

Factors limiting the use of technical assistance and prospects for use in ALS patients

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ABSTRACT

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Amyotrophic Lateral Sclerosis, due to its rapid evolution and the localization of functional disorders (upper limbs and speech), significantly reduces the effectiveness and use of disability aids. To develop and optimize the Pictocom system for communication and domotic control, we assessed all factors that could hinder its use, with questionnaires and a user-centered observation study during periods of system use. The results show that these factors may be related to the disease, such as the loss of motor skills that makes difficult the interaction with a computer system. The personality of the patient and his psychological state influence the use or not of technical assistance. Finally, the physical and social environment of the patient are elements that can hinder the use of the system. Through the identification of these factors, improvement tracks are applied and demonstrate progress in the use of technical assistance.

1. INTRODUCTION

Any pathology leads to disability and social isolation resulting in heavy functional repercussions. Technical assistance appears to be the most appropriate way to compensate for at least some of the deficiencies [1]. In the future expectation of curative treatments, particularly for neurodegenerative pathologies, any tool for helping people with disabilities to be effective must be perfectly in line with the needs and abilities of the user according to his or her physical and cognitive abilities. These cognitive and attentional disorders, beyond motor disability, are limiting factors in the deployment of technical assistance for the user. In this sense, Amyotrophic Lateral Sclerosis (ALS) represents a pathology that is difficult to access for current aid because of its rapid progression, the resulting motor deficits and the great fatigability felt by patients. The purpose of this research was to determine the factors that limits the deployment of technical assistance from an approach combining dual expertise in ergonomics and occupational therapy and in the context of an assessment in ecological conditions, closer to the reality of use [2-3]. Several factors influencing the use or non-use of technical assistance were then updated. The results made it possible to optimize the Pictocom / Head Pilot system with the aim of making it adaptable regardless of the degree of autonomy and the speed of evolution of SLA.

2. ALS AND ITS COMMUNICATION AND DOMOTIC NEEDS

ALS or Charcot's disease is a neurodegenerative disease. It is linked to a progressive degeneration of the motor neurons

of the brainstem and the spinal cord. The attack is progressive and variable. It results in paralysis of the limbs and labio-glosso-pharyngolaryngeal muscles, and considerable fatigability. The oculomotor and sphincter muscles are unaffected, as well as the cognitive abilities remain intact. Due to its evolution, life expectancy is limited to an average of forty months. ALS exists in many forms, the two most common being bulbar and axial.

In the bulbar form, the lesion predominates in the labio-glosso-pharyngo-laryngeal muscles, the first affected. It results in a fasciculation of the tongue, disorders of the phonation and the speech of the type dysarthria, a nasal voice, but also by disorders of the swallowing, with risks of false road and choking which are extremely distressing for the patient [4].

In the axial form, the upper four limbs are impaired with amyotrophy of the hand and weakness of the thumb-index finger. The lower limbs impairment results in stepping and exaggerated patellar reflexes. Muscular fasciculations may be present in all four limbs [4].

From a functional point of view, ALS hampers the daily activity of patients, progressively and very rapidly increasing their level of dependence on the family and the medical team [5]. According to the form of ALS, the repercussions on daily life are different even if the final outcome is unfortunately the same. In the bulbar form, patients have difficulties to communicate with others, while the axial shape first reduces the patient's physical interaction with his environment.

All patients and their entourage express a strong need in terms of communication [6] and environmental control [7], with priority access to telephony, domotic and computing including the Internet.

3. HEADPILOT AND PICTOCOM SOFTWARE

3.1 Communication and domotic software PICTOCOM

PICTOCOM is a software for access to domotic and communication help, running on Windows. It controls any element using infrared transmission (TV, radio, lamp, etc.), access to internet networks (web page, games, e-mails, etc.), and offers various communication possibilities. The communication is performed with pictograms, coupled to a speech synthesis. The system offers a rapid exchange and a simple and fast understanding of its use. Major point, this software allows a high personalization of the trees according to the needs and past habits of the patient including the adding of pictograms already used and mastered on paper for example. In addition, the software offers different modes of interaction: direct pointing with the finger or a mouse, a contactor with sequential flow or head movements (with the HeadPilot System).

