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Diagnosing patients with Parkinson's disease by community/family nurse

Parkinson's disease (PD) is a chronic illness of the nervous system, which despite medical treatment, causes gradual loss of the patient's abilities to function independently in their home environment, which results in the decrease of the quality of life. PD incidence in a general population averages 150/100 000 inhabitants and rises with age (2).

Deficits in the PD patient's self-care increase the role of the caregiver, and the patient becomes more and more dependent on the caregiver's 24-hour help. In order to function independently in their environment for the longest possible time the PD patient must remain under the professional care of an interdisciplinary therapeutic team because of the disease symptoms, which make difficult performing activities of daily living such as eating, walking, getting dressed, leaving home.

One of the members of such a team is a community/family nurse. The nurse works with the patient and his/her family in accordance with the selected method of work and model of nursing care. The basic method of the nurse's work in the patient's home environment is nursing process. The data collected in stage I – identification – are the basis to formulate the nurse's diagnosis. The diagnosis is 'the conclusions from the patient's data assessing (evaluating) his/her condition in terms of the extent and kind of advisable nursing care, including the genesis and prognosis of such condition' (7).

In his/her work with PD patients the nurse uses three kinds of diagnoses: individual, family, and local environment diagnosis. The scope of the data necessary for individual diagnosis should include such data which provide the basis for assessing the following: the patient's health condition in terms of biological-emotional-social functioning and the level of his/her capacity; the patient's emotional condition, the subjective feeling concerning his/her health; the patient's level of independence, vitality, managing on their own in the situation of the disease or disability (6).

INDIVIDUAL DIAGNOSIS

The starting point for individual diagnosis is the information on the patient's health and social conditions as well as his/her capacity (5). Measuring of various phenomena in PD, e.g. evaluating the patient's independence, is a difficult task due to the following: parkinsonism symptoms: bradykinesia, characteristic facial expressions, speech disorders, problems with writing, tremor, muscular rigidity; changing character of the disease symptoms (clinical fluctuations, 'on-off' phases) caused by the side-effects of the medicines (mainly levodopa).

The data relating to the PD patient's physical condition, collected by the nurse, determine the extent of the necessary care, indicate the possibilities of the patient's self-care using unimpaired

physical skills and abilities, facilitate independent functioning in the environment improving the patient's quality of life (5). The nurse collects data on the abilities and disabilities in the functioning of particular organs and systems, taking into account the changes which occur in the organism of an older person as a natural part of ageing.

The data concerning the spheres of the patient's emotional functioning observed or collected by the community/family nurse ought to enable the evaluation of the following: • intellectual abilities of PD patients (such patients maintain the ability to understand but have problems with expressing themselves, finding appropriate words or phrases) • PD patients' awareness concerning themselves and their environment (whether they feel ill, whether they are aware of their abilities, how they react to particular disorders in their organisms) • the PD patient's ways of reacting to actions and activities done to him/her in a particular health condition and nursing care situation • the degree of acceptance of the disease and difficulties in everyday functioning caused by PD • the patient's behaviour – difficulties in performing certain activities, e.g. completing forms in an office, interpersonal communication, a lack of self-confidence prompt the tendency to social isolation.

The PD patient's quality of life is influenced by co-existing depression. It affects about 40–64% of the patients (10). Evaluation of the patient's abilities to remember is essential to establish the method of communication with him/her (recent memory disorders, problems with events chronology occur as medications side-effects). Such information will be useful to establish the extent and form of the PD patient's education.

The data relating to the sphere of social functioning comprise the following: • the patient as a member of the family and community that he/she lives in (social conditions, occupation, performed social roles and their significance to the patient, social relations); • family or other people close to the patient who will provide non-professional care in the future (8).

For the purposes of individual diagnosis the nurse should complete the collected data with information on the following: \bullet the patient's knowledge about the disease \bullet his/her attitude towards the change of the lifestyle due to the disease \bullet following nursing, therapeutic, rehabilitation guidelines by the patient \bullet the patient's behaviours which are detrimental to his/her health (5).

