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Support for People Living with Alzheimer's Disease: Local Solutions to Strengthen the Caregiving Potential of Families

Wsparcie osób żyjących z chorobą Alzheimera – lokalne rozwiązania wzmacniające potencjał opiekuńczy rodziny

ABSTRACT

As the population ages, it is becoming a challenge to provide dignified care to the growing number of elderly people with Alzheimer's disease or other types of dementia. In the absence of systemic solutions, the only way to provide dignified care for people with Alzheimer's disease is to implement local strategies to strengthen the caregiving capacity of families of people living with this disease. The subject of this study was the institutional support of families of people living with Alzheimer's disease and their families. The cognitive goal of the research was to identify forms of support for such families in Szczecin. The practical goal, in turn, was to identify recommendations for optimizing institutional support. The research procedure used an analysis of foundational data. The forms of support for families in the care of people living with Alzheimer's disease developed in Szczecin are designed to strengthen the caring capacity of families, in line

KEYWORDS
Alzheimer's disease, old people, family, informal carers, support

SŁOWA KLUCZOWE:
choroba Alzheimera, osoby starsze, rodzina, opiekunowie nieformalni, wsparcie

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with the Strategy for Solving Social Problems until 2027. Key forms of support include the only financial benefit in Poland, i.e. "Alzheimer 75 Benefit," daily support centers for people with Alzheimer's disease, a day respite care center, and the "Niezapominajka Caregiver Support Centre", including a mobile team providing support in the home environment.

ABSTRAKT

W obliczu starzenia się społeczeństw wyzwaniem staje się zapewnienie godnej opieki rosnącej liczbie osób starszych chorych na chorobę Alzheimera lub inne choroby otępienne. W sytuacji braku systemowych rozwiązań jedyną szansą w zakresie zapewnienia godnej opieki w chorobie Alzheimera jest wdrażanie lokalnych strategii ukierunkowanych na wzmacnianie potencjału opiekuńczego rodzin osób żyjących z tą chorobą. Przedmiotem badań przedstawionych w artykule było instytucjonalne wsparcie rodzin osób żyjących z chorobą Alzheimera. Celem poznawczym badań było natomiast rozpoznanie instytucjonalnych form wsparcia rodzin osób żyjących z chorobą Alzheimera w Szczecinie. Cel praktyczny badań wyraża się w określeniu rekomendacji służących optymalizacji wsparcia. W postępowaniu badawczym zastosowano analizę danych zastanych, jedną z metod badań niereaktywnych. Zgodnie z przyjętą Strategią Rozwiązywania Problemów Społecznych do 2027 roku, rozwijane w Szczecinie instytucjonalne formy wsparcia rodziny w opiece nad osobami żyjącymi z chorobą Alzheimera mają wzmacniać potencjał opiekuńczy rodzin. Do kluczowych form wsparcia zaliczyć można: jedyne w Polsce świadczenie pieniężne „Bon Alzheimer 75", dzienne ośrodki wsparcia dla osób z chorobą Alzheimera, świetlicę wytchnieniową, Centrum Wsparcia Opiekunów „Niezapominajka", w tym zespół mobilny świadczący wsparcie w środowisku zamieszkania.

Introduction

In caring for dependent older people, families constitute the main caregiving potential (Iwański 2016). According to the principle of subsidiarity, when an elderly person is ill, the caregiving potential of the family and their immediate environment is activated first; later, as the need for care increases, other informal groups, non-governmental organisations and public institutions are involved in the support system. Caregiving is one of the key functions performed by the family

in relation to the elderly. Its scope increases with advanced age, when the risk of multimorbidity and dependency on others increases. Bearing in mind the transformations of the modern family, which are influenced by demographic and economic factors, and taking into account the fertility rate, which remains low and does not guarantee a stable population, it can be expected that in the coming years the demand for care for dependent elderly people will increase, whilst the caregiving potential of families will decrease (Iwański, Bugajska 2019). The current social policy model for meeting the needs of the elderly (excluding the pension system and health sector financing) mainly depends on the potential and commitment of local authorities and family resources (Bugajska, Iwański 2018). Meanwhile, as Józefina Hrynkiewicz notes, "public institutions of local government—under the current legal, financial and organisational conditions—are incapable of performing the increasing scale of caregiving tasks for elderly dependents" (Hrynkiewicz 2022: 57). The lack of systemic, comprehensive care for the elderly, especially at an advanced age, when dependency levels are higher, is an increasingly discussed social problem, even regarded as a new societal risk (ibidem).

In the face of an ageing population, including the phenomenon of double ageing, i.e. the predicted ageing of the population combined with the simultaneous increase in the proportion of elderly people over 80 years old, the challenge is to provide dignified care to the growing number of those with Alzheimer's disease. Supporting carers of people with dementia is one of the key areas for action identified by the World Health Organization (WHO 2020). The risk of developing dementia, including Alzheimer's disease, increases with age (Hausz-Piskorz, Buczkowski 2013: 200; Wojszel, Bień 2002). According to estimates, between 300,000 and 500,000 people in Poland may suffer from Alzheimer's-type dementia (Gabryelewicz 2014: 17; NIK 2016). It is a progressive disease that cannot be cured or prevented (Kozak-Putowska, Iłżecka 2016). The ageing of the population will lead to an increase in the number of people with Alzheimer's disease, which in turn will increase the demand for caregiving services provided by family members as well as for local and government support programmes (Bugajska, Iwański 2021). A nationwide audit of Alzheimer's care and support for families conducted by the Supreme Audit Office shows that the universal health

care and social assistance system operating in Poland has not created tools to effectively and efficiently address the problems of people with Alzheimer's disease and their families (NIK 2016). In the context of an ageing society, local governments have to come up with local strategies with alternative, effective and economically efficient solutions to support the elderly.

