WP3 -Joint Training programme for Social, Cultural, and Health Sectors -Module 2-

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Module Overview (1 page max.)

Module 2	The main mental health disorders in old age: behavior changes, changes in the daily life, and non-pharmacological approaches
Module summary / main contents	Module 2 aims at extending the knowledge and developing important skills for learners regarding the identification and understanding of the behavioral and psychological changes that occur in the neurodegenerative disorders, the changes that these pathologies imply for the daily life of patients and their carers, and also the non-pharmacological approaches of these disorders. This can help learners to improve their knowledge regarding old age and mental health, and also to adapt their practices for an improved work with older people. With the information obtained in this module, learners will be more able to respond to older people needs and build up new practices with the final aim of reaching an improved quality of life for this population.
Timetable & schedule	*(Effective division of the module activities/ didactic methodology/ Activities duration) – 4 hours in total* 4 hours: • 60 min: Presentation of key concepts and overviews of the module and of each chapter • 40 min: Active learning activity #1 • 40 min: Active learning activity #2 • 45 min: Active learning activity #3 • 25 minutes: Multimedia activities • 30 minutes: Self-assessment quiz

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Learning outcomes of the module	• Understanding the characteristics of the main behavior changes that may occur in people diagnosed with neurodegenerative disorders • Learning about the changes in daily life that neurodegenerative disorders generate for the persons diagnosed and for their care partners • Developing the skills for identifying and using non-pharmacological approaches for neuro-degenerative disorders in their contexts

INTRODUCTION

This module deals with behavioral changes in people with neurodegenerative disorders, paying attention also to the attitudes that caregivers can adopt to cope with the behavioral symptoms of the person they care for and the daily life changes that these disorders bring in for the persons diagnosed and their care partners.

Throughout the module, the behavioral and psychological symptoms of people with neurodegenerative disorders and what can influence their onset will be explored, as well as the impact that behavioral alterations can have. Within the module, non-pharmacological approaches for neurodegenerative disorders will be explored too.

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Chapter 1 Behavioral changes in neurodegenerative disorders

The Behavioral and Psychological Symptoms in neurodegenerative disorders is a term that refers to emotional, perceptual, and behavioral disturbances, which are neither neurological nor cognitive.

These symptoms could be classified into several domains, such as: motor (agitation, pacing, wandering, repetitive movements, and physical aggression), perceptual (delusions, hallucinations), emotional (depression, euphoria, apathy, anxiety, irritability), verbal (repetitive speech, verbal aggression), and also vegetative (disturbances in sleep and appetite) (Cloak & Al Khalili, 2019).

The majority of the persons diagnosed with dementia will experience at some point BPSD, during the evolution of the disease, as it progresses over time. The impact of BPSD on family carers is very powerful, being a sources of stress and burnout for them, due to the difficulties of managing these symptoms and to the interference with daily life. The severity of these symptoms correlates with the institutionalization of the patients (Cloak & Al Khalili, 2019).

Studies show that a proportion of 90% of the people with dementia experience BPSD during the course of the disease, enhancing the rate of hospital admissions, but also the wrong use of medicines.

Moreover, one patient will usually develop several BPSD which co-exist, making it even more difficult for carers to cope with. It is not clear yet what are the causes of BPSD, research showing that the causes are a mix between biological, social and psychological aspects (Cerejeira et al., 2012). What is of

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major concern regarding the BPSD is that it causes an increased mortality and morbidity for persons with dementia, but also for carers, especially due to aggression and agitation (Baharydin et al., 2019). Also, some BPSD are associated with admission in the acute care department in hospitals, of patients from residential facilities (Tunis et al., 2002)

There are also assessment tools for evaluation the BPSD, such as: Dementia Observation System (DOS) Tool, or Cohen Mansfield Agitation Inventory (CMAI) , which can be used by professionals in order to identify the symptoms and its situation.

Trying to reduce these symptoms will determine an improvement of the quality of life of people with dementia and family carers, being a desirable outcome during treatment.

