

## Review Article

# Social Support and Care for Patients with Alzheimer's Disease in the Community

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### Abstract

Alzheimer's Disease (AD) is described as a chronic, progressive, degenerative disease of the Central Nervous System (CNS) and the most common type of dementia which affects mainly people over 65 years old. Its symptoms can be misdiagnosed as age-related brain deterioration with memorising difficulties. Epidemiologic studies have documented a lot of causative factors but no specified aetiology has been attributed to the onset of Alzheimer's Disease. Patients are cared for by healthcare professionals and relatives, when in home. Emotional, esteem, network, information and physical support, social support on the whole, is provided to individuals by their caregivers aiming at making them feel having control over the disease. Care delivered mainly by close family members is complicated and time-consuming, with difficulties in everyday life and social limitations. Local social services, such as "Home care services", are needed to be involved in the care of a patient with Alzheimer's disease. Furthermore, support groups, such as patient and/or relative groups, can provide mutual support, sense of belonging and any information needed.

**Key words:** Alzheimer's Disease, social support, caregivers

### Introduction

Alzheimer's Disease (AD) is considered to be a chronic, progressive, degenerative disease of the Central Nervous System (CNS) and the most common type of dementia. It was in the early 1900 that the scientific community, with first A. Alzheimer, started to address this new mental disease. It is mainly diagnosed in people over 65 years old, with the disease onset earlier in the patients' life (Brookmeyer et al 2007). World Health Organisation has reported that AD is affecting, worldwide, approximately 35.6 million people, a pattern that is doubling every 20 years, and has made a prediction that more than 115 million are going to be affected by the mid-21<sup>st</sup>

century (Bertolote 2008). The prevalence of AD has been reported to be 4.4% in Europeans over 65 years old and 9.7% in the United States of America (Povova et al. 2012). In Greece in particular, 150.000-200.000 people are currently treated for AD, of various stages, and the disease is projected to affect approximately 500.000 people by 2050.

The disease is often misdiagnosed, as its symptoms are similar to brain deterioration due to aging or mental manifestations due to anxiety or stress (Devanand et al. 2008). In the early stages, memory loss and difficulties in recalling and memorising recent events are described. Referral to a specialised neurology healthcare

team and assessment of the person's attitude and cognitive ability is mandatory in order for the treatment to be implemented. Brain CT is proposed complementary to the neurological assessment. In more advanced stages the person could experience confusion, irritability, aggressiveness, mood changes, cognitive impairment, loss of memory, withdrawal and emotion disorders (Winblad et al. 2016, Devanand et al. 2008). AD could be evolving indefinitely, before any symptoms can be detected.

Scientists have not yet succeeded to determine the aetiology of AD. Epidemiologic studies have documented a lot of causative factors, such as age, family history, Down Syndrome, head trauma, history of depression, atherosclerosis, stroke, Diabetes Mellitus, hyperlipidemia, plasma homocysteine level, smoking, thyroid disorders, exposure to certain toxic conditions and intoxications (Ates et al. 2016). Genetic studies have also, linked the gene connected to apolipoprotein E (apoE)  $\epsilon 4$  gene, responsible for transporting cholesterol to the brain, with the occurrence of AD (Tiraboschi et al. 2004).

### **Social support**

Chronic patients, such as Alzheimer's patients, are cared for not only from relatives and healthcare professionals, but, also, from the society as a whole. Depending on the type of care, caregivers can be divided into "formal carers", healthcare professionals, and "informal carers" or "unpaid caregiver", usually family and close friends (Gallicchio et al. 2002). Social support has been in the scope of interest of various humanitarian sciences, such as psychology, sociology, nursing, medicine and public health.

Social support has been described as having multiple dimensions and various definitions. The most accepted one describes social support as "a verbal and nonverbal communication between recipients and providers that reduces uncertainty about the situation, the self, the other, or the relationship, and functions to enhance a perception of personal control in one's life experience" (Albrecht & Adelman 1987, Gottlieb 2000).

According to the literature, social support refers to any type of communication that enables individuals to feel that they have control over a situation, or to any type of social resources that

are available to them by non-professionals, such as support groups or family and friends (Cohen et al. 2000). Another, more recent, definition that is recognising the multiple types of support, argues that it is "a network of family, friends, neighbors and community members that is available in times of need to offer psychological, physical and financial help" (Kohler et al. 2015).

According to Gurung (2006) actual or enacted support, the support that a person receives, and perceived or subjective support, the self-perception of support availability, are the main components of social support. Early in the 1980s' scientists, such as Schaefer et al. (1981) reported five types of social support: emotional, esteem, network, information and tangible or instrumental support.