Szczecin is one of the cities where different forms of support for dependent elderly people, especially those with Alzheimer's disease, are being systematically developed, with attention being paid to the need for family support in the caregiving process. The Szczecin Municipality, like most municipalities in Poland, is facing the problem of a growing population of people with dementia. The percentage of people aged 65 and over in 2022 will account for 24% of Szczecin's population. Of the 85,310 people aged 65 and over, 32.1% are 65–69, 45.15% are 70–79, 18.58% are 80–89 and 4.18% are 90 and over (*Population Register...* 2022). Demographic forecasts indicate a phenomenon of double ageing of the population, understood as an increase in the share of the oldest group in the population, i.e. those aged over 80.

Caregiving potential of the family of an older person with Alzheimer's disease

Old age is a phase of life in which the family becomes the most important reference group, and its absence is perceived as a problem more strongly than in earlier periods of life (Szatur-Jaworska 2014). The family is the primary environment for the emotional functioning and everyday activity of older people. It assists in the process of adapting to old age, provides a sense of security and supports the old person in various areas: financial, emotional and spiritual (Fabiś, Wawrzyniak, Chabior 2015). Each chronic illness represents a difficult situation for the family, requiring the implementation of effective coping strategies in the face of a new situation and an increased need for nursing and care (Doroszkiewicz 2007). In case of illness, the family is the first to provide assistance to an elderly person, which is crucial from the point of view of the elderly care system, but it does not mean the family is willing to take total responsibility for the care of the

dependent elderly person, despite the fact that a family carer is the most common caregiving solution in Poland (Rosińska et al. 2018).

The concept of the family caregiving potential is defined "as the family's capacity to provide care to needy members of its own close family […], the exchange within the family of care and nurturing services; grandparents to grandchildren, parents to children, children to parents, grandchildren to grandparents, their own siblings and siblings of their parents (grandparents)" (Hrynkiewicz 2022: 52).

The changes taking place in the family structure (the disappearance of multigenerational families and living in separate houses) and loosening intergenerational ties lead to a lower family caregiving potential (Fabiś, Wawrzyniak, Chabior 2015). Intergenerational relationships depend on transfers of gifts such as time, space and emotions (Szukalski 2002). It is good that family carers of the elderly in Poland strongly identify with the caregiving role and cope well with it, despite the underdeveloped system of support from external services (Czekanowski, Synak 2006). The main motives for taking on the role of caring for a close elderly relative are emotional ties (47.5%), a sense of duty (22%) and a sense of obligation to the elderly person as a family member (21%) (ibidem). More than 80% of the people participating in the PolSenior study rated the relationship with their immediate family positively (Szatur-Jaworska 2014).

The factors contributing to the decline in the family's caregiving potential include demographic changes in the family that affect its size and structure, economic conditions (e.g. labour migration) and social situations (e.g. disrupted relationships among family members) (Szweda-Lewandowska 2014, Hrynkiewicz 2022). The caregiving capacity of the family depends on a variety of internal and external factors. Among the internal factors, Zofia Kawczyńska-Butrym (2008) lists family members' level of physical and mental fitness, family structure, number of children, phases of family life, motivation, availability of family members, financial situation, knowledge and skills, level of education and special situations, such as the occurrence of social pathology. The fulfilment of the family's elder care function is also hindered by the carers' professional activity and poor health (Halicka 2006).

The expected increase in the number of people with Alzheimer's disease will influence the lives of many families, as immediate family

members become informal carers of dependent older family members (Lepore, Ferrell, Wiener 2017). The regressive and progressive nature of Alzheimer's disease places a heavy burden on carers. The worsening symptoms of the disease make the patient increasingly dependent on their family, necessitating assistance with the most intimate personal hygiene activities, which can be a source of stress and exhaustion for carers (Fauth, Femia, Zarit 2016). Caring for people with dementia is associated with higher levels of anxiety, stress and depression, as well as a reduced immune response, which may lead to frequent infections (Beard, Donkin 2009). Carers are less likely to engage in preventive health behaviours than non-carers, which may further contribute to the former's poorer health (Grunfeld, Coyle, Whelan et al. 2004). The role of the family carer is more exhausting than that of the formal carer (Halicka 2006). Daughters and daughters-in-law of the elderly are the most involved in the caregiving process, providing essential daily living, care and nursing services to those family members who need it (Szukalski 2002).

Physical burden results from carers' taking on too many household responsibilities and helping elderly relations with daily activities (Sadowska 2014). Carers, especially when they cannot rely on the support of others, neglect their own needs and develop chronic fatigue, and consequently, a syndrome of physical, psychosomatic and psychosocial symptoms called "caregiver syndrome" (Grochmal-Bach 2007). The involvement of family carers in the care of an older person can lead to burnout manifested in inefficient caregiving. "The caregiver's state of psychological and physical exhaustion may trigger hostility, resentment, mistreatment and even aggression in the caregiver themselves, which may be directed not only towards the elderly person, but also towards other people in their environment. Such a situation may result in care neglect in the family" (Halicka 2006: 250).

According to the results of the PolSenior study, as dependent persons grow older, the proportion of family members providing assistance decreases, which is related to both the ageing of carers and the increasing range of care activities requiring professional support (Błędowski 2012). At the same time, the decreasing number of people in a single generation due to lower fertility rates, combined with an more generations living simultaneously due to rising

life expectancy (so-called family network verticalisation), leads to more older people requiring support and fewer potential family carers (Szweda-Lewandowska 2014). Thus, taking action at the level of local government to support the families of dependent people with Alzheimer's disease in the absence of systemic solutions within the social assistance and health care system, combined with the lack of early diagnosis and the possibility for early interventions, becomes a priority and, at the same time, the only chance to provide dignified care to the increasingly large group of people dependent on the care of loved ones (Bugajska, Iwański 2021).

