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PART I. DISEASES AND PROBLEMS DISTINGUISHED BY WHO AND FAO
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DEMENTIA IN THE AGING POPULATION OF POLAND: CHALLENGES FOR MEDICAL AND SOCIAL CARE

ZESPOŁY OTĘPIENNE W STARZEJĄCYM SIĘ SPOŁECZEŃSTWIE POLSKI JAKO PROBLEM MEDYCZNY I SPOŁECZNY

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Summary

With a projected rise in the percentage of elderly people in the population of Poland, the incidence of neurodegenerative diseases, including dementia, will increase. The aim of this paper is to present dementia as an increasing health and social problem in the aging Polish population. In 2015, the number of people with dementia of the Alzheimer's type in Poland was estimated to be between 360,000 and 470,000, which indicates a growth of almost 20% compared to 2005. The onset of dementia symptoms causes a relatively rapid impairment of patients' daily functioning, creating the need for assistance by others. In Poland, caring for an elderly person with dementia is primarily non-institutional and provided by the closest family members in a home setting. Due to the shrinking care potential of Polish families, one should expect a growing need for formal forms of support to ensure proper care for elderly individuals with dementia. At present, Poland has a poorly developed system of formal assistance for dependent elderly people and the existing infrastructure of formal care services includes only a small proportion of potential beneficiaries. The prospect of further aging of the Polish population along with the growing risk of dementia and the shrinking family care potential justify the development and implementation of a comprehensive Alzheimer's Plan at the central and local level of our country.

Keywords: dementia, population aging, formal and informal care

Streszczenie

Wraz z prognozowanym wzrostem odsetki osób w starszym wieku w populacji Polski, rosnąć będzie częstość występowania chorób neurodegeneracyjnych, w tym zespołów otępiennych. Celem pracy jest przedstawienie otępienia jako narastającego problemu medycznego i społecznego w starzejącej się populacji Polski. W 2015 r. liczbę osób z otępieniem typu alzheimerowskiego w Polsce szacowano w przedziale 360-470 tys., co oznacza wzrost o niemal 20% w porównaniu do 2005 r. Wystąpienie objawów otępiennych dość szybko upośledza codzienne funkcjonowanie chorego, rodząc konieczność zapewnienia pomocy ze strony innych osób. W Polsce opieka nad osobą starszą z otępieniem to głównie opieka pozainstytucjonalna, sprawowana przez członków najbliższej rodziny we własnym domu. Ze względu na zmniejszający się potencjał pielęgnacyjny polskich rodzin, należy spodziewać się coraz większego zapotrzebowania na formalne formy wsparcia w opiece nad osobami starszymi z otępieniem. Na obecną chwilę Polska jest państwem o słabo rozwiniętym systemie formalnej pomocy dla niesamodzielnych osób starszych, a istniejąca infrastruktura formalnych usług opiekuńczych obejmuje margines potencjalnych świadczeniobiorców. Ze względu na prognozowane dalsze starzenie się populacji Polski, rosnące ryzyko wzrostu zachorowań na otępienie oraz zmniejszający się potencjał opiekuńczy rodziny konieczne jest stworzenie i wdrożenie kompleksowego Planu Alzheimerowskiego, zarówno na poziomie centralnym jak i lokalnym naszego kraju.

Słowa kluczowe: otępienie, starzenie się populacji, opieka formalna i nieformalna

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Introduction

There is an urgent need to improve understanding and awareness of dementia across all levels of Polish society. This is especially true for health and social policy makers, who have an opportunity to improve the quality of life of both patients with this devastating disease and their caregivers. In 2012, the WHO declared dementia to be a public health issue in the face of rapid global population aging [1]. Although the condition mainly affects older people, it is not part of normal aging.

Demographics and epidemiology of dementia in Poland

The process of aging has become more noticeable in the Polish population and the growth rate of the aged population is likely to increase in the near future. According to data from the Central Statistical Office (GUS), there were about 6.5 million people aged ≥65 years in Poland in 2017, accounting for 17% of the total population [2], and the number is expected to nearly double to over 11 million (32.7%) by 2050 [3]. Moreover, the percentage of the oldest old (80+) will increase within this time frame from 1.63 million (4.2% of the general population in 2017) to 3.54 million (10.4% in 2050). Along with the aging of the population, the risk for neurodegenerative diseases, including dementia, rises. The prevalence of dementia dramatically increases in the older and oldest age groups [4], and the incidence rates for dementia including dementia of the Alzheimer's type (DAT) increase across the 5-year age groups from 2.8 per 1000 person-years within 65-69 years up to 56.1 per 1000 person-years in the older than 90-year group [5].

