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# Eye tracking impact on Quality-of-life of ALS Patients

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**Abstract.** Chronic neurological disorders in their advanced phase are characterized by a progressive loss of mobility (use of upper and lower limbs), speech and social life. Some of these pathologies, such as amyotrophic lateral sclerosis and multiple sclerosis, are paradigmatic of these deficits. High technology communication instruments, such as eye tracking, can be an extremely important possibility to reintroduce these patients in their family and social life, in particular when they suffer severe disability.

This paper reports and describes the results of an ongoing experimentation about Eye Tracking impact on the quality of life of amyotrophic lateral sclerosis patients. The aim of the experimentation is to evaluate if and when eye tracking technologies have a positive impact on patients' lives.

## 1 Introduction

Persons with neurodegenerative diseases are affected by several kinds of symptoms and problems during the development of the illness (sometimes over a long span of years), that have a severe impact over the quality of life. In advanced phases, amyotrophic lateral sclerosis (ALS) and multiple sclerosis (MS) are characterized by the complete loss of communication abilities, even with common augmentative/substitutive systems, due to the total loss of movements of limbs and neck and immobilization, with a total dependence on other persons for the common activities of daily life.

A great deal of literature highlights the various aspects related to the care and to improving the quality of life of these patients, through palliative care. In palliative care, it is fundamental to control pain, symptoms, and social, psychological and spiritual problems. They aim at improving the quality of life of patients and their families. This type of care must adapt, day after day, to the needs of the patients and of their family. Every treatment needs to be re-examined continuously. From the literature we find that home is the ideal place where to apply palliative care. The efforts to improve (or to allow) an effective communication in ALS belong fully to the topic of palliative care. Patients with very severe disability, thanks to *communication tools*, may have chances to re-enter their social and family life [1]. Such systems may allow ALS or MS patients to gain autonomy, even if limited, in their personal life choices.

The potential of eye tracking in ALS is extremely high, since these patients retain their full cognitive capabilities, and while paralysis progresses, in most cases eye movements are still controllable.

There are few research results on using eye trackers with ALS or MS patients. A former study [6] identified some fundamental requirements for Augmentative and Alternative Communication (AAC) systems in these patients: communicating instructions, achieve the satisfaction of their needs, clarify their needs, having an "affective" communication and transfer informations. The results of such research, even if they offer significant information, are limited by the *lack of a direct involvement* of patients.

A deeper knowledge about real patient needs, and of their caregivers, is therefore necessary to define and evaluate effective tools for AAC through eye tracking devices. This paper reports the trials performed, over a span of 2 years, on a significant fraction of Italian ALS patients. The trials were conducted in collaboration between Politecnico di Torino, the hospital San Giovanni Battista of Torino, and the University of Torino (dept. of Neuroscience).

The main aim of the experimentation is to evaluate if and when eye tracking technologies have a positive impact on patients' lives.

## 2 Methodology

The research is based on the following main principles:

- Adoption of Quality of Life (QoL) assessment scales
- Experimentation with off-the-shelf devices
- Involving a large user base.

A multi-disciplinary team, composed by Neurologists, Psychologists, Speech therapists and Computer Science Engineers, lead the experimentation.

The neurologists select the patients in according with the following recruitment criteria:

- **Ethical:** patients who are able to understand the aim of the study and to give an informed consent.
- **Motivational:** patients who are unable to speech intelligibly and having various degrees of hand function impairment.
- **Efficacy:** patients who have basic to good level of computer literacy.

During the trial, each patient uses an eye tracking system for a week in their own domestic environment.

The research team schedules two visits and one telephone contact for each patient during the eye tracking lending period. The speech therapists train patients and their caregivers to calibrate and use the eye tracking system. The training also includes a brief course about using applications for writing, communication and Internet browsing in eye tracking mode. Other applications are installed in according to users' needs and interests.

