Scientific Perspective for Future Research Work in Communication Systems for People with Neuro-muscular Disability

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Abstract - **The paper presents the scientific perspective of a research project in communication systems for people with neuro-muscular disabilities. The project promotes research connected to the design and implementation of an electronic system designated for the communication with people with major neuro-muscular disabilities. At international level, considerable efforts have been made to find solutions for developing complex communication systems for people with severe disabilities. Our research is focused on the development of a system made up of two units - one for the patient and one for the caretaker -, which enables good radio communication between the patient(s) and the attendant(s). The system will be used in medical care, both in treatment units and homes. The project offers an answer to some of today's challenges in medical care, as it provides autonomy for the people with neuro-muscular disabilities and makes communication with them possible. In Romania, neither medical institutions nor the majority of people with serious disabilities have the resources to purchase expensive communication equipment. Starting form this reality, the goal of our project is to design an efficient low-cost communication system.**

Index Terms: communication system, people with neuro-muscular disabilities, research work.

INTRODUCTION

The topic of the project, the design and implementation of an electronic system for the communication with people with major neuro-muscular disabilities is of great importance in the context of recent medical and psychological research. Neuro-muscular disabilities affect the patients' mobility and movement, their manipulation of objects and their interactation with the physical and social world. Aware of the importance and the practical implications of this topic, the project team has set to contribute to the studies in this area and produce an efficient low-cost communication system, which can be used successfully both at home and in care units.

At international level, there is increasing interest in helping the people with severe neuro-loco motor disabilities, and in elaborating the necessary technology for making communication with these patients possible and providing patient autonomy. Although they may possess a fairly good level of perception and understanding, i.e. their hearing and/or seeing and comprehension are not affected, they may not be able to react or signal comprehension in usual modes (i.e. by speech, writing or sign language). Many of them can produce inarticulate sounds, make some movements, show muscular contractions but without the amount of muscle control that is necessary for communication. Whether in hospital or at home, they need round the clock care and attendance. Finding out about the needs of these patients, either urgent (urination, defecation) or less urgent (pain, thirst, hunger) is a big problem as this implies the constant effort of the attendants/caretakers, who cannot leave the patient's bed side.

Communication with the people with disabilities is a world priority, reflected in the Framework program 7 of the EU. This points to information technologies, which are capable of providing autonomy, mobility and safety to patients, as well as the integration of technologies in order to implement individual devices for connecting patients to services and resources [1], [2], [3].

Communicating with the disabled is the object of research in several places of the world. We can mention among others, the Institute on Disabilities at Temple University of Philadelphia, Augmentative Communication Inc., Pennsylvania State University, etc. In Romania, there are research groups in this area in all the Faculties of Medicine and Bioengineering in the country. They cooperate with research groups in electronics, telecommunications and computer science in other universities and research institutes.

For hearing-impaired people there are many low cost hearing aids, for the sight-impaired there is the Braille system, and for patients with less severe neural disabilities there are ringing devices, keyboards, and displays, many of them provided by radio transmission [4], [5]. However, the issue of producing and implementing simple, flexible, accessible, low-cost devices for people with major neuro-muscular disabilities, whose intellect is slightly damaged or unaffected, in order to provide them with a means of communicating with the surrounding world (caretakers, family) has not been solved so far, in spite of the fact that their number is quite high. There are about two million in the USA (i.e. 0.8% of the population [6]). The situation cannot be different in Europe.

In Iaşi, Romania, the number of the disabled that belong in the category addressed by our project has not been precisely assessed. Starting form the personal experience of

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the neurologists, social assistants and other people involved in working with the disabled that we consulted - some of them members of our research team -, we appreciate that in Iaşi only (a city of about 400.000 inhabitants) there are at least 200 people in this situation (permanent or temporary). A percentage of 0,5‰ of the population is not negligible. This rather high percentage can be explained by the fact that Iaşi is a big regional center for treatment and recovery. Moreover, the number of disabled people has risen over the past years and is expected to continue to increase. All these patients need adaptive equipment for overcoming communication obstacles with the real world. In addition, they may also face unique challenges in a various situations of emergency (e.g. a fire), as without an efficient communication system they are at a greater risk of death or injury in such situations.

