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SUPER training course

Integrated care applied to Parkinson disease

CASE STUDIES

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SUPER

Case study 1

Anthony is a 59-year-old man who was born in Liverpool and now is living in Manchester. He works as a salesman. He has been divorced since 2015 and is in daily contact with his parents, which live near him. He has a good relationship with his siblings.

His clinical picture began in 2016, with tremor at rest in the lower lip and left hemi body, predominantly in the upper limb, of a sporadic nature, which manifested itself in stressful situations.

At the beginning of 2017, he felt difficulty articulating words, which led him to consult a doctor.

In the directed anamnesis he reported hypomimia and bradykinesia, manifested by a slowness in grasping objects that occasionally interfered with his work. He denied symptoms related to sleep, sexual or urinary dysfunction or hyposmia; he also reported no mood disturbances, memory disturbances or other dysautonomia symptoms.

As medical history, he mentioned surgical correction of left tibia and fibula fracture, secondary to a traffic accident in 2014 as a motorbike driver; active smoking with a pack-year index of 1, and a sister with systemic lupus erythematosus who died without a clear cause.

He reported no family history of Parkinson's disease or other movement disorders.

General physical examination was normal, neurological examination revealed mild dysarthria, motor examination revealed the presence of cogwheel rigidity, bradykinesia, resting and postural tremor of moderate intensity in the left hemi body, and a short-stepping, no festinating gait, without turning blocks, but with decreased swinging of the left upper limb. In the cranial pairs, including eye movements, no alterations were found.

In a recent appointment with the specialist, he reported increased tremor, slower movements in his activities of daily living, more noticeable and generalised rigidity as well as increasingly marked motor fluctuations and dyskinesias, with no apparent effect of the drugs despite increased doses at previous reviews.

In addition, his communication problems have increased, with a faster rate of speech and lower voice volume. He also reports that lately he has noticed that he chokes when drinking liquids.

The aforementioned symptomatology increases his sadness, symptoms of anxiety and stress as he is unable to carry out his work activities normally, which in turn interferes with his social and family relationships.

Case study 1 – ASSESSMENT QUESTIONS

1. Based on clinical exposure, what would be the initial syndromic diagnosis?

- a) **Idiopathic Parkinson's disease** (Correct. As this clinical case shows, the most common symptoms of idiopathic Parkinson's disease are tremor, rigidity and slowness of movement).
- b) **Vascular Parkinsonism** (Incorrect. The most common symptoms of vascular parkinsonism are problems with memory, sleep, mood and movement, not declared in this clinical case).
- c) **Drug-induced parkinsonism** (Incorrect. The symptoms of drug-induced parkinsonism tend to remain the same over time; only in rare cases do they progress in the way that Parkinson's symptoms do. Drug-induced parkinsonism affects only a small number of people, and most people recover within months - and often within days or weeks - of stopping the offending drug).

2. What additional tests would be indicated in this case study?

- a) **Genetic testing** (Incorrect. 85-90% of cases of Parkinson's disease are sporadic forms; they occur in a single family member and are not due to a specific genetic alteration. Therefore, at present and with the information available to us, genetic forms of Parkinson's disease represent a small percentage of the total (10-15%). It is therefore not common to undergo this test if there are no relatives with the disease as in this clinical case).
- b) **Blood tests, X-ray and muscle biopsy** (Incorrect. When there is a marked reduction in the level of dopamine in the brain, such as in people with Parkinson's disease (PD), the structures that receive these substances (dopamine receptors located in a region of the brain called the 'striatum') are not adequately stimulated. However, these tests, which are useful for the diagnosis of metabolic and neuromuscular diseases, would not be as useful in this clinical case, so probably they would not be requested).
- c) **Electromyography, magnetic resonance imaging and positron emission tomography** (Correct. These tests help us to rule out Parkinson's-like diseases, like Progressive Supranuclear Palsy, Multisystem Atrophy and Corticobasal Degeneration, so that the correct treatment and prognostic information can be obtained. The neurologist would probably request them in this clinical case).

3. What would be the initial therapeutic approach in this case study?

- a) **Deep brain stimulation** (Incorrect. Surgery should be considered in all people with idiopathic PD, more than 5 years of pathology evolution, responsive to levodopa, younger than 70, without cognitive impairment or psychiatric disorders and without axial symptoms and poor control of motor symptoms (tremor, motor fluctuations and/or dyskinesias). However, as it is a serious and invasive procedure, it would probably not be one of the first to be carried out in our case).