3.2 HeadPilot software to interact with the computer interface

The software HeadPilot allows a user to control the computer's cursor without any physical contact, thanks to the movements of its head [8]. This software can be used alone or integrated into the PICTOCOM communication and interaction software. HeadPilot offers a parameterization adapted to the motor capacities of the user: the vertical and horizontal sensitivities of the displacement of the pointer are adjusted, the time necessary to validate an icon is flexible, it is impossible to click two times on the same icon, it is possible to define the color and the thickness of the pointer as well as its degree of freedom in the movement (free, magnetic, sequential). These features are regularly enriched by iterative development phases. The performance of use of this system with people with disabilities has already been demonstrated [9].

These two modular and customizable computing devices have been integrated into digital computers and tested for use in a population of ALS patients.

4. METHOD

4.1 Population

Six patients with ALS participated in this clinical study after collecting the informed consent of the patient and those around him (CPP A17-D03-VOL.31 DOME 6: Développement Optimisation Mesure d'Efficacité du Système d'Interface et Contrôle d'Environnement). Three patients had a bulbar form and three had an axial shape, each with specific needs. All participants resided in Normandy, allowing regular monitoring by the biomedical research team, of the order of one visit every four to six weeks.

4.2 Measured parameters, tools and implementation of the study

The ALS Center of the University Hospital of Caen, with its active line, offered a significant recruitment potential. An interview with the occupational therapists of the service made it possible to preselect patients. This interview was

based on a collection of needs in terms of communication, access to leisure and domotic, as well as the attractiveness of patients for the computer tool. This first interview with expert interlocutors is a valuable aid in the pre-selection of patients because it allowed to select patients with a problem in line with the technical system used in this study.

A clinical interview was then carried out by a pair of ergotherapists and ergonomists with the patient and his family and professional entourage, which is still essential for adapted medical care [4]. During this first meeting, several elements are reviewed. First, a motor assessment, based on the ALS reference scale (National Coordination of ALS Centers - Occupational Therapy Assessment and Monitoring) was conducted with the patient. The motor abilities of the upper and lower limbs (proximal and distal), trunk and head were assessed. This score makes it possible to set up the mode of interaction most adapted to the capabilities of the patient (i.e. the easiest to use).

The environment, both in its human and material components, has also been studied. An interview with the patient, and a member of his family allows to collect the different people with whom the person is in communication and the communication needs [10]. The interview also allows to collect the various technical and technological installations of the patient: bed, electric wheelchair, and the connectable material, in view of the installation of the support used for the study in the environment of the patient and its configuration.

The evaluation of the life habits by a directed interview also permits to parameterize the software by creating the tree closest to the needs of the patient. The knowledge of the habits of use of computer systems also makes it possible to list the technical aids already tested in the past, in order to build on the patient's experience in the accompaniment.

Following the interviews, scenarios were conducted to test the use of the system. By this implementation use situation, have been observed the adequacy between the motor abilities and the mode of interaction with the system, as well as the level of fatigability of the patient. The interaction mode (finger, contactor, head movement) patient-system was then finalized from the motor balance when installing the computer in the living area. The sensitivity of both the amplitude and the scanning speed of the pointer on the screen are adjusted from a calibrated pointing test of pictograms so that the use is simple and the least motor and cognitive costs. Particular attention in observations is given to the quality of the score and the stabilization of the gesture. The computer system was then available to the patient for an average of four months.

During follow-up sessions, which are essential in this type of pathology [11], readjustments of the system to the needs and capacities of the patient are carried out: additions of pictograms, new motor assessment and possible change of the mode of interaction. During the follow-up, the various problems related to the real use (problems of sensitivity of the system, bugs of the computer software, display parameters) or the suggestions of improvements related to the software were also recorded. Software development was then done through several iterative cycles. During the test phases, questions about the utility and perceived use of the software were asked. This was performed at the beginning, before the setting up of the technical help, during the use and after the use of the device. ALS patients performed feedbacks on their use of computer systems, making it possible to highlight the

limits of use of technical assistance.