The psychologists fill in the patients' assessment questionnaires just before the training phase. The questionnaires measure the QoL, the satisfaction about Life, the Depression level, and the perception to represent a burden.

The following international recognized quantitative scales are been adopted:

- Mc Gill scale (MGS). This scale, developed at McGill's University [3, 4], analyzes five factors: physical comfort, physical symptoms, psychological symptoms, existential comfort and support.
- Satisfaction With Life Scale (SWLS) [5, 8] which evaluates the satisfaction about life.
- Zung scale: self rating depression scale [9]; it is fast, simple and it has quantitative results.
- Self-Perceived Burden Scale (SPBS) [7, 2]: this questionnaire consists of 25 statements about feelings the patients may or may not have about their relationships with caregivers.

The same questionnaires are proposed again at the end of the evaluation period with the purpose of verifying the impact of the eye tracker usage on the measured parameters. A further questionnaire, developed by the ALS center, is additionally proposed at the end of the lending period. The ALS questionnaire focuses on qualitative aspects and feelings, and analyzes the time spent with the system, the training process, subjective satisfaction, and influence on life quality.

### 3 Experimental settings

The eye tracker used in the experimentation was the *Eye Response Technologies' ERICA Standard System* equipped with Assistive and Communication software such as ERICA keyboard, mouse emulators, *Sensory Software's The Grid*. Standard Windows and Internet applications are also used in the tests.

The experimentation involved 16 patients (12 men, 4 women) from April 2006 to August 2007. The patients average age was 45 years (min 32, max 78). The patients were in the advanced phase of the disease, in detail: 7 of them were tracheotomized, 8 had percutaneous endoscopic gastrostomy tube (PEG), while 6 patients where anarthric and 7 had a severe dysarthria.

### 4 Case studies

Three particular user case studies are hereafter reported to give a qualitative outlook of the impact of eye tracking technology on ALS patients. Permission to publish this information, in a partially anonymous form, has been obtained.

*Marco* – Marco is 47 and lives in his house with his family. Before the disease he was a traveling salesman, frequently traveling around the country. At the time of the experimentation he was using a communication system (virtual keyboard) with a computer and a foot switch (in scanning mode). When he tried the eye

control system he was very excited; he used a screen keyboard for communication and for sending emails quickly and easily. More recently, he started having a lot of problems with his current system because he has less and less movement on his feet. He really wants an eye control system, but the Piemonte Regional Government denied him a grant. He later succeeded, thanks to the help of the Italian ALS Association, to raise funds for buying an eye tracker, and is currently collaborating with the device manufacturers. He is also in the process of writing a book, in collaboration with other ALS patients who use eye trackers.

*Paolo* – Paolo is 52 and lives at home with his wife. Before the illness, he was a web designer, and he still is. During the experimentation he was using two mouse devices, one for moving the cursor and the other for clicking. He needs the eye tracker for his work, only, because he still successfully uses labial movements for communication with his family. He uses many programs for his work, and tried them all on the Erica system. The results were positive and he wants to buy the software and camera add-on to his computer. In the past he tried other eye tracking systems but he didn't like them because "they didn't work well with web design programs." He recently lost the ability to use mice as input devices, and he is waiting for the national health system to fund him the purchase of an eye tracker.