PD patients' health condition keeps changing, the disease progresses irreversibly, this is why, in his/her work with such patients, the nurse should constantly update the information for the purposes of nursing, therapy and rehabilitation – activating the patient, health promotion (1, 14).

In collecting data about e.g. self-care, activities of daily living, changing disease symptoms, the nurse uses various rating scales. The rating scales used in Parkinson's disease can be divided as follows:

1. Rating scales assessing the degree of damage to the nervous system. These include: the five-degree Hoehn and Yahr Staging of Parkinson's Disease (1967) describing intensity of PD symptoms, Webster Rating Scale (1968) evaluating the degree of disability, the Columbia Scale (1969) assessing 14 PD symptoms in 5-point rating scale.

2. Activities of Daily Living Scales (ADL) (evaluating functional skills and abilities) are used to assess therapy and rehabilitation results, the patient's independence, his/her capability of self-care, and to determine the patient's needs for care. These scales include: • basic ADL scales (ADL-BADL assess basic activities of daily living) • instrumental ADL scales (ADL-IADL assess activities necessary for independent living in the environment) (8, 11, 15). Professional literature also describes Barthel Index, Functional Independence Measurement (FIM), Northwestern University Disability Scale (NUDS), Unified Parkinson's Disease Rating Scale (UPDRS) (9, 11).

Scales assessing the quality of life, where the most typical scales for Parkinsonism are:
PDQ-39- assesses groups of issues, i.e.: mobility, activities of daily living, emotional well-being,

stigma due to the disease, family and social support, cognitive functions, communication, bodily discomfort • PDQL examines the quality of life in the four spheres: PD symptoms, systemic symptoms, emotional sphere, social functions (11).

FAMILY DIAGNOSIS

As the disease progresses – despite therapy – the patient becomes more and more dependent on the environment (3, 4). For this reason family diagnosis allows to determine who and to what extent will be able to provide non-professional care during the patient's therapy and nursing care, whether the family assistance does not limit the patient's independence, whether the family will be able to manage to provide care on their own or will need external support.

The nurse ought to collect the following information: • whether the family have sufficient knowledge on Parkinson's disease • whether the family have the necessary abilities in the area of communication, ensuring security, adapting the flat to the patient's needs, using basic mobility improvement activities ensuring patient's independence (without entirely relieving the patient of his/ her activities) • what the social and health conditions of the family are • what the family's potential and their capabilities are (the family's nursing and care-giving capability) (5).

LOCAL ENVIRONMENT DIAGNOSIS

Local environment diagnosis is an integral element of a comprehensive nursing diagnosis of a PD patient. It is important for the nurse whether in a particular area there are groups, associations which can support the PD patient and his/her family in providing non-professional care and what kind of assistance they can provide for people who need support (5).

The local environment potential is various formal and informal social support systems that can provide different kinds of support: information, emotional, material, etc. In the initial stages of the disease the patient is entirely independent, this is why the nurse should find out if there are any support groups in the area which such a patient could take an active part in. As the disease progresses, the family provides 24-hour nursing and care, and for this reason the family needs external support (this includes support groups for family caregivers). In order to relieve the family of providing care there is a possibility of institutional support, which includes intensive nursing care, therapy and rehabilitation.

All data obtained from the patient, his/her family or the environment – by means of available methods and techniques of collecting information – are included in nursing care records by the community/family nurse. Such data are used for the following purposes: health promotion, activating PD patients in their daily lives, or to increase the extent of independent, active and creative life despite the disease and disability (6).

The activities of the community/family nurse – as a person professionally prepared to work with chronically ill, disabled patients with self-care deficits (according to Dorothy Orem's Professional Nursing Practice Model) – are divided into 3 systems depending on PD stage: educative-development, partially compensatory, or compensatory system (12, 13).

Consequently, in accordance with her/his competences the community/family nurse is obliged to: constantly update his/her nursing professional knowledge and other abilities necessary for providing care; acquire knowledge and abilities associated with specific problems of the patients; co-operate with the therapeutic team in order to devise a common strategy for solving problems of the patients.

