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9. Design and Prototyping for Disability. WARNI Case Study

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Abstract

The present paper introduces the methodology applied for the development of Warni, a night alarm for people affected by ALS. The project was developed during the "Intelligent Products" Design Studio, of the Product Design Master Course at the IUAV University of Venice (Romero, Ferrari and Toso, 2018).

WARNI was designed for ALS (Amyotrophic Lateral Sclerosis), a neurodegenerative disease that leads to the immobilization of all the muscles of the body except the eyes.

According with UCD approach (Norman and Draper, 1986), end-users has been involved in the design process. In collaboration with AISLA (Italian Association of ALS) patients and caregiver communication during night as been recognized as a key problem.

The research is carried out in an Open-source project that allows people affected by ALS to call the assistance of the caregiver during the night-time: it consists in an alarm activated by the movement of eyes of the user that sends an audible alert on the app installed on the caregiver's smartphone.

The system is based upon an infrared eye-tracking to allow the use during night time, when other communication devices are switched off.

The basic idea also brought attention to the materials used in design and prototyping, finding many useful features in an existing product, specifically the Jansjö lamp by Ikea, in which we found many favorable structural features that, through elaborations and the addition of some electronic components and some 3D printed pieces, allowed us to obtain a reproducible object.

Keywords: *Amyotrophic Lateral Sclerosis, User Centered Design, Eye tracking, Design Open Source, Learning Experience, Hacking IKEA.*

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9.1 Introduction

Amyotrophic Lateral Sclerosis – ALS (Kiernan *et al.*, 2011, pp. 942-955), also known as Lou Gehrig syndrome, is a creeping neurodegenerative disease in the adult caused by the loss of spinal, bulb and cortical motor neurons, leading to the paralysis of voluntary muscles and involving also the involuntary ones.

Motor neurons are the cells responsible for the contraction of voluntary muscles in charge of movement as well as of vital functions such as deglutition, phonation, and breathing: their degeneration brings to progressive paralysis of the muscles they innervate[1].

9.2 Background

In people affected by ALS cognitive and sensory capacities remain unimpaired in the majority of cases. The average number of people affected by ALS amounts to 5-7 cases out of 100.000 per year, thanks to the improvement in diagnosis of the disease. In fact, only in Italy, there are about 5000 cases.

The incidence is about 1-3 cases every 100.000 people per year. Post diagnosis life expectancy is on average about 3-5 years, though its progress has different phenomena in each patient.

Due to the great heterogeneity of the disease, diagnosis is still problematic and, at the moment, there are no effective pharmacological therapies which can stop or slow down the illness.

Possible consequences of ALS are:

- Dysphagia, difficulty in deglutition;
- Dyspnoea, difficulty in breathing;
- Muscular atrophy, reduction of muscle mass causing the loss of muscle functionality;
- Dysarthria, difficulty in verbal communication;
- Muscle spasticity, pathological increase of muscle tone at rest causing muscle stiffness and, as a consequence, progressive slowing down and impossibility of movement[2].

9.3 Methods

The main methodology used in the development of the project was the "double diamond method" (Design Council, 2005) which is mainly characterized by four phases:

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1. identification and discovery of the issue and the problem by collecting a lot of information in an objective way (divergent phase);
2. definition of priorities and precise identification of the problem to be solved (convergent phase);
3. development and conception of the greatest number of solutions on the problem, without assessing their feasibility (divergent phase);
4. selection of the most suitable solutions for solving the problem, with the aim of creating a prototype as a response to the problem (convergent phase).

Course methodology has been mainly based on the interaction with the patient/user, in order to find a solution to real problems.

This has been developed through/following specific steps:

- general research;
- contacts with the user;
- research on the state of the art;
- brief definition and following concept;
- models;
- project development;
- final working prototype.

9.3.1 Problem Identification

The final stage of ALS causes the almost complete immobilization of the patient, making him/her progressively non-autonomous and much more dependent on other people, equipment, and systems.

Thanks to the meeting with dr. Gioia Marcassa, occupational therapist at the San Camillo Hospital IRCCS (Lido di Venezia), and Andrea Ranza, President of the AISLA Association of Venice, we have identified several problems (connected to the daily assistance).

Communication Limitations. At the advanced stage of the disease, when communicating with the patient becomes difficult[3], are used ETRAN tablets[4] or PCs equipped with eye-tracking display and systems. Physical tablets are often self-made, whereas more sophisticated technological systems are disposable on the market. Later on, the SSN (Sistema Sanitario Nazionale/National Healthcare System) should provide patients with technologic communication systems/devices (tablet + eye tracking device).

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Loss of Autonomy. The weakening of muscles llimits the use of arms and gradually disables the patient from autonomous feeding, destabilizing the conviviality during meals[5].

Collars/Impacting and Uncomfortable Supports. The weakening of muscles diminishes the possibility of keeping the neck erect. This requires the use of collars, often uncomfortable, difficult to fit, that enhance the unability to make various actions (for example, feeding).

