## THE NURSE'S ROLE IN CARING FOR ALZHEIMER'S PATIENTS

# ROLA PIELĘGNIARKI W PIELĘGNOWANIU OSÓB CIERPIĄCYCH NA CHOROBĘ ALZHEIMERA

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Authors' contribution Wkład autorów: A. Study design/planning zaplanowanie badań B. Data collection/entry zebranie danych C. Data analysis/statistics dane - analiza i statystyki D. Data interpretation interpretacja danych E. Preparation of manuscript przygotowanie artykułu F. Literature analysis/search wyszukiwanie i analiza literatury G. Funds collection zebranie funduszy

**Summary** 

The number of Alzheimer's disease (AD) patients is rapidly increasing. To date, there may be half a million Alzheimer's patients in Poland. World Health Organization forecasts that the total number of patients with dementia will amount to 75.6 million in 2030 and increase to 135.5 million by 2050. Modern care includes health strengthening activities, disease prevention, shaping the ability to live with the disease or disability, and assisting in dignified and peaceful death. This paper aims to present a model method for nursing of an Alzheimer's patient, taking into account external and internal factors. Problems with everyday activities arise in each stage of the disease. Yet, their largest number is observed in the third and final stage. A nurse providing professional help and support to caregivers of patients with AD formulates nursing and caring instructions accommodated to the disease stage. According to the authors, the adjustment of individual care to the specific stage of the disease improves the patient's quality of life. The synthesis of nursing activities performed for Alzheimer's patients should be focused on the cooperation between the nurse and the patient's caregiver. The patient's family and caregivers' education should be emphasized as their awareness and knowledge of the disease will result in better care. Caregivers' insufficiency of expertise concerning the appropriate care may deepen the patient's illness and intensify its consequences. Patients with advanced AD need constant, day-and-night care. Creating such conditions is often connected with sacrificing one's personal life. Therefore, apart from imparting the knowledge concerning the right care, a nurse provides mental support to Alzheimer's patients' caregivers.

Keywords: Alzheimer's disease, nursing, care

#### Streszczenie

Liczba osób cierpiących na chorobę Alzheimera rośnie coraz szybciej, aktualnie w Polsce może być nawet pół miliona pacjentów. Światowa Organizacja Zdrowia prognozuje, że łączna liczba osób cierpiących na demencję na świecie w 2030 r. wyniesie 75,6 mln, a do roku 2050 wzrośnie nawet do 135,5 mln. Współczesne pielęgnowanie to działania na rzecz wzmocnienia zdrowia, zapobiegania chorobom, kształtowania umiejętności życia z chorobą lub niepełnosprawnością oraz towarzyszenia w godnym i spokojnym umieraniu. Celem pracy jest prezentacja modelu pielęgnowania osoby cierpiącej na chorobę Alzheimera uwzględniającego czynniki zewnętrzne i wewnętrzne. W każdym stadium choroby pojawiają się problemy w realizacji czynności codziennych. Jednak największą ilość obserwuje się w trzecim końcowym etapie choroby. Pielęgniarka udzielająca profesjonalnej pomocy oraz wsparcia opiekunom osób z chorobą Alzheimera, formułuje wskazówki pielęgnacyjno-opiekuńcze dostosowane do stopnia choroby. Zdaniem autorów dopasowanie indywidualnej opieki do konkretnego etapu choroby polepsza jakość życia pacjenta. Syntetyczne ujęcie działań pielęgnacyjnych osób z chorobą Alzhaimera powinno skupiać się na współ pracy pielęgniarki z opiekunem pacjenta. Należy położyć nacisk na edukację rodziny i opiekunów chorego. ponieważ ich większa świadomość i wiedza dotycząca choroby będzie w konsekwencji dawała lepszą opiekę. Deficyt wiedzy opiekunów dotyczący sprawowania właściwej opieki może spowodować pogłębianie się choroby u podopiecznego oraz nasilenie sie skutków, które niesie ze soba choroba. Pacjenci z zaawansowana choroba Alzheimera wymagają opieki, która będzie stała i całodobowa. Stworzenie takich warunków wiąże się niejednokrotnie z poświęceniem własnego życia osobistego, dlatego pielęgniarka oprócz przekazywania wiedzy dotyczącej właściwej opieki, niejednokrotnie udziela wsparcia psychicznego opiekunom osoby cierpiącej na chorobę Alzheimera.

