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The Lived Experiences and Occupational Performance and Satisfaction of Young Adults with Multiple Sclerosis (MS) as Related to Fine Motor Skills

Mary Squillace

New York Institute of Technology – USA, msquil01@nyit.edu

Pamela Linden

USA, drpamlinden@gmail.com

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The Lived Experiences and Occupational Performance and Satisfaction of Young Adults with Multiple Sclerosis (MS) as Related to Fine Motor Skills

Abstract

Background: Young adults with multiple sclerosis (MS) may experience fine motor (FM) challenges that prevent them from engaging in age-appropriate occupations. Disease mediated changes in occupational skills can affect how a young adult perceives their occupational performances. This study aimed to gain an understanding of how young adults with MS perceive their FM abilities and social and emotional performance during daily activities.

Method: Eighteen young adults with MS who previously scored equal to or less than the low average range on FM pegboard tests and who reported high satisfaction and low performance on a modified self-report were interviewed. The interviews explored the participants' perceptions of their occupational performance regarding FM skills and social-emotional performance.

Results: Analysis of interviews resulted in the following themes: relationship changes, attribution theories, FM deficits and symptoms that affect daily performance, avoidance of assistive equipment, and lack of knowledge of occupational therapy services. This analysis found that despite low performance on their FM testing, the participants were satisfied with their ability to perform tasks.

Conclusion: Young adults with MS presented with FM deficits that affect their occupational performance in age-related tasks.

Comments

The authors declare that they have no competing financial, professional, or personal interest that might have influenced the performance or presentation of the work described in this manuscript.

Keywords

fine motor skills, multiple sclerosis, occupational therapy, occupational performance

Credentials Display

Mary Squillace, PhD, OTR/L

Pamela Linden, LMSW, PhD

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Multiple sclerosis (MS) is an auto-immune disease characterized by the neurodegeneration and destruction of the myelin protective sheath of nerve cells in the central nervous system (CNS). Damage to the white and grey matter of the CNS interrupts communication between the nerves of the CNS and the body resulting in a range of physical and cognitive dysfunction (Kalb et al., 2018). MS presents as periodic acute phases, described as attacks or exacerbations, with a slow worsening of neurological symptoms. The manifestation of symptoms can have a gradual increase of disability with occasional relapses that result in a deterioration of neurological function within 20 years (Tullman, 2013).

MS symptoms can have deleterious effects on an individual's occupational performance. Young adults with MS face future impairments that may affect their ability to perform the typical tasks associated with independence. Symptoms that affect motor performance can interfere with typical activities of daily living (ADLs) and instrumental activities of daily living (IADLs). The symptoms of MS, physical and cognitive, may occur at separate instances. At times, physical symptoms present less than cognitive, thus showing clinical MS as benign and mild (Rahn et al., 2012). Occupations change during the life span of a typical young adult. Physical impairment may impede work activities, reduce socialization because of fatigue, or cause performance problems with typical ADLs. Symptoms and the associated disruption of life plans can affect how young adults perceive their daily occupational task performance.

The occurrence or recurrence of a significant neurological event can affect the quality of life of young adults with MS. An exacerbation or attack may require hospitalization and disrupt vocational, social, and family life. The physical disabilities along with cognitive and psychosocial deficits acquired from frequent attacks may temporarily or permanently affect the functional skills required for age-appropriate occupational performance. Weakness, fatigue, and cognitive impairments can lead to depression and isolation and increase the likelihood of economic stressors because of the inability to work (Naci et al., 2010).

Depression and fatigue commonly appear early and remain significant throughout the disease course. Fatigue has been found in 65%–90% of the MS population, with physical disability and disease course being independent of fatigue (Nunan-Saah et al., 2015). Often, fatigue and concentration appear similar to depressive symptoms, creating a challenge for an accurate diagnosis of MS (Nunan-Saah et al. 2015).

Newly diagnosed patients report that cognition problems and fatigue are initial symptoms of MS. These symptoms are linked to complaints of depression and anxiety, but the person with MS may regard them as fatigue (Nunan-Saah et al., 2015). Combined with more obvious physical symptoms, these symptoms add to the limitations of occupational performance for independent living (Rahn et al., 2012).