Research method

The subject of the research was support for family carers of people living with Alzheimer's disease, while the cognitive aim was to identify institutional forms of support for family carers of people with Alzheimer's disease in Szczecin. The practical aim of the research was to identify recommendations for optimising institutional support. The research problem was formulated as a question: What kind of institutional support for family carers of people with Alzheimer's disease exist in Szczecin? Three specific problem areas were identified: (1) What is the rationale for developing a support system for family carers of people with Alzheimer's disease in Szczecin? (2) What institutional forms of support for family carers of people with Alzheimer's disease are being developed in Szczecin? (3) How do social care homes for the chronically somatically ill and the elderly care for people with Alzheimer's disease, and what kind of measures do they take to cooperate with families? The research procedure was to analyse existing data (a non-reactive research method) (Babbie 2008): two strategies for solving social problems, i.e. the strategy for 2015–2020 and the one in force until 2027, as well as annual reports on their implementation, statements prepared by the Szczecin Benefits Centre concerning the "Alzheimer 75" benefit for the period 2018–2022 and information on the activities of social care homes submitted to the Department of Social Affairs of the Szczecin City Hall for 2022–2023. Diagnoses of support for family carers of people with Alzheimer's disease, on which institutional forms of support for older people in Szczecin are planned, were also analysed.

Research results

Rationale for developing a support system for family carers in the care of people with Alzheimer's disease in Szczecin

In order to identify the process of development of forms of support aimed at strengthening the caregiving potential of families of people with Alzheimer's disease, an analysis of the rationale behind such solutions in Szczecin was taken as a starting point. For this purpose, documents such as the Strategy for Solving Social Problems for the Municipality of the City of Szczecin for 2015–2020 (*Strategia...* 2015) and the Strategy for Solving Social Problems for the Municipality of the City of Szczecin until 2027 (*Strategia...* 2022) were analysed, as well as other internal documents made available by the Department of Social Affairs of Szczecin City Hall evaluating the tasks in the policy that concern the elderly. It was also important to identify the diagnoses and recommendations on which these activities were based.

Comparing the analysis and demographic forecast in the two strategies, one can notice a much greater identification of the challenges resulting from the ageing of Szczecin's population in the Strategy for Solving Social Problems until 2027, especially in connection with double ageing. In the strategy in force from 2015 to 2020, the demographic analysis was limited to presenting the general demographic structure in 2012–2014, showing the number of people aged 65 and over without breaking it down into further categories of old age. The demographic forecast highlights the expected increase in the number of people aged 60 and over, the feminisation of old age and the decline in the population, generally indicating the consequences of the ageing of Szczecin's population. The risk of dependency increasing along with advanced age and the role of the family in caring for the elderly were not taken into consideration.

The current strategy refers to demographic forecasts of an increase in the number of people over 65, divided into particular age groups (*Strategia...* 2022). Attention was drawn to the sharp increase in the number of people aged 85 and over, the feminisation of old age and the phenomenon of double ageing. The link was recognised between demographic processes and the decline in the potential support ratio

(the number of people at working age divided by the number of people aged 65 and over) and the potential support ratio of elderly parents (the subpopulation of pre-old-age people divided by the subpopulation of seniors aged 85 and over). A clear decline was identified in the caregiving potential of families, and thus a rising demand for care services provided to dependent older people by institutions in the social assistance and health sectors.

The Strategy for Solving Social Problems for the Municipality of the City of Szczecin for 2015–2020 did not directly indicate the problems of people with Alzheimer's disease and the need to support families in providing comprehensive care among the most important social problems related to the elderly, which then provided the rationale for the recommended and adopted courses of action. However, most of the problems identified as key ones were related to issues of inadequate care. Attention was drawn to the insufficient number of 24-hour care centres (including temporary care), overly formalised admission procedures to day care homes and their limited hours of operation, insufficient access to hot meals and the inability to pay neighbours for their care. With regard to the families of the elderly, two problems were identified: limited awareness among seniors and their families about forms of assistance and limited awareness among the public of the family's responsibility for caring for the elderly.

In the Strategy for Solving Social Problems until 2027, the diagnosis of needs highlighted the challenges resulting from the expected increase in the elderly population, including the problems associated with the growing group of people suffering from Alzheimer's disease or other types of dementia. The strategy emphasised the need to provide such people with comprehensive care, which expands in scope as the disease progresses in its course. The following issues were identified as priority problems in the area of support for the elderly: too few 24-hour rest care places (short-term and long-term), insufficient family support in caring for dependent elderly people, insufficient support for elderly people in the community, limited public awareness and understanding of the needs of the elderly, limited access to care services due to the high costs, rising costs in institutional care and the need to adapt available resources to the growing proportion of elderly people who do not leave their beds.

It is worth noting that even at the stage of evaluating the Strategy for Solving Social Problems for the Municipality of the City of Szczecin for 2015–2020, the solutions were evaluated by expert opinion, as a result of which the assumptions of the senior policy of the Municipality of the City of Szczecin were detailed and new solutions were designed (cf. Bugajska et al. 2017). The basis for setting directions of the policy concerning seniors in Szczecin was the need to change the approach to elderly care, in line with the modern vision of social welfare and the idea of deinstitutionalisation, understood as a process of transitioning from institutional care to community-based services (*Ogólnoeuropejskie wytyczne...* 2012). Recommendations were developed in five areas: (1) bringing the approach to elder care in line with the idea of deinstitutionalisation, (2) developing forms of 24-hour care to serve as alternatives to social care homes, which are less costly and more acceptable to the elderly (e.g. sheltered housing or assisted living), (3) improving the day and community support system, (4) supporting people with dementia and their families and (5) creating a Seniors' Centre.

