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ORIGINAL PAPER

SELF-CARE IN PATIENTS WITH PARKINSON´S DISEASE

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Abstract

Aim: The aim of research was to describe self-care changes in two patients with Parkinson´s disease (PD) who were living in the home environment. *Methods*: For the method of data collection was used semi-structured interviews, structured observation, medical record´s analysis and chosen measuring tools. The main source of information was two patients diagnosed for PD. The secondarily source of information was the family relatives and the medical records. *Results*: Principally in relation with primary symptoms (with motor impairments) of Parkinson´s disease were identified patient´s problems in areas activities of daily living (ADL) and instrumental activities of daily living (IADL). *Conclusion*: Patients from initial stages of Parkinson´s disease are confronted with reduction of functional status with partial loss of self-sufficiency in realization ADL and IADL. Nursing care must be oriented at maintaining the maximum extent of self-sufficiency already in the early stages of Parkinson´s disease.

Key words: self-care, ADL, IADL, Parkinson´s disease, case study.

Introduction

Parkinson´s disease (PD) is an idiopathic progressive neurodegenerative disease of the central nervous system caused by gradual dying out of the dopaminergic neurons. Primarily, the motoneurons from the cerebral stem are affected, especially from the area of substantia nigra (Hort, Rusina et al., 2007, p. 333; Seild, Obenberger, 2004, p. 275).

The main motoric symptoms of PD are bradykinesis/akinesis, postural disorders, rigidity and rest tremor have essential impact on gradual, long-term dependence on help when performing IADL (instrumental activities of daily living) and ADL (activities of daily living) (Pretzer-Aboff, Galik, Resnick, 2009, p. 55-63; Cianci et al., 2006, p. 6). The functional potential is decreased also by the occurrence of immediate halt while walking, so called "freezing", which affects most frequently the lower extremities and manifests like the inability to walk in the particular situation for a short period of time (Jankovic, 2008, p. 371). PD progression leads to high risk of falls caused by the postural instability, what supports further development of dependence in the self-care. Besides the progression of disease, also the long-term medicamentous stimulation of the dopaminergic receptors can cause the mobility disorders (swings between "off" condition with highlighted symptoms of Parkinsonism and „on" condition of good mobility) (Preiss, Kučerová et al., 2006, p. 256), and reduction of self-sufficiency. Next limitation of the functional potential is caused by the accessory non-motor symptoms (vegetative, mental, sensory and others) (Valkovič, 2006, p. 257). For example, in the area of urination and excreting faeces the irritating urinary bladder, frequent urination, urge to urine, nocturia, urgent urinal incontinence, constipation, and diarrhea are present (Parkinson´s Disease Society, 2008, p. 12, 17). Depression causes apathy and the lack of interest in performing ADL and IADL. In the terminal stage of PD in most patients the cognitive dysfunction, even dementia and immobility are developed (Valkovič, 2006, p. 256).

One of the goals of the multidisciplinary care management about the patients with Parkinson´s disease is to keep maximal functional level and self-sufficiency when performing ADL and IADL as long as possible (Skelly, Lindop, Johnson, 2012, p. 12-13).

Aim

The aim of the research was to describe reduction of the functional potential in self-care in patients with

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PD living in the family environment and the way of its compensation.

Methods

Design

To reach the goal there was chosen a qualitative research method - the medical case study. Taking into consideration the selection of respondents with typical course of PD and the goal of the research the presented medical case studies are descriptive in their character and are simple in their design (Thomas, 2012).

Sample

The selection of the respondents was made intentionally, based on the following criteria: PD diagnosed by a doctor according to the current international criteria MKCH-10, the occurrence of the disease for more than 5 years (it is associated with the occurrence of fluctuations present also in the stable condition by means of L-DOPA or other medication), without presence of the cognitive deficit and depression, the willingness to co-operate, the information-sheet approval signed by the patient, living in the private environment. The set of the respondents consists of two patients, a 63-year-old man and an 81-year-old woman. The patients of different gender and course of disease were selected in order to describe as wide range of changes in self-care as possible.