Słowa kluczowe: choroba Alzheimera, pielegnowanie, opieka

Figures: 0 References: 27 Submitted: 2020 Jun 23 Accepted: 2020 Sep 22

Tables: 0

Ławnik A, Sakowicz D. The nurse's role in caring for Alzheimer's patients. Health Prob Civil. 2021; 15(1): 23-28. https://doi.org/10.5114/hpc.2020.99251

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#### Introduction

The modern nursing is often referred to as professional nursing. According to Ciechaniewicz, it is the most expected range of professional activities that a nurse should undertake within the professional role. The activities include health strengthening, disease prevention, shaping the abilities to live with the disease or disability, and accompanying the patient in dignified and peaceful dying [1].

In 2015 it was estimated that 360 to 470 thousand people in Poland experience Alzheimer's dementia. It is nearly 20% more than in 2005. In the years 2005-2010, the annual increase in the number of Alzheimer's patients persisted on the level up to 2%. In the years 2010-2015, the dynamics amounted to 3-4%. The number of Alzheimer's patients is rapidly increasing. There may now be even half a million patients in Poland. World Health Organization forecasts that the total number of patients with dementia in the world will amount to 75.6 million in 2030 and will increase even to 135.5 million by 2050. This means that the number of Alzheimer's patients will triple by 2050 [2,3].

Alzheimer's disease's (AD) typical symptoms include cognitive function disorders, behavioral disorders, and problems with everyday activities' independent performance. During the illness, the patient experienced three consecutive behavior phases. Initially, problems with the memory of recent events occur. Next, the patient starts to withdraw from social life. The more advanced the disease, the more frequently patients need help from their relatives. Finally, they depend on caregivers in day-and-night care. Currently, a medicine that could "reverse" or stop brain alterations caused by AD does not exist. The only therapeutic possibility consists in medications that minimize and mitigate symptoms, but they do not guarantee significant improvement [4].

Taking care of an Alzheimer's patient requires many sacrifices and medical knowledge from the family. Caregivers need support and help from the therapeutic team, which includes a nurse. According to the references, one of the main tasks of a nurse in a therapeutic team is the cooperation with the doctor to provide information about the state of the patient's health, education of the patient's family, and taking care of obtaining the best possible conditions of healthcare. A nurse can professionally plan the appropriate care considering caregivers' current knowledge concerning the care for the patient. The insufficiency in these areas presents nursing problems that should be minimized by determining and fulfilling the appropriate healthcare and subsequent assessment of the nurse's introduced activities. The nurse's role in preparing the family to take care of an Alzheimer's patient cannot be restricted to the explanation of certain activities or the proper behavior towards the patient's actions. The nurse becomes a supporter and comforts the caregivers in challenging situations during day-and-night care [5,6].

This paper aims to present a model for nursing an Alzheimer's patient, taking into account external and internal factors.

## Adjustment of living arrangement to the patient's requirements

Research papers show that one of the requirements allowing the proper care for Alzheimer's patients is attending to the patient's suitable accommodation conditions. It is connected with the patient's deteriorating health, who has to remain at home for a longer time. A nurse's role includes educating caregivers in matters of living space adjustments necessary for caring for the patient [7-9].

Considering the patient's worsening memory disorder and decreasing learning skills, radical and excessive changes in the patient's surroundings should be avoided. They can only intensify the disorientation and cause anger defiance. According to Misiak and Kopydłowska, the best solution is the introduction of changes in furnishing and renovation gradually in the first phase of the disease. A flat that is adequately adjusted to the patient's needs is safe. Places frequently used by the patient should not have any obstacles which make tripping and falling possible. The staircase should be separated with a gate. Equipment dangerous for the patient includes cables, chemicals, drugs, sharp objects, lighters, and sockets. They should be appropriately secured so that the patient cannot access them [9]. Alzheimer's patients experience the need to go outside. Therefore, windows should be secured so that the patient cannot open them. It is also advisable to install locks to prevent the patient from wandering outside. The patient's room should be equally safe as the rest of the flat. Cabinets should be equipped with photos and souvenirs used in reminiscence therapy and a calendar and a clock with a large dial that allows the patient to keep track of time. A significant piece of furniture in the room is the bed, accessible from three sides. In the advanced stages, the bed should be exchanged with a rehabilitative model with an antibedsores mattress. The patient should also spend time in the living room where they should have a place to sit. Such behavior will minimize the feeling of rejection and isolation from the other family members. The kitchen should be equipped with locks inhibiting the opening of cabinets in which dangerous kitchen tools are stored. Gas stove constitutes a fire danger and may be a cause of gas poisoning. Therefore, gas and fire detectors should be installed. It is best to install a shower without the base, which causes no problems with getting into it or a tub with non-slip mat and handles, which should also be installed near the toilette. It is essential to remove chemicals from the bathroom that can be swallowed by the patient and all the electric equipment. A properly equipped and furnished flat, and calculated precautions, allow the patient to function safely and efficiently in everyday life [9,10].

