

REVIEW / PRACA POGLĄDOWA

Weronika Jurczak, Katarzyna Porzych, Anna Polak-Szabela

NURSE'S ROLE IN TAKING CARE OF A PATIENT WITH ALZHEIMER'S DISEASE**ROLA PIEŁĘGNIARKI W OPIECE NAD PACJENTEM Z CHOROBAŁ ALZHEIMERA**

Department of Geriatrics Nicolaus Copernicus University in Toruń, Collegium Medicum in Bydgoszcz

Head: prof. dr hab. n. med. Kornelia Kędziora-Kornatowska

S u m m a r y

Along with the development of medicine, the duration of human life lengthened. Thus, the number of people that live to a great age has increased. One of the main health issues concerning people in old age is dementia. The most common cause of dementia that occurs after 65 years of age is Alzheimer's disease. The course of the disease is progressive and it gradually leads to the situation when a patient is dependent on others. In most cases, the burden of care of a

person with Alzheimer's disease falls on the family members and friends. It is not an easy task. Often the family is not able to provide a proper patient care and therefore, it requires comprehensive medical, social, educational and financial help. The present study describes an important role of nurses, who not only accompany patients and their caregivers, but also educate and support them.

S t r e s z c z e n i e

Wraz z postępowaniem medycyny wydłużyło się trwanie życia ludzkiego. Zwiększa się więc liczba osób dożywających wieku sędziwego. Jednym z największych problemów zdrowotnych osób w podeszłym wieku jest otępienie. Najczęstszą z przyczyn otępienia występującego po 65 roku życia jest choroba Alzheimera. Przebieg schorzenia jest postępujący i stopniowo prowadzi do uzależnienia chorego od innych. Przeważnie ciężar opieki nad człowiekiem z

chorobą Alzheimera spada na osoby najbliższe. Nie jest to łatwe zadanie. Często rodzina nie jest w stanie zapewnić odpowiedniej opieki choremu, dlatego wymaga wszechstronnej pomocy medycznej, społecznej, edukacyjnej i finansowej.

W niniejszej pracy opisano bardzo ważną rolę pielęgniarek, które towarzyszą chorym i ich opiekunom, edukują i wspierają ich.

Key words: dementia, Alzheimer's disease, old age**Słowa kluczowe:** otępienie, choroba Alzheimera, wiek podeszły**INTRODUCTION**

Aging is a normal physiological process. If there are no complications in the course of the process, it can be described as normal aging. However, in most cases it is pathological aging, i.e. aging that has been accelerated or complicated by chronic disease processes [1].

Dementia is one of the most challenging health problems in the elderly. Alzheimer's disease is the most common cause of dementia and accounts for approximately 50-70% of all cases of dementia. The disease is named after the German neurologist Alois

Alzheimer, who first described the pathological changes characteristic of this disease [2, 3].

Number of people affected by Alzheimer's disease is constantly growing; the incidence of the disease is up to 8% in people over 80 years of age and concerns almost half of this population [4]. The number of people with Alzheimer's disease in the world is estimated at around 15-21 million. In Poland, the various forms of dementia concern around 500,000 people, and half of that number is dementia of the Alzheimer type [5].

Due to an increasing incidence of this disease it is crucial to raise awareness and spread knowledge about the disease as well as to develop support for patients

and their families. Taking care of a person with Alzheimer's disease is a very difficult and responsible task that demands devotions from a caregiver. Help of a professional therapeutic team is important. Nurse's tasks include not only care, performing specialist treatments, help with everyday activities but also accompanying, supporting and mainly educating caregivers and patient's family.

NATURE OF THE DISEASE

Alzheimer's is a primarily degenerative dementia process characterised by the loss of neurons and synaptic connections of the brain. It is a continuously advancing process [2, 3].

In the brain of the patient two proteins with altered conformation are deposited. β -amyloid is deposited in the form of extracellular amyloid senile plaques. Tau protein accumulates inside of neurons as neurofibrillary tangles. Symptoms of the disease are visible after many years of this pathological process in the brain. Loss of neurons and connections cannot be compensated by the abilities of brain plasticity. It is macroscopically manifested by atrophy of the brain [5].