The main behavioral and psychological symptoms in dementia

Agitation and aggression – It occurs in approximately 60% of people with dementia. It can be verbal, such as complaining, moaning, angry statements, threats, or physical, such as resisting to carers, restlessness, spitting, hitting out.

Apathy – It is estimated to occur in 55–90% of people with dementia, most frequently in vascular, Lewy body and frontotemporal dementia cases. It presents as lack of initiative, motivation and drive, aimlessness and reduced emotional response. Reduced motivation can be a feature of depression, but a pure apathy syndrome can be distinguished from depression by the absence of sadness and other signs of psychological distress.

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Depression – It occurs in approximately 20% of people with dementia, and is more prevalent in early stages. Its manifestations are sadness, tearfulness, pessimistic thoughts, withdrawal, inactivity or fatigue.

Anxiety – It is estimated to occur in 16–35% of people with dementia, being one of the most disabling BPSD. In later stage dementia, this may be an exaggerated response to separation from family, a different setting or a reduced capacity to make sense of the environment. It manifests as a feeling of fear without a specific cause, which can become very intense and can interfere with all activities of the person with dementia.

Psychotic symptoms – This is a symptom that causes a lot of stress for the family and for carers, and not to the person. Approximately 25% of people with dementia will experience psychosis, causing delusion or hallucinations. In dementia, delusions are usually reflective of the underlying memory loss or changes in perception, like accusation of theft of personal items, infidelity of a spouse or that family members are imposters.

Wandering – It is sometimes related to agitation. Wandering may be circular, pacing between two points, random or direct to a location without diversion. This is often one of the most challenging and problematic BPSD due to safety concerns.

Nocturnal disruption – Sleep disturbance can occur secondary to depression, anxiety, agitation or pain and may cause other BPSD to be exacerbated at night, such as wandering. Sundowning, an increased agitation in the late afternoon, is also common (www.bpac.org.nz/2020/bpsd.aspx), which is experience by 20% of people living with dementia

Sundowning means the confusion and agitation experienced by people with dementia when the sun is setting

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Nocturnal disruptions can be associated with anxiety, depression, agitation, pain and can also intensify other behavioral disturbances at night time

Factors that may cause the behavioral and psychological symptoms in dementia

Dementia can have an impact on a person's personality and habits, which may lead to changes in behaviour.

Knowing the person – how they react to and deal with things, their preferences, routines and history – can help when it comes to supporting them.

For example, if the person has always been stubborn or anxious, they may be even more so now they have dementia.

We all have the same basic needs – a mix of physical, psychological and social factors. People with dementia may be less able to recognise their needs, know how to meet them, or communicate them. Because of their dementia, they may also find it more difficult to tell what they need by using words.

Their behaviour may be the best way for them to communicate what they want.

Physical needs that may cause the behavioral and psychological symptoms in dementia

There may be physical needs that cause the symptoms:

The person may be in pain or discomfort – they may be constipated or thirsty, or in pain from an infection such as a urinary infection or from being in one position for too long.

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Too many medications or the side effects of medication may lead to a person becoming drowsy and confused. This can make it harder for the person to meet their needs or communicate them.

The environment may not be supporting the person. For example, it could be too hot or too noisy, or there might not be enough for the person to do.

Other conditions (such as sight or hearing loss) might mean the person misunderstands or misperceives things in their environment (mistaking something they see, hear, smell or touch for something else).

The person may be having delusions or hallucinations. These can be confusing and frightening and may affect how the person reacts to.

Social needs that may cause the behavioral and psychological symptoms in dementia

Social needs that can cause the symptoms:

The person may be feeling lonely or isolated. They might not spend much time with others or they may not feel included.

They may be bored and not have much to stimulate them or their senses (sight, hearing, touch, smell and taste).

If the person has different people coming into their home, such as care workers or neighbours, they may all have their own approaches and routines. This can be confusing.

The person may be trying to 'hide' their condition from others or may not be aware of the difficulties that they are having.

