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RECOMMENDATIONS OF THE ALZHEIMER'S DISEASE INTERNATIONAL CONCERNING THE CARE OF PATIENTS WITH DEMENTIA AND THE SITUATION IN POLAND

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Abstract

According to data of WHO research, there are an estimated 36,5 million people with dementia worldwide. They need long-term care. The nature of this care depends on economic situation of the country - the higher developed it is, the bigger participation of institutions specialized in long-term care and smaller participation of home care.

In high income countries around one-third to one-half of people with dementia are cared for in care homes. Alzheimer's Disease International (ADI) predicts that by 2030 number of patients with dementia will double and triple by 2050. This prognosis requires advanced planning, monitoring and coordination actions to improve system of long-term care. To achieve this goal, ADI recommends: promoting broad public awareness of dementia and combating stigma, identifying dementia capable support services at all stages of the disease, assessing and improving the quality of health care, social care and long-term care support and services, assessing availability and access to diagnostic services, promotion of brain health. Caregivers should be valued by society for they demanding and difficult work. Also patients should keep their autonomy and choice.

92% of suffering from dementia patents in Poland are cared at home since beginning of disease until their death. Other 8% stays at different types of home cares. There are also short-term care, daily care and ambulatory care available. The reasons of small participation of those institutions are: maladjusted to growing number of patients with dementia system of care, complicated administrative procedures, lack of money to cover up costs of care and lack of knowledge about dementia in society.

Keywords: Dementia, long-term care, Alzheimer's disease

Alzheimer's disease is the most common causeof dementia andaccounts for approximately70percentof the disease. 24·3 million people have dementia today, with 4·6 million new cases of dementia every year (one new case every 7 seconds). The number of people affected will double every 20 years to 81·1 million by 2040. Most people with dementia live in developing countries (60% in 2001, rising to 71% by 2040). Rates of increase are not uniform; numbers in developed countries are forecast to increase by 100% between 2001 and 2040, but by more than 300% in India, China, and their south Asian and western Pacific neighbours [1].

The worldwide number of persons with dementia in 2000 was estimated at about 25 million persons. Almost half of the demented persons (46%) lived in Asia, 30% in Europe, and 12% in North America. Fifty-two percent lived in less developed regions. About 6.1% of the population 65 years of age and older suffered from dementia (about 0.5% of the worldwide population) and 59% were female. The number of new cases of dementia in 2000 was estimated to be 4.6 million. The forecast indicated a considerable increase in the number of demented elderly from 25 million in the year 2000 to 63 million in 2030 (41 million in less developed regions) and to 114 million in 2050 (84 million in less developed regions). In conclusion, the majority of demented elders live in less developed regions, and this proportion will increase considerably in the future [2].

An estimated 5.2 million Americans have Alzheimer's disease in 2014, including approximately 200,000 individuals younger than age 65 who have younger-onset Alzheimer's. Almost two-thirds of American seniors living with Alzheimer's are women. Of the 5 million people age 65 and older with Alzheimer's in the United States, 3.2 million are women and 1.8 million are men. The number of Americans with Alzheimer's disease and other dementias will escalate rapidly in coming years as the baby boom generation ages. By 2050, the number of people age 65 and older with Alzheimer's disease may nearly triple, from 5 million to as many as 16 million, barring the development of medical breakthroughs to prevent, slow or stop the disease [3].

Report drawn upin the UKforpeople with dementia shows that greatersusceptibilitytoearlydisease(agebelow65 years)are characterized bythe men, and lateronsetdisease occurs more oftenin women.Alzheimer's diseaseis the predominanttype ofdementia, especially among the elderlyand women. 11,392peopleamong blackpeople andethnic minoritiessufferfrom dementia.What is interestingin this circleis a6.2%incidenceofearly-onsetwheretheentire population ofthe UKonly 2.2% are gettingless than 65 years. Approximately 10% of death in menover the age of65 years and15% of deathover 65 yearsin women canbe attributed todementia.59.685deathper yearcould be preventedifdementiadid not existin society.Statisticallymore or lessoneach patient,a mancarries 2sick women [4]. The reportalsopointed outanother problem-lonelinessandsocial isolationof peoplewith dementia. Invariably,in 2013and 2012as thethirdpopulationof England, Wales and Northern Ireland,says thatdoes not play wellwith dementia.33% of patients saidthatshe losther friendsafter exposurediagnosis.Althoughonly a quarter ofpatientsadmitpublicly thatshe feltlonely inthe last month,conductedanonymoussurveysindicateas many as 40% of patients declaringa sense ofloneliness.And62% of those patients whocontinue to beindependent andlive ontheirconfirmedexperiencingfeelings ofloneliness [5].