In Poland, epidemiological studies on dementia are scarce and limited to selected urban environments. The PolSenior study, which was conducted 10 years ago and involved cognitive function screening, was the only epidemiological analysis of dementia covering the entire Polish population. The study included 4,979 respondents aged 65+ years divided into six 5-year cohorts, and 716 respondents aged between 55 and 59 years. The Mini-Mental State Examination and the Clock Drawing Test were used to assess cognitive function. Among people aged 65+, cognitive impairment of varying severity was detected in 68.4% of the respondents and normal cognitive function in only 31.6% of the respondents (Figure 1). Dementia was diagnosed in one in 10 respondents (10.6%) and mild cognitive dysfunction was observed in every third respondent (33.6%) in the 65-69-year-old cohort. In the oldest cohort (90+ years), normal cognitive function was reported for only 8.7% of the respondents, mild cognitive impairment for 25.3%, and dementia for 66% (Figure 2) [6]. Nevertheless, from the epidemiological point of view, the cohort design of the study precludes the precise estimation of dementia prevalence in Poland due to an over-representation of the condition in the oldest old and an under-representation of the disease in the youngest age groups. In 2015, the number of people with DAT was estimated in the range of 360-470 thousand [7, 8], which indicates a growth of almost 20% compared to 2005. It is emphasized that while in the years 2005–2010 the annual growth rate of new DAT cases remained at a level not exceeding 2%, while in 2010–2015 this rate was already 3%–4% [8]. The increase in these parameters is likely due to the aging of the population and probably an increase in society's awareness about brain diseases leading to dementia. On the other hand, the true prevalence of dementia in Poland is most probably much higher due to missed or delayed diagnoses, as it is in other countries [9].

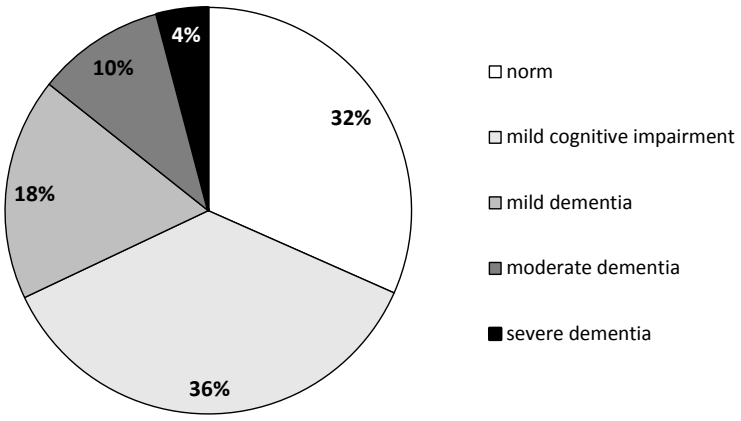

Figure 1. Cognitive status of older Polish population – results of the PolSenior study
Source: Klich-Rączka A, Siuda J, Piotrowicz K, Boczarska-Jedynak M, Skalska A, Krzystanek E, et al. [Cognitive impairment in the elderly]. In: Mossakowska M, Więcek A, Błędowski P., editors. [Medical, psychological, sociological and economic aspects of population aging in Poland]. Poznań: Termedia Wydawnictwa Medyczne; 2012. p. 112 (in Polish).