### **Types of support provided to Alzheimer's Disease patients**

In the case of AD, patients' emotional support could help to elevate the individual's mood and not try to solve the problem of deteriorating cognitive function. Furthermore, esteem support refers to encouraging persons to take some actions, according to their physical and mental status, and convince them that they are able to perform selected actions, increasing their self-confidence and decrease their feelings of stress. Network support is the one that is more applicable to AD patients. It reflects that the person is not alone and that there is a network of people that are present to help in any situation needed. Information support is necessary to be provided for both patients with AD and their caregivers. Not knowing details about the disease and treatment/management options is an additional source of anxiety. Finally, physical support, tangible support, is needed when the AD advances and the patient could not be self-sufficient.

### **Family care as a source of support**

Due to the chronicity and the degenerative nature of the disease, family members are often responsible for promotion of the patient's general well-being, the correct medication administration and the implementation of any non-pharmacological interventions (Grand et al. 2011). It is apparent that their role as caregivers is extremely important. Caring for a patient in the familiar home environment could delay symptom manifestation and the need for professional nursing care.

Caring for patients with a chronic deteriorating disease, such as Alzheimer's, demands plenty of the caregiver's time away from work, change in working conditions or even the need to quit his/her job in order to provide for the helpless patient. In case of women caregivers, the process could come as a natural role imposed by the social structure of the society, especially the Greek one, whereas when the situation is inversed men could feel more helpless and inadequate in the new acquired role of providing care (Saxena & Wortmann 2012).

When the patient is unable to be treated at home, a nursing home or a facility specialising in providing care for AD patients should be chosen. Spouses and/or families need to be prepared for the psychological stress and feeling of depression and anxiety caused by the separation of their loved ones (Schulz et al. 2013, Marvardi et al. 2005).

Difficulties in everyday home routine, limitations in social life and changes in sleep patterns are reported by AD patients' caregivers (Thommessen et al. 2002). Primary caregivers, such as spouses and/or children, need to explore the possibility of getting help and support from other caregivers, such as close friends and relatives, as it is going to be extremely time-consuming and difficult to care for the patient at the end-of-life period. Research data suggest that social support could reduce the psychological and non-psychological disease burden (Han et al. 2014), prevents social isolation and loneliness (Thompson et al. 1993) and promotes social integration and interpersonal relationships (Lilly et al. 2003).

Caregivers should have investigated the availability of any social services provided either by the local health center or the local municipality health services for the elders, prior to the health deterioration of their loved one. He/she will be informed for any "Home care services" in the area and register to their patients' list. Furthermore, the local police station should be informed about the patients' state of health, so that help can be provided in case of a missing person report. Security within the home environment is essential, as the patient is going to have movement disability as well as cognitive one. In addition, AD patients should not be allowed to go outside their homes without any escort, as it, usually, is difficult for them to orientate (Mougias 2003).

### **Social support provided by healthcare professionals**

Social support could be delivered by specialised healthcare professionals who focus on educating both the patient and the caregiver on the disease itself and the management needed. The main aim of this intervention is to maintain a secure, but not limited, environment promoting the patients' well-being. Interacting with other caregivers, who face the same problems and limitations, is reported to be helpful and healing. Social support has been correlated with lower comorbidity and mortality, as it prevents people from adopting unhealthy attitudes, while it promotes healthy ones such as work out and compliance to treatment, and increases well-being (DiMatteo & Martin 2011).

Furthermore, on the one hand befriending and peer support interventions have been proven to have positive effects in addressing social isolation and emotional stress caused by the disease itself (Greenwood et al. 2013) and on the other hand, family interventions equally affect satisfaction from social support and network availability (Roth et al. 2005, Drentea et al. 2006).

### **Patients' groups as a source of social support**

In addition, social support could be offered by groups individuals with common health problems that relate better to one another and provide mutual support and information. Such groups provide support in a more formal way with meetings, talks and booklets or leaflets with information and helpful tips. The key benefit of support group is reduction in isolation both for patients and their caregivers, and offering a sense of belonging.

### **Conclusions**

In conclusion, the deterioration of cognitive and motor function in a patient with Alzheimer's disease causes also deterioration in the quality of life and psychosocial functioning of both the patient and his/her family. Long-term illness, as Alzheimer, raises a lot of challenges for caregivers as well as for healthcare professionals involved in the delivery of care for patients. Social support expressed as formal or informal relationships, with verbal and nonverbal communication can improve a person's ability to manage his health status with self-esteem, dignity and sense of belonging.

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