5. RESULTS

This study shows the needs and motor and cognitive characteristics of ALS patients regarding the establishment and use of palliative technical assistance. It revealed the complexity of this use because of the multiple factors in co-presence. Four patients showed their willingness to stop the trials during the study. All these characteristics have been the subject of qualitative investigations (interviews, observations) and can be defined according to several categories:

5.1 Factors related to the disease

5.1.1 Interaction with the system depends on motor skills

The duration of use of the technical systems with the patients was between 1 and 13 months because of the different evolutions of the disease and the inclusion of the patients at various stages of the disease.

For two patients, the mode of interaction was modified to accompany the decrease in motor abilities.

According to these results, and according to the clinical symptoms, the patients suffering from the bulbar form have more motor possibilities and therefore more possibilities of interaction. For being more efficient and to protect them from fatigue, the patients interacted primarily by direct pointing with the touch pad.

In four cases of six, there was no change in the mode of interaction. This because of two deaths and two stops of experimentation. The two stops, at the request of patients, were caused by: - Patient #1: the fatigue due to technical aid was higher to the gain brought by its use, particularly following the drooping head symptom, which is a frequent consequence of the disease [12]. In addition, the head restraint orthosis was incompatible with the use of the HeadPilot system.

Patient #6: This patient chose to stop because he was testing a new domotic device that was more convenient (access by the control of the electric wheelchair).

For two cases (patient #3 and #4), a change in the interaction followed the motor loss related to the progress of the pathology was necessary. For patient #4, following the use of the mouse, head pilot tests were performed. The use of head-pilot has been conclusive, without pointing error and with good stabilization. However, the patient could not use it in a real and prolonged situation because of the fatigue caused by the movements of head. The patient has therefore chosen to use the contactor. He still found Head Pilot more intuitive and faster. As the illness progressed, the patient decided to leave the study, as the use of the software was physically too costly. In the case of patient # 3, who had chosen voice recognition as an interaction modality, with the progress of the disease and the loss of breath, his voice became undetectable by the software. He therefore continued to use the PICTOCOM software via HeadPilot to finally stop because of report fatigability / unfavorable benefit.

In conclusion, there is a relatively similar evolution of interaction patterns for patients in this study, depending on their abilities. For the patients included in the study who still had good motor skills (score of at least two on a scale of three on the upper extremity motor assessment test), all were in direct finger pointing and then in the mouse. When the

motor capacities decrease, HeadPilot then the contactor were used successively.

5.1.2 Limited life expectancy and strong fatigue

Several explanations factors limits the implementation of a technical aid due to late medical care of the patient while the life expectancy is reduced. Indeed, first, there is a delay between the announcement of the diagnosis to the patient and the completion of the first medical and administrative analyzes. During this period, the patient is in a process of mourning that may lead him to refuse technical assistance, as a sign of refusal of the disease [11]. Then comes the information delivered by the SLA center to the patient of the current study and the possibility of having a technical help and finally the effective implementation of the technical system to the patient. The inclusion in the research protocol is then very late, often when the patient has no motor skills of the upper and lower limbs, that causes a great fatigability. Two patients died between the initial contact and the first clinical interview, so they were not included in the study. Second, the periods when patients are physically able to use technical systems are limited because of health issues. Patients with ALS undergo surgery (e.g.: gastrostomy) or develop specific problems (e.g., pulmonary infection). Finally, the use of a technical aid becomes secondary because of the symptoms of the disease which become more and more present for all patients.

The important fatigability hinders the investment in another technique, even if it seems more evolved. In fact, of the eight short-listed patients, two did not respond, although they were not satisfied with their communication support available at the time.