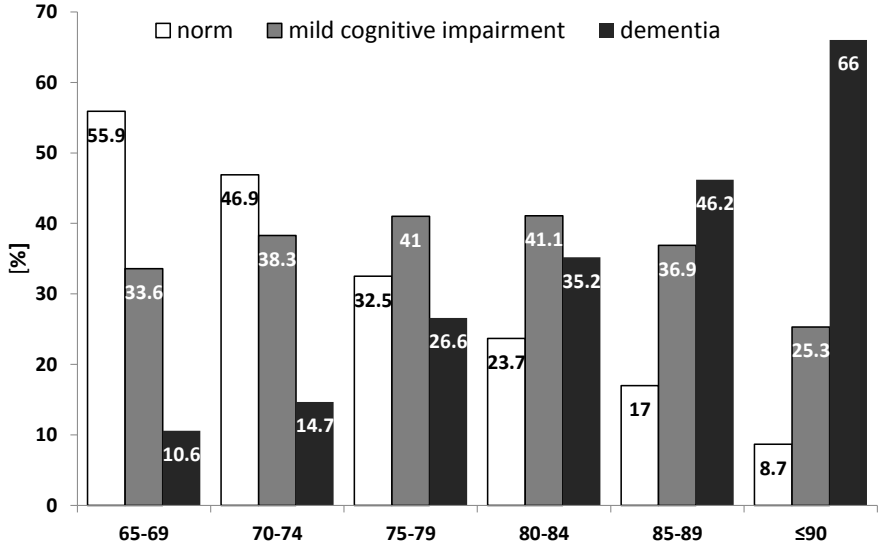

Figure 2. Cognitive status of older Polish population divided into age groups – results of the PolSenior study
Source: Klich-Rączka A, Siuda J, Piotrowicz K, Boczarska-Jedynak M, Skalska A, Krzystanek E, et al. [Cognitive impairment in the elderly]. In: Mossakowska M, Więcek A, Błędowski P., editors. [Medical, psychological, sociological and economic aspects of population aging in Poland]. Poznań: Termedia Wydawnictwa Medyczne; 2012. p. 114 (in Polish).

Due to the rapid increase in the number of older adults in the Polish population, there seems to be an urgent need for early diagnosis and treatment of dementia, as well as the development of a service support network not only for patients, but above all for the family caregivers of those afflicted with dementia. The current solutions of the senior policymakers in Poland fail to address the specifics of dementia-related problems. The key government programs for seniors, both those already implemented ("The Assumptions of the Long-Term Senior Policy in Poland for the period 2014–2020", "Program for Social Activity of Older People for the years 2014-2020") as well as those planned ("Social Policy for Older People 2030. Safety-Participation-Solidarity") lack solutions for both people affected by dementia and their caregivers. In 2011, at the initiative of the Polish Alliance for Alzheimer's Organizations, a project was developed for the 2011 National Alzheimer's Program for Poland. This included recommendations for the organization of medical and social assistance for elderly people with dementia [10]. Thus far, however, this document has not been given a legal framework by public authorities, which could be the first step towards the systemic solving of the health and care problems of people with dementia. It should be added that Alzheimer's Plans have long been adopted in many European countries.

The aim of the work

The aim of this paper is to present dementia as an increasing health and social problem in the aging Polish population by investigating the nature of dementia and its impact on health and social services as well as informal caregiving.

Dementia as a medical problem

Definition and types of dementia

Dementia is a clinical syndrome of brain disease involving gradual and progressive memory loss in line with other cognitive disorders that cause difficulties in daily living, with the exception of consciousness confusions (ICD-10). The typical presentation of dementia, apart from memory deterioration, is: problems with spatial orientation, language, judgment, reasoning (including prominent apraxia), and executive functions causing difficulties in daily living [11]. It has been shown that DAT is the most common cause of dementia in older age [1]. The course of the disease is progressive and long-lasting, usually beginning from a clinically asymptomatic stage lasting even several years or mimicking age-associated memory impairment through gradually progressing signs of impaired cognition (mild cognitive impairment) to the core symptoms of dementia [12]. The variety of symptoms changes with the phase of the disease, which is accompanied by anxiety, agitation and/or behavioral

disorders. The medical diagnosis of probable DAT is usually delayed due to social unawareness of dementia, the insidious onset of the disease, lack of proper knowledge in family practitioners and unsatisfactory access to specialists in Poland. The diagnostic process is complex and time consuming. It is important to rule out treatable and potentially reversible causes of dementia in individual patients, including depression, drug-induced memory loss, delirium, sleep apnea, recurrent hypoglycemia, vitamin B12 deficiency, hypothyreosis, and others, although this group of cognitive disorders accounts for a rather small proportion of potentially reversible dementias.

