Critical Review:
Do eye-tracking communication devices improve quality of life for people with amyotrophic lateral sclerosis?

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This review examined the published evidence regarding the impact of an eye-tracking communication device on quality of life in Amyotrophic Lateral Sclerosis (ALS). A literature search using computerized databases was completed resulting in five articles meeting the inclusion criteria. Study designs include: Mixed Randomized Clinical Trails, Mixed Non-Randomized Clinical Trials, and Within Groups (Repeated Measures) designs. The articles were evaluated using a critical appraisal template and examined level of evidence, validity, and importance of the information included in the article. Overall, the research is suggestive that eye-tracking communication devices have a significant and positive impact on quality of life in ALS patients, however further research is suggested. Recommendations for future research are provided.

Introduction

Amyotrophic Lateral Sclerosis (ALS) is a devastating neurodegenerative disease that the World Health Organization recognizes as one of the most important and challenging human diseases of the twenty-first century. It typically progresses into quadriplegia and results in respiratory failure 3-5 years after diagnosis (Hwang, Wong, Wang, Tsai & Chang, 2014). Without the ability to move, many patients experience obstacles to both oral and limb-based modes of communication, which can lead to emotional distress and mental illness when needs cannot be expressed. “Communication has been rated by ALS patients as a key domain for their independence” (Londral, 2015).

Fortunately, many ALS patients that present with quadriplegia retain control of their eye movements for a long period of time, which allows for an alternative method of communication (Hwang et al., 2014). To date, late stage interventions for people with ALS have typically focused on support of vital functions, however, attention is beginning to shift towards enabling the best possible communication as an essential component of human life (Caligari, Godi & Guglielmetti, 2013). Many assistive devices require the caregiver to translate the needs of the patient, making them undesirable as they are inconvenient and time-consuming. Eye tracking communication devices track the pupil of the eye to control a computer, allowing patients to communicate without the assistance of a caregiver (Hwang et al, 2014). Despite an increased interest in eye-tracking software, few studies have analyzed the advantages of commercially available devices on quality of life in ALS patients.

“The loss of speech is one of the most profound changes that ALS patients and their families will experience” (Korner et al., 2013), therefore it is critical that we understand the benefits that alterative communication systems, such as eye-tracking communication devices, can have on these patients. By allowing people with ALS to maintain effective interactions with their family, friends and medical team, we are helping to preserve their dignity and improve their quality of life.

Due to the immense cost of eye-tracking communication devices, this critical review sought to determine if eye-tracking communication devices improve quality of life in individuals with ALS. The following analysis contains five critical reviews of past literature. Recommendations for future research are provided.

Objectives

The primary objective of this paper is to critically evaluate existing literature regarding the impact of eye-tracking communication devices on quality of life in patients with ALS.

Methods

Search Strategy

A variety of computerized databases, including: PubMed, Psych Info, and Scholars Portal were searched using the following terms:

> (Quality of life) AND (ALS) AND (eye tracking) OR (alternative communication)

The search was limited to articles written in English between 2000 and 2016.

Data Collection

Results of this literature search yielded five articles congruent with the predetermined selection criteria. Two of the studies employed a mixed randomized clinical trial design. Two studies employed a within groups (repeated measures) design. The final study was a mixed non-randomized clinical trial.

Results

Mixed Randomized Clinical Trials allow for random allocation to groups and can measure cause-and-effect relationships as the confounding variables should randomize between the groups. This design is considered to be the strongest type of design to provide evidence around a specific question.

Hwang, Weng, Wang, Tsai and Chang (2014) examined whether the use of an eye-tracking assistive device improves the quality of life in patients with ALS. Participants (n=42) were randomly assigned to two equal groups (with unspecified exceptions): user group and non-user group (used a phonetic board for communication).

The subject selection criteria were reported in detail, with minimal difference in baseline data between the two experimental groups (exception: education level higher in non-user group). In addition, there was a large variance in the amount of device use per day by the user group which could have been better controlled (range: 1-3 hours for 40% of the patients to 5-8 hours for 20% of the patients). The researchers used numerous gold-standard outcome measures and questionnaires. One questionnaire incorporated cultural features (not specified) that are helpful for Taiwanese patients. They presented a thorough description of the analysis procedure such that the study could be replicated. Appropriate statistical tests were conducted throughout the study.

Results of the study indicate that non-user patients were significantly more depressed and had significantly lower quality of life than the user group.

Overall, the study provides compelling evidence that the use of an eye-tracking communication device improves the quality of life in patients with ALS.

Londral et al. (2015) assessed the introduction of assistive communication devices with eye-tracking communication capabilities on quality of life in bulbar-onset ALS patients. Participants (n=21) were randomly assigned to either the early intervention with an assistive communication device (n=12) or late intervention (n=9) groups, and were assessed three times over a 10-month period.

The selection criteria employed by the researchers was thorough and adequate for the design. The researchers ensured a definite diagnosis of ALS by using a gold-standard diagnostic tool. No significant differences were found between or within groups at baseline. The researchers accounted for confounding variables to the best of their ability. Appropriate statistical measures were used to measure differences within groups. The treatment proceedings were clearly described and allow for replication. A quality of life questionnaire that is frequently used with ALS patients was used as the outcome measure for the study. A limitation of the research was that the authors did not quantify the number of hours per day participants were required to use the assistive device, leading to great variability within the group (range). In addition, participants generally had poor technology training which might not be representative of the general population.

The first assessment showed that quality of life was higher for patients in the early intervention group, however, differences between the groups were reduced by the second assessment. Overall, the patients' quality of life decreased over time for both groups.