5.2 Factors related to the patient

5.2.1 Effective but limiting pictographic communication

The pictogram communication software (PICTOCOM) was proposed to eight patients and six patients who had a progressive loss of oral speech used it. Three patients acquired a quick communication of key elements thanks to the pictograms (e.g.: the pictogram of the food can trigger the speech synthesis "I would like to eat"). In particular, this pictogram communication is particularly useful for conversations with persons outside the family circle, such as home helpers, since the pre-recorded messages make it possible to give the same information to several different carers, which is necessary because high turnover. For example, a tree was created for the patient #4 which presented the location of the main specific objects for the care and maintenance of the house: "It helps a lot, he can explain to the caregivers what they should do, and help them when they have questions about the tasks they have to do " (his wife).

Despite the apparent effectiveness of the system for communication with health personnel, all patients reported that pictograms restricted their exchanges with their family circle. For example, patient #6 said: "I am frustrated, I want to say something other than pictograms to my family, but I cannot". To compensate this restricted communication, three patients systematically asked for additions of pictograms. After two to three enrichments, their demands decreased, which indicated that the available pictograms were sufficient for their communication. For the patient #4, a digital virtual keyboard was even installed because his motor skills allowed

him to use it, unlike other patients. His wife stated that he used it in addition to the pictograms: "depending on the people [with whom he communicates], he uses one or the other".

Although the effects of dysarthria were felt more and more, two patients refused to use the communication module after a few days of testing and those, despite the absence of other technical assistance compensation. For patient # 3, the reason was that "I prefer to use a tool with which I say everything, I do not want to be frustrated", patient #1 said that "with my wife we understand each other, and she translates my words, I do not need it [technical help]".

5.2.2 High expectations for domotic

Although patients expressed high needs, few of them used software for domotic use. Of the four patients with domotic, two had declared high expectations for the system: "I want to be able to order my TV, open my shutters, my door, and order my bed" (patient #6). Patients had a strong attraction for technical support, including the idea of a presupposed increase in their abilities, leading to increased autonomy, and the encouraging prospect of having free access to computer entertainment-often the last ones they have. For example, "I might be able to read my emails again" (Patient #1), "I can do things even when my wife is away from shopping" (Patient #3). However, the gap between patient expectations and the actual orders that can be achieved by the system has created some frustration among the four patients. Indeed, the system only supports infrared commands and not all patients have infrared equipment. For the four patients, only the management of the television and the HIFI set was feasible.

However, this strong expectation of domotic was not present in all ALS patients. In particular, the patient #1 declared to privilege the moments with his wife rather than to watch television. He actually considered that these instants much more valuable than television entertainment: "I prefer to enjoy moments with my wife for the time I have left".

5.3 Factors related to the environment

5.3.1 Physical and computer support

Regarding the management of television by the computer, the second screen in front of the eyes causes an eye fatigue and discomfort for all users. The screen must remain permanently lit in order to take into account the actions of users. Institutional patients also reported that if the health professional forget to turn off the computer in the evening, then it stayed on all night, obviously causing discomfort to sleep.

Similarly, the first computers bought were relatively bulky and heavy (1.4 kg), which required the establishment of an adaptable or table. This then leads to new developments in the environment and these additions of furniture in the space close to the patient entail constraints for the caregivers. Patient #3 add difficulties carrying and maintaining his computer during his travels (no chair pad), which lead him to leave the study in favour of a lighter and more compact tool.

From the software point of view, the DOME6 project was in a development phase (and not a finalized turnkey system), when, at the time of the installation, the software presented bugs, they over-added fatigue and frustration, already present basic in patients because of the disease.

5.3.2 The social and professional environment as resources for the use of technical assistance

For all the patients met in this study, none had health professionals or home contacts to supervise and readjust the needs through tree enhancements. Despite the desire to have easily usable and modifiable technical assistance, social and / or professional carers never made changes due to lack of computer skills and/or lack of time to do it.

