Effectiveness of Occupational Therapy Interventions in individuals with Down Syndrome and Alzheimer's disease

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Abstract

Dementia in adults with Down syndrome (DS) causes progressive impairment in their daily occupations, affecting both individuals with DS and their carers. Although the treatment approach is the same as in the general population, cognitive impairment can complicate the management of dementia in people with DS and thus a multidisciplinary approach is essential. Occupational therapy (OT) aims at maintaining function throughout the disease course, by using a variety of interventions, including sensory-based OT interventions. Sensory modulation can positively affect the emotional well-being of these individuals and their ability to participate in occupations. OT provided to individuals with Alzheimer's disease and DS has favorable effects on their activities of daily living, behavioral and psychological symptoms, as well as their quality of life (QOL). Moreover, from the family caregiver standpoint, OT exerts positive impact on their overall imposed burden, through reducing their depression and improving their QOL. OT interventions aim at consolidating, modifying, and maintaining occupations. In order to be effective, daily occupations, physical exercise and error reduction techniques should be incorporated into the daily routines of adults with DS and Alzheimer's disease. The implementation of these techniques can enhance occupational performance and sustain function. Home -based OT may lead to important outcomes in both individuals with dementia and their family caregivers. Hence, health professionals should consider referring individuals with DS and Alzheimer' s disease to occupational therapy services.

Keywords: Occupational Therapy, Alzheimer, Dementia, Down Syndrome, Sensory - based Interventions

Introduction

Down syndrome (DS) is a genetic disorder in which a person has three copies of the 21st chromosome instead of two. The disorder is not related to gender, race, ethnicity, or socioeconomic status and is still the most common chromosomal disorder. Each year, approximately 6,000 babies are born with DS, (1 in 700 babies) in the US (Centers for Disease Control and Prevention, CDC, 2020) and

1 in 750 babies in Canada (Congenital Anomalies in Canada, 2013) and worldwide it is estimated to be approximately one in 800 to one in 1000 births (Pape et al., 2021). The clinical features of DS 'become visible' after the first year of life and are consisted of motor milestones, communication difficulties and generalized cognitive impairment. There is wide variation in cognitive ability, but most individuals with DS have an IQ <50 (Fryers and Russell, 2003).

In addition, this chromosomal disorder results in physical disorders and specific facial features (Livingstone et al., 2015; Malakooti et al., 2014). The syndrome may be associated with premature aging, cognitive impairment, and Alzheimer's-type neuropathology, among others (de la Torre, 2012). Alzheimer's disease accounts for 55-70% of all cases of dementia and is clinically characterized by progressively worsening severe memory loss causing impairment in daily life (Alzheimer's Association, 2019).

The prevalence of dementia in individuals with DS has increased due to increased life expectancy (Lamsal Lamichhane et al., 2022). Premature ageing in adults with DS is a growing health concern as many develop early onset dementia (Esbensen, 2010). The process of premature aging and dementia onset for these individuals may begin in the third decade of life due to chromosomal abnormality (Hithersay et al., 2018; Carfi et al., 2014). However, the mean age for developing dementia in adults with DS is 53 years (DS = 8.2, range 30-75) (Janicki and Dalton, 2000). The prevalence is 10% between the ages of 40-49 years, 40% between the ages of 50-59 years and 56% in people over 60 years (Pape et al., 2021; Livingstone et al., 2015).

Individuals with DS may develop symptoms of Alzheimer's disease earlier in life than other individuals, due to increased production of amyloid precursor protein (APP), the precursor peptide of beta-amyloid located on chromosome 21 (de la Torre et al, 2012). According to a recent study, increased levels of amyloid beta-peptide cause increased levels of oxidative stress and subsequent neurodegeneration in these individuals (Perluigi et al., 2012). In addition to this genetic predisposition, some studies have reported some factors that also influence cognitive functioning and increased risk of dementia, especially regarding the sporadic occurrence of AD. These risk factors include obesity, poor diet, smoking, alcohol consumption, cardiovascular disease, high blood pressure and low level of socialization (Pape et al., 2021).

According to the DSM-5 (American Psychiatric Association, 2013), in the definition of dementia, activities of daily living (ADLs) are listed as an important diagnostic criterion along with cognitive factors. Research has extended to non-pharmacological therapy as a strategy to improve the performance of ADLs and maintain cognitive functioning in patients with Alzheimer's disease (Grasel et al. 2003; Onor, et al., 2007). The role of occupational therapists in addressing the decline in ADLs in these individuals is very important (Smallfield, 2017; Raj et al., 2020). Alzheimer's disease is a progressive disorder that affects the ability to remember and think clearly as well as to function and participate in daily life. People with dementia experience difficulties in completing daily routines, solving problems, and orienting themselves in time and space (Alzheimer's Association, 2019). Due to these factors, they become socially withdrawn and experience personality changes and significant barriers to performing tasks with huge consequences on their well-being and quality of life.

