

Occupational Therapy Intervention for Individuals with Neurodegenerative Diseases

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Abstract

The goal of the Occupational Therapy Intervention is to enhance people's health and the general quality of their life by applying a holistic approach. That is, supporting the ability of the individuals to engage and perform substantial and meaningful everyday tasks. Involvement in occupations takes place in the individual's social and natural environment and it is highly dependent on their developmental stage and their cultural background. Indeed, one's environment can either support or limit the people's engagement in occupations. Even if the best care is provided, individuals suffering from Neurodegenerative Diseases face difficulties in performing daily tasks.

Although the decline regarding individuals' skills with Neurological Diseases is quite inevitable, Holistic Approach focuses on improving their functionality through constant training. Indeed, the literature mentions the positive effect of Occupational Therapy which aims at improving the individual's functionality in activities of daily life, modifying his environment and/or behavior, training mental functions and extending the caregiver's education. In addition, Assistive Technology is widely used from Occupational Therapists during the evaluation process or intervention. Individuals with ND seem to be quite familiar with this type of intervention. The whole environment plays a key role in maintaining the individual's functionality. In addition, at-home interventions allow Occupational Therapists to intervene in one's personal space where the individual performs everyday tasks. Even if the interventions aim in specific areas, the association between the individual's personal characteristics and its domestic and outer environment shows that the interventions must be holistic in nature.

Keywords: Occupational Therapy, Activities of Daily Living, Functionality, Neurodegenerative Diseases

JEL Classifications: I00, I29, I31

Introduction

Neurodegenerative Diseases (ND) are characterized by a gradual decline in the level of cognitive functions. ND exhibits different clinical features and causes. Conditions such as Alzheimer's Disease (AD), strokes, Lewy Body Dementia (LBD), Frontotemporal Dementia (FTD), craniocerebral injuries, infections and alcohol abuse are driven by common causes (Sachdev et al., 2014). In the US, the high economic cost of AD pressures the health system, as more funds are invested on AD than on any other disease (Smallfield, 2017). Health organizations aim to reduce the cost of care, improving the quality of life and individual health and preventing health professionals' burnout (Roberts et al., 2020). Even with the best medical care, people with ND find it difficult to perform daily occupations. Despite their reduced functionality, a continuous training in improving their functionality should be an integral part of holistic care (Foster, 2014). ND affects cognitive skills such as memory and concentration, resulting in reduced functionality, and minimizing their participation in the Activities of Daily Living (ADL). Additionally, individuals with AD face difficulties in completing daily tasks and problem-solving activities, while they also face difficulties with spatial orientation and time management. Individuals with AD often lose objects, withdraw from social life and exhibit behavioral changes (Smallfield, 2017).

AD affects not only the individual, but also his/her family and caregivers. Therefore, the Occupational Therapist (OTs) has to consider the needs of all the family members when applying the Occupational Therapy (OT) intervention. One of the main Occupational Therapy concerns is to improve, or at least, maintain the individual's self-care skills. However, as the disease progresses, it is imperative that the Occupational Therapist educates the person with AD and the family members in order to complete every day activities with or without the caregiver's support (Tzonihaki, 2019). The increasing incidence and frequency of AD, along with the need of providing high-quality care, makes it essential for OTs to understand the needs of individuals with AD. Further understanding could support OTs in applying alternative and evidence-based approaches in order for the patients to engage in occupations, while taking into account the individuals' and their caregivers' wishes, aspirations and preferences (Padilla, 2011).

