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Prevention of social exclusion of seniors with cognitive disorders and the families who care for them

Profilaktyka wykluczenia społecznego seniorów z zaburzeniami poznawczymi i opiekujących się nimi rodzin

Abstract

Aim. The purpose of this paper is to analyze and present effective strategies and programs to prevent social isolation of seniors with cognitive disorders and the families who care for them. Numerous studies show that factors such as lack of social support, low public awareness of cognitive disorders and insufficient institutional resources contribute to deepening exclusion.

Methods and materials. Qualitative method. Content analysis of scientific articles on the prevention of social exclusion of seniors with cognitive disorders and their family caregivers.

Results and conclusion. Prevention should include educational activities, emotional and psychological support, development of social support networks, and access to medical

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and rehabilitation services. The support of families, who often become the main caregivers of people with cognitive impairment, is also an important element. The implementation of comprehensive prevention programs can help improve the quality of life for both seniors and their caregivers, counteracting social exclusion and promoting social inclusion. It is also important to develop public policies and local initiatives that support the creation of a friendly environment for seniors, including access to education, culture, and recreation. It is crucial to involve various social sectors, such as health care, NGOs, local governments, and communities, in creating coherent and integrated actions for seniors and their family caregivers. Only through coordinated and multifaceted efforts can social exclusion be effectively countered and dignified and active aging be ensured.

Keywords: family, prevention, senior, cognitive disorders, exclusion.

Abstrakt

Cel. Celem niniejszej pracy jest analiza i przedstawienie skutecznych strategii oraz działań służących zapobieganiu izolacji społecznej seniorów doświadczających zaburzeń poznawczych i ich rodzinnych opiekunów. Liczne badania pokazują, że czynniki takie jak brak wsparcia społecznego, niska świadomość społeczna na temat zaburzeń poznawczych oraz niedostateczne zasoby instytucjonalne przyczyniają się do pogłębiania wykluczenia tej grupy osób. A to wszystko niewątpliwie przyczynia się do obniżenia jakości życia zarówno samych seniorów, jak również członków ich rodzin.

Metody i materiały. Metoda jakościowa. Analiza treści publikacji naukowych dotyczących profilaktyki wykluczenia społecznego seniorów z zaburzeniami poznawczymi i ich opiekunów rodzinnych.

Wyniki i wnioski. Profilaktyka powinna obejmować działania edukacyjne, wsparcie emocjonalne i psychologiczne, rozwój sieci wsparcia społecznego oraz dostęp do usług medycznych i rehabilitacyjnych. Ważnym elementem jest również wsparcie rodzin, które często stają się głównymi opiekunami osób z zaburzeniami poznawczymi. Wdrażanie kompleksowych programów profilaktycznych może przyczynić się do poprawy jakości życia zarówno seniorów, jak i ich opiekunów, co przeciwdziała wykluczeniu społecznemu oraz promuje integrację społeczną. Istotne jest także rozwijanie polityk publicznych oraz inicjatyw lokalnych, które wspierają tworzenie przyjaznego środowiska dla seniorów, w tym dostępu do edukacji, kultury i rekreacji. Kluczowe jest zaangażowanie różnych sektorów społecznych, takich jak służba zdrowia, organizacje pozarządowe, samorządy oraz społeczności lokalne, w tworzenie spójnych i zintegrowanych działań na rzecz seniorów i ich rodzinnych opiekunów.

Słowa kluczowe: rodzina, profilaktyka, zaburzenia poznawcze, wykluczenie, senior.

Introduction

At the beginning of this reflection, one should ask: Do Polish seniors experience social exclusion? More precisely, one could also ask: Are seniors experiencing cognitive disorders, including dementia diseases, and their families at risk of social exclusion? The answer to a question phrased in this way is yes. How many of us, when we meet a disoriented person who doesn't know where they are or where they want to go, leave them on their own and don't give them help or support? How many of us minimise contact with relatives, friends or acquaintances when we find out that they have a person with dementia or cognitive impairment among their loved ones? How many of us, if a loved one – our mother or father – was diagnosed with a dementia or other cognitive disorder, would begin to isolate ourselves socially and isolate that person at the same time?

No one doubts that our society is ageing. Year after year, there are more and more people who have stopped working and, as a result, their quality of life has deteriorated, as evidenced by research studies (*cf*. Gierek, 2021; Lada, 2018; *Sytuacja osób starszych w Polsce*… [Situation of the elderly in Poland...], 2023). Very often, retirement is equated with reduced social activity, seniors becoming isolated, as well as isolated by the social environment in which they live. The loneliness very often accompanying that isolation experienced by older people worsens with age and is a contributor to the development of mental disorders, especially dementia syndromes and disorders of consciousness. There is no doubt that such disorders can be a challenge in pedagogical work with older people.

