

Alzheimer's disease: Psychosocial dimensions of a modern plague?

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Summary

The way that people perceive health and disease in different historical, social and cultural contexts shows various differences. Although chronic diseases of today compared to the epidemics of the past are nowadays characterized by a scientific way of identifying them, both diseases of the past and new diseases show a similarity: that they continue to identify with the "evil" or punishment, and to accompany the individual-patient and family members with a social stigma. A typical example is Alzheimer's disease, which causes issues related to the emotional management of the experience of this chronic condition for both the patient and the caregiver, and problems of management of the stigma. Consequently, the role of family, community ties and associations as factors contributing to the support of the patient and his/her relatives should be included in planning of the government for prevention, early diagnosis and treatment of this disease. Urgent is the need for training and awareness of medical personnel to be able to help the patient and especially their relatives, particularly at a psychosocial level. Result of the foregoing is the emphasis on the offer of organizations/associations, which provide support and information on Alzheimer's disease. These associations are invited to cover the inadequate services of the health care system, aiming not only to a limited pharmacological approach to the patient, but also to psychological and social interventions for caregivers, physicians and the general public.

Keywords: Alzheimer's disease, cultural dimensions, social dimensions, psychological dimensions

Epidemics of the past and present diseases

Health and disease is a dipole, which has been treated in a variety of ways at the individual level, and socially during different historical periods and cultures. Nowadays, the study of this dipole is in the spotlight (even when health is not threatened) as a social issue for which engagement and reflection is needed (Bradby, 2010; Nettleton, 2002). The experience of past epidemics (including examples as the black plague, leprosy and syphilis during the Middle Ages) emphasized the element of collective calamity and divine crisis-punishment which did not concern the individuals, but the whole community. The disease was perceived as the "absolute evil" or divine punishment (because of the limited scientific knowledge, the dominance of unjustified restrictions from the church and the impossibility of effective therapeutic treatment) which led the social environment of the patient to feelings of fear. Consequently, the community through the creation of scapegoats, could justify the actions of neglect, exclusion and abandonment of patients (Adam & Herzlich, 1994).

Instead, health and illness in the 20th century are characterized by a predominance of the scientific methods of determining the diseases and a strong interest of the state in emerging chronic diseases. Developments, such as the upgrading of the role of social and environmental factors, the development of medical science, the establishment and consolidation of social protection and the introduction of technology and pharmacology in health care have led to the phasing out of previous epidemics, while non-communicable, chronic and degenerative diseases prevail in the modern era (e.g. cardiovascular disease, diabetes, cancer, etc.) (Mantis, 2000).

Of course, for this shift in the perception of the diseases, not only the real-physical variation of the external world and the objective medical progress with the new problems that accompany these changes (changing lifestyles and material conditions) did play an important role, but an essential role seems to be given to the new emerging social representations. The social representa-

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tions are born through the communication of a concept or a mixture of ideas and images that exist in people's minds and which are in circulation in the society. Representations are transferred nowadays mainly through talks and texts presented by mass media and other networking e-platforms, but (although socially created) they emphasize the individualisation of the disease.

From the foregoing it is clear that modern diseases and epidemics of the past have similarities and differences. They are similar, because despite the historical, social, economic, and cultural variability, modern diseases and old epidemics remain major threats to society (forms of Evil), causing feelings of fear to the members of various social groups (although perhaps with possible differences in emotional reactions regarding the gender and the social class), while they are also similar as to the direct or indirect allusion that connects them with death. Current, however, diseases compared with epidemics of the past have significant differences, such as the current emphasis on the individuality of the disease, the non-infectious nature, and to the chronicity of the diseases (Mantis, 2000).

For Alzheimer's disease, in general, a similar negative socio-cultural interpretation framework is given (Robertson, 1991; Herskovits, 1995), which is in contrast to the more positive way that this specific disease is understood by the patients themselves during the initial stages of the disease (MacRae, 2008). But beyond that, patients with other memory disorders, such as mild impairment expressed in Mild Cognitive Impairment (a transitory memory disorder-state with high risk of conversion to Alzheimer's dementia), seem to continue to have strong fear for the pervasive stigma of Alzheimer's disease, and they are trying to differentiate their situation and achieve their integration into other diagnostic category-group of patients (Beard & Neary, 2012). A similar perspective of fear holds true for the adult children of patients with Alzheimer's disease, which in their case is related to stigmatization (regarding the cognitive, emotional and behavioral implications of the disease) (Werner, Goldstein & Buchbinder, 2011).

Alzheimer's dementia: Experience of a chronic disease and social dimensions

Dementia of the Alzheimer type is a neurodegenerative disease of the Central Nervous System, characterized by the presence of senile plaques and neurofibrillary tangles in the brain. Patients present a progressive decline in cognitive functions (memory, attention/concentration, executive functions), coupled with functional disorders and problems in their social behavior. Apart from the organic pathology and neuropsychological

decline, elderly patients exhibit also social problems, such as self-care problems, home and living, entertainment, communication and financial problems (Tsolaki & Kazis, 2005). The difficulties in complex activities of everyday life and in relation to the self-care of the individual cause notable effects on the family and other relatives who are obliged to carry the burden of patient care in the long term (Robinson, 1997; Tsolaki & Kazis, 2005). The 'sick' elder and the caregivers (usually spouses and children) are forced to learn to live with the limitations imposed by this disease, to adapt to their new role, and to cope with the requirements of social, family and professional life.

