The importance of support and forms of kinesiotherapeutic activity of family members of persons affected by Parkinson's disease

Znaczenie wsparcia oraz formy aktywności kinezyterapeutycznej członków rodzin osób dotkniętych chorobą Parkinsona

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Summary

Parkinson's disease is a chronic and progressive degenerative disease of the central nervous system. The disorder is classified as extrapyramidal system disease. In order to improve the patient's condition and increase the level of quality of life, pharmacological treatment and rehabilitation are used to eliminate progressive disability. The help from friends and family affects not only the course of the disease, but above all the emotional well-being of the patient. Family support and its participation in the whole therapeutic process greatly optimize its results. The purpose of this paper is to present the most important issues regarding kinesiotherapy in Parkinson's disease and to demonstrate the impact of the involvement of the entire family system on the course and results of therapy. Kinesitherapy plays a very important role in the process of improving and adapting the patient to perform everyday activities. Kinesiotherapeutic treatments have not only a significant impact on the symptoms occurring in the course of the disease, but also on the overall health. The personalized selection of therapy and the involvement of the entire team of therapists is extremely important in eliminating both motor and non-motor symptoms. The correct implementation of the physiotherapist's instructions, the patient's involvement, as well as the active participation of the patient's friends and family, are the condition determining the effectiveness of the entire process of maintaining patient's health and fitness. Kinesitherapy process prevents permanent disability and helps maintain independence and good quality of life for as long as possible. The involvement of the entire family support system has an impact on the results of the therapy.

Keywords: Parkinson's disease, kinesitherapy, family, support

Characteristics of the disease

Parkinson's disease (Latin: Morbus Parkinsoni, PD) is one of the most common degenerative diseases of the nervous system. In a neuropathological study, PD is characterized by the loss of neurons of the compact part of the substantia nigra, the presence of extracellular myelin released from degenerating neurons, reactive gliosis, and the presence of eosinophilic intracytoplasmic inclusion bodies (Lewy bodies) in the remaining neurons of substantia nigra [1]. It mainly affects persons over 50 years of age (the average age of incidence is 58 years of old). The incidence of parkinsonism in Europe among persons over 60 years of age is about 1.6%, this rate increases with the age of the patient. It is estimated that about 10 to 20 persons per 100,000 residents gets affected by it during the year. Male incidence is much higher compared to female one. The incidence rate in the US is 19 per 100,000 residents, where male to female incidence ratio is 19 to 9.9 per 100,000 persons. In Poland, it is estimated that 60 to 80 thousand of persons suffer from Parkinson's disease, that is, about 1.5 to 3% of the population. Despite significant advances in diagnosis techniques, the etiology of the disease has not been fully understood, which directly translates to the use of purely symptomatic treatment [2, 3]. The developed picture

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of the disease consists of such symptoms as: general slowdown (bradykinesia), manifested in, among others, mimic disorder (hypomimia), synkinesis, slow speech, which becomes monotonous; resting tremor, bent posture, significant resting tremor, especially of the fingers, resembling the movement of rotating a pill, tremors sometimes also affect the lower limbs and head; gait with small steps, sometimes accompanied by pro- or retropulsion; posture stability disorders; significant increase in muscle tone of stiffness type with cogwheel symptom; micrographia; autonomic symptoms in the form of drooling, oiling of the face (increased activity of sebaceous glands, paroxysmal sweats); slight mental slowdown, sometimes emotional disorders, some patients may develop dementia at a later stage. Resting tremor that does not occur during sleep mainly affects the upper limb. Muscle stiffness is characterized by resistance to passive movement of the limb. These disorders cause difficulties in carrying out everyday activities such as: walking, taking a sitting position, changing bed position, eating, daily care activities. The disease among some patients progresses slowly but leads to complete disability, but the rapid and aggressive course of the disease also happens. Limiting the patient's daily activities leads to a significant reduction in the level of quality of life, both subjective and objective [4, 5]. In addition to motor symptoms, patients with Parkinson's disease have urinary and genital dysfunctions, cardiovascular, thermoregulatory, gastroenterological, emotional and psychotic disorders. Parkinson's disease is incurable, the therapy includes both pharmacological and surgical treatment. The latter, however, carries a significant risk of complications. One of the possible procedure options is to perform surgery involving the reduction of pathological hyperactivity of the thalamus, globus pallidus or hypothalamic nuclei. It has been shown that a patient undergoing deep brain stimulation under local anesthesia can respond better to physiotherapy [6]. The results of studies conducted by Kułakowska et al. indicate that access of patients with Parkinson's disease to rehabilitation treatment is still unsatisfactory. Approx. 50% of patients regularly perform exercises at home, and only every fourth patient has been looked after by a professional physiotherapist [7]. A significant part of the problems of patients in this group results from the fact of „being sick", which forces them to confront the life-threatening situation, the unpredictability of the course of the disease and changes in life activity. The co-occurrence of neuropsychological and social problems experienced by the patient requires the involvement of the entire family system in the course of therapy [8].

