The Eye-tracking technology in the healthcare settings: an observational, cross sectional, multicenter study

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Abstract

Successful communication is considered an essential component of the quality of care and safety of the patient with Amyotrophic Lateral Sclerosis (ALS). Recent technology has provided alternative communication systems, including the Eye-tracking technology, which enables interaction with others in the more advanced stages of the disease. The aim of the study is to investigate patients' difficulties in using the eye tracker, their problem in obtaining the device and the clinical complications resulting from it. A "snowball sampling" method study was conducted from April to September 2020 until sample saturation. The results of the study demonstrate the countless difficulties in obtaining the eye- tracker, with long waiting times, which are not followed by adequate training in its correct use. Among the consequences linked to the use of this device, the most frequent were nystagmus (8.8%), onset of eyelid ptosis (16.2%) and the appearance of increased fatigue. 56.1% of the sample used the eye tracker to surf the Internet whereas 9.1% used it to write e-mails. Overall, the use of the eye tracker led to an improvement in overall quality of life (24%). In Conclusions, the Eye-tracking technology is a valuable device for Alternative Augmentative Communication (AAC) in ALS patients and can be used with good performance, therefore the need for information, training and improvement on this topic is essential

Keywords: Eye-tracking technology, Eye tracker, Amyotrophic Lateral Sclerosis

1. Introduction

The incidence of Amyotrophic Lateral Sclerosis (ALS) is about 1-3 cases per 100,000 inhabitants per year and the relationship between physical impairment and psychological condition is an important issue that involves a direct correlation between severity of depression and physical disability. In recent decades, the progress of biomedical technologies has led to great benefits in the field of healthcare, with the aim of improving the health of individuals and offering alternative solutions to traumas and various diseases. Among these, ALS patients have always used computer media, including computers, writing and digital language systems to communicate with the outside world. (Beukelman and Mirenda, 2014). Studies on the mental evaluation of ALS patients have reported complaints such as depression, anxiety, loss of emotional control and alienation, as well as a high risk of suicide in the early stages of the disease (Cui et al., 2015). In the presence of this debilitating neurodegenerative disease, the

home environment becomes the core of life, where the need to communicate grows and although the progression of language symptoms may vary from person to person, almost all people with ALS have severe communication disorders (Beukelman and Mirenda, 2014). The spread of Alternative Augmentative Communication (AAC) strategies has offered great possibilities to improve the communicative effectiveness of people with ALS, also improving their quality of life. There is a great technological variety of eye-tracker, in computerized systems that are called "Eye-tracking technology". The concept of Eye-tracking refers to a series of technologies that allow the monitoring and recording of the way a person looks at a given scene or image, in which areas they focus their attention, for how long and what order is followed in their visual exploration. Eye-tracking analyses, through a digital camera (eye-tracker), the movement of the eye and in particular the position of the pupil. These devices do not provide new possibilities for curing or improving the disease condition but can improve and increasing the efficiency of responses to some essential needs for autonomy: communicating, working, having fun, and spending free time, controlling the living environment. The eye is usually 'illuminated' by an infrared light emitter that defines the contour of the pupil and creates a light reflection that is captured by the high-resolution camera. These reflections are then processed by special software to calculate the position of the gaze in relation to an object or a position on the computer display. Another feature is the ability to move the head during use. This is only important for those who can still move their head, but not at all for those who cannot. When evaluating instruments, much attention should be paid to the software, as the software represents the 'autonomy functions' that the instrument is able to handle. Eye-tracker-based systems also require a previous calibration process. This new technological availability represents a great opportunity to improve or compensate for those conditions of disadvantage due to disability. In addition to the still excessive cost of these devices, an aspect emerges that is little considered in the studies present in the literature: not all participants are suitable for these studies and the time required for calibration, the difficulty of analyzing and interpreting the results is highlighted as one of the most important barriers (Hassan Montero and Herrero Solana, 2007). The aim of the study is to investigate patients' difficulties in using the eye tracker, their problem in obtaining the device and the clinical complications resulting from it.