In the older population, most dementia results from DAT coexisting with multi-infarct dementia (MID). The latter presents as recurrent small cortical or subcortical strokes that are too small to manifest focal neurological deficits, however they may play an important role in the occurrence and severity of DAT symptoms. MID and DAT both frequently coexist in the same persons [13]. Other types of dementia are next most common, like dementia with Lewy bodies (DLB) and Parkinson's dementia. They account for up to 25% of all dementias and symptoms may overlap with DAT and MID [14]. Also, frontotemporal dementia, progressive supranuclear palsy, corticobasal degeneration, normal pressure hydrocephalus, and others should be ruled out. The most prevalent types of dementia share typical features, however they differ in the character of symptoms, sequence of symptoms, associated signs and behaviors.

Depressive *pseudodementia* is a term referring to patients who have mostly reversible impairments of cognitive function due to depression. Depression may precede or coexist with dementia and can produce cognitive deficits. A careful trial of an antidepressant is justified to improve overall functioning and quality of life.

Clinical picture and stages of dementia

According to ICD-10, the stages of dementia severity for any type of dementia are described as mild, moderate, or severe.

- In the mild stage of dementia, the person is able to function independently, although they have memory lapses that affect daily life, like forgetting words and recent events or misplacing things. Typical signs of the mild stage of dementia are memory loss of recent events, changes in personality (more subdued or withdrawn), difficulties with problem-solving tasks, managing finances, and organizing or expressing thoughts.
- In moderate dementia, people need more assistance in daily functioning. Performing daily activities and self-care (getting dressed, bathing, and grooming) becomes harder. A progression of memory loss, confusion, poor judgement, agitation, unfounded suspicion and changes in sleep patterns can be observed.
- In the severe stage of dementia, further deterioration of cognitive functioning is observed. A severe loss of the ability to communicate dominates along with disabilities in basic activities of daily living (eating, swallowing) and failure in bladder and bowel control.

Disruptive behavior like aggression (verbal and/or physical agitation, aggression, delusions or hallucinations, poor hygiene, insomnia, incontinence) or confusion can co-occur in all stages of dementia, quite frequently precipitated by environmental or potentially modifiable factors (noise, darkness, sleep disorders, urinary or other infections, inappropriate medications, etc.). They require an adjusted approach and substantial engagement of family members.

Dementia as a major cause of disability in later life

According to the Global Burden of Disease, dementia is one of the main causes of disability in older adults. It contributes to 11.2% of all years lived with disability compared with stroke (9.5%), musculoskeletal disorders (8.9%), heart diseases (5%), and cancer (2.4%) [15].

Early diagnosis of dementia, a condition for early management and care planning

In contrast to other long-term diseases, dementia screening, diagnosing, management and care currently constitutes only a small proportion of the general practitioner's (GP) time and workload. In Poland, dementia is rarely suspected by a GP, especially in the first phase of the disease when a patient may complain about many other co-existing conditions. Any postponement of the right diagnosis delays proper treatment and care, which results in further neuropsychological degradation and disability in daily living. The problem of underdiagnosing dementia in Poland probably results from the lack of specialty knowledge and diagnostic skills in primary care medical staff, as well as the case-complexity and inability to access specialists (geriatricians, neurologists, psychiatrists). A dementia diagnosis is a shared responsibility between the GP and specialists [16]. Dementia

in older adults is usually one of many chronic conditions. The first signs of the disease may be masked by other health conditions and atypical complaints.

Proper treatment, management and care plans for people with dementia depend on the type of dementia from the beginning. The diagnostic process is long and time-consuming due to the need to complete many additional examinations, including assessment for delirium and depression, identification of other chronic conditions (e.g. sensory impairment), functional assessments, mental status examination, and laboratory examinations to rule out potentially reversible causes of dementia and delirium. The process goes beyond primary care. The patient requires a referral to a specialist (geriatrician, neurologist, or psychiatrist) and many tests. The results of selected laboratory examinations, computed tomography or magnetic resonance imaging of the head, as well as neuropsychological testing are complex. Obtaining and interpreting them is time-consuming. The examinations are extended in time and engage many professionals, but the process is an essential prerequisite for establishing the most probable reason for dementia.

General principles of dementia management

After diagnosing dementia, the patient and his family must be involved in developing a care plan to address the health and care problems and their implications. The plan should be flexible, allowing for any revision appropriate to the circumstances. The components of dementia management are as follows:

- optimize the patient's physical and mental functions through physical activity,
- provide ongoing care and treatment of underlying conditions (e.g. Parkinson's disease, depression, hypertension and other cardiovascular diseases, diabetes), avoiding drugs with adverse effects in the central nervous system,
- assess the environment and provide advice on any changes, if needed,
- inform and prepare the person for changes in location,
- avoid stressful situations and be friendly towards the patient,
- identify and manage behavioral symptoms and complications (wandering, dangerous driving, agitation, aggressiveness, malnutrition, incontinence),
- provide information to the patient and family (about the disease, extent of impairment, prognosis),
- provide social service information to the patient and family caregivers,
- protect the caregiver from burnout and other effects of caregiver stress.