The presence of neurofibrillary tangles and senile plaques in brain tissue is considered to be a base of pathological diagnosis of the disease. Disorders of certain neurotransmitters are an important factor in the pathophysiology of the disease. The number of cholinergic neurons is reduced and the activity of choline acetyltransferase is limited; however, activity of acetylcholinesterase increases. This is connected with a decrease in acetylcholine synthesis and an increase in its distribution. Disorders in serotonergic, dopaminergic and glutaminergic systems are also noted [2].

No definite cause of Alzheimer's disease has been found. Multiply causation is indicated as there are many factors that can be important in the etiology of the disease. These include aforementioned pathological changes in the brain as well as: genetic predisposition, theories of free radicals, viral infections, inflammatory processes in the brain and environmental factors.

Alzheimer's disease is a process that develops very secretly and slowly. No rapid changes in clinical condition of the patient are observed. Dementia in Alzheimer's disease occurs in stages following one after another. The course of the disease depends greatly on individual characteristics of the patient and may

differ from other cases. There are several stages depending on the clinical phase [6].

The beginning of the Alzheimer's disease is elusive and often invisible for the patient and the family. It is believed that mild cognitive impairment (MCI) may be an early stage of Alzheimer's dementia. Cognitive impairment may occur along with memory disorders, language and visual-spatial disorders. With the development of the disease, the patient is becoming less independent and requires more care. In the last stage of the disease the patient is completely dependent on the caregiver [7, 8].

Despite the continuous development of science, there are currently no therapeutic possibilities that would allow a complete cure for the disease. Treatment of Alzheimer's disease still remains symptomatic. Applied treatments modify the clinical course and may slow down the occurrence of symptoms but they do not influence the regression of the disease. It is desirable to combine pharmacological treatment with non-pharmacological one. The effect of the use of medications is to slow down and delay the appearance of new symptoms, while the goal of non-pharmacological treatment is to reduce the results of progressive damage to the central nervous system. The combination of these two types of therapy can improve the quality of life of patients and their daily functioning [3, 5].

ORGANIZATION OF CARE

Taking care of a person with Alzheimer's disease should be comprehensive. The team holding the therapeutic care of patients includes: a doctor, a nurse, a caregiver, a social worker and a physiotherapist. They must work closely together. However, it is also required for the specialists to cooperate with the patient's family, mainly in the aspect of mutual exchange of information on the biological, psychological and social state of the patient, which allows a better implementation of protective activities. Proceedings in working with patients require an adjustment of the surrounding of physical and social environment. Interventions of the entire therapeutic team aim to inhibit the progression of the disease and prevention of complications. The goal is to ensure that a patient stays self-reliant and independence as long as possible. This allows improvement in self-esteem of the patient and reduction of the burden on a caregiver.

Protective activities lead to improving the quality of life of the patient and ensuring his safety [2].

Due to the large variation in the course of disease, it is not possible to establish uniform rules of procedure with the patient. When organizing care, it is crucial to assess patient's ability, capabilities, needs and interests as well as to define the types and number of existing deficits. Type and scope of caregiver's tasks change with the progression of the disease. From the first stage the needs of the patient should be fulfilled and his future should be planned. It is important to create an atmosphere of safety and trust and present the attitude of kindness, respect and acceptance of the patient's behaviour [2, 9].

In majority of cases, these are the family members who take care of a patient with Alzheimer's disease; usually a spouse or children. With the progression of the disease, more difficult problems that unable the family to provide the sick with proper care occur. Patient's family can count on emotional support and information from the doctor, nurse and social worker as well as Alzheimer's organizations as it is essential to have the knowledge of Alzheimer's disease, its stages and symptoms to implement proper care. Along with cooperation with the patient's family, education of the therapeutic team is important. A person suffering from Alzheimer's disease should remain in their own home for as long as possible since providing permanent environment gives a sense of security and prevents the appearance of additional negative behaviours of the patient. When taking care in the home environment becomes impossible, placing the patient in a care institution should be considered [10].

CARE PROBLEMS

Care problems related to the Alzheimer's disease change during its course. Early recognition of symptoms is very difficult; therefore, many patients and their families do not notice or ignore them. As the disease progresses, the scope of required assistance increases and the type of help changes. Dementia is the main symptom of Alzheimer's. In the patient cognitive function disorders, problems with memory and orientation (awareness of the place, date, season, time, people) and other disorders of intellectual function appear. Initially, these are sporadic but occur more often with time. Problems in everyday functioning also appear.

