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Assistive Technology and In-Home Use for Individuals with Tetraplegia

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Clinical Scenario

Tetraplegia (otherwise known as quadriplegia) is a common impairment treated by occupational therapy. It is defined as the impairment or loss of motor and/or sensory function of upper extremities (UEs), lower extremities (LEs), and trunk as a result of damage to the cervical segments of the spinal cord (Atrice et al., 2020). Damage to the vertebrae or spinal cord can result in spinal cord injury (SCI). The National Spinal Cord Injury Statistical Center (NSCISC) (2020) indicated the prevalence of spinal cord injuries in the United States is approximately 294,000 people. Average age of injury has reportedly increased from 29 to 43 years of age since the 1970's, and approximately 78% of new spinal cord injury cases are male. The most common cause of spinal cord injuries are motor vehicle accidents closely followed by falls. Incomplete tetraplegia, when there is some motor or sensory function below the level of injury, is the most frequent category of injury at approximately 47.2% of cases (Bautista & Grossman, 2014; NSCISC, 2020).

Many interventions available to those with tetraplegia resulting from SCI utilize assistive technology (AT). According to Assistive Technology Industry Association (ATIA) (2020, para. 3), AT is “any item, piece of equipment, software program, or product system that is used to increase, maintain, or improve the functional capabilities of persons with disabilities.” AT is an encompassing term and there are many items within the AT literature that can be classified as being under the umbrella term AT. Various terms used include: Environmental Control System (ECS), Environmental Control Unit (ECU), and Environmental Aids to Daily Living (EADL) (Etingen et al., 2018; Hooper, Verdonck, Amsters, Myburg, & Allen, 2018; Myberg, Allan, Nalder, Schuurs, & Amsters, 2017; Rigby, Ryan, & Campbell, 2011; Verdonck, Nolan, & Chard, 2018; Verdonck, Stegges, Nolan, & Chard, 2014).

Atkins and Bashar (2015) reported that occupational therapy (OT) helps to facilitate participation in the individuals' meaningful activities and return to productive lives. Some aspects that an occupational therapist can assist with include teaching individuals to perform activities of daily living (ADLs) such as feeding and dressing. Occupational therapists also provide the appropriate adaptations and equipment necessary to complete these tasks, evaluate and recommend wheelchair seating and positioning to optimize function, mobility, and engagement in the community, facilitate development of activities and resources that are available to engage in, support the individual and their families/caretakers, and empower them to direct their care effectively (Atkins & Bashar, 2015). These roles of occupational therapists can include the use of AT as a mode of intervention to improve the engagement of their clients in occupations.

Reasons for skepticism regarding recommendations for environmental control systems and other assistive devices from occupational therapists include the cost, frequent denial of third-party reimbursement for assistive devices, and the detailed knowledge some devices require to operate (Holme, Kanny, Guthrie, & Johnson, 1997). Another area of concern when providing services to those with SCI is the feasibility of using assistive devices to provide telehealth services. Telehealth video conferencing with practitioners and other individuals with spinal cord injuries can be beneficial, however individuals in the more rural areas may have difficulties with connectivity (Newman, Toatley, & Rodgers, 2019; O'Connell et al., 2018).

The need and type of occupational therapy services in home for individuals who endure a spinal cord injury may differ based upon sex, age, culture, and level of injury. A study done by



Hsieh et al., (2013) identified varying therapy services and amount of services between older and younger adults. The oldest group (60+) received more therapy hours while in rehabilitation, had longer rehabilitation stays, and spent more time completing preparatory activities in OT compared to activities of daily living (ADL) therapy. These differences may exist because the older population needs to build strength before they can successfully work on functional activities like ADLs. However, the youngest group (16-29) received significantly more post-discharge therapy than the oldest group (Hsieh et al., 2013). The evidence regarding sex differences in usage of AT is equivocal. Monden et al., (2019) found that women with tetraplegia were almost twice as likely to use AT, but Rigby et al., (2011) found that men with tetraplegia were more likely to be AT users. Both studies included significantly more men than women which is representative of the population of those with tetraplegia resulting from SCI, but the small sample size of women in both studies could have skewed the results. Lastly, most studies available on assistive technology, independence in the home, and those with tetraplegia resulting from SCI are done in countries traditionally with a patriarchal culture. Common places for studies included the United States, Canada, and Australia (Etingen et al., 2018; Gottlieb et al., 2019; Hooper et al., 2018; Monden et al., 2019; Rigby et al., 2011). The patriarchal culture housed within these countries could contribute to the importance placed upon achieving greater independence for individuals with spinal cord injuries, especially due to the greater male injury prevalence.