Cognitive performance makes up our daily functioning and has an impact on our quality of life, including functioning in social environments. Whether an older person will experience cognitive impairment, according to Roberto Cabeza and colleagues (2018), depends on several factors: level of education, occupational status, performance of physical activities, participation in extra-curricular activities, active leisure time, involvement in voluntary and social activities and performance of activities that are demanding.

Cognitive disorders in the elderly – dementia syndromes, disorders of consciousness from an educational perspective

The quality of life decreases as a result of the development of cognitive disorders, but also the occurrence of dementia or neurodegenerative diseases. Cognitive impairments include, for example, perceptual disorders, attention disorders, memory disorders or thought disorders (thought emptiness, delusions, obsessions, somatic delusions,

ambivalence) (Sumińska, Grodecka, 2022). In addition to these, diseases such as Alzheimer's disease or dementia can occur, which usually affect people over 65 (Sumińska, Grodecka, 2022).

The International Statistical Classification of Diseases and Related Health Problems ICD-10 (ICD-11 was introduced on 1 January 2022, however, in Poland, we still use its older version, i.e., ICD-10, as we have a 5-year transition period, which will end in 2025 at the earliest) mental disorders in the elderly (over 60 years of age) are divided into:

- organic mental disorders (e.g., dementia, including Alzheimer's disease, vascular dementia);
- syndromes of consciousness disorders (e.g.. mood disorders, confusion, delirium, and organic personality and behavioural disorders);
- neurotic disorders (e.g., adjustment disorders, phobias, obsessive-compulsive disorders);
- behavioural disorders (e.g., eating or non-organic sleep disorders) (Gutowska, 2016).

Lifelong social participation may reduce the risk of dementia by increasing cognitive reserve, reducing stress and improving cerebrovascular health. This may therefore have important implications for individual behaviour and for public health policies aimed at reducing the burden of dementia. Observational studies by Andrew Sommerlad and colleagues (2023) indicate that greater participation in social life in middle and later life is associated with a 30–50% lower risk of dementia, although some of these factors may not be causal. Interventions in the field of social participation have led to improved cognitive functions, but due to the short observation period and the small number of participants, the studies did not reduce the risk of dementia.

The study of cognitive impairment in senior citizens as part of the *PolSenior 2* study showed that the frequency of this type of impairment in Poland is high. On average, one in six people aged 60+ experience cognitive deficits to an extent that suggests dementia. Moreover, cognitive deficits are more common in the oldest seniors and those with a lower level of education, and the frequency and severity of cognitive deficits increase with age (Klich-Rączka, Piotrowicz, Kujawska-Danecka, Zagożdżon, & Mossakowska, 2021).

Social exclusion of the elderly and their families

The consequence of these disorders for senior citizens and their family members can be social exclusion. In the *National Strategy for Social Integration for Poland* (2003,

p. 22), social exclusion is defined by the Task Force for Social Reintegration as "[...] the lack or limitation of opportunities to participate in, influence and benefit from basic public institutions and markets that should be accessible to all, especially the poor." The authors of the *National Strategy*, however, point out that it is difficult to clearly define the phenomenon of social exclusion because it encompasses several interrelated dimensions of marginalisation, including:

- living in unfavourable material conditions;
- facing the consequences of unfavourable social processes resulting from developmental changes, e.g., deindustrialisation, the decline of industries or regions;
- lack of life capital (low social position, low level of professional qualifications);
- lack of or limited access to institutions that enable the building, development and utilisation of life capital;
- experiencing discrimination due to a lack of appropriate legislation and stereotypes and prejudices;
- having characteristics that make it difficult to use social resources (disability, long-term illness);
- actions of other people, e.g., indoctrination, violence (*National Integration Strategy…*, 2003).

Joanna Grotowska-Leder, meanwhile, distinguished four dimensions of social exclusion:

- exclusion from economic activity (unemployment, disability);
- exclusion from consumption (poverty);
- exclusion from mechanisms of influence and power (cultural and political marginalisation);
- exclusion from the community (loneliness) (Grotowska-Leder, 2005).

Social exclusion can have many causes, manifestations and consequences. Barbara Szatur-Jaworska lists the following causes of exclusion among the elderly:

- lack of independence in everyday life due to illness and disability;
- low level of education;
- limitations of position in the family related to the ongoing systemic transformation;
- limitations of the current labour market;
- commercialisation of a culture in which old age is not recognised and has a low presence;
- the cult of youth resulted in the displacement of the image of old age and death from the public consciousness (Szatur-Jaworska, 2005).