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The symptoms may be due to underlying depression, unmet needs, boredom, discomfort, perceived threat or violation of personal space.

Psychological needs that may cause the behavioral and psychological symptoms in dementia

Psychological needs that may be the cause of the symptoms:

The person may be frustrated by their situation and not being able to do the things they used to.

They may be frustrated if other people assume they can't do things for themselves and take over or leave them out of decisions.

The person may be depressed or have other mental health problems.

They may feel threatened by an environment that doesn't seem right or familiar. They may think they are in the wrong place.

They may not be able to understand and work out the world around them. Their sense of reality may be different to those around them. For example, they may believe they have to go to work even though they are no longer working.

The person may not understand the intentions of those caring for them. For example, they may see personal care as threatening or an invasion of their personal space. It can be especially confusing and frightening if the person doesn't understand what is happening.

Behavioral and psychological symptoms in Parkinson's Disease

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People diagnosed with Parkinson's disease are also facing behavior changes along with motor disorders, during the evolution of the pathology

The main behavioral disturbances that occur in Parkinson's disease are the following:

- Anxiety
- Depression
- Hallucinations
- Cognitive deficits that can result into dementia

All these symptoms have a major impact on the quality of life of the patient and place a major stress on caregivers.

Particular attention should be paid to addressing these changes for an improved functionality of the patient.

Behavioral and psychological symptoms in Multiple Sclerosis

People diagnosed with Multiple Sclerosis will also develop behavioral disruptions as the disease progresses.

30%-80% of people diagnosed with Multiple Sclerosis will face these changes.

Most common are:

- Agitation
- Agression
- Opposition

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- Depression
- Anxiety
- Attention problems
- Panic attacks
- Obsessive-compulsive symptoms

Chapter 2 Changes in the daily life for the persons diagnosed with neurodegenerative disorders and for their care partners

Changes in the daily life

On a day-to-day basis, people with neurodegenerative disorders have to cope with the loss of cognitive and functional abilities.

Activity and daily routines such as having a bath, brushing their teeth, eating and drinking, dressing, going to the toilet, etc. are ways of maintaining the person's identity.

Everyday activities keep the task from being hard work and can become a form of letting go, requiring much less effort to be carried out.

Routines in daily life

It should be borne in mind that in daily routines there is no need to think about how to do things, but only to do them.

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In daily routines there is no need to think about how to do things, but only to do these activities in the same way every time.

EATING AND DRINKING

Loss of memory and problems with judgement can cause difficulties in relation to eating and nutrition for many people with this diagnostic.

However, meal times provide us with an opportunity to spend time with family and friends, as well as sharing food together.

When caring for someone with neurodegenerative disorders, meal time can sometimes become stressful.

There are many routines that can improve the eating and drinking of a person with neurodegenerative disorders, such as:

The use of low lighting levels, music, and simulated nature sounds to improve eating behaviours.

Encourage physical exercise to cope with loss of appetite.

Providing choice of food for the person keeping in mind to limit the choices to two.

During the day several small meals, healthy snacks, finger foods, and shakes should be made available to a person if requested or if there are signs of hunger or a missed meal.

Use eating and drinking tools to assist with independence as recommended. For example, use a bowl instead of a plate or a straw to assist in drinking.

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GETTING DRESSED

Getting dressed can be a very complex and overwhelming task because there are so many steps involved.

There are many reasons why a person with neurodegenerative disorder might have problems dressing:

- · physical or medical causes,
- · forgetting how to dress,
- · problems with the environment,
- · lack of privacy,
- · problems making decisions about what to wear.

Some routines recommended are:

- Develop a dressing ritual that is to be performed at the same time daily, consistent with the preferences of the person.
- Allow the person as much independence as possible when dressing.
- Laying out the clothing in the order in which they should be put on provides a visual cue to help increase independence.
- Promote independent choice from a limited selection of outfits to ensure independence.
- Assist the person with clear, concise instructions to avoid confusion.