2. Methods and design of the study

An observational, cross-sectional, multicentre study was conducted between April and September 2020. The study was carried out through the electronic dissemination of an online questionnaire, as it was considered an effective and inexpensive method to find a significant number of participants among ALS patients. The study was conducted nationwide, through conventional, non-probability sampling. Each patient, contacted through two social networks (private facebook and instagram groups), could join the study through a link to the study. The questionnaire used for data collection consists of two sections: the first section is aimed at collecting socio-demographic information from the patients (age, gender, marital status, educational qualification, profession held before the disease, region and municipality of origin, stage and onset of the disease, heredity, etiopathogenesis) the second section explores everything about the eye-tracker, both the benefits and risks that the use of this device can bring, how to use it and problems that have arisen. All sections of the questionnaire were computerised by using a pre-set form from the Google Drive platform. People affected by ALS, coming from the different Italian regions, who were older than 18 years and who use the eye-tracker for communication and who signed the informed consent were included. Patients who do not use the eye-tracker, who are younger than 18 years old and who have not signed the informed consent were excluded.

3. Ethical considerations

The ethical characteristics of the study were set out in the questionnaire presentation. Participation in the study, being free and voluntary, was considered as an expression of consensus. It was specified that participation was voluntary,

and that the participant could refuse to participate in the protocol whenever he or she wished.

4. Tools

The 68 patients willing to participate in the survey were given an ad hoc online questionnaire (consisting of 21 multiple-choice questions) to obtain more detailed information on the satisfaction and use of this specific aid and the QUEST (Quebec User evaluation of satisfaction with Assistive Technology) (Demers et al., 2000) to have a standardised reference on the degree of satisfaction with the product, the service and the supply, support, and verification service.

5. Social and demographic sample characteristics

The sample consisted of 68 patients affected by ALS with a prevalence of the male gender (76.5%; n=52) and an average age of 57.13 years and DS= 11.729. The prevalence of the sample came from the Puglia Region (29.4%; n=20). The 42.6% (n=29.4) are graduated, and the 29.4% (n=20) are employed. 64.7% (n=44) are married, and the partner appears to mainly take care of them (60.3%; n=41). 82.4% (n 56) receive a pension, which is not enough to cover their care expenses (52.3%; n 34). 63.2% (n=43) move only their eyes (Table 1).

Table. 1 Social-demographic data (n =68)	N (%)
Age (average, ds)	57.13 – 11.729
Gender	
Male	
Female	52 (76.5)
	16 (23.5)
Qualification	
Regional diploma	29 (42.6)
University diploma	14 (20.6)
Middle school	20 (29.4)
Anything/Elementary school	5 (7.4)
Civil status	
Celibate / Maiden	9 (13.2%)
Married	44 (64.7%)
Divorced	6 (8.8%)
Windower	9 (13.2%)
Geographical distribution	
Abruzzo	3 (4.4)
Basilicata	1 (1.5)
Calabria	1 (1.5)
Campania	1 (1.5)
Emilia Romagna	5 (7.4)
Lazio	4 (5.9)
Liguria	3 (4.4)
Lombardia	5 (7.4)
Marche	9 (13.2)
Molise	1 (1.5)
Piemonte	3 (4.4)
Puglia	20 (29.4)
Sardegna	3 (4.4)
Sicilia	4 (5.9)
Toscana	1 (1.5)
Umbria	3 (4.4)
Veneto	1 (1.5)
Professional role	
Artisan	13 (19.1)
Housewife	4 (5.9)
Trader	5 (7.4)
Employee	20 (29.4)
Nurse	1 (1.5)
Engineer	3 (4.4)
Teacher	8 (11.8)
Doctor	5 (7.4)
Worker	9 (13.2)
Caregivers	
Friends	2 (2.9)
Carer	2 (2.9)
Children	18 (26.5)
OSS	1 (1.5)
Partner	41 (60.3)
Brothers/Sisters	3 (4.4)
Healthcare facilities	1 (1.5)
Do you receive a disability pension?	
Yes	
No	56 (82.4)
	12 (17.6)
Is the pension sufficient to cover the costs of providing care needs?	
Fairly	14 (21.5)
Slightly sufficient	34 (52.3)
Not sufficient	17 (26.2)
Missing	3 (4.4)
Depending on the stage of the disease, which part of the body can still move?	
Regional course	11 (16.2)
University Diploma	2 (2.9)
Master's Degree	7 (10.3)
Bachelor's degree	43 (63.2)
Master 1st Level	5 (7.4)