The Science of Occupational Therapy

Occupational Therapy is a client-centered health profession that promotes the patients' health and wellbeing through their engagement in occupations (WFOT, 2012). OT intervention focuses on "occupations", which are different kinds of daily tasks in which individuals, groups, or populations are engaged (AOTA, 2014). Similarly, the World Federation of Occupational Therapy (WFOT, 2012) defines occupations as the "everyday activities that people do as individuals, in families and with communities to occupy time and bring meaning and purpose to life. Occupations include things people need to, want to and are expected to do." Indeed, the performance of occupations play a decisive role in one's forming of identity and establishing a sense of fulfilment and competence, and thus should be

carefully considered. The OT intervention is achieved through the collaboration between the individuals and the community and wishes to improve the former's skills. That is, enhancing their performance by modifying their tasks so as to achieve better results (WFOT, 2012). Occupational Therapy specializes in a specific field of practice and all of its features have a dynamic interdependence with each other. In other words, all of its concerns including the individual's specific needs, his executive skills, his background influences and the execution patterns followed are equivalent and equally influence the individual's identity, health, wellbeing and participation in daily life (AOTA, 2014). According to the clinical OT framework, field and process third edition of the AOTA (2014), OT life activities consist of eight main areas: 1) Activities of Daily Living (ADL), 2) Instrumental Activities of Daily Living (iADL), 3) Rest and sleep, 4) Education, 5) Work, 6) Play, 7) Leisure, and 8) Social participation (AOTA, 2014). Functionality and independence in the Activities of Daily Living, contribute greatly in the individual's healthy aging (Hunter & Kearney, 2018). Most individuals with AD living in the community need support in performing ADL (Grigorovich, 2016).

Specifically, ADL are activities that are associated with one's capability of taking care of his own body and consist of nine areas: 1) Bathing/showering, 2) Toileting and toilet hygiene, 3) Dressing, 4) Eating, 5) Feeding (the setting up, arranging and bringing food to the mouth), 6) Functional mobility (the ability to move while performing ADLs, with or without the assistance of an assistive device), 7) Personal device care (utilizing essential personal care items such as hearing aids, glasses, orthotics, walker, etc.), 8) Personal hygiene and grooming, 9) Sexual activity. Thus, the understanding and analysis of occupations, in combination with one's preferences, skills, execution patterns and the environment where the individual lives, guide the OT practice through proper interventions (AOTA, 2014). Further, ADL consist of: 1) Caring for other people, 2) Caring for animals, 3) Raising a child, 4) Functional communication (phone use, use of writing tools, etc.), 5) Financial management, 6) Health and medication management, 7) Housework, 8) Meal preparation, 8) Grocery shopping, 9) Driving and commuting by using means of transport etc. (AOTA, 2014). Instrumental Activities of Daily Living are closely related to the fulfillment of executive functions such as planning, working memory, maintaining attention, problem solving, functional communication, self-concentration, flexibility and performing multiple actions at the same time (Hunter & Kearney, 2018). Research shows (Katsouri et al., 2019) that individuals suffering from cognitive disorders who had previous experience in driving, drive better when compared to those without experience.

One way to support individuals with AD is to understand the difficulties they face and develop strategic interventions aiming at performing the activities of daily living successfully (Woodbridge et al., 2018). The literature mentions the positive effect of OT, which aims to improve the functionality of the ADL by modifying the environment and the patient's behavioral pattern, training the mental functions, and fostering the caregivers' education (Schmid et al., 2015).

The effectiveness of Occupational Therapy intervention for individuals with AD

Reviewing the literature regarding AD is very important for the clinical practice of OT. Specifically, in a study on the effectiveness of Occupational Therapy intervention for individuals with AD by Arbesman and Lieberman (2011), questions were developed that served as the focus of the review. The questions concerned the areas of the occupations: i.e. "What are the elements that influence the interventions and aim at modifying, maintaining or improving the skills of execution and participation in the basic and Instrumental Activities of Daily Living, entertainment and social participation?", "what are the elements of the impact of programs that aim to modify and maintain skills to perform tasks that focus on mental functions?", "what are the elements that affect interventions with the environment?", "what are the elements that effectively influence occupation modification interventions?", "what is the evidence for the impact of fall interventions?", "what is the evidence for the impact of caregiver education and support strategies?", "what is the effect of interventions on the individual's habits and routines?" (Arbesman & Lieberman, 2011).

