

SURVEILLANCE

Alzheimer's disease patients: quality of life in the Republic of Croatia

Josipovic-Jelic Z, Soljan I

Polyclinic „Medikol“, Zagreb, Croatia. zeljka.josipovic-jelic@si.t-com.hr

Abstract: The most common among dementias is Alzheimer's disease (AD). At the beginning it is controllable by medications but, as the disease advances, the patient needs a 24-hour care and very often one family member has to devote him/herself to the permanent care of the ill. AD dictates both patient's and family member's lives. The illness demands routine, patient behaviour, adjustments in living conditions as well as a lot of sacrifice. Although AD patients need adequate care in medical and social institutions, the caregiver's role is crucial. Therefore, the care for AD patients implicates the care for family members, i.e. caregivers. Such care should consist of medical care to caregivers, joint planning of the progress of illness and full daily patient care as well as legal advice. Croatia still hasn't got a fully developed care system for neither of the participants in the Alzheimer's disease (Ref. 22). Full Text (Free, PDF) www.bmj.sk.

Key words: Alzheimer's disease, family, caregiver, psychosocial help, family and caregiver education, society.

Old age, a natural physiological process, is characterized by numerous physical and mental changes that result in illness. One of these is dementia, a progressive deterioration of intellectual function that manifests itself as a set of specific symptoms and signs of a central nervous system disorder that persist longer than three months (1, 2). The dementia syndrome is clinically diagnosed when the disorder of cognitive functions is severe enough to impede the social and professional activities of the afflicted individual. The list of disorders that can lead to dementia is very long. There are over 70 conditions, in which dementia is involved to a smaller or greater degree. With respect to pathological causes, dementia may be brought on by neurodegenerative, vascular, infective, traumatic, metabolic-toxic, and neoplastic conditions.

Alzheimer's disease (AD) and vascular dementia (VaD) are the two most common types of dementia. According to some research, the share of Alzheimer's-related dementia in total dementias is as high as up to 70 %.

Dementia mostly affects elderly people and is characterized by slow and certain progression from 2 to 10 years or more, until death. It causes changes in behaviour and personality, disorientation in time and space, inability to independently perform everyday activities, and neglect of one's own safety, hygiene and nutrition.

A dominant feature in the clinical manifestations of dementia is a diminished short-term and long-term memory accompanied by disorders of abstract thinking and judgment, disorders

of other complex cortical functions and/or personality changes of the affected person. It is estimated that 5 % of the population over the age of 65 years is affected by some form of dementia, and thereafter the prevalence of dementia doubles every four years reaching around 30 % at the age of 80 (3). According to statistical data, between 1 and 3 percent of the total population suffers from AD.

In the initial stage of illness, the patient's condition is alleviated by medication. The American Food and Drugs Administration (FDA) has approved four drugs for use in Alzheimer's: Donepezil (Aricept), Galantamin (Razadyne, Remynil), and Rivastigmin (Exelon), Memantin (Axura, Ebixa, Namenda). These drugs belong to the groups of inhibitors of acetylcholinesterase and NMDA antagonists. Medicines from both groups can be combined as they have a different mechanism of action. However, the currently available medications have a symptomatic action and substitute the function of deteriorated neurons. Their efficiency is of limited duration. In this stage of illness, the person needs occasional care and supervision, while in the advanced stages of illness the affected person needs a 24/7 care.

This paper deals with the following issues: social context of illness, caregiver as a key factor in adequate care of the patient, and guidelines for the normal functioning of the families of AD patients.

The social context of Alzheimer's disease

“The question of health and illness, and thus the quality of life has a huge significance for the individual, the family and the social community as a whole” Kozarevic (4).

Illness is understood as the departure from the *normal* and *normal* means *the right, as it should be, usual, regular, average,*

Polyclinic “Medikol”, Zagreb, Croatia, and Europapress Holding Ltd., Zagreb, Croatia

Address for correspondence: Z. Josipovic-Jelic, MD, Polyclinic “Medikol”, Vocarska str. 106, 10 000 Zagreb, Croatia.

natural (5). Not being normal results in stigmatisation, which under certain circumstances can lead to isolation. The society always examines the responsibility for deviations, which is why stigmatizing of the sick is to some extent linked with the issues of personal responsibility, shame, reproof, and guilt. In the past, the illness was a factor of isolation from the social community of both the patient and his/her family. Examples are known of sick people being „confined“ indoor to keep them away from the eyes of the public. Even today, though to a lesser extent, some communities tend to isolate their members who are affected by some health problem (physical anomalies, unusual behaviour of the sick person etc.). Thus, illness represents a deviation not only from the biomedical norms, but also a deviation from the social norms. According to leading experts in gerontology, the primary problem of aging is the isolation of senior citizens from the social community (6).