Data Collection

The main source of information was two patients diagnosed for PD, who had been informed about its purposes, ensuring their anonymity and they signed the information-sheet approval on processing the data before the beginning of the research. The secondarily source of information was the family relatives and the medical records. The combination of different types of methods was used to get the empirical data. The recording sheets, prepared in advance, were used in the semi-structured interviews with the patients and their relatives. The changes in self-care resulted from the disease were the key topic of the interview. The structured observation was focused on performing the activities of daily living by the patients, on the way of self-care deficit compensation, on the symptoms and the way of arranging their home environment. The measuring tools: Barthel Index of Activities of Daily Living (Barthel ADL) (Mahoney, Barthel, 1965, p. 61-65) and The Lawton and Brody Instrumental Activities of Daily Living Scale (The Lawton and Brody IADL Scale, Lawton-Brody IADL) (Lawton, Brody, 1969, p. 179-186) were used as a background for the interview and observation. Various authors recommend them to be appropriate for assessing the PD patients, such as Pirogovsky et al. (2012, p. 988), Yanko et al. (2009, p. 9). The analysis of medical records was focused on getting information about provided health care and patients´ health condition. The obtained data were written down in the forms prepared in advance.

Data analysis

The data analysis is based on the model describing the relationship between damages resulting from PD and disability (Schenkman, Butler, 1989, p. 538-547). The patient´s case records are divided to the anamnesis and catamnesis (Žiaková et al., 2009). In the anamnesis the information about patient´s health condition and habits in self-care before the onset of the disease are mentioned briefly. Catamnesis shows the period from the start of the disease up to the present time with regard to the identification of problems in ADL, IADL developed in the connection with PD motoric signs. The authentic utterances of patients and their relatives, marked in the quotation marks and italics, are provided in the description of the cases.

Results

The patient´s record A

A 63-year-old male patient has been diagnosed PD since 1998, now he uses the monoamine oxidase inhibitor typ B levodopa, the decarboxylase inhibitor, and the inhibitor COMPT (katechol-O-methyl transferase). Also he has been diagnosed the arterial hypertension NYHA II and arthritis psoriatica which are compensated pharmacologically. He lives in a family house with his wife, now he is retired on pension. Since 2002 he has been on disability pension, before that he was a locksmith for living. He was absolutely self-sufficient in ADL sphere before the disease burst out. From IADL he could manage work around the house/garden, keeping house in order, but he didn´t take part in keeping household. Sometimes he helped with shopping, tiding up to his wife.

The catamnesis of the patient A

The tremor and mobility difficulties of the upper extremities, problems in gait, and fine motor skills of the hands were the first signs of the disease noticed by the patient. *"My hand started to tremble, I couldn´t do anything (to shave, wash, drink, tie the shoe laces), I couldn´t stop it. I tried to hide it, so I kept my hands together, touching each other but it*

was even worse. I noticed that I am slower in some way, when walking I felt like shuffling, said literally". Objectively, the rest tremor in one upper extremity, gradually accessorized with the tremor in the other hand, the lower extremities and the head had been found. The changes in mobility, walking difficulties (slowing down, small steps, and a shuffling gait) occurred. *"I was still trembling, my legs were stiffed, heavy, I couldn´t move my legs up. They were like stuck to the floor by glue"*.

He had had problems with getting dressed, eating and fluids intake, getting his appearance in order, hygiene already in the beginning of the disease. *"To get dressed took me up to half an hour. I felt like unskillful, unable to hold a razor, had problem to catch and hold a comb, cutlery, couldn´t control my hands as I could before."*

In the course of the disease also the periods of clinical condition improvement had been present, especially when starting and adjusting PD pharmacotherapy. *"The problems had alleviated, but my legs still felt heavy and stiffed, despite of the medication I was slowed down. I have tried to be independent, but some works made me very tired."*

In ongoing progression of the disease the semiflexive body position, the rigid muscles, the facial mimics' problems, the sleeping disorder, and the pain in the extremities had been present. This caused problems to climb the stairs and to overcome the barriers, e.g. door threshold; he wasn´t able to prepare particular dosages of prescribed medication, manage work in the garden/around the house. Besides that, the problems with urination, such as frequent urination during the night and urge to urinate appeared; he wasn´t able to comb his hair, shave his face, button up, get dressed, use cutlery, and tie the shoe laces. *"My hands were shaking a lot, I couldn´t comb my hair, dry my body on a towel, I had big problems with getting shower, holding a razor in the hand when shaving, I couldn´t hold cutlery"*. He needed help when button up and unbutton his clothes, tying the shoe laces, sometimes when cutting meat, when changing position in the bed and when getting up from the bed or chair.

