Connecting with Dysphonia: Human-Computer Interface for Amyotrophic Lateral Sclerosis Patients

Chun-Yang Su[1] and Ju-Joan Wong[2]

[1] Department and Graduated Institution of Industrial Design,
College of Management, Chang Gung University, Taiwan R.O.C,
259 Wen-Hwa 1st Road, Kwei-Shan Tao-Yuan,Taiwan, 333, R.O.C.
[2] Department of Industrial Design,
National Yunlin University of Science & Technology,
123 University Road, Section 3, Douliou, Yunlin 64002, Taiwan, R.O.C.

Abstract. This research studied how Amyotrophic Lateral Sclerosis patients can communicate after losing speech and typing abilities. To create a friendly and useful HCI system, this research studied the graphical user interfaces (GUI) through participant observations, to understanding how to innovate a better communication device for ALS patients and the elderly, to gaining a better quality of life.

Keywords: Amyotrophic lateral sclerosis (ALS), pictograph, human-computer interface (HCI), dysarthria, universal design (UD).

1 Introduction

This study examined human-computer interfaces (HCI) for amyotrophic lateral sclerosis (ALS) patients that are able to communicate after losing the abilities of speech and to type. Creating an accessible HCI requires a universal design applied to people with disabilities or the elderly. To establish the needs of patients, we followed typical user-centered design procedures and interviewing ALS patients. We discovered what ALS patients wanted for daily living and what they really needed to create a new HCI that overcomes disabilities caused by disease.

ALS is a motor neuron disease and is also known as Lou Gehrig's disease. ALS causes muscles to degenerate until the patient becomes disabled. Most patients develop dysarthria and have dysfunctional hands. Previous research has shown another symptom is shoulder dysfunction. The health of the patient soon declines after this symptom. Prior to shoulder failure and death, other symptoms such as foot drop, fasciculation, spastic gait, and respiratory problems occur as well.[2]

ALS does not lead to a vegetative state. ALS patients are conscious and can think and have emotions and feelings. Many ALS patients share their perspectives on life through broadcasting, publishing, and on the internet. They need to communicate with each other to realize they are not alone.

Creating an HCI system for ALS patients has several distinct problems. The first problem is dysarthria. When a patient is unable to talk to others, they need a tool that

C. Stephanidis (Ed.): Posters, Part II, HCII 2011, CCIS 174, pp. 453–457, 2011.

allows them to communicate. Unfortunately, HCI systems are always manually controlled, using a mouse or a keyboard. However, ALS patients often have split hand syndrome and are unable to grip a mouse. Shoulder dysfunction makes them unable to lift up their hands to use a keyboard. The design of the user interface must be simple so that it can be easily controlled by ALS patients.

To create a friendly and useful HCI system, we studied the use of graphical user interfaces (GUI). In 1973, Xerox PARC developed a personal computer called Xerox Alto, which was the first GUI computer. To understand if GUIs were appropriate, Xerox interviewed users and asked about their experience using the GUI.

As a tool to be used in everyday life, an ALS HCI system must be able to be learned quickly and easily. Research has shown that patients are often elderly. After they become ill, patients typically had one year to figure out how to use the adapted devices. A method to help patients get use to the adapted device is to translate the functions into graphics through pictography. In computer science, this is also known as iconification.

An HCI system can be a part of a cloud computing system on the client side. Patients can use the client interface to communicate with each other. By sharing information, patients will change their roles and form spontaneous self-help groups. Moreover, they can connect with different hospitals to share their situation. The attendants and other patients can understand them immediately.[3]

To assess an HCI system, we used four steps. The first step is user identification. This creates a list of relevant characters including potential users. The second step is to gain the user requirements by making proposed applications are supported. The third step is to develop prototypes. The fourth and final step is to implement a final version of the application and create formal usability tests. (see Fig. 1)