Societies that make early and adequate preparations for the health and social problems of old age and aging will be better equipped to respond in an adequate manner. Disturbed mental health can lead to conflicts with the narrow and wider environment, alienation, self-conflicts, disrupted family relations, criminogenic behaviour, murder and suicide. Alzheimer's disease, a condition with decreased cognitive functions, is preceded by changes in emotional control and behaviour, mental incompetence, and inability to comprehend or control the consequences of one's behaviour.

Attitude towards disease and persons afflicted began to change in the second half of the 20th century when disease was recognized as a social phenomenon. Scientists increasingly focus their interest on disease research, support groups are being formed for those afflicted by disease, and the sick people are becoming more and more integrated in everyday life.

Disease can put a stigma on both the person afflicted by disease and his/her family. The society should accept the fact that AD is an illness of everyday life and that struggle against the illness at the same time represents the struggle for the human dignity of persons afflicted by disease and the members of their family. Early diagnosis and treatment create the conditions for ensuring a quality of life worthy of human dignity.

Changes in the family: while providing care to an AD patient, the caregiver himself/herself becomes a patient

The care of an AD patient becomes the priority of such person's family members, and due to social isolation of the afflicted person and the need for constant supervision, the family members themselves become isolated over time. According to the testimony of the son of an AD patient that the authors spoke to while preparing this article, Alzheimer's robs a person of their mind and memory, but emotions, desires and the main character traits still remain and are expressed in a number of different ways: warmth, glances, the preserved personality *faade*, but also in the sense of being lost, in devastating anxiety and fear. The disease hugely affects the life of the family caregiver who often feels helpless and unprepared for the pain and suffering. "It is not

only my mother that is afflicted by Alzheimer's, but in a way our whole family".

If the family decides to care for their member who is suffering from AD, usually one person needs to make a "sacrifice". If this is the case, a redistribution of duties is indispensable and necessary. To ensure the continuity of an organized family life, the family must use appropriate control mechanisms and endeavour to maintain their usual life and family routine, try not to give up on small pleasures, and attempt to include the person with AD in as many family activities as possible.

The care of an AD patient often requires a greater mental and physical effort than the care of patients suffering from many other diseases. Namely, ageing and somatic diseases manifest themselves in the change of the physiological structure and function of the body, resulting in the decline of self-regulating biological, social, and mental abilities. These changes require old and sick persons to constantly adjust their perception of their own biological condition while attempting to maintain and improve their health and own identity. Furthermore, this process does not depend solely on the person who has the disease, but on external factors such as healthcare, family, housing conditions, social relations, and the financial situation. Persons suffering from dementia (due to declined cognitive functions) are not aware of their own condition, are unable to seek help, have no adjustment capabilities (resulting in inability to take care of oneself), are unable to feed themselves, maintain their personal hygiene, dress themselves, adapt themselves to climate changes, go to the toilet, keep their house clean, and most importantly, are unable to recognize the dangers in or outside their home (electricity, gas, fire, water, traffic, protection against harsh weather, etc.). In case of more severe cognitive deficits, the elderly person is not able to express his/her basic physiological needs, and untimely care can lead to complications (severe dehydration, metabolic electrolyte imbalance, urine retention, and finally vital organ failure), and a fatal outcome. Such patients should therefore be provided a 24-hour supervision and adequate care in accordance with the patient's general condition.

In Sweden, which has one of the most advanced elderly care system, a primary care physician identifies a disorder in cognitive functions while talking to the patient and prescribes necessary examinations. In case of suspected dementia, the patient is referred to the *Memory Centre* where the patient is subjected to CT, MR, cerebrospinal fluid and other examinations and tests. The *Memory Centre* is staffed by a psychologist, a speech therapist, and a psychotherapist, and examinations are performed in an outpatient's clinic and last four to eight days. If dementia is diagnosed, the patient returns to his/her environment where the family and the local community assume the care (7). What is more, the costs of care of patients suffering from dementia amount to around 40 billion Swedish kronas per annum (3.7 billion euros), which is equivalent to the aggregate cost of care of cardiologic and oncologic patients! It would be good if such *Memory Centres* could be set up in Croatia as well in order to improve the diagnostics and treatment of dementia.