Occupational therapists are members of the multidisciplinary management team for people with Alzheimer's disease and often address the impairment in the ADLs of people with DS and dementia. The provision of therapeutic remediation to DS individuals and their carers, require a collaborative approach. Occupational therapists are members of the multidisciplinary management team for people with Alzheimer's disease and often address the impairment in the ADLs of adults with both DS and dementia (Raj et al., 2020). As not much is known about the treatment and management of dementia in adults with DS, this literature review aims to explore the scope of OT practice for this population and their carers in relation to improving their quality of life and wellbeing.

Occupational therapy interventions for people with Dementia or Alzheimer's disease

Occupational therapy services for people with DS and dementia do not change from those provided to the general population of older people with dementia, although due to cognitive impairment the challenges are higher. Numerous studies show the beneficial effect of occupational therapy intervention for patients with dementia (Bennett et al., 2019; Kim et al., 2012; Graff et al., 2007). Occupational therapists help people to participate in their desired occupations through the therapeutic use of daily activities based on the client's personal interests and needs.

Occupations are those activities that people of all ages need and want to do such as self-care, managing their medication, driving, mobility, caring for other family members. Occupational therapy considers the complex relationship between the client, the activity, and the environment in which the activity takes place (American Occupational Therapy Association, 2023). Domains of occupation include activities of daily living (ADLs), instrumental ADLs (iADLs), education, work, play, leisure, social participation, rest/sleep, and health management (American Occupational Therapy Association, 2020).

Occupational therapy is recommended as one of the non-pharmacological interventions for individuals with dementia along with other therapies/approaches such as sensory stimulation, multisensory stimulation, art therapy, music therapy, aromatherapy, physical activity, exercise, memory recall, cognitive stimulation, cognitive training, and cognitive rehabilitation. Wood et al. (2017) found ten research studies of animal-assisted interventions (mainly dogs) with positive outcomes in quality of life in institutional settings. Cognitively oriented approaches are widely used in combination with other non-pharmacological interventions, such as occupational therapy, for improving cognitive function to improve daily functioning (Takeda, et al., 2012; Grazia, et al., 2016).

Taking care of the sensory needs of people with dementia can positively affect their emotional wellbeing and their ability to participate in meaningful occupations. Sensory integration has a significant impact on functioning and appropriate sensory stimulation can increase arousal and attention, whereas deprivation can lead to disorientation, excitability, and lethargy (Collier, 2012; Ward Smith et al., 2009). Sensory stimulation is often provided in dementia care in multi-sensory environments of specially designed equipment,

within an approach described as 'Snoezelen' suggesting relaxing and stimulating effects (Chung and Lai, 2009). Snoezelen care appears to have a particularly positive effect on disruptive and withdrawal behaviors. Sensory diets and the use of sensory profiles can be implemented in everyday home environments, with results comparable to sessions in specific sensory rooms with individualized support (Haigh and Mytton, 2016).

In Smith and D'Amico's (2020) systematic review, there was strong evidence for the use of massage in people with dementia and modest evidence for occupation-centered and environmentally based multisensory activities, including light, gardening, mealtime, music, Montessori, animal-assisted therapy, dance, and yoga interventions. Current literature supports evidence-based environment-based occupational therapy interventions to address behavior, cognition, and fall/accident prevention for people living with dementia, the use of music (especially at mealtimes), multisensory interventions in private, individualized rooms is recommended for positive behavioral interaction in people with dementia (Jensen and Padilla, 2017).

Smalldfield and Heckenlaible (2017), found strong evidence in their systematic review, of occupation- centered interventions designed to modify and maintain occupations for people with dementia, in promoting the performance of daily activities and the routine use of physical activity programs. In addition, occupational therapy intervention to maintain body function was shown to improve the ability to handle daily tasks for these patients (Gitlin, et al., 2003). The interventions aimed to enhance occupational performance and delay functional decline using a no-error learning strategy to maintain performance of the ADLs and iADLs using multicomponent interventions for total quality of life.

There is also evidence-based occupational therapy interventions that include training and support for caregivers of individuals with dementia to promote psychosocial wellbeing and quality of life and to assist them in their ADL, safety, and efficacy (DiZazzo-Miller et al., 2017). Caregivers are helped more by interactive cognitive-behavioral interventions guided by professionals than by educational materials alone. Interventions that include developing communication skills between the individual with dementia and the caregiver, memory goals to promote interaction between them, and mindfulness and caregiver stress and burden reduction training should be provided regularly (Piersol et al., 2017).