In the early stages of the disease the patient may have problems remembering names and names of objects. Often the patient does not remember the steps he has just performed (he does not know why he has opened the wardrobe or where he has put away a certain item. These symptoms are very common and may be ignored by the family and the patient. Only when such situations are repeated and become annoying, patient's family start to understand that they can be associated with the disease. In the initial period of illness help is based primarily on supporting the patient by reminding him names, names of objects, dates or words. The patient may need guidance regarding the location of various objects. Therefore, this assistance is mostly related to patient's memory disorders [11].

In subsequent stages of the illness, the patient begins to have language difficulties and a gradual loss of communication skills occurs. There are problems with articulation, and in an advanced stage of the disease the ability to speak can completely disappear. While the ability to communicate deteriorates, it is very important for caregivers to constantly communicate with the patient.

Along with the progress of the disease, patients require more assistance with everyday chores such as cleaning, preparing meals or shopping. Later, patients also need support in the performance of personal hygiene activities such as dressing and washing. Changes in personality or behaviour disorders occur. In Alzheimer's disease the patient may also suffer from depression and hallucinations or delirium so for safety reasons, people affected by Alzheimer's disease require supervision most of the time. In subsequent stages of the disease, physical impairment, problems with walking, unnatural stiffness or tremor appear. There is a need of assistance in performing daily activities such as moving and satisfying physiological needs. In the late stage of the disease, the patient becomes completely reliant, both physically and mentally. Often patients are not able to move around, make contact or satisfy their physiological needs. There are also disturbance of consciousness and a total loss of contact with the environment

The problems that may arise during the care of a person with Alzheimer's disease show how difficult the role of guardian is. Only memory disorders in the early stage of the disease when the patient is still physically fit can constitute a huge psychological burden for a caregiver. In subsequent stages emotional, mental and

physical problems become such a large burden that a caregiver may not be able to cope with alone. Often, financial situation and family affairs cause additional problems. That is why, help of the therapeutic team in terms of knowledge, ways of coping, daily needs and providing time off for a caregiver is crucial. In some situations, despite help from the therapeutic team, nursing care at home may become impossible. It may be necessary to place the patient in a nursing home with 24/7 supervision. Such decision is very difficult to take and is often associated with a variety of concerns, mostly a sense of guilt. It causes unpleasant emotions for both caregiver and the sick. However, the carer should be aware that if patient cannot be offered proper care, the decision to transfer the patient to the health care facility may be the best solution [10, 11].

Caregivers of people with Alzheimer's disease should try to avoid situations that may exacerbate the symptoms of the disease. One should be provident, take care of the environment of the patient and act in such a way as to avoid additional problems and accidents. To ensure proper patient care and safety it is important to take some precautions. If a patient requires intensive supervision, the following should be done:

- secure the apartment door to prevent escape and disappearance of a patient;
- protect the windows so that the patient cannot open them without help;
- remove the locks from the doors to the rooms such as the bathroom or the patient's room;
- remove rugs, high thresholds and other obstacles that pose a risk of falling;
- keep sharp, dangerous objects out of reach of the patient,
- protect electrical appliances, gas stoves, sockets, junkers and others that may pose a risk to the patient;
- make it easier to move around the apartment with the use of facilities such as attaching strong stair railing, brackets used to hold when going out of the bath or when using the toilet;
- inform friends and close neighbours about the state of the patient;
- sign the doors of rooms, objects, cabinets in order to increase the sense of orientation in space;
- take care of the proper use of medicines by the patient;
- protect documents and valuables because the patient may unwittingly throw away or hide items important to relatives;

- establish the daily routine of the patient;
- allow regular contact with a medical specialist;
- take care of caregivers' mental and physical health as well as relaxation;
- settle legal matters such as financial management of the patient, will, incapacitation [12].