Pharmacological management

The approach to pharmacological treatment of dementia involves four rules:

1. avoid drugs that worsen cognitive function, especially those with anticholinergic activity,
2. use medications that enhance cognitive functions (donepezil, rivastigmine, memantine),
3. treat coexisting depression,
4. drug treatment of complications like paranoia, delusions, psychosis, agitation.

Antidepressants may provide benefits in patients with dementia [15, 17]. Antipsychotic treatment in dementia is highly controversial due to the high risk of death. It is better to find a potential underlying cause that precipitates the behavioral or psychotic complications to be eliminated. Experimental use of paracetamol sometimes provides symptom resolution, since pain may be especially hard to detect in demented patients.

Dementia as a social problem

The onset of dementia symptoms causes a relatively rapid impairment of patients' daily functioning, forcing the need for assistance provided by others. The provided care becomes increasingly absorbing and challenging as the disease progresses. In the early stages of the disease, the assistance is provided mainly in the area of more complex activities, such as making payments and administering medications, etc. Over time, however, assistance is needed even when performing simple daily activities, such as self-care or meal preparation. In the most advanced stages of dementia, patients are unable to function independently and require 24-hour care [18]. Due to behavior disorders (wandering, aggression, cursing) and psychotic symptoms (hallucinations, delusions) which frequently accompany dementia, the care poses a particular challenge.

Family caregiving

Dementia affects the functioning of entire families faced with the need to provide demanding care for their afflicted relatives. In Poland, caring for an elderly person with dementia can be primarily described as non-institutional and provided by the closest family members in a home setting. Typically, one person in the family becomes the main caregiver, carrying the basic burden of care and responsibility. This often leads to negative consequences in the form of social isolation, neglect of their own needs, and often diseases [19]. Usually spouses or children (predominantly women) of the affected individuals become the caregivers [8, 20]. They are often older adults themselves, who also have to deal with their own health issues. In the case of younger caregivers (primarily children), taking care of their parent may force a total change in the organization of family and work life [21].

Considering the demographic forecasts, a significant decline in the care potential of Polish families should be expected in the near future. According to the Central Statistical Office (GUS) forecasts, the so-called generational support ratio, which indicates the potential possibility of supporting older generations resulting from the age structure of the population, will systematically decrease in the next decades. The potential support ratio, i.e. the number of people aged 15–64 years per one older person aged 65 years or older, will decrease from 458 in 2013 to 169 in 2050; whereas the parent support ratio, which is the number of persons 85 years old and over per 100 people aged 50 to 64 years, will increase from 8 in 2013 to 38 in 2050 [22]. The shrinking care potential of Polish families results in a growing need for formal forms of support to ensure proper care for dependent elderly individuals.

Formal support system

Formal support in providing care for patients with dementia should be comprehensive and include health, social and psychological services in both community-based and institutional care. The support should be provided not only to patients but also to their caregivers. An appropriate formal support network is necessary to provide proper care for elderly patients affected by dementia as well as to reduce the excessive care load of their caregivers.

There are three basic instruments of formal support for a family caring for an elderly dependent person. The first one is financial support in the form of cash payments to the caregivers and those in their charge. The second one is to enable or facilitate combining the caregiver's work with their care-related responsibilities [23]. The third (and most likely the most important) form of support is access to care services relieving the caregivers of their duties, including periodic respite care. This form of help improves not only the quality of care provided to the elderly, but also the mental and physical condition of the caregiver [24]. Comparative research from six European countries, which was conducted as part of the EUROFAMCARE project, demonstrated a correlation between fewer unmet social needs and a greater number of social and environmental services available for patients and their caregivers. However, such a relationship was not found for the 'richest' offer of health services [25].