Occupational therapy group cognitive rehabilitation programs can positively affect the quality of life and daily memory function in individuals with dementia (Griffin et al., 2022) with significant improvements in memory and relative daily functioning. Occupational therapy that includes cognitive interventions improves the abilities of patients with Alzheimer’s disease in the performance of daily activities (Graff et al., 2007).

Assistive technology and artificial intelligence, (monitoring, tracking, and signaling technologies, smart homes, and cognitive orthoses) seem promising applications for people with dementia, especially for their home stay and independence, but further research is needed to determine good practices and their integration into care programs for these people (Cagnon-Roy et al., 2017).

Finally, multimodal occupational therapy interventions are used to alleviate occupations imbalances (loss of balance during daily activities) caused by dementia (Grasel et al, 2003). Furthermore, in previous studies, multimodal

occupational therapy programs, with cognitively oriented approaches, appear to have positive effects on cognitive functioning and ADLs in patients with dementia (Takeda, et al., 2012; Regan, et al., 2017). Therefore, occupational therapy is strongly encouraged in the treatment of patients with mild to moderate dementia (Ham, et al., 2021).

Occupational therapy for people with intellectual disability and dementia.

Occupational therapy intervention for individuals with both intellectual disability and dementia is not different from the general population, although intellectual disability can make it more difficult to manage dementia. DS is the most common syndrome with intellectual disability. Intellectual disability is characterized by significant limitations in both cognitive functioning (reasoning, learning, problem solving) and adaptive behavior, (daily social and practical skills) (American Association on Intellectual and Developmental Disabilities, 2018).

In addition, people diagnosed with an intellectual disability may demonstrate limitations in physical functioning and emotional development, which may affect their ability to complete self-care and mobility activities and interact socially in the same way as their typically developing peers. Discounting of daily occupations for this population and increased caregiver burden are common factors for seeking support from health professionals (Carling-Jenkins et al., 2012).

Diagnosis - Clinical Symptomatology of Alzheimer's and Dementia in Down Syndrome

DS adult onset dementia, usually presents the same symptomatology as in the general population without cognitive impairment. However, there may be a difference in presentation because of underlying cognitive impairment, coexisting illnesses, poor communication to indicate symptoms by the patient, and increased reliance on caregivers to communicate information. These factors can sometimes lead to delayed diagnosis, misdiagnosis and/or delayed treatment (Evenhuis, 1990. Lai, 1989).

The clinical appearance of dementia often includes cognitive impairment, loss of adaptive skills, behavioral problems, seizures, and physical symptoms. Some other symptoms may also occur such as mood changes, sleep disturbances, dysphagia, and weight loss, wandering during the day, apathy, deterioration in gait, hallucinations, sphincter incontinence and release of abnormal reflexes. A person with DS may initially experience short-term memory loss and over the next 4-7 years may exhibit the more typical features of dementia until the advanced stage when he or she may be bedridden, requiring fulltime nursing care (Evenhuis, 1990. Lai, 1989).

The National Task Group on Intellectual Disabilities and Dementia Practices (Moran et al., 2013), recommends that at least one standardized tool be used for cognitive assessment and lifelong assessments, in order to provide more

valuable information than a cross-sectional assessment. The change in symptoms over time is considered important. Some standardized tools recommended are the Dementia Questionnaire for People with Intellectual Disabilities, the Dementia Scale for Downs Syndrome, the Dementia Screening Questionnaire in Intellectual Disability, the Adaptive Behavior Dementia Questionnaire, and the CAMDEX-DS (for detailed assessment of orientation, language, memory, attention, praxis, abstract thinking, and perception). The AAMD Adaptive Behavior Scale or the Vineland Adaptive Behavior Scale can be used to assess daily living skills (Prasher et al., 2016).

Treatment includes pharmacological and non-pharmacological interventions. All members of the multidisciplinary team are involved in the treatment and management of Alzheimer's disease. This includes the psychiatrist/neurologist, specialist nurse, psychologist, occupational therapist, speech and language therapist, physiotherapist, etc. (Prasher et al., 2016).

Occupational therapy for adults with Down Syndrome (DS) and Dementia or Alzheimer's disease

The adult population with DS often experiences additional age-related health problems, such as visual and auditory impairments (Esbensen, 2010), contributing to reduced occupational performance and escalating dependence on others in their environment. Dementia in adults with DS further causes progressive impairment in daily occupations, affecting both individuals with DS and their caregivers (Raj et al., 2020). Adults with DS with or without dementia have difficulties maintaining performance in their personal ADLs (Janicki, Zendell, & DeHaven, 2010; Lin et al., 2013).