In Romania, there are few qualified caretakers for patients with neuro-muscular disabilities, and the situation may be similar in other former socialist countries and in the developing countries. Caretakers often succeed in understanding some of the major needs of the patient only due to their emphatic and affective abilities, their commitment and experience (based on trial and error procedures). The few qualified people may be expensive to hire and available a small amount of time per day. In such circumstances, one cannot speak of much communication between patient and caretaker.

There are many types and levels of neuro-muscular disabilities that can affect movement and mobility, from minor ones (affecting either permanently or temporarily elderly people or victims of accidents), to those that make patients incapable of moving a limb or speaking but leaving their intellect unaffected, to those of the patients with major locomotor disabilities and seriously affected intellectual functions (as a consequence of encephalitis, for instance). Whether mobility impairment is permanent or temporary, the patients must be attended for as well as possible, which also involves mental, affective and social care. This approach to care cannot be made possible without a duplex communication system, from caretaker to patient and back. Practical communication issues depend on "how much the patient can understand", that is, how affected the patient's intellect is, and also on "how the patient can communicate" – i.e. the type and level of the disability.

Worldwide, the care of people with neuro-muscular disabilities is provided in various types of units: clinics, hospitals, care centers, university and independent centers, homes for the retired, etc. These institutions provide treatment, care, recovery and research. In the city Iaşi, there are four big university hospitals with clinics and centers for neuro-muscular recovery, neurosurgery, prosthetics, and speech therapy. There are also three big independent centers for psychology, speech therapy and neuro-muscular recovery.

To the best of our knowledge, complex communication systems for people with severe disabilities do not exist. There are simple systems used for patients with less severe disabilities, which allow only calling or alarming, such as bells. Nothing similar to our system can be purchased either on the international market or in medical units in Romania, in the EU or in the USA. This project will produce a system based on radio communication, capable of allowing autonomy and improved safety for the patients and more freedom for the attendants. It will use integrated technology to implement an individual interface that interconnects patients with temporary or permanent disabilities to services and resources The final product has the potential of being widely used in medical care: in treatment units, homes, asylums, etc. The essential novelty element of the project is the idea that people with severe disabilities could communicate both ways: to and with the surrounding world.

PROJECT DESCRIPTION

As results from the thematic areas S&T in PC7, efforts are being made to improve the quality of care for the people with disabilities. The intensification of these efforts goes hand in hand with a limitation of expenses to reasonable levels. In order to satisfy these two opposite requirements, one solution is to use equipment and technologies based on information and telecommunication technologies on a larger scale. Among these, an important part is played by embedded systems that have become more and more effective at an ever decreasing price.

Our research dedicated to designing, testing and implementing a communication system for patients with neuro-muscular disabilities involves developing smart sensors and instrumentation for these applications. The system will help the disabled patients to interact to the greatest possible extent with their caretakers, their family, and their community, contributing thus to their autonomy and improved quality of life. The potential users are people who can receive and understand stimuli but cannot answer to them, i.e. they have disabilities which make possible usual communication (by speech, writing or sign language) only from caretaker to patient. In brief, the people who need round-the-clock supervision in order to have their basic physiological needs satisfied are the potential users of this system. The output of the project will be the production of a communication system at the level of "certified prototype", with a few units that can be operated and tested.

The system is composed of two units: one for the patient and one for the caretaker. The *patient's unit* includes: the generator of key phrases (sweeping device for key phrases), an amplifier and headphones/loudspeaker, possibly a display, the decision sensor which detects the patient's will, and the radio transmitter - a small power radio transmitter (1-10 mW), SRD type in UHF or EHF frequency band. The decision sensor can be a switch, a muscular contraction sensor or a transducer/amplifier for bio-current generated by muscular contraction. This block also includes the analog or digital signal processing system.

