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The role of government and non-government organisations in the promotion of knowledge on Alzheimer's disease in Poland and the European Union

Abstract

The article presents the role of government and non-government organisations in promoting knowledge on Alzheimer's disease in Poland and the European Union. There is a detailed analysis of the EU documents and non-government organisations in promoting knowledge on Alzheimer's disease in Germany, France and Holland. There is a discussion on the National Alzheimer's Plan on the basis of an example of introducing such a plan in Finland. Additionally, the rules of helping people suffering from Alzheimer's disease and their attendants in Poland are presented.

Keywords: Alzheimer's disease, government organisations, non-government organisations, National Alzheimer's Plan.

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INTRODUCTION

Alzheimer's Disease (AD) belongs to frequently occurring degenerative diseases of the brain. This is a problem concerning a wider and wider group of society after 65 years of age (in Poland this is at least 200 thousand people) [1]. AD is a result of necrosis of the brain nerve cells caused by accumulation of amyloid protein, tau protein and alpha-synuclein. The consequence of this is atrophy of functions that are normally performed by these cells, i.e. creation of cerebral relay. In the course of AD, a lowered production of acetylcholine takes place, which is the basic cerebral relay necessary in appropriate functioning of memory and other cognitive processes, but also noradrenaline, serotonin and dopamine [2].

The factor that has the greatest influence on the possibility of developing AD is age. Moreover, another important fact is having a beta-APP or PSEN1 and PSEN2 gene mutation, and occurrence of gene ApoE (apolipoprotein E – a component of lipoprotein plasma) polymorphism [3,4]. The condition of brain cells also significantly influences the time of disease occurrence and the intensity of the symptoms of dementia. When using protective factors to study AD, it has been discovered that the level of education affects the risk of the disease development and the intensity of its course. Other factors that increase the risk of AD is excessive alcohol consumption, vascular risk factors (e.g. obesity, diabetes, heart illnesses), being a female and exposure to heavy metals in environment. It needs to be remembered that any head injuries and occurrence of Down syndrome are also likely to increase the risk of AD [5,6]. Alzheimer's disease

belongs to the group of dementia illnesses. It is characterised by aphasia, amnesia and agnosia. Basis symptoms of AD are mainly problems related to forgetting the latest events and remembering relevant facts (i.e. phone number, address or surname). As the disease progresses, difficulties with performing basic activities occur. An ill person may lose their way in their own home, has problems with pronunciation and a range of vocabulary decreases. A patient also has problems with correct assessment of a situation they are in. A disease is frequently accompanied by rapid mood changes, e.g. from cheerful to tearful mood for no particular reason. A patient may also present symptoms such as anxiety disorders, suspiciousness, apathy, abnormal behaviour, violence, fear, inappropriate sexual behaviour or psychotic disorders [7,8].

The role of government organisations in promoting knowledge on Alzheimer's disease.

One of the documents that determines the role of government institutions in promoting knowledge on AD is the Conclusion of the Council of the European Union concerning strategies from public health domain that are to combat degenerative diseases of central nervous system and connected with ageing, especially AD of 16 December 2008 during French presidency in the EU [9]. In the document in question, the Council recalls the fact that the ageing society is a great challenge and prolonging the citizens' life is impacted by constant improvement of medical health care. Additionally, co-operation between the Member States is indispensable while preparing preventive activities and promoting health, and supporting European activities by the European Parliament; activities that are aimed at combating AD and similar

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disorders. Moreover, the document in question emphasises how complex the care over patients is as well as the importance of ensuring that patients could live through their old years in a dignified way. There is also a commitment connected with the necessity to give AD a priority in the field of public health care in EU and, as a consequence, the necessity to ensure legal protection and the human rights to those suffering from AD, and the need for more thorough and accurate epidemiological data concerning dementia diseases.

In the document in question, the Council urges the Commission and the Member States to recognise AD a priority owing to the fact that the EU society is ageing. It also urges to consider any possible side effects of the constantly increasing number of AD cases which impacts the financial stability of health and social care, and to the mutual assessment of current form of patient care and assistance their carers receive, and also to reflection on how to improve these aspects. Moreover, the Conclusion obliges the Member States to create national plans of preventing dementia to effectively improve the patient and their carers' quality of life, improve the information flow to patients to make it easier for them to access the sources of knowledge on the disease and proper care. It is important to promote co-operation between public and private sectors, especially on local level. The Conclusion also urges the Committee of Social Care to promote and publish experiences on permanent basis, exchange proper solutions connected with the quality of long-term care, most of all treatment plans other than pharmacological ones, assistance for carers, organisations of long-term care and the meaning of holistic care, constant performance of activities that aim at improving the quality of long-term care, paying special attention to dementia diseases. The document appeals to the Commission that projects be created that would allow foreseeing the influence of these diseases on the society of the Member States within the rules. It also aims at promoting appropriate health in ageing Europe presented in the white book "Together for health: strategic approach for the EU for the years 2008-2013", using the already existing programmes and community activities as well as current works of the Commission in the field of health care and long-term care to achieve these goals.