The disease progression was the reason to ask for disability pension. *"I couldn´t go to work and work as usual, do my hobbies, work in the garden"*. To alleviate the muscle rigidity, to improve balance when standing, walking and avoiding falls, by his doctor he was recommended to consult a physiotherapist, to adjust the interior and use the compensation aids. He followed pharmacotherapy as prescribed; with help of his family the changes of interior in the home environment – removing thresholds, installing handles next to the bed, have been made. He didn´t do any exercise giving no reason for it, and he refused to use the compensation aids while walking and getting around, when consuming food, getting dressed. He argued: *"I don´t want to be dependent on an aid"*.

In the last six months his mobility has got worse, he has been slowed down and stiffed, the condition of immediate blockage of movement has been frequently occurred, sweating and production of skin wax in the face has been increased, he has been felt severe pain in the extremities and has been suffered sleeping problems. That is why his wife provides him more intensive help, especially in the sphere of food and fluids intake, in hygiene, when getting his appearance in order, getting up from the bed.

The impact of the clinical symptoms on the stage of patient´s self-care has had negative effect to his behaviour and mood. He felt bad when people were looking at him. He was anxious, felt inner tension, was afraid of impairment his health condition. Their intensity has been changed according to the current physical condition.

The summary information about patient´s self-care is given in the Table 1 and 2.

The patient´s record B

An 81-year-old female patient has been diagnosed PD since 1993, now treated by the monoamine oxidase inhibitor type B levodopa, the decarboxylase inhibitor, and the inhibitor COMPT. Besides that, she has been diagnosed the arterial hypertension NYHA II and osteoporosis which are stabilized. She is a widow living in a flat with her daughter. Before the diseases burst out she was self-sufficient in making ADL. From IADL activities she did almost all housework. "I liked cooking, went shopping. When cleaning the windows and carpets my daughter helped me".

The catamnesis of the patient B

The tremor in the upper hand was one of the first signs of the disease noticed by the patient. *"I noticed shaking my left hand, fingers, more and more and couldn´t do anything about it. I felt like my legs got frozen to the floor"*. The rest tremor in the upper extremity, the postural instability, the changes in mobility, problems with a gait and its slowing down, hypokinesis, small steps were found also objectively. That was the reason why *"I was not able to take care about myself, I couldn´t eat or went to the bathroom"*. According to her daughter, the female patient needed help when getting dressed and undressed, in hygiene, getting her appearance in

order, moving around and walking, preparing meals and their intake, fluids intake, shopping, preparation of dosages of medication, keeping household. *"Making food took me long time; sometimes more than two hours. Nor I could cut a slice of bread or spread the butter on the bread. I swallowed the wrong way when eating, couldn´t hold a spoon in my hand. Everything dropped down of my hands, I broke a glass here and then when drinking water. When I wanted to make a call, I had problem to dial the number. I couldn´t embroider; hold the knitting needles, everything dropped down of my hands, even the drugs. My daughter had to help me all the time."*

The impairment of motor signs had been the cause of repeated falls in which she sustained repeated injuries of the backbone. *"I trembled awfully, my legs got stuck to the floor, I couldn´t move, I fell down. In the night I couldn´t turn over on my own."* The doctor has suggested consulting a physiotherapist, to adjust interior in the flat and to use the compensation aids. In the interior the door thresholds have been removed, the handles have been installed, the carpets have been fasten to the floor, the handlebar has been placed to the headboard, lever taps have been installed, the patient have started to use a walking frame when moving around. The patient followed the medication as prescribed and did exercise as recommended by the physiotherapist. *"I do exercise holding the handles approximately 10 minutes self-sufficiently, especially it helps my legs. I try to do it daily."*

