

Institutional Services for Dementia Care in Turkey

Türkiye'de Demans Bakımında Kurumsal Hizmetler

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Öz

Tüm dünyada doğuştan beklenen ortalama yaşam süresinin uzaması ile birlikte toplam yaşlı nüfus oranı da artmaktadır. Türkiye'de demans prevalansını belirlemeye yönelik yapılan çalışmalarda; düşük eğitim düzeyi, ileri yaş, kadın olma, kırsal alanda yaşama, fiziksel bir hastalığın bulunması, çoklu ilaç kullanımı, kronik başka bir hastalığın eşlik etmesi (özellikle diyabet), alkol ve sigara içme öyküsü olması demans görülmesi yönünden risk faktörleri olarak bildirilmiştir. Türkiye'de demans belirtileri nedeniyle biraşlık kurumundan tedavi arayışı genelde gecikmektedir. Bu derlemede, Türkiye'deki demansın durumu, hastalara yönelik verilen hizmetler ve hemşirelik bakımı ile ilgili bilgiler sunulacaktır.

Anahtar sözcükler: Türkiye, demans, yaşlılık.

Abstract

The total older population is growing due to the increase in expected average life expectancy at birth all over the world. The risk factors for dementia reported by the studies in Turkey include low level of education, older age, being female, living in a rural area, having a physical disorder, multiple drug use, accompaniment of another chronic disease (especially diabetes), and having a history of smoking and alcohol use. Seeking care from a healthcare institution because of dementia symptoms is usually delayed in Turkey. In this review, information on the status of dementia in Turkey, services provided for the illness and nursing care will be provided.

Key words: Turkey, dementia, elderly.

OLDER POPULATION is growing due to the increase in expected average life expectancy at birth all over the world (Prince et al. 2013). In Turkey, the proportion of the 65-and-older population increased to 4.3% in 1990, 5.7% in 2000, 7.2% in 2010 and 7.5% in 2012 (TUIK 2013). According to the TURKSTAT Population Projections, while the growth rate of the population was 11.2 per thousand in 2013, it will decrease to 8.4 per thousand in 2023 (TUIK 2013). The reason for this is believed to be the rapid decline in fertility and the increased life expectancy rates. Demographic structure is changing gradually. For instance, rural-to-urban migration has increased, the traditional family structure has been replaced by the nuclear family, women have begun

to take a more active role in working life and the total fertility rate has decreased to 2.23 in comparison with the previous years. With the increase in the elderly population, life expectancy at birth is also increasing. According to TURKSTAT data, in Turkey, the life expectancy at birth was 65 years for men and 70 years for women in 1992 and 74.7 years for men and 79.2 years for women in 2012. These figures are estimated to be 75.8 for men and 80.2 for women by 2023. It is estimated that this number will gradually increase even more (TUIK 2013).

This review contains information on services offered to demented and demented individuals and nursing care. In this review, dementia in Turkey was intended to provide a broad framework of the services offered to individuals.

Prevalence of Dementia in Turkey

The prevalence of chronic diseases increases in parallel to the increasing age. In Turkey, studies are conducted to determine the prevalence of dementia at local level, but the data is still limited. On the other hand, according to the Europe 2012 report on dementia prevalence in the 60-and-older population in European countries, the prevalence of dementia in Turkey is 3.2% and this percentage put Turkey in the last rank among the other European countries (OECD 2012).

Different studies that were conducted in different cities in the seven geographical regions of Turkey provide projections on the prevalence of dementia in Turkey. A cross-sectional study about the prevalence of dementia in İstanbul found that the prevalence of dementia among individuals older than 70 was 20% (Gurvit et al. 2008). If this percentage is generalized to the population structure of Turkey, the number of individuals with dementia is estimated to be around 400.000 in the country. This number is estimated to increase gradually because people in the country are expected to live longer and, therefore, the nation's population is estimated to get older in the future (Özdemir and Taşçı 2013). A similar study about the prevalence of dementia in low socio-economic area in İzmir found that it was 22.9% (Keskinoğlu et al. 2006). Another study in Elazığ found that the prevalence of dementia was 5.9% for men and 9.0% for women, with an average of 7.3% (Bulut et al. 2002). A study in Eskişehir found that the overall prevalence of dementia in the city was 8.4% and the types of dementia prevalent in the city were Vascular and Alzheimer's types of dementia (Altıntaş et al. 2011).

