PSYCHODESIGN OF INTERACTION: COMMUNICATION SYSTEM DESIGN FOR PATIENT SUFFERING AMYOTROPHIC LATERAL SCLEROSIS

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SUMMARY

The purpose of this paper is to describe a interactive telethesis communication system called EDITH, designed for persons suffering amyotrophic lateral sclerosis and deprived of the possibility of interacting with their environment. The objective of telethesis is to reveal possibilities of causality putting the mental universe of the patient and his/her environment into perspective. These new causalities emerge from a confrontation between the patient's mental model and the metaphorical possibilities offered by the objects in the prosthesis to be manipulated. Consequently, the design of this prosthesis is envisaged as a metaphorization of possible actions.

After a brief introduction about the functions of telethesis (controlling TV programs, listening to records, writing texts, producing pre-recorded sentences and calling medical staff), the authors present some results concerning possible uses of this equipment by a patient affected by amyotrophic lateral sclerosis. Results show that there is a dramatic improvement of functional and emotional comfort for the patient; consequently, authors develop the concept of interactive enrichment.

Key words:

Augmentative and alternative communication, Palliative communication, Telethesis, Human automation

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Designing new technologies is all too often set in the framework of a technology-oriented mode of thinking on reality, separating the technical factor from the human factor. There is a clear tendency to elaborate innovations for machines rather than for men and, consequently, to develop technical systems that are more powerful, work faster, are less expensive but not taking the human dimension into account.

To gain a better understanding of problems involved in designing new technologies, it is necessary to raise the question of the way the representation of a problem interacts with the development of an automaton. Conceiving is – in the strict sense of the term – similar to shaping concepts. More specifically, conceiving technical tools is not to be equated with designing computer-based applications, but rather assessing what use people will make of these applications; in short, it means conceiving the possible uses and the social function linked to such tools. In other words, we should have a clear understanding of what machines actually do, rather than just how they work. The purpose of the design process is specifically to reveal structured possibilities for use.

As a consequence, the task of designing a technical tool entails first that a given situation has been thoroughly analyzed, leading to the elaboration of an automated application changing this situation. In this context, this application is either palliative, or interactive, i.e. aiming at respectively replacing or supporting man's operations. In this case, designing means elaborating a specific mode of man-machine communication or conversation. The point is then to elaborate a medium for a dialogue whose efficiency is comparable to that provided by language such as it is manipulated by human beings (Winograd & Florès, 1989), including in such cases when the ability to talk is impaired or lost. Designing also means modifying the possibilities users have to act, thus leading them to develop operational strategies for an appropriation of the new tool. In that sense, designing is closely connected to the process of learning how to use the equipment. Thus, the designing process should anticipate on and incorporate the path the use will take to approach and the master the functional mode of the tool designed.

Consequently, the psychological dimension ought to be taken into account when designing new technologies. This approach of the designing process is now called psychodesign (Brangier, 1994). It can be defined as an type of approach combining the psychological and technological aspects when designing new technologies. Psychodesign is based on a clear understanding of the psychic operating modes of individuals when they have to cope with a specific problem, in this case a severe disability. The description of these operating modes entails a description of the situation, an identification of the user's needs, and finally the technical specification of the object to be designed.

The purpose of this article is to provide the outlines of a new form of approach when developing aids designed for severely motor-disabled persons in the final phase of their life, in particular patients affected by Amyotrophic Lateral Sclerosis (ALS). ALS is a fatal illness that gradually destroys motricity and speech in patients. As they become unable to move or to talk, patients are condemned to silence and exclusively internal psychic life.

After a brief presentation of the features of this affection, we will describe the user's representation that we will take as a basis for the development of a communication system dedicated to the end phase of life. We will then introduce the communication interface called "Edith" and, finally, provide an illustration of its use by a patient named Jacques.

I. THE SITUATION OF THE FINAL STAGE OF LIFE FOR PATIENTS AFFECTED WITH AMYOTROPHIC LATERAL SCLEROSIS

Designing a tool for patients suffering ALS amounts to trying to alleviate a severe deficit in possibilities for interaction by means of an equipment offering some practical comfort in

the final phase of life. The assumption is then that the equipment should be compatible with the psychic processes developing in the wake of the social condition caused by the disease. These processes should be apprehended from three angles:
- the patient and his relation with his/her illness ;
- the patient and his relations with his/her environment ;
- the patient and his relation with the medical profession.