According to the American Alzheimer's Association, more than 80% of family member caregivers feel stressed, and over

50 % suffer from depression (8). In addition, according to the American National Family Caregivers Association, persons between the ages of 66 and 96 who care for their ill spouse have a 63% larger risk of dying than those who are not caregivers (9). Aggression, loss of memory, inappropriate behaviour in public, hallucinations, paranoia, and, in the final stage of disease, inability to recognize the spouse, puts an additional strain on the spouse caregiver.

Children – future caregivers – find themselves in a reversed role: instead of the natural role in which parents, even if indirectly, care for their children, the children assume care of their parents. Children caregivers feel used, isolated and even underestimated, and are very often tormented by a sense of guilt because they feel they are not doing enough for their parent. The same feeling is shared by those children who are unable to care for their parent, because they live far away.

Over time caregivers start to show various signs of “being worn out” that are manifested in a number of ways:

- 1) psychic symptoms: anger, fear, denial, lack of concentration, irritability, depression;
- 2) somatic symptoms: tiredness, chronic fatigue, different somatic conditions (gastric disorders, hypertension, headache, myalgias, joint pain, allergies...), insomnia;
- 3) socio-economic symptoms: social isolation and financial problems caused by illness.

Guidelines for caregivers

Early diagnosis and treatment slows down the progression of the disease resulting in improved quality of life of both the patient and his/her family members. Perhaps the most difficult part of the process is to recognize and learn to live with the disease, which is why it is important to inform the caregiver in detail of the possible development of the disease. As one doctor put it poignantly: “It looks as if the patient’s life cycle is moving in the opposite direction: instead of enjoying his retirement, he more and more resembles an irresponsible child who loses the sense for the world around him or for what is socially acceptable until he becomes like an infant whose life revolves around primary life functions: food, drink and digestion. In the end he needs a *mum* to take care of him like a newborn baby”.

The Alzheimer’s Disease International and the Croatian Alzheimer’s Disease Association have provided guidelines for recognizing AD (10):

- 1) memory disorders through months or years - the patients finds it difficult to remember recent events;
- 2) difficulties in performing daily activities such as cooking, cleaning and maintaining personal hygiene;
- 3) speaking, reading and writing difficulties – the patient replaces forgotten words with others, sentences are not easily understandable and lack a deeper meaning and sense;
- 4) loss of orientation in space and time – not knowing what day, month or year it is, inability to find previously familiar places;
- 5) wrong estimates and decisions such as inappropriate clothing;

- 6) difficulties in abstract thinking – inability to handle money transactions, to fill out forms or understand concepts such as “birthday”, “love” or “justice”;
- 7) things frequently get lost, displaced or left in unusual places;
- 8) inappropriate fluctuations in mood and changes in behaviour;
- 9) personality changes;
- 10) loss of interest in social activities.

Once the family comes to terms with the disease and starts adequate care of the patient, another problem often appears: the caregivers develop a fear that they may begin to suffer from hypertension and/or depression as a result of stress. Furthermore, the descendants are afraid that they too may become victims of dementia considering genetic conditioning. It is therefore essential for the caregiver to take care of his/her own health and to pay greater attention to his/her well being than he/she would normally do under different circumstances. A first step would be to have annual medical checkups and to draw the physician’s attention to the existence of AD in the family. Another important component is psychosocial help in following forms:

- 1) education that will help to develop the cognitive, behavioural, and social mechanisms – improvement of the psychosocial condition;
- 2) courses to improve the skills and basic knowledge of the disease and care;
- 3) group therapy (of 3 month’s duration).

The 2008 Signe and Elmstlhl research has shown that caregivers who were subjected to such group therapy and courses had significantly lower levels of tension and disappointment after 6 months, and were able to maintain this level even after 12 months (11).

Since the aging process involves significant individual differences, there is only one general rule for handling elderly persons, and that is that aging like any other life process requires active involvement of individuals in trying to come to terms with the existing situation. Therefore, any form of help and care for the elderly should include encouragement to take self-activities and to accept the life situation with all its possibilities and restrictions (12).

What the society can and should do to help?

The factors of quality and duration of life depend on genetic predisposition, health behaviour, attitudes, lifestyle, and the social environment. The life span of an elderly person is structured by biological and psychological determinants, but also the social norms and customs. Still, aging is often perceived as a social problem (13). Whether an elderly person is going to become a social problem depends not on such person’s age, but on the society that is responsible to provide for a dignified old age. In order for this to happen, the predominant negative attitude to old and sick persons must change. The same is true of persons with Alzheimer’s. The functional ability of elderly people, which includes the ability of self-care, depends on the cognitive capabilities which are significantly reduced in persons with AD. It is, therefore, vital for the society to make appropriate preparations in or-

der to provide care in a humane, efficient and reasonable way (14).