As a result of the diagnostic and screening tests administered to the residents of a nursing home for the elderly in Denizli, the prevalence of dementia was found to be 70.2%. That study enrolled a total of 88 subjects and 67% of the subjects were diagnosed with Alzheimer's disease, 25% were diagnosed with vascular dementia, and 8% were diagnosed with other types of dementia (due to Parkinson, etc.) (Amuk et al. 2009). In Turkey, the elderly traditionally prefer to live with their families, but preference for professional elderly care organizations has increased due to the social changes over the last few decades. Therefore, the problems of the elderly living in these organizations have been a topic of concern. Some studies carried out in nursing homes in Turkey found that the cognitive dysfunction rate was 43.3% in a nursing home in Gaziantep (Ilhan et al. 2006) and 32.8% in a nursing home in Ankara (Altıntaş et al. 2011). Also, the prevalence of dementia among the elderly in a nursing home in Edirne was 41.5% (Şahin et al. 2005).

The risk factors for dementia reported by the studies in Turkey include low level of

education, older age, being female (Şahin et al. 2005; Keskinoğlu et al. 2006), living in a rural area, having a physical disorder, multiple drug use (Bulut et al. 2002, Amuk et al. 2009), accompaniment of another chronic disease (especially diabetes), (Çuhadar et al. 2006), and having a history of smoking and alcohol use (Amuk et al. 2009). Alzheimer's disease and other types of dementia rank 19th by a prevalence of 0.5% among the diseases that cause death in Turkey. Among the reasons why dementia is less prevalent in Turkey than other European countries can be the fact that the rate of patients who refer to a healthcare center due to dementia symptoms especially in regions with lower socio-economic levels remains behind the rates in developed regions of Turkey and of the western society in general (Karlıkaya et al. 2005).

Due to the socio-cultural condition and patriarchal family structure of Turkish society, decline in mental functioning ability can be considered to be a result of normal aging and kept within the family. However, with the advancement of the disease, emergence of psychotic symptoms such as hallucinations or delusions, increase in memory impairment and agitation can oblige the family to refer to a family healthcare provider and seek remedy (Soygür 2000). In addition, primary healthcare centers in Turkey do not currently provide any services to determine the prevalence of dementia. The early stage symptoms of dementia that may occur in the elderly who are not examined by healthcare personnel are usually considered by family members as the natural aging process and the elderly are usually taken to hospital when the middle-stage symptoms become more pronounced and start to affect everyday life. This situation affects the prevalence of dementia as well (Gürvit et al. 2008).

Treatment of Dementia in Turkey

In Turkey, dementia is usually diagnosed at the end of the first stage or at the beginning of the middle stage. Dementia-related symptoms are usually mistaken for signs of aging and family members or patients are late to go to a healthcare facility. After the diagnosis of dementia, its disease-specific symptoms may progress rapidly. In this case, a treatment approach aimed at stopping forgetfulness and other relevant losses of ability, which reduce the quality of life, is adopted in the treatment of dementia (Onat et al. 2013). In order to prevent acetylcholine reduction, which causes the disease, acetylcholine esterase inhibitor is used. However, psychiatric help is added to the treatment so that problems such as comorbid behavior changes and sleep and eating disorders can be controlled and, therefore, the patient and the disease become more stable (Dişçigil 2013). In addition to medical treatment, dementia services that individuals with dementia are given by nurses will vary depending on the stages of the disease. Nevertheless, these services basically aim to help patients maintain their cognitive functions, provide them with physical safety, reduce their anxiety and agitation, improve their communication, support their independence and self-care activities, meet their socialization needs, supply them with adequate nutrition, improve their sleep quality, and support and educate their family members (Lök and Buldukoğlu 2014).

Caring for the Elderly with Dementia in Turkey

In the early and middle stages of dementia, 80-90% of the elderly are cared for at home by adult children or spouses whereas they are usually cared in nursing homes in the late

stage of dementia (Özdemir and Taşçı 2013). Therefore, the family undertakes important responsibilities in the care of individuals with dementia. Among family members, especially women and daughters are regarded as natural caregivers (Ganguli and Hendrie 2005). The care provided by the family is the basis of caregiving activities in many countries. Due to the progressive nature of dementia, it is a process that causes patients to suffer from continuous changes and affects and challenges family members' and caregivers' lives in different ways (Ganguli and Hendrie 2005).

Because institutional care is expensive and long-term institutional care can be a new stress factor, it leads to increased depressive symptoms and it isolates individuals who need care from social life, it is essential that support services facilitate caregiving by family members (Nikmat et al. 2013). In fact, developed countries have adopted community-based care in order to strengthen and promote the individual's relationship with his or her family members and friends in cases such as disability, chronic illness and old age, to ensure that the individual continues his or her life freely in a familiar social environment, to respond to the individual's wishes and expectations, to enhance the individual's social functionality and, at the same time, to reduce the state's costs in the field of institutional care (OECD 2012).