The expectations of the people in the patient's environment were often very high compared to the capacities of technical assistance. A wife expresses the fact that "I will be able to speak again as before with my husband". Just like the frustration felt by patients, the entourage also expresses some form of disappointment, resulting in a decrease in investment in the implementation of the computer. In a house where the use of technical assistance is dependent on its implementation by a third person, it becomes essential that it is satisfied with the product.

The involvement of the social and professional environment also depends on its level of appetite and computer literacy. In all the structures and homes visited, all persons expressed their feeling of helplessness in the face of technical assistance on the touch pad and their lack of attraction towards the latter. The family circle of all the patients indicated during the interviews measuring the habits of life to have a much more limited knowledge than nursing staff. Indeed, during the protocol, the patient's primary caregiver was trained in all the basic features of the computer system like turning off the computer and using the mouse to enable them to start the communication software. This fear of the computer system generates much longer bug-fixing or tree-complexity, because it depends on someone outside the home.

6. DISCUSSION

This study has updated the limiting points of the use of a technical aid. We propose favourable factors for setting up and using a computer interface to help communication and domotic.

6.1 The technical system must adapt to patients' abilities

The main factors are the adequacy between the motor capacities of the patient and the modality of interaction with the computer system. The technological advances of the last few years allow to foresee means of interaction requiring very little or almost no physical resources (e.g. BCI). The quality and complexity of the communication capabilities of the system must also match the "normal" cognitive levels of ALS patients. Our study allows to conclude that pictographic communication is not an appropriate modality for this population that wishes to express complex phrase. Our analysis is consistent with previous studies that suggested that pictographic communication was primarily aimed at people with mental disabilities [13].

6.2 The continuity and scalability of the computer interface

The rapid decrease in motor skills linked to the progress of the disease requires a modification of the interaction modalities, without compromising the entire computer

system. Indeed, the advantage of PICTOCOM software is that the change of an interaction modality does not change the functionality of the system such as the presentation of pictograms for example. Our results demonstrate that assistive technologies with scalable interfaces are ideal for ALS patients, as some authors in this field have suggested [11].

6.3 Early implementation of technical assistance

The advances and the physical consequences of the pathology (motor falls, great fatigability), lead to a more and more difficult search of the adjustment of the system in order to compensate for the motor incapacities. This is even truer as patients arrived late in the study. The insertion of a technical aid to an ALS patient must be performed as soon as possible following the announcement of the diagnosis, to ensure that the patient had motor skills sufficiently preserved.

6.4 Physical media adaptation

For a guaranteed use of the technical system, its physical installation must be optimal. In other words, the technical aid should not be a hindrance for the various actors around the patient. For example, if the computer system is cumbersome for the body care performed by the health staff, they removed it from the patient. Indeed, the technical aid is much less used if installation time is required for each use or if the computer is not close to the patient. For two of the patients, the technical system was in the room but at a distance because it impeded the passage of the medical teams. It is obvious that this remote positioning of the patient considerably reduces the spontaneous character of the conversation and accentuates the dependence on a third person to bring the device to the patient [14].

6.5 Taking into account the social and professional environment

Finally, one of the factors to be solicited when setting up and using a technical aid is the social and professional environment of the patient. Relatives must also be involved from the outset of the design to monitoring the use of technical assistance. Indeed, it is their computer skills and their determination that play a major role in the success or otherwise of setting up technical support for an ALS patient who is highly dependent on these individuals [15].

7. CONCLUSION

The study presents the use of palliative technical assistance by six people with ALS. The aim of this work of joint analysis of uses by an ergonomist-ergotherapist duo was to detect the limits of use of a technical system to propose design recommendations. Factors linked or not to the patient explain the complexity of the aid in a neurodegenerative disease and the multiple factors that lead the success or the failure of the establishment of a palliative technical assistance.

Once highlighted and taken into consideration, these factors open the field of a suitable technical assistance design and a reflection on the system, which is all the more important than the follow-up time is short, because of the

limited life expectancy of patients.

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