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The Effectiveness of an Educational Video Intervention for People with Amyotrophic Lateral Sclerosis Prior to Power Wheelchair Evaluations

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Abstract

PURPOSE: Amyotrophic Lateral Sclerosis (ALS) is a neurodegenerative disease that ultimately requires a power wheelchair (PWC) as the main source of mobility. The purpose of this project was to determine the effectiveness of an educational video to prepare a client for a PWC assessment by addressing four themes: PWC features, home environment, transportation, and client self-efficacy.

METHODS: An educational video was created and used in an ALS Multidisciplinary Clinic to better prepare clients for the PWC evaluation process. The effectiveness of this video was measured using a seven-question Likert scale survey focusing on the themes of the video. Individuals living with ALS answered the survey before and after viewing the video, and gave feedback regarding the video prior to their PWC evaluation.

RESULTS: Following the video intervention, Wilcoxon signed-rank analyses showed there was significant improvement across all four themes: improved knowledge of PWC features ($p < .001$), improved understanding of transportation options ($p = .017$), improved understanding of potential home modification needs ($p = .027$), and improved feelings of self-efficacy in the PWC process ($p = .001$). Each theme had a mean increase of three or more points following the video, and Cohen's d effect sizes were large for all four themes.

CONCLUSIONS: This study demonstrates the effectiveness of the educational video intervention in improving the knowledge and understanding of the PWC evaluation process for individuals living with ALS. Increased knowledge and feelings of empowerment could lead to improved acceptance and usage of a PWC, and enhanced quality of life.

Keywords

Amyotrophic Lateral Sclerosis (ALS), power wheelchair (PWC), video, patient education

Cover Page Footnote

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Introduction

Amyotrophic Lateral Sclerosis (ALS) is a fatal neurodegenerative disease which leads to the death of motor neurons in the brain and spinal cord, leading to paralysis and loss of function (ALS Association, 2020; Jaffa et al., 2017). Access to medical care, assistive technology (AT), and skilled rehabilitative services are essential for this vulnerable population. As the disease progresses, individuals living with ALS require increasing assistance in the form of caregivers and adaptable AT, especially a custom power wheelchair (PWC) (ALS Association, 2020; Ward et al., 2010). Individuals living with ALS typically receive treatment and PWC evaluations at specialized ALS multidisciplinary clinics (MDCs) (Arbesman & Shear, 2014; Hogden et al., 2013; Lewis & Rushana, 2007). The average life expectancy for persons with this diagnosis is three to five years after initial onset of symptoms (Kehyayan et al., 2014). In the United States, individuals living with ALS qualify for Medicare, which will cover the cost of only one PWC every five years. As a result, it is imperative that individuals with ALS choose a PWC that will meet their changing needs (ASL Association, 2020).

While ALS is a rare disease, current research confirms that the incidence of ALS is rising (Longinetti & Fang, 2019). It is predicted that by 2040, worldwide cases will increase by almost 70% (Arthur et al., 2016). This highlights a growing need for consumer-friendly ALS education, particularly in the area of assistive technology. PWCs have been shown to have a positive

impact on feelings of competence and self-esteem (Pousada et al., 2021), as well as improving the amount of participation in home and community-based activities (Ward et al, 2009; Arbesman & Shear, 2014). In addition to improving mobility and participation, a PWC equipped with features to support individuals with ALS can promote postural alignment, aid in transfers, help control edema, prevent respiratory infection, and decrease the risk of joint contracture or the development of pressure ulcers (Ward et al, 2009; Dicianno et al., 2015; Paganoni et al., 2015).

Individuals living with ALS spend an average of ten hours per day in their custom PWC, making it imperative that the PWC is outfitted with features that will meet their progressive needs (Sonenblum et al., 2008; Ward et al., 2015). Navigating PWC feature selection can be difficult and emotionally charged as decisions must be made regarding wheelchair selection before the client will become reliant on it (Hogden et al., 2013). Therefore, there is a need for accessible education resources to help support individuals living with ALS as they prepare for a wheelchair evaluation.