The following forms of support for people with dementia and their families were recommended:

1. extending the range of support for people with dementia and related diseases, involving specialists and NGOs
2. optimising the operation of day care centres by profiling their work, paying particular attention to supporting people with dementia, including Alzheimer's disease
3. gradually adapting one of the social care homes to meet the needs of people with dementia, including Alzheimer's disease, as well as gradually specialising the home in subsequent years, including support for families
4. developing and implementing a health policy programme for older people that entails comprehensive geriatric assessment and screening for dementia problems
5. supporting family carers in the care of dependent senior citizens with dementia and similar diseases (counselling, psychological support, training, support groups and a rest centre).
6. introducing a financial family benefit for carers of people with Alzheimer's disease.

These recommendations have been implemented or are in the process of being implemented, and a health policy programme has been developed. What proved to be important in the process of planning activities and improving the forms of support, in addition to the analysis of existing data (including demographic forecasts), were the opinions of carers of people with Alzheimer's disease collected as part of the "Alzheimer 75" benefit introduced in Szczecin in 2018.

The diagnosis of the needs of family carers of people with Alzheimer's disease, which was carried out in 2018 in Szczecin as part of the "Alzheimer 75" benefit (N=486), allowed for the support to be tailored to the needs of carers. According to the research, the care of people aged 75 and older with Alzheimer's disease is mainly provided by women (72%)—first of all by daughters (48%)—followed by wives and husbands (26%) (Iwański, Bugajska 2019). The average age of carers was 62 years, with the oldest being 90 and over. The caregiving lasted an average of 5.4 years. Thirty-one percent of working-age carers, especially women, had to permanently or temporarily reduce their working activity, which has a direct impact on pension benefits. The research indicates a declining caregiving potential of the family, yet a willingness to care, as can be seen from the fact that 73% of the respondents would not consider placing an ill person in a nursing home and 94% believe that an ill person should be able to stay at home for as long as possible, with appropriate family support (ibidem). The analysis of empirical data obtained from carers of people with Alzheimer's disease aged 75 and over indicates that most families feel responsible for providing care for their loved ones, but they need systemic support from public institutions that is tailored to their needs and caregiving potential. The results were used, among other things, to develop a project subsidised under the Regional Operational Programme of the West Pomeranian Voivodeship 2014–2020 (RPZP.07.06.00 – Support for the development of social services provided in the general interest) entitled "Under care: Systemic strengthening of the caregiving potential of families", which tested solutions to support carers in providing day-to-day care to an ill person between 2020 and 2023.

Institutional forms of support in Szczecin for family carers of people with Alzheimer's disease

The institutional forms of support for family carers of people with Alzheimer's disease which have been developed in Szczecin are intended to strengthen the caregiving potential of families, as adopted in the Strategy of Solving Social Problems until 2027. The key forms of support include the "Alzheimer 75" benefit voucher, day support centres for people with Alzheimer's disease, a day rest centre and the "Niezapominajka" Carers Support Centre, including a mobile team that provides support in the patient's home.

"Alzheimer 75" benefit care voucher

The "Alzheimer 75" benefit care voucher is a cash benefit addressed to family carers of persons aged 75 and over with Alzheimer's disease. The legal basis for the benefit is Article 22b of the Family Benefits Act of 28 November 2003 (Act... 2003), according to which the Municipal Council, taking into account local needs, may establish a family benefit for residents of its municipality. The Benefits Centre in Szczecin is responsible for the implementation of the voucher and other family benefits.

Table 1. Statistics of applications and payments related to the "Alzheimer 75" benefit voucher from 2018 to 2022

Year	Number of applications submitted	Number of decisions of payment	Amount of money paid within the "Alzheimer 75" benefit voucher (PLN)
2018	534	486	823 000,00
2019	757	731	1 764 000,00
2020	782	763	1 947 000,00
2021	773	662	1 818 000,00
2022	676	590	1 133 000,00
Total			7 485 000,00

Source: Based on data from the Department of Social Affairs of Szczecin City Hall.

The condition for receiving the benefit is caring for an elderly person aged 75 or over who has been diagnosed with Alzheimer's

disease by a psychiatrist, neurologist or geriatric doctor, specifying the disease according to the ICD-10 classification: F00.0, F00.1, F00.2 or F00.9 or equivalent G30.0, G30.1, G30.8 or G30.9.[1] In addition to the doctor's certificate, which, due to the progressive nature of the illness, does not need to be updated annually, the recipient of the benefit is required to provide the following documents: a statement of personal details of the carer and the senior, a statement that the elderly person does not live in an institution providing 24-hour care, a statement of residence in Szczecin, a statement of support for the senior and the recipient's relationship with them. The following family members may apply for the benefit: spouses, children, grandchildren, parents, siblings, daughters-in-law and sons-in-law. The catalogue of beneficiaries had to be limited due to the lack of a clear definition of family in the Act of 28 November 2003 on family benefits (Act 2003). In the first year of the programme's operation (2018), funds were secured in the budget of the Municipality of Szczecin for the payment of two tranches of PLN 1,000 each. In 2019–2021, as a result of the ongoing evaluation of the programme, the benefit was increased to PLN 3,000 per year (three tranches). From 2022, the annual amount was reduced to PLN 2,000 due to the Municipality of Szczecin's need to secure funds to counteract the lower income of the local government (a nationwide problem). The voucher was designed based on the idea of social trust. Among other things, it did not specify the scope of expenditure for which the voucher funds could be used. It was assumed that the needs of carers are diverse and that the recipients would be able to decide for themselves whether to spend the money on, for example, a new bed or mattress, medicine and hygiene products, a bathroom renovation to accommodate a person with reduced mobility, etc. The granting of the voucher was also no longer dependent on an income criterion. With the assumption that the benefit exceeds the scope of the Act of 12 March 2004 on social assistance, it is addressed to everyone and is not combined with social assistance. From the point of view of designing new solutions,