Invasive Ventilation Masks. The progressive weariness of the muscles in charge of breathing obliges patients to appeal to external ventilation systems[6] for several hours a day. Often they are scarcely conformable, and uncomfortable for long-term use. At the beginning ventilation masks are not particularly invasive, but can then cover the whole face and finally can lead to tracheostomy.

Following the confrontation with the experts, we have chosen to concentrate on the first problem, that is COMMUNICATION.

The patient can't keep an easy and quick connection with the persons around her. This is particularly relevant during nighttime, when the majority of communicative devices are switch off and there is no direct way to communicate with the caregivers, that need to stay awake and watch the patient.

Thanks to the collaboration with AISLA Association (Venice), we have come to the conclusion that a device designed for night use could help to improve the life quality of people suffering from ALS, of their familiars and their caregivers.

9.3.2 State of Art

The development of the project was based on the discovery and direct study of open source projects that fulfill the communication needs of the patient in the final stage of the disease. There are several open source projects on the web giving accurate and detailed information about how to create a cheap/low cost eye-tracking device. One of the main reasons is the high cost of machinery/equipment, up to ten thousand euros. We have identified Eyewriter7 as interesting case study to start our research. The basic idea of the project is to develop a low cost technology allowing all creative talents suffering from ALS to go on designing and divulge their art, by using their eyes. Eyewriter consists in a customized software allowing people suffering from ALS to communicate through their eyes. Originally, the design consisted in a pair of glasses. Later on,

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the project was developed as Eyewriter 2.08, by improving the device precision and allowing it to be employed by people still able to move their head, unlike the original Eyewriter, which had been designed to be fitted on stock-still head.

Eyewriter 2.0 uses a PS3 IR sensitive TV camera (computer and software connected), and an infrared system on its sides through an adjustable wooden frame, to simplify the calibration.

The second open source project, foundational for the concept development, was Eye Motion Tracking9, which detects eye movement through two IR sensors placed on a plastic sheet and connected to the eyeglasses frame. The distance between the two sensors is given by the eye's own width. When the iris draws near a sensor, the reflected light decreases and the sensor ratio grows. Vice versa, when the iris distances itself, the reflected light grows and the sensor ratio of the photo-reflector decreases.

9.3.3 Brief

Considering the issues emerged from the comparison of the two systems, we have set some fundamental points on which proceed for the development of the project, in order to keep the users' real needs at the core of the design process.

People suffering from ALS gradually find themselves in critically growing conditions, forced to change their lifestyle and to adapt themselves to the disadvantages of the illness, therefore it is important to preserve the psychological sphere without underestimating it.

Our goal was to design a project that didn't enhance the embarrassment of the patient and helped him/her to feel included. The choice of adopting a non-invasive intervention followed this line of thought, so the project needed to neither vex nor hider the patient and the assistants as a preliminary requirement.

- **Preserving the dignity:** a device which does not embarrass the patient in his relationship with himself and the other people.
- **Non-invasive:** a device which does not vex the patient and does not hinder the movements of those who assist him/her in the various actions and moments of the day.
- **Easily adjustable:** the patient, due to repeated movements during the day, is obliged to repeat calibration.
- **Usable without display:** to prevent the patient from being annoyed by the brightness of the display during sleep.

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- **Usable night:** a device allowing to read the eye movements in the dark.
- **Low cost:** a device everybody may avail oneself.

9.3.4 Concept

After a deep analysis of the existing projects we have defined the concept, based on the second of the existing projects in the state of the art, that is the one employing two IR sensors detecting eye movement and transmitting it through led lights.

The aim is that of starting from the analysis of the *Eye Motion Tracking* mechanism, in order to use it as a practical basis to then develop and adapt it.

Once identified the problem to solve, that is the communication between patient and caregiver during night hours, we have proceeded to the development of simulation models.

Given the goals defined within the brief, we have thought of a small, non invasive device easy to use for the patient and for the caregiver, both for moments of need and for calibrating options. The necessity of creating an object at a minimum cost derives from the fact that the open source project should be within everyone's reach, unlike the technologies used by current market. Thanks to the two sensors positioned near the eye of the patient, a process of immediate alarm is triggered through tracking of the eye movement. This makes the alert reach the caregiver instantly.

9.4 Results

After three months of iterative process of research-design-prototype and test with caregivers, the final result was WARNI.

Warni does not require a pc display, its peculiarity being the very possibility to instantaneously transmit an alert through an application on a smartphone, in a more versatile way. It discreetly integrates itself in the environment, and does not embarrass the user. The structure of warni is based on an IKEA floor lamp, Jansjö, chosen for the accessibility of the product in different parts of the world and the low cost. As a whole Warni is cheap, since it is built with low cost and easily available components. Its assemblage is available to everybody; it is enough to follow the instructions to assemble it.