I.1.   THE PATIENT-DISEASE RELATIONSHIP

Amyotrophic lateral sclerosis, or "Lou Gehrig's disease", corresponds to a progressive degeneration of the pyramidal bundle. It affects typically elderly people aged 40 to 65, both male and female. Voluntary motricity is then reduced gradually and eventually disappears, whereas involuntary muscles are generally not affected by the disease. When the diagnosis has been established, - approximately 2 cases out of 100 000 persons - life expectancy is estimated 3 to 5 years. The persons affected pass away due to a paralysis of respiratory muscles or a pulmonory infection. The disease causes an irreversible loss of muscular potential whereas intellectual capacities are not affected. The most dramatic symptom if the affection is spasmodic paraplegia: it appears in the form of partial paralysis of limbs, then the nervous fibers of the pyramidal bundle are affected, causing total paralysis. The disease thus entails a reduction in voluntary motricity, with multiple fits of stiffness in the limbs and an amplification of reflexes. Muscular atrophy affects first the muscles of the hand and the forearm, then spreads to all muscles of the arms, the shoulders, the trunk and the neck, then extends to the muscles of the lower limbs. Later, bulbar symptoms also appear, causing i.e. paralysis of the tongue , the velum, the larynx, the muscles for mastication, and consequent difficulties to talk, swallow, and short heart failures. Eventually, the disease causes death by asphyxiation or pulmonary infection.

However, the degeneration of the pyramidal bundle does not affect the cognitive capacities of the patient. It should be noted also that the eye-controlling muscles of the patient are not affected, so that there is no impairment of sight.

After the disease has been diagnosed, patients keep their jobs and assume their family and social responsibilities. Then, they are forced to give it up and they are enventually taken to a specialized care unit. Patients are gradually discouraged and the degradation of their physical capacities induces a constant irritation. Deprivation of anatomical functions are often accompanied by a sense of frustration linked to a deterioration of social roles, the loss of friends, and all too often, a loss of family support.

Patients develop individual forms of adaptation as the effect of the disease worsen. Montgomery & Erickson (1987) described the patients affected by ALS as acquiring a kind of temperament characterized by enhancing self-control and denying the impact of stress. This attitude is considered as a way to adapt to the new living conditions, prolong lifetime and provide hope for the future. Some patients affected by ALS may display significant motivation and positive attitudes. McDonald *et al..* (1994) have shown –after surveying a population of 144 ALS patients - that psychological distress is linked to a higher death rate and shorter life expectancy as compared to psychological comfort. Scientists have collected valuable information about the patients' ability to adapt (denial of sufferings, self-control, enhanced motivation, positive attitude) and developed new procedures to accompany the patients and their relatives. Efficient strategies for adaptation to the disease (coping) have also been investigated on the basis of a close observation of thirteen patients coping exceptionally well with the effect of the disease (Young & McNicoll, 1998). Attitudes including a reappraisal of the self-image, intellectual stimulation, a development of a sense of wisdom, and the importance of the interpersonal relations proved to be powerful ways to adapt to the new living conditions that can be recommended to assist people suffering ALS.

In short, the procedures to accompany the patients in the final phase of their life should lay the stress on coping mechanisms making it possible to play against the disease and develop some forms of emotional comfort.

I.2. THE FAMILY-PATIENT RELATIONSHIP

The verdict of the disease is generally a shock for the close members of the family who then have to adapt to a new situation. In most cases, patients go on living in the family circle during the first phase and this situation has far-reaching emotional, social and financial consequences. It is often necessary to reorganize the distribution of responsibilities in daily life : the members of the family are requested to assist for the preparation of meals, health care, physical exercise. However, the relatives generally do not have access to the patient's stream of consciousness filled with a sense of physical degradation, isolation, anguish and irritation. They have rather an idea that their efforts are not acknowledged (Finger, 1987). In spite of these enormous difficulties, Moss *et al..* (1996) pointed out that, for patients staying at home, quality of life as evaluated as being superior to that of patients taken to hospital.

Families need assistance to be able to cope with their own resentment and better understanding of their limited capacity to provide proper care. Norris, Holden, Kandal and Stanley (1986) have shown that teaching families the basics of caring procedures and methods brings about an improvement of their capacity to assume their new role as care providers and an enhancement of the patient's comfort.

Joining associations of patients' relatives has also been identified as way to provide better assistance to the victim of the disease (Kitto, Garry & Roelofs, 1986). It has also appeared recently that social support could be provided on-line in the form of Internet forums (Feenberg *et al.*, 1996). However, even if electronic communication can indeed be a way to get in touch with other patients, this form of communication does not offer any guarantee as to the quality of the recommendations made, a way to check on hear-say, and the capacity of patients to confront the problem.

