Alzheimer’s Care at Home: A focus on caregivers strain

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Abstract
The aging population is increasing worldwide. According to Italian authors, Italy is one of the leading and increasing aging populations in the world. Placing more numbers on the elderly increases the number of people who will live with dementia in the future and in our case of study, in an increase of people with Alzheimer’s disease. Researchers have demonstrated that Alzheimer’s disease comes with aging and it eventually affects the person’s cognitive, emotional, and physical well being. Those who become diagnosed with Alzheimer’s will eventually need assistance in their daily living, especially when it begins to progress to a higher stage. Daily assistance can come from staff at a hospital or from family members at home, but whether it is the patient’s spouse or offspring, the person caring for the patient forms a burden of responsibility on themselves over time. The objective of this paper is to discuss and compare the effects of the burden placed on the Alzheimer’s caregiver: sleep, anxiety and depression, stress, and use or nonuse of support services. The focus of this literature review is to submit what on the research of caregiver strain at home.

Keywords
Alzheimer’s statistics; Alzheimer’s Caregivers stress; Alzheimer’s caregivers in the home; Caregiver strain

INTRODUCTION
The senior population (60 years old and older) is increasing worldwide. In Italy, the aging population has been increasing with statistics showing that in 2006, the population was about 58.8 million (Eghbal, 2007). In the year 2000 until the year 2050, the world’s aging population will triple more than 600 million to 2 billion and most of this number will increase in developing countries (WHO, 2006). The direct affect of the aging population with the population’s health go hand in hand. For example, health promotion and prevention helps to delay or prevent disease such as heart disease, stroke and cancer (WHO, 2006). Pharmaceutical companies would sell more drugs to the elderly which would result in higher government expenditure on health services (Eghbal, 2007). The growing aging population provides care to their families, helps with volunteering, and provides the community with knowledge and past experiences.

Alzheimer’s is the most common type of dementia that results in brain cell damage or injuries to the connection between brain cells. The disease affects the person’s memory, ability to generate speech, identify object, think abstractly, and sometimes even deteriorates their ability to perform motor activities. Although every individual is different, Alzheimer’s disease affects an estimated 5.4 million people and 14.9 million unpaid caregivers exist in
the United States (American Alzheimer’s Association, 2011). With these statistics, it can be said that an estimated four percent are under 65 years old, six percent are 65 to 74 years old, 45 percent are 75 to 84 years old and 45 percent are 85 years old or older (American Alzheimer’s Association, 2011).

In Italy, 5.3% of men and 7.2% of women over the age of 65 suffer from dementia and 57% from Alzheimer’s (The Italian Longitudinal Study on Aging Working Group).

Nearly 15 million North Americans provide unpaid care for a person with Alzheimer’s disease or another dementia. Eighty percent of care provided at home is delivered by family caregivers (American Alzheimer’s Association, 2011). Caregivers may range from spouses, family members, friends and even healthcare personnel such as doctors and nurses. Caregivers, in many cases, are spouses who are themselves elderly with increased risks for physical injury or medical illness (Grant, 2002). A person with Alzheimer’s not only forgets, but mostly does not recall the past and this creates a burden on the person taking care of them (Grant et al, 2002).

According to the Caregiver guide, it is important to define who will administrate the decision making, how the needs will be met and where the person will live after diagnosis. The first step in caring for a person with Alzheimer’s is to recognize what stage the patient is in order to be acquainted with their ability for decision making because the severity of the disease plays a role in choosing the correct care for the patients needs. Including the person with Alzheimer’s in the preparation and decision-making of their care is essential. Whether the person is in the early or late stage of Alzheimer’s disease, the person will eventually need around the clock care. Care must be given in a routine fashion and consistent. According to the literature, the person with Alzheimer’s must be informed as to what to expect even though it is inevitable to know whether they have understood or not (Caregiver Guide, 2010). Next, the decision to where the person will remain must take place: home or institutionalized. This article will focus on home care.

In home care, there are several options for help such as day programs, respite care and in-home help (Russell et al, 2011). Day programs also known as adult day care, allow the caregivers to work or attend to other needs. Respite care refers to a temporary place for patients with Alzheimer’s and in-home help refers to caregivers that are hired to help in the home for a few hours (Russell, 2011). The main theme in our research was to find Alzheimer’s caregiver affects in the home.