Purpose Statement

Assistive technology is a broad and wide-reaching intervention. It is important for occupational therapy practitioners to be aware of the variety of technology available, potential barriers, and the scope of practice to better serve clients with tetraplegia. It is for this reason that a review of the current literature is necessary to determine what impact AT can have on clients with SCI.

Focused Question

What impact does assistive technology have on the ability to engage in meaningful occupations for adults with tetraplegia resulting from spinal cord injury within their home?

Methodology of Literature Search

The researchers used various combinations of search terms within CINAHL, PubMed, and Clinical Key databases when conducting the literature search. The search terms that were used in many different pairings included, spinal cord injury, environmental controls, assistive technology, home, rural, education, quality of life, tetraplegia, occupational therapy, and home safety. Articles were then screened for inclusion and exclusion criteria. Articles were included if they mentioned tetraplegia resulting from spinal cord injury, use of assistive technology, and occupational therapy. Articles must have been published in the English language. Periodicals published before 2015 were only included if, upon further examination, they included seminal information on the topic or provided evidence that was not available in an article published more recently. Articles were included regardless of sample size. However, if they had less than 20 subjects per condition as Lieberman and Scheer (2002) defines a small sample, it was noted as a limitation to the research rigor of the article. The literature was gathered February through April of 2020. A total of 33 articles were chosen for the final screening process and were examined based on the inclusion and exclusion criteria. Nineteen articles were excluded upon further review and a secondary search was completed to gather more information on the culture and



needs of this population, resulting in a final summation of 14 references to be used in the final literature review.

Methodological limitations of the current study include a narrow range of databases used to access information, an unsystematic way of searching and eliminating articles, and selection bias. Researchers used three databases when completing the literature review which limited the amount of information that was accessed and reviewed. Due to the unsystematic way the researchers conducted the literature search process, systematic error was not controlled for (MacDermid & Law, 2014). This unsystematic review of literature makes it more difficult to replicate and limits the amount of information accessed. Lastly, all researchers are occupational therapy students and included only articles pertaining to occupational therapy. Evidence from other disciplines were fully not explored; thus, information from other disciplines' perspectives regarding assistive technology and its impact on adults with tetraplegia resulting from SCI are missing from the current review. Some studies did, however, include perspectives from multiple disciplines, but the researchers search terms and selections did not reflect a multidisciplinary approach to reviewing literature (Gottlieb et al., 2019; Khan et al., 2019; Mortenson et al., 2019).

Articles included in the final literature review had some common limitations that is representative of the current state of evidence on this topic. Limitations within the sample included small sample sizes (Baldassin, Shimizu, & Fachin-Martins, 2018; Cohen & Schemm, 2007; Folan, Barclay, Cooper, & Robinson, 2015; Gottlieb et al., 2019; Mortenson et al., 2019; Myberg et al., 2017; Rigby et al., 2011; Verdonck et al., 2018; Verdonck et al., 2014), and samples collected from one facility (Folan et al., 2015; Gottlieb et al., 2019; Mortenson et al., 2019; Myberg et al., 2017).

Other limitations included samples collected from a few locations, primarily the United States, Canada, Australia and Switzerland (Etingen et al., 2018; Gottlieb et al., 2019; Hooper et al., 2018; Monden et al., 2019; Muller et al., 2017; Rigby et al., 2011,), and poor or non-existent operational definitions of assistive technology and tetraplegia (Baldassin et al., 2018) . There is also a lack of rigorous quantitative research surrounding the impact of assistive technology within the home. In terms of the levels of evidence, as defined by Lieberman and Scheer (2002), only three of the total articles included in this review were level III and above (Baldassin et al., 2018; Cohen & Schemm, 2007; Khan et al., 2019). Much of the current literature surrounding in-home AT interventions for individuals with tetraplegia is less rigorous quantitative, mixed methods, and qualitative studies; the total amount of each of these included in the final product include: (n=4) level IV, (n=5) level NA, and (n=1) mixed methods and (n=1) participatory action research. After fully reviewing all of the articles to be included in the final literature review, four main themes emerged: the independence AT granted, technological discouragement and suggestions for improvement, improved occupational engagement and quality of life resulting from AT utilization, and the importance of training.

