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Voices from the Field

Benefits of Smart Home Technology for Individuals Living with Amyotrophic Lateral Sclerosis

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ABSTRACT

In this information age, smart home technology has become a familiar tool to enhance communication and control home-based electronic devices. For those living with disabilities, however, smart home devices fall into the broader category of assistive technology. Smart home devices provide end-users multiple methods with which they can interact with others inside and outside of the home environment. The emergence of this technology has been of widespread interest to the disability community. Recent efforts have been made to introduce smart home technology to the Amyotrophic Lateral Sclerosis (ALS) community by a local chapter of the ALS Association to enable communication and alternative access to electronics within the home environment. A pilot program was implemented and outcome data was collected in an attempt to establish a nexus between smart home technology use and the impact of that use on occupational performance.

Keywords: assistive technology, occupational performance

TARGET AUDIENCE

Amyotrophic Lateral Sclerosis (ALS), commonly referred to as Lou Gehrig's Disease or Motor Neuron Disease (MND), is a progressive and fatal neurodegenerative disease affecting motor neurons in the brain and spinal cord (ALS Association, 2017a). The deterioration of motor neurons eventually leads to neuronal death, and thus inhibits the brain's ability to control muscle movement (ALS Association, 2017a). Symptom onset and rate of disease progression varies (ALS Association, 2017b). ALS adversely impacts voluntary muscle control, taking away one's ability to move, communicate, and eventually, breathe (ALS Association, 2017b). The lifespan from the time of diagnosis until death is typically between two and five years (ALS Association, 2017b).

Due to the progressive nature of ALS, frequent and ongoing adaptations are required to enhance an individual's ability to manage the disease and to enable function (Soofi et al., 2017). With ALS, there is no cure, muscle deterioration is inevitable, and complete physical independence, once lost, cannot be restored. Through this progression, assistive technology devices may be introduced as a way to compensate for functional deficits. By educating and training individuals about the benefits of assistive technology, therapists can help individuals explore and adapt to a new and different way.

RELEVANCE

The Assistive Technology Act of 2004 defines assistive technology as "any item, piece of equipment, or product system, whether acquired commercially off-the-shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities" (29 U.S.C. § 2202). The intended use of assistive technology is to optimize performance and enable individuals living with disabilities to reclaim life roles (American Occupational Therapy Association, 1998). Lahm and Sizemore (2001) suggest that assistive technology can bridge the gap between environmental demands and an individual's capacity. Smart home devices can be used widely as a form of assistive technology, given their potential to remove barriers and enhance performance (Gentry, 2009).

Due to their degree of sociability, ease of integration, affordability, and reliability, smart home products have grown in popularity and adoption continues to accelerate (Purington et al., 2018). By default, many smart home devices are universally designed and can work with people of all abilities to help maximize participation. These devices follow several principles of universal design including: equitable use; flexibility; and minimal deployment effort (Center for Universal Design at the University of North Carolina, 2008). Commensurate with the principals of universal design, smart home technology provides individuals with disabilities greater access to mainstream technology and new ways to communicate and maintain autonomy and control (Pradhan et al., 2018; Schulz et al., 2014).

Smart home devices are connected to an in-home network and enable remote control of select electronics based upon end-user preference (Wilson et al., 2016). Smart speakers, from Amazon, Google, or Apple, are among the most popular mainstream devices in this category and can serve as voice-activated environmental controls. Embedded speech recognition software, otherwise known as a digital assistant, allows for a high degree of customization (Purington et al., 2018). Personalized skills can be created by setting up voice profiles and developing routines, reminders, or blueprints. Collectively, smart speaker devices are readily paired with other smart devices to allow for greater connectivity and functionality in the home environment. In this regard, they provide alternative methods for controlling small appliances, lights, or even a television.

The ALS Association of Minnesota, North Dakota, and South Dakota manages a communication and assistive technology program. This multifaceted program provides complementary adaptive equipment and select technical support services to those living with ALS. In an attempt to embrace innovation and potentially enhance quality of life, the chapter elected to start a smart home pilot program. To optimize integration, the program included: provision of equipment, training and education, and technical support. Referrals for program participation came directly from speech or occupational therapists following individual quarterly multidisciplinary clinic visits. Subsequent screening to assess access, technological comfort level, and user preference, and to provide education about device functionality, was completed by the ALS Association staff occupational therapist. Prerequisites for participation were minimal, and included possession of an existing smartphone or tablet device along with Wi-Fi/internet within the home. Those with documented cognitive impairments, such as frontotemporal dementia (FTD), were excluded. Devices supplied by the ALS Association included: one smart speaker (Amazon Echo Plus); two remote smart speakers (Amazon Echo Dot); two smart plugs (TP Link); three light bulbs (Phillips Hue); and one optional smart home entertainment unit (Harmony Hub or Amazon Fire Cube). These smart home devices were selected for program integration because they were perceived to have the greatest potential to enhance one's ability to complete practical and meaningful activities within the home environment, and to enhance occupational performance (American Occupational Therapy Association, 2016).