Table 1 Activities of Daily Living

Activities of daily living	**Male patient A**		**Female patient B**	
	Problem	Compensation	Problem	Compensation
Eating, drinking	- using cutlery - drinking from a glass - pouring liquid into a glass	- the relatives - a mug	- cutting - using cutlery - breaking dishes - spilling liquid when drinking - swallowing rice and small sort of pasta	- the relatives - the plastic dishes - an anti-slip dish drying mat - putting rice and small sorts of pasta out of the menu - a drinking straw - a plastic bottle with small opening in the lid
Getting dressed, getting undressed	- button up the clothes, unbutton the clothes - putting on a shirt - tying shoe laces	- the relatives - the shoes with hoop-and-loop fastener - clothes with zipper, hook-and-loop-fastener	- getting dressed, getting undressed - button up, unbutton the clothes - putting on and off Shoes	- the relatives - a long-handled shoehorn - a sock and stocking puller
Personal hygiene, getting the appearance in the order	- getting shower - shaving the face	- the relatives - a shower commode	- morning hygiene - getting shower - nail clipping - hair washing	- the relatives - the handles in the bathroom - a bath lift - an anti-slip bath mat and a rug - the lever taps - a long-handle bath brush
Checking excretion of urine and feaces	-	-	- urgent incontinence	- the incontinence pads
using WC	-	-	- she doesn´t come to the toilet on time when feeling urge to urine	- the handles next to WC - a walking frame
Changing position, gait	- changing the position - getting up from the bed - climbing the stairs - moving in the narrow space	- the sturdy shoes - the interior without thresholds - the handles next to the bed	- sitting down - changing the position in the bed - getting up from the bed - walking	- the relatives - a walking frame - a handlebar - the interior without thresholds - the carpets fasten to the floor - the removed rugs - a rehabilitation - the sturdy shoes

Legend: „-„ means that the problem in the particular sphere is not present.

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As the disease has progressed, it was accompanied by the problems of fine motor skills, the urination problems, such as frequent urge to urine, urgent particular dosages of drugs, has done shopping, has done laundry, has tidied up, and has cooked. She put small sorts of pasta and rice out of her menu. The female patient could use a spoon self-sufficiently when eating, could drink liquids from a plastic bottle or from a glass when using a drinking straw, she could go to the toilet when defecating, could do exercise when using the handles. Patient´s repeated falls caused that she has been afraid of walking. *"I have been afraid of falling down; I couldn´t control my legs. I was told that when I have the walking frame, I won´t fall down. But I rather won't walk at all."* She has refused to make even the short walks related to go shopping.

In the recent year she has been demanded more intensive help and control when making ADL because of the deterioration of the motor signs, the occurrence of pain in the extremities, weakness and sleeping disorders.

The summary information about self-care of both patients is given in the Table 1 and 2.

Table 2 Instrumental Activities of Daily Living

Instrumental Activities of Daily Living	**Male patient A**		**Female patient B**	
	Problem	Compensation	Problem	Compensation
Making phone calls	-	-	- dialing the number	- a big button phone
Transport	- getting in - getting off	- the relatives	- getting in - getting off - to fast a seatbelt	- the relatives
Doing shopping	- climbing the stairs - the inability to go through the narrow space - holding things - tiredness, weakness	- the relatives	- she cannot manage it at all - risk of falling down	- the relatives
Cooking	- the motor non-dexterity - the inability of the target movement - holding things	- the relatives	- she cannot manage it at all	- the relatives
Doing housework (keeping household), work around the house	- the motor non-dexterity - the inability of the target movement - tiredness, weakness - the risk of an injury	- the relatives	- the motor non-dexterity, inability of the target movement - holding things - the risk of falling down - she cannot manage it at all	- the relatives
Taking medication	-	-	- holding drugs - batching drugs	- the relatives - having drugs at her fingertips
Finances	-	- the relatives (finances was managed by the wife also before patient´s disease)	- she cannot manage it at all	- the relatives

Legend: „-„ means that the problem in the particular sphere is not present

Discussion

Under the influence of the motor and non-motor symptoms the typical changes in self-care of PD patients do occur resulting in their constant dependence on other people's help, as described by Wressle, Engstrandm Granérus (2007, p. 131-139), Fange, Iwarsson (2005, p. 184-190), Holroyd, Currie, Wooten (2005, p. 2134-2135) and others. In the patients included in the case report study the changes in their self-care were present due to occurrence of