Occupational performance challenges are increasing for individuals with DS and dementia due to progressive loss of cognitive skills and progressive escalating dependency on their care (Janicki et al., 2010). According to the AMR/IASSID practice guidelines for clinical assessment and care management of Alzheimer’s disease and other dementias among adults with cognitive disabilities, early healthcare services and individualized interventions are recommended. These include adapting daily routines according to the needs of the care recipient and providing appropriate care strategies for intimate caregivers (Janicki, Heller, Seltzer, & Hogg, 1996). However, there is limited published evidence on occupational therapy practice for adults with DS and dementia and their caregivers, and there is a lack of clarity on the types of occupational therapist’s services provided to these individuals (Raj et al., 2020).

Most families typically undertake the care and support of their adult children with DS on their own (Carling-Jenkins, Bigby, & Iacon, 2014) and when dementia co-occurs, the demands for care to maintain their performance in daily occupations increase (Carling-Jenkins et al., 2014; Carling-Jenkins, Torr, Iacono, & Bigby, 2012). Some caregivers have no professional help, leading to a breakdown in their role with consequences for their health (Janicki et al., 2010). Occupational therapists could address these caregiving demands by suggesting alternative strategies to meet their needs, supporting both caregivers and adults with DS (Raj et al., 2020).

Researchers report that non-pharmacological interventions can improve the performance of daily occupations for adults with cognitive impairment and dementia (De Vreese et al., 2012). These interventions involve environmental modifications such as visual cues, decompression to improve environmental safety, interventions to address ADL needs, and sensory interventions (e.g., music) (Jokinen, 2014). Practice guidelines (AAMR/IASSID) have also suggested the use of non-pharmacological interventions to enhance occupational performance in daily activities (Janicki et al., 1996). Occupational therapy interventions integrated within a client-centered approach can achieve positive performance outcomes for adults with both DS and dementia, like the general population of older adults with dementia (Padilla, 2011).

It is very important that early referrals are made to address various challenges for adults with DS especially with the onset of dementia. The recommendation in the AAMR/IASSID guidelines (Janicki et al., 1996) emphasizes the early identification of age-related health problems, including dementia, by health professionals through regular health screening (Määttä et al., 2011). With regular screening, it may be possible to identify age-related performance decline in adults with DS early and access appropriate services to improve performance in their daily occupations and possibly reduce the burden of care.

In the study by Raj et al. (2020), which involved occupational therapists providing services to adults with both DS and dementia from UK, USA, Australia and Canada, the most common reasons for referring individuals with both DS and dementia for occupational therapy included: a reduction in ADL (68%), iADL (54%) and support regarding caregiver strain (46%). In the same study, in terms of theoretical models to guide occupational therapy practice, more than half of the participating occupational therapists (52%) working with adults with both DS and dementia reported using the Model of the Human Project (MOHO) (Kielhofner, 2008). 26% of the participating occupational therapists reported using the Canadian Model of Occupational Performance (CMOP) (Law et al, 1990) and the Person-Environment-Occupation Performance Model (PEOP) (Bass, Baum, & Christiansen, 2017). The remaining 17% reported using "other" models, including the Occupational Therapy Intervention Process Model, Occupational Science theories, Allen's Model for Cognitive Disabilities, Winnie Dunn's Sensory Processing Model, no model, or "any approach needed." Most respondents reported using a combination of theoretical models to adapt their interventions according to the changing performance needs of adults with both DS and dementia.

In the same study, the most frequent areas of assessment for adults with both DS and dementia by occupational therapists were home environment (85%), ADL (81%) and daily routine (74%). Also, a lower percentage of formal/unformal educational activities (21%) and paid/unpaid work (11%) were assessed. Only 53% of the occupational therapists participating in the study reported that they included caregivers in the assessment, mainly regarding risks and safety (80%), manual handling (53%) and quality of care (38%) (Raj et al, 2020).

In terms of assessment tools for adults with both DS and dementia, a wide range is used as reported by occupational therapist participants in the Raj et al. (2020) study. Almost three quarters (74%) of occupational therapists reported using non-standardized assessment. Over half (56%) use the Assessment of Motor and Process Skills (AMPS) (Fisher & Jones, 2010) and 44% of occupational therapists use 'other' assessment tools such as the Pool Activity assessment tool, Winnie Dunn's Sensory Profile in non-standardized form and the Montreal Cognitive Assessment.