Greece, like all other countries, is characterized according to recent statistics from a course of increasing life expectancy (for both women and men), but unfortunately not without diseases (European Commission, 2016; OECD, 2016; World Health Organization, 2016). The ageing of the world population and the rapid increase of various types of dementia that occur in this age range requires the management of dementia in Primary Health Care, and decisive cooperation of caregivers-family, physicians and other mental health professionals (Alzheimer's Association, 2012).

Caregivers of patients with Alzheimer's disease

Caregivers of patients with Alzheimer's disease are primarily the spouse, children, grandchildren, other relatives or third persons-professionals who may be paid or help as volunteers. The tasks of caregivers include emotional support of the elder, help at home, personal care, managing finances while making various kinds of decisions (Gatz, Bengston & Blum, 1990).

Caregivers of patients with Alzheimer's disease abroad (mainly in English-speaking countries, due to the small number of surveys on the satisfaction regarding the role of the caregiver of patients with dementia) seem to experience negative emotions (anxiety, sadness, anxiety for the loved one), but also positive emotions related to the provision of care (Andren & Elmstahl, 2005). The causes for negative emotions are related mainly to the issue of insufficient medical treatment, the cognitive deficits demonstrated by patients themselves (e.g. memory loss, distraction etc.), possible behavioral changes, consequent changes in interpersonal relationships, supervision difficulties, and finally the sensed discomfort (Dulin & Dominy, 2008). The positive emotions are stemming mainly from the interpersonal relationships between caregivers and patients, the existence of intrapersonal orientation of caregivers and the desire to promote a positive result for both patients or to avoid negative events (Andren & Elmstahl, 2005). There is also

a classification depending on the cause-source of satisfaction: 1) as a criterion of satisfaction only the patient is important (e.g. maintenance of dignity and pleasure of the loved elder patient), 2) as a criterion only the caregivers are important (e.g. in order the caregiver to feel useful and his/her work valued by family and friends), and 3) as a criterion both the caregiver and the elder patient are important (e.g. as a bilateral action for earlier benevolence or as current exchange of emotions through the acting of giving care) (Andren & Elmstahl, 2005). Other factors that relate to satisfaction is the meaning that the caregivers give in each situation, and the pleasure and appreciation that caregivers experience through giving and/or receiving in this special relationship (Andren & Elmstahl, 2005). So, it is obvious that the welfare of the elderly in need of care depends on the physical and mental health of those who are take care of them. Thus socially-shared responsibilities regarding the caregivers, reduce the supply of material and emotional support on their part, and our aim should be to help these people.

Support for patients and their caregivers

As the progression of the disease involves gradual loss of the patient's independence, increased needs for help in performing basic daily activities, and deterioration of the physical and mental health, it seems that these conditions require more advanced treatment strategies and personalized care. Additionally, caregivers of the elderly with mental disorders usually have feelings of entrapment, isolation, anger, guilt and resignation, which result in a high prevalence of anxiety disorders and depression in themselves. The majority of the caregivers begin to withdraw socially, stop seeking the company of friends and do not participate in activities they had before. They are in an extreme situation of complete isolation, not only because of the emotional burden, the social stigma and the negatively charged views that the modern society shares for this disease of old age, but also due to practical problems of time constraints, and because of the many demands of caring for the elderly patient. Very often, relatives and friends stop visiting the patient, because they do not know how to behave, something that frightens them (Tsolaki & Kazis, 2005).

The subjective burden experienced by caregivers is shaped by many factors, such as the characteristics of the caregivers themselves, the characteristics of the elder patient, and the specific characteristics of the social context (Etters, Goodall & Harrison, 2008). It seems that the behavioral symptoms of the patient to be the best predictive factor for that, and a possible direct field

for interventions (non-pharmacological programs) could improve the lives of both the patient and the caregiver (Wolfs et al., 2012). In addition to that, the social stigmatization of relatives of a person with a diagnosis of mental disorder, significantly affects the subjective burden and identity of the caregivers (Werner et al., 2011), as they are wrongly imposed the requirement of hiding the individual-handicapped patient (Goffman, 1963) with a simultaneous-parallel and debilitating preoccupation with this matter. Therefore, regarding the support issue, it is an urgent need to include both patients and their caregivers into specially designed support groups (Vassiliou, 2012), to familiarize them with the use of social services in order to solve everyday problems (e.g. the official retirement processes), to include them in programs not only of the type Help at Home, and day care centers, but also to assist them in choosing the institution for the patient when in advanced stages of the disease, and finally raise awareness of the whole society regarding all aspects of dementia (Tsolaki & Kazis, 2005).