- b) **Pharmacological: Dopamine agonist alone or in combination with L-Dopa** (Correct. When the disease progresses and affects daily activity is when drug treatment should be started. Management should be individualised and may be started with levodopa or another drug such as an MAO-B inhibitor or agonist, depending on factors such as age and severity of symptoms. Levodopa is one of the drugs for Parkinson's disease that produces a rapid initial improvement in the symptoms of the disease. Lack of response to this drug suggests that a differential diagnosis should be made. It is generally well tolerated and its effectiveness persists throughout the course of the disease, increasing the life expectancy of people. However, it does not halt the progression of Parkinson's disease and some later symptoms improve little or not at all with levodopa).
- c) **Second-line therapies: Apomorphine/Duodopa** (Incorrect. Apomorphine is indicated in any person with PD with motor and non-motor fluctuations uncontrolled by conventional oral treatment; Duodopa is an indicated therapy in people with advanced Parkinson's disease (PD) who have motor fluctuations that do not respond to conventional oral medication. Both options could be valid for PD but after the initial treatment (first-line) has failed, stopped working, or has side effects that aren't tolerated).

4. What would be the new therapeutic approach for Anthony?

- a) **Surgical Treatment: Deep brain stimulation/thalamotomy** (Incorrect. Surgical treatment may be considered for people with Parkinson's disease who have severe motor symptoms that are not adequately controlled by medications or who experience significant medication-related side effects. However, it does not usually work so well for non-motor symptoms such as shown in this clinical case. So, it would probably not be the new therapeutic option for this person).
- b) **Second-line therapies: Apomorphine/Duodopa** (Correct. Apomorphine is indicated in any person with PD with motor and non-motor fluctuations uncontrolled by conventional oral treatment; Duodopa is also an indicated therapy in people with advanced Parkinson's disease (PD), who have motor fluctuations and also non-motor symptoms (including sleep) that do not respond to conventional oral medication, as in this clinical case).
- c) **Continuing the same drug treatment despite no improvement in motor fluctuations** (Incorrect. Optimising the amount of levodopa delivered to the brain is the main focus and can be achieved by increasing the dose of levodopa, adjusting the timing of administration and/or adding adjuvant agents. Adjuvant agents such as dopamine agonists, catechol-O-methyltransferase (COMT) inhibitors and monoamine oxidase-B (MAO-B) inhibitors have been shown to improve fluctuations).

5. What should be the approach when carrying out an intervention with Anthony?

- a) **Focus solely on medical treatment** (Incorrect. Focusing solely on medical treatment is an incomplete approach. It may address immediate medical issues but can neglect the underlying lifestyle factors and social support, which are crucial for long-term well-being and health outcomes).
- b) **Combining medical treatment and changes in life style** (Incorrect. While combining medical treatment and lifestyle changes is a step in the right direction, it's not

comprehensive enough. Neglecting the social aspect can still leave the person without necessary emotional and practical support, which can hinder their recovery and overall health).

- c) **Prioritizing medical treatment, lifestyle changes, and seeking support from social resources** (Correct. The correct approach should prioritize a holistic intervention strategy that includes medical treatment, lifestyle modifications, and social support. This is essential because many health issues are not only influenced by medical factors but also by an individual's lifestyle and the support they receive from their social network. A comprehensive approach helps address the root causes and provides better chances of successful treatment and recovery.).

6. Which are the health and care needs of Anthony?

- a) **Initial diagnostic and patient education and empowerment** (Correct. Given that Anthony presents symptoms suggestive of Parkinson's disease, obtaining an accurate diagnosis in the early stages is crucial. Additionally, patient education and empowerment are essential for Anthony to understand his condition, manage symptoms, and actively participate in his own care).
- b) **Spiritual and practical needs** (Incorrect. In the provided case, specific spiritual or practical aspects requiring immediate attention have not been mentioned. The focus has been more on motor and non-motor symptoms related to Parkinson's disease. Spiritual and practical needs may become relevant over time, but at this point, they are not the priority).
- c) **Homecare** (Incorrect. Anthony is having the first symptoms and his status is not deteriorated enough to have home care. However, if the situations deteriorates and his ability to do daily activities gets worse, this might be an ideal approach to keep Anthony at home).

7. What are the benefits of approaching this case from a 'Patient navigators' role?

- a) **Intense care to address the complex needs** (Incorrect. While Patient navigators' role offer valuable support, their primary function is navigating the healthcare system rather than delivering direct medical care).
- b) **Support to navigate complex healthcare systems** (Correct. This role will provide support in navigating the labyrinth of medical decisions, insurance processes, and treatment options. This aligns with the concept that Patient Navigators serve as invaluable sources of support and information to help patients understand their options and rights, ultimately empowering them to become active participants in their healthcare).
- c) **Allows multidisciplinary discussion regarding the case** (Incorrect. While collaboration and communication with various healthcare professionals are important, the primary focus of Patient Navigators is on guiding patients through medical decisions, insurance processes, and treatment options).