In addition to receiving the aforementioned suite of smart home devices, all participants were provided technical assistance from the Best Buy Geek Squad for installation and training. Funding and third-party referrals were managed by the ALS Association. Despite variation in training procedures, collaboration with a national electronics retailer with a large geographical footprint provided a mechanism to reach smart home program participants in the tristate area. While installation of commercially available smart home technology, such as the smart speaker, is relatively simple, it was recognized that installation of a smart home entertainment unit requires greater technical expertise. Technical support and training was offered by the retailer in an effort to reduce or eliminate barriers to usage.

After one year, the smart home pilot acquired a total of 36 users. This group represented individuals with a probable or confirmed diagnosis of ALS, willing to try a novel tool with potential to improve autonomy. Subsequently, in an attempt to determine impact, a survey was developed and IRB approval obtained. Surveys were then distributed initially via email with follow up via standard mail; participation was entirely voluntary. Of the 36 individuals originally identified for participation, 19 individuals (12 males and 7 females) completed the survey. The survey collected information on participant demographics, usage, access methods, and overall impact on occupational performance. Questions on socioeconomic status and education level were not included.

According to results, 47% of participants had been living with ALS for 2–3 years, 21% of participants had been living with ALS for 1–2 years, 16% less than one year, and 16% more than three years. Ages ranged from 28 to 86 and were fairly evenly distributed. Two participants were between ages 18–36, five participants were between 36–50, six were between 51–65, and six participants were over the age of 65. All individuals included in this particular sample had spinal or limb-onset ALS. In total, eligible participants represented those living with ALS in three different states, attending eight unique multidisciplinary clinics. Despite the relatively small response, participants were representative of a large geographic area.

OUTCOMES AND BENEFITS

Survey results revealed that all participants used their smart home technology devices daily. Majority (58%) of respondents accessed devices via voice versus 37% respondents using touch as a method of direct selection. Only a single participant reported using mixed access methods of both touch and voice. Of the 19 participants, 18 reported that the use of smart home technology gave them greater control of electronics in their home environment. A majority of participants (89%) reported that the use of smart home technology allowed them to regain some functional independence in their home environment. One respondent commented, "now I don't have to struggle with things like switches or dials." With respect to functional independence, over half of the participants (63%) felt that smart home technology had given them ability to complete tasks that they had lost the ability to complete. A program participant reported, "I don't have to depend on someone else to do another thing for me. I feel that I can do some things for myself. It is very important to feel like you're not being a burden." Another participant reported, "nothing is so frustrating as to not be able to do something that you've spent your entire life doing and not even thinking about it, or have to ask someone else to do these simple things for you (i.e., turning on and off lights). Smart home technology makes this possible, thus ending a lot of problems for me and my caretaker."

Findings revealed that participants used smart home devices for a wide range of tasks including: recreation and leisure (e.g., games and music); gathering information; communicating with others, both inside and outside the home; and completing home management activities (e.g., shopping, setting up routines, and calendar management). This technology allowed individuals to circumvent physical and environmental barriers, to embrace ability rather than disability, and to become more engaged in daily occupation (American Occupational Therapy Association, 2016). A participant reported "using this technology makes it possible for me to do things without having to struggle to do them and it makes a very big difference in my life." Users recognized that integration of this technology into daily routines provided a mechanism or tool to aid in participation of meaningful activities. Another participant reported, "any bit of independence that is restored is greatly appreciated as I become more and more unable to do things for myself. It has helped me feel less depressed." Participant input suggested that this technology might also support well-being, as evidenced by reported improved sense of safety, work simplification, and energy conservation. These users reported, "it makes things much easier, safer, and saves my energy" and "makes for more efficient living." Of the 19 participants, 18 reported having a positive experience with the integration of smart home technology into their daily routines (one neutral experience was noted). Users' acceptance of this technology implies that benefits outweighed potential risks (e.g., security and privacy; Wilson et al., 2016). Participant feedback on usefulness and satisfaction suggests that the suite of smart home devices provided, in combination with training and support, struck the right balance of device complexity and user capability, providing an experience that was empowering (Wilson et al., 2015).