1 International Statistical Classification of Diseases and Related Health Problems: F00.0—Dementia in Alzheimer's disease with early onset (G30.0), F00.1—Dementia in Alzheimer's disease with late onset (G30.1), F00.2—Atypical or mixed dementia in Alzheimer's disease (G30.8) and F00.9—Dementia in Alzheimer's disease, unspecified (G30.9).

it is worth noting that at the application stage, carers agree to participate in surveys to evaluate the programme and identify the needs of carers and patients in order to optimise the institutional support system for people with Alzheimer's disease. Building and improving local support systems based on evidence from the direct beneficiaries of the programme is a valuable practice that does not require the additional expense of a survey and sampling process. In designing the benefit, it was also necessary to establish an age limit for the patient who would be entitled to the benefit. At the budgeting stage it was difficult to establish exactly how many older people in Szczecin have Alzheimer's disease. It was mainly based on demographic estimates. The age of 75 and over was established due to the fact that with advanced age comes an increased risk of multimorbidity, both for the patients and their caring spouses, which entails greater expense. People under 75 are offered other institutional forms of support through community-based services.

Day support centres for people with Alzheimer's disease or other kinds of dementia

According to the idea of deinstitutionalisation, support is offered in day support centres for older people in Szczecin. Two of the seven centres specialise in caring for people with Alzheimer's disease or other types of dementia; a total of 40 people are supported in such centres. These centres are open from 6.30 a.m. to 4.30 p.m., i.e. two hours longer than other centres, which is in response to carers' reported need to combine care and professional work. Older people who stay in such centres receive two meals: breakfast and lunch. Fees for the centres' services and the method of admitting someone to the centres are defined in the Act of 12 March 2004 on social assistance (Act... 2004). Day support centres provide care services for people living with Alzheimer's disease or other kinds of dementia, in particular for those awaiting placement in a social care home for the elderly and chronically somatically ill. The centres offer memory therapy, general development gymnastics, art therapy, cleanliness and personal hygiene training, social skills training, bibliotherapy, music therapy and relaxation classes, including playing in the world experience rooms. The participants meet together at the nursing home and

attend concerts and performances (according to the stage of their illness). Counselling and assistance in dealing with everyday life issues are provided, as are counselling and support for those caring for the person with the illness. In the case of people who have no family, day care centres for patients with Alzheimer's disease make it possible, together with other forms of support, to postpone their move to a nursing home. In the case of persons in family care, the centres provide support for the families involved in the care. Therefore, out of concern for the quality of care, the staff of the centres seek direct contact with the family to exchange information on the health status, the forms of care and nursing and the older person's behaviour and habits. The information on the activities of the homes, which is provided to the Department of Social Affairs, shows that the willingness of the family to cooperate depends on their degree of involvement in the care process. The lower the degree of involvement, the lower the need to participate in the patient's life. The biggest problem in day support centres is the difficulty regulating the issues connected with the termination of the patient's stay when their health deteriorates to such an extent that day care becomes insufficient.

Day care rest centre

A rest centre is a short-term, day care service that provides care for people with dementia-related dependency. The care services provided in a rest centre support family carers in the care process by providing them with the opportunity to rest from their daily duties and deal with their personal matters. The rest centre is open from Monday to Friday from 6.30 a.m. to 4.30 p.m. The services are provided at "Dom Kombatanta" [Veteran's House] Social Care Home at 17 Krucza Street in Szczecin. In order to rest, a carer may leave the dependent person in the centre for up to 9 hours a day. The care is free of charge for 18 months during the project. The rest centre may support a maximum of 14 people per day, with a maximum of 10 people in the centre at the same time. The rest centre provides the following services: care, support services, i.e. facilitating activities, health-orientated activities, art classes, music activities and other forms of therapy adapted to the participant's health. The centre also provides food during the day (breakfast and lunch).

Between March 2020 and March 2023, 176 carers (116 women and 60 men) benefited from the rest centre. A total of more than 23,000 hours of support were provided during this period. Carers appreciate this type of support because they can use the rest centre occasionally, in special situations, when they need to take care of their own affairs or when they are not provided with care at home or are ill themselves. The procedure for using a day care centre is not complicated, unlike the formal procedure for placing an ill person in a day support centre (by administrative decision).

"Niezapominajka" [Forget-Me-Not] Support Centre

The "Niezapominajka" Support Centre offers support to carers in the form of individual specialist counselling, which includes the following:

1. psychological counselling, in particular crisis intervention, working on emotions, counteracting burnout related to the long-term care of a dependent with dementia, as well as support after the loss of a loved one
2. legal advice, in particular on the rights and entitlements of dependents and their carers, incapacitation, disability assessments and entitlement to benefits—pensions, guardianship benefits and allowances
3. socioeconomic counselling, in particular service and support options in institutions for social welfare, health and social security
4. care advice, in particular advice on caring for a dependent person with dementia, assistance in adapting the home to the patient's needs, training in caring activities, including the development of skills to assist with activities of daily living and coping with difficult situations.

The following are provided within the framework of individual specialised counselling at the carer's place of residence (mobile support team): care counselling, physiotherapy counselling, therapeutic counselling and socioeconomic counselling.

The counselling schedule is set according to the needs of carers. It includes a website with a fact sheet, instructional videos for carers,

information about the support system in Szczecin and support from an information consultant—telephone advice and email exchanges.

The centre runs self-help groups and a therapy group, as well as training for factual carers of dementia dependents. Between March 2020 and March 2023, 351 carers (251 women and 100 men) benefited from the support. A total of 1,221 hours of support were provided (individual support: 892 hours; group support: 329 hours).

The forms of support for families caring for people with Alzheimer's disease that were selected for analysis do not represent all possible forms of support available to elderly people within the social assistance system, for example, care services in the home or a hot meal. Some individuals with Alzheimer's disease may occasionally be directed to the systematically created sheltered housing in Szczecin, but these forms are by definition not addressed to older people with Alzheimer's disease.