Literature Synthesis

Impact of AT on Independence

The first theme identified was the impact AT had on improving the independence and feelings of independence for individuals with tetraplegia resulting from a SCI. Users of the various forms of AT and ECS reported that they felt less dependent on caregivers, the technology offered them a sense of freedom, and enabled them to complete tasks by themselves (Folan et al., 2015; Gottlieb et al., 2019; Hooper et al., 2018; Myberg et al., 2017; Verdonck et al., 2018). The



small functional gains the technology allowed—like being able to change the channel independently—returned some sense of normalcy to the individuals with tetraplegia resulting from SCI (Verdonck et al., 2018). Users also reported feelings of safety and tranquility because the AT granted them the ability to spend more time home alone without worry and it reduced the amount of time spent with a caregiver (Hooper et al., 2018; Myberg et al., 2017; Verdonck et al., 2018). This feeling of safety and empowerment was felt by users as they knew they could contact anyone using the AT device if there was an emergency, and it allowed them to have more financial independence through better utilization of paid caregiver time (Hooper et al., 2018; Verdonck et al., 2018). Much of the current research available on this topic was user experiences of AT and was qualitative in nature. One study included in this review was a quantitative study measuring functional independence after training individuals to use an exoskeleton; the study found that the wearable exoskeleton technology improved the skills needed for independence in the home for individuals with SCI (Khan et al., 2019). The current research supports the use of an AT occupational therapy intervention for SCI clients to increase their independence at home.

Technological Discouragement and Suggestions for Improvement

Another theme that was identified was technological discouragement and the suggestions for improvements. Users have become discouraged with the frustration of the technology itself, when the device isn't working properly, the process to complete the tasks was considered tedious, and it was often simpler to have the caregivers complete the simple tasks, such as turning on the TV (Myberg et al., 2017; Verdonck et al., 2014). Other discouragements for using AT included the cost of the device, cost of upkeep, and navigating the system to acquire the AT which is often difficult (Hooper et al., 2018; Verdonck et al., 2014). Users spend a lot of time learning how to use the device and there is a sense of lacking support around the device which creates a sense of discouragement in using the devices (Hooper et al., 2018). There were incidents when the device is frustrating to install, as well as low speed of the device (Hooper et al., 2018). When the device was not working, users reported experiencing feelings of “uselessness” and “frustration” (Myberg et al., 2017, p.132). With these discouragements there were suggestions for improvements of the devices. Suggestions for improvement included that the device should be user-friendly and compatible with a wide range of software and devices that access the internet (Gottlieb et al., 2019; Mortenson et al., 2019). Users have requested that the devices are also accessible when the user is sitting upright in a wheelchair, maneuverable so it allows individuals to change positions, and having the device small and aesthetically pleasing was important for individuals as it gave them a sense of “normalcy” (Gottlieb et al., 2019; Myberg et al., 2017, p. 133). Gottlieb et al., (2019) also found that AT used to operate computer systems should mainly be on a desktop. Suggestions also included that users would like their AT to further enable their independence by being expanded to perform more daily tasks, and the device needs to work simply and efficiently otherwise it isn't worth the hassle of using the device (Myberg et al., 2017; Rigby, Ryan & Campbell, 2011). Overall, the research shows that there are discouragements with use of AT, but there are also suggestions to better individuals' experiences with AT.

Improved Occupational Engagement and Quality of Life

Cohen & Schemm (2007) found that participants who received in-home occupational therapy services had significant increases in their quality of life (QOL) when compared to individuals who did not receive in-home OT services. It was stated in several articles that AT increased an individual's ability to participate in meaningful occupations by allowing them greater access to their devices (Baldassin et al., 2018; Hooper et al., 2018). With greater access