Care of people with dementia is quite a difficult task. It is a real challenge for caregivers as the transition between the stages of dementia is fast and the relevant care changes at every stage and becomes increasingly challenging (Çetinkaya and Karadakovan 2012). In general, caregivers of patients with dementia in our country and around the world are mostly family members (Şahiner 2012). Among family members, those who are expected to give care first are often daughters, spouses or other female relatives (Özyeşil et al. 2014). It is just considered natural that this burden is borne by these people. In fact, it is especially daughters and women looking after their husbands that take on this burden of caregiving caused by dementia all over the world. According to findings from studies conducted in Turkey, 80% of caregivers are women (Karlıkaya et al. 2005).

Institutional Services in Dementia Care

1. Home Care Service

In Turkey, home care services are provided for free by the home healthcare units of hospitals or local governments if patients are disabled, have a chronic illness or are too old to perform their self-care (Dölek 2012).

Regulations for the daycare of the elderly in nursing homes and home care for the elderly were introduced on 2008 in order to provide the elderly with psycho-social support and offer day care to patients diagnosed with Alzheimer's disease and other types of dementia. Those in need of home health care services can dial 444 38 33 (444 EV DE) from all over Turkey and contact the coordination centers. They can also call or visit community health centers, family physicians, state hospitals or home healthcare units in state hospitals. According to 2012 Home Health Data, 50% of the 65-and-older populations served by a home care center in a city in Turkey were diagnosed with Alzheimer's disease and other types of dementia. If the family members of an individual with dementia make a request to receive home care, a team consisting of a nurse and a physician visit and examine the individual at home. The elderly who need home care

are offered services such as wound dressings, required tests, urine catheter placement, and prescribing drugs (including those that are used continuously and requires a report). These individuals and their family members are provided with social and psychological support services as well (Özdemir and Taşçı 2013).

The primary goal of home care services is to respond to the needs of the elderly on the basis of self-respect, support the elderly and their families, increase their functioning ability, help them maintain their strength and live independently as much as possible, and promote their wellbeing. Home care involves a wide range of services. These services include household chores (e.g. laundry, shopping, cleaning), personal care (e.g. dressing, bathing and personal hygiene), meal preparation at home, personal emergency response (i.e. 24-hour emergency service), heavy works that individuals cannot perform alone, transportation, financial counseling, education and solution of the problems related to the specialty of professionals in home care teams (Ulaş and Uçku 2012). Home health care services in Turkey are offered in three ways. First of all, home health care services are provided free of charge by the Ministry of Health. On the other hand, there is no care insurance in Turkey. Secondly, local governments offer both health services and care support services. Local governments often provide these services free of charge to the poor. Thirdly, private healthcare institutions offer health services, care services and support services for a fee. However, the services provided by private institutions are usually expensive. As of December 2012, a total of 398.335 people benefited from home care services in Turkey (T.C. Aile ve Sosyal Politikalar Bakanlığı 2017a).

In Turkey, patients' clinical dementia scores play a key role in determining the disability rate of the elderly with dementia. The disability rate of patients is rated as 25% and considered as mild if "they can perform their daily activities despite some occasional deterioration, it is rated as 50% and considered as mild-to-moderate if "some of their daily activities are deteriorated so as to require assistance", it is rated as 70% and considered as moderate if "most of their daily activities are deteriorated so as to require assistance", and it is rated as 90% and considered as severe if "they cannot perform their self-care and they need assistance for their safety". In Turkey, caregivers of the elderly with dementia are provided with monthly financial support called as home care payment. The disability rates and income levels of the care receivers play an important role in receiving this payment. The disability rate of the elderly receiving care must be 70% and over and the per capita income level of families cannot exceed 2/3 of the minimum wage in Turkey (Öztürk 2011, Ulaş and Uçku 2012, Camkurt 2013, Mehtap et al. 2015).

The elderly with dementia in Turkey are usually relocated in a nursing home at the end of the middle-stage or at the later stages of the disease. The prevalence of all psychiatric disorders in nursing homes is 80.2%. Dementia accounts for 67.4% of psychiatric disorders (Şahin et al. 2005). The traditional notion of care in nursing homes is characterized by "medical model". The primary goal of the medical model tradition is regarded as the provision of health and safety. In this model, healthcare staff in institutions makes and practices all kinds of decisions while the elderly in these institutions are regarded as patients "in need of care". The elderly are dependent and in need of care in such an environment (Lök and Lök 2015).