In Poland, the estimated monthly costs associated with caring for a person with dementia are about 690 PLN [8]. State financial support received by Polish seniors in the form of an allowance or care allowance does not cover even half of this amount. There are no solutions in Poland that would make it easier for caregivers to combine care with work. Quite the contrary, the current system eliminates caregivers from the labor market, as they are entitled to financial support (520 PLN per month) only if they abandon their professional work for care. As shown in the report of the Supreme Chamber of Control (NIK), the support system in the form of care services provided to elderly individuals in the place of residence is still insufficient. Although these services are managed within the scope of self-government's own tasks, which are of a mandatory nature, almost 20% of municipalities fail to offer such support to seniors. In 2016, about 1% of the population over 60 years old took advantage of care services in the place of residence [26]. As a result, the whole care process is a burden for the family and privately paid caregivers. In the case of patients with no family, a care gap emerges, increasing the risk of negligence [27].

In addition to formal organizational state assistance, support may be also provided by foundations and associations, including a wide range of Alzheimer's associations. Currently, there are 35 non-governmental organizations in Poland working in the area of dementia [28]. Their activities are focused on providing support to patients and their caregivers through support groups, guidebooks, help lines, conferences, as well as trainings for doctors, nurses, social workers, and caregivers. Furthermore, foundations and associations also offer day-time and 24-hour centers for dementia patients [18]. Such facilities are most often located in large urban areas (Warsaw, Poznan, Krakow), which may be an access barrier for patients from smaller towns or rural areas.

If adequate care in a home setting is not possible, a patient with dementia could theoretically be placed in a part-time (daytime) or full-time (24-hour) care institution. There are only a few such institutions in Poland, and they are mainly located in urban areas. In practice, however, such institutions are unavailable or difficult to access due to the limited number of places and thus long waiting time. Daytime support centers function in Poland as part of social welfare structures or non-governmental organizations. They offer several hours of care during the day, usually on weekdays. Stationary care facilities are mainly state social welfare homes or long-term care centers (state or private). Usually, the caregivers of patients with end-stage dementia apply for this type of institutional care. Interestingly, dementia is an independent prognostic factor for replacing family care with institutional care already after one year [29]. While the costs of state institutional care are up to 70% of the senior's monthly income (the rest is covered by the local government or the caregiver), the costs of private facilities range between 2400 PLN up to 6000 PLN per month, depending on the standard and the services offered [30].

According to a survey conducted in Poland in 2016 among caregivers of individuals with Alzheimer's disease, the system of support provided by state institutions is far from sufficient. The respondents claimed that they were left to their own devices. From the possible forms of care support, the respondents most often had access to hospital treatment (58%) and community nurse services (48%) (Table 1), while they considered facilitating access to specialists, reimbursement of rehabilitation equipment and hygiene products as well as financial assistance to be most important aspects [8].

Table 1. Experiences of the Polish caregivers of people with Alzheimer's disease with the support and care system (in %)

Type of support/care	Taken advantage of	Difficult to access	Quality is good
Hospital treatment	58	51	69
Visiting nurse	48	44	82
Paid caregiver/care	29	43	73
Long-term care facility	24	69	75
Daily care center	22	66	76
Caregiver support group	22	48	80
Paid residential care	21	51	74
Support group for people with Alzheimer's disease	18	43	65
Nursing home	18	72	69
Residential care facility for people with Alzheimer's disease	16	71	58
Voluntary support	15	52	70

Source: Najwyższa Izba Kontroli. [Care of patients with Alzheimer disease and support for their families]. Warszawa: Najwyższa Izba Kontroli; 2017 (in Polish).

Conclusions

Dementia is a growing challenge to the public health of aging societies in Poland and worldwide. In Poland, the problem of dementia among seniors is often ignored and the disease is diagnosed late. The care needs of patients with dementia are not systematically met by the national health and social care services. Although family care for seniors with dementia is still the primary 'care institution' in Poland, it is becoming increasingly inefficient as a result of demographic changes, including the emigration of young people and the aging of potential caregivers. Lack of a coherent health and social care system for patients with dementia leaves their caregivers without systemic support. This special group of dependent seniors and their caregivers, who are often also dependent and elderly, requires professional care and support, and these go beyond the universal system of inefficient social support in Poland. The existing infrastructure of formal community-based and institutional care services addresses only a small proportion of the potential beneficiaries. The prospect of further aging of the Polish population along with the growing risk of dementia and the shrinking family care potential justify the development and implementation of a comprehensive Alzheimer's Plan at the central and local levels of our country.

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