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Problems with the Care of a Patient with Huntington's Disease Hospitalised in a Psychiatric Ward — Case Report

Problemy pielęgnacyjne pacjenta z chorobą Huntingtona hospitalizowanego na oddziale psychiatrycznym — opis przypadku

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Abstract

Introduction. Huntington's disease is a neurodegenerative disease, autosomal dominant inherited, characterised by a slow death of central nervous system cells. One of the most common causes of death is suicide.

Aim. The aim of the paper is to present the problems and needs of a patient with Huntington's disease, hospitalised psychiatrically because of organic mood disorders.

Case Report. The case report concerns a 60-year-old patient with Huntington's disease who, due to suicidal thoughts and tendencies, was admitted to the psychiatric ward. The paper presents selected care problems observed in the patient.

Discussion. Almost every patient with Huntington's disease experiences psychiatric symptoms. They appear at different stages of the disease. The described patient, hospitalised psychiatrically, experienced mental and somatic problems. The main objectives of nursing care were to reduce or eliminate the identified problems, mainly to ensure safety and improve functioning. Interventions included, in particular, close observation, assistance in self-care activities, motivating the patient to exercise and perform tasks independently, care in the event of fever, education on sleep hygiene.

Conclusions. Patient care problems were related to mental and somatic disorders, in particular suicidal thoughts and tendencies and fever, difficulties in sleeping, moving and passing urine. The main nursing interventions included close observation and a holistic approach in collaboration with all members of the therapeutic team. The patient was discharged in a good general condition, in a balanced mood, without suicidal thoughts. He did not attempt suicide during hospitalisation. (JNPN 2020;9(1):33–38)

Key Words: Huntington's disease, care problems, suicide

Streszczenie

Wstęp. Choroba Huntingtona to neurodegeneracyjna choroba, dziedziczona autosomalnie dominująco, która charakteryzuje się powolnym obumieraniem komórek ośrodkowego układu nerwowego. Jedną z częstszych przyczyn śmierci jest samobójstwo.

Cel. Celem artykułu jest przedstawienie problemów i potrzeb pacjenta z chorobą Huntingtona hospitalizowanego psychiatrycznie z powodu organicznych zaburzeń nastroju.

Opis przypadku. Opis przypadku odnosi się do sześćdziesięcioletniego pacjenta z chorobą Huntingtona, który z powodu myśli i tendencji samobójczych został przyjęty na oddział psychiatryczny. Praca przedstawia wybrane problemy pielęgnacyjne zaobserwowane u pacjenta.

Dyskusja. Prawie każdy pacjent z chorobą Huntingtona doświadcza objawów psychiatrycznych. Pojawiają się one na różnym etapie chorowania. Opisany pacjent hospitalizowany psychiatrycznie doświadczał problemów natury psychicznej i somatycznej. Główne cele opieki pielęgnarskiej obejmowały dążenie do zmniejszenia lub niwelowania rozpoznanych problemów, w tym głównie zapewnienie bezpieczeństwa i poprawę funkcjonowania. Interwencje uwzględniały w szczególności ścisłą obserwację, pomoc w wykonywaniu czynności samoobsługowych, motywowanie pacjenta do ćwiczeń i samodzielnego wykonywania zadań, opiekę w momencie wystąpienia gorączki, edukowanie na temat higieny snu.

Wnioski. Problemy pielęgnacyjne pacjenta dotyczyły zaburzeń psychicznych i somatycznych, w szczególności myśli i tendencji samobójczych oraz gorączki, trudności ze spaniem, poruszaniem i oddawaniem moczu. Główne interwencje pielęgnarskie obejmowały ścisłą obserwację i holistyczne podejście we współpracy ze wszystkimi członkami zespołu terapeutycznego. Pacjent został wypisany do domu w ogólnym stanie dobrym, bez gorączki i cech zapalenia układu moczowego, w wyrównanym nastroju, bez myśli samobójczych. W czasie hospitalizacji nie podjął próby samobójczej. (PNN 2020;9(1):33–38)