Communication with the social environment is here again an essential component for greater comfort in the final phase of life.

I.3. THE DOCTOR-PATIENT RELATIONSHIP

Very often, patients have no great liking for the neurologist who breaks the news of their having a disease which is incurable, a psychological shock and a financial disaster. What is more, diagnosing a disease linked to motor neurons is an extremely difficult task for the medical doctors, due to the negative prognosis and the lack of significant treatment (Johnston *et al.*, 1996). The authors have interviewed 50 persons six months after the diagnosis was made. They sought to evaluate the incidences of the diagnosis and the expression of the diagnosis on the patient. In their report, they show that patients are more critical if the diagnosis is worse than anticipated ; however, they were in a more positive frame of mind if they considered that they had had the opportunity of asking all the questions they wanted to raise.

Gelinas (1997) has also emphasized that communication between neurologists, patients and the members of the family was an essential component of care. The doctor-patient communication has to be improved and include the differences in perception modes between patients and doctors. Doctors should therefore be trained to relevant communication strategies, from the first consultation and the need to break the bad news and to the very last moments.

Patient-doctor communication, however uneasy it may be in the case of ALS, is pivotal in the structuring of the physical and psychic comfort of the patient. It is therefore advisable to find ways to compensate for its shortcomings.

II. THE DESIGN OF A COMMUNICATION SYSTEM FOR PATIENT AFFECTED BY A DEFICIT IN INTERACTIONAL CAPACITIES

Having the capacity of interacting with the environment means being able to "break the shell" and make an expression of feelings possible, in short, improve general comfort by enhancing a feeling of relative well-being, or rather – to be more modest – a willingness to face the disease.

A better understanding of the deprivations imposed to persons with motor impairments suggests to reconsider comfort and define it as a simplification of operational functions (e.g. switching the TV set on), and – at the same time – an expression of suffering when life, understood as an image of one's own self, is submitted to the test of looming death. The new instrument should therefore be designed with the idea of organizing the patient's survival. With this in mind, the purpose of the project (Brangier, Pino, Le Drezen & Lamazière, 1997; Pino, Arnold & Brangier, 1998) is to remedy a progressive decrease of interactive capacities by developing a kind of "telethesis" equipment compatible with psychic processes and offering to the patient improved functional and emotional comfort. It has the form of a communication interface named "Edith" (for *Environnement Digital de Téléactions pour Handicapé* or Digital Remote-action Environment for Disabled persons) based on the process of understanding, establishing the meaning, and metaphorizing actions.

II.1. THE MEANING OF ACTIONS

When describing the patient's situation, we have to list some of the components making up his/her life, i.e. the characteristics of his/her psychic operation. Design new technologies dedicated to the final phase of lifetime has to take account of the psychic processes at work when the individual is confronted to imminent death. Fischer (1994) has emphasized the alterations emerging in the set of values fostered by the individual experiencing an extreme situation : he/she is submitted to a kind of psychological desensitizing towards what was – until that time - experienced as having crucial significance and reorganizes the components of everyday life. These components allow him/her to introduce some fun into daily life. Consequently, the psychodesign of mechanisms to provide assistance is based on the idea that daily life is neither void nor meaningless. Saying "hello" or "you are getting on my nerves!", writing "love xxx", watching TV, listening to a record, reading a novel, etc. are not just trivial and tedious actions for individuals, particularly if they are ALS patients. Thus, the psychodesign of assistance mechanisms for patients incorporates the relationship between the individual and his/her own daily life as the very principle of the designing process.

The psychodesign of instruments for disabled persons in the final phase of their life rests on both knowledge in psychology and technological expertise to design or improve equipment for technical assistance meant to offer improved operational, cognitive, social or emotional capacities. It aims at enhancing quality of life by adapting technical equipment to the type of the communicative and cognitive strategies to be implemented by patients. Psychodesign can therefore be defined as an adaptation of technical aid for patients as they are trying to give meaning to their surroundings. Thus, this quest for meaning – which can also be defined as a form of cognitive, social and emotional data processing - aims at giving some sense to the last moments of life and to thwart the anxiety of death. In other words, the objective of psychodesign is to adapt the external features of equipment to the constraints of the user's mode of psychological operation, with the purpose of providing efficient functional and emotional assistance.

