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JAKOŚĆ ŻYCIA PACJENTKI Z CHOROBAŁ ALZHEIMERA PRZEBYWAJĄCEJ W ZAKŁADZIE OPIEKUŃCZO-LECZNICZYM – STUDIUM PRZYPADKU

**The quality of life of a patient with Alzheimer's disease
staying in a health care centre – a case study**

Streszczenie

Wstęp. Jakość życia stała się jedną z form oceny satysfakcji życiowej. Stanowi ona dla naukowców zachętę do prowadzenia badań i pomiarów. Pacjenci z chorobą Alzheimera stanowią liczną grupę badanych, którzy w zależności od etapu choroby mają liczne problemy.

Cel pracy. Ocena jakości życia pacjentki całkowicie niezdolnej do samoopieki. Przedstawienie przypadku pacjenta z otępieniem w chorobie Alzheimera, przebywającego w Zakładzie Opiekuńczo-Lecznicznym.

Opis przypadku. Kobieta, 73-letnia, przebywa w Zakładzie Opiekuńczo-Lecznicznym od trzech lat z rozpoznaniem otępienia typu alzheimerskiego. Z kart informacyjnych przebytego leczenia szpitalnego wynika rozpoznanie wielochorobowości.

Wnioski. Jakość życia pacjentki jest znacznie ograniczona z powodu występujących objawów chorobowych. Choroba Alzheimera jest chorobą zmieniającą nie tylko życie chorego, ale także rodziny. Na pewnym etapie wymaga zapewnienia całodobowej opieki.

Słowa kluczowe: jakość życia, choroba Alzheimera, pacjent

Abstract

Introduction. Quality of life has become one of the forms of life satisfaction assessment. It provides scientists with an incentive to conduct tests and measurements. Patients with Alzheimer's disease are a large group of respondents who have a number of various problems, depending on the stage of their disease.

Aim of the study. The present study aims at assessing the quality of life of a patient who is totally incapable of self-care, and presenting a case of a patient with Alzheimer's dementia staying in a health care centre.

Case study. The patient is a 73-year-old woman who has been staying in a health care centre for three years. The diagnosis: dementia, Alzheimer's type. The information included in her hospitalization history records leads to a diagnosis of multiple morbidities.

Conclusions. The quality of life of the patient is significantly reduced because of the disease symptoms. Alzheimer's disease is changing not only the patient's life, but also her family members' life. At a certain stage, it is required that the patient is provided with full-time care.

Key words: quality of life, Alzheimer's disease, patient .

Introduction

Quality of life is currently one of the forms of life satisfaction assessment. Given the numerous aspects of human life, one can determine life satisfaction using this method. Increasingly, it is becoming an incentive for researchers to perform analyses and measurements. Also, the development of our civilization clearly affects our desire for perfection, fulfilment and improvement in the quality of our functioning

in all the dimensions of life. With the increasing number of studies on quality of life, there is also a need to evaluate the quality of life of patients with Alzheimer's disease. The term 'quality of life' comes from the social sciences and is associated with a sense of satisfaction related to material and non-material needs. According to the World Health Organization, quality of life is defined as 'an individual's feeling concerning their station in life in terms of their culture and value system, and with reference to their achievements, expectations, standards and interests' [Łój, 2007; Chrobak, 2009].

Alzheimer's type dementia is listed as one of the most common causes of dementia among patients who are over 65 years of age. Research indicates that it constitutes more than 50% of all the cases of dementia in this age group. With age, the frequency of Alzheimer's type dementia diagnosis increases significantly. It is currently reported as a serious social problem in many countries. Statistical data shows that in Poland about 400,000 patients are diagnosed with the disease, whereas outside Poland this problem is already experienced by 10% of the population.

As the percentage of diagnosed Alzheimer's disease continues to increase, the number of patients requiring assistance is greater and greater. In Poland, the responsibility for looking after a patient diagnosed with Alzheimer's disease rests with the family of this patient. Research shows that the two largest groups of caregivers are the patients' spouses and children. This is often a vital social issue resulting from a number of factors and appearing at various stages of the disease [Misiak and Kopydłowska, 2011].

The role of the caregiver is connected with a lot of dedication, sacrifice and adaptation to the situation. Apart from personal resources, adequate financial resources are needed. This is related to providing expert medical assistance and adjusting the household and rehabilitation equipment to mentally ill patients' needs. A number of such patients are still professionally active, which is a problem in terms of planning the care for them during the day. The difficulties connected with the organization of the care are also closely related with the ability to care for such patients. Care and nursing problems may also appear at night-time, so 24-hour care is needed. This is directly related to the disease progression, which could threaten both the health and life of the patient. Even at the early stages of diagnosis, patients with Alzheimer's disease have cognitive impairments in varying degrees of severity. The onset of the disease can be latent, but due to its involuntal nature, the disease progresses rapidly. In many cases, the only solution to this problem, if the family for some reason cannot care for the patient, is to put him or her in a health care centre [Kłoszewska, 2001; Pfeffer, 2004].