Another document is the European Parliament Resolution of 19 January 2011 concerning the European initiative on AD and other types of dementia, which was accepted at the meeting of the European Parliament between 18-20 January 2011 in Strasbourg [10]. It is based on four main aims. The first one concerns promoting early diagnostics. AD symptoms are frequently understood and misinterpreted as signs of ageing. Despite the advances in medicine, AD is usually recognised in many patients in its rather advanced phase. There is still a considerable number of people who live with the disease without being aware of it. Another aim is to raise the level of epidemiological knowledge on the disease and coordinate the already existing research because neurodegenerative diseases constitute one of the main reasons for disabilities among the elderly. Incidence of AD increases with age. This is of particular importance for people over 65. If the phenomenon of dementia spreads, it will exceed the financial capabilities of any state.

Another point is to support solidarity between the Member States through exchange of experience. The last assumption is the respect for the rights of people with dementia since no efficient medicine has been discovered so far. Pharmacotherapy's aim is to ease the symptoms. Sustaining independence and learning how to live with the disease will help prolong the life in dignity. What is more, apart from the listed aims, much attention was paid to the health care employees who provide medical care, to the improvement of care and training systems and to support families who struggle with problems connected with AD. The aim of this document is to improve coordination between the Member States in terms of treating people with dementia, AD in particular. It draws attention to health care employees' cooperation with the carers of ill patients. It is of relevance to elaborate national plans of action in the Member States. It is also important to focus on early diagnostics and to gather and process epidemiological data concerning this disease. Early studies are indispensable as well as complex health care performed by appropriately educated medical personnel. It also is an incitement to action towards activities that increase social awareness concerning the phenomenon of the disease and life with dementia. European strategy must also try to guarantee access to most versatile services and treatment of patients regardless of their age, sex, financial possibilities or a place of residence.

Overriding objectives of this strategy should include improving the dignity of every patient during the course of the disease and minimizing health inequalities. This carries the necessity to increase the engagement of individual people – from medical organisations to patients' associations, since their role will be of significance in integrating various activities and guaranteeing their efficiency.

European non-government organisation

One of the key issues of NGOs places emphasis on creating national plans to combat dementia and promotes knowledge on Alzheimer's is Alzheimer Europe. This organisation aims to raise awareness about all types of dementia and is the source of information about Alzheimer's a well. They also hope that through the activities they organise, it will become possible to help societies that struggle with dementia, patients themselves in particular. Alzheimer Europe also believes that cooperation, exchange of experiences and knowledge gained so far will motivate people to take action that would allow elaborating new solutions to problems concerning AD [11]. There are currently 34 associations in the organisation from 31 Member States. Four of them are temporary members [12]. Alzheimer Europe is a pioneer of the National Alzheimer's Plans (NAP). They are created in order to improve the situations of patients with AD. They outline the standards of nursing include aims and manners in which a given country is planning to combat AD.

Currently, 11 European countries (Denmark, Finland, France, Italy, Jersey, Holland, Norway, Sweden, England, Northern Ireland, Scotland and Wales) have the National Alzheimer's Plans. The organisation urges the countries that do not have the plans yet to undertake actions that would lead to their creation [13].

So, as to bring the plan of combating AD closer, Finnish NAP plan is presented. Currently, there are about 120 thousand

Finns suffering from diseases connected with memory, 7-10 thousand of whom is of productive age. There are 13 thousand new cases of the disease. On 8 May 2012, Finland launched a national plan to combat dementia, entitled "National Memory Programme 2012-2020". The aim was to create the so-called "Memory friendly Finland". It was prepared by the Ministry of Health and Social Matters and other organisations as well. Dr Eila Okkonen, executive director of Muistiliitto (organisation operating within Finnish Alzheimer Society), claims that there are four main areas of action.

Firstly, there is promotion of education concerning brain functioning throughout the whole life and prevention of the diseases connected with memory. Efficient brainwork will be promoted on both the personal and social level, including social and health services, and education.