**LITERATURE AND FINDINGS**

In our search for Alzheimer’s Caregiver strain in the home, we found an abundant amount of articles. For this literature review, we used twelve articles that fit the inclusion and exclusion criteria. The inclusion criteria we used for our search was to find articles from the year 1997 to 2011 and the exclusion criteria was to eliminate articles that did not pertain to Alzheimer’s care given in the home. First we searched for the definition and explanation of Alzheimer’s disease and the statistics using keywords such as “Alzheimer’s statistics”. We found a search with numerous articles that explain the several stages of Alzheimer’s along with the planning and preparing for what is to come after this diagnosis and statistics. We used Google scholar, PubMed, CINAHL, and MedLine as our search engines. In the search engine, we used keywords such as “Alzheimer’s Caregivers stress” which granted us access several articles and other keywords such as “Alzheimer’s caregivers in the home”. In this literature review, several topics that affect caregivers of Alzheimer patients cared for in the home are stress, anxiety and depression, sleep and the use or nonuse of support services. Study results will be discussed and compared.
Stress, anxiety and depression

According to Ferrara et al., in the Anglo-Saxon literature, caregiver is defined as “one who gives care” and is therefore the person who takes daily care of the patient which in the end may become a full-time occupation for the caregiver. Acknowledging and recognizing someone has Alzheimer’s can be demanding and emotional for both the patient and the caregiver. Most outcomes become negative because of the strain placed on the caregiver and the emotional issues it presents. Emotions may range from shock to anger and grief. Some caregivers even feel stressed, anxious and depressed. In preparing for a new diagnosis of Alzheimer’s and the effects that come with it, support is needed. In this section, we will discuss the literature and findings that we found on emotional and physical strain, stress, affect on sleep and the support services used with the caregivers.

According to Sansoni’s study of 34 female Italian caregiver’s, results showed that 56% of the caregivers suffered from physical illnesses and 32% stated they suffered from psychological illnesses. Several instruments (General Questionnaire about Care giving, the Spielberg State-Trait Anxiety Inventory and the Geriatric Depression Scale) were used to measure the degree of anxiety and depression in the caregiver’s which resulted in findings correlated with the fact that caregivers suffering from physical illness have an additional burden when giving care to a person with progressing Alzheimer’s (Sansoni et al., 2004). Although anxiety is common in Alzheimer’s caregivers, the number of hours providing care has an effect on the psychological well-being of the caregivers (Sansoni et al., 2004).

In Ferrara’s study, prevalence of stress, anxiety and depression in Alzheimer caregivers in Italy was reported with data on 200 caregivers collected using several instruments. The instrument used in this study to evaluate caregiver burden focuses on psychological, physical, social, and emotional burden of the caregiver. The Mini-Mental Status Examination (MMSE) along with the Activities of Daily Living- Instrumental Activities of Daily Living (ADL-IADL) tool assessed the cognitive, behavioral and function of the patient and the (Caregiver Burden Inventory) CBI tool was used for the caregiver (Ferrara, 2008). By using these instruments, results demonstrated that caregiver’s lives change with 53% declaring that they have little time for themselves and feel that their own social life has been influenced. It was also reported that 59% of the Italian caregivers feel emotionally drained (Ferrara, et al., 2008).

In Italy, the home caregivers are usually relatives that choose to have the patient living in their home (65%) and are usually daughters or wives (78%) (Ferrara, 2008). Consequences brought upon the caregiver are those of physical health and subjective psychosocial well-being. Caregivers run the risk of not receiving support from others and exposing themselves to depression or physical vulnerability. The patients disturbing behavior such as cognitive and physical deterioration can become stressful to the caregiver (Ferrara, 2008).

Another important factor to recognize in caregiver strain is the stress they receive from taking care of a patient with Alzheimer’s. According to Grant, caregivers tend to have longer term physiological alterations that cause the cardiovascular system to continue to respond to acute stressors for a period of six to twelve months (Grant et al., 2002). The reason for this impact is the proposal of the alteration in the sympatoadrenalmedullary axis which activates the presence of a stressor. In short term activation, the system increases heart rate and blood pressure in a transient manner while in long term activation; the system promotes the development of these pathophysiological conditions (Grant et al., 2002). Caregivers reported poorer perceived health, more chronic illness such as hyper-tension and have an increased risk of poor wound healing.
Moreover, in a comparison group study, 38 caregivers continue to take care of their Alzheimer’s disease spouse at home, 28 caregivers place their spouses at a home-placed location and 27 caregivers whose spouses died at home (Grant, 2002). Results showed that depressive symptoms were being driven by biologic symptoms or emotional changes, serious medical symptoms were not changing in relation to transition experiences yet some experienced decreased immunity function and blood pressure reflected a tendency to have higher systolic blood pressure in all caregivers.

In addition, the stress that can be created by caring for someone with Alzheimer’s not only affects the cardiovascular system but may also affect the immune function. In a study that focuses on the strain of caregivers, it was expressed that caregiving for Alzheimer’s has an effect on the physiology of the person such as the immune function, decreased wound healing, autonomic and neuroendocrine dysregulation, and it worsens with increased stress (Lutgendorf et al., 2009). Caregivers experiencing emotional or physical strain were found to have a 63% of greater mortality than caregivers without strain or noncaregivers (Lutgendorf et al., 2009).

Support services

For those Alzheimer’s patients that are taken care for at home, some have the option of having someone visit them and provide care. Certain activities that caregivers provide are getting the patient in and out of bed, feeding, dressing, getting to and from the toilet, bathing, managing incontinence and diapers (American Alzheimer’s Association, 2011).

