Identifying the Role of Occupational Therapy in Supporting Engagement in Leisure Occupations for Individuals Diagnosed with ALS

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Abstract/Literature Review

The purpose of this study was to uncover the role of occupational therapy in supporting engagement in leisure occupations for clients with Amyotrophic Lateral Sclerosis (ALS). The focus of this investigation is to uncover the exemplars of practice where OT's have creatively supported clients who have been diagnosed with ALS - part of the pursuit is engagement in leisure activities. To understand the strategies used by experts in the field which can advance the practice of OT for this underserved population. Many individuals who are diagnosed with ALS receive very limited OT services. This investigation could reveal how the “master clinician” is able to support the client by promoting engagement in leisure pursuits.

Researchers reviewed relevant literature pertaining to ALS, the impact of ALS on leisure participation, and the role of OTs. Statistics show as many as 30,000 people are diagnosed with ALS in the United States today (ALSA, 2014). ALS primarily affects an individual's physical functioning; in disease progression neurons degenerate and critical motor movements are lost (McGovern-Denk et al., Nowak et al., 2003). Currently, multidisciplinary teams comprised of PTs and OTs prioritize maintaining independence in functional mobility and activities of daily living (ADLs) for clients with ALS. However, literature addresses the necessity and benefits of leisure. Various studies reveal that participants who experienced significant loss in their lives maintained an increased overall well-being when leisure interventions were implemented (Caldwell, 2005; Kleiber et al., 2008). Leisure is a beneficial coping strategy for individuals adjusting to a disability or serious illness (Iwasaki & Mannell, 2001). Finally, OTs can positively influence the QoL of their clients by implementing meaningful and purposeful client-chosen activities, or leisure pursuits (Mitsumoto & Del Bene, 2000).

Methods

The study was qualitative in nature with a phenomenological approach and used an in-depth semi structured open-ended interview outlined from Polit & Beck (2012). Three OTs who have worked with at least 5 clients with ALS in the last 5 years. The three OTs have a combined average of 33 years of experience. Participants were asked to describe in detail their experience supporting clients with ALS in leisure pursuits. One researcher conducted phone interviews and asked sixteen open-ended questions. Another researcher recorded the interview on a password protected cellphone application titled, “TapeACall.” The same two researchers then transcribed the interviews verbatim in a password protected computer and saved the interviews onto a password protected USB flash drive. Researchers compared notes to combine codes and themes. Researchers determined and agreed upon the final codes, and summarized the general meaning of the results that were found.

Results

The data collected from the three participants created three common themes including client centered care, client and caregiver education and adaptations. These intervention strategies are used to help foster leisure interventions for clients. The research suggests that OTs are providing leisure interventions covertly through other interventions such as energy conservation, education, and adaptations.

Discussion

Most ALS patients have deficits in ADLS/IADLS that prevent them from participating in leisure activities and are therefore a top priority for clients and OTs. The results also indicate how healthcare guidelines focus in function in ADL and IADL before more meaningful activities. The therapists interviewed indicated how they would like to spend more time focusing on what is important to the client outside of ADL and IADLs, however they are guided by what the insurance companies will reimburse.