The interventions and arrangements required for dealing with problems specific to dementia for the elderly with dementia in a nursing home are not different from the

interventions for other older people. Regulations for official retirement homes do not suggest any differences for the elderly with dementia and all seniors are evaluated in the same context (SHÇEK 2006).

On the other hand, according to regulations for private retirement homes, individuals with dementia are regarded to be different from healthy seniors and admitted to these centers as “special care seniors”. The services offered in this context include assisting the elderly with dementia to eat their meals, have a bath, clean their bodies daily or instantly, go to toilet, change their adult diapers if they use them, changing their clothes and linens daily or when necessary, make and clean their beds, go the departments within the organization, do their exercises, do their wound dressings, take their medications appropriately, monitor their blood pressures and injections, go to the healthcare organizations that they are referred to and stay in a hospital when they are hospitalized (Soygür 2000).

In addition, there can be special care departments within retirement homes in order to care for and protect the elderly who are mentally healthy, who do not have a disease requiring continuous medical care, who have severe disability like dementia or Alzheimer’s disease, or who are bedridden or have a disease requiring continuous medical care. The relevant institutions can also be established to deliver care specifically for patients in these conditions (Regulations For Private Retirement Homes And Nursing Care Centers For The Elderly Official Gazette of the Republic of Turkey: 07.08.2008 Official Gazette No: 26960, Section 4., Article 25.).

2. Adult Day Care Home

Adult day care homes represent another service model for the elderly that promotes functioning ability and independence of older individuals who have reduced functioning ability, who are disabled, who are chronically ill or who are in need of rehabilitation. Day care services play a key role in preventing premature and unnecessary institutional care for the elderly. These services aim to increase self-respect of the elderly and maintain their wellbeing by helping them live in a strong and independent way (Aştı 2002, Lök and Lök 2016). The most important feature of these centers is that they provide the elderly with solution by helping them with their health, nutrition, rehabilitation, diet, and personal care issues, solving their legal and financial problems, and providing them with a number of activities and opportunities in daily life such as leisure time activities (Beder 2006).

The “Regulations for Adult Day Care Offered in Service Centers for the Elderly and Home Care Services”, which was published and enacted in the Official Gazette dated 07.08.2008 and numbered 26960, was revised by the Prime Ministry Administration Development Department as a part of “Administrative Simplification Studies” and published in the Official Gazette dated 31.07.2009 and numbered 27305 (T.C. Aile ve Sosyal Politikalar Bakanlığı 2017b). This legislation states that “Adult Day Care Services” involve improving living environments of the healthy elderly who live with their families, family relatives or alone at home and who have disease like dementia or Alzheimer’s disease, offering leisure activities, responding to their social, psychological and health needs, providing assistance, guidance and professional counseling, providing support services for issues and daily life activities that they cannot deal with on their own, enriching their social relations by making social activity groups and arranging

social activities according to their interests, increasing their activities, and improving the quality of their lives by facilitating collaboration and sharing with their families.

In the same way, "Home Care Services" involve improving the living environment of the elderly so that they can continue to live at home when family members feel inadequate about caring for the elderly who are mentally healthy, who do not need medical care, and who do not have any disabilities, and improving their daily life activities (T.C. Aile ve Sosyal Politikalar Bakanlığı 2017b).

3. Adult Day Care Center for People with Alzheimer Disease

The Adult Day Care Center for People with Alzheimer Disease was founded by the cooperation of a local government and the Turkish Alzheimer Foundation in 2011. The family members of dementia patients with Alzheimer's disease can relocate their patients in the "Adult Day Care Home" for free of charge. The center serves the elderly who have mild-to-moderate stage of the disease and whose intellectual capacity has not declined yet. The center aims to ensure that Alzheimer's disease spend quality time through socializing, patients' family members are supported in patient care and, therefore, they can make time for themselves. In the Adult Day Care Center, Alzheimer's Disease can both receive training to continue their daily routines comfortably by means of rehabilitation activities under the control of physicians, nurses and psychologists and socialize with their peers and have a good time by means of dancing, physical education, music and handcrafting activities prepared by the specialists in the center. The center is open from 09:00 am to 05:00 pm. The patients are served by a total of six people: a nurse, a healthcare assistant, a psychologist, a social worker, support staff and a person assigned by the foundation. The center can accommodate up to 20 people at a time, but a patient cannot visit the center more than three times a week. The center has a bus for the transport of patients. The center also carries out activities for the elderly such as mental, psychomotor, physical, artistic, musical, spiritual care activities, and celebration of special days and sightseeing activities.