6. Communication system and the use of the eye tracker

92.6% (n=63) were immediately in favor of using the eye-tracker. 51.5% (n=35) used other systems for accessing the PC prior to the eye-tracker, of which 37.8% (n=14) were reported

to have used head-controlled mouse emulators, while 36.8% (n=25) used alphabetical communication tables as other systems for AAC. 42.6% (n=29) became aware of the eye-tracker through their medical specialist (neurologist, physiatrist), whose requirements for the use of the eye-tracker were assessed (30.9%; n=21). The test for the use of the eye-tracker was carried out both at home (45.6%; n=31) and in hospital (47.1%; n=32), and only one type of eye-tracker was used (73.5%; n=50). The prescription was made by the NHS specialist doctor (Neurologist, Otolaryngologist, Physiatrist) (55.9%; n=38), with long timescales (57.4%; n=37). 32.4% (n=22) had been using the eye-tracker for 4-12 months. Only 5.9% (n=4) had such difficulties during training that they were unable to use it and 39.7% (n=27) were able to use it "always" or "quite a bit" after training (39.7%; n=27) without difficulty. The technical problems associated with the device that make it difficult to use are the need for continuous recalibration (33.8%; n=23). 69.1% (n=47) also use the eye-tracker for other purposes in addition to communication, for surfing the Internet (56.1%, n=37). Over the course of the day, 36.8% (n=25) spent between 2 and 5 hours using the eye gaze eye-tracker, of which 36.8% (n=25) were in bed. Using the eye-tracker caused 41.2% (n=28) eye fatigue, but 30.9% (n=21) had no health problems that made its use necessary. Only 8.8% (n=6) were not at all satisfied; 41.2% (n=28) felt that the device had brought "enough" improvement in the overall quality of their lives. The 33.3% (n=19) would ask for a greater health comfort (Table 2).

Table. 2 The Eye-tracking technology use	N (%)
Were you immediately in favor of using the eye tracker?	
Yes.	63 (92.6)
No	5 (7.4)
Before using the eye tracker, did you use other systems to access the PC?	
Yes	35 (51.5)
No	33 (48.5)
If yes, please indicate which ones:	
Membrane mouse emulators	7 (18.9)
Scanning mouse emulators	4 (10.8)
Head-controlled mouse emulators	14 (37.8)
Computer voice command software	4 (10.8)
On-screen keyboards	4 (10.8)
Reduced keyboards with mouse emulation	4 (10.8)