The process of receiving a custom PWC begins with a wheelchair evaluation involving numerous health care providers, including a physician, occupational therapists, physical therapists, and assistive technology professionals (ATPs). These healthcare professionals will ideally work with the client to customize a PWC that will meet their individual needs and is frequently completed in an ALS-specific MDC (Ward et al., 2010; Lewis & Rushana, 2007; Dicianno et al., 2015; Garcia et al., 2015). The following are PWC features typically prescribed for persons with ALS: tilt in space, elevating leg rests, adjustable headrest, recline, and controls that can be adapted over time (i.e. joy stick, sip and puff, head control, foot control). However, there are features that may be selected based on personal preference (Ward et al., 2010; Dicianno et al., 2015; Ward et al., 2015; Schiappa et al., 2019; Trail et al., 2001). These include

color, power seat elevation, the choice between front and mid-wheel drive options, and padding for armrests.

When preparing individuals living with ALS for a PWC evaluation, timing is everything; acquiring a PWC too early may interfere with maintenance of gait function, while obtaining one too late could result in decreased participation and may have a detrimental effect on the client's mental health (Hogden et al., 2013; Trail et al., 20001). The time frame for a wheelchair evaluation is complicated by the variable progression of the disease (Arbesman & Shear, 2014; Hogdent et al., 2013). The wait time to receive a PWC following a wheelchair evaluation can be as long as four months (Ward et al., 2015). While there is no "one size fits all policy" for power mobility solutions for individuals living with ALS, proper timing of a PWC evaluation involves clinical judgement of a qualified practitioner, who also needs to decide how to best introduce the PWC process to the client (Ward et al., 2015; Rolfe, 2012).

In their scoping review of use of video as an educational tool to empower persons living with chronic conditions, Navarro et al., found that video is effective and well received by patients (Navarro et al., 2021). They also found that use of video improved patient knowledge, adherence to treatment, and feelings of self-efficacy (Navarro et al., 2021. Use of video can improve in-person discussions between patients and medical professionals, leading to outcomes that are more productive and client centered (El-Jawahri et al., 2016). Though no video resources specific to persons with ALS were found in the literature, we hypothesize that a video resource will aid in the understanding of the long-term effects of ALS, including the potential need for future home and vehicle modifications. In order to prepare individuals living with ALS for a PWC evaluation, a high-quality video resource was created to address common themes in PWC selection. This video was produced by occupational therapy students and faculty at Louisiana State University Health Sciences Center-New Orleans (LSUHSC-N.O.) and is not connected with any wheelchair vendor or brand (Vance et al., 2021).

The purpose of our video is to provide an evidence-based, consumer-friendly, and independent resource to educate individuals living with ALS to make informed decisions during the PWC selection process (Vance et al., 2021).The purpose of this study was to determine if our video resource effectively educated clients with ALS on PWC considerations and features, as well as whether it made them feel more prepared for their PWC evaluation.

Methods

Research Design

Our prospective pilot study used a pre and post intervention survey design. This design allowed us to answer our research question regarding the effectiveness of the educational video. Institutional Review Board approval and waiver of consent from LSUHSC-N.O. was obtained.

Participants

All participants were adults living with ALS who had not yet received a PWC evaluation and who attended the New Orleans ALS MDC. Participants were selected via convenience sampling from the ALS MDC. Inclusion criteria for potential participants were: a diagnosis of ALS, intact cognition, English or Spanish language proficiency, and the ability to communicate survey responses. Individuals with ALS who had already received a PWC evaluation or were already PWC users were excluded from the study.

Intervention

A pilot video was created in 2018 by a group of Masters of Occupational Therapy students and the principle investigator (PI). To inform content of the video, ten stakeholders and experts were interviewed, and their responses were coded using thematic analysis. These stakeholders consisted of two PWC users living with ALS, three caregivers of persons living with

ALS, two Assistive Technology Professionals (ATP), two occupational therapists (OT), and one physical therapist. Four themes were identified: environment, PWC components, self-advocacy, and transportation. These themes were used to guide the creation of the video resource. The draft video was sent to the stakeholders for feedback, resulting in a revised script used to create a final professional quality video resource (Vance et al., 2021). The five-minute-long video addresses PWC features, home and transportation modifications, and encourages self-advocacy. Final content of the video was validated by two experts in the field; a licensed OT who is also a certified ATP, and a second certified ATP. A Spanish language version was created, and the video resources were provided to the local ALS MDC via this YouTube link: https://www.youtube.com/watch?v=e0G584pwE1Q.