Despite the solutions for developing services for the elderly in the community, in line with the idea of deinstitutionalisation, it may turn out that the family of people diagnosed with Alzheimer's disease, depending on the course of the disease—despite their involvement in the care process and the support received from public institutions—are unable to cope with the difficulties of care. In situations in which the patient's behaviour threatens their life or health (self-aggression) or that of their carers (aggression), it is necessary to provide 24-hour care in a social care home, which does not exclude and even points to the need to involve the family in the care process.

Organising care for people with Alzheimer's disease in residential care homes

The Municipality of Szczecin runs three social welfare homes with a total of 564 places. Two social welfare homes specialise in the care of the elderly and chronically somatically ill. One is for people with mental disorders. In addition, the city has the option to direct its residents to social welfare homes outside the region (poviat), and it subsidises 100 places in a private social welfare home in Szczecin (Bugajska 2020). In the social care home "Dom Kombatanta" (DPS DK), at 17 Krucza Street, there are 240 residents, 60 of whom have been diagnosed with Alzheimer's disease or another kind of dementia. In the social care home "Dom Kombatanta i Pioniera Ziemi Szczecińskiej" [The House of a Combatant and Pioneer of

the Szczecin Region] (DPS DKiPZS) in Romera Street, 115 of the 250 residents have dementia. The fact that almost 70 per cent of the residents of the above-mentioned homes are more than 80 years old increases their risk of a health crisis due to multimorbidity, as well as the development of Alzheimer's disease or other types of dementia. Regardless of the community-based services being developed, the social care homes are preparing for the expected increase in the number of people requiring care due to their dementia. In DPS DK, there is a separate residential ward dedicated exclusively to people with Alzheimer's disease. There is no such ward at DPS DKiPZS, but residents in the more advanced stages of dementia live in supervised parts of the building.

At DPS DKiPZS, those people with Alzheimer's disease whose health allows it can passively and actively participate in individual and group therapeutic activities in the house. These include activities using elements of culinary therapy, music therapy, bibliotherapy, art therapy (drawing, papermaking, handicrafts and painting) and elements of ergotherapy (knitting, sewing, carpentry and horticultural therapy). In addition, dog therapy classes and cognitive function exercises (e.g. memory training, playing bingo, solving crosswords, board games and puzzles) are held regularly at the facility. Once a week, group general fitness classes are held. During the warmer months of the year, residents spend time in the garden near the house. An important part of the therapeutic process is the therapy carried out by the carers providing direct care for the residents, which involves motivating the patients to perform intimate activities, such as washing, dressing, using the toilet, combing their hair or eating, for as long as possible.

DPS DK offers art therapy, i.e. drawing (pencil, crayons or pastels), painting (watercolour paint), applied arts (collage or paper cutouts), occasional and seasonal decorations, music therapy (passive, i.e. relaxation training or activity music, as well as active, i.e. singing popular songs) and bibliotherapy (passive, i.e. the therapist reads aloud texts from newspapers, excerpts or whole books, individual reading in residents' rooms or poetry meetings). Depending on the severity of the illness, sociotherapy is provided (group meetings), as are play therapy (didactic, manipulative and construction games), recreation (silvotherapy, i.e. therapy through walking in the garden), relaxation

training sessions (interaction with the senses in the world experience room), memory training and reminiscence training.

Assuming that the family remains involved in the care for their family member even after the family member moves to a 24-hour social welfare home, it can be concluded that such institutional forms also strengthen the family's caregiving potential. From the information provided by social care homes to the Department of Social Affairs in Szczecin, it can be concluded that families participate in the care of residents to a very limited extent. They occasionally go to medical appointments outside the social care home, and they rarely walk with their loved ones or help feed them. The vast majority of families withdraw from providing care once their loved ones start living in an institution. In addition, the COVID-19 pandemic has resulted in family members reducing face-to-face contact with residents in favour of telephone contact.

Family members of nursing home residents mostly participate in organised celebrations (e.g. Christmas, Easter, World Alzheimer's Day celebrations, bonfires or outdoor parties). Occasionally, especially at first, they collect materials used in various kinds of therapy.

Among the problems identified by managers of nursing homes in providing care to people with Alzheimer's disease, attention was drawn to a lack of access to doctors specialising in the disease and long waiting times for appointments with psychiatrists, neurologists and other doctors. Other situations that need to be resolved are the lack of proper diagnosis of dementia diseases prior to residence in a social care home and the lack of a regulated formal and legal situation (no appointed legal guardian, interim counsellor or notarial proxy), which hinders and prolongs the treatment process during residence in a social care home.

Conclusions and recommendations based on the research

The analysis of the collected empirical material leads to conclusions that can form the basis for further recommendations to optimise support for people with Alzheimer's disease and their families. First of all, a comparative analysis of the Strategy for Solving Social Problems for the Municipality of Szczecin until 2027 and the strategy in force in the period 2015–2020, as well as the recommendations

developed from the evaluation of the planned activities carried out during the implementation of the adopted strategic assumptions, draws our attention to the increased awareness of the challenges resulting from the ageing of the city's population, which is visible in both the diagnosis and the planned activities. In particular, the intensification of support for dependent older people and family support in the care process, as well as the creation of short-term and long-term rest care places, were considered priorities.

Secondly, the analysis of measures taken for the benefit of people with Alzheimer's disease indicates a purposeful strengthening of the caregiving capacity of families and solutions based on a diagnosis of needs and the close participation of carers. The most important forms of support include the only cash benefit in Poland ("Alzheimer 75" benefit, day support centres for people with Alzheimer's disease, a rest centre and the "Niezapominajka" Carer Support Centre, including a mobile team providing support in the home.