Physical impairments because of MS are readily identified, but cognitive deficits are not as apparent. These undetected symptoms are seen in 43% to 70% of those diagnosed with MS (Goverover et al., 2015). These deficits affect performance of activities that support independent, community, and social life skills (Goverover et al., 2015). Young adults may experience gross or fine motor (FM) issues that prevent engagement in occupations for self-care, productivity, and leisure tasks. A common early symptom of MS is upper limb dysfunction that can cause a loss of dexterity and eliminate FM abilities during functional tasks (Dezfuli et al., 2015). To our knowledge, there is no previous research that has explored the effects of MS symptoms on the age-appropriate occupations of young adults with MS, such as vocational skills, home management, self-care, and leisure tasks as it relates to their FM skills.

This paper presents the qualitative findings of 18 out of 40 participants as a part of a mixed methods study that examined the relationship of the FM skills and occupations of young adults with MS (Squillace,

2020). The quantitative component of the mixed methods study used a screening tool, the Extended Disability Status Scale (EDSS), that quantifies the disability status of those with MS (Kurtzke Expanded Disability Status Scale, n.d.). Each participant in this study had an EDSS score of equal to or less than 3, indicating a moderate disability but fully ambulatory at the time of the testing (Kurtzke Expanded Disability Status Scale, n.d.). The Purdue Peg Board Test (PPBT) and Grooved Peg Board Test (GPBT) were used to measure FM performance in terms of speed and manipulation. An adapted Canadian Occupational Performance Measure (COPM) was used to determine the level of perceived satisfaction and performance of daily tasks of the participants. Author permission was obtained to adapt the COPM for the purpose of this study. The adaptation consisted of using tasks offered on the COPM that require FM skills during activities. This study revealed relationships between FM skills and the perceived satisfaction and performance of occupations of young adults with MS (Squillace, 2020). Nearly half (45%) of the participants reported a low performance on their peg board and COPM tests but high satisfaction with how they performed on the tests and their daily tasks. Qualitative methods were used to increase understanding of how low performance and high satisfaction with performance impact participants' daily occupations.

Method

Each of the 18 participants who scored within or less than the low average range or slower on the pegboard tests agreed to participate in an interview following the collection of quantitative data. The aim of the qualitative investigation was to increase understanding of how young adults with MS scoring in average to below average level on the pegboard tests perceived their current occupational performance, including the psychosocial factors that impact their occupational performance and how their FM performance affects their lives.

Recruitment

Participants were recruited from private outpatient neurological and support groups in the New York metropolitan region. This sample was a convenience sample because of the specific inclusion criteria of the age of the population, diagnosis, and symptoms. The participants included 14 females between 22 to 30 years of age and four males between 27 to 30 years of age from the Long Island and New York City regions. Young adults are typically in the early stages of MS or were diagnosed as an adolescent.

The study protocol was approved by two institutional review boards. Recruitment flyers were distributed to clinics, support groups, and community-based MS organizations. Inclusion criteria included men and women 18 to 30 years of age who had no other prior history of neurological or physical impairment, had an Expanded Disability Status Scale (EDSS) (Kurtzke Expanded Disability Status Scale, n.d.) score of 6.0 or less, retained some self-care abilities, expressed an average level of independence, and had experienced no exacerbation in the last 1 to 2 months. Full recovery from an exacerbation can be weeks to months. An exacerbation is considered a true exacerbation if it lasts at least 24 hrs and is at least 30 days from a prior exacerbation (My-MS.org, 2021).

Procedures

Qualitative data were taken by the primary investigator of this study. The data were derived from interview transcripts and investigator memos during both the quantitative and qualitative components of the mixed methods study. Interview transcripts were hand coded, and thematic categories were identified. An open dialogue with the participants helped in maintaining reflexivity in this study.

A lay version of the study findings was shared with the interviewed participants. This member checking procedure asked the participants the extent to which they agreed or disagreed with the findings.