Measurement Instrument

A seven-item Familiarity Scale survey was created in both English and Spanish to assess change in client familiarity with PWC features following the video intervention (Figure 1). The survey questions covered content seen in the video and was constructed using person-centered language to match the major themes identified by the thematic analysis used for the video's creation. In order to obtain reliable comparison results between the surveys, the survey was scored with a ten-point Likert scale (Taherdoost, 2019), with one defined as 'not at all familiar' and ten as 'extremely familiar.' There was also one open-ended question, "Did you find this video helpful in better understanding the power wheelchair selection process? (Y/N) Please explain/describe".

Figure 1

Pre and Post Familiarity Scale Survey

FAMILIARITY SCALE									
Not familiar at all		Slightly familiar		Moderately familiar		Very familiar			Extremely familiar
1	2	3	4	5	6	7	8	9	10

1. How familiar are you with different seating features in power wheelchairs like recline, tilt & power elevating legs? _____
2. How familiar are you with the purpose of power seat elevation in a power wheelchair? _____
3. How aware are you of any home changes needed to make room for a power wheelchair? _____
4. How well do you understand power wheelchair drive controls? This includes joystick, head array, and attendant controls. _____
5. How familiar are you with transportation options for your power wheelchair? _____
6. How familiar are you in knowing the differences between front-wheel drive base and mid-wheel drive base? _____
7. How well do you understand your rights when choosing custom wheelchair features? _____

Appropriate ALS patients were selected by the occupational therapist on staff at the local ALS MDC. The clients completed the pre-video Familiarity Survey, watched the video with the occupational therapist, and then completed the post-video Familiarity Survey. The average amount of time required to watch the video and take both surveys was 10 minutes.

Data Collection Procedures

Data collection began in January of 2020 and ended in April of 2021. No personal identifiers or private health information were collected. Optional identifiers (e.g. age, time since diagnosis) were collected to prevent sampling error but did not impact results.

Data Analysis

Study data were analyzed with IBM SPSS Statistics (Version 25; IBM Corp., Armonk, NY). Descriptive analyses were conducted in addition to nonparametric Wilcoxon signed-rank tests. The magnitude of change was determined with Cohen's *d* effect size calculations. Effect sizes were interpreted as follows: .10 = small effect size, .30 = medium effect size, .50 = large effect size (Field, 2013).

Results

Seven persons with ALS who met the inclusion criteria watched the video and completed the pre and post survey. Five were female and two male, with an average age of 63.4 years. The majority had a family member or other caregiver with them who also watched the video and who supported the participant in communicating responses to the survey questions.

The survey results were analyzed by question (Table 1), and according to the four themes of self-efficacy, familiarity, transportation, and environment.

Table 1

Pre and Post Video Rating Scores Mean and Significance

Question Number	Question Theme	Pre-Video Rating *N* = 7		Post-Video Rating *N* = 7		*P* Value
		M	**SD**	**M**	**SD**	
1	Self-Efficacy	2.86	3.29	6.57	2.70	.027
2	PWC Components	3.29	2.93	7.14	2.67	.018
3	Environment	5.00	3.06	7.71	1.60	.027
4	PWC Components	3.14	2.61	7.00	2.52	.018
5	Transportation	2.29	2.63	6.14	2.73	.017
6	PWC Components	1.43	.79	5.0	2.38	.017
7	Self-Efficacy	1.14	.38	5.86	2.34	.017

Self-Efficacy

The rates of self-efficacy in the PWC evaluation process improved significantly after viewing the video, $X^2(3) = 16.11$, $p = .001$. There were large effect sizes for both the rates of understanding the need for a PWC evaluation ($T = 21$, $r = .59$), and familiarity with their own role in the process ($T = 28$, $r = .64$). This theme was aptly illustrated by one of the patient's caregivers, "Very well done and informative. Know more now than we did. With his situation, he can still get around in the home, but know he is going to need it soon."