the motor and non-motor symptoms of the disease. From the group of motor symptoms there were fluctuations, problems with gait, rest tremor and rigid muscles in both patients. The tremor is considered the most frequent clinical sign in the very beginning of the disease (Valkovič, Benetin, 2011, p. 13). The most often it is present in the distal parts of the limbs (the fingers and the toes), rarely on the head, the chin, the lips. From time to time it occurs also in the soft palate when causing dysphagia and it is the risk factor of aspiration (Hickey, 2009, p. 692). It cannot be affected by taking antiparkinsonics (Seidl, Obenberger, 2004, p. 276-277). Its intensity alleviates or disappears entirely when moving as well as during sleeping. On the contrary, it increases when there is inner tension, fear, worries, and anxiety (Valkovič, Benetin, 2011, p. 12-13). The rigid muscles and movement initiation problems were present in both patients. This resulted in higher effort when walking, and gradually it was reduced (e.g. they stopped to go shopping). The fine motor skills, non-dexterity, sloth of movement have impaired due to the occurrence of the tremor, the rigid muscles in both patients. This was represented as having problems to hold a comb, cutlery, a cup and the other aids, to button up and unbutton the clothes, to hold clothes, to tie the shoe laces; when turning on/off water tap, shaving the face for the patient A. These problems are characterized in PD patients as serious and very frequent (Hickey, 2009, p. 692-695). For example, the inability to eat self-sufficiently is a reason of malnutrition onset (Anderson, Sidenvall, 2001, p. 69-78).

In the patient B the presence of the postural instability caused falling down repeatedly. The occurrence of the falls is the sign of disease progression. Most of the falls take place in the interior, usually in the well-known environment. The preventive measures reducing the risk of falling down have been done in both patients (the handles, removing door thresholds). The adjustment of the environment significantly helps to improve and keep the level of dexterity, and thus also to support self-sufficiency, to ensure safety (American Medical Directors Association, 2010, p. 6-7).

At the same time, the fear of further falls described by the patient B can be the cause of the lost of self-confidence resulting in limiting mobility. At first, there is elimination of activities out of the house, and then there is reduction of getting around at home and gradually the immobility syndrome is being developed (Valkovič, 2009, p. 364).

In both patients the feeling of getting frozen/being stuck to the floor and feeling of heavy legs had occurred when walking. It can be described as sudden freezing of a gait or a motor block lasting from couple of minutes up to half an hour. It usually occurs when walking through the narrow space, e.g. through the door, the narrow corridors (Kaňovský, 2004, p. 215). This sign makes the level of self-care significantly worse and it can be influenced pharmacologically only in very little extend (Bareš, 2008, p. 105). Both assessed patients have been recommened physiotherapy by their doctor in order to reduce the motor signs. The patient A refused it without giving any reason, the patient B did exercise daily. Doing regular izotonic exercise has the direct positive effect on the muscle rigidity, improving the joint articulation and the blood circulation (Benetin, Valkovič, 2009, p. 93). The rehabilitation improves the movement patterns, maintaining balance, movement (a gait) initiation, what is associated with supporting the independence when making the activities of daily living (Grimes et al., 2012, p. 14). Doing exercise makes the whole therapy of disease more effective, and eventually this has the direct effect on higher quality of patient´s life. It represents the adjuvant non-pharmacological method in PD treatment and it is a part of the complex therapy (Ressner, Šigutová, 2001, p. 31).

In the clinical condition of PD there are also neuropsychiatric complications which are frequent during the whole course of the disease (Masopust, Vališ, 2004, p. 154). The patient B has experienced anxiety, fear and worries about the future. Their occurrence is associated with the problem of adaptation to the disease, the limits in professional life, in personal life, in self-care (Masopust, Vališ, 2003, p. 255; Lowenstein, Tickle-Degnen, 2008, p. 233).

From the field of the sensitive disorders the patients suffered from the pain in the extremities and acatisia (in the clinical condition of the patient A). The pain caused limitation of the motor skills, even the disability to change the position in the bed self-sufficiently. The sleep was interrupted and then the patients were tired, which reflected their motivation and making ADL, IADL; that is supported also by the results of the research studies by Shulman et al. (2008, p. 790-796), Schrag et al. (2000, p. 67-73).

From the autonomous PD signs the urinary bladder dysfunctions (frequent urination, frequent urge to urine, nocturia) were present in both patients. In the patient A the urgent incontinence was associated. The patient A didn´t commented on how was this problem solved out. The patient B used the disposable continence aids what helped her to decrease the fear of wetting herself.