In addition, the reasons for the exclusion of seniors with cognitive impairments include:

- lack of or low public awareness of cognitive disorders, which can lead to stereotypes, prejudice and stigmatisation, making it difficult for people with these disorders to integrate into society;
- lack of access to resources or limited access to specialised medical care, therapy, social support and appropriate education and training programmes, often due to place of residence or resources available;
- cognitive impairments, which can also lead to difficulties in communication and social interaction, which can cause older people with these impairments to feel isolated;
- difficulty in performing daily activities independently for elderly people with cognitive impairments, which can lead to dependence on family carers (or non-relatives if they use care services or specialised care services) and limit their participation in social life. This often leads to self-isolation, which is one of the manifestations of social exclusion.

Among the manifestations of exclusion of seniors with cognitive impairments or neurodegenerative diseases, the following can be identified:

- social isolation, where older people with cognitive impairments may withdraw from social interaction due to communication, social or emotional difficulties;
- lack of acceptance and understanding from society, which leads to feelings of isolation and, in extreme cases, loneliness for both senior citizens and their family carers;
- loss of autonomy and independence when older people with cognitive impairments are unable to participate in social life and make their own decisions.

Social exclusion has some consequences that can be particularly felt by elderly people with cognitive impairments and their family members. These consequences include:

- a reduction in the quality of life for both people with cognitive impairments and their families, which can lead to depression, anxiety and other health problems;
- difficulty in coping with the challenges associated with cognitive impairments, which increases the burden on families;
- limited social, personal, educational and professional development opportunities for people with cognitive impairments (and above all for their

family carers, as they are often forced to give up work to care for a family member), which can lead to a further deterioration in their social and economic situation.

Society needs to take action to prevent the social exclusion of people with cognitive impairments through education, awareness raising, sensitisation, social support and the creation of more inclusive environments.

Preventing social exclusion of the elderly

In the context of these disorders, the educator can provide support or assistance to the senior citizen and his or her family carers by using communication methods tailored to the individual's needs, promoting mental and physical activity, and collaborating with other specialists. It is also important to promote an environment conducive to the mental and social health of older people. Preventing cognitive impairment plays a huge role. Activities that can be proposed to seniors are those that improve physical fitness, the so-called "SEEDS." The letters of the acronym stand for: *social support*, *exercise*, *education*, *diet*, and *sleep* (Sumińska, Grodecka, 2022).

Preventing social exclusion among elderly people with cognitive impairments and their families is crucial to ensuring they can live a dignified life and participate fully in society. Here are a few preventive strategies:

- Education and public awareness: educational campaigns to raise public awareness of cognitive disorders can reduce stigma and prejudice, facilitating the integration of older people with these disorders into society.
- Access to healthcare: ensuring access to high-quality healthcare, including diagnosis, treatment and rehabilitation for seniors with cognitive disorders, is crucial for preventing the progression of the disease and maintaining the highest possible quality of life.
- Support for carers: providing support for carers of seniors with cognitive impairments, such as training, advice and respite care, can help prevent burnout and social exclusion for both seniors and their families.
- Creating a friendly and inclusive social environment for seniors with cognitive impairments through the availability of services, communication facilities, and the organisation of events and activities tailored to their needs.
- Promoting social activity among seniors with cognitive impairments by organising support groups, therapeutic activities, recreational activities, senior clubs and other forms of social activity.

– Continuation of independence: Encouraging seniors with cognitive impairments to maintain as much independence and autonomy as possible through appropriate support, training and adaptation of the environment to their needs.

At the level of government administration, a document entitled *Polityka społeczna wobec osób starszych 2030: Bezpieczeństwo – Uczestnictwo – Solidarność* (Social policy towards the elderly 2030: Security – Participation – Solidarity) was adopted in 2018. The Ministry of Family, Labour and Social Policy was responsible for implementing its provisions. The document provides for several measures to be taken to ensure optimal living conditions for the elderly. Among the seven areas indicated in the document, the chapter entitled "Uczestnictwo w życiu społecznym oraz wspieranie wszelkich form aktywności obywatelskiej, społecznej, kulturalnej, artystycznej, sportowej i religijnej [Participation in social life and support for all forms of civic, social, cultural, artistic, sporting and religious activity]" is significant from the point of view of preventing the social exclusion of senior citizens, including those with cognitive impairments] (*Polityka społeczna wobec osób starszych* [Social policy towards the elderly]…, p. 10).

In particular, care should be taken to improve cognitive functions in dependent elderly people (including those suffering from dementia and other demential syndromes) by developing educational programmes to help them exercise their memory, concentration, perception and other cognitive functions. It is also important to conduct socio-educational campaigns on dementia to break the stereotypes associated with it (Korycki, 2020).

By implementing preventive strategies and measures, the risk of social exclusion for seniors with cognitive impairments and their families can be reduced and they can be enabled for full participation in social life.