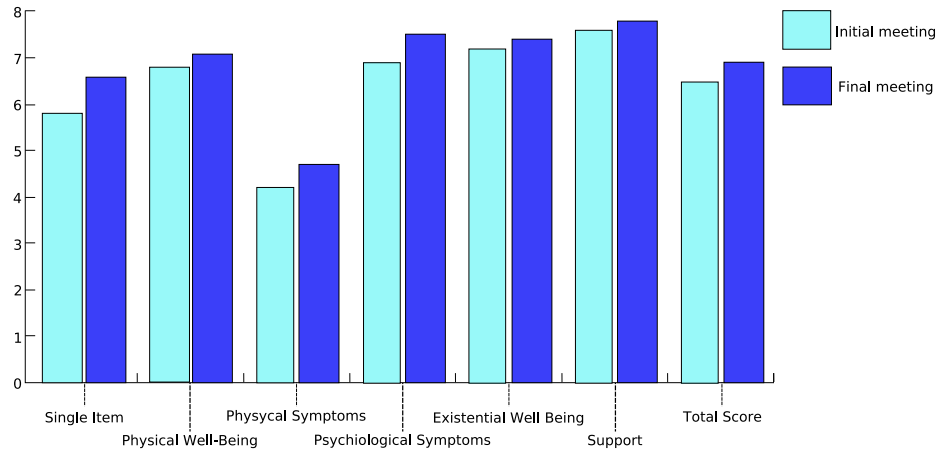
*Domenico* – Domenico is a young man, he lives at home with his wife. He was eager to try the eye control system to be able to speak, for the first time, with his 2-years old nephew, and also to be able to express his feelings with bad words! When he tried the eye tracker, finally he could speak with his nephew who could listen for the first time his "voice".

## 5 Quantitative Results

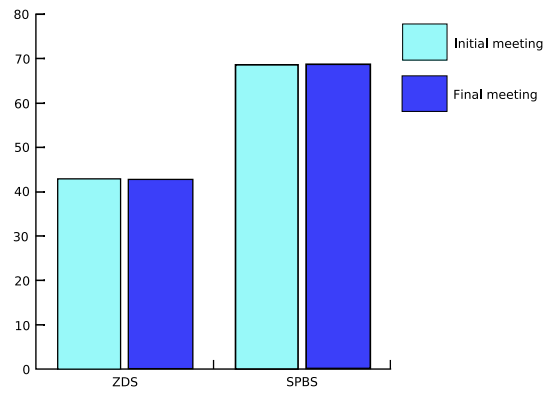
During the initial and final meetings of each trial, the responses of the patients to the various questionnaires were recorded, and SPSS 12.0 was used to analyze them from a statistical point of view. The test results showed a clear improvement in the perceived quality of life, in both the MGS and SWLS Scales.

A particularly noticeable improvement was shown in the patients' perception of their condition overall, including their psychological well-being and physical symptoms, although the amount of support required by each patient, and their perceived depression did not show a significant change (less than 0,05). However, it must be remembered that these results were achieved over a relatively short trial period of seven days.

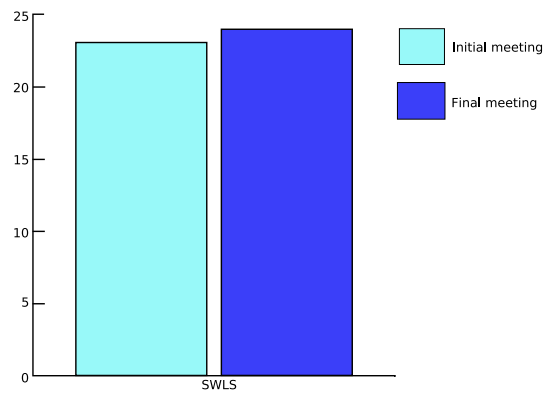
More in detail, Figures 1, 2, 3 report the main results on the four main scales. The McGill scale (Fig. 1) measures a slight, but generalized, improvement on all aspects of the quality of life that may be attributed to the eye control equipment. On the other hand, Fig. 2 shows that there were no significant modifications on depression and burden scores, while we could measure an improvement on the satisfaction with life scale (Fig. 3).



**Fig. 1.** Quality of Life (McGill Scale)



**Fig. 2.** Depression (ZDS) and self-estimated burden (SPBS)



**Fig. 3.** SWLS (satisfaction with life scale)

Specific evaluations about the eye control device are analyzed using the ALS Center questionnaire. In particular, we may notice that the vast majority users are quite satisfied with eye control devices (Fig. 4(d)); they use it quite often (Fig. 4(a)), and find it easy to use (Fig. 4(b)) and to learn (Fig. 4(c)).