The *caretaker's unit* is a small portable radio receiver with loudspeaker and/or headphones which can be carried in a pocket or round the neck, and/or a computer monitor display. The hardware structure of the system is represented in Figure 1. The figure shows both the patient's unit and the caretaker's unit.

The patient unit is developed around a logical control unit (LCU) with a microprocessor (μP), ROM, RAM, analog to digital converter (ADC), digital to analog converter (DAC), a (patient mounted) muscular activity sensor with signal conditioning circuit, loudspeaker/headphone (mounted on or near the patient), a display mounted within visual range of the patient with appropriate control circuit, a radio transmitter, a control panel (which can be a keyboard) to adjust the sweeping speed and sound level and to select a specific set of key phases, etc.; The LCU can be a PC - desktop, laptop, industrial PC -, a personal digital assistant (PDA) or even an iPOD. It provides the control of all operations in the patient's unit; its RAM stores the key-words (KW). The electrical signal produced by the sensor is applied at the input of the LCU. The state of this input is permanently monitored and the occurrence of a change triggers the operation.

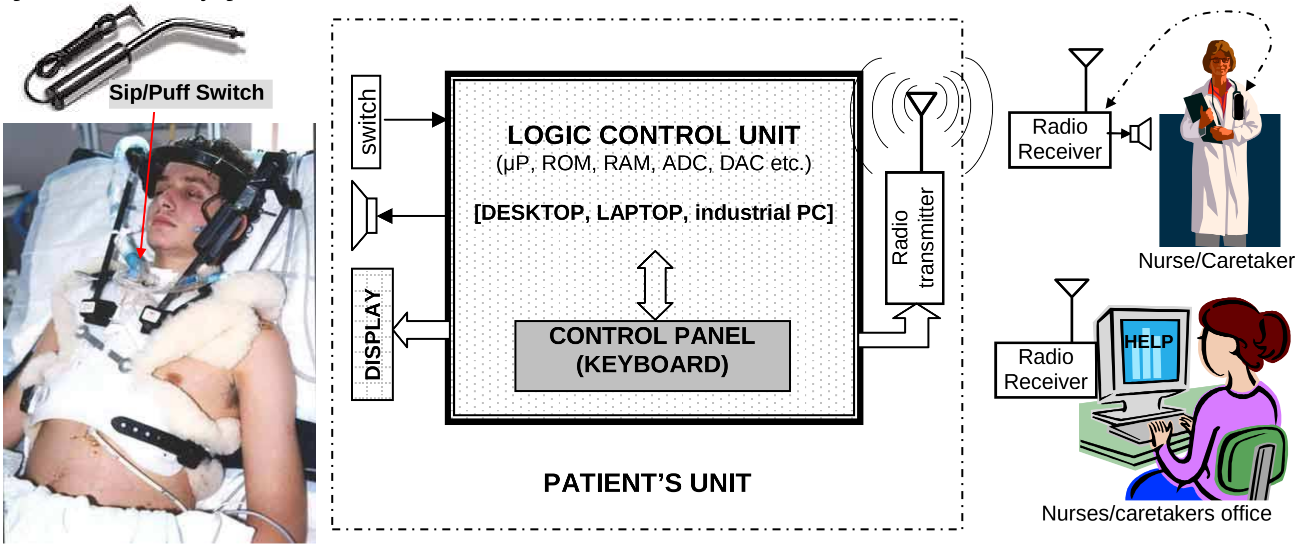

FIGURE 1
THE HARDWARE STRUCTURE OF THE SYSTEM

The audio and/or video sweeping with key phrases is performed under control from the LCU using specialized circuits: a digital to analog converter (DAC), an audio frequency amplifier for sound production and a video controller for the written text. The AF signal is applied to the loudspeaker or headphones, and the video signal to the computer's LCD display monitor. When the patient effects the selection by acting the switch, the new state is detected and a signal is applied to the logic control unit (LCU), the transmitter is activated and starts transmitting.