The device is easy to calibrate and to use. It is enough to focus the pupil through the hole in the viewer and move the eye sideways until the validation leds light up. Then the alarm will be activated and transmitted to the caregi-

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ver's smartphone with a repetitive sound/tone, as if it were an alarm clock. The possibility to immediately alert the caregiver allows both him and the patient to face the nighttime more serenely. Moreover, Warni does not disturb the user's sleep because, unlike pcs, it does not shed intense light, but only a faint led light when in use.

Warni project envisages bluetooth interaction between Arduino and the caregiver's smartphone, as well as an apart connection through walls, thus enabling the caregiver to move from the patient's room. This is facilitated by a dedicated app allowing to activate the alarm through the input sent by the patient with his/her eye movement.

The sensors in the viewer detect the movement and transmit the input to the Arduino connected to the caregiver's smartphone, that rings until the caregiver switches it off. The alarm may be activated through the eyes, and also with a light brushing near the two sensors: this allows the adaptability of the project to the different physical condition of the patient. If he/she can still move his/her fingers, he/she can use the touch mechanism, otherwise his/her eyes will activate Warni through the eye-tracking modality.

The device versatility is fundamental in the case of neurodegenerative disease, as it allows to employ one's physical functionalities as far as possible.

The viewer is hold up by a foldable arm allowing the user to adjust it in height and grade. The arm is made up with a stiff base on the ground, and an arm that can be folded or moulded according to the needs of the patient and the position of the bed. The device is little invasive, and may be folded through a cogging joint mechanism to be stowed away during the day.

9.4.1 Prototype

Warni (Fig. 9.1) consists in three main elements: the IKEA Jansjö lamp, three 3D printed pieces and the electronic components. To build the prototype, the lamp needs to be disassembled and modified, and the pieces printed following the digital models provided with the project.

Then, the electronic components are assembled following the instruction and the app, previously downloaded, set up on the caregiver's smartphone.

9.5 Conclusions

The project follows the open source philosophy and therefore the list of materials and instructions to build a prototype are made available on the italian-ar-

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gentinian cooperation project “POSTA” (Progetti Open Source di Tecnologia Assistiva)[10].

Warni is an assistive technology that can be reproduced freely but is not certified as a medical device.

Fig. 9.1 - Warni, final prototype

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Notes

[1] AriSLA, “Che cos’è la SLA?”.

[2] AriSLA, “Che cos’è la SLA?”.

[3] AssiSLA, “Difficoltà di parola”.

[4] AssiSLA, “Tavolette per la comunicazione ed Etran”.

[5] AssiSLA, “L’alimentazione”.

[6] AssiSLA, “La respirazione”.

[7] Free Art and Technology (FAT), OpenFrameworks and the Graffiti Research Lab, “The EyeWriter”.

[8] Thesystemis, “The EyeWriter 2.0”.

[9] HomeMadeGarbage, “Eye Motion Tracking Using Infrared Sensor”.

[10] Website: www.postaproject.org.

References

AriSLA, *Che cos’è la SLA?*. Text available at www.arisla.org/?page_id=75. Accessed February 22, 2019.

AssiSLA, *Difficoltà di parola*. Text available at www.assisla.it/difficolta-di-parola/. Accessed February 22, 2019.

AssiSLA, *La respirazione*. Text available at www.assisla.it/la-respirazione/. Accessed February 22, 2019.

AssiSLA, *L’alimentazione*. Text available at www.assisla.it/lalimentazione/. Accessed February 22, 2019.

AssiSLA, *Tavolette per la comunicazione ed Etran*. Text available at www.assisla.it/tavolette-per-la-comunicazione-ed-etran/. Accessed February 22, 2019.

Design Council (2005), *The “double diamond” design process model. Design Council, HomeMadeGarbage, Eye Motion Tracking Using Infrared Sensor, Instructables circuits*. Text available at www.instructables.com/id/Eye-Motion-Tracking-Using-Infrared-Sensor/. Accessed February 22, 2019.

in Free Art and Technology (FAT), OpenFrameworks and the Graffiti Research Lab, The EyeWriter. Text available at www.eyewriter.org. Accessed February 22, 2019.

Kiernan M.C., Vucic S., Cheah B.C., Turner M.R., Eisen A., Hardiman O., Burrell J.R., Zoing M.C. (2011), “Amyotrophic lateral sclerosis”, *The Lancet*, 377: 942-955. Text available www.sciencedirect.com/science/article/pii/S0140673610611567.

Norman D.A., Draper S.W. (1986), *User Centered System Design; New Perspectives on Human-Computer Interaction*, L. Erlbaum Associates Inc. Hillsdale, NJ, USA.

Romero M., Ferrari C., Toso F. (2018), *Designing and prototyping intelligent products for users with disabilities, a teaching experience*, in *ICERI2018 Proceedings,* 11th annual International Conference of Education, Research and Innovation, Seville, Spain (pp. 5570-5577).

Thesystemis, *The EyeWriter 2.0, Instructables workshop*. Text available at www.instructables.com/id/The-EyeWriter-20/. Accessed February 22, 2019.

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