Thirdly, the progressive nature of Alzheimer's disease, especially in the case of worsening psychiatric symptoms, involves professional care that cannot be provided by family carers. The possibility for a dependent elderly person to live in a nursing home can be seen as a form of family support, which is not tantamount to excluding the family from the care process. The trust-based cooperation with the family of the older person requires special care, which implies the need for the professional competences of the formal carers working in the social care home.

Faced with an ageing population, the challenge is to provide decent care for the growing number of elderly people with Alzheimer's disease or other kinds of dementia. In the absence of systemic legal and financial solutions, the only chance to provide dignified care for a patient with Alzheimer's disease is to implement local strategies aimed at strengthening the caring capacity of families. The family is an invaluable source of support throughout the course of a person's life. During old age, especially at its advanced stage, the need for support and care from family carers increases. However, without the development of systemic support mechanisms appropriate to their needs, the family will not be able to care for the patient without suffering excessive health, social, psychological and financial costs, which may eventually lead to a situation in which the carers

themselves will need help. This, in particular, refers to the spouses of the ill elderly person, but also the person's children—especially daughters.

Taking into account the growing demand for support for people with Alzheimer's disease and the decreasing caregiving potential of the family, organising care in social welfare homes may turn out to be the only solution, due to the high cost of care in the community and the lack of related legal regulations. Thus, irrespective of the development of community forms of support for dependent elderly people, and irrespective of convictions regarding deinstitutionalisation, in the absence of systemic legal and financial regulations, local governments will be faced with the growing problem of financial security due to the growing costs of care in the community (e.g. the cost of care services in the place of residence and in sheltered accommodation), and, in future, with the increasingly serious challenge of ensuring access to services for a growing number of dependent elderly people, including those with Alzheimer's disease.

Bibliography

Act 2003. Act of 28 November 2003 on family benefits (Journal of Laws 2023, item 390 as amended).

Act 2004. Act of 12 March 2004 on social support (Journal of Laws 2023, item 901).

Babbie E. (2008). *The Basic of Social Research*, Belmont (CA): Thomson Higher Education.

Błędowski P. (2012). "Potrzeby opiekuńcze osób starszych," [in:] M. Mossakowska, A. Więcek, P. Błędowski (eds.), *Aspekty medyczne, psychologiczne i ekonomiczne starzenia się ludzi w Polsce*, Poznań: Wydawnictwo Termedia, pp. 449–466.

Brodaty H., Donkin M. (2009). "Family Caregivers of People with Dementia," *Dialogues in Clinical Neuroscience*, vol. 11, no. 2, pp. 217–228.

Bugajska B. (2020). "Idea miasta przyjaznego starzeniu się i jej realizacja w mieście Szczecin," [in:] E. Frąckiewicz, B. Kryk (eds.), *Srebrna gospodarka. Ujęcie społeczno-ekonomiczne*, Warszawa: Wydawnictwo CeDeWu, pp. 302–331.

Bugajska B., Iwański R. (2018). "Zaspokojenie potrzeb mieszkaniowych niesamodzielnych osób starszych. W poszukiwaniu optymalnych rozwiązań," *Exlibris: Biblioteka Gerontologii Społecznej*, vol. 15, no. 1–2, pp. 12–25.

Bugajska B., Iwański R. (2021). "Local Strategies of Strengthening the Caregiving Potential of Families of People with Alzheimer's Disease: Good Practices Introduced in Poland," [in:] M.K. Shankardass (ed.), *Dementia Care*, Singapore: Springer, pp. 137–154.

Bugajska B., Iwański R., Giezek M., Ciemniak A. (2017). "The Optimization of Elderly Care in Szczecin – Research Report," *Exlibris: Biblioteka Gerontologii Społecznej*, vol. 13, no. 1, pp. 107–119.

Czekanowski P. Synak B. (2006). "Wybrane elementy obrazu rodzinnych sytuacji opiekuńczych ludzi starych w Polsce," [in:] M. Halicka, J. Halicki (ed.), *Zostawić ślad na ziemi*, Białystok: Wydawnictwo Uniwersytetu w Białymstoku, pp. 167–181.

Doroszkiewicz H. (2007). "Rola pielęgniarstwa rodzinnego w opiece nad osobami starszymi," [in:] K. Kędziora-Kornatowska, M. Muszalik (eds.), *Kompendium pielęgnowania pacjentów w starszym wieku*, Lublin: Wydawnictwo Czelej, pp. 72–78.

Ewidencja ludności miasta Szczecin za 2022 r. (2022). Wydział Informatyki Urzędu Miasta Szczecin.

Fabiś A., Wawrzyniak J.K., Chabior A. (2015). *Ludzka starość. Wybrane zagadnienia gerontologii społecznej*, Kraków: Oficyna Wydawnicza „Impuls".

Fauth E. B., Femia E.E., Zarit S.H. (2016). "Resistiveness to Care during Assistance with Activities of Daily Living in Non-Institutionalized Persons with Dementia: Associations with Informal Caregivers' Stress and Well-Being," *Aging & Mental Health*, no. 9, pp. 888–898.

Gabryelewicz T. (2014). "Epidemiologia choroby Alzheimera," [in:] *Sytuacja osób chorych na chorobę Alzheimera. Raport RPO*, Warszawa: Biuro Rzecznika Praw Obywatelskich, pp. 33–34.

Grochmal-Bach B. (2007). *Cierpienie osób z otępieniem typu Alzheimera. Podejście terapeutyczne*, Kraków: Wydawnictwo WAM.

Grunfeld E., Coyle D., Whelan T. et al. (2004). "Family Caregiver Burden: Results of a Longitudinal Study of Breast Cancer Patients and Their Principal Caregivers," *Canadian Medical Association Journal*, vol. 170, no. 12, pp. 1795–1801.

Halicka M. (2006). "Problemy rodziny w opiece nad człowiekiem starym niesprawnym," [in:] M. Halicka, J. Halicki (eds.), *Zostawić ślad na ziemi*, Białystok: Wydawnictwo Uniwersytetu w Białymstoku, pp. 242–254.