Słowa kluczowe: choroba Huntingtona, problemy pielęgnacyjne, samobójstwo

Introduction

Huntington's disease (HD) is a degenerative disease of the central nervous system (CNS) described by George Huntington in 1872. It is autosomal dominant inherited, which means that the risk of transferring a mutated gene encoding hunting in to the offspring is 50% [1]. The incidence of the disease is estimated at 4–15/100,000. HD is characterized by slow death of CNS cells, including the caudate nucleus and frontal lobes [2]. The adolescent form of the disease (4–19 years old) and the early adulthood form (20–34 years old) affects every tenth case [3] and is associated with the transmission of the mutation by the father. The duration of the disease is usually 7–10 years [4]. The middle age (35–49 years) and late age (after 50 years) form of the disease accounts for approximately 90% of cases; it is associated with the transmission of the mutation by the mother, and the duration of the disease is 15–20 years [4,5].

The earliest symptoms of HD are non-pathognomic symptoms, such as weight loss with normal eating habits, minor motor deficits, personality disorders or minor mental disorders [6]. The most characteristic symptoms of the developed form of the disease are involuntary and uncontrolled motor disorders, jerky body movements, cognitive disorders (including problems with concentration and loss of memory), affective and personality disorders (e.g. emotional instability, aggressive behaviour, irritability) and behavioural disorders [7]. The symptoms of the disease progress over time and lead to disability and dependence on the carer. HD leads to death within a few years of its diagnosis, most often due to secondary complications occurring as a result of intensification of primary symptoms [8].

The aim of the paper is to present the problems and needs of a patient with Huntington's disease, hospitalised psychiatrically because of organic mood disorders.

Case Report

A sixty-year-old patient, hospitalised in a psychiatric ward in 2018 due to organic mood disorders. Brought by the medical rescue team to the psychiatric emergency room and admitted as a matter of urgency. At home, he

declared suicidal thoughts and intentions. He threatened to jump out the window if he didn't get help. He also reiterated the intentions during the admission process. He consented to the treatment. In the patient's family, several people committed suicide. The patient was previously treated psychiatrically in an outpatient clinic due to depressive disorders. He had not taken any medication for a year. The patient was diagnosed with HD 15 years ago (i.e. at the age of 45) and his father and grandfather also had the disease. However, three adult daughters of the patient, so far, have not shown any symptoms of this illness.

Mental Health Assessment

Patient treated for depression for 5 years, previously not hospitalised psychiatrically. He has not taken antidepressants in the last year. He stated that suicidal thoughts and intentions were the consequence of current urological problems, such as urination difficulties and prostate pain. At the admission he was self-aware and oriented as to time and place, in a depressed mood, affectively labile. No perceptual disturbances were observed. The patient did not express delusional content. He spoke in an understandable, factual and exhaustive way and answered questions. Individual words were blurred, the course of thinking was lengthy. He behaved in a calm and controlled manner, appropriate to the situation. Facial expression with visible grimaces, lively but distorted by involuntary movements. He reported reduced motivation to act and problems with sleeping manifested by long periods of falling asleep and waking up at night.

Somatic Evaluation

On the day of admission, the patient received a Glasgow Consciousness Scale score of 15 points. BMI — 25.04 kg/m² (height 166 cm and body weight 69 kg). In the Nutritional Risk Score used to assess the risk related to nutritional status, the patient scored 0 points. Nutritional habits were assessed as normal: 3 meals a day, no coffee, no cigarettes, no alcohol, no allergies. The temperature was 36.6 degrees Celsius, heart rate 74

beats/minute, blood pressure 120/80 mmHg, heart sounds normal, correctly accented. Vesicular murmur, normal on both sides, 18 breaths per minute. There were visible involuntary jerky body movements, and no restrictions on passive mobility. Active mobility has not been tested due to the presence of neurological symptoms. The tension in the upper and lower limbs was correct, the strength within normal limits. Superficial and deep sensations normal. He was brought to the ward in a wheelchair. He moved with a walker. Pupils reacting correctly to light, nystagmus was observed at the extreme position of the eyeballs. Forehead wrinkling weakened. Hygienic condition of the skin good, scars on the left lower extremity. Heel spur present, which according to the patient was a hindrance to movement. The functioning of the senses was correct. Meningeal symptoms were negative. In palpation, the abdomen was soft, pain-free, and peristalsis normal. The patient was focused on the problem of urination and prostate pain both during admission and in the first period of hospitalisation. He manifested increased severity of the ailment when he saw the staff. He periodically reported pain while urinating. He was convinced he had stones in his bladder. Despite presenting an ultrasound result that did not reveal any abnormalities in the bladder, he still claimed to have stones.