Case study

The patient is a 73-year-old woman who has been staying in a health care centre for three years, placed there by her spouse and children. She was admitted with a diagnosis of Alzheimer's type dementia and chronic cerebrovascular insufficiency. In addition, the information sheets provided by her family following numerous hospital stays reveal ischemic heart disease, erosive gastritis and duodenal ulcers. The anamnesis provided information about multiple infections of the urinary tract and respiratory system. Before the patient was admitted, the treatment had been conservative and surgical. In 2012, a pacemaker implantation was performed; the full documentation provided by the family shows that the patient received care from a Promoter Control Clinic. Earlier, a coronary angiography was performed, which resulted from constant retrosternal pain which has now disappeared. In 2013, a gastrofiberoscopy examination was conducted; it revealed the inflammation of the mucous membrane of the stomach wall and individual erosions. The patient was given a targeted drug therapy.

The patient completed her secondary education as a chemical technician; she was professionally active until her retirement. Family status – married with two children, a daughter and a son. Her housing conditions were very good. According to her family members, the first symptoms appeared when the patient was at the age of 68, and were associated with episodic short-term memory disorders. In addition, there were difficulties with remembering and limited space and time orientation. Her husband says that during conversations she would lose her thread and could not recall what she was saying a moment before. Gradually, the symptoms intensified and later there were attacks of aggression against the closest family members, psychomotor hyperactivity, and temporary mood disturbance.

On admission to the health care centre the patient was able to walk, partly requiring assistance in identifying things to do at certain moments; it was difficult for her to start doing the basic activities of everyday life

such as dressing, washing, eating, etc. The staff helped her to start the activities, pointed out to the possible solutions of the problem and explained how to do the activities. There was no aggressive behaviour, the patient was calm and her mood was balanced. She was indifferent to her staying in the centre; at this stage of the disease the patient did not recognize her family. In addition, she was disoriented as to time, place and herself. The main problems identified with nursing care were insomnia and urinary and faecal incontinence.

After the diagnosis, it was discovered that the patient required full-time care and partly compensating help with everyday activities. In 2013, at the request of her family and after consideration by a family court, the patient was incapacitated. The adjudicating committee questioned the possible symptoms of her mental illness or mental retardation. Thus, it confirmed the previous diagnosis, i.e. Alzheimer's disease and the need for constant care resulting from the patient's considerable difficulty in satisfying the basic necessities of life.

Currently, the patient's condition is moderately severe; depending on her health and well-being, she is sat in a wheelchair. She is fed with liquids, which results from swallowing and chewing disorders. It is being considered whether or not to use a gastric probe; the patient repeatedly refuses to eat her meals. Her appetite and thirst tend to be poor; they do not improve despite the administered drugs. In order to hydrate the patient's organism, infusion fluids are shunted when advised by the attending doctor, under the supervision from laboratory tests and observation. As a result of the patient's immobility, complications have occurred in her digestive, respiratory, urinary and osteo-articular-muscular systems. Despite the preventive activities and pharmacological treatment, the patient frequently suffers from constipation. The nursing care consists in controlling her bowel movements, supplying the medications prescribed by her doctor and adequate amounts of fluids as well as foods high in nutrients to help her to defecate. Despite the prophylaxis of respiratory complications, there are numerous upper respiratory tract infections. Although certain measures tailored to the patient's needs are implemented, infections return periodically. As a result of fecal incontinence and the patient is diapered and cathetered using aseptic and antiseptic techniques. The laboratory tests have revealed urinary tract infections. On the basis of the diagnosis, pharmacological agents advised by the attending doctor are used and the principles of personal hygiene are strictly adhered to. As a result of the prolonged immobilization and some problems with maintaining the appropriate level of protein contained in the patient's body, there is a stage 4 bedsore around her coccyx. Relevant skin care measures; healing the bedsore, repositioning every 2 hours (optimally); tapping and massage of most vulnerable areas of the body in order to reduce the existing bedsore and prevent the formation of new ones. The introduction of regular bedside rehabilitation resulted in lowering the risk of upper and lower limb contractures. Apart from passive exercises performed at the patient's bed, there is also irradiation of the body areas prone to the formation of bedsores done by means of a Sollux lamp.

Discussion

Quality of life does not have a precise definition. It is a subjective assessment of one's existence, which is conditioned by variable properties and a commitment to excellence and one's inner convictions [Łój, 2007; Chrobak, 2009].

Evaluating the quality of life of the patient staying in the health centre, we must take a number of factors into consideration. Given the essence of Alzheimer's disease, it should be emphasized that despite the lack of logical contact with the patient, she does not feel satisfaction in her everyday life. The main role in terms of looking after the patient is played by the staff of the institution. In this paper, based on the case of our patient, the multidisciplinary team includes a physician, nurses, a physiotherapist, a masseur and carers. Given the scope of activities and professional competence, the patient spends most of her time with the nurses, who are responsible for the 24-hour care [Barcikowska, 2008].