As attention is focussed on the meaning of action, psychodesign recognizes the deeply symbolic nature of human nature: the strength of human action lies in the quest for the meanings built on social interaction. Consequently, the question "why do I interact ?" has precedence on the other question "how do I interact ?". From that point of view, psychodesign

is a complement to the technological approaches focussing on the development of interaction mechanisms dedicated to the disabled. Numerous engineers have designed technical devices meant to allow seriously disabled persons who are unable to communicate with their environment to have access to the social environment through more or less enriched interaction. This applies in particular to the "Manus" manipulator arm fixed to the side of the electric wheel-chair (Gelderblom, 1999; De Witte, 1999). Recent research in communication neurophysiology (Kubler *et al.*, 1999), covering 3 patients affected with ALS and having total paralysis of the motor muscles, made it possible to develop an electronic sensor working on the basis of the electric potential of the brains. After some training, the patients gain control on the electric potential of the white matter, and are then in a position to pilot an automaton offering letter or word selection. Similar research has been carried out by Miner, McFarland and Wolpaw (1998) who showed that men can learn how to control the electro-encephalographic rhythm to pilot the movements of a cursor on a computer screen. This work gives new hopes to the patients who could then benefit from enhanced autonomy. However, this research does not address the question of the meaning of actions and is content with providing sophisticated equipment for interaction rather than contents at the end of life.

The designing process of the interface described in this paper rests, on the contrary, on the assumption that the patient does not act for the sake of action, but rather for the sake of existence, to be a full actor, a partner in his/her own right. When performing actions – understood as activities targeting a specific project - the person concerned gives a meaning to his/her situation. He/she modifies the world which surrounds him/her while changing him/herself and vice-versa. In concrete terms, the meaning of the patient's actions depends on the interactions which can go on in a hospital ward and therefore on the quantity and quality of medical (Johnston *et al.*, 1996; Gelinas, 1997); relational (Kitto *et al.,* 1986; Feenberg *et al.,* 1996; McDonald *et al.,* 1994) and cultural (Young *et al..* , 1998) interactions.

III.2.   THE PROPERTIES OF ACTION.

In spite of the great variety of our actions, Lakoff & Johnson (1985) have identified the features that they have in common. They have in particular shown that action is a specific form of cognition structuring the relationship between the individual and the world. Action is used, among other things, to make inferences between the initial intentions and the results obtained. Action thus represents the "paradigm of direct causality". The properties of action can therefore be defined as follows:
- through action, man has an objective of changing the condition of the world ;
- the change of condition occurs in the physical world ;
- to act, the individual elaborates a plan or a representation for him/herself, allowing him/her to achieve his/her objective ;
- the implementation of action involves the actualization of motor schemata designs ;
- the individual is solely responsible for the implementation of actions ;
- the individual and the environment are in turn source and target of action ;
- because of action, there is a space-time connection between the individual and the environment ;
- the modification of knowledge in acting individuals is perceptible ;
- the individual monitors the changes in the environment through his/her own perceptive capacities.

These properties characterize a relationship of causality specific to the acting systems. When the action has been performed, the physical or social object is apprehended in a different way as it has been modified, at least from the cognitive viewpoint.

When applied to designing technical aids for ALS patients, the objective of psychodesign is therefore to give rise to the potentialities of causality which will put in a perspective the

patient's mental universe and his/her environment while the person concerned does not avail of an enlarged method for action. These new causalities stem from the confrontation of the mental model of the person concerned with the metaphorical possibilities of the concepts and objects that can be handled by the technical aid. Technical aid should therefore be considered as being basically a metaphor of action.

In the context of growing loss of interactive possibilities, the aim of our approach was to design a interface with the specific aim of making it possible for a person with serious motor impairments person to be able to communicate with his/her environment and to be able to act on one's environment while promoting :
- the improvement of the quality of the care by offering to patients the possibility of expressing requests for bodily care (medical environment) ;
- the maintenance of interpersonal relations (relational environment) ;
- the development of cultural activities (cultural environment).

The designing process is therefore based on the idea that using technical aids will depend on the meaning that the user gives it : aids are related to the relevant use and the meaning of the mode of action is enhanced by the action made possible by them (Lebahar, 1994). The use of technical aids depends on the structured possibilities of action offered by them.

III.3.   THE METAPHORS OF ACTION

Physical deterioration, causing tetraplegia and aphasia, can be compensated by defining the ergonomics of the forms of patient-software interaction which will substitute for the actions that cannot be performed because of the disease. The actions that cannot be carried out are open to metaphorization. These metaphors substitute by analogy for failing actions and ensure interaction between the patient and his/her environment. The metaphors of actions can be specified and implemented by a machine (Brangier & Pino, 1997). The metaphorical possibilities of the seriously disabled person enable him/her to act remotely (or tele-act) on his/her environment. In short, the assistance device should be compatible with the perceptive and cognitive processes of the patient (as it is cannot be able with the motor processes) when dealing with the information concerning his/her physical and social environment. Following Norman (1986), we may claim that the metaphor brings closer the implementation and evaluation processes. It therefore aims at having an overlap between the psychological and physical images of the system.