#### Recommended methods of communication with the patient

According to research papers, AD causes alterations in brain structure, which leads to communication disorders. The more advanced is the disease, the more difficult it is to communicate with the patient. Patients experience difficulties with expressing their opinions, naming items and repeating sentences. They cannot understand questions and their replies are unclear. The nurse's role in the area is to explain to the patient's caregivers the rules of conducting communication and provide information about the possible communication mistakes [11-13].

According to specialists, proper disposition of the caregiver and compliance with key rules is crucial for effective communication with the patient. The attitude towards the patient should be kind, warm, and full of empathy. It should also be characterized by composure and patience. Optimal conditions should be created for conducting a conversation. This means that the surroundings should not be noisy; the interlocutor should be facing the patient so that the patient can see them and use non-verbal communication. The caregiver's body language plays a significant role in communication as it is understood in every phase of the disease. Friendly facial expression and touch directed at the patient facilitate the conversation [14,15]. According to many authors, this behavior helps build an emotional bond that minimizes aggression and anger between patients and caregivers. Simple terms and short, easy to understand sentences should be used in the conversation with the patient. Questions that can be answered with yes or no are advisable. Active listening and listening to patient's silence is a significant element of communication. If the patient does not understand the questions, they should be repeated slowly multiple times. Activation of the patient is a crucial aspect of communication. Reminiscing youth and stories, reciting poems, and singing songs allow the patient to use long-term memory. Activation leads to improved health state and self-esteem and makes communication with caregivers more manageable and more efficient [14,16-18].

## Methods of conduct in care of behavior disorders

As research papers suggest, cumbersome behavior disorders occur in Alzheimer's disease. They can be divided into two categories of symptoms: psychological and behavioral. Behavior disorders affect care, which becomes more problematic. In this situation, the nurse should teach the patient caregivers about the correct methods of managing these symptoms [19,20].

According to Flirski, psychological symptoms manifest themselves during a conversation with the patient. They include listlessness, delusions, hallucinations, insomnia, misidentification, memory disorders, and depression. Listlessness, characterized by a lowered interest in social life, family affairs, and everyday activities, is the main symptom in Alzheimer's patients. Additionally, patients do not want to go outside their flat [19]. Behavior connected with listlessness may be shown as prolonged sadness, tearfulness, indifference, and reluctance towards activities, one's condemnation, and declarations of willingness to die. Actions altering the negative disposition to positive thinking through watching television, listening to relaxing music, looking at family photos, visits paid by relatives (upon patient's agreement) should be introduced in this situation. In the case of depression, it is necessary to contact a psychiatrist who may suggest appropriate pharmacological treatment [20]. The next symptom is memory disorder. It causes Alzheimer's patient difficulties with learning new information based on old memories. In this situation, patients should not be made aware that they are wrong. This behavior might lead to aggression or anger. The right coping method is accepting the patient's opinion, which should be supported by a conversation and looking at photos from that time. English references encourage participation in group therapy consisting in reminiscence. This type of therapy is directed to people with mild or moderate dementia [21]. When a problem with understanding new information occurs, a daily schedule should be placed in a spot accessible for the patient. The caregiver should write down activities that should be performed by the patient at a specific time. This type of schedule decreases the feeling of fear and helplessness as well as increases the feeling of independence. It is advisable to set up a clock and a calendar in a visible place for a patient who experiences orientation disorders so that it is easier to determine date and time. Delusions, hallucinations, and misidentifications resulting from them cause suspiciousness towards relatives. Alzheimer's patients suffer from persecutory delusions, cannot recognize family members and their reflection in a mirror, falsely accuse caregivers of stealing. Showing an understanding of what the patient is saying to avoid causing frustration and not being bothered by accusations of stealing are the best coping methods in such situations [7,22,23]. The last psychological symptom is insomnia caused by many factors. Górna, and many other authors, claim that to minimize this disorder, the patients day should be organized to include physical activity that fosters falling asleep at night. Additionally, napping during the day should be avoided. The patient should have a regular time of going to sleep and waking up. Noise during sleep hours should be reduced. Administration of fluids and food should also be limited before going to bed. The patient should have a light duvet instead of a heavy blanket to cover during the night. If there is no improvement, the caregiver is obliged to contact a doctor [15,24,25].