NURSE'S ROLE IN TAKING CARE OF ALZHEIMER'S DISEASE PATIENT

Nursing is a very complex and diverse field. Today's nurses hold many functions that result from the mission of the profession. These include mainly tasks related to health promotion, preventive care, education, diagnosis, medical treatments and rehabilitation. Nurses also perform functions for personal development through continuous training, obtaining qualifications and gaining broad theoretical and practical knowledge. This profession also gives the opportunity to teach and conduct research work in the field of nursing. In carrying out the above tasks, the nurse acts according to certain standards and models respecting all the rights and obligations contained in laws and regulations related to the profession. Before taking actions, it is important to accurately define the needs, conditions and nursing problems. The nurse provides services independently and in collaboration with the physician by executing orders [13, 14].

Caring for a person with Alzheimer's disease is a very difficult task. Therefore, people taking care of patients require assistance of competent persons. At each stage of the disease support from the specialists is needed. Although, for providing proper care it is important to cooperate with all members of the therapeutic team (doctors, nurses, social workers, physiotherapists, psychologists, speech therapists), role of a nurse is special. Her help aims at reducing the burden on caregiver and maintaining the patient's independence in everyday life for as long as possible. It also includes not only caring for the patient during the caregiver's incapacity but also accompanying, supporting and identifying sources of help, educating and facilitating access to specialist care and social assistance. The nurse strives to provide the highest quality of life of the sick and caregiver and prevents complications of the disease. Educational role of the nurse is very important, especially when it concerns care of patients with Alzheimer's disease so a caregiver needs to be well-prepared for providing such care [15, 16].

Making a diagnosis for a patient who is taken care of at home, it is necessary to collect reliable data on the patient, his family and environment. Firstly, it is important to establish if relatives are able and want to take care of the sick; one should also obtain information about biological, psychological and social state of the patient and about functioning of his family. When planning to leave the patient in care of his relatives, a nurse must carefully check their resources and verify the scope of preparations needed for conducting proper care. These depend not only on patient's health but also on relatives' knowledge, and skills deficits, which determine the scope of nurse's activities. The nurse must define information that should be passed to the family members and what activities should be taught [17].

A nurse taking care of a person with Alzheimer's disease and supporting a caregiver of that person has the required knowledge and practical skills, recognizes the patient's problems correctly, and shows support and understanding. She can also determine the level of functioning of the patient and adjust the appropriate forms of therapy. The nurse, in collaboration with the physiotherapist, selects the type and scope of the exercise suitable to the phase of the disease. In order to prevent muscle contractures and thrombotic disease, passive gymnastics is used in lying patients, while a nurse performs preventive actions against bedsores. It is very important to educate family members and help them to solve everyday problems. Another important aspect of cooperation with a caregiver is offering psychological support; a nurse must demonstrate a lot of empathy and availability to carers and patients.

Nursing interventions improve the quality of life of the patient and his caregiver. The main objectives to be obtained by a nurse are:

- maintaining patient's efficiency as long as possible;
- delaying the occurrence of negative symptoms of the disease;
- ensuring a sense of security to the patient and his relatives;
- early detection and treatment of comorbid conditions;
- suitable adaptation of living environment [15, 18].