comes increased engagement in occupations (Baldassin et al., 2018; Folan et al., 2015; Hooper et al., 2018; Muller et al., 2017; Verdonck et al., 2018) and valued roles (Folan et al., 2015). This aligns with the Person-Environment-Occupational Model's description of how a person's life satisfaction depends upon the "fit" between the person, occupation, and environment (Law et al., 1996). Current literature continues to support this as many participants reported that their experiences were heavily impacted by their ability to engage in meaningful occupations and roles (Baldassin et al., 2018; Folan et al., 2015; Mortenson et al., 2019; Muller et al., 2017; Verdonck et al., 2014; Verdonck et al., 2018). Another important finding is that AT was beneficial for individuals in reducing social isolation and increasing their ability to independently communicate (Hooper et al., 2018; Mortenson et al., 2019). An important finding from Muller et al. (2017) was that individuals living with complete or incomplete tetraplegia for fewer than ten years found participation in occupations to act as a buffer for the negative effects of chronic pain on both mental health and QOL. This is important to consider when working with individuals with high level SCI and should be considered when deciding on appropriate intervention plans. In summation, the articles included in this report demonstrate that assistive technology increases occupational engagement and improves the user's quality of life.

Importance of Training

The last theme identified within the literature is the importance of thorough training when prescribing an AT intervention for a client. A survey done by Etingen et al. (2018) found that veterans who were hospitalized for a SCI emphasized the need for facilities to provide comprehensive training on ECUs and how to troubleshoot with the devices if problems arose. This can be translated into in-home services as well. A study done by Myberg et al. (2017) found that tetraplegic SCI patients recently discharged agreed that the training on AT was vital to their success for completing daily activities at home. While the participants in the Myberg et al. (2017) study did not agree on a time to introduce the AT training, the participants in Folan et al. (2015) found it vital to introduce the technology and start training early within in the recovery process. Occupational therapy practitioners should consider the needs and wants of their clients first before prescribing an AT intervention, but if one is decided on, the therapist should ensure an early start and thoroughness to training (Etingen et al., 2018; Folan et al., 2015; Myberg et al., 2017).

Summary of Literature Review

- Assistive technology has the capability to improve independence for tetraplegic users. The technology offered a sense of safety when caregivers were away, small functional gains that gave them autonomy, and created less dependence on caregivers.
- Although there are many things that make AT helpful to users, there were also aspects that caused frustration, such as some things were easier for the caregiver to complete, cost of the device and upkeep, and the device not working properly. There is also frustration around the sense of lack of support around using the device, and the training for the device. With the frustrations, came suggestions for improvement. Suggestions include being user-friendly, compatible with a wide range of software and devices, accessible when sitting up in a wheelchair, maneuverable, a smaller size to promote normalcy, being expanded to perform more daily tasks, and working simply and efficiently.
- Assistive technology helps to increase the independence and occupational engagement for individuals with tetraplegia. It was also determined that AT improves reported quality



of life and decreases self-reports of social isolation through increasing independent communication.

- Users of AT found it helpful to start training on the technology early and for the training to be comprehensive in nature so that the users could troubleshoot if problems arose.

Clinical Bottom Line

Injury to the vertebrae or spinal cord can result in a spinal cord injury (SCI); this type of injury can lead to a loss of motor and/or sensory function of the extremities. A subset of this population within this injury type, and one of the most common, is those with tetraplegia or those with loss of motor and/or sensory loss in the upper and lower extremities (Atrice et al., 2020, NSCISC, 2020). Clients with tetraplegia resulting from spinal cord injury are a population that Occupational Therapy (OT) commonly serves. Although OT services have been shown to be valuable when provided in the home for clients with tetraplegia resulting from SCI, the research on the use of assistive technology (AT) as an intervention for this population is wide reaching and diverse (Cohen & Schemm, 2007). The researchers compiled current evidence to identify the impact assistive technology had on the ability to engage in occupations in adults with tetraplegia resulting from SCI. This information provided in this article is beneficial for a variety of stakeholders and team members, including but not limited to, behavioral aids, caregivers, nursing staff, physicians, assistive technology inventors, individuals living with tetraplegia, occupational therapists and assistants, and any other persons interested in learning about the benefits, drawbacks, and usefulness of assistive technology.