PAIN MANAGEMENT

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Pain is recognized as an important concern in care homes and may be under-diagnosed and/or under- treated in people with dementia, particularly if they cannot communicate verbally.

Staff needs to be vigilant in watching for signs of pain through regular pain assessment and reduction measures.

Furthermore, individuals with dementia who have communication difficulties will use responsive behaviors (e.g. they will refuse to eat, become quiet or shout out, sit down when they usually wander) to express their pain.

Therefore, caregivers need to be trained to pay attention to signs and indicators to identify and assess pain or discomfort such as:

- changes in breathing patterns,
- hyperventilating,
- moaning,
- crying,
- grimacing,
- shouting,
- pushing away caregivers,
- difficulty being comforted,

Relieving suffering and managing pain are the best ways to enjoy every day and improve the quality of life for individuals living with dementia.

Chapter 3 Non-pharmacological approaches of neurodegenerative disorders

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Although there is no cure for dementia, treatment and prevention can slow each stage of theses disorders.

The goal of treatment is to manage mental function and behavior and slow the symptoms down.

Dietary changes, supplements, exercises for the body and mind, and medications can have positive impacts on symptoms of the disease.

However, these drugs will not cure the disease. Other non-pharmacological approaches are needed for controlling the symptoms and slow down the progression of the disease.

Understanding available options can help individuals living with the disease and their caregivers to cope with symptoms and improve quality of life.

Symptoms of cognitive impairment and the behavour and psychological symptoms of neurodegenerative disorders may be treated with a variety of non-pharmacological interventions that span psychological, behavioral and environmental domains.

Such interventions are low cost, without physical side effects, and can be delivered by professionals in the care field or by family caregivers themselves.

Goals of the Non-pharmacological approaches of neurodegenerative disorders

- Improving the person's cognition, in areas such as memory, concentration, language skills or reasoning.
- Improving the person's ability to function in real-life, everyday situations, for example, from remembering appointments or food preparation in mild

dementia, to improving dressing skills in instances where the dementia is more severe.

- Reducing distress and mood disturbances in the person with dementia, for example, by reducing depression and anxiety or by increasing adjustment or coping in the early-stages of dementia.
- Promoting positive changes for the caregiver
- Making changes in disturbing and distressing behaviours, such as aggression, inappropriate sexual behaviour, restlessness. Depending on the behaviour and the factors contributing to it, the goal may be to reduce the frequency of the behaviour, or its severity; where the behaviour does not appear to be causing problems for the person with dementia, the goal may be to reduce the impact of the behaviour on others, including family caregivers or care-workers.

Types of Non-pharmacological approaches of neurodegenerative disorders

- **Cognitive stimulation** is typically delivered in a social setting in small groups involving cognitive based tasks and activities, including word games, puzzles, drawing, painting, storytelling, music activities, gardening, crafting, theatre activities etc.
- **Environmental approaches/modification** – encourage creative solutions to dementia symptoms, targeting the environment of the person with dementia. The ideal environment for a patient with dementia is one that is non-stressful, constant and familiar.
- **Alternative therapies** – light massage and aromatherapy, dance therapy, animal assisted therapy, multi-sensory therapy.

- **Behavioral Management Therapy** – may be useful in targeting challenging (difficult to manage) behavioral patterns in persons with neurodegenerative disorders. Such behaviours may include wandering, agitation and repetitive questioning.
- **Psychotherapy and psycho-educational interventions** may assist carers to cope with assisting the person and to maintain their own health and wellbeing.
- **Reality orientation** – aims to decrease confusion and behavioral symptoms in people with dementia by orienting the individual to time and place.
- **Validation therapy** is a form of "therapy for communicating with persons with dementia. Focused on validating the personhood and emotions of a person with dementia. Validation therapy is found to alleviate stress, promote contentment, and decrease behavioral disturbance.
- **Reminiscence therapy.** Reminiscence therapy encourages participants to speak about past experiences therefore decreasing the demand on impaired cognitive abilities while encouraging those preserved abilities.

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