Information on the number of persons suffering from AD varies. It is estimated that a total of 24 to 30 million persons are afflicted by the disease (15). The exact figures for the Croatian population are not available, with estimates ranging between 50,000 to 76,000 (16). It is believed that approximately 4.5 million people are diagnosed with Alzheimer's each year (17–19). The percentage of elderly people is almost the same everywhere in Europe, including Croatia, which means that about 17 percent of the population are older than 65. At the moment, 750,000 Croatian citizens are older than 65, and it is estimated that by 2050 this number will reach 24 percent (1,650,000). In this case we may speak of a dementia epidemic.

Acknowledging the fact that the number of dementia patients is growing, great advances have been made in recent years in the care and support of elderly, both in Croatia and the world. The socio-medical interventions are focused on improving the health-care of elderly and include timely checks of the health condition, ensuring of the necessary conditions for improving prevention, diagnostics, treatment and rehabilitation of patients, and organizing of free time and care outside the family. The local community has an especially important role in this process. The Croatian Alzheimer's Disease Association, active since 1999, supports its members in the following ways: it holds monthly meetings with family members, operates an SOS phone that offers help in form of advice and support, and organizes public events to raise the public awareness about the disease (20).

At the moment there are only few hospital wards in Croatia that provide care to AD patients. However, the solutions they provide are temporary and inadequate and lead social decompensation. The condition of patients with dementia is rapidly deteriorating with accompanying behaviour disorders such as agitation and psychotic attacks. A new environment leads to impairment of adaptive abilities with resulting decompensation of preserved mental and other abilities. Therefore, in order to avoid social decompensation, it is vital to allow the senior citizens to stay active as long as possible, especially in intellectual, emotional, and social sense. It is important to maintain the normal rhythm of life in the family, to stay sexually active, maintain social relations, and take part in professional and other activities (21). This requires organized assistance of the family, and, if required, home treatment (22). Conventional hospitalisation should be substituted by care at psycho-geriatric wards. An example of adequate care is the future in-patient clinic of the Intensified Care Centre in the town of Pula, that, thanks to last year's donation of the World Bank (160 000 euros), will provide 24-hour psychosocial support to AD patients and their families.

Prevention of social decompensation is a complex process that requires a multidisciplinary approach. Hospitalisation makes sense only if it has a preventive role and saves lives of elderly people.

In lieu of conclusion: how to live together?

Symptoms of dementia set in gradually, almost unnoticeably, so that neither the family nor the patient is able to define the

exact onset of illness. In the advanced stages of illness, the disorders become aggravated and the patient fully depends on the permanent foreign support and care. Once the caregiver has accepted the disease as an inseparable part of life and has gained the basic knowledge of the disease, he/she should acquire the skills that will make his/her daily life with the disease easier. In order for the patient's condition to stay stable, it is important to maintain routine, to repeat specific activities and rituals, which demands a great deal of patience. It is essential to maintain a warm, emotional relationship instead of ineffective confrontations or unnecessary critique. The patient should be encouraged to independently perform some simple tasks and intellectual obligations, but one should not insist that they be completed perfectly. The patient should also be encouraged to maintain personal hygiene, as this represents the basis for keeping the body and mind in good shape, in addition to saving the energy of both the caregiver and the afflicted. Regular social contacts and meetings with relatives, friends, and other AD sufferers and their caregivers impart the patients with a sense of being connected with the outer world. It is necessary to adjust the household environment by removing potentially hazardous objects and, if required, by moving to a more suitable living space. Considering that AD is a prolonged and as yet incurable disease, it is highly important to avoid the unnecessary costs of buying new and insufficiently studied medicines.

Dementia, a syndrome induced by a brain disease, manifests itself in the loss of intelligence – higher cortical functions that were previously fully developed. A patient with dementia needs social, legal and medical assistance. As no guidelines have as yet been defined to assist the staff and family members of AD patients, valid criteria must be set and high ethical principles applied when organizing the joint life, the legal, moral, and social relations. It is important to note that everyone caring for an AD patient must focus on quantifiable medical parameters as a basis for making the right medical decision, as well as on emotional and ethical aspects of the patient's behaviour.