The current state of research on AT interventions specific to occupational therapy, this population, and in-home services is discussed further here. Current research supports the use of an AT occupational therapy intervention for SCI clients to increase their independence in their home (Folan, 2015; Gottlieb et al., 2019; Hooper et al., 2018; Khan et al., 2019; Myberg et al., 2017; Verdonck et al., 2018). Overall, the research shows that there are discouragements with use of AT, but there are also suggestions to better individuals' experiences with AT (Folan, 2015; Gottlieb et al., 2019; Hooper et al., 2018; Mortenson et al., 2019; Myberg et al., 2017; Rigby et al., 2011; Verdonck et al., 2014). The articles included in this report demonstrate that assistive technology increases occupational engagement and improves the user's quality of life (Baldassin, 2018; Folan, 2015; Hooper et al., 2018; Mortenson et al., 2019; Muller et al., 2017; Rigby et al., 2011; Verdonck et al., 2018; Verdonck et al., 2014). Occupational therapy practitioners should consider the needs and wants of their clients first before prescribing an AT intervention, but if one is decided on, the therapist should ensure an early start and thoroughness to training to improve the individuals' user experience (Etingen et al., 2018; Folan et al., 2015; Myberg et al., 2017).

Although the current findings provide a lot of valuable information, there are aspects of research that are still missing. There is limited research regarding rural populations and how AT can benefit them, or if AT is accessible to individuals who are in rural areas. There is also limited research about AT in many countries around the world. Most of the research that was found is based out of the United States, Canada, Australia, and Switzerland (Etingen et al., 2018; Gottlieb et al., 2019; Hooper et al., 2018; Monden et al., 2019; Muller et al., 2017; Rigby et al., 2011). There was a small sample size in many of the studies that were reviewed because of availability to the population; therefore, future research needs larger sample sizes for increased statistical power and population applicability (Baldassin et al., 2018; Cohen & Schemm, 2007; Folan et al., 2015; Gottlieb et al., 2019; Mortenson et al., 2019; Myberg et al., 2017; Rigby et al.,



2011; Verdonck et al., 2018; Verdonck et al., 2014). The current state of research on this topic include levels of evidence that are lower on Lieberman and Scheer's (2002) level of evidence pyramid. Of the fourteen articles included in this review, only three were at or above a classification of level III (Lieberman & Scheer, 2002). Most of the research included (n=11) was of lower quantitative rigor or qualitative in nature. Directions for future research should be directed towards more quantitative implementations, using more rigorous study designs, of AT interventions for adults with tetraplegia resulting from SCI.

Recommendations

Occupational therapists. Assistive Technology can be beneficial for clients with tetraplegia in increasing their engagement in meaningful occupations (Baldassin et al., 2018; Folan et al., 2015; Hooper et al., 2018; Muller et al., 2017; Verdonck et al., 2018) and valued roles (Folan et al., 2015) which is believed to improve the "fit" between the person, occupation, and environment to better the overall life satisfaction (Law et al., 1996). There are discrepancies based on user reports of when the best time to begin training for AT use and usefulness of the device when compared to caregiver support so this should be discussed with the individual (Myberg et al., 2017; Folan et al., 2015; Verdonck et al., 2014).

Assistive technology users. The researchers suggest that the utilization of assistive technology shortly after a spinal cord injury is beneficial for increasing engagement in meaningful occupations, valued roles, and independence needed to be alone for periods of time (Folan et al., 2015; Gottlieb et al., 2019; Hooper et al., 2018; Myberg et al., 2017; Verdonck et al., 2018). Technology users did experience frustrations while using the AT, but overall, the increased independence and freedom was important to the participants (Folan et al., 2015; Gottlieb et al., 2019; Hooper et al., 2018; Myberg et al., 2017; Verdonck et al., 2018). It will be extremely important to self-advocate in order to have the AT setup to meet their needs and to make adjusts as needed for optimal occupational performance.

Innovators of assistive technology. There are many frustrations that have been reported from AT users. Some of these frustrations include inefficiency of the technology such as low speeds or being difficult or impossible to maneuver, high costs both upfront and in long-term maintenance, inadequate training and continued support, and feelings of "uselessness" when the technology malfunctions or breaks (Hooper et al., 2018; Myberg et al., 2017, p. 132; Verdonck et al., 2014). Suggestions for future improvements included making the technology more user friendly and efficient and increasing the compatibility with a wider array of products to allow for more daily tasks to be completed (Gottlieb et al., 2019; Mortenson et al., 2019). AT users emphasized how important it was for them to be able to complete tasks simply and efficiently, otherwise it was easier to ask a caregiver to complete the task for them (Myberg et al., 2017; Rigby, Ryan & Campbell, 2011).



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