Results

Eighteen young adults scoring average to below average in manipulation and speed on the peg board tests participated in a semi-structured interview designed to respond to the question, “What are the lived experiences of the occupations and occupational performance associated with the FM skills of young adults?” The primary themes that emerged included: relationship changes, disease attributions, FM deficits that affect daily performance, avoidance of assistive equipment, and lack of knowledge of occupational therapy (OT) interventions.

Relationship Changes

Young adults with MS described losing friends or experiencing a reduction in their social network after being diagnosed with MS. Some had close friends who remained in contact, but other friends evolved into acquaintances, or in some cases, relationships ended. The participants said, “friends disappeared after my diagnosis,” and “you learn who your friends are.” They attributed relationship changes to their symptoms affecting mobility and energy, making it difficult to keep up with social activities. One participant shared, “I’ve been told I’m lame because I don’t party much,” after her medications slowed her down, causing fatigue. Social visits became infrequent, and friends would eventually stop calling. One said, “It definitely diminished my social life because I can’t do things that I used to do. Even like little things just because I have to avoid certain temperatures and certain places, I stopped doing things.”

The participants relied on family for support and socialization. Some found new social networks through MS support groups, which enabled friendships with others who had a shared understanding of life with MS. Some reported that it was stressful for them to begin new friendships or intimate relationships because they were unsure how to raise the topic of their MS diagnosis. One participant shared she would only discuss her MS if her symptoms were visible, saying “there needs to be a visual for others before I can tell.” Another was fearful of developing a serious romantic relationship. She said, “In terms of dating, it brings out a lot of ‘how would I tell someone, or should I tell them,’ - that thing.” The primary factor affecting relationships involved the lack of understanding that people have about MS. One said, “They really cannot understand what it is I’m going through because they are not going through it themselves.”

Attribution Theories

Satisfaction with occupational performance was influenced by belief systems that explain why they acquired MS. Many attributed their MS to stressful experiences, including ending intimate relationships, and environmental factors, such as electronics, diet, and food preservatives. Others suggested that their diagnosis was related to physical experiences such as pregnancy, postnatal complications, autoimmune disease, and Lyme disease.

FM Deficits and Symptoms that Affect Daily Performance

Common MS symptoms that affected the participants’ ADLs were hand shakiness, pain in the arms and fingers, hand fatigue, hand weakness, spasms, and numbness and tingling of the hands. Some tasks that the participants described as difficult were related to typical daily tasks, such as holding objects steady; manipulating fasteners, writing tools, and utensils; and mobility needed daily tasks like dressing and ambulation. One participant said, “Just because I get it done doesn’t mean it was easy to do,” “My right hand is going to drop a lot,” and “My left hand is bad. I have trouble with it.” One participant described frequently dropping objects and having slow mobility, saying, “You would think I was drunk.”

Fatigue affected dressing skills and many reported feelings of exhaustion after a typical morning routine. Dressing was a common problem when manipulating buttons and fasteners. In some cases, stabilization in sitting or dressing was required when dressing their lower extremities. One participant said, “On a day like today, if I had to button up or something, it may take a bit longer for me to get to that button.” The participants said they needed to focus when grasping objects during work or when performing an ADL task, such as using writing tools or eating utensils. One said, “If I concentrate hard enough, I could do it very well. But if I am just trying to do it because it is something that you normally do like hold the fork or spoon, I tend to drop it.” Paying bills, which requires signing checks, and cutting and prepping food is affected by hand fatigue and weakness. One shared, “Like cooking, definitely if—I need to be more careful, it’s again concentrating more when I’m cutting veggies and stuff and prepping meals, making sure that—yeah, making sure I don’t cut myself.” IADL skills, such as driving and house cleaning, were affected by fatigue, hand spasms, numbness and tingling, and weakness. One participant said, “If I’m using a screwdriver for too long, I get tired very fast, things like that.” The participants said that manipulation of knobs both inside and out of a car requires increased focus, and low spatial awareness affects knob manipulation. One explained,

Often still I’ll go to reach for something, and I’ll hit my hand on it because my distance doesn’t seem to be working that well in my brain. I’ll hit my hand on the counter or on the faucet even though I’m trying to go under it.