Caring for the patient with Alzheimer's disease requires a holistic approach, including certain assistance in terms of bio-psycho-social and personal support in solving problems. The scope of duties to the patient depends on the current state of her health and the restrictions that may impede her proper functioning. The patient has a lot of nursing, care and social problems. As a result of her chronic disease, the quality of her life has significantly decreased [Opala and Ochudło, 2004; Wojcierowska, 2008].

The role of the nurses working in the health care centre is to provide the patient with a sense of security and emotional support. Taking into account all the changes in her behaviour, the nurses should inspire confidence and demonstrate patience and commitment to the work performed on the patient. Many situations and actions

are incomprehensible for the patient. Taking into account the difficulties in communication, the nurses should calmly explain any action taken in relation to the patient [Rachel et al., 2014; Schindler, 2008]. In this way, calm approach to the activity significantly improves the relationships and induces confidence. It is important to recognize the needs of the patient, plan the nursing care, take proper measures and evaluate the results on a daily basis. In this way it is possible to take proper care of the patient. In the physical aspect, one would have to ensure proper conditions for sleep and relaxation, and – taking into account the risk of further complications – observation and proper care. Prevention and monitoring should include both the skin and mucous membranes as well as the whole body. The risk of systemic complications is much greater due to the immobilization [Jurczak, Porzych, and Polak-Szabela, 2014; Krzyczkowska-Sendrakowska, 2013]

Working with the patient in this stage of the disease significantly reduces the educational function. The reason is the lack of logical contact and a wide range of dysfunctions in her self-care. As a result of her cognitive disorders, the patient is unable to perform any activities; the staff must now perform overall care. All the activities should be performed professionally and efficiently, so as not to arise fear or anxiety in the patient. No or limited nursing skills could cause pain.

Caring for a patient requires appropriate knowledge, skills and experience. Nursing staff are expected to constantly improve their qualifications in order to increase their professional competence. Looking after patients requires one's full commitment and devoting the right amount of time. Raising the standards of care provided to patients with Alzheimer's disease aims at improving the quality of such care and, consequently, the quality of these patients' lives [Tomaszewski et al., 2010].

Despite the numerous limitations, the patient does not show – through her behaviour, gestures or facial expressions – that she disapproves of the activities which the staff has performed for her. In dealing with the staff she seems calm; sometimes there is a smile on her face that may mean she has recognised a person or a that she is in a cheerful mood. In the case of this patient with Alzheimer's disease, I believe that the quality of life is satisfactory. The most difficult issue to resolve in this case is to identify criteria for assessing the quality of life of the patient. I believe we should take into account the opinion of the family members on the patient's behaviour. According to the family members, the nursing care meets the expectations; they cannot complain about anything, which may also prove their satisfaction with the nursing care [Klich-Rączka, 2012; Daniluk and Borkowska, 2008].

Taking everything into account, the quality of life of patients diagnosed with Alzheimer's disease is difficult to evaluate. Specialist literature evaluates only the caregivers, whereas the disease affects not only the patient, but also his or her family and friends. In the case of the patient's quality of life, it consists of the satisfaction with the care provided and the extent to which his or her needs are met. In many cases, including the present one, the patient's family members, bearing in mind the numerous factors, cannot deal with around-the-clock care [Jaworski, 2010; Ruda and Rymaszewska 2013]. The only solution to this problem is to send the patient to an appropriate health care centre. Unfortunately, in Poland there are not enough institutions of this type. Improving the quality of life of patients is undoubtedly affected by the appropriate care, focused on eliminating deficits and satisfying the needs in the bio-psycho-social sphere. Professionally trained staff and their proper professional attitude can fully guarantee the quality of life at an optimal level [Siemianowski, 2007].

Conclusions

Depending on the stage of the disease, a patient diagnosed with Alzheimer's disease needs appropriate, professional care; in advanced stages of the disease – 24-hour care. This applies not only to easing the patient, but also to the possible problems encountered by the patient's family. It is required to take action on welfare and nursing care. Families often cannot look after such demanding patients. In such cases the only solution is to send the patient to a health care centre [Przydatek and Bień, 2002; Ziółkowska - Kochan, 2002] .

Any action connected with the patient is taken over by the staff of the institution. Thanks to their full professionalism and commitment, the patient is provided with adequate quality of care and life. Nurses show full understanding towards the patient's family members, and give them emotional support, including psychological assistance and information which help them to understand the difficult situation.

The quality of life of patients with Alzheimer's disease is greatly reduced at a certain stage of the disease. You can specify it by observing the patient's behaviour, facial expressions and gestures. Although patients

lose their cognitive abilities as the disease progresses, which is an irreversible process, much can be done to maintain or improve the quality of their life. Particular attention should be paid to respecting the patient's dignity and providing them with the same respect that healthy individuals get [Gauthier, 2008; Hausz - Piskorz and Buczkowski, 2008; Kaliszan and Macur, 2010] .

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