Rehabilitation (kinesitherapy) in Parkinson's disease

The goal of kinesitherapy in Parkinson's disease is to improve patients' motor skills and physical fitness so that they can perform self-service activities and actively participate in family, professional and social life. Patients of this group, due to progressive motor, cognitive and emotional deficits, avoid physical activity, isolate themselves from family, social and professional life. Studies in this field carried out in recent years shows that multidisciplinary physiotherapy in Parkinson's disease, which includes kinesitherapy, can be effectively used to prevent or reduce complications caused by reduced mobility. A specific management plan applies to neurological rehabilitation. It means a fixed order of the stages of rehabilitation, which includes diagnostics, prognosis assessment, functional assessment, rehabilitation planning and implementation. Rehabilitation understood in this way is not limited to physical improvement, but covers other areas of rehabilitation. The therapist's task is to eliminate speech and swallowing disorders, solve psychological problems, help with social and living issues. The pedagogical aspects of therapy, raising awareness of the risks and opportunities it brings, pointing to the purpose of training in the skillful use of compensatory movement strategies are also important here. In the advanced stage of the disease, the goal of kinesitherapy is to reduce the effects of progressive disability, prevent the complications of immobilization, and minimize the degree of dependence on those who care for the patient. It has been shown that stimulation of the range of physical activity in Parkinson's disease reduces mortality and degree of disability by increasing muscle strength and improving the sense of balance. The aspect of greater faith in the patient's own abilities and general improvement of his/her emotional state is also of considerable importance here. Regular physical activity is important for a patient with Parkinson's disease because it helps prevent cardiovascular incidents, diabetes and osteoporosis, and is also likely to have general anti-inflammatory effects. The literature says that exercise has a positive effect on suppressing or stopping symptoms typical of Parkinson's disease, such as depression or progressive cognitive impairment. As Yousefi et al. [8] show, the combination of pharmacological treatment with mobility exercises gives much better results in the treatment of Parkinson's disease than only pharmacological treatment. Malicka and Chamera-Bilińska showed in their studies an improvement in muscle function in the lower limbs within 10–20%, after a two-month period of regular general fitness exercises. A team of researchers headed by Struensee examined the effectiveness of a therapeutic program using kinesitherapy exercises in improving the overall mobility of patients in this group [9]. Most studies suggest running one-hour exercises 2–3 times a week for 4–12 weeks at the peak of drug effects. It is extremely important to continue the exercises because patients stop exercising because of the lack of motivation and encouragement from caregivers. A positive impact of physical exercises on the patient's social functioning has also been demonstrated. The improvement of motor skills motivates the patient to engage in social life, develop their interests, and spend their free time actively [10].

Family and the disease

When one of the family members is recognized as a patient, especially in the case of a chronic disease, it affects the perception of him/her by others and the expectations expressed towards him/her. It arouses positive feelings, such as compassion, forbearance, cordiality, but can also become an object of resentment and even hostility. Chronic disease often becomes a specific element of the family system structure. This is particularly visible in the case of mental illnesses, which have a very special interpersonal dimension from a family perspective. The interdependence between the sick person and others in the family may affect and does affect processes occurring within the family. This impact is modified by the importance that the family associates with the situation caused by the disease. It is different when the family perceives the disease as a serious threat, differently when it perceives it as a kind of a challenge. In the first case, the typical reaction is anxiety and depression, states of apathy and discouragement, in the second one – mobilization of energy and resources needed to fight the disease. Families use different styles of coping with the disease, which depend on the compilation of many factors such as: emotional bonds in the family, communication skills of individual family members, openness, readiness to change, self-esteem, personality of individual family members, disease pattern, intensity of symptoms, and life-threatening degree. H. I. McCubin distinguishes three groups of family coping strategies in a disease situation. The first one consists in focusing on family life, the second on maintaining well-being among healthy family members by caring for social life as well as cultural and professional development; the third involves maintaining contact with medical staff, following the doctor's instructions, and exchanging information with other families affected by a similar disease. Studies show that patients attach the greatest importance to help from formal institutions. Sick women are more likely to adopt a passive attitude, and more often than their partners seek help in prayer and among clergy. Sick husbands, in turn, seek help among relatives, family and friends. The ways of dealing with stressful situations also differentiate the patient's mental process. Cognitive strategies can be distinguished (using defensive mechanisms, underestimating the problem, selective perception of elements of a difficult situation), strategies focused on emotions such as anxiety, panic, depression, a sense of helplessness and behavioral strategies – from active, intense activity to total passivity [11].