The symptom’s effect on manipulation skills led to job loss for some, particularly jobs like cashiers, which rely on FM performance. One hairdresser said, “I braid hair sometimes, but I had to stop doing that because my fingers get like locked.” A nurse noted she presented with difficulty in handling and manipulating needles, which drew on ethical considerations of performing in her role with shaky hands. Some of the participants described other difficulties with work related tasks because of symptoms of MS. Pain, spasms, and constant tingling feelings of the hands and arms result in slower writing, slow moving hands, and less spatial awareness when performing typing tasks. Most of the participants said frequent dropping of objects is a serious problem. One said, “My hands do not do what my brain tells me to do.” Another stated, “I do drop things more. Sometimes I was dropping more often, like I wasn’t conscious of how tight I was holding it and I was just dropping it more.” “Things fly out of my hands,” said one participant who described dropping her phone. “If it’s something, if it had some weight to it, it would bounce out of my shaking hands, but if it doesn’t have weight to it, I might fumble and things like that.” Handling of smaller objects, such as makeup wands or shaving tools, affects performance. The participants said manipulation of small objects during work is problematic. One said, “Like even right here, paper clip, I’ll find I’m having trouble getting a grip of it and smaller items like that I have trouble.” For some, MS symptoms led to job changes and required accommodations for schoolwork. One described feeling embarrassed when dining out because of weakness leading to dropping their fork.

Avoidance of Assistance

The participants expressed a desire for independent mobility and self-care. Some said they would refuse assistive equipment to maintain their independence:

I just don't want to rely on the people, like as far as my kids go. My mom is in the house, but I would rather do it on my own, even if it's a year from now, to start doing it completely on my own again because I had one daughter before it even happened.

One participant leans on walls for balance but rejects the idea of using a cane. She says, "Yeah, I use the walls a lot, or when I walk out of my yard into the door, I stumble, and I keep going. Well, I did actually fall one time though." Another uses ankle foot orthoses for ambulation stabilization and leans on walls for balance but rejects a cane. They said, "What happened was I felt like it makes me walk even worse than how I would walk so I never used that, like, I've been—I stopped using it." Others use assistance devices like canes, walkers, and grab bars, but associate wheelchairs with an expectation of future debilitation. One said, "I feel like the more I rely on something [equipment] that the more I'm going to deteriorate," adding "I hear from people who are, you know, in a wheelchair, and I'm like, that freaks me out. So, I push it aside." Another participant said, "Everybody has been talking to me about a cane and I'm like, no I don't, because it's going to put me into depression. I know that." Another said, "I really don't want to walk with no cane. That will probably make me depressed."

Lack of Knowledge of OT Services

Each of the participants received treatment from neurologists, however, few saw allied health professionals to address MS symptoms. Two of the 18 reported receiving occupational therapy. One indicated they did not find the occupational therapist helpful, and the other had seen an occupational therapist as a child for an unrelated condition. After hearing how OT can help people with MS, several expressed interest in receiving OT services. One said that their physical therapist recommended that they see an occupational therapist for self-care strategies and to improve their hand skills. One confused OT and PT treatment approaches and was not certain which therapy they received at home. One participant who had both an occupational therapist and a physical therapist said, "I did both; it didn't help." They continued, "The MS gave me a bulging disc on my spine . . . so that's why they referred me to the PT." This participant reported that depression resulted in lack of motivation to take part in therapy. A participant having difficulty with manipulation of writing tools, buttons, small objects and typing said although she was in PT for balance, she is not getting OT for hand therapy. She said, "I've done it before with my balance. They want to help me with my balance because it is really bad, but they say that my hands, that they don't see anything wrong with them." Eight of the participants reported having received PT. Some thought PT would improve their balance, but one explained why they discontinued PT services:

I did PT for a while for the balance, but I feel like it's not going to be improved so I don't want to do it. The doctors told me it's going to be like this forever so there's no—I'd rather use my time to do something better.