Hausz-Piskorz B., Buczkowski K. (2013*)*. "Diagnostyka i leczenie choroby Alzheimera w warunkach praktyki lekarza rodzinnego," *Forum Medycyny Rodzinnej*, vol. 7, no. 4, pp. 198–207.

Hrynkiewicz J. (2022). "Niesamodzielna starość jako nowe ryzyko socjalne," [in:] J. Hrynkiewicz, M. Halicka (eds.), *Niesamodzielna starość. Materiały z III Kongresu Demograficznego*, part 2, Warszawa: Rządowa Rada Ludnościowa, pp. 46–76.

Iwański R. (2016). *Opieka długoterminowa nad osobami starszymi*, Warszawa: Wydawnictwo CeDeWu.

Iwański R., Bugajska B. (2019). "Rodzina w sytuacji opieki nad osobą chorą na chorobę Alzheimera w wieku 75 i więcej lat," [in:] M. Wysokiński, Z. Sienkiewicz, W. Fidecki (eds.), *Człowiek w podeszłym wieku w ujęciu interdyscyplinarnym*, Warszawa: Warszawski Uniwersytet Medyczny, pp. 32–41.

Kawczyńska-Butrym Z. (2008). *Wyzwania rodziny: zdrowie, choroba, niepełnosprawność, starość*, Lublin: Wydawnictwo Makmed.

Knapik-Czajka M. (2010). "Choroba Alzheimera rosnącym wyzwaniem dla starzejącego się społeczeństwa," [in:] G. Dębska, J. Jaśkiewicz (eds.), *Interdyscyplinarne aspekty nauk o zdrowiu*, Kraków: Oficyna Wydawnicza AFM, pp. 139–146

Kozak-Putowska D., Iłżecka J. (2016). "Jakość życia chorych na chorobę Alzheimera," *Pielegniarstwo XXI Wieku*, vol. 15, no. 2, pp. 50–53.

Lepore M., Ferrell A., Wiener J. (2017). *Living Arrangements of People with Alzheimer's Disease and Related Dementias: Implications for Services and Supports*, https://aspe.hhs.gov/system/files/pdf/257966/LivingArran.pdf [access: 28.04.2023].

Najwyższa Izba Kontroli (2017). *Opieka nad osobami chorymi na chorobę Alzheimera oraz wsparcie dla ich rodzin*, Warszawa: Najwyższa Izba Kontroli, https://www.nik.gov.pl/plik/id,13694,vp,16130.pdf [access: 28.04.2023].

Ogólnoeuropejskie wytyczne dotyczące przejścia od opieki instytucjonalnej do opieki świadczonej na poziomie lokalnych społeczności (2012). https://www.power.gov.pl/media/70778/ogolnoeuropejskie_wytyczne_deinstytucjonalizacja.pdf [access: 28.04.2023].

Resolution No. XV/501/20 of the Szczecin City Council of 25 February 2020 amending the resolution on implementation in the territory of the Municipality of Szczecin of the cash benefit "Voucher for Care: Alzheimer 75" and authorizing the Director of the Szczecin Benefits Centre to conduct proceedings, including issuing administrative decisions concerning the cash benefit "Voucher for care: Alzheimer 75", https://rada.szczecin.pl/UMSzczecinBIP/files/ED694C2F2FAA49579893EDEF77A6410F/501.pdf [access: 28.04.2023].

Rosińska A., Jaźwińska E., Kiełkowska M., Kloc-Nowak W., Radziwinowiczówna A. (2018). "Seniorzy i ich rodziny – migracje i rozwiązania opiekuńcze," [in:] M. Okólski (ed.), *Wyzwania starzejącego się społeczeństwa Polska dziś i jutro*, Warszawa: Wydawnictwo Uniwersytetu Warszawskiego, pp. 287–310.

Sadowska A. (2014). "Organizacja opieki nad chorym na chorobę Alzheimera w Polsce," [in:] *Sytuacja osób chorych na chorobę Alzheimera. Raport RPO*. Warszawa: Biuro Rzecznika Praw Obywatelskich, pp. 42–45.

Szatur-Jaworska B. (2014). "Starość w polskiej rodzinie," [in:] P. Szukalski (ed.), *Relacje międzypokoleniowe we współczesnych polskich rodzinach*, Łódź: Wydawnictwo Uniwersytetu Łódzkiego, pp. 25–40.

Strategia Rozwiązywania Problemów Społecznych (2015). www.mopr.szczecin.pl/strona_glowna/strategia_rozwiazywania_problemow_spolecznych_dla_gminy_miasto_szczecin_na_lata_2015-2020/ [access: 28.04.2023].

Strategia Rozwiązywania Problemów Społecznych do 2027 r. (2022). http://mopr.szczecin.pl/dokumenty/Strategia-Rozwiazywania-Problemow-Spolecznych-dla-Gminy-Miasto-Szczecin-do-roku-2027r.pdf [access: 28.04.2023].

Szukalski P. (2002). *Przepływy międzypokoleniowe i ich kontekst demograficzny*, Łódź: Wydawnictwo Uniwersytetu Łódzkiego.

Szweda-Lewandowska E. (2014). "Starzenie się ludności a sektor usług opiekuńczych," [in:] P. Szukalski (ed.), *Starzenie się ludności a solidarność międzypokoleniowa*, Łódź: Wydawnictwo Uniwersytetu Łódzkiego, pp. 134–147.

WHO (2020). *Global Action Plan on the Public Health Response to Dementia 2017–2025*, https://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/ [access 1.05.2023].

Wojszel Z.B., Bień B. (2002). "Choroba Alzheimera – problem diagnostyczny i terapeutyczny," *Medycyna Rodzinna*, no. 1, pp. 2–6.

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