We consider that the human conceptualization system, or more specifically the user model – as we are talking of man-machine dialogue - is structured metaphorically : in relation to a context, concepts are understood in terms of other concepts. However, the borderline between an object and another object is clear only in exceptional cases and the objects handled by the user are very seldom discrete. Consequently, when trying to make a distinction between procedures, or screens, users impose artificial limits to physical phenomena so that they are made discrete, i.e. entities separated by a borderline in the form of a surface. This separation of concepts – that is made possible by metaphors – works in two ways: representation and action.

A disabled person does not have effective motor schemata any longer so that he/she is no more in a position to perform actions, but only to have a representation of them. Consequently, technical aids should be capable of :
- metaphorizing the representation of the action ;
- Automatize the action proper.

Indexes for a development of the criteria for the designing of metaphors have been proposed by Carroll, Mack and Kellogg (1987) and Brangier & Gronier (2000). The idea is :
- to identify, from the user's point of view, potential metaphors or combination of

metaphors ;
- to provide comprehensive data for metaphor-software matchings in relation to scripts representative of real actions; the metaphors selected often are a common abstraction shared by a large number of users of a specific physical object ;
- to identify matchings that are probably wrong and the corresponding implications ;
- to identify design strategies as a means to assist users to manage the wrong concept matchings.

Generally, metaphors have to be defined in terms of general categories to facilitate a generalization of a concept to a class of concepts.

III.4.   THE CONTENT OF METAPHORIZED ACTIONS

Actions are set in the patient's three-dimensional environment (figure 1) :
1. The medical dimension : medical interactions are based on two functions :
- calling medical staff : the patient has the possibility of informing the medical staff about a specific problem or making a request (selecting the command activating the call button at bedside). The equipment should include a device monitoring proper operation of the automaton and activating the bell in case of failure (software problem or power cut).
- The selection of pre-recorded sentences corresponding to requests for medical assistance (for example: "could you rub some balm on my shoulders ?"), for comfort (for example: "could you turn me over on my belly ?") and to the satisfaction of physiological needs (for example, "I am hungry !").
2. The interpersonal environment ; this refers to the possibility for the patient to interact with his/her relatives, family, friends though he/she can neither move nor talk. In this case, the EDITH system offers the possibility of having control on two functions :
- The selection of pre-recorded sentences corresponding to social phrases (for example: "Goodbye, see you soon !"), the expression of an emotion (for instance :"You are getting on my nerves !") or affection (for instance :"love xxx").
- Written communication with the family, friends and the medical staff, with the assistance of an editor offering optimal character selection and a word proposal system after the first few characters have been entered. This function supplements and enhances verbal communication.
3. the cultural environment is captured through three functions :
- reading of texts stored on the computer hard disk : tracing the text, novel, or work; opening it, reading it, moving to the next or previous page, using a bookmark; leaving the text in a given state and going back to this position.
- controlling the TV set: controlling the basic commands (switching on and off, selecting channels, controlling the volume)
- controlling a compact-disk player and listening to music or pre-recorded documents.

Thus, the patient has the possibility of controlling some of the dimensions in his/her environment and can therefore, to some extent, inform, read, write, listen to and watch. This interactive telethesis offers therefore an extension of the operational and patient's cognitive capacities who, without it, would have no means of interacting with his/her environment. The EDITH system submits "representations" by means of a digital interface, even if it involves a reduction of the patient's symbolic and operational stock.

In this specific case, emotional comfort is closely to everyday life. ALS involves primarily a dramatization of daily life ! Due to the disease, the array of daily existence collapses. As the patient is not capable any longer of carrying out the most basic gestures, a set of minimal

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signs necessary for communication with the patient's environment, or grammar of relationships with other people and objects adapted to the patient's contingencies has to be developed and then implemented in a machine following the principles of ergonomics.

III.5. IMPLEMENTING ACTION METAPHORS

From the technical point of view, the EDITH system is a kind of software for environment control installed in a multimedia, portable PC for reasons of convenience in a hospital environment. The PC-control box connection is made through the LPT and the mouse dedicated port. The control box is equipped with a universal TV set remote control. It also offer the possibility of connecting additionally an on-off sensor and to control alarm calls. The EDITH system can therefore be defined as an interface for communication between a patient using exclusively an on-off sensor with the corresponding environment.