Member Checking Results

Investigators emailed a lay summary of findings to the 18 interview participants. They were asked to review the summary and indicate the degree to which they agreed or disagreed with the findings. Nine of the 18 participants responded. Six endorsed the interview themes and three agreed with most of the themes, even if they were not directly related to their lives. One participant stated the findings applied to her lived experiences with MS, except that her friends remained loyal throughout her diagnosis with MS. Another participant disagreed that his FM skills interfered with his current ADL skills and work tasks but agreed that fatigue played a major role in self-care performance. Family and spousal support was

universally strong with this group, except for one participant who cited that the end of his engagement was because of his MS diagnosis. Another participant stated that she mostly agreed, but not all of the findings applied to her. Another member check participant echoed the sentiments of the others, saying that MS is a “snowflake disease” because no two MS patients are alike and that although the findings may not all apply to them, they may be relevant to others with MS.

Discussion

Young adults with MS who scored average to below average on their FM performance on the peg board tests and reported low performance and high satisfaction on the adapted COPM reported experiences of loss of friendships, decreased social networks, depression, and reliance on family and close friends for emotional support when symptoms of MS are present. The tenor of social activities changes because of fatigue and exhaustion, requiring energy conservation. Their disease etiology attribution varied from biological (stress, pregnancy) to environmental pollutant exposure. Disease attribution and meaning-making helps young adults with MS build a conceptual framework to cope with FM deficits that affect daily occupational performance in self-care, work or school productivity, and house care.

This study found that as symptoms increasingly affect daily occupational performance, the young adult maintains avoidance of assistance, associating it with future severe impairment and disability. The participants reported using naturally occurring assistance, like wall leaning, for as long as possible to put off the inevitable increase in need for assistance as symptoms worsen.

The lack of awareness of the rehabilitative contributions of OT for young adults with MS was consistent with other studies that found fewer OT referrals compared to PT referrals by medical practitioners like physicians and neurologists. Lexell et al. (2014) found a lack of knowledge about rehabilitation services and the contribution it makes in improving functional skills and ADLs for people living with MS. Participants reported that they sought PT for their initial symptoms related to balance and ambulation, however, they were unaware that loss of independence in occupations related to self-care, work or school, or leisure tasks could be addressed by occupational therapists.

The unpredictability of MS presents challenges for young adults during their transition to adulthood. Symptoms can interfere with the achievement of typical milestones. Adaptations in occupational engagement of tasks compromise their well-being. Adjusting to challenges brought on by MS symptoms will require practice of prior occupational skills and adaptations to face future challenges associated with the disease (Lexell et al., 2014).

The findings of the current study are consistent with Rumrill’s (2009) finding that young adults with MS desire to complete their education and establish a career; however, MS symptoms are associated with unemployment as people have difficulty in meeting the physical demands of the job (Rumrill, 2009). Physiological symptoms are strong factors in job loss or leaving a job for adults with MS. Fernandes et al. (2015) found significant relationships between motor coordination and cognitive functioning in which visual motor coordination and visual selective attention can affect functional occupations that require cognitive functioning, such as employment. There is limited independence with functioning in the community, work, and at home for those with MS effected by fatigue. Unemployment is related to a poor quality of life while those without fatigue have shown a better quality of life (Nunan-Saah et al. 2015).

Other factors, such as cognitive deficits with visual and memory impairments, and physical deficits, such as ataxia and low mobility skills, are high predictors of job loss associated with MS (Alosaimi et al., 2017; Rahn et al., 2012).

Ben-Zacharia (2011) report that loss of concentration, memory loss, delayed thought processes, and depression are secondary and tertiary symptoms that can also affect daily functioning and keep people with MS from working or changing work because of a lack of confidence in job performance.

Symptoms of FM impairment for young adults with MS led to a change in occupations, thereby influencing individuality, including the context in which they perform their occupations. For example, a young mother was unable to care for her child to the standard she felt appropriate because of her MS symptoms (e.g., diaper changing and play tasks). The recognition of the effects of their impairments may lead to a change in self-perception. Lexell et al. (2014) found in a study using the COPM that personal care, functional mobility, and household management were reportedly perceived to be the most problematic for those with MS.

