three: Connecting with compassion. All participants felt their providers were helping the best they knew how and cared for the care recipient with compassion, but not for the unpaid caregiver. One participant described that she was called on the telephone by her mother’s doctor. She and driving on the highway when the doctor called to tell her that her mother had dementia and to call for an appointment if there are any problems. She stated, “my heart sank, I knew there was something wrong, my mother loves her doctor and has been going to him for years, but I didn’t understand how he could call and give me the diagnosis like that, he might be a good doctor for Mom, but to call like that, I did not think that was right.”

The three themes were synthesized into a descriptive structure of the overall meaning as Embracing Unpredictability. All twelve of the participants described that they were positioned to be ‘ready for anything’, that there was a ‘new normal’ even before the official diagnosis. One participant stated, “Being ready for anything and accepting whatever is happening” was embraced by the unpaid caregiver participants. The unpaid caregiver participants lives and their energy fields are evolutionary and in constant diversity. The ‘new normal’ ‘is created within the human-environmental process, there is no reason, cause and effect situations most days. The human and environmental fields as ever changing, living, evolving, and becoming more complex as humans move though life’s experiences such as the unpredictability of dementia care.
Discussion and Implications

The findings from this pilot study will guide future research to address unpaid caregivers challenges associated with transition to caregiver role following diagnostic disclosure of early-stage Alzheimer’s dementia, to foster positive unpaid caregiver responses to the challenges presented by their new role, and to increase health care providers such as nurse practitioners awareness for providing initial and ongoing support to unpaid caregivers. Diagnosis and support with education must go hand-in-hand when informing a person and their caregiver of the diagnostic disclosure of dementia. Implications from this study is that an earlier diagnosis allows treatment to begin early, allowing care recipients to be able to participate in decision making, preparing and planning for present and future. In addition, both unpaid caregiver and care recipient can receive and benefit from support services sooner.

Healthcare providers are diagnosing people with dementia much earlier in the disease process. Earlier diagnosis provides opportunities to begin pharmaceutical and psycho-education interventions. However, research has been directed towards persons with later stages of dementia and focused on preparing the caregiver to address behavioral problems, incontinence, activities of daily living, nursing home placement (Sorensen, Waldorff, & Waldemar, 2008; Whitlach, Judge, Zarit, & Fermia, 2006). Many of these issues addressed are not relevant to those in the early stages of dementia, and are thus not relevant to the caregiver. It is thought that too much information given too early may overburden families (Moniz-Cook, Manthorpe, Carr, Gibson, & Vernooij-Dassen, 2006). Few studies have focused on the experience of unpaid caregivers in early stages of dementia (Hellstrom, Nolan, & Lundh, 2007; Quinn, Clare, Pearce, & van Dijkuizen, 2008). Therefore, unpaid caregivers may struggle in the new role of caregiver without support. The results of the pilot study will be used to prepare a proposal for increased external funding from the National Institute of Aging (NIA) to further study the transition to the unpaid caregiver role and provide an educational and support system for caregivers caring for persons newly diagnosed with early stage dementia syndromes of the Alzheimer’s type.

References