Upon receiving the radio signal, the receiver at the caretaker's end extracts the key phrase that was transmitted and applies an audio signal to the loudspeaker or displays it on the monitor. The caretaker hears and/or sees the phrase and acts accordingly.

The sequence of the operations is given in Figure 2.

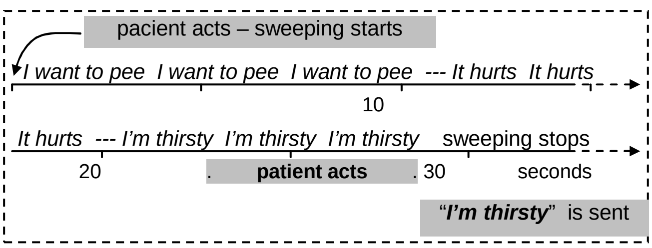

FIGURE 2
SUCCESSION OF OPERATIONS

The succession of operations is: idle state (the patient has no need) - the LCU is in stand-by, followed by the stage where the patient wants to transmit that he/she is thirsty:

- patient activates the sensor switch (for instance s/he moves her/his foot sole);
- LCU receives input and starts the sweeping of key phrases;
- key phrases are heard on the loudspeaker or seen on the display in sequence. Each phrase is repeated a number of times (3): kw_1-kw_1-kw_1···kw_2-kw_2-kw_2···kw_n-kw_n-kw_n (kw= key word);
- upon hearing/seeing the suitable key phrase, the patient activates the sensor and the LCU input becomes active. The transmission of the selected key phrase is activated by driving the transmitter with an appropriate signal;
- receiver extracts the useful signal and applies the corresponding audio/video signal to the caretaker's loudspeaker/monitor. For instance, the caretaker hears "I'm thirsty" repeated several times and takes the appropriate action.

To use such a procedure and a communication system properly, the patient needs a minimal set of abilities – hearing, seeing, speaking, or moving – and s/he can be trained to activate the switch when and how is needed, to have patience until the suitable key phrase appears and the appropriate action is carried out by the caretaker.

The caretaker also needs to be trained in how to use the units, how to mount the sensors and switches, how to change batteries, etc. However, the system is simple and robust enough for the caretaker not to need a high level of education or training.

In the following we present the components and the hardware structure. The necessary hardware components are in current use and can be purchased.

Appropriate sensors are available in a large variety of types and variants. All sensors contain a switch with two positions: active and inactive. Some may have two active positions. The differences in control mode, shapes and dimensions are illustrated in Figure 3. Switch contacts are normally off (inactive) and get on (active state) upon patient's action: hand or foot pressing, muscle flexing (ribbon switch), breathing in or out (pneumatic switch). Switches are connected by means of two wires to a port of the logical control unit (serial, e.g. RS232 or parallel, e.g. LPT1).

FIGURE 3
SENSORS (SWITCHES)

The Logic Control Unit (LCU) can be a cheap PC, a desktop, a laptop or even a PDA. All these have audio headset or loudspeaker outputs as well as video display monitor output. What needs to be still imagined is the monitor and loudspeaker mounting systems, to ensure patient access [7].

The key phrases will be recorded, digitized and possibly compressed (e.g. on MP3) and stored in the key phrases memory, e.g. on the PC hard disk.

The radio link should use a frequency in the SRD bands, which does not need licensing [8].

Two transmission variants are possible, each with its advantages and disadvantages:

- telephone transmission of the key phrase in the analog or digital technique;
- the sending of a code attached to the key phrase selected by the patient, which triggers at the receiver end the extraction of the key phrase from a local memory.