Secondly, ageing of the population causes considerable increase in the number of illnesses connected with memory in Finland. The plan will promote positive attitude towards people with dementia, to guarantee the basic human rights for them, including the right to self-determination.

Another point is the necessary care and rehabilitation. It is important that diseases connected with memory be diagnosed and treated as early as possible.

The last relevant area of action is financial support to increase the competences of employees and the quality of tests. Research must be financed appropriately to support the above-mentioned areas and to ensure further development. This includes developing knowledge and competences of health care workers. Muistiliitto is the key supporter of "Memory friendly Finland". Mr Pekka Laine, the former president of the association, was particularly active in his efforts to support the plan. The association was a member of working group that has been designing the programme since 2010. It was also Muistiliitto, who ordered working out a survey concerning memory and played a key role in preparing a national structure concerning high quality of service and care for elderly people. Muistiliitto will continue their efforts to ensure dignified life for people with dementia and their attendants, despite the difficulties the disease causes [14].

Alzheimer's organisations are a key of some sort that may help people suffering from AD but also their attendants. They were created mostly to provide the most necessary information about AD. They also deal with providing support for the carers and enable exchange of experience between the association members.

In Germany, the most important organisation that undertakes the actions concerning promoting knowledge on AD and operating together with the national associations is Deutsche Alzheimer Gesellschaft e. V. This organisation understands how important it is to provide help to the community suffering from AD and other forms of dementia, which is why they try to help people through their activities. Additionally, this organisation is dedicated to promoting education and emotional support for the carers. Deutsche Alzheimer Gesellschaft e. V. also cooperates with regional Alzheimer's associations and supports research into dementia and new forms of care that could be used in this disease. What is important, it also searches for new forms of support and assistance for people with dementia [15]. Around 1.4 million of the whole population in Germany lives

with dementia, 60% of which are Alzheimer's type of dementia. Two-thirds of the patients are people under the care of inmates.

According to the conducted research, by the year 2050, the number of cases will have reached 3 million. As an official organisation, the Alzheimer Deutsche Gesellschaft e. V. was established on 2 December 1989. Currently, 135 regional organisations belong to it, mostly supported by volunteers. This organisation holds many conferences and meetings and conducts a telephone line for those who are interested as well. The headquarters are in Berlin [16]. Organisation engages not only the patient's family, but also personnel from various professions. Any work performed for the association is voluntary. Everybody has equal rights and their relationships are based on mutual trust. This activity may be performed thanks to raising donations, membership fees, public funds and subsidies.

Additionally, the German organisation represents interests of the ill people and their attendants. The aim is to achieve a situation in which the society can learn to accept people suffering from this disease so that the patients feel comfortable. Alzheimer Deutsche Gesellschaft e. V. provides individual advice, assists with making difficult decisions connected with the disease and gives the necessary knowledge on the subject. They strive to educate the society on Alzheimer's and other forms of dementia because they understand that it is also a social problem. Representatives of this organisation also participate in political life. Deutsche Gesellschaft e. V. elaborates the concept of better care for patients with dementia, offers help to the families and ensures and promotes knowledge on AD and exchanges the gained experiences [17]. They also cooperate directly with the European Alzheimer's Association (Alzheimer Europe) and organisation associating Alzheimer's associations worldwide – Alzheimer Disease International (ADI). Moreover, they also organise support for the newly established organisations as well as those already existing. They allow access to information and experience gained to groups and individuals alike. In cooperation with regional associations, they elaborate and introduce programmes that are to raise funds. Through group work and within legal possibilities, they advise and care for the rights of the disables and chronically ill. In addition, they support the association members, the patients and their families in all relevant areas as can be seen from the perspective of the patient [18].

On the other hand, in France, thanks to the initiative of health care workers together with patients' families and the social sector, Association France Alzheimer was established in 1985. France Alzheimer was established for families who were touched by AD and any aspects connected with this disease. There are over 850 thousand people living with AD and similar disorders in France. It is estimated that this number may double within the next 40 years. Every year, 225 thousand new cases are diagnosed [19]. France Alzheimer opens up new associations and their number exceeds one hundred. All of them are driven by mutual values, such as respect for another human being, ethics, solidarity and selfless actions. One of the main aims is to provide help to every family regardless of their personal, geographic or financial situation.

Additionally, the association supports families affected by the disease, tries to help in solving problems so as to minimise their fears and meet the needs. It also operates in other areas, i.e. not only changes the image of the organisation and focuses on the disease and patients, but also emphasises development of research and activities that are to increase the interest of the government in the issue of AD.