According to many specialists, behavioral symptoms are visible during a profound observation of the patient carried out by the caregivers. They include wandering, excitement, and aggressive behavior. If the patient wants to go outside, caregivers should ensure that it does not lead to their disappearance. Aside from those mentioned above, caregivers' appropriate practice is informing neighbors about the possibility of this type of behavior. In consequence, if neighbors notice the patient, they can inform or help the caregivers. Caregivers should have a recent photo of the patient, which they can share for creating a description. It is also recommended to place identifying cards with address and caregiver's phone number on patient's clothes or hand [7,15,25]. According to many authors, if the patient gets lost or confuses rooms, caregivers may place cards on doors with each room's name. Another behavior problem is excitement, which may be accompanied by aggression. Excessive activeness of the patient, characterized by general anxiety, attempts at directing attention at oneself through complaining and negative attitude towards surroundings should be a signal for the caregivers to search for the source of these actions. Verbal or physical aggressiveness may be caused by delusions and hallucinations, orders, and restrictions made by the caregiver, and rushing or raising voice at the patient [12,19]. Bartków, and many other authors, presents several behaviors that may mitigate the patient's aggression. The first of them is remaining calm and not reacting to verbal of physical aggression. The patient should not be rapidly approached; caregivers should avoid standing behind his back. It is also recommended to check if the patient does not have any dangerous objects to hurt someone. It is appropriate to distract patients with something they enjoy, e.g., film, music, or activity. Caregivers who cannot control the patient's aggression are obliged to inform a doctor who will prescribe tranquilizers [26].

## Managing everyday difficulties connected with care for the patient

Problems with everyday activities arise in every stage of the disease. Their most significant number can be observed in the third, final, stage of the disease. A nurse providing professional help and support to caregivers of patients with AD formulates nursing and caring instructions accommodated to the disease stage. Tailoring care for the specific needs of the patient improves a patient's life quality [7-9].

The initial stage of the disease is not characterized by many problems with self-care. Yet, they start at this stage. The nurse should educate caregivers about the activation of the patient in everyday activities. If patients cannot perform the activities independently, caregivers should help them but not perform the actions for them. One of the problems is maintaining the patient's clean body, which he may neglect as the disease develops. Caregivers should make sure that the grooming is appropriately done. Another problem is the lack of control over urinating and defecating. In such care, the patient should be equipped with adult absorbent briefs and disposable incontinence napkin. Research shows that patients very often take off and tear off briefs. In this situation, the patient should be dressed in a bodysuit fastening in the back over the clothing. The ability to dress oneself may also become problematic and the patient should have appropriate clothing that is loose and easy to put on. In the case of bed-bound patients, care should be completed with anti-bedsores and anti-contracture activities. According to research papers, there are several ways of preventing bedsores. It is essential to change the position on the bed at least once every 2 hours, use anti-bedsores pillows, make sure there is enough protein in the patient's diet, place the patient at the angle of 30 degrees. In case there is reddening on the skin, caregivers should perform massage with cream. Passive exercises and altering the patient's position from lying on the back to lying on the stomach should be performed in case of contracture [7-10,12,25,27].

There is still little experience with a professional approach to care and nursing of dementia patients in Poland. Good examples can be obtained from English or Scandinavian guidelines, which, apart from the patient's nursing, draw attention to the caregiver's needs. These documents show that apart from the education about the disease and communication with the patient, caregivers should also know how to take care of their own physical

and mental health and emotional and spiritual well-being. Caregivers should know about support groups and use them [21]. Not many non-governmental organizations support caregivers of dementia patients in Poland.

The support for caregivers should be adjusted to their needs and expectations, designed to help support a dementia patient. The message should have the form suitable for the caregiver, e.g., individual, group sessions, or online training. It should be conducted in a place that is easily accessible for the caregiver. It should also be remembered that the caregiver of an Alzheimer's patient is prone to depression [21].

#### **Conclusions**

The synthesis of nursing activities performed for Alzheimer's patients should be focused on the cooperation between the nurse and the patient's caregiver. It is significant to educate patient's family, and caregivers as the awareness and broader knowledge of the disease will result in better care. Caregivers' insufficiency of expertise concerning the appropriate care may deepen the patient's illness and intensify its consequences. Patients with advanced AD need constant, day-and-night care. Creating such conditions is often connected with sacrificing one's own private life. Therefore, apart from educating about appropriate care, a nurse provides mental support for Alzheimer's patient's family and caregivers.

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