CONCLUSION

According to this survey, findings revealed that both males and females living with ALS readily embraced smart home technology as a form of assistive technology to support occupational performance in the home environment. Participants found smart home technology useful at different ages and stages of disease progression. It is believed that multiple access methods allow for adaptability and prolonged usefulness of smart home devices. Intermittent assessment and adaptation is recommended to accommodate for gradual loss of function (including speech) over time. In this program evaluation, individuals living with ALS used several smart home devices to complete tasks with modified independence that perhaps they would not have been able to control due to their decreased level of function. Smart home devices removed barriers, enabling individuals to become actively involved in daily activities.

The smart home devices provided to this group offer a cost-effective method to support individuals with ALS in their home environment. This technology can enhance functional communication and offers opportunities to foster independence and control of the home environment (despite disease progression) and may also be used similarly for those living with other mobility or communication impairments. While more research is needed to determine the impact of smart home technology on one's emotional and physical well-being, there is indication of value. In a society in which technology is embedded in nearly all aspects of human occupation, it is critical that mainstream technology is explored and appropriately integrated.

DECLARATIONS

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REFERENCES

ALS Association (2017a). *What is ALS?* http://www.alsa.org/about-als/what-is-als.html

ALS Association (2017b). *Symptoms and Diagnosis*. http://www.alsa.org/about-als/symptoms.html

American Occupational Therapy Association (2016). Assistive technology and occupational performance. *American Journal of Occupational Therapy*, *70*, 7012410030p1-7012410030p9. https://doi.org/10.5014/ajot.2016.706S02

American Occupational Therapy Association. (1998). The use of general information and assistive technology within occupational therapy practice. *American Journal of Occupational Therapy, 52*(10), 870–871. https://ajot.aota.org/article.aspx?articleid=1862622

Assistive Technology Act of 2004, Pub. L. 118 29 U.S.C § 3001 *et seq.* (2004). https://www.govinfo.gov/content/pkg/PLAW-108publ364/html/PLAW-108publ364.htm

Center for Universal Design at the University of North Carolina (2008). Principles of universal design. https://projects.ncsu.edu/design/cud/about_ud/udprinciples.htm

Gentry, T. (2009). Smart homes for people with neurological disability: State of the art. *Neurorehabilitation, 25*(3), 209–217. https://doi.org/10.3233/NRE-2009-0517

Lahm, E. & Sizemore, L. (2001). Factors that influence assistive technology decision making. *Journal of Special Education Technology*, *17*(1), 15-26. https://doi.org/10.1177/016264340201700102

Pradhan, A., Melta, K., & Finlater, L. (2018). *Accessibility came by accident: Use of voice-controlled intelligent personal assistants by people with disabilities* [Paper Presentation]. Conference on Human Factors in Computing Systems, Montreal QC, Canada. https://dl.acm.org/doi/10.1145/3173574.3174033

Purington, A., Taft, J. G., Sannon, S., Bazarova, N. N., and Taylor, S. H. (2018). Alexa is my new BFF: Social roles, user satisfaction, and personification of the Amazon Echo. *CHI Conference Extended Abstracts on Human Factors in Computing Systems* (pp. 2853–2859). Association for Computing Machinery. https://doi.org/10.1145/3027063.3053246.

Schulz, T., Fuglerud, K. S., Arfwedson, H., & Busch, M. (2014). A case study for universal design in the internet of things. *Universal Design Conference, Assistive Technology Research Series* (pp. 45-54). IOS Press. https://doi.org/10.3233/978-1-61499-403-9-45

Smith, R. O. (2017). Technology and occupation: Past, present and the next 100 years of practice. *American Journal of Occupational Therapy, 71*(6), 7106150010p1-7106150010p15. https://doi.org/10.5014/ajot.2017.716003

Soofi, A., Bello-Haas, V., Kho, M. E., & Letts, L. (2017). The impact of rehabilitative interventions on quality of life: A qualitative evidence synthesis of personal experiences of individuals with Amyotrophic Lateral Sclerosis. *Quality of Life Research, 27*, 845–856. https://doi.org/10.1007/s11136-017-1754-7

Wilson, C., Hargreaves, T., & Hauxwell-Baldwin, R. (2016). Benefits and risks of smart home technologies. *Energy Policy*, *103,* 72–83, https://doi.org/10.1016/j.enpol.2016.12.047

Wilson, C., Hargreaves, T., & Hauxwell-Baldwin, R. (2015). Smart homes and their users: A systematic analysis and key challenges. *Personal and Ubiquitous Computing, 19*(2), 463–476. https://doi.org/10.1007/s00779-014-0813-0.