Patient lives with his wife, has three adult children who live separately. Until 2001, he was vocationally active and then supported himself with a social pension. After being diagnosed with HD, he changed his lifestyle: he ran and cycled regularly in order to maintain his mobility for as long as possible. After 15 years from the diagnosis, he was able to perform many everyday activities on his own: self-care activities, moving around, preparing meals, shopping.

During psychiatric hospitalisation the patient underwent laboratory tests (haematological, biochemical, TSH, urine — general and culture), ECG and ultrasound of the urinary tract and abdominal cavity (as a matter of urgency). No abnormalities were found. Urological consultation was carried out, in which no stones in the bladder were diagnosed.

Problems with Care

Problem 1: Risk of Suicidal Thoughts and Attempted Suicide

Characteristics of the problem. Patient admitted because of suicidal thoughts and tendencies. There had been cases of suicide deaths in the family.

Purpose of nursing care. The patient is to report suicidal thoughts and not attempt suicide while in the ward.

Nursing interventions:

1. Ensuring patient's safety by closely observing him and removing dangerous objects (cords, cables, shoelaces, glass and ceramic objects, cutlery, fire sources, other sharp objects).
2. Limiting the number of stimuli that contribute to the increase of tension, e.g. persons, sounds, smells, decoration.
3. Concluding the therapeutic contract with the patient and obtaining his declaration that each time he will report suicidal thoughts and that he will not harm himself within the time specified in the contract. When the contract expires, a new one will be concluded.
4. Providing the patient with individual contact in case of anxiety, tension, anger, irritation and other unpleasant emotions. Conducting a conversation using therapeutic techniques. Using short, calm messages and listening to the patient actively.
5. Encouraging the disclosure and verbalisation of experiences.
6. Avoiding the "why?" question, judging, arguing with the patient.
7. Declaring a willingness to help and striving for cooperation, e.g. offering the patient time spent together (availability).
8. Distracting the patient from events related to suicidal thoughts. Encouraging redirection of attention, e.g. by talking to a member of staff or other persons, participating in occupational therapy (if the presence of other persons does not exacerbate suicidal thoughts).
9. Offering to talk to a psychologist.
10. Administering antidepressants and anxiolytic drugs as prescribed by the doctor.

Assessment. During the first day, the patient reported suicidal thoughts to the staff, and denied their occurrence during further hospitalisation. He did not attempt suicide while hospitalised. He was discharged home without suicidal thoughts or intentions.

Problem 2: Sleep Disorders that Make it Difficult to Function

Characteristics of the problem. The patient had difficulty falling asleep and the process took him more than half an hour. At night he woke up several times, sometimes he had difficulties with falling asleep again.

Purpose of nursing care. Restoring the proper sleep rhythm.

Nursing interventions:

1. Talking to the patient about his sleeping habits and the ways of facilitating falling asleep that have been used to date.
2. Observation of the patient's sleep and analysis of the related aspects: behaviour before falling asleep,

time needed to fall asleep, number of hours of sleep at night, awakening and time needed to fall asleep again, time of getting up, presence of naps during the day, medications used.

3. Talking about giving up naps during the day. Explaining that the patient can sleep up to 30 minutes during the day in case of significant fatigue.
4. Informing the patient about the rules of sleep hygiene and encouraging him to follow them: refrain from drinking strong tea; introduce warm drinks (e.g. herbal tea, milk) in small quantities, avoid eating heavy meals in the evening, avoid bright light (e.g. emitted by a phone).
5. In the event of difficulties in falling asleep for more than half an hour, administration of medication to facilitate falling asleep according to the doctor's recommendation.
6. Talking to the patient about the sleep hygiene rules that can be applied at home, e.g. warm bathing before bedtime, room ventilation, evening walks.

Assessment. The patient initially fell asleep after administration of emergency sleeping pills, later during hospitalisation he fell asleep without any additional drugs. He slept for at least seven hours. Sometimes he would wake up at night and go to the toilet, but when he returned to the room he would fall asleep in less than half an hour. In the morning he declared that he felt rested after the night.