A study by Calkins (2018) highlights practice recommendations for the promotion of a human-centered therapeutic supportive environment which are: 1) Creating a sense of community within the environment of care. Support in building relationships resulting in the exchange of common behaviors, interests and goals for individuals with dementia and their caregivers. 2) Improving comfort and dignity. The environment should be designed to enhance the preservation of the individual's identity and to support his or her orientation in place, time and activity. 3) Support courtesy and security. The environment can compensate for physical and cognitive changes by maximizing other abilities. 4) Providing opportunities for choice. Self-expression and self-determination are reinforced by the individual's ongoing need to make decisions for himself or herself. 5) Opportunities, easily accessible, for effective participation in activities, meaningful for both themselves and others.

Furthermore, Padilla (2011) reports four main outcomes of Occupational Therapy: 1) Programs should be individualized to select activities that match the individual's existing cognitive and physical skills, rather than trying to achieve independence by using difficult tasks. Activities that individuals choose based on their personality, and previous interests and which match their abilities, achieve their involvement in the Occupations for a longer period of time; 2) the instructions given to the individuals for the completion of the occupations should be short, provide clear directions and appropriate to the cognitive level of the individual; 3) Caregiver education is essential. When caregivers are trained in activity analysis and provide appropriate guidance, then individuals with AD are able to participate in everyday activities, resulting in the caregivers themselves feeling greater satisfaction and an improvement in their quality of life; 4) Compensatory strategies of modifying the environment with simple equipment is used according to the needs of the individual. Visual direction symbols, signs, drawer and cabinet labels are effective strategies. Organizing the space and removing useless items help maintain functionality (Padilla, 2011).

Assessment of the Activities of Daily Living

Activities of Daily Living are an important predictor of functionality and independence of the individual. In addition, the analytical measurement of the areas of activities of daily life is a guidance to indicate the level of health and quality of life of the individual (Wu et al., 2018). The information collected by self-report scales is usually short and easy to provide. Unfortunately, standard assessment tools have limitations in diagnosis, as they only evaluate the success or failure of an activity without taking into consideration the execution process. In addition, they have low sensitivity in detecting mild cognitive impairments and do not respond to the detection of changes in the level of abilities of the individual (Cornelis et al., 2018). Finally, there are no instructions on how to deal with activities that a person does not perform.

The widely used evaluation tools for Activities of Daily Living, like the Katz Index of Independence in Activities of Daily Living (Katz et., 1970) and the Lawton Instrumental Activities of Daily Living Scale (Lawton & Brody, 1969) have been studied extensively. Subscales from the KATZ and Lawton scales were linked to the definitions and codes from the International Classification of Functionality and Disability (WHO, 2013). The ICF describes the day-to-day functionality, understanding and measuring disability, by developing a performance scoring system. The evaluation showed greater accuracy in measurements and the ability to improve the differential diagnosis between healthy individuals or individuals with mild cognitive impairment and individuals with severe neurodegenerative disorders (Cornelis et al., 2018).

Assistive Technology devices for individuals with Neurodegenerative Diseases

Occupational Therapists use assistive devices in their daily practice. Assistive devices help individuals that are cognitive or physically disabled support their daily activities. These devices can also monitor in a constantly manner the progress of the disease (Letts et al., 2011). Examples of available assistive devices are, timers, mobile phones, speed dial phones, digital clocks, alarm tones, alarm clocks, notebooks, calendars, pictures, pill boxes, electronic voice devices and computers. These aids act as a compensator against the cognitive and motor deficits of the individuals, promoting the facilitation of activity performance. The right choice of assistive technology products is based on the socio-economic conditions of the individuals, the educational level, the habits, the motivation status and their mental abilities (Bernardo & Raymundo, 2018).

In a home-based study of people with Parkinson's disease, participants reported that computer equipment and sensors were easy to use. Most people with Parkinson's disease become familiar with the use of sensors. Future studies are proposed for interventions with continuous monitoring of activities (Thorp et al., 2018).