The choice of tools used by occupational therapists is usually influenced by three factors, information obtained from other occupational therapists (93%), availability of assessment tools in their workplace (88%) and familiarity with the assessment tools (88%) (Raj et al., 2020). A wide range of assessments are reported, which may be related to the lack of appropriate standardized tools to capture the complexity of performance limitations caused, because of multiple age-related health problems, of adults with DS and dementia (Stanton & Coetzee, 2004). The use of non-standardized tools includes difficulties in comparing data between clients and evaluating intervention outcomes (Goodman & Christine, 2009). The use of standardized assessments such as the Canadian Occupational Performance Measure (Law et al., 1990), the Sensory Profile for Adults (Brown, Tollefson, Dunn, Cromwell, & Filion, 2001), and the AMPS (Fisher & Jones, 2010) would allow for better measurement or evaluation of treatment outcomes.

The most common OT service areas, in this population like the general population of older persons with dementia, are the use of compensatory strategies for ADLs and environmental modifications to address occupational performance limitations (Bennett et al., 2011; McGrath & O'Callaghan, 2014). The OT literature for the general elderly population with dementia and people with intellectual disabilities supports the use of compensatory intervention strategies adapted to the individual's performance needs (Janicki et al., 1996; Padilla, 2011). Intervention strategies must be individualized to achieve results in meaningful occupations. The three most frequently reported occupational therapy interventions in the Raj et al. (2020) study, were: compensatory strategies for ADLs (66%), environmental modifications (63%) and counselling for future functional needs (62%). Participants also reported that it is important to incorporate appropriate intervention strategies within people's daily routines and the use of relevant sensory cues (visuals) to promote their participation and performance in meaningful occupations.

Only half of the participants reported providing occupational therapy services to caregivers, with the most common intervention being education and training on home safety. This strategy has been supported by the AAMR/IASSID (Janicki et al., 1996) and by the literature for the general population of older adults with dementia (Gitlin, Corcoran, Winter, Boyce, & Hauck, 2001). Occupational therapists who provided services to caregivers of adults with DS were only 56%, and they reported primarily three areas of occupational therapy intervention, training for safety related to the home environment (80%), training to use equipment/assistive devices (74%), and training to use activity adaptations to assist care recipients (70%). The least recommended intervention was relaxation techniques (11%). The other types of interventions reported involved referrals to community services and ongoing care.

The AAMR/ IASSID recommends the provision of client-centred collaborative care by relevant services (Janicki et al., 1996). Collaborative approaches with relevant team specialties can assist in planning long-term services for adults with both DS and dementia (Collings, Dew, & Dowse, 2016). Providing services through a multidisciplinary team, with occupational therapists with expertise in this population and using a client-centred model of care, has very successful outcomes. In contrast, fragmentation of services and lack of cooperation and client-centred care were identified as barriers to providing collaborative and integrated care for adults with DS (Raj et al. (2020). Service fragmentation and lack of collaborative approaches have not been identified as barriers to service delivery for older people with dementia, where limited treatment time

and role constraints appear to be prominent (Bennett et al., 2011; McGrath & O'Callaghan, 2014).

Appropriate professional training for occupational therapists enables the provision of effective services for adults with both DS and dementia and their carers, with many highlighting the need for appropriate training to develop relevant skills and knowledge in this area. To address the specific training needs for occupational therapists it may be necessary to first establish current training practices for therapists and assess whether training is in line with the recommendations of the practice guidelines for intellectual disability and dementia (Janicki et al., 1996; Raj et al. 2020).

Some other identified barriers to effective services for adults with both DS and dementia and their carers were lack of funding for occupational therapy services, lack of occupational therapists to cover services and insufficient therapeutic resources. Some occupational therapists interviewed reported that these limitations caused delays in timely treatment support. It is likely that these unmet timely service demands will further escalate the care of these individuals and subsequently impact the level of funding required to address the long-term care needs of adults with both DS and dementia. Addressing these barriers requires a shift in the focus of policymakers and funding from primary health care issues for this population to long-term care services to maintain their health and well-being (Covelli, Raggi, Meucci, Paganelli, & Leonardi, 2016). This shift requires advocacy from health professionals including occupational therapists (Raj et al., 2020).

Conclusion

The role of occupational therapy for adults with both DS and Alzheimer disease or dementia and their caregivers is very important. Occupational therapists could support these individuals and their families in many areas. Although their service provision is not very different from that for people with dementia without DS, it is important that there are more studies on the outcomes of occupational therapy practices in this population so that evidence-based good practice is available to promote the wellbeing and quality of life of people with DS and dementia and their carers.

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