The most frequently mentioned changes in the family functioning system in the event of a crisis caused by the disease are: disruption of daily routine, financial problems, disturbances in short- and long-term plans, loss of physical intimacy in marriage, conflicts and communication disturbances in the family. The family, participating actively in the process of nursing and caring for the sick, participates and should participate in the therapeutic process. Certainly the considerable difficulty in the case of Parkinson's disease is usually the advanced age of the guardian-spouse. It determines the perception of the disease, motivates or demotivates in struggling with the disease. In the case of a disease with damage to the musculoskeletal system that characterizes Parkinson's disease, the patient is often facing the loss of a job. It often becomes necessary for a person taking over the function of a patient's guardian to resign from the job, due to the amount of time it takes. Focusing on the internal problems of a family affected by chronic disease causes gradual isolation from all that is happening outside. Changes in physical appearance, a decrease in libido and sexual performance do not have a positive effect on intermarriage relations, which in turn cause further repercussions in the relationship between the spouses. Marriage is often dissolved because of this. The tremendous burden that caring for a sick family member brings with it leads to physical and emotional overload. There is a burn-out syndrome, similar to that which is sometimes caused by work overload. In the first phase, the symptoms resemble normal fatigue. Then the burned-out person tries to distance themselves from the problems. This phenomenon is called depersonalization. Finally, there is a transition to the so-called terminal phase, the essence of which is emotional isolation from the sick person and, consequently, neglecting them. This condition is usually accompanied by somatic complaints, a tendency to aggression and high impulsiveness. The ability to solve tasks and make decisions decreases, which affects the level of self-esteem and self-worth. The deepening of high mental tension closes the vicious cycle of reaction. In this situation, family members become less empathic and their behavior towards the patient takes the form of hostility. Stimulants become the solution to the problem and worsening depression leads to self-harm or even suicide attempts [12].

Importance of social support

The concept „support" belongs to a group of ambiguous terms, and attempts to define it are associated with the definition of its structure and function. Supporting is always about acting in a difficult situation, in a situation of instability, when without „support" there is a risk of falling. This term has unusual connotations in the case of Parkinson's disease, in which falls, their „history" are inscribed in the clinical picture and everyday life of the sick. The presence of other people, their closeness is conducive to coping with difficult situations, but it should be emphasized that, as psychological studies indicate in this regard, the stereotypical view on the benefits of relationships with other people is not entirely true. „Not every help, not in every situation and not for every person is beneficial." Even if someone's help is beneficial, it cannot be determined what kind of benefits are these, long-term or short-term, whether they relate to well-being, health or other social factors of human functioning. Support is defined as the availability of relationships through which the basic, interpersonal needs of a man are met. This need is considered not so much in a situation of life stress, but as a permanently available property of relations, serving adaptation and health, as a direct effect on health [13].