No other systems used	37 (56.1)
Have you used other systems for AAC (Alternative Augmentative Communication)?	
Portable alphabetic communicators	8 (11.8)
Alphabetic communication tables	25 (36.8)
VOCAS	17 (25.0)
No system	18 (26.5)
How did you find out about the eye tracker?	
Other patients	4 (5.9)
Acquaintances	5 (7.4)
Media	13 (19.1)
Attending physician	1 (1.5)
Specialist doctor (neurologist, physiatrist)	29 (42.6)
Internet sites or magazines dedicated to disabled people	16 (23.5)
Who carried out the assessment of your requirements for the use of the eye tracker?	
Specialist outpatient clinic of your local health authority	15 (22.1)
Specialist outpatient clinic of another health authority	14 (20.6)
Specialist doctor	21 (30.9)
Technician of the supplier company	18 (26.5)
In which setting was the eye tracker test carried out?	
At home	31 (45.6)
In an outpatient clinic	5 (7.4)
Hospital	32 (47.1)
Did you try only one type of eye-tracker or more than one?	
Do not remember	3 (4.4)
More than one	15 (22.1)
Only one type	50 (73.5)
Please indicate other models:	
Dialog and Eyetech	1 (6.7)
Dylog	2 (13.3)
Eye Gaze	3 (20.0)
Medicair	1 (6.7)
MyTobii	1 (6.7)
PC	1 (6.7)
The Grid 3	2 (13.3)
Tobii Dynavox	3 (20)
Vivisol	1 (6.7)
Missing	53 (75.0)
Who prescribed it?	
Territorial district director	8 (11.8)
Dedicated outpatient specialist doctor	21 (30.9)
NHS specialist (Neurologist, Otolaryngologist, Physiatrist)	38 (55.9)
None (on loan)	1 (1.5)
What difficulties did you encounter in obtaining the device?	
Long delays	39 (57.4)
District refusal	4 (5.9)
Delivery of another type of device	10 (14.7)
Other (please specify...)	15 (22.1)
How long have you been using the	

eye tracker?	
1-3 months	11 (16.2)
4-12 months	22 (32.4)
12-36 months	21 (30.9)
>36 months	14 (20.6)
Did you find any difficulties in training to use it?	
Many difficulties	13 (19.1)
So many difficulties that you could not use it	4 (5.9)
No, none	24 (35.3)
Some difficulty	27 (39.7)
How long did the training take?	
One day	17 (25.0)
A few days	15 (22.1)
One month	13 (19.1)
Several months	23 (33.8)
Can you use it easily?	
Fairly	27 (39.7)
I still have some difficulties	12 (17.6)
Yes, all the time	27 (39.7)
I find it too difficult to use	2 (2.9)
Have you encountered technical problems with the device that make it difficult to use?	
Machine malfunction	17 (25.0)
Need for continuous recalibration	23 (33.8)
Positioning and installation	13 (19.1)
No problems	15 (22.1)
Are you satisfied with the way and speed with which you can communicate your care needs using the eye tracker?	
Very satisfied	3 (4.4)
Fairly satisfied	40 (58.8)
Satisfied	19 (27.9)
Not at all satisfied	6 (8.8)
Can you use the eye pointer for purposes other than communication?	
No	15 (22.1)
No, but I would like to	6 (8.8)
Yes	47 (69.1)
If the answer is "yes" or "no, but I would like to" please specify:	
Environmental control	4 (6.1)
Managing files such as photos, videos, films, books, documents	14 (21.2)
Work, study, research	4 (6.1)
Send text messages	1 (1.5)
Surfing the internet	37 (56.1)
Writing e-mail	6 (9.1)
Missing	2 (2.9)
How many hours per day do you spend using the eye-tracker?	
Less than 2 hours	12 (17.6)
Between 2 and 5 hours	25 (36.8)
Between 5 and 10 hours	20 (29.4)
More than 10 hours	11 (16.2)
What position do you assume when using the eye reacker?	
Sitting in a wheelchair	23 (33.8)
In bed	25 (36.8)
In both	20 (29.4)
Has using the eye tracker caused problems for your eyes?	28 (41.2)
Fatigue	6 (8.8)
Headache	8 (11.8)
Conjunctivitis	14 (20.6)
Dehydration	12 (17.6)
None	
From the beginning of the use of the eye pointer to the present day, what health problems make its use difficult?	
Redness and tearing	1 (1.5)
Burning in the eyes	2 (2.9)
Occurrence of increased fatigue	7 (10.3)
Difficulty constructing words and reduced ocular mobility, which makes it difficult to optimize dwell time on the letters	
Onset of nystagmus (difficulty in keeping one's gaze fixed)	1 (1.5)
Onset of palpebral ptosis (lower upper eyelid)	19 (27.9)
Reduction in ocular motility	6 (8.8)
No problems	11 (16.2)
	21 (30.9)
Do you think that the device has led to an improvement in the overall quality of your life?	
Yes, very much	24 (35.3)
Somewhat	28 (41.2)
A little	15 (22.1)
No, not at all	1 (1.5)
Are there any further requests, in general?	
Yes	37 (78.7)
No	10 (21.3)
Missing	1 (1.8)
If yes, please indicate type of request	
More assistance to relieve my wife	1 (1.8)
More home cares	1 (1.8)
More health comforts	19 (33.3)
More care prepared for ALS	12 (21.1)
More heart in the hands of caregivers	10 (17.5)
More care supports	13 (22.8)
More care by qualified staff	1 (1.8)
Missing	11 (16.2)