According to Sansoni, the Italian Health Care System provides little support for caregivers. The permanent care that is given to the Alzheimer’s patient produces high levels of stress and a barrier for using social support services are the expenses that the caregiver has to pay the health care professionals or assistants (Sansoni, 2002).

Moreover, a study in Canada that deals with caregiver burden demonstrated that although community based services were offered, caregivers had a higher burden when using the services (Strain et al., 2002). Some of the services offered were day centers, homemakers or cleaning services, personal care services, in-home nursing services, home delivered meals such as meals on wheels, respite services in the hospital and in the nursing homes (Strain et al., 2002). One would think that using these services would decrease the caregiver burden to relieve stress, yet there are various reasons why caregivers choose not to use the services. Some reasons for not using the services are the reluctance to leave the care receiver with a stranger, some cultural attitudes about caregiving are involved and of course psychological barriers. Other reasons tended to be the lack of knowledge of the services, perceptions that services are too expensive and perceptions that care receivers present too many behavioral and emotional problems (Strain et al., 2002).

In another article that we found which shows that home care services in Hong Kong are likely to facilitate the ability of older adult’s functional ability. In fact, it shows that nurses are good collaborators in health care services which strengthen the effectiveness of alternate services. Home care services provided are home nursing services, day care centers, medical services, home medical services, group activities, outdoor activities and nursing talks with training. From this article we learned that the day care center supports counseling, training, interest-raising and empowerment to patients and nursing talks help older people recover from transitory decline in functional ability (Cheung, 2005).

Sleep

Sleep quality in caregiver’s is not always adequate or sufficient. Caregivers are often awakened by their care-recipients at night which contributes to caregiver sleeping issues,
and because of this, caregivers find themselves sleeping better when they take breaks from taking care of the person with Alzheimer’s. Studies have even shown that caregiver sleep problems continue even after the Alzheimer’s patient has moved out of the home or died (McCurry et al., 2009). It was demonstrated in the McCurry et al., study that caregivers with less social support have a relationship with worse sleep quality.

According to McMurry et al., a study that followed 164 caregivers of individuals with Alzheimer’s and their family over a 5-year interval, assessments were made and evaluated on the caregiver sleep, mood and burden every six months for up to five years. The caregiver sleep quality was evaluated with the instrument Caregiver Sleep Questionnaire (CSQ) and scores greater than 12 (out of 26) indicated to have “sleep disturbance” (McCurry, 2009). Results showed that higher sleep disturbance levels were associated with lower caregiver quality of life.

According to the Caregiver’s Guide, caregiver sleep problems come from the demand that needs to be provided for the patient at home. Some advice that is given to caregivers to decrease sleep problems are to make sure the patient gets enough sleep at night so that daytime napping is discouraged and increasing physically demanding activities earlier in the day. Recommendations made to the patient for sleeping helps the caregiver with their own sleeping issues because its reciprocal (Caregiver Guide, 2010).

**DISCUSSION AND CONCLUSIONS**

When relating the stress that a caregiver of a person with Alzheimer’s experiences, it can be said that the stress is powerful. The stress is so powerful that the research studies we found show that caregivers of Alzheimer’s patients have an association with poor immunity, cardiovascular issues such as higher blood pressures and decreased wound healing mechanisms. According to Ferrara and Grant (2008), this is when the burden of taking care of someone becomes an issue for the caregiver and it is reflected in physical characteristics.

The stress the person receives can be compared with the quality of sleep that the caregiver receives; which according to our research, it is not sufficient or adequate. Caregiver’s lives change because of the stress that is caused upon them and their own physical characteristics are affected. Depending on the Alzheimer’s patients progression of the disease might depend on the burden of the caregiver. For example, an Alzheimer’s patient who is in the later stage where they need assistance for daily living situations might need more assistance from the caregiver than a patient in the earlier stages, therefore; this increases the burden of the caregiver leading them to higher levels of stress and less quality of sleep (Ferrara et al., 2008). If the patient does not have a normal routine sleep cycle, the affect might be presented upon the caregiver. For example, if the patient sleeps during the day and wakes up at night, this will disturb the sleep cycle of the caregiver. According to Merlini et al., excessive daytime sleepiness is associated with Alzheimer’s patients which reflects a poorer sleep at night and disturbs that caregiver’s sleep quality. In other words, less quality sleep produces negative physical effects.

**FURTHER RESEARCH**

In our opinion, further research needs to be done on the sleep disturbances that caregivers receive from taking care of people with Alzheimer’s at home. Not only do we know that caregivers have problems sleeping, but further searches on what exactly takes away their sleep, maybe with different questionnaires or instruments should be performed. Although studies show that the stress caused from care giving can cause cardiovascular issues especially hypertension, further research should be done on poor wound healing mechanisms that occur with caregiver stress.
Another aspect of this topic that needs to be researched is the exact immunology that is affected with stress and care giving. It would be interesting to find, how the immune system is scientifically affected and have studies prove how it is affected.

**BIBLIOGRAPHY**