Studies on social support initiated in the 1960s were inspired by the colloquial understanding of the word and the experience of psychological therapy. Their goal was to determine whether social support promotes individual health and helps in coping with stress. As the reflection on the subject deepened, it was realized that the common name „social support" hides various ways of understanding this phenomenon, that it is a multidimensional concept and mechanisms of the impact of social support on stress, health and the overall quality of human life are very complex. At the turn of the 80s and 90s, the first theoretical models were developed, which were later verified. The so-called buffer hypothesis was focused on, which states that social support protects against negative health effects that are a reaction to high and long-term stress levels. Unfortunately, these studies have not led to unambiguous conclusions, also due to incorrectly selected methods of statistical analysis. With the spread of multivariate methods of analysis, studies have entered a new stage. It was stated that it was necessary to clarify the mechanism of support functioning, taking into account various factors and numerous intermediary variables. The role of personality variables and matching the type of support provided to the situation and the intensity of demand for this support began to be emphasized. Despite this, the researchers admit that their achievements do not allow to formulate definitive answers, but the benefit of this situation is that new hypotheses are formulated and new studies are still underway. The classification of social support results from the assumption that persons located in the social support network of an individual perform specific functions in relation to it. So, above all, emotional support stands out, based on the transmission of supporting emotions, showing concern, compassion, understanding, defining a positive attitude towards the supported person. In addition, it concerns the information support, expressed in the exchange of information facilitating the understanding of the situation experienced by the individual, this is providing legal and medical advice, information that can help solve the individual's problems; instrumental support, regarding the transmission of information on possible ways of acting; material support, providing material assistance, consists in providing specific material, service, and monetary assistance; valuing support, consisting in showing acceptance, respect, acknowledgment of the value of a person; spiritual support, which is a very important element of the spiral of kindness that should surround the individual. It appears when, despite their own efforts and support, a person remains in a difficult situation. He/she is in a state of apathy, resignation, illusion when he/she sees the causes of the crisis and failures outside his/her own person. Spiritual help may consist mainly in indicating the role of difficulty, suffering, disability in human life and showing the sense of these experiences. Specific classifications of social support are treated complementarity, and its functional properties are expressed in triggering positive emotions, giving advice, information, helping to strengthen self-worth and positive self-esteem, feeling of trust in oneself and others as well as a sense of belonging and social bond. Social support is treated as an external personal resource related to the process of coping with difficult situations. The internal characteristics of the individual are required to run it. The mechanisms for using support are individually diversified and depend on certain characteristics of the individual. These are the personality resources of an individual that facilitate or hinder the functioning of support. This applies to the sense of identity, independence, level of self-esteem, placement of sense of control, resistance to stress, social competences, expressed in openness to interpersonal relationships, empathy and assertiveness. These are closely related to such situational elements as the type and source of stressful situation and the quality of social relations [14].

Family participation in the therapy

An extremely important aspect of the discussed issue is the need for access to psychological help for sick family members. As already mentioned, deterioration of the patient's condition, their cognitive difficulties or behavioral changes affect the entire family system, and excessive focus on the patient's needs causes disturbances in meeting the needs of the caregivers. The reorganization of the entire family system and the involvement of caregivers in the therapeutic team taking into account the individual needs of each person, as well as modifying behavior towards the patient (e.g. overprotectiveness) are the main challenges for a psychologist cooperating with the family. The data indicate that it is the family that is the most important support group for patients with CNS diseases (among others, due to limited healthcare services in this group and low availability of therapy). Insufficient awareness of this issue means that the claim attitude, passivity and conviction that the burden of treatment rests only on healthcare services is still frequent [15].

Because patients with Parkinson's disease have their range of motion within the spine joints disrupted relatively quickly, the participation of a family guardian in the patient's performance of exercises improving range of motion in individual segments of the spine is indicated. Rotating 180 degrees is a challenge for posture stability – if patients have limited head torsion and cervical spine rotation, they have problems with the field of view when walking and turning. Depending on the patient's current condition, it is indicated to perform exercises recommended by a specialist in physiotherapy. Although there is no evidence indicating the effectiveness of the physiotherapeutic process in reducing flexion of the body or in the process of delaying these lesions, the importance of family assistance in increasing cognitive strategies, such as concentration and exercises to maintain the upright position or „high walking" is pointed out. Arranging the equipment in the patient's home to facilitate taking the correct position, such as rollers, wedges and appropriate equipment to facilitate night rest is also of considerable importance. It has been shown that gait speed and stride length is significantly improved after daily, caregiver-controlled training on a treadmill [16]. Analysis of the history of falls of patients in this group indicates that instability when trying to reach, turn or stand up may indicate the need to improve balance control. Balance activities undertaken at home or in a support group improve the balance possibilities by increasing the limits of stability [17]. Performing daily exercises of a purposeful nature, such as changing positions or walking on stairs, have a very positive effect on the patient's functional activity. In the case of activities that the patient is not able to perform independently, it is necessary to educate caregivers about ways to provide assistance or help in everyday existence. Regular exercise, even such prosaic as everyday walking in the fresh air, assisted by caregivers, facilitates maintaining general fitness, functional activity, prevents atrophy from inactivity and significantly improves emotional well-being [18]. Studies indicate that aerobic exercise, as well as undertaking cardiovascular training, strength training, stretching and the already mentioned balance exercises, undertaken regularly with the assistance of caregivers, improve patients' fitness [19].