Familiarity with PWC Component Options

The rates of familiarity of PWC component options improved significantly after viewing the video, $X^2(5) = 28.07$, $p < .001$. There were large effects sizes for all three questions related to this theme: familiarity with seating options ($T = 28$, $r = .63$), familiarity with drive controls ($T = 28$, $r = .63$), and familiarity with drive base options ($T = 28$, $r = .64$). Illustrating this theme, one patient stated, "I didn't know they had so many options, I just knew about the standard joystick." Illustrating both this theme, and self-efficacy, another caregiver stated, "The explanation of front/mid was good, mentioning size was good, knowing rights and that she has a choice."

Transportation

The rates of familiarity of transportation options for a PWC (i.e., van, lift, etc.), improved significantly after viewing the video (*Mdn* = 6) as compared to before (*Mdn* = 1), and demonstrated a large effect size, $T = 28$, $p = .017$, $r = .638$.

Environment

The level of understanding of home modifications necessary to accommodate a PWC improved significantly after viewing the video (*Mdn* = 8) as compared to before (*Mdn* = 5), and demonstrated a large effect size, $T = 21$, $p = .027$, $r = .59$. After viewing the video, one caregiver

explained that their current apartment will not accommodate a PWC through the entrance. They realized that they will need to make arrangements to find a new apartment or consider an institution that specializes in care for individuals living with ALS.

Discussion

This project was undertaken to determine the efficacy of an educational video when persons with ALS are preparing for their PWC evaluation. To determine this, a pre and post survey was created and administered. The results showed that the video intervention prior to a PWC evaluation was effective in improving consumer knowledge of wheelchair features, environmental and transportation modifications, and client autonomy. Overall knowledge of the PWC selection process improved by an average of 3.75 points on the familiarity scale after watching the video; this improvement was statistically significant.

Our results mirror the Snyder-Ramos et. al study that demonstrated the effectiveness of using videos to educate and improve knowledge gain of clients prior to making decisions about their personal healthcare (Snyder-Ramos et al., 2005). They are also similar to the improvements in self-efficacy and knowledge found in several studies in Navarro's scoping review of video education with persons with chronic conditions (Navarro et al., 2021).

Though client-centered care in which the patient's opinion is solicited and respected is frequently referenced in healthcare literature, in the context of an ALS MDC, in which there are multiple medical professionals, there is always a risk that the client is not fully heard. In Pousada's study of the outcome of assistive technology procurement for persons with ALS, it was determined that when the client's opinion was solicited and respected, the outcomes for feelings of competence, adaptability, and self-efficacy regarding the PWC or other assistive technology (AT) was improved (Pousada et al., 2021). In their study, an occupational therapist interviewed each client to obtain their concerns and goals regarding AT. Pousada's results

reflect the results of this study, in that our five-minute video significantly improved the feelings of self-efficacy amongst persons with ALS and their caregivers in regard to their role in the PWC procurement process. This could lead to improved usage of the PWC when it becomes available for the clients.

Limitations

The main limitation of the study was the low number of participants. ALS is a rare disease and due to the fear, anxiety, and depression related to this diagnosis, finding the ideal participant who is ready to watch a video of this nature made it difficult to find appropriate participants. There is a need for further research on video effectiveness on a larger scale, especially as healthcare continues to make use of the digital setting.

Conclusion

This study shows that the educational video created by LSUHSC-New Orleans's Department of Occupational Therapy is effective at improving the knowledge and understanding of the PWC evaluation process, including PWC features, modifications to environment, and client autonomy, for individuals with ALS. Increased knowledge and feelings of empowerment could lead to improved acceptance and usage of a PWC, and enhanced quality of life. The video is appropriate to distribute as an additional resource for MDCs and individual occupational therapists who treat persons living with ALS.

Implications for Rehabilitation

- The PWC assessment process should ideally begin early in the course of the disease in persons with ALS.

- Our free user-friendly video resource is designed to facilitate dialogue between the person with ALS and the medical professionals involved in the PWC assessment process.
- The video has been shown to improve understanding of important aspects of PWC selection and feelings of self-efficacy in persons with ALS, regarding the PWC assessment process.

Declaration of Interest Statement

There are no conflicts of interest. There were no external sources of funding.

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