Around half of all people with dementia need personal care (and the others will develop such needs over time). The traditional system of “informal” care by family, friends, and community will require much greater support. Globally, 13% of people aged 60 or over require long-term care. Between 2010 and 2050, the total number of older people with care needs will nearly treble from 101 to 277 million. Long-term care is mainly about care for people with dementia; around half of all older people who need personal care have dementia, and 80% of older people in nursing homes are living with dementia [6,7].

People with dementia have special needs for care, starting early in the disease course, and evolving constantly over time, requiring advanced planning, monitoring, and coordination. It is inevitable that numbers of dependent older people will increase markedly in the coming decades particularly in middle income countries. All caregivers of people with Alzheimer's – both women and men – face a devastating toll. Due to the physical and emotional burden of caregiving, Alzheimer's and dementia caregivers had $9.3 billion in additional health care costs of their own in 2013. Nearly 60 percent of Alzheimer's and dementia caregivers rate the emotional stress of caregiving as high or very high, and more than one-third report symptoms of depression. Not only are women more likely to have Alzheimer's, they are also more likely to be caregivers of those with Alzheimer's. More than 3 in 5 unpaid Alzheimer's caregivers are women – and there are 2.5 more women than men who provide 24-hour care for someone with Alzheimer's. Because of caregiving duties, women are likely to experience adverse consequences in the workplace. Nearly 19 percent of women Alzheimer's caregivers had to quit work either to become a caregiver or because their caregiving duties became too burdensome [3].

A comprehensive system of long-term care for people with dementia comprises both health and social care services.Care in care homes is a preferred option for a significant minority of older people, particularly when presented with a scenario of dementia with complex intensive needs for care.Societal costs of care in care homes and care at home are similar, when an appropriate cost/ value is attached to the unpaid inputs of family carers. Care in care homes is, and will remain, an important component of the long-term care system for people with dementia. Currently around one-third to one-half of people with dementia in high income countries, and around 6% of those in low and middle income countries are cared for in care homes. Caregiver multicomponent interventions (comprising education, training, support and respite) maintain caregiver mood and morale, and reduce caregiver strain [8].

Quality of care can be measured through structures (available resources), process (the care that is delivered), and outcomes. No two families are alike in their needs for care and support, and we need to find ways to make care more person-centred, and care packages more flexible and individualised. Accessible information regarding the quality of care provided by services, assessed using person-centred outcomes as well as inspection data, should inform choice and encourage competition based upon driving up standards. Quality of life, and satisfaction with services are person-centred holistic outcome indicators that summarise the impact of all relevant structure and care process issues. While good quality dementia care can be both complex and resource intensive, the systems and services must be made as simple, seamless, transparent and accessible as possible. Case management should also facilitate coordination of care, helping clients to use services more efficiently. Family carers and paid caregivers share much in common. They all carry out difficult, demanding and socially useful roles, with minimal training and preparation. All caregivers, paid or unpaid, should be valued and recognised by society for the essential, difficult and demanding work that they carry out, and recompensed appropriately [6-9].

Recommendations from World Alzheimer Report for the care ofpatientswith dementia:

- All governments should make dementia a priority. This should be signified by developing National Dementia Plans to ensure that health and social care systems are adequately structured and funded to provide high-quality care and support to people throughout the dementia journey
- All governments should initiate national debates regarding the future of long-term care, with all stakeholders and an informed public. For future generations of older people, the numbers of older people requiring long-term care, and their profile of needs is already predictable within narrow limits of uncertainty.
- Governments should ensure there are systems in place to measure and monitor the quality of dementia care and support in all settings.
- Health and social care systems should be better integrated so that there are co-ordinated care pathways that meet people’s needs.
- Governments and providers of care should ensure that healthcare proffessionals and the dementia care workforce are adequately trained to provide person-centred care.
- Governments and other stakeholders should ensure that autonomy and choice is promoted at all stages of the dementia journey.
- Care in care homes is, and will remain, an important component of the long-term caresector, and should be valued as such [8].