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Using the compensation aids helps to keep self-sufficiency, e.g. using a long-handle brush when making personal hygiene, using a walking frame with brakes when getting around as in the patient B; using a mug in the patient A. The synthetic shoe laces, the long-handle shoehorns, the sock and stocking pullers, the big button phones belong to very useful compensation aids as well (Pretzer-Aboff, Galik, Resnick, 2009, p. 58). Meals homogenous in their consistence will make self-suffiency in food intake easier when using a spoon. So the patients can be avoided the stress from using a knife and a fork (Schwartz-Peterman, 2008, p. 60). In the presented case studies the patients had problems to use cutlery, and therefore they used only a spoon. The fluid intake makes problems as well (Andersson, Sidenvall, 2001, p. 76). Because of the tremor in the hands the patients had problems to hold a glass, when pouring the liquid it was spilled, the patient B broke glass. The self-sufficiency in the fuild intake can be achieved by placing a drink at patient´s fingertips, using a mug, a drinking straw, a plastic cup and a bottle. The anti-slip table mat can be used to make dishes stable (Schwartz-Peterman, 2008, p. 60).

The closest relatives represent the key factor in supporting the functional potential of the patient in the home environment, in maximizing his/her abilities, in avoiding to be dependent on one´s help as long as possible, and in developing own strategies of stress management related to the symptomatology of the disease (NICE Clinical guideline, 2006, p. 142). It is good when the patients are given the particular housework, including going shopping, cooking, doing work around the house, in the way which is not stressful and tiring to them. Stress gives rise to deterioration of the motor signs of the disease (Preiss, Kučerová et al., 2006, p. 264). Both patients have been given necessary help and support by their relatives. Performing most of IADL was difficult, too tiring and challenging to them, and thus they took only minimal part in it. The patient A didn´t do any house housework before the diagnose was made; keeping household was done by his wife. Since he has been sat in the wheelchair, he started to help when making meals and tidying up. The patient B had been stopped doing housework gradually; keeping household has been completely done by her daughter instead. However, it may be related also to her age (81 years) and to the involutional changes (Andersson, Sidenvall, 2001, p. 69-78). Therefore, the need of intensive co-operation with the relatives by means of counselling, education, emotional help is closely related with keeping patiens´ self-sufiiciency, with prevention against the complications (Grimes et al., 2012, p. 5-6; Pretzer-Aboff, Galik, Resnick, 2009, p. 58).

Conclusion

From the very beginning of PD the patients are faced the reduction of their functional potential, their partial loss of self-sufficiency when making ADL and IADL. During the progression of the disease the significant reduction of the functional condition and dependence on one´s help occurs. The deficiency in self-care can be reduced by means of the compensation aids chosen adequately and accepted by the patient and auxiliary people. From the very beginning the nursing care has to be focused on reducing dependence on help of the others and maintaining as maximal extend of self-sufficiency as possible. How to provide the complex care focused on keeping self-sufficiency is recommended in the clinical guidelines, e.g. Parkinson´s disease - National clinical guideline for diagnosis and management in primary and secondary care (NICE Clinical Guideline, 2006), Clinical guideline for the management of inpatients with Parkinson´s disease (2013).

Our research study has several limitations, thus our findings cannot be generalized. Using the tools of Barthel ADL index and Lawton IADL as a base for interviewing and observing the patients, which are not intended specifically to assess the level of self-care in PD patients and do not detect the whole range of the problems in this field, are some of the examples. The Parkinson´s Disease Activities of Daily Living Scale (PADLS) which is derived from Barthel ADL index is a more specific measuring tool (Hobson, Edwards, Meara, 2001, p. 241-246). When taking into consideration the clinical condition of the patients only some of the problems in self-care are described, and only their partial description is provided in this study. The characteristic of self-care, in the relation to the treatment methods, other physical comorbidities, was not in the center of our attention.

Ethical aspects and conflict of interest

The study was run according to the basic rules of the Helsinki declaration. The participants were learnt about the purpose and the aim of the study, about keeping their anonymity, the way of getting data and about their voluntary participation in advance. The written approval to participate in the study was obtained from both patients and their family relatives. The authors of the contribution are not aware of any conflict of interest.

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