The results of this study were suggestive that an early intervention with an eye-tracking communication device can improve quality of life for bulbar-onset ALS patients in the short-term and potentially increase their skills using devices in later-stages of disease progression.

Within Groups (Repeated Measures) Designs reduce variability between the participants and are useful for monitoring performance trends over time.

Caligari, Godi, Guglielmetti, Franchignoni and Nardone (2013) evaluated the impact of eye-tracking communication devices (ETCDs) on communication ability and quality of life in patients with late-stage ALS who are regular ETCD users. The researchers sought to compare the impact of three conditions: ETCD use, Eye Transfer Communication Boards, and without device conditions, on quality of life. Participants (n=35) completed three assessment measures for each experimental condition throughout the study.

The selection criteria employed by the researchers were adequate for the design and there were no significant differences within the groups at baseline. Appropriate statistical analyses were performed throughout the study.

The assessment questionnaires employed by the researchers are less common and provided qualitative rather than quantitative data. In addition, the treatment proceedings were not clearly described in a way that allows for replication. All participants were equipped with the same devices which limits generalizability of the results.

Results of the study are suggestive that an ETCD is an effective communication option for improving quality of life and significantly reducing communication disabilities in a group of patients with late-stage ALS.

Calvo et al. (2008) investigated if and when eye-tracking technologies have a positive impact on ALS patients' quality of life. Participants in advanced phases of ALS (n=16) used an eye-tracking communication device at home for one week. Questionnaires were completed pre- and post-trial.

The participant selection criteria were detailed, however there were confounding variables (age and medical intervention) among the participants. The study methodology was not clearly defined which makes it difficult to replicate. The researchers provided sound rationales for the outcome measures that were used, and chose a gold-standard quality of life questionnaire. An additional questionnaire was developed that provided qualitative data in addition to the quantitative data collected by the standardized measures. All participants used the same communication device which limits generalizability of results. A limitation of the study was the short experimental period of seven days. Also, the researchers did not include the quantitative data in the paper to demonstrate and confirm results of the study.

Results of the study demonstrate significant improvement in psychological well-being and physical symptoms, and slight, but generalized improvement on all other aspects of quality of life that may be attributed to the eye-tracking equipment.

Overall, the results of this study were equivocal. Changes to the methodology could have strengthened the reliability and validity of the study. Clinicians should seek additional information prior to applying these findings to clinical practice.

Non-Randomized Clinical Trials (Cohort Studies) are considered to be the strongest design following the Randomized Clinical Trial.

Korner et al. (2013) compared the impact of speech therapy and eye-tracking communication devices on quality of life and mood in patients with severe dysarthria secondary to ALS. Participants (n=38) who underwent speech therapy and/or used communication devices answered three questionnaires at one point in time.

The researchers used three gold-standard outcome measures which are frequently used with ALS patients. Appropriate participant selection criteria was employed, however functional impairment was significantly more severe in the patients who used a communication device. The researchers used appropriate statistical analyses throughout the study. Clearly defined experimental proceedings make it easy to replicate the experiment in a randomized clinical trial format in the future.

The results are suggestive that the use of a communication device increased quality of life, however the results were not statistically significant when compared to the scores of the speech therapy-only group.

Discussion

Overall, the results of the five reviewed studies are suggestive that eye-tracking communication devices have a significant and positive impact on quality of life in patients with Amyotrophic Lateral Sclerosis. Inherent weaknesses of the methodology reduce the strength of evidence and the ability to confidently apply the findings to a clinical setting. This is not a stable disease, and rapid decline inherently makes studying quality of life more difficult. Based on the impact that loss of communication has on individuals with ALS, as well as the high cost of these devices, understanding the effect that eye-tracking communication devices have is essential for helping to preserve quality of life in this patient population.

Limitations:

a) One of the limitations for the selected studies was the small sample size of participants. Due to this limitation, findings from these studies may not be representative of the entire target population.

b) Confounding variables between and within groups were another common limitation throughout the studies. In the Korner et al. (2013) study, functional impairment was significantly more severe in participants who used a communication device, especially with respect to bulbar function. This may have influenced the results of the study.

c) There was a lack of detail when quantifying the number of hours that the eye-tracking communication device should be used by the experimental groups per day in each of the studies. In the study by Hwang, et al. (2014), device usage ranged from 1-3 hours for 40% of the patients to 5-8 hours for 20% of the patients.

d) Each of the studies used a short experimental period (ranging from 7 days in the Calvo et al. (2008) study to 10 months in the Londral et al. (2015) study. Due to the nature of the ALS, however, this is a limitation that is difficult to avoid.

Future research considerations:

In order to improve the level of evidence provided by the existing literature, it is recommended that future research take the following into consideration:

a) For generalization to other devices, a wider range of commercially available eye-tracking communication devices should be used in a single study.

b) The researchers should clearly quantify the number of hours per day that the device should be used since it is difficult to control how participants use the device outside of the clinic/research environment.

c) Although difficult due to the rapid progression of ALS, research studies should aim to incorporate larger sample sizes and longer experimental periods to increase the confidence of clinical implementation.

d) Researchers should aim to recruit patients with similar disease progression to avoid significant differences between the groups, as in the Korner et al. (2013) study.

e) Future research should employ study designs that offer a stronger level of evidence, such as mixed randomized clinical trials.

Clinical Implications

Although limitations exist within each of the studies, the evidence is suggestive that eye-tracking communication devices positively impact quality of life in patients with ALS. The critical review provided important findings for which to direct future research.

Speech-language pathologists should continue to evaluate the use of eye-tracking communication devices for each individual patient to ensure that this is the best communication option for them. The use of these devices should continue to be considered for ALS patients while further research of their impact on quality of life is conducted.

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