

Review Article

Family as Caregiver: Understanding Dementia and Family Relationship

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Received: March 10, 2018; **Accepted:** April 14, 2018; **Published:** April 21, 2018

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Abstract

This literature review aimed to highlight the effect of lack of adequate training for family caregivers of people with dementia. This literature will show an overall theme that family caregivers are not duly trained/informed on the effect and changes caused by dementia. While caring for person with dementia, participants stated that they experienced decrease in social life and sleep. Lack of adequate information/ resources decreased the option of deciding to place person with dementia in a facility or even hiring a qualified private caregiver for proper care. Proper training process and adequate information on dementia and its progression could further assist family caregivers in preparing for the effect of dementia and better adapt to the position of a caregiver. Family caregivers need to be recognized as partners in care and caring for the dementia could have adverse effect on their health.

Keywords: dementia, training, family, caregiver

Introduction

Dementia has been recognized as a significant public health problem has played a vital role in increasing the morbidity rate and global non-communicable disease burden thereby increasing the for significant healthcare interventions. Dementia is a syndrome that affects the memory, thinking, behavior and the ability to perform regular activities of daily living like feeding and bathing. This task can be overwhelming for individuals living with dementia, and they usually would require a caregiver who could be a family member. There's a lapse in proper awareness and understanding of this disease, and this has led to social labeling, barriers to diagnosis and care which affects patients, family and caregivers physically, psychologically [1].

The World Health Organization [2] predicts that the total number of people living with dementia is expected to increase to 75.6 million in 2030 and this might double by 2050 to 135.5 million. Dementia is also recognized as a significant cause of disability and dependency among older people in the world [2]. Family members assume the role of caregiving for their loved ones without questions, this could be due to loyalty or love but research states that the stress and burden of a family member caring for a dementia patient can have significant negative effects like resentment, hostility and even frustration on the caregiver [3].

Caregivers of people living with dementia are said to provide longer hours of care than the average caregiver for older adults, and this is due to the complexity of caring for a dementia patient. This disease puts a strain on the family relationship, and adult children are usually the first one to assume the role of a caregiver. There is often a lack of training and proper understanding of the disease, and this could result in stigmatization and barriers to diagnosis and care [3]. This research aims to help family caregivers decrease the frustration and stress level. The statistics stated in the introduction shows there's a high possibility of increasing amount of people diagnosed with dementia in the nearest future, this means that dependency rate would grow; there's a significant likelihood of more families becoming caregivers to people living with dementia. Some impacts on family caregivers are stress, depression, and abuse.

Stress

Caring for a loved one could be a fulfilling process but also has its negative aspect, Research shows the burdens of caring for a spouse/family member living with Alzheimer's disease or other dementia disease can include some of the negative consequences on the caregiver, this could include emotional, physical, and social problems. Stress associated with caregiving alongside other conditions such as depression, low morale, social isolation and feelings of guilt has been identified in caregivers of people living with dementia. The stress and burden of a loved one caring for a dementia patient can take a toll on the caregiver that could lead to hostility, frustration, and resentment which even affect the level of care received by the patient [3]. Chronic stress could negatively affect health and well-being of an individual, and a great population of informal dementia caregivers is said to experience chronic stress associated with the extraordinary demands of caring for a loved one with dementia [4].

Depression

Dementia caregivers are said to have health problems that are often overlooked and overshadowed by those of their care recipient until a major crisis occurs. Persistent agitation/aggression of dementia patients could be associated with subsequent depressive symptoms in many caregivers [5]. Advancement of the disease is a predictor for agitation and depression; this means that in the advanced stage of dementia, depression in some patients might be a major cause of aggressive behavior [6].

Abuse

Agitation and confusion of dementia patients combined with stress, depression/frustration of the caregiver could lead to abuse and neglect of a patient [7]. Dementia patients are particularly more vulnerable to abuse. The most cases of abuse of dementia patients are usually under-reported because most of the abusers are family caregivers. For example, dementia is known to be associated with a high level of dependence; this could make victims of abuse reluctant to disclose their ordeal due to the fear of retaliation or loss of support. Also, certain physical signs of abuse, such as withdrawal from communication or increased dependence, may be difficult to distinguish from the dementia symptoms [7].

The literature review in the previous sections of this work, emphasizes on family caregivers of people living with dementia, there is a lot of discussion on the impact of the disease, the stress faced by caregivers, depression, and abuse of dementia patients due to lack of proper knowledge but something that was rarely discussed is, how these individuals (family caregivers) cope with the stress or burnout they face while caring for their loved ones. Research shows how stressful and tedious caring for a loved one with dementia can be on the physical and psychological health of caregivers.