REFERENCES

- 1. Calne S. M., Kumar A.: Nursing care of patients with late-stage Parkinson's disease. J. Neurosci. Nurs., 35 (5), 242, 2003.
- de Rijk M. C. et al.: Prevalence of parkinsonism and Parkinson's disease in Europe: the Europarkinson Collaborative Study. European Community Concerted Action on the Epidemiology of Parkinson's disease. J. Neurol. Neurosurg. Psychiatry, 62, 10, 1997.
- 3. Ellring H. I. et al.: Psychosocial aspects of Parkinson's disease. Neurology, 43, 41, 1993.
- 4. H a b e r m a n n B., D a v i s L. L.: Caring for family with Alzheimer's disease and Parkinson's disease: needs, challenges and satisfaction. J. Gerontol. Nurs., 31 (6), 49, 2005.
- 5. K a c h a n i u k H.: Diagnoza pielęgniarska w pracy z człowiekiem starszym. In: Z. Kawczyńska-Butrym (ed.): Diagnoza pielegniarska. PZWL, Warszawa 1999.
- 6. K a w c z y ń s k a B u t r y m Z. (ed.): Diagnoza pielęgniarska. PZWL, Warszawa 1995.
- 7. Kawczyńska-Butrym Z.: Podstawy pielęgniarstwa rodzinnego. PZWL, Warszawa 1995.
- 8. Kuran W.: Żyję z chorobą Parkinsona. PZWL, Warszawa 2002.
- 9. K w a d r a n s E., B i a ł k o w s k a J.: Pielęgnacja pacjentów przewlekle chorych. Skala Barthela. Magazyn Pielęgniarki i Położnej, 11, 28, 1999.
- Meara J. I. et al.: Use of GDS-15 geriatric depression scale as a screening instrument for depressive symptomatology in patients with Parkinson's disease and their carers in the community. Age and Ageing, 28, 35, 1999.
- Opara J.: Klinimetria w Parkinsonizmie. Neurologia i Neurochirurgia Polska, 32, 6, 1497, 1998.
- 12. Orem D. E.: Nursing: Concepts of Practice. 4th edn. Mosby, St. Louis 1991.
- P a d u l a C.A.: Self-care and the elderly: review and implications. Public Health Nursing, 9 (1), 22, 1992.
- 14. Reid J.: Diagnosis of Parkinson's disease: why patient education matters. 19 (1), 33, 2001.
- 15. Wojszel B.: Instrumenty pełnej oceny geriatrycznej zastosowanie w praktyce lekarza rodzinnego. Gerontologia Polska, 5,1, 48, 1997.

SUMMARY

Parkinson's disease (PD) is the most common disease of the central nervous system. PD often affects people over the age of 50. The disease is progressive and needs a long medical treatment. For this reason, it is important that both the patient and his/her family members know a lot about the disease when the first symptoms occur. Healthcare professionals, including nurses, have the task of improving general health and the quality of life of PD patients. Nurses' duties consist in helping and supporting people with Parkinson's disease, increasing awareness of PD through education and training of patients and family members. The treatment should begin with a correct nursing diagnose.

Diagnoza pielęgniarki środowiskowo-rodzinnej u osób z chorobą Parkinsona

Choroba Parkinsona (drżączka poraźna) jest jedną z najczęstszych chorób OUN. Dotyczy ludzi starszych, ale pierwsze jej objawy pojawiają się w większości przypadków po 50 r.ż. Jest to choroba przewlekła, wymagająca stałego, wieloletniego leczenia i pielęgnacji. Stąd ważne jest, aby zarówno

pacjent, jak i rodzina wiedzieli o tej chorobie jak najwięcej już w momencie rozpoznania. Wszystkie działania całego zespołu terapeutycznego, a więc także pielęgniarki środowiskowo/rodzinnej powinny służyć przede wszystkim poprawie jakości życia tych podopiecznych. Działania pielęgniarki to: udział w leczeniu, pielęgnowaniu, rehabilitacji oraz szeroko pojęta edukacja zdrowotna ukierunkowana na chorego i rodzinę. Punktem wyjścia jest jednak prawidłowo postawiona diagnoza pielęgniarska.