LITERATURE

1. Pędich W.: Procesy starzenia się człowieka. Gerontologia i geriatria. W: Grodzicki T., Kocemba J., Skalska A.: Geriatria z elementami gerontologii ogólnej. Podręcznik dla lekarzy i studentów. Via Medica, Gdańsk 2007: 2-5.
2. Klich-Rączka A.: Otepienie. Choroba Alzheimer. W: Wieczorowska-Tobis K., Talarska D.: Geriatria i pielęgniarstwo geriatryczne. Podręcznik dla studiów medycznych. Wydawnictwo Lekarskie PZWL, Warszawa 2008, 2010: 255-263.
3. Geppert A.: Podstawy kliniczne zespołów otepiennych - choroba Alzheimer. W: Jaracz K., Kozubski W.: Pielęgniarstwo neurologiczne. Podręcznik dla studiów medycznych. Wydawnictwo Lekarskie PZWL, Warszawa 2008: 286-289.
4. Ślusarz R.: Pielęgnowanie chorego w starszym wieku z chorobą Alzheimer. W: Kędziora-Kornatowska K., Muszaliak M. (red.): Kompendium pielęgnowania pacjentów w starszym wieku. Podręcznik dla studentów i absolwentów kierunku pielęgniarstwo. Wydawnictwo Czelej, Lublin 2007: 259-269.
5. Barcikowska M., Bilikiewicz A.: Choroba Alzheimer w teorii i praktyce klinicznej. Wydawnictwo Czelej, Lublin 2004.
6. Biercewicz M., Ślusarz R., Szrajda J.: Postępowanie pielęgniarstwa wobec pacjenta z chorobą Alzheimer. W: Biercewicz M., Szewczyk M. T., Ślusarz R.: Pielęgniarstwo w geriatrii. Wybrane zagadnienia z zakresu pielęgniarstwa specjalistycznych. Wydawnictwo Medyczne Borgis, Warszawa 2006: 49-63.
7. Sobów T.: Zaburzenia psychiczne wywołane organicznym uszkodzeniem ośrodkowego układu nerwowego (otępienia, organiczne zaburzenia psychiczne). Choroba Alzheimer. W: Jarema M., Rabe-Jabłońska J.: Psychiatria. Podręcznik dla studentów medycyny. Wydawnictwo Lekarskie PZWL, Warszawa 2011: 61-66.
8. Sobów T.: Choroba Alzheimer. W: Praktyczna psychogeriatryka. Rozpoznawanie i postępowanie w zaburzeniach psychicznych u chorych w wieku podeszłym. Wydawnictwo Continuo, Wrocław 2010: 114-124.
9. Górna K., Kiejda J., Wasilczyk U.: Udział opiekuna medycznego w opiece nad osobami z otępieniem. W: Opieka nad osobami przewlekle chorymi, w wieku podeszłym i niesamodzielny. Podręcznik dla opiekunów medycznych. Wydawnictwo Lekarskie PZWL, Warszawa 2009: 277-286.
10. Gabryelewicz T., Barcikowska M. (red.): Jak radzić sobie z chorobą Alzheimer. Poradnik dla opiekunów. Polskie Stowarzyszenie Pomocy Osobom z Chorobą Alzheimer, Warszawa.
11. Gustaw K.: Kontakt czyli strategie komunikacji z pacjentem z chorobą Alzheimer. Poradnik dla pacjentów i opiekunów. Lundbeck Poland, www.lundbeck.pl (02.04.2013, godz. 12:10).
12. Jankiewicz A. (red.): Poradnik dla opiekunów osób dotkniętych chorobą Alzheimer. Wielkopolskie Stowarzyszenie Alzheimerowskie, Poznań 2008.
13. Ustawa z dnia 15 lipca 2011 r. o zawodach pielęgniarki i położnej.
14. Ślusarska B., Zarzycka D., Zahradniczek K. (red.): Podstawy pielęgniarstwa, Tom I, Założenia teoretyczne, Wydanie II, Wydawnictwo Czelej, Lublin 2008: 21-79.
15. Misiak K., Kopydłowska E.: Przygotowanie rodziny do opieki nad osobą starszą, cierpiącą na chorobę otępienną; Pielęgniarstwo i Zdrowie Publiczne, 2011; 1: 65-75.
16. Ślusarska B., Zarzycka D., Zahradniczek K. (red.): Podstawy pielęgniarstwa, Tom II, Wybrane działania pielęgniarstwa. Podręcznik dla studentów i absolwentów kierunków pielęgniarstwo i położnictwo, Wydanie I, Wydawnictwo Czelej, Lublin 2004: 23-36.

17. Kawczyńska-Butrym Z. (red.): Diagnostyka pielęgniarska, Wydawnictwo Lekarskie PZWL, Warszawa 1999: 152-163.
18. Wilczewska L., Roszmann A.: Standard opieki nad pacjentem z chorobą Alzheimera. W: Krajewska-Kułak E., Sierakowska M., Lewko J., Łukaszuk C. (red.): Pacjent podmiotem troski zespołu terapeutycznego. Tom I. Białostocka Biblioteka Pielęgniarki i Położnej, Akademia Medyczna w Białymstoku, Wydział Pielęgniarstwa i Ochrony Zdrowia, Białystok 2005.

Address for correspondence:

Katarzyna Porzych

Department of Geriatrics

Nicolas Copernicus University in Toruń

Collegium Medicum in Bydgoszcz

ul. M. Curie Skłodowskiej 9

85-094 Bydgoszcz

Received: 27.11.2013

Accepted for publication: 17.03.2014