In Poland suffers from dementia more than 200,000 people, but the data are incomplete, because the diagnosis has received only about 20 percent. In Poland,the care of peoplewith dementiaexercises inthe operation of thedifferentstructures,underthe Ministry of Health.Careservices are available designed forolder people, but there is specific servicesfor people withdementia. Taking care ofpatientswith dementiaoccurs inthe home,care and treatment, nursing and care institutions, nursing homes, daypsychogeriatricwards, twenty-four hourpsychogeriatricwards, municipalsocial assistance centers andnursing homes[10] and the privatenursing homes.It is possible tohire ababysitter replacementdealing withpatientsat home.Helpin the care ofpatientswith dementia arealsoclinicsandthe Alzheimer'sAssociationandsupport groups.

In Poland,the registrydoes not leadtofamily caregivers, notso you candetermine thedetailed data onthe number, the more the socio-economicsituation[11]. Nearly92% of patients with dementiain Poland,staying homefromonsetuntil death[12].It follows that thecare ofpatientswith dementiacaregiversrestsmainlyderived fromfamilyor engagedby the family.The largest group ofcaregiversarespousesin Poland, which is close tothe age ofpatients (≥ 65 years).Such personsfrequentlyare disabled and tiredof life.Large sharein the care ofchildrenare alsosick.InPoland, asin the world,a greater shareofthose caring forpatientswith dementiaare women[12].

Patientswith dementiain Polandcan staypermanentlyora longer periodin the followingtypes ofinstitutions:nursing homes, care and treatment, nursing and care institutions and privatenursing homes.Depending onthe financial capacity ofthe patient andcaregiverscan choose froma variety ofpossibilities:fromprivate residences, institutions, thechurch organizationsandcharities [13].

One form ofcare for patients withdementiain Poland is part timecare, day careandshort-term care. Outpatientservicecaringmostlytakes placewith the participation oftrained nurseorcaregiver/babysitter. Their assistanceis primarily for thedaily careandwound care. In Polandcare agenciescooperating with thesocial welfare centersthat employcaregivers.Whenit becomesnecessaryto organizea need forcare at home, should bereported toa social workersocial welfare center [13].

The objectives ofthe functioning ofAlzheimerassociations and foundationsare: the popularizationand dissemination of knowledge aboutdementia, especially Alzheimer's disease, the organization of variousforms of assistance topatients and their families, information exchange and training ofcaringfor the sick, cooperation with national and internationalcentersfor the exchangeof experiences, create support groups(self-help caregivers) [12], as well as taking andsupport efforts todevelopdiagnostic and methods for treatingdementia syndromes(especially Alzheimer's disease)anddevelopment activities research[13].

In 2013, University of Medical Sciences and Orthopaedics and Rehabilitation Hospital Clinical them. W. Dega joined the international research project AAL UnderstAid - a platform that supports and helps to understand and assist caregivers in the care of a relative with dementia. The aim of the project is to look UnderstAid knowledge-based solutions that serve caregivers of the elderly and disabled, developing solutions that facilitate patient care. Such actions are aimed at providing carers significant educational support that will be individualized, based on modern models of e-learning. The tools developed will provide support to form a guide for caregivers, answer the questions and problems faced by carers.

Conclusion

In Poland, as in most countriesworld, the availability of care services forpeople with dementiais insufficient.In contrast todeveloped countries, carefor patients withdementiamainlycaregiverburden, and the share ofstructuresdesignatedby the government tocare for patientsis negligible.For all of thesecaregiversof patientswith dementiacertainlywould be helpfulonline platformthat combinespeoplestrugglingwith the dailycare ofa relative.This couldbe asource of knowledgeabout the disease, as well as a placeto exchange valuableinformation, tips andexperienceswith peoplein a similar situation.

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