Figure 1: Synopsis of the EDITH Interacting Telethesis system.

The patient's disability allows him/her to do no more than controlling a on-off sensor. This
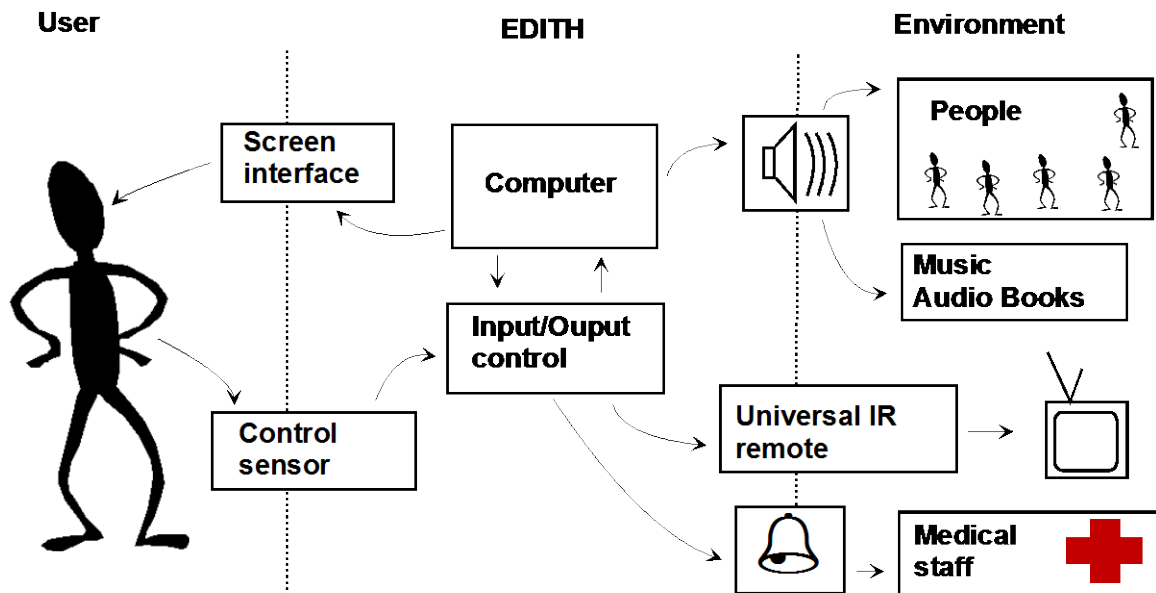
physical exercise is achieved by the hand driven by the arm. Thus, neither moving the cursor, nor letter typing are possible actions. Consequently, only validating of a pre-recorded action after covering potential functions is possible. In other words, the interface submits a menu of possible actions sequentially and the patient validates an option during the selection process. The engine selection of a specific function is performed to a large extent by the machine itself, and the patient just validates the current selection.

III.   AN EXAMPLE OF INTERACTIONAL ENRICHMENT

Parallel to the designing process proper, the EDITH system has been implemented by a patient, Jacques, who participated in the development as a user, designer and evaluator. Jacques was thus very deeply involved in this telethesis project; he actually played the key role in it. He used the telethesis system for over six months. The equipment was set up at his bedside, at eye level, with a sensor placed under his right forearm, next to the palm of the hand. The system was on permanently, round the clock.

Jacques was in hospital - in a specialized care unit – for a year until he passed away by asphyxiation at the age of 56. Jacques was aware that he was doomed; he was accompanied by family members and close relatives up to the last breath. He agreed that all procedures be recorded. Every 30 minutes, a specific file was updated with the recording of the time (day,

hour, minute, second) and the type of action performed. These data were recorded with the purpose of optimizing man-machine interactions by making them as compatible as possible with the user's cognitive processes with due consideration for the deficiencies he suffered.

The analysis of the results collected over a 10-day period (as detailed in Brangier & Pino, 2000) provides evidence of enhanced interaction and valuable information about its characteristics.

III.1. INTERACTIVE ENRICHMENT

A quantitative examination of the way Jacques used the EDITH system (results in Table 1) shows that all functions available have been used.

Types of interaction with Edith	Number of selections		Duration of selections	
	Nb	%	seconds	%
Interactions with the medical environment	854	40.07	55897	6.30
Interactions with the interpersonal environment	1052	49.34	98400	11.08
Interactions with the cultural environment	225	10.55	732603	82.61
TOTAL	2131	100	886900	100

Table 1: Types and statistical values for the various types of interaction selected and corresponding duration over a ten –day period.