7. Discussion

The aim of the study was to investigate the patients' difficulties in using the eye-tracker, the problems in obtaining the device and the resulting clinical complications. The study shows a clear predominance of men over women. This is in accordance with literature, where the disease affects both sexes, with a slight prevalence of men (Trojsi et al., 2012) whereas there is an

equal frequency between the two sexes in family forms (Mora and Chiò, 2010). The mean age of our study was 57.13 years, which is in line with other Italian studies (Borasio et al., 2005; Trojsi et al., 2012) in contrast to another Italian study in which the average age was over 65 years old (Garzillo et al., 2015). Rarely are cases of juvenile ALS with onset under 20 years of age and in 5% more cases can be observed in the same family nucleus, often with autosomal dominant inheritance (familial ALS). The various risk factors investigated in the various studies include cigarette smoking, mechanical trauma, intense physical activity and sport, exposure to toxic substances (pesticides, herbicides, some insecticides), heavy metals (mercury, lead, arsenic) and electromagnetic fields. Studies are therefore focusing on finding genetic factors that alter individual susceptibility to external stimuli and thus modify the risk of developing the disease. ("A. Gemelli" et al., 2016). ALS is an event that affects not only the patient, but also the whole family that is forced to face relational, social, and organisational discomfort daily. As highlighted by the study, it is often the partner who takes on the role of caregiver (58.9%; n=40). Numerous studies have investigated the importance of the caregiving activity carried out by caregivers and the effects on the quality of life and psychophysical well-being generated by being constantly in contact with the invalidating disease of a family member or friend. One study in the literature investigated the caregiving needs of the caregiver of a patient with a severe disability, especially in the early stages of the caregiving role, and found that the caregiver felt a greater need for emotional and social support, communication, and information. (Moroni et al., 2008). Patients suffering from ALS need high-intensity health and social care, as well as environmental retrofitting, to first adapt their home to a person in a wheelchair or bedridden, and then to provide artificial ventilation. Having adequate economic resources and space makes a difference in terms of opportunities for care and quality of life. These costs can be transformed into unequal opportunities for access to cure and to-care support, given that the number of hours of home care provided by the public system is often largely insufficient. (Bosco and Cappellato, 2016). In fact, in the study it emerged that 82.4% (n=56), expressed that they receive an invalidity pension, compared with 17.6% (n=12) who expressed that they do not receive it at all, and of that population who stated that they receive an invalidity pension, 47.1% (n=32) and 38.2% (n=26) complained that it is insufficient or even not sufficient to cover the expenses to guarantee the best possible care needs. In the second section, everything concerning the eye-tracker was evaluated: benefits and risks that the use of such a device may provide, ways of using it and problems that have arisen. The possibility of using eye-tracking PC interface systems has offered a new possibility in enabling communication in subjects with severe motor disabilities, such as those who are unable to communicate verbally in oral and written form. It is therefore essential to make use of the resources that the subject possesses, including eye movement, one of the few parts of the body that subjects can still control (63.2%; n=43), around which the eye-tracker technology was created, and which immediately received favourable opinions among the patients in this study (92.6%; n=63). The evaluation of the requirements to use the eye-tracker was carried out by the specialist doctor of the local health authority (30.9%; n=21) as well as the prescription, data in line with another Italian study (Gasperini M.; 2010). The place where the test was carried out appears to be divided between hospital and home, unlike another Italian study in which home was the unanimous answer. Regarding the model of eye tracking device, only 22.1% (n=15) confirmed having used more than one. Each tracker has its own characteristics that should be evaluated based on factors such as the subject who is going to use it, the presence of a monocular/biocular tracker or one that allows access to other multimedia systems. There are no eye-tracker that are better than others, but simply subjects with different needs. According to our data the most used eye-tracker is the Tobii Dynavox (4.4%; n=3) and the Eye Gaze (4.4%; n=3), while 77.9% (n=53) of the sample did not answer. This could lead to the hypothesis that not all the subjects were made aware of the model with which the test was carried out, nor were they aware of other models with different characteristics, which would perhaps be essential for that subject rather than another. Moreover, not