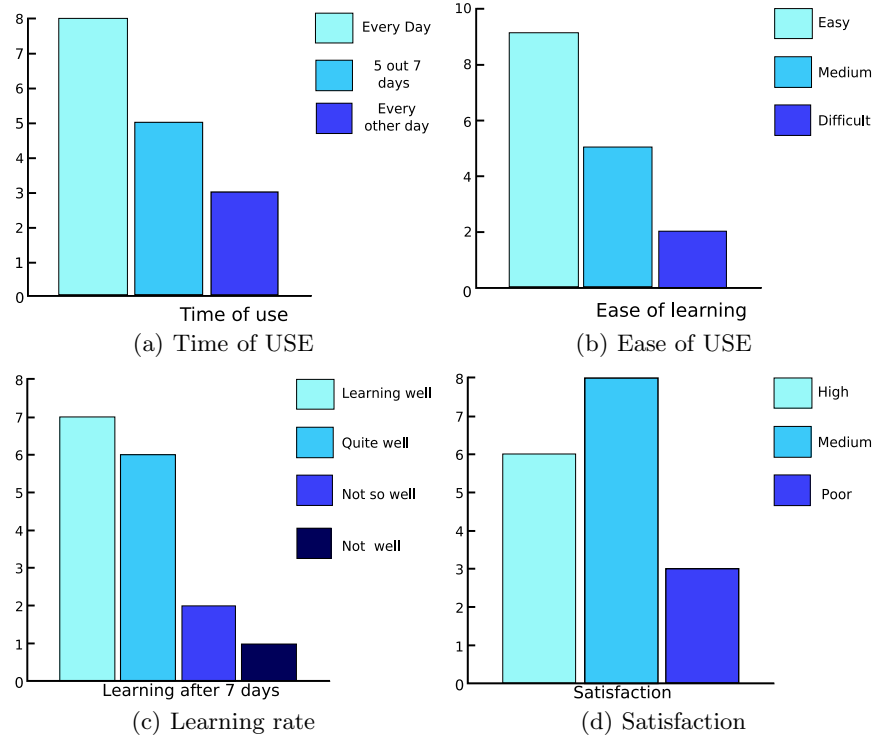


Fig. 4. ALS Centre questionnaire

## 6 User comments

Users agree that the system is efficient and effective, and allows more complex communication, beyond the primary needs. In fact, the majority of patients used the system every day with a high level of satisfaction. They felt that eye-control was comfortable and flexible, and required relatively little effort. A great perceived advantage is that, after calibration, the user is independent in using applications (compared with Plexiglas tables commonly used for eye-contact dialogs, which rely on a communication partner). For typing applications, users appreciated the prediction dictionary and the voice synthesis features. On the other hand, some patients expressed negative comments, which were mainly due

to loss of motivation after some initial technical problems, or to the difficulty in calibration or the need of repeating the calibration procedure too often. Some patients using multi focal lenses could not calibrate the system, but this was solved by changing the glasses. For users less expert with computers, learning to use the screen keyboard was somewhat difficult. Finally, some patient with a residual mobility on some parts of their body had difficulties in keeping their head perfectly still.

## 7 Conclusions

All patients showed a strong interest in eye tracking systems, and most of them had already looked for information about this technology. The Erica system has generally been well accepted and considered easy enough to be used by ALS patients with severe disability. The patients with worse clinical conditions had better acceptance.

Eye tracking benefits are lower for patients with residual arm mobility, while tracheotomized patients had stronger motivation probably because of two main reasons: anarthria represents the first motivation for communicating and tracheotomized patients have better ventilation, and brain oxygenation, than patients with dispnea. The patients who tried the eye tracker system perceived an improvement of QoL because they were able to communicate independently and the communication was easier, faster and less laborious.

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