The distribution of results according to the type of activities performed by the patient shows that time is filled with several components:

The first component refers to cultural activities which took up most of the time (82.61% of the time using the EDITH system) though they were least frequent in terms of number of selections (only 10.55%). This difference between duration and frequency shows that interaction with the cultural environment is the backbone of the patient's activity. In other words, the TV set and the compact-disk player are on most of the time, though the patient does not necessarily pay attention to them. We can observe that there is not necessarily a parallel between the function selected by the patient and his activity. For instance, when the patient controls his compact disk player, the sequence of actions, including switching the compact-disk player on, started reading the disk, and adjusted the sound level, is duly, but we do not know whether he has actually listened to the disk, or slept for a while, and if there was a visitor in the hospital room.

The second component shows that interpersonal relations correspond to actions which rank first in terms of occurrences (49.34% interactions) with 11.08% of the time used. In this case, the EDITH system "pronounces" the pre-recorded sentences corresponding to requests for more physical comfort (changing positions, asking for food, opening the window, etc.) and psychological comfort (expressing feelings).

Finally, the third component shows that requests for medical care account for 40.07% of selections taking up 55897 seconds. We can observe that requests for care (asking for balm, massage, eye drops etc) account for 30.83% of interactions.

These quantitative results can be supplemented by an analysis of the texts written by Jacques. These texts fall in four categories. First, Jacques makes requests for care and more comfort, i.e. asking the medical staff for specific medical action or obtaining some favorite dishes. For example "*I would like some yogurt with some strawberry syrup (and a topping of fresh cream), and then some orange juice and a cup of fresh coffee; thank you* ". Second, Jacques asks the assistants to help him perform specific actions to optimize the use of the EDITH system. For example "*please close the CD rack I have once again opened accidentally. Thank you*". Third, Jacques writes rather trivial sentences for his relatives, in sharp contrast with the moving remarks passed about life and death: "*Nicole, it's true that*

family members, friends, but also the nursing staff and helpers gave a meaning to life. The other night, during the "fit", I understood that, being surrounded by so much love, as I was at the time, death could be peaceful. Thank you." Fourth, Jacques comments on the way he is taken care of, in particular by the medical staff. The sentences are in turns demanding, ironical, sometimes full of warmth in the tone. Jacques often conveys feelings of resentment against the treatment he has to undergo and expresses his willingness to thwart the disease. For instance "*Jacqueline. Why are you suddenly in such a bad mood ? Do you think I like doing what I do ? You can be sure that, if I could turn over all by myself, I would not ring the bell. I wouldn't even be here, I must say: I am a tetraplegic . Do not tell your colleagues: they think it is all pretence.*"

Jacques' life develops on a day-to-day basis. It is captured as an experiment for itself, void of any project or plan. But, with the assistance of the EDITH system, words can again come out of a body petrified by disease. These words make sense again, they become tools to defend oneself against other people's actions, and also to keep in touch with people you like and love. When there is a possibility of "producing" words again, the patient is no longer isolated to experience suffering. He can express his pain and share it. Thus, the fear of death, the fear of asphyxiation, the physical pain take on another meaning. Just a few days before he passed away, Jacques wrote "*As far as I am concerned, I just have a bad cold*"... thus giving to understand that he had given a new meaning to his life.

In brief, the EDITH system puts the patient in a position to perform actions by remote control that, otherwise, would have been impossible. This experiment shows that a large share of our actions, discourse, and even emotions, can be conveyed by a person suffering severe communication restrictions to another person by using automated equipment, provided that the instrument designed be compatible with the characteristics of the situation at the end of life.

III.2. THE CHARACTERISTICS OF INTERACTIVE ENHANCEMENT

Interactive enhancement is characterized first and foremost by a translation of an on-off signal into a metaphor for action : producing a word, conveying a feeling, change the T.V. program, producing a sentence, etc. Enhancement is therefore basically of technological nature. Technology is then conceived on the basis of the user's logic and makes it possible to re-create the forms of interaction which had gone lost.