The activities include Turkish coffee service, Making clocks, Ranking objects from largest to smallest, Talking about functions of objects, Doing puzzles, Ebru activity with a teacher, Painting, Coloring activity, Line completion, Finding animal names-products, Doing crosswords, Playing Mikado, Sewing buttons, Poetry reading, Singing, Talking about memoirs, Special day celebrations, Gardening, Playing backgammon, Doing exercises, Breathing exercises, Rhythm along with music, Reading newspapers, Cutting-pasting activity, Rope beading, Binding shoes, Preparing rice or peas for cooking, Pairing socks, Building towers with wooden blocks, Sightseeing activity (e.g. Maslak Pavilion Activity), Going for a walk (e.g. Park Tours), Dancing, Playing basketball, Counting numbers, Playing ball games, Kneading and cooking cakes and cookies, Painting fabrics, Preparing calendars and so on. The center leads to positive changes for both the elderly and their family members as it ensures that the elderly are happy at home, it increases their quality of life, it reduces the burden of care and their family members are relaxed to some extent, it brings about a decrease in family problems, it provides an opportunity for patient education, it slows down the disease process, it decreases treatment costs due to decreased need for medication, and it leads to increased support system among families. However, the cost is quite high. Although the cost is high, it is required that these centers should spread around the country beca-

use their goal is in favor of the patient and these centers bring about positive outcomes for both the elderly and their family members. On the other hand, individuals with dementia need adult day care homes rather than nursing homes (Türkiye Alzheimer Derneği 2017).

4. The Center for Alzheimer's and the Life Village

The center is located in Tepebasi district of the city of Eskisehir and serves 18 residential patients and five patients in need of day care who were diagnosed with Alzheimer's disease. The center aims to improve the quality of life of the elderly and support their family members for their problems by reducing the burden of patient care. The Life Village is a project yet. It is planned that the village will be composed of the 57 villa-style buildings and serves a total of 250 people consisting of the elderly with disabilities and the elderly with Alzheimer's disease or other dementias (Eskişehir Tepebaşı Belediyesi 2017).

5. Nursing Responsibilities in Dementia Care

Dementia progresses quickly and makes the elderly increasingly dependent. In this sense, patients gradually lose their ability to perform self-care, eventually become dependent, both their physical and psychological needs increase (Lok et al. 2017). The purpose of nursing interventions to be made at this point in relation to psychiatric care is to help patients maintain their optimal cognitive function, ensure their physical safety, reduce their anxiety and agitation, improve their communication, support their independence and self-care activities, meet their socialization requirements, provide them with adequate nutrition, resolve their sleep disorders, and support and educate their family members (Lök and Buldukoğlu 2014). Therefore, nursing care of the elderly with dementia should address the following points (Çetinkaya and Karadakovan 2012, Lök and Buldukoğlu 2014):

- a. The nursing care to be given to the elderly with dementia should involve understanding and evaluating specific needs of the elderly and care activities that are carried out with knowledge and skills in planning and implementation of psychiatric care.
- b. The nursing care to be given at the early stages of older ages aims to help the elderly adapt to their own environment.
- c. It requires dealing with patients at any time of the day. Care of the elderly with dementia should primarily focus on physical care. These activities include reminding the elderly their meals or helping them eat their meals, mobilizing them, reminding them to have a bath or helping them to have a bath, ensuring that they get enough sleep, changing their adult diapers, etc.
- d. Ensuring physical care is followed by ensuring their safety. Patients should never be left alone because they may demonstrate escape behavior. They may see anything around them as a threat. For this reason, the place of the care or the caregiver should not be changed as much as possible.

Another concern is one's need to belong to a group or community and find love and respect. At this stage, especially patients in the early and middle stages of the disease should be involved in activities that they previously enjoyed doing and meetings or social groups they participated before. It should be kept in mind when caring for these

patients that they are adults. The required love and respect must be shown to them.

Conclusion

Despite the local prevalence studies in Turkey about dementia, there are not clear rates yet. Therefore, the prevalence of dementia seems to be lower than other European countries. Seeking care from a healthcare institution because of dementia symptoms is usually delayed in the country. Since Turkish society has inadequate knowledge about the early-stage symptoms of dementia, dementia patients are usually taken to a healthcare institution late and primary healthcare units do not have dementia-screening program for the elderly. Therefore, we do not have clear figures related to dementia. In fact, there can still be older people in certain regions who cannot perform activities of daily living but who have not been even diagnosed with dementia yet. It is essential that the prevalence of dementia across the country be determined first of all. Currently, the treatment of the elderly diagnosed with dementia is still mostly based on medical treatment. However, medication is not enough in the care of the elderly with dementia. Psychosocial applications increasing the cognitive activity of the elderly are also required in addition to drug therapy.

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