all the devices are equipped with automatic re-calibration; in fact, the need for continuous re-calibration appears among the technical problems related to the device that make its use difficult (33.8%; n=23). Despite the difficulties during training, 79.4% (n=54) once they have learnt how to use the ring eye-tracker, they are able to use it with ease, even for other purposes besides communication, such as surfing the Internet (56.1%; n=37), but despite this 36.8% (n=25) state that they still use alternative systems for alternative augmentative communication, such as alphabetical communication tables. However, some typical eye movement problems such as nystagmus and strabismus, mydriasis or miosis and eyelid ptosis can interfere with eye tracking. For this reason, some eye-tracker have correction filters to compensate for these problems. To use this type of instrument, there must also be adequate ocular vision, i.e., the absence of objective eye problems such as double vision, cataracts, etc., the ability to maintain the position in front of the monitor, cognitive skills appropriate to the task, such as being able to read and memorise the procedures necessary to use the various functions, and the motivation and interest of the user (Gasperini et al. 2011). The survey also assessed the clinical complications encountered, considering the months of use, which vary from 1 month to >36 months. The complication found by most of the sample (41.2%; n=28) was fatigue, which can be related to the hours of daily use of the device, 2-5 hours for 36.8% (25), and 5-10 for (29.4%; n=20) data in line with another Italian study (Gasperini et al. 2011). Complications according to 21% are not such as to make their use difficult. 51.5% of the population were quite satisfied with the way and speed with which they were able to communicate their care needs and complex thoughts using the eye-tracker and 76.5% stated that the new eye-tracking technology had led to an improvement in the overall quality of their lives.

8. *Limits of the study*

The limitations of the study may be represented by possible selection bias and by a small sample not representative of the entire Italian population affected by ALS.

9. *Conclusions and perspective*

The aim of the study was to investigate the patients' difficulties in using the eye pointer, the problems in obtaining the device and the resulting clinical problems. The results obtained, confirming previous studies in the literature, show how long waiting times are for obtaining the device and some difficulties in training its use. In addition, clinical complications arising from the use of the device, such as nystagmus, reduced ocular motility, eyelid ptosis, fatigue, redness, lacrimation, ocular dehydration, conjunctivitis, and headaches. But the principal aspect that emerges is precisely how the ocular pointer has proved, in the end, capable of improving the global quality of life of every ALS patient, making it possible to communicate all care needs and complex thoughts with the outside world. In front of these results, it is necessary to reach an important conclusion: the eye-tracking computer system is a valuable device for CAA in ALS patients and can be used with good performance, so the need for information, training and improvement on this issue is essential. This will be an important step towards eliminating the difficulties encountered and therefore less stress and isolation for each individual patient. This study highlighted very interesting aspects about a patient population with an extreme need to communicate. There are very few studies in the literature on alternative communication, so it would be good to explore this aspect further in multi-center, prospective studies.

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