Another system called ADL Recognition System has been developed, which uses data from a mobile phone sensor. The data is collected by an application of the ADL Recorder App on the individual's phone, which contains many built-in sensors such as microphone, telephone orientation, short-sighted eye contact, step detectors, etc. The

purpose of the system is to collect information about the user's behavior in the environment (Wu et al., 2018). In another study, the benefits of the Information and Communication Technologies (ICT) programs that support the range of ADL in people with dementia were presented on five basic research principles. These principles consist of: 1) Supportive technologies used by people with dementia, 2) Supportive technologies used by caregivers, 3) Monitoring systems, 4) The true supportive environment - Ambient Assistive Living (AAL) with the (ICT), 5) Tracking and way finding. The above principles suggest the use of ICTs to support people with dementia at home and improve the quality of life of caregivers by reducing the cost of health care (D'Onofrio, 2017).

Occupational Therapy and the environment

Environmentally-focused interventions refer to the strategies used by individuals in the natural and social environment (Padilla, 2011). The engagement in occupations depends on the developmental stage of the individual, on the cultural environment and finally on the human or material ecosystem in which oneself lives in (Tzonihaki, 2019). The individual's adaptative ability is achieved through the engagement in occupations in which they have to adapt to the environmental requirements, or on the contrary in which the environment has to be adjusted to their needs and aspects. The physical, individual, or general environment identifies the occupations being performed as responses by the individual (Reed & Sanderson, 1992, 1999; Tzonichaki, 2019). The environment is a factor that can support or limit the functionality of individuals, and is divided into natural and social. The natural environment contains structures, physical features and objects within them, such as buildings, furniture, tools, soil and plants. The social environment includes the interpersonal relationships, the people with whom the individual has a close relationship (family, friends, caregivers), people who can affect daily living (Bernardo & Raymundo, 2018). Environmentally-focused interventions have emerged from the Learning theory, which is based on the individual's ability to understand, process and integrate sensory information to plan and organize their behavior. Interventions aiming at increasing the individual's sensory stimuli can enhance the ability of the central nervous system to process and respond effectively (Padilla, 2011). Understanding the effects of the natural environment on how people with dementia perform their daily activities is methodologically quite complex, yet vital for the design of dementia-friendly communities.

There is strong evidence that the environment affects the occupation performance. However, it is quite difficult to identify those aspects of the environment that have an impact on activities of daily living. One of the difficulties lies in the lack of clear boundaries between the impact of both the natural and the social environment. Researches that have focused in cognitive environmental interventions, such as the removal and placement of labels on objects, the contrast of colors, the management of clutter and so forth, have shown that there is a limited effect on the ADL performance in people with moderate to severe mental disorders (Woodbridge et al., 2018). The use of room identification signs and the notebook as a process of modifying the environment may be a facilitator for temporal and spatial orientation. The existing body of literature indicates that reducing the requirements of an activity lowers parallelly the cognitive performance requirements. For example, in the kitchen, labels can be placed in drawers to find utensils (natural environment), or family members can offer information to the individual and place objects in

an accessible place, reducing this way the cognitive requirements (Bernardo & Raymundo, 2018).

Home-based Occupational Therapy

Following an assessment, individualized information can be gathered and a holistic home care program can be drafted, which focuses on the person's needs based on the natural environment (Read et al., 2020). The Tailored Activity Program (TAP) is a home-based program that is applied at home by a specially trained occupational therapist and lasts four months. The person, the environment and the caregiver are evaluated and afterwards the occupational therapist suggests activities adapted to the executive function of the individual. This home program refers to the Community Occupational Therapy in Dementia program (COTID) and aims to improve functionality and the quality of life through personalized and customized daily activities. The activities are chosen by demented patients themselves using their existing mental abilities, and environmental adaptations and techniques are employed to strengthen and support the caregivers (Lanzoni, 2018). Tzonichaki (2019) highlights the need for a complete re-evaluation of the individual at home and in the community in order to remove barriers. The goal of independence of people with minor or major disabilities is very important, as it ultimately aims to ameliorate their quality of life through occupational therapy programs with emphasis on self-care, but also on creating a better living environment. With regard to the reintegration of the individual at home and in the community in terms of accessibility, many interventions have been proposed. These interventions concern the external space, the entrance and exit ground, the stairs, the elevators, the entrance dimensions of an apartment, door approaching manners but also objects and spaces of the house such as the dining room, the kitchen, the bathroom, the sink and the basin, the bedroom, aiming at maximizing the functionality and independence of people with disabilities (Tzonichaki, 2013).