In addition, a whole range of indications for the family and friends of a person suffering from Parkinson's disease can be specified. It is helpful to stick the tape pieces on the floor, hints and signs on the cards placed at the level of the patient's eyes. Removing carpets, fitted carpets, maintaining order and adequate home space (no unnecessary decorations, flower beds, too much of furniture, so as to minimize the need for sudden turns). Removing sharp, glass furniture edges will minimize the risk of injury in the event of a fall. The importance of the guardian's proprioceptive daily guidance has also been demonstrated (step back before walking, weight transfer from right to left). Marchese et al. proved the importance of touch in the course of this disease, sensitive gestures that reduce tension [20]. Many sources emphasize the need to start physiotherapy immediately after diagnosis, even if the patient's condition is good, as well as the need to cover the entire family with a physiotherapeutic program due to the overload of patient care. The problem of the patient's informed consent for his/her caregivers to participate in the therapy remains an open issue. It happens that the patient refuses to give one. There are various reasons for this. One of them is the advanced age of the spouse-guardian and psycho-emotional disorders [21].

The implementation of therapeutic tasks by family members of the patient also depends on the degree of cooperation with the community nurse, whose task is to help understand and implement pharmacological treatment, facilitate access to institutional assistance and services that patients need. This procedure is of educational nature. The importance of daily task training is emphasized here, aimed at increasing the scope and precision of functional activities. It should be emphasized that as Parkinson's disease develops, side effects appear, such as a decrease in the effectiveness of pharmacological treatment (mainly dopamine replacement drugs) and the occurrence of the „on-off" phase, consisting of rapid change of motor function, depending on the degree of action of the drugs. It has been shown that during the therapeutic dose, the patient is able to move completely freely and when the drugs stop working, the patient's mobility is rapidly reduced. These distinct changes resemble turning on („on") and turning off („off") the light. Initially, these phases largely depend on drug intake, but over time their changes become more accidental [22]. An important aspect of the issue is the occurrence of dyskinesia.

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Streszczenie

Choroba Parkinsona jest przewlekłą i postępującą chorobą zwyrodnieniową ośrodkowego układu nerwowego. Schorzenie zalicza się do chorób układu pozapiramidowego. W celu poprawy stanu pacjenta oraz podniesienia poziomu jakości życia stosuje się leczenie farmakologiczne oraz rehabilitację, niwelującą postępującą niesprawność. Pomoc najbliższego otoczenia wpływa nie tylko na przebieg choroby, ale przede wszystkim na dobrostan emocjonalny chorego. Wsparcie rodziny i jej udział w całym procesie terapeutycznym w znacznym stopniu optymalizuje jego wyniki. Celem niniejszej pracy jest przedstawienie najważniejszych kwestii dotyczących kinezyterapii w chorobie Parkinsona oraz wykazanie wpływu zaangażowania całego systemu rodzinnego na przebieg i wyniki terapii. Kinezyterapia odgrywa bardzo ważną rolę w procesie usprawniania i przystosowania pacjenta do wykonywania czynności dnia codziennego. Zabiegi kinezyterapeutyczne mają nie tylko istotny wpływ na występujące objawy w przebiegu choroby, ale też na ogólny stan zdrowia. Niezwykle istotny jest tu indywidualny dobór terapii i zaangażowanie całego zespołu specjalistów, w niwelowaniu zarówno objawów ruchowych jak i pozaruchowych. Poprawne wykonywanie zaleceń fizjoterapeuty, zaangażowanie pacjenta, a także aktywny udział otoczenia chorego, jest warunkiem efektywności całego procesu poprawy, utrzymywania zdrowia i sprawności chorego. Postępowanie kinezyterapeutyczne zapobiega trwałej niepełnosprawności oraz wspomaga utrzymanie jak najdłuższej samodzielności i dobrej jakości życia. Wpływ na wyniki terapii ma zaangażowanie całego systemu wsparcia rodzinnego.

Słowa kluczowe: choroba Parkinsona, kinezyterapia, rodzina, wsparcie