The 'supplies' that medical staff is necessary to have in order to be able to help both the patient and his/her caregivers-relatives, especially at the psychosocial level should address methods of intervention for both parties in order to strengthen-improve their quality of life through individual and group counseling and/or through support programs and reintegration that will reduce the stigma and exclusion.

The type of assistance offered by associations for Alzheimer's disease directly relates to these psychosocial dimensions of the dementia (since there is not yet an effective pharmacological treatment). The reduction of the emotional burden of caregivers through sharing with other people might be blocked by the refusal of some caregivers to show and to share physical and emotional burnout experiences. Perhaps the fact that they might be considered insufficient to do things, and the fear for further stigmatization pushes them to isolate more, and this distance becomes a barrier in their attempt to seek help and support from other relatives and non-relatives who may be able to help. Therefore, beyond the immediate family and the network of friends, it is very important that services and support groups exist, which can guide and help caregivers cope with the demands of dementia. Support groups seem to play a particularly important role in emotional support and connection to the wider society for the caregivers, with ultimate goal the effective care (improving skills and learning strategies for problems coping) of patients. They are an important opportunity to teach caregivers how other caregivers experienced common symptoms of the disease and how these changes contributed to various aspects of their lives. Thus within the group, ca-

regivers share information and better understand their experiences, making them more effective. The local numerous Greek companies and associations for Alzheimer's Disease are invited to cover this gap in the healthcare system (Tsolaki & Vassiliadis, 2002).

Informing the family is needed on issues relating to both the results of neuropsychological assessment of the patient, the course of the disease, and the legal issues which arise, while family support is equally important (Margaritidou, 2010). The family support reduces the stress of the caregivers, allowing family members to express their feelings, improves adaptation to the new situations, reduces the severity and frequency of depression, improves communication skills among members, reduces management problems, and finally reduces the burden of the caregiver (Eisdorfer et al., 2003; Haupt et al., 2000; Hinchcliffe et al., 1995; Knight, Lutzky & Macofsky-Urban, 1993; Marriott et al., 2000).

The necessary interventions to improve the services provided to these patients and their caregivers-relatives should be based on a general active policy aiming at designing government-financed and government-organized programs, which will include actions for the patients themselves [providing protection at centers of open care, care at home programs and day centers (Benos, 1999)], and actions for their caregivers. Following this line, the realization of educational programs (seminars, workshops) for doctors of all specialties and other healthcare professionals will provide them with skills for better diagnosis and treatment of dementia, but also will make them aware of the issues of psychological problems and social stigma. At the same time, the effort for the dissemination of information should be directed to the general public (since the early detection of possible people-patients in the community is as important as proper later medical diagnosis) through the organization of events and lectures not only in Athens-Thessaloniki, but also in other provincial cities of Greece in cooperation with local Alzheimer associations and other non-for-profit organizations (Tsolaki et al., 2009).

In conclusion, health and disease in a constantly changing world make necessary for the improvement and expansion of services provided to patients and caregivers, that the state cares actively for coordinated cooperation of all health professionals at national, European and international level, through participation in shaping prevention policies and programs addressing the 'new epidemics' of the 21st century.

Psychosocial support structures for Alzheimer's patients

The available psychosocial support structures for patients with dementia in Greece although limited in number, aim to assist efforts by neurological and psychiatric clinics of public and private hospitals and memory clinics, with their services in different cities across the country. These are public initiatives, but also sponsored by private foundations, which rely on grants from the state-Ministry of Health, the Church and the voluntary participation of individuals, such as the Athens Association of Alzheimer's Disease and Related Disorders, the Greek Association of Alzheimer's Disease and Related Disorders Thessaloniki, and Associations in peripheral municipalities such as the "Nestor" Psychogeriatric Association, the Greek Association of Alzheimer Disease and Related Disorders of Volos, Alzheimer's Ioannina "Hippocrates" Association, the Alzheimer's Society for Heraklion "Allilengii" (Solidarity), the Society for Alzheimer and Related Disorders Larissa Prefecture, the Children and Adults Mental Health Community Services Development Federation "Panacea" Rhodes, the Alzheimer's Disease Support Association - Related Disorders of Pella, the Alzheimer's Disease & Related Disorders, "Saint Nicholas" Kozani, the Xanthi Caregivers Association, Association of Families and Friends for Mental Health (S.O.F.P.S.Y.) Serres, the Greek Health Education Society Annex Chios, the Greek Association of Alzheimer's Disease & Related Disorders Halkida, the Greek Association of Alzheimer Disease and Related Disorders Branch of Chania, etc. (Athens Association of Alzheimer's Disease and Related Disorders, 2017; Greek Association of Alzheimer's Disease and Related Disorders Thessaloniki, 2016). In these indicative listed structures attempts are made to cover in the form of programs, which aim at various dimensions of emotional, physical and cognitive health, the needs of both patients and their caregivers-families with multiple actions in day centers, in-home care, caregiver support centers, and psycho-geriatric boarding homes.

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