A case study described the Occupational Therapy intervention at home for a person with Alzheimer's disease. The intervention included home visits in order to improve their morning routine. Using special aids for the use of the bathroom and the toilet, transport training was carried out in such a way that it was easy and safe for the person. The caregiver also participated in the training. Several repetitions were performed with the occupational therapist preventing the person's mistakes, correcting the position of their hands and ensuring the correct sequence of movements. The Occupational Therapist, while training the caregiver also used written instructions for the successful execution of the activities. The training continued in the department of personal care and clothing activities, relying on previous habits to ensure the best possible morning routine. The multiple objects in the closet and the sink appeared to upset the patient, as a result of which he would withdraw and would not complete the process. With the help of the caregiver, the number items was reduced and only the absolutely necessary ones remained. During the dressing process, the person was placed in his favorite chair and the procedure kicked off with the support of the caregiver. Multisensory stimulation with soft lighting and relaxed music has been shown to reduce individuals' tendency to become upset. The afternoon visits focused on improving sleep and avoiding falls. The individual's interest in gardening was used as a physical activity in his daily routine. In the afternoon, he would go for a walk with the caregiver in a municipal garden and participate in gardening activities. To avoid falls at night, the occupational

therapist suggested placing an alarm on the bed and automatically turning on the lights in the room and the bathroom. The results were very encouraging and the person managed to maintain or improve the execution of his occupations (Piersol, 2018).

Occupational Therapy modification interventions

Occupational Therapists have the ability to intervene and predict the factors associated with falls among the elderly. As injuries associated with falls are a major cause of morbidity and mortality among the elderly, many of them may need support in daily life activities. The fear of a future fall may lead to reduced functionality and social interaction. The proposed interventions are mainly aimed at practicing motor skills such as balance, strength and endurance, and have been proven to be the most effective in reducing the total number of falls (Jensen & Padilla, 2011).

Cognitive status reflects on the thinking skills and process, in order to successfully perform daily activities in different environments. In Occupational Therapy, interventions focus on cognitive skills support, which are related to the successful engagement of an occupation. Every occupation performance requires the simultaneous use of multiple mental and executive skills (Giles, 2017). In the same line, mobility and in particular gait represent one of the areas of functionality that can potentially be modified and improved through appropriate occupational therapy intervention programs (Vlotinou et al, 2020). The requirements of an activity and its characteristics affect the type and degree of effort required to perform it. Modifications to the requirements of an activity lead to the adjustment of the individual. This means that, as soon as the requirements of the activity are modified, the individual also modifies their approach to perform the activity in-question. At the same time, environmental changes in the natural and social system are used to increase the autonomy of the individual. Finally, simplifying the steps of each activity and organizing routines and habits can be helpful for persons to perform and participate in occupations (Bernardo & Raymundo, 2018).

Conclusions

Occupational Therapists recognize the importance of occupations which promote an individual's mental, physical and social wellbeing. Occupational Therapists specialize in assessing the individual's ability to participate in activities deemed important for them, and in designing interventions that facilitate their involvement in projects. The effects of interventions that support a holistic approach appear to produce positive effects on the daily lives of individuals and their caregivers. Assistive technology is widely used during the evaluation and intervention process of individuals with ND. Individuals with dementia seem to be quite familiar with this type of intervention. The environmental adaptations made by Occupational Therapists make an impact in the functionality of the individual. Home-based interventions provide Occupational Therapists the opportunity to intervene in the individuals' personal space where they perform occupations. In addition, home-based interventions aim in specific functionality areas, while taking under consideration the connection of the individual's characteristics, the occupations and the environment. Conclusively, literature shows that Occupational Therapy interventions for individuals with ND must be holistic in nature.

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