Finally, persons suffering from AD will feel the best in the midst of their family. It is therefore crucial that, in addition to good care, patients receive abundant love and understanding, because this is what most of them once provided to their family members. Still, in the terminal stage, when the caregiver's knowledge and abilities are no longer sufficient for adequate care, appropriate institutional care must be sought.

At the government and local community level basic guidelines must be regulated for the care of all senior citizens, including those with dementia. The social community must assume the responsibility for the implementation of medical and social care, thus lifting the burden from families and caregivers. Regardless of the material status of the patient, financial resources and accommodation in adequate healthcare or social institutions must be provided, as is the case in developed north European countries. Until adequate in-patient care is secured, care can be provided in out-patient facilities.

References

1. **Josipovic-Jelic Ž, Rajkovic I.** Morfološki supstrat kognitivnih promjena kod oboljelih od vaskularne i Alzheimer demencije. Available at: www.psihliška-komora-hr.
2. **Basic principles of neuro-knowledge.** Available at: www.hiim.hr
3. **Henigsberg N.** Epidemiologija demencija. In: Zbornik radova Druge hrvatske konferencije o demencijama; 17. rujna 2004; Zagreb, Hrvatska. Zagreb: 2004, p. 3—4.
4. **Kozarevic DJ.** Socijalno-medicinski aspekti starenja. In: Gerijatrija I (Ed). Izabrana poglavlja za liječnike opće medicine. IX seminar za stručno usavršavanje; Opatija, Jugoslavija: 1978. p. 25—40.
5. **Klaic B.** Rječnik stranih riječi. Zagreb: Nakladni zavod Matice hrvatske; 1983.
6. **Ljubičić D, Vučić Peitl M, Peitel M.** Psihološki i socijalni aspekti starosti. Available at: www.alzheimer.hr/images/simpozii.pdf.
7. **Bogdanovic N.** Cijepit cemo se i protiv demencije. Available at: www.jutarnji.hr/clanak/art-2009,1,19,,148895.j.
8. Available at: www.alzheimersanddementia.org/home.
9. Available at: www-thefamilycaregiver.org/index.cfn.
10. Promjene u svakodnevnom ponašanju koje upućuju na Alzheimerovu bolest. Available at: www.alzheimer.hr, www.alz.co.uk, www.alzheimer.ca and www.alzforum.org.
11. **Signe A, Elmstahl S.** Psychosocial intervention for family caregivers of people with dementia reduces caregiver's burden: development and effect after 6 and 12 months. *Scand J Caring Sci* 2008; 22 (1): 98—109.
12. **Krizmanic M.** Psihološki aspekti starenja. In: Gerijatrija I. – Izabrana poglavlja za liječnike opće medicine. IX. Seminar za stručno usavršavanje — Opatija; 1978; p. 41—50.
13. **Ajdukovic M.** Društvena skrb o starijim osobama – izazov 21. stoljeća. In: Starost i starenje – izazov današnjice. Savjetovanje. Makarska; 1995, 97—102.
14. **Bennett D.** Public health importance of vascular dementia and Alzheimers disease. *Int J Clin Pract* 2001; 120 (Suppl): 41—48.
15. **Fratiglioni L, De Ronchi D, Aguero-Torres H.** Worldwide prevalence and incidence of dementia. *Drugs Aging* 1999; 5: 365—375.
16. **Pandžić Sakoman M, Pecotic Z.** Hospitalizacija dementnih bolesnika. In: Zbornik radova Prve hrvatske konferencije o demencijama; 18—20. rujna 2003.; Zagreb, Hrvatska. Zagreb: 2004. p. 39.
17. **Šimic G.** Rana dijagnostika Alzheimerove bolesti u gerijatrijskih bolesnika. In: Gerontološka tribina; 4. prosinca 2007; Zagreb. Hrvatska. Objavljeno na CD ROM-u.
18. **Ivankovic V, Grbic K, Šimic G, Mimica N.** 1906—2006: 100 years of Alzheimer's disease. *Neurol Croat* 2006; 55: 95.
19. **Pecotic Z, Babic T, Dajčić M, Zarevski P.** Demencija kod Alzheimerove bolesti. U: Brošura Hrvatske udruge za Alzheimerovu bolest Zagreb; 2001: 1—7.
20. **Dajčić M, Dajčić T.** Counseling center for family members/caregivers of patients with Alzheimer's disease. *Neurol Croat* 2008; 57: 58—59.
21. **Durakovic Z et al.** Medicina starije dobi. Zagreb: Naprijed 1990, 337 pp.
22. **Poredoš D.** Alzheimerova bolest i obitelj. Available at: hrcak-srce.hr/file/5864.

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