Case Study 2

Kate is a 76-years-old housewife who lives in Dublin. She has elementary education, is widow and has 2 daughters (49 and 54 years old) and a 52-years-old son. She also has 5 grandchildren between 14 and 23 years old.

She has a professional caregiver living with her from Monday to Friday, and her two daughters make turns for caring her during weekend. She lives in her own home in Valencia and has a medium socioeconomic level.

She has a likely diagnosis of Parkinson disease for 13 years, Diabetes and a hip prosthesis as a consequence of a fall 3 years ago.

She has great difficulties initiating movement, severe gait impairment, freezing and postural instability, frequent falls. She also shows moderate cognitive impairment, hard-to-understand speech (hypophonia and dysarthria), impaired swallowing (weight loss, sialorrhea/drooling, choking) and has had pressure ulcers for a relatively short time. As a consequence, she has an important limitation in their autonomy and difficulties in her activities of daily living.

She has been receiving dopaminergic treatment for 10 years, with complications (on and off fluctuations/ dyskinesias) and physiotherapy and speech therapy sessions twice a week.

She is nowadays being monitored by the Movement Disorder Unit of a Public Hospital. She also has a 45% of disability and grade II of dependence.

Case Study 2 – ASSESSMENT QUESTIONS

1. Which roles should make up the team in order to offer a holistic approach to care?
 - a) **The neurologist, nurse and primary care physician are solely responsible for Parkinson's disease care** (Incorrect: Due to the complex nature of this disease, it is essential to recognise that its management often requires the involvement of a wider variety of health and care professionals, including clinicians but also rehabilitators, social workers, as well as people in the person with PD's environment).
 - b) **The team should include: neurologist, movement disorders specialist, nurse, primary care physician, occupational therapist, physiotherapist, speech therapist, social worker, psychologist, psychiatrist, nutritionist, pharmacist, home health aides, caregiver/family support, assistive technology specialist, and in the case of surgery, the neurosurgeon** (Incorrect: Providing a comprehensive care team, including all the mentioned professionals, is essential for a holistic intervention to Parkinson's disease care but we cannot leave out of the sphere of care the family members and non-formal carers who are part of it).
 - c) **The professional team listed under option B, plus formal and informal carers play an invaluable role in the care and support of people with Parkinson's disease** (Correct: This is the best approach. It is important to highlight the important contribution of informal or family carers in supporting people with Parkinson's disease together with the health and care professional teams. Their invaluable role extends to care giving, supervision and monitoring, ensuring adherence to treatment and comprehensive care management).
2. What services/resources could be requested to help Kate's usual caregivers with daily care due to her significant impairment?
 - a) **Incapacity for work** (Incorrect: This is an economic benefit that tries to cover the loss of income suffered by a worker when, due to illness or accident, his or her working capacity is reduced or cancelled. But it can be claimed by people under the age of 65 years who are registered as a worker or assimilated and Kate is already 76 years old).
 - b) **Home help service (personal care, home support) and tele-assistance** (Correct: Almost all countries in Europe have a universal health care system and this type of services intended to help achieve the personal autonomy of dependent persons and their caregivers are common).
 - c) **Legal incapacity** (Incorrect: Legal incapacity is a judicial declaration which, after an exhaustive study of the personality of the alleged incapacitated person and with the participation of the latter in the process, establishes whether or not he/she is capable of adequately governing his or her person and property. Even though Kate is experiencing important symptomatology, she still seems to be able to manage herself, so this option would not be the best one yet at this stage of her disease).
3. Due to the swallowing problems in this clinical case, it would be advisable:

- a) **When this person would swallow liquids, she should not use straws or syringes. She could use thickeners that added to liquids would increase their consistency** (Correct: In Kate's case, those would be good recommendations to follow when swallowing liquids. The use of straws or syringes may increase the risk of aspiration, as the flow of liquid may be faster and less controllable than drinking directly from a glass. It may also increase the feeling of bloating and discomfort. As for the use of thickeners, by making liquids thicker and slower, it facilitates swallowing by reducing the risk of flowing into the trachea instead of the stomach and ensuring the necessary hydration in a safe way. However, these recommendations should be made by a speech therapist or health professional specialised in dysphagia).
- b) **Use mixed consistencies such as orange which makes the mouth water and can prevent choking.** (Incorrect: When liquids and/or solids are difficult to swallow, always avoid mixed consistencies such as orange, which makes the mouth water and can cause choking).
- c) **Better to take solid food than to take soft diets or turmix. The consistency of the food should not be homogeneous.** (Incorrect: If you have difficulty swallowing solid food, take soft diets or turmix. The consistency of the food should be homogeneous, without lumps, avoiding a puree with lumps, soup with pasta nodules, etc...).
4. In addition to the weekly physiotherapy and speech therapy sessions that the person receives, what other therapies do you think that might be appropriate for this clinical case?
- a) **Occupational therapy:** (Incorrect: Occupational therapy could improve the quality of life of Kate as it promotes autonomy and independence in both basic activities of daily living (BADL) and instrumental activities of daily living (IADL) but she would also benefit of psychological intervention in order to improve her psychological state and cognitive status).
- b) **Individual psychological intervention for the affected person and the usual caregivers** (Incorrect: The aim of psychological intervention is to improve the quality of life and the psychological state of the person with the disease, as well as that of the family and caregiving environment. Kate would benefit from this kind of therapy but not only, also from occupational therapy intervention which would promote her autonomy and independence in daily living).
- c) **A and b are correct** (Correct: The combination of occupational therapy and psychological intervention can address both the physical and emotional aspects of Parkinson's, providing a holistic approach to disease management. Working in collaboration with professionals in both disciplines can contribute to improved quality of life, independence and emotional wellbeing for people affected by Parkinson's disease.)
5. In relation to the prevention of pressure ulcers what do you consider to be the most appropriate intervention?
- a) **Special support surfaces and prevention devices (mattresses, cushions, special beds, heel protectors...) are not necessary as long as the ulcer does not appear.** (Incorrect: Prevention measures, including special support surfaces and devices, are essential even before ulcers appear. Waiting for ulcers to develop before implementing prevention

measures is an incorrect approach and can lead to avoidable complications. Pressure ulcer prevention is a multidisciplinary approach that involves healthcare professionals, and the use of preventive devices is an integral part of this strategy, especially for people at high risk. Non-compliance with prevention standards can have legal and ethical implications).

- b) **In people with some mobility, standing and walking should be encouraged, and in people with little or no mobility, the caregiver should mobilise them 3-4 times a day and change their posture frequently (every 2-3 hours).** (Correct: For individuals with some level of mobility, encouraging standing and walking, within their capabilities, helps maintain muscle function, prevents stiffness, and promotes overall physical well-being. It also supports circulation and joint health. For people with little or no mobility are at a higher risk of complications like pressure ulcers (bedsores) due to prolonged pressure on specific areas of the body. Frequent repositioning, typically every 2-3 hours, helps redistribute pressure and reduces the risk of pressure ulcers).
- c) **Skin care and hydration are not important to prevent them** (Incorrect: Hydration and skin care are essential for both preventing and managing ulcers. Proper skin hydration promotes healing, reduces the risk of skin damage, and minimizes friction and pressure. Skin care involves early problem identification, risk factor management, person with PD and caregiver education, and the use of specific products when needed. Both aspects play a crucial role in ulcer prevention and effective treatment.).

6. Which are the health and care needs of Kate?

- a) **Initial diagnostic and patient education and empowerment** (Incorrect. Kate already has a likely diagnosis of Parkinson's disease for 13 years. The focus of her current needs is more on managing the existing conditions, complications, and limitations. Patient education and empowerment are important, but the primary emphasis should be on ongoing care and support rather than initial diagnosis).
- b) **Spiritual and practical needs** (Incorrect. While spiritual and practical needs can be important aspects of holistic care, the given case primarily describes Kate's physical and medical needs. The emphasis is on the management of Parkinson's disease, diabetes, hip prosthesis, and associated complications. The immediate care needs are more focused on addressing her complex health conditions).
- c) **Homecare** (Correct. Kate has severe mobility issues, cognitive impairment, speech difficulties, and other challenges that limit her autonomy. Homecare is crucial in this scenario, considering her difficulties in activities of daily living, the need for ongoing medical support, and the fact that she already has a professional caregiver during weekdays. Homecare provides a suitable environment for her specific needs).

7. What are the benefits of approaching this case from a 'Multidisciplinary' collaboration?

- a) **Intense care to address the complex needs** (Incorrect. The intensity of care is not necessarily the primary benefit of a multidisciplinary approach. Multidisciplinary collaboration is more about leveraging the diverse skills and perspectives of professionals from different disciplines to comprehensively address complex patient needs).

- b) **Support to navigate complex healthcare systems** (Incorrect. While multidisciplinary collaboration can provide support, it is not specifically for navigating complex healthcare systems. The primary benefit of multidisciplinary collaboration is the ability to draw on different specialties and approaches to address the complex aspects of a clinical case).
- c) **Allows multidisciplinary discussion regarding the case** (Correct. One of the key benefits of approaching a case from a multidisciplinary perspective is the ability to engage in discussions involving professionals from different fields. This facilitates combining knowledge and experiences to more comprehensively address the patient's needs).