A model of social support in the place of residence for people with cognitive impairments and their families – examples of good practice

There is no doubt that social support is needed by every person, regardless of their current stage of life. It is particularly important for the elderly, especially those affected by cognitive impairment. The families and carers of these people also need information, practical and, above all, emotional support in their daily responsibilities of caring for the elderly. Informal sources of support can be family members, friends, acquaintances, neighbours or self-help groups. In addition to these, action by public institutions and local authorities is essential in this area.

Social support should take place on three levels, i.e., material, organisational and social. The social support model proposed by Piotr Błędowski, Barbara Szatur-

Jaworska, Zofia Szweda-Lewandowska, and Maria Zrałek (2017) covers various needs and ways of meeting them and does not focus exclusively on the dependence of senior citizens and the care services that can be provided to them. The authors mentioned the following areas of support: financial security, health, care, safety at home, leisure, education and housing. For people with cognitive impairments, it is important to provide medical and social support. Examples include the organisation of daycare or temporary care places, as well as a psychological and organisational support system for families caring for seniors with cognitive impairments. Depending on the severity of the disorders, various forms of support should be adapted to the senior's situation – from those provided at the senior's place of residence, through semi-open facilities, to the provision of specialist support and care, e.g., a geriatric doctor and other specialists depending on comorbidities (including rehabilitation).

In addition to the components of the support model for people with cognitive impairments and their families in their place of residence mentioned by the authors, it can also include other elements:

- Psychological support: offering psychological therapy to both people with cognitive impairments and their families to help them cope with stress, frustration and difficulties related to the disease.
- Social support: creating support groups for people with cognitive impairments and their families, where they can share their experiences, and receive emotional support and valuable information from others experiencing similar situations.
- Education and training: organising training for families and carers of people with cognitive impairment to better understand the disease, its symptoms and methods of coping with it.
- Practical support: providing help with everyday activities such as shopping, cooking and cleaning the house to take the strain off both the person with cognitive impairment and their family.
- Integrated approach: cooperation with various institutions, such as healthcare, social services and NGOs, to provide comprehensive support for people with cognitive impairments and their families.

Providing social support for people with cognitive impairments and their families can significantly improve their quality of life and enable them to better cope with the challenges associated with the disease.

These are some examples of good practice in social support models for people with cognitive impairments and their families:

- Activity centres, including senior clubs, offer a range of activities for people with cognitive impairments, such as therapeutic classes, creative workshops

and sports activities, and help with social integration by organising events and meetings in local communities.
- Respite care: a programme that provides families of people with cognitive impairments with periodic rest by providing care for the sick person in the absence of caregivers. This can be in the form of short-term stays in care facilities or home visits.
- Support groups: regular group meetings for people with cognitive impairments and their families are an effective form of emotional support and exchange of experiences. They can be self-help or professionally led, depending on the preferences of the participants.
- Home care: Home care programmes enable people with cognitive impairments to remain in their environment while receiving appropriate support. Home carers can help with daily activities, health monitoring and companionship.
- Community initiatives: local community initiatives such as volunteering in elderly care or organising social events can contribute to the integration of people with cognitive impairments in the local community and promote acceptance and understanding.
- Education and training: education and training programmes for the families of people with cognitive impairment can help them understand the disease, learn effective coping strategies and provide support in caring for the person with the disease.

The prevalence of cognitive impairment among older people in Poland is high. Based on the results of the *PolSenior 2* study (Błędowski, Grodzicki, Mossakowska, & Zdrojewski, 2021), it is estimated that 16.8% of people aged 60 and over in Poland present mild cognitive impairment and 15.8% are suspected of having dementia. On average, one in six people aged 60 and over has a cognitive deficit to the extent that dementia is suspected. These disorders include problems with memory, perception, attention and thought processes. Examples of good practices can inspire the development of support models for people with cognitive impairments and their families in different communities.

The role of health education for seniors in preventive measures

Health education objectives focus on three aspects of human functioning: health, risk factors, and coping with illness. Andrew Tannahill has therefore developed three health education models:

- a health-oriented health education model (e.g., promotion of a healthy lifestyle, undertaking health-promoting activities);
- a health education model focused on risk factors (e.g., providing advice on how to improve health);
- a health education model focused on disease (raising awareness of the relationship between risk factors and disease) (Tannahill, 1990).

Health education for senior citizens is certainly important for the prevention of cognitive disorders, including neurodegenerative diseases. It promotes continuous human development, allows maintaining responsibility for one's own life for a long time, contributes to improving the quality of life, and thus ensures self-sufficiency and resourcefulness, broadens social competencies and allows the development of new skills, e.g., the use of modern technologies in everyday life, as well as coping with difficult situations. Furthermore, it encourages senior citizens to take action and influence their personal and social lives.

It is essential to take preventive measures to counteract the exclusion of senior citizens with cognitive impairments and their family carers. This should include comprehensive prevention, which consists of educational measures, social support and integration programmes. All these measures are crucial for improving the quality of life of seniors with cognitive impairments and their families.

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