However, this interaction enhancement process is not comparable to what it is with able-bodied people. It can be defined using six features :

1. There is extreme simplification of interaction : it is then reduced to a combination of elementary actions, mostly in the form of controlling automatic devices (T.V. set, compact-disk players, alarm equipment, etc.) and to a selection of items with a very limited set of possible combinations (drafting sentences, pronouncing sentences)
2. There is structural linkage between the interaction and the digital environment producing it, and, therefore, the designing and the implementing of the functions in the framework of interactive telethesis.
3. The purpose of interaction is necessarily utilitarian: to have actions be performed. Using remote control functions, the disabled person has aims at obtaining a change of the state of the world. For that purpose, he/she devises a plan for actions, implements it, monitors the changes in his/her close environment and steadily checks on it. He/she is in charge and his/her actions on the world actualize a causal link. When the action has been completed, the physical or social object will be apprehended in a different way as it has been modified, concerning either the physical characteristics (e.g. changing the TV program) or the cognitive properties (e.g. "I've got a cake for you !") or the emotional dimension (e.g. "you are getting on my nerves")

4. Interaction aims at fulfilling basic intentions reduced to actions that can be carried out in the patient's physical and social environment. As a consequence of this reduction process, the medium undoubtedly has precedence on the message. It is a form of communication where the message can be equated with the medium as the latter, in this specific case, becomes the prominent communication factor. Using this medium is the necessary condition for the creation of a certain form of communication.

5. Thus, interactive enhancement gives rise to possibilities of causality which will put the patient's mental universe and his/her environment into perspective whereas the patient has no capacity for enlarged action. These new causalities stem from a confrontation between the patient's mental model (Norman, 1986) and the metaphorical possibilities offered by the concepts and objects that can be handled in telethesis. The latter controls a form of communication which can therefore be viewed as the minimalist metaphor of interaction as it is experienced by able-bodied people.

6. Interaction corresponds to the activation of ready-made operations : interaction is indeed conceived as sequence of operations involving ready-made actions and thoughts. Interactive telethesis lends its own representations via a digital interface. This corresponds to an operational reduction of the patient's wealth of symbols. This reduction process is submitted to specific rules :
   - the operational mode is minimal : selection is an on-off procedure ;
   - the syntax is minimal : the operational flow-chart and the structure of sequences is geared by technological equipment ;
   - the set of functions is very reduced: it is made up of those functions that are available in the digital environment ;
   - information is minimal : it is restricted to an implementation of intentions in relation to the patient's minimum environment ;
   - messages should be relevant : they should primarily utilitarian, with the purpose of modifying a state of the physical or psychic world.

III.3. THE FUNCTIONS OF INTERACTIVE ENHANCEMENT

The objective of interactive enhancement is to reduce suffering by raising the degree of comfort, i.e. by improving :
1. the patient's **functional comfort,** i.e. the practical benefits of telethesis (calling medical or nursing staff, controlling the T.V. set, etc.). Our approach refers to software ergonomics whose aim is to make man-machine interfaces compatible with the patient's physical and psychic characteristics.
2. the patient's **emotional comfort,** i.e. the possibility that he/she has to voice his/her sufferings, onveying his/her feelings, communicating with relatives, and, in a way, preparing for the end. The notion of emotional comfort entails that telethesis should allow the patient to get organized for the period of survival and to prepare for death.

Offering some objects of comfort to the patient calls for, on the one hand, the devising of ways to circumvent functional deprivations preventing him/her from acting on his/her environment by giving orders to automated equipment. On the other hand, to offer greater comfort to the patient, we should find ways to give him/her the possibility of conveying his/her feelings along familiar lines.

IV. CONCLUSION

This experiment shows that the designing of technical aids for disabled people cannot be reduced to an improvement of control sensors, but rather depends on the way interaction between man and his/her environment is conceived, i.e. "interaction psychodesign" (Brangier,

1994). The design process of an aid should be based on the user's psychological reality (Spérandio, 1996). In the case of ALS, the starting point should in all cases be the physical deterioration typical of the development of the disease and the adaptive strategies elaborated by the patients, to specify the users' needs. It is then possible to establish a set of specifications.

This interaction can serve as a resource for interactive enhancement modifying the structure of communication between the patient and his/her environment. This enhancement entails a sensorial, cognitive and emotional transformation in the patient. The individual is then again in a position – relying on his/her psychic and technological assets – to play an active role as he is in touch with his/her social environment. The disabled person can do more than just coping with an unbearable situation; he/she can also respond and interact with other people for whom he/she is again a citizen in his/her own right. In brief, interactive enhancement makes room for the implementation of a social phenomenon allowing for minimal information exchange between a severely disabled individual, a digital environment making an editing of communication possible, a physical environment, and a human, emotionally affected environment.

The authors would like to pay homage Jacques' memory s and offer posthumous thanks for his sense of cooperation and an extraordinary display of confidence.

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