Problem 3: Difficulties in Everyday Life Activities

Characteristics of the problem. Due to the presence of choreiform movements, the patient had difficulty in performing hygienic activities and meeting the needs of everyday life.

Purpose of nursing care. Achieve an optimal level of self-reliance for the patient.

Nursing interventions:

1. Recognition of the types and degree of deficits in terms of independent functioning.
2. Informing about the planned activities and striving for their acceptance by the patient.
3. Motivating the patient to take action where possible. Recognition of effort and use of positive reinforcements.
4. Refraining from performing tasks for the patient that he can do on his own.
5. Assistance in hygienic activities and in getting dressed.
6. Assistance in preparing meals and documenting the amount of liquid and food intake.
7. Determining together with the patient the periods during the day when he has the most motivation and energy. Performing activities which are most

difficult for the patient at the time indicated by him. Strengthening the sense of influence and decision-making.

8. Accompanying the patient in situations to prevent undesirable events, e.g. falls due to a drop in blood pressure.
9. Encouraging the patient to participate in social skills training, especially on self-care issues.
10. Psycho-education of the patient and caregivers about the benefits of daily activity.

Problem 4: Mobility Issues

Characteristics of the problem. The patient had difficulty moving due to the presence of choreiform movements. Purpose of nursing care. Striving to ensure the safety of the patient during physical activity.

Nursing interventions:

1. Identifying difficulties in the area of mobility and movements.
2. Adjusting the conditions in the room to the patient's needs. Providing a room closest to the bathroom, treatment room, nursing station, dining room, common room and a bed — closest to the exit, with access from 3 sides.
3. Assessing the risk of falls and developing, in collaboration with the patient, a movement pattern that allows for specific body postures.
4. Helping with activities that the patient cannot do on his own, e.g. getting into bed.
5. Offering a walker.
6. Suggesting a wheelchair and transporting the patient in order to cover a longer distance, e.g. a consultation in another part of the hospital.
7. Motivating the patient to cooperate with a physiotherapist and perform the exercises proposed by him/her.
8. Monitoring vital signs before the exercises, and if necessary, during and after the exercises. Monitoring fatigue, shortness of breath, skin colour and problems with balance.
9. Encouraging the patient to participate in morning gymnastics, performing exercises in the recreation room (stepper, stationary bicycle, other equipment).
10. Encouraging the patient to participate in occupational therapy and minor motor skills exercises: writing, drawing, plasticine/play dough forming, carrying small objects, solving puzzles.
11. Encouraging the patient to exercise minor motor skills while performing everyday activities, e.g. buttoning, closing the zipper, putting things in a drawer, unscrewing a bottle, using cutlery, etc.
12. Participation of the patient in relaxation and music therapy, help with lying on a mattress and getting up.

13. Participation of the patient in dog therapy classes (organised in the ward every two weeks).
14. Setting an individual home exercise plan with the physiotherapist.

Assessment. The patient was moving around with a walker. He needed to be transported to specialist examinations. He participated in classes with a physiotherapist, occupational therapist and dog therapy classes. He tried to move and practice on his own in the recreation room.

Problem 5: Pain During Urination

Characteristics of the problem. The patient reported that he had been experiencing pain during urination and prostate pain for 2 weeks.

Nursing interventions:

1. Transportation of the patient to an ultrasound examination as a matter of urgency, on doctor's request.
2. Catheterization of the patient and ongoing evaluation of the patency of the catheter.
3. Keeping a fluid balance.
4. Observation of excreted urine.
5. Care of the urethra outlet.
6. Instructing the patient on the principles of catheter handling, lying down and hygiene.
7. Administration of medication prescribed by the doctor.

Problem 6: Fever

Characteristics of the problem. The patient had a fever of 38 degrees Celsius and more for three days in the ward.

Purpose of nursing care. Restoring normal body temperature.

Nursing interventions:

1. Measurement of basic parameters.
2. Collection of blood and urine samples for tests (morphology, biochemistry, general urine examination, urine culture).
3. Administration of medicines according to medical order: Paracetamol, ascorbic acid and rutoside.
4. Help with hygienic activities, eating and movement.
5. Changing bed linen as needed.
6. Keeping a fluid balance.
7. Control of food intake.

Assessment. After three days the temperature dropped to 35.7–36.9 degrees Celsius. The patient did not require antibiotic therapy.