Avoidance of use of assistance may delay their self-perception as a disabled person unable to perform expected activities in their expected occupational roles. Yeung et al. (2016) found that the use of adaptive equipment was lower than the self-perceived need for various adaptive equipment in those with disabilities. This study found that there was a disparity between the objectivity and subjectivity and self-perceived need for the equipment. A change in self-perception may foster stronger efforts in maintaining their normal routines and attempts to achieve performance expectations.

Limitations

The convenience sample was small and limited to young adults with MS recruited from local clinics and support groups. Theoretical validity may have been threatened because of the limited sample size impacting the ability to develop more theories that may have emerged with a larger population. Unpredictable relapses of the population and the need for subjects to be at least 1 month out of a relapse also limited this population. Other factors of the disease, such as fatigue, cognitive impairments, depression, disease modifying, and depression medications could have influenced the participants' responses at the time of the interviews.

Implications for OT Practice

As young adults transition into adulthood, occupational adaptations must occur daily for successful engagement in future occupations throughout the life course. OT practice follows theoretical approaches in occupations to break down the barriers that hinder engagement and participation in occupations for those with an injury or illness, such as MS. Interventions are aimed at creating strategies toward enhancing occupational performance while adapting to the changes experienced by the symptoms of MS.

Occupational therapists can develop personalized goals that address the individual's self-care, productivity, and leisure needs as well as client-centered strategies that can reduce the psychosocial stressors that are associated with a decreased sense of self and independence. Setting goals that are achievable and measurable will promote a sense of success and encouragement for young adults with MS who struggle with psychosocial issues because of impairments related to MS symptoms. Strategies can be developed with a focus on the person, specific client-related occupations, and the environment in which those tasks occur (Finlayson et al., 2013). The symptoms of MS that cause fatigue, visual and cognitive deficits, psychosocial and emotional issues, and impaired upper extremity functioning require specific interventions that include the therapeutic use of self, task specific training, and patient education. Occupational performance, participation, and quality of life can be obtained through the occupational therapist's use of restoration, remediation, compensation, and environmental adaptation (Finlayson et al., 2013).

Difficulty attending school because of physical limitations, such as fatigue or deficits in motor planning, can be mitigated by the availability of online courses. Occupational therapists can offer resources in helping young adults with MS find educational or vocational training programs. Modification suggestions at home and in class can be helpful in addressing the physical, visual, and cognitive symptoms that may arise. Occupational therapists can suggest methods of reducing fatigue by leaving a second set of books at home rather than carrying them to campus; allow for easy exit out of a room for bowel and bladder issues; offer suggestions for in seat exercises to reduce spasms; tape classroom lectures and recommend visual aids or optimal positioning in a classroom to accommodate any visual complications.

Occupational therapists can provide education to young adults with MS, including learning how to balance their environment and engagement in meaningful occupations and provide encouragement for active participation in meaningful occupations that can lead to more satisfied and fulfilled life roles (Yu & Mathiowetz, 2014). Occupational-based education for caregivers of those with MS will provide support and resources for the family member.

Conclusion

In this study, the lived experiences of young adults with MS who have FM impairments were investigated. The interviews revealed that the FM impairments contribute to social-emotional and age-related performance. The burden of FM impairments for young adults puts them at risk for worse outcomes regarding their education, family planning, vocation, and social skills as they transition to adulthood. FM skill impairment might impede performance in the daily occupations of young adults who are transitioning into adulthood.

Participants have found that adjusting to the disease required the maintenance of their support systems, such as family and support groups, and keeping open discussions with others that experience the same symptom-related occupational limitation.

Future Research

Little is known about the etiology and onset of FM impairment in young adults with MS. Research that involves comprehensive FM testing should be conducted to develop deeper understanding of variables underlying FM control, including tremors, muscle atrophy, and muscle weakness. The finding that young adults with MS rely on caregiver support suggests an imperative to attend to caregiver needs. Future research should investigate the role of occupational therapists in ameliorating caregiver stress. In addition, symptomatic issues such as fatigue, cognitive and visual issues, and psychosocial problems that influence the performance of occupations and the overall quality of life for young adults with MS should be further explored.

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