The choice of the best variant can be performed only after a complete analysis of the technical characteristics, and of the implications regarding care quality and costs.

In principle, radio communication resources can be used, with which all modern computing systems are or can be equipped. The popular Bluetooth systems are inadequate as their action range is too small – of only a few meters. The radio systems based on the IEEE 802.11 standard, also known as Wi-Fi, are more suitable, and they can also equip PC systems. They function in the 2.4GHz band and can ensure indoor connections of over 35 – 50 meters and over 100 meters outdoor ones. A major advantage of the Wi-Fi systems is the possibility of using them in Wireless LAN networks. Consequently, the same monitoring equipment in the nurses/caretakers office in a hospital, for instance, can be connected to several patient units. In addition, several caretakers can receive signals from several patients. It is not impossible, however, that in certain circumstances the action range of the Wi-Fi systems be too small. Then, more powerful radio equipment can be used, which has larger action range, such as Chipcon CC1000 and CC2400.

The system is perfectible; it can be further developed, after a period of piloting. For instance, one could increase the number and complexity of the key phrases or introduce extra switches so that the patient may have more than two options, etc. Another possible development is bilateral transmission: that is from caretaker to patient, too. In this case, the radio system should use transceivers (transmitter and receiver in the same unit), both at the patient and caretaker ends. The caretaker equipment should ensure the audio and/or video transmission of key phrases. The conversion of free speech into written form is neither easy nor really necessary, as we can hardly expect patients to read words spoken in real time. However, the possibility of sending a set of phrases such as "In a minute", "Don't worry", "OK", etc. from the caretaker to the patient by pressing a few keys seems a likely improvement. The system could also be used to distance control audio and video equipment or other automation devices by patients. The perspectives are limited only by our imagination.

CONCLUSIONS

The understanding of the nature of disability is a challenging topic in itself. Catering for the needs of the people with disabilities, and in particular for the people with different types of neuro-muscular disabilities using technology in order to provide them with increased autonomy, safety and mobility is another challenge. In recent years, there has been an increased interest in helping people with neuro-muscular disabilities to improve their life and their communication with the world around them. The efforts that have been made in this area so far are focused on providing technical assistance, which generates increasing autonomy, better communication, and the re-insertion of patients into the real world. Motivated by these developments and by the necessity of offering better living conditions to patients, our research work is concentrated on improving the interaction between people with neuro-muscular disabilities, technology, and the environment.

As modern technology cannot thrive without skilled staff and a cross-disciplinary approach, the project team includes specialists in several fields: engineers, physicists, medical doctors, psychologists, philologists, social workers, PhD students and other people involved in work with the disabled. The complexity of the project and its novelty impose the concentration of a large number of different specialist researchers: this responds to the international policy of developing cross-disciplinary research. The project also applies the principles of the most recent national policy in research, by encouraging and promoting cross-disciplinary research teams, capable of initiating and developing complex projects.

The proposed technology allows more complex exchanges with these patients; it will hopefully have a significant technical impact on the design of communication equipment for the disabled. The social impact of the new system may also be significant, as it allows the (re-)insertion of the people with severe disabilities in society. We anticipate that some disabled people who will use the system may even continue their intellectual and social life, writing poems for instance, or solving mathematical problems. Cases like that of a young mathematician affected by myopathy, incapable of coherent speech, but with an intellect in perfect shape and high intelligence, who despite total lack of mobility wrote papers using a modified PC keyboard, are a clear incentive. For a few more years, the same person was unable to move his hands but managed to communicate with his parents by Yes/No. The system developed by this project may be a solution for more complex communication with such patients.

The system may also have an economic impact, as patient care can be improved in medical units with reduced expenses if a caretaker could take some time away from one patient and attend upon others. In addition, taking into account that many people with disabilities do not have the financial resources that may allow them to purchase suitable communication systems, this low-cost system could successfully replace more expensive ones.

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