The result of treatment and care. During hospitalisation, the patient received antidepressant treatment and urological treatment was modified. A

gradual improvement in mood, drive and sleep was observed in the patient, as well as a reduction in urinary tract ailments. The patient was discharged home in a balanced mood, without any suicidal thoughts or intentions, without any psychotic symptoms, in a condition enabling continuation of treatment in an outpatient environment.

Discussion

Mental disorders in HD are observed in as many as 80% of patients. The most common are affective disorders, including depression (30–40%) and mania or hypomania (approximately 10%). Patients have an increased risk of a suicide attempt, which affects every fourth person. Suicides in people with HD are 4–6 times more common than in the general population. The causes include emotional instability, irritability and aggressive behaviour [8,9]. The patient described in this paper was admitted because of suicidal thoughts and tendencies, which indicates that the data presented here address a life-threatening problem. Nursing care consists in careful observation of the patient's behaviour from the point of view of suicidal and depressive thoughts appearing or intensifying. In case of their occurrence, the nurse is obliged to ensure the patient's safety, which is described in the analysis of the care problem 1 [10].

Patients with HD are also diagnosed with other symptoms and mental disorders. Approximately 30% of patients present psychotic symptoms similar to those of schizophrenia [11]. In some cases, there are obsessive-compulsive or anxiety disorders [9]. In the patient described here no perceptual abnormalities were observed, no delusional content was manifested. When the above described mental disorders occur, the nurse's tasks include observing the patient and documenting the observed behaviour as well as the emotions and thoughts reported by the patient. Sometimes the patient cannot describe his or her own experiences, so the nurse tries to define the experiences together with him or her, taking into account the principles of therapeutic contact. One should avoid naming thoughts and emotions for the patient. Questions that are helpful in this regard should be open and encourage verbalisation. If, however, the patient has difficulty in determining his or her feelings, the nurse can direct him or her [10]. In HD, disease insight is at least partially preserved [11], which facilitates critical evaluation of patient's experiences and reduces discussions or disputes.

Every patient develops dementia. The patient described in this paper also showed dementia features. In the majority of patients, deficits in the first phase of the disease are discreet and relate to difficulties in recalling information in situations of stress or rapid action. Patients

most often have the ability to remember new messages and to recall information after hearing prompts. Patients often experience attention deficit. One of the most characteristic symptoms of cognitive impairment is a slowdown in thinking and following instructions, which often occurs hand-in-hand with apathy and refusal to cooperate. Aphasia, agnosia and apraxia occur only rarely and usually only in the advanced stages of the disease [5]. If the above-mentioned disorders are observed, the nurse is required to be attentive, empathic and to show acceptance. The patient may show annoyance, anger or anxiety in connection with memory disorders. Nursing care should focus on ensuring that the patient remains in as stable and predictable environment, i.e. that the rhythm of the day is set in a similar way on a daily basis and that the patient's environment is organised in such a way that it is as constant as possible. To the extent possible, appointing one on-call person to take care of the patient strengthens the patient's sense of security.

In the described patient, mobility issues due to the presence of choreiform movements were observed. This is the most common, characteristic neurological symptom, which significantly hinders everyday life and adversely affects the quality of life of patients. In addition, dystonia may be present in patients. Sleep disorders and difficulty in passing urine, which were also present in the described patient, are common. In the late stages of the disease, difficulties with swallowing occur, resulting in weight loss and various disorders of the gastrointestinal tract.

Conclusions

Caring for a person with Huntington's disease can take many years. Over time, symptoms intensify, and uncontrolled body movements, emotional changeability and dementia make it very difficult for the patient to function. The consequence of these changes is the patient's disability, and at some point full dependence on others. The lack of drugs to cure Huntington's disease makes the cooperation of a nurse, a physician and other members of the therapeutic team primarily aimed at providing comprehensive care and improving the quality of life of the patient [12]. The patient described in the paper experienced problems resulting from mental and somatic disorders, such as suicidal thoughts and tendencies and fever, difficulty sleeping, moving and passing urine. The main nursing interventions included close observation and a holistic approach in collaboration with all members of the therapeutic team. The patient was discharged home in a good general condition, in a balanced mood, without suicidal thoughts. He did not attempt suicide during hospitalisation.

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