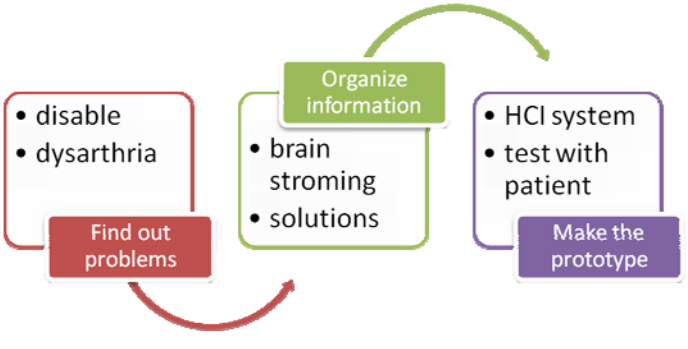

Fig. 1. HCI system design method

An HCI system must be planned according to universal design principles to create a useful communication tool that will service the disabled and elderly by making it easily controllable. By using this cloud computing system, patients can exchange information, chat with each other, and even have access to entertainment. This project could help ALS patients and the elderly achieve a better quality of life.

2 Method

Through participant observations, there is a lot of software developed for ALS patients to enhance their experience by using computers. These systems are controlled by different devices. Each has their own unique interface because of the different input methods.

When patient's symptoms escalate, they must learn a new, yet unfamiliar device. They must try to communicate with the new system with an unfamiliar interface. When patients have dysarthria symptoms, they may use a normal keyboard until their hands are unable to function. Then the one-click control button fulfilled their needs for the first year. After their hands become completely dysfunctional, many patients already knew how to use the computer before they became ill. They were able to send e-mail, write articles, and chat online. In these cases, patients were already used to working a simple operating system, meaning that patients did not have to learn a new system. Setting up selections and key-in tools on a simple operating system interface was a better choice.

3 Result

Grid 2 is software that allows patients to control a computer easily with onscreen keyboards. By using a one-click device, patients can select words by moving a target. The selection tool has vertical and horizontal markers. The vertical marker will move until the patient selects, they can select the horizontal marker. The point where they cross is the icon that the patient selected. In Chinese, patients will select about eight targets and then choose the words they really want after. This system can be installed on a normal operating system such as Windows. If the patient was a pc user, the tools will be learned quickly. In other cases, Patient A was using Grid 2, to key in about 100 Chinese words in an hour. Patient A used it to chat with friends and co-workers before. Patient A shares his story with others not only in the hospital but also in public. “One day, I received a message from Patient A. He thanked me, and told me that he is better now," said his nurse.

Patient A has symptoms of dysarthria, and his feet and hands were disabled. He cannot move his mouth. The last muscle he can be use, is the left orbicularis oculi muscle. By moving his left eyebrow, Patient A uses Grid 2 with one-click. He can use the computer with the familiar system with only his eyebrow. In some cases, to patients that had not used a computer before they become ill, especially middle-aged patients, learning computer is a difficult challenge. Because the symptoms of ALS symptom worsen quickly, it is not suitable to learn a complex operating system.

The ‘Spring’, the Maid is a choice for this type of ALS patient. The system is setup with eye-controlled equipment. The system has a simple interface that uses large icons, large buttons, and wide keyboards. Because eye-tracking systems are not precise, large icons help patient to control the computer more easily. This system applies to patients that were unfamiliar with using computers. The ‘Spring’, the Maid has a unique interface that is simple and clearly marked with large words. The patient can learn the system quickly.

Patient B never used any operating system. But, she is able to quickly key in words with 'Spring', the Maid. (see Fig. 2) When we interviewed patient B, she talked using this system. "Nice to meet everybody, thanks for the hospital and the system. I feel happy now," she said. The eye-tracking system is a solution that works quickly. However, Patient C had some settings problems with this system. When we met Patient C, the nurse spent half an hour setting up the eye-tracking system. With light or physiology problems, the system is not a solution for some patients. The other reason is the cost of the system. An expensive system is only afforded by a few patients.

Fig. 2. HCI system design method

4 Conclusion

The interface design needs for ALS patients will change as the patients symptoms change. As the symptom become worse, patients will need to change devices and adapt to a different interface. The suggestion for the interface is that it might be an adjustable display interface to overcome the problem of change and may be more suitable for every dysarthria patient.

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