Theoretical Framework

A theoretical framework can assist family caregivers who are assisting love ones with dementia. The theory is a guide to using and understanding the complexities of social life; theories are also generated to explain and help us understand a particular phenomenon [8]. The theory to be discussed in this research paper is the Bowen Family Systems theory. This is a theory that is closely related to family relationships and the impacts on family members. Bowen's research and observations led him to define the family as a complex unit of systems and subsystems [9]. According to Bowen refers to the organized body of knowledge within the framework of natural sciences. Bowen's family systems theory is a theory of human behavior, and it views the family as an emotional unit, Bowen also uses the systems thinking to describe the complex interactions in the family unit [10].

This theory emphasizes on the family as a unit that is usually emotionally connected, and members of this unit would seek attention, approval from each other and would expect each member to react to their needs. It is the norm for members of a family to be intensely connected emotionally and this connection makes family members interdependent on one another, the interdependence could lead to conflict and stress when expectations are not met. There are usually one or more people that accept this responsibility to reduce the burden on other family members, and they eventually become overwhelmed, Isolated or out of control [10]. As an emotional unit, families develop an emotional interdependence on one another, and this could transform into the development of their principles for an organization [10].

The theory also talks about the concept of positioning which according to Bowen is central to the evolving focus of the family as a multigenerational emotional system; this theory states that people are born and accustomed into roles based on several variables such as birth order, gender and even family patterns [10]. The literature on family caregiving illustrates that older members of the family are usually the ones who assume the role of a caregiver for other dependent members of the family [11]. This literature further explains Bowen's theory of members of a family unit getting accustomed to specific roles due to specific variables and connections among family members.

This theory about this research assists the researcher and reader to understand how and why family members assume the role of caregiver for people living with dementia. Throughout the world, family members provide care to their loved ones living with dementia. It is also stated that in the United States and Japan, approximately 70% and 85%, respectively, of people living with dementia reside at home [12].

It has been well recognized that caring for a loved one with dementia can be a tedious caregiving experience, and the cognitive and behavioral impairment of people living with dementia makes it worse [12]. Dementia is a cognitive disease unlike other diseases like cancer, diabetes, conflicts with the patient's cognition and mental functioning. This is usually a leading cause of stress as activities of daily living like eating, bathing or even dressing is almost impossible to accomplish with or without help. Family members living with a dementia patient are usually left with the responsibility to provide care/ supervision all day long and would often have difficulty adapting to the patient's personality changes and communication problems. Performing this task (caregiver) requires particular knowledge, skills, and motivation [12]. The Bowen's family systems theory illustrates our emotions and affection towards an individual can lead to making decisions and taking steps we might not usually take like in the case of these family members. It is the usual circle of life to want to care for someone who has once cared for you. This illustration could make us understand that as complicated as the role of a caregiver for people living with dementia as proven to be, family members are still quick to assume this role.

The literature review shows that there's been lots of research conducted on dementia and caregiving, but the focus on family caregivers has been insufficient. In the world today, family members are known to assume the role of

caregiving for their loved one with dementia, this could be in the form of a spouse, child, grandchild or even friends [3]. Caregivers of dementia patients are exposed to a significant risk of being overburdened and usually develop physical and psychological symptoms of stress during the caregiving process [13].

Research proves that approximately 70% and 85% of dementia patients live at home in the United States and Japan respectively [12]. This means that with the increase in diagnosis of dementia among older adults, more family members would assume the role of caregiving. This increase could lead to significant increase in the stress level of family caregivers.

Proper insight has been given on the difficulty of caring for a loved one with dementia, from the statistics to impacts which proves that family caregivers can be stressed, depressed frustrated and burnout, this could lead to abuse and neglect of a person living with dementia. We can see the gap in this literature, we can see that there's not enough awareness of the importance of family caregivers of dementia patients and burnout. Instead, research on dementia only discusses and focuses on the disease and training of non-family caregivers of persons living with dementia. There is a significant need for more awareness on the importance of training family caregivers and the impact the disease can have on them. Also, more coping techniques on how to live a healthy stress-free life should be developed for family caregivers.

There have been major dialogues on how tedious caring for a dementia patient can be and this research has also proved that caring for a person with dementia can be overburdening but even worse for a spouse/family member acting as the caregiver. This burden can negatively affect family caregiver's physical, emotional and social life. Some of the proven impacts on family caregivers stress, depression/frustration which could lead to burnout of family caregiver and abuse and neglect of a person with dementia. These are the reason why people with dementia and their caregivers need the support and care of a trained workforce, with the appropriate knowledge, understanding and skills of dementia to offer the best quality care and support for them [14]. Most of these needed support is not extended to family caregivers due to lack of knowledge of resources available to them.

The major gap can be seen in literatures on dementia as it mainly focuses on the disease's impacts on the patient and training of non-family caregivers while there's lack of focus for people with dementia residing at home with family members playing the role of a caregiver.

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