All activities are performed for people suffering from AD and their families [20]. Since it has been established, the Association is responsible for explaining the use of financial means, especially coming from public donations since over 80% of all funds come from donors. Since April 2011, Alzheimer France has been a member of Le Comité de la Charte, thus guaranteeing financial transparency. The Association is obliged to follow the code of ethics and agrees that its management and organisation as a whole be monitored on an ongoing basis. The aim of this activity is to maintain full trust of 150 thousand donors and their families [21].

Poland and its activities for AD

The main NGO that takes care of people affected by AD and their carers is Polish Association for People with Alzheimer's Disease that was established in 1992 and in the same year it joined the European Federation of Alzheimer's Organisations Alzheimer Europe. The task that this association placed for themselves is organising comprehensive help for patients and their families, and promoting knowledge on dementia diseases in society. This affects health and social policy of the Polish government and the Parliament, aiming at improving the quality of life for both patients and their carers [22].

Additionally, it is involved in counselling and psychological support for those who suffer from AD, it conducts random memory tests that are free of charge, helps patients to obtain hygiene and care products and frequently also rehabilitation equipment. The Association makes every effort for the nurses to visit patients in their homes free of charge, obviously as far as their budget allows, but also it stores data concerning nursing homes and assists in selecting the most suitable place for a patient, depending on the stage of the disease development. Between the years 1994-2006, the Association organised rehabilitation holidays for both patients and their carers. It also conducts the national hotline and personal meetings duties.

Polish Association for the Protection of People with AD is the initiator of educational activities directed to family carers, but also to volunteers and professional nurses from social care centres. Members of the Association conduct monthly educational meetings as well as street and media campaigns. From the funds they collect, the Association finances issuing guide books for family and professional carers, a quarterly newsletter "Closer to Alzheimer's", leaflets for the carers and potential patients and a guidebook for the doctors "Early Detection of Alzheimer's Disease" [23]. Representatives of the Polish Association for the Protection of People with AD together with the other members of the Alzheimer's Coalition, acknowledged preparing the National Alzheimer's Plan and supporting epidemiological and social research as their main goals in combating AD as these would be the key points of their work. During Polish presidency

in the EU, Alzheimer's Coalition aimed at including brain diseases into the priorities of health policy. In addition, it rationally supports the functioning of neurology, psychiatry and geriatrics that would be reasonably thought-through in terms of AD and, due to the low level of knowledge among the Polish population, is supports social educational campaigns for society, GPs and nurses [24].

Additionally, currently Poland has no National Alzheimer's Plan. Polish Alzheimer's Association elaborated key conclusions and findings that should be included in the National Alzheimer's Plan. This strategy has been presented to the Ministry of Health and is awaiting acceptance and implementation.

It was the initiative of the Polish Association for the Protection of People with the Alzheimer's that on 24th August 2004 an Alzheimer's Coalition was established which members of the Polish Alzheimer's Society and representatives of Nationwide Agreement of Alzheimer's Organisations. Honorary patronage was acquired by the Ombudsman, Professor Irena Lipowicz [25]. The Coalition pointed out to the issues that should absolutely be included in the National Alzheimer's Plan. First of all, organising diagnostics lies in their realm and it is performed by a GP. Additionally, there is a demand for opening health centres focusing of memory disorders. Patients should be provided with access to percutaneous therapy, which is one of the ways in which medications are administered in cases of AD. Another important element is nursing patients. The plan also concerns educating society, doctors and nurses.

Polish Alzheimer's societies have outlined preliminary assumptions concerning caring for patients [26]. They mainly focus on providing AD patients with access to modern technologies in treatment and in care. It is also of importance to elaborate norms concerning caring for people with dementia and palliative care at home, and organise financial means for that purpose. Furthermore, it is important to provide opportunities to participate in rehabilitation holidays for both patients and their attendants. An idea worth noting is the one concerning elaborating an educational programme, carrying out humanistic and social research. Acknowledging activities performed by Alzheimer's associations should not be neglected here.

CONCLUSION

Alzheimer's disease is a problem that concerns every State. Demographic forecasts assess that the phenomenon of ageing society will grow. Educating society in this issue is an important aspect as well as providing credible information about AD.

NGOs in EU help the AD patients and their attendants so that they could live in a dignified way despite the disease. They actively co-operate with the authorities in their countries and in EU, by for example introducing projects of National Alzheimer Plans to improve the situation of patients. Government organisations emphasise that AD should belong to the priorities among public health issues. Planning and undertaking early actions will not only protect the health of ageing population against the disease, but it will also protect the State budget against undue expenditures.

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