Design of Technologies for the Support of Disabled Persons: Representations from Carers and Assisted Individuals with Regard to the Use of Technologies

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Abstract: Our article deals with the issue of the role of technologies in the support process for disabled persons. This work falls within the scope of the INTERREG IVA COALAS project which brings ICTs and robotics into play with regard to the issues of helping dependent individuals to stay in their own homes and to improve their mobility. Our approach incorporates the hypothesis that one of the main preoccupations of disabled individuals is seeking social relationships. Our methodology is based on semi-structured interviews and direct observations of a sample made up of young adults, elderly people, family and medico-social carers. The results confirm our working hypothesis and underline the importance of human contact. It also emphasises the need to adapt the design of the technologies to the individuals' daily lives.

Key words: Disability, Social survey, Assistive technology, Assistive robotics

1. Introduction

For several years now there has been an increasing use of technologies (Information and Communications Technology - ICT, robotics, etc.) in the support of disabled and/or elderly people to supplement the work carried out by families and medico-social teams (Rialle, 2007). The initial technologies which were widely distributed in France were in the 80's and used telephony (pendant alarms) (Reguer & Toutain, 1996). Since then, humanoid robots such as NAO (made by the company Aldebarran) and technologies in the home automation sector have been developed. As soon the subject of their inclusion into the individual's normal living environment is mentioned, several controversies emerge, both socially and ethically (Cornet & Carré, 2008).

These controversies often escape those involved (manufacturers, researchers, etc.) who are preoccupied with the use of their technology for the benefit of human beings and able to substitute for them (Broekens, Heerink, & Rosendal, 2009). This position differs from that of the users, the assisted individual and carer looking for reciprocal relationships. The underlying question may be asked in these terms: do the technologies lead to dependency or a relationship? In all cases, the technologies are not something apart from the social link (Musso, 2008). It is important to gather representations from the various actors involved, both assisted individuals and carers, with regard to the contribution these technologies can make in supporting the organization of a social life (Lecompte, 2003). The INTERREG IVA COALAS (Cognitive Assisted Living Ambient System) project falls within the scope of this field of research and aims to bring into play information and communication technologies and robotics as a response to the issues of allowing dependent individuals to stay in their homes and to improve their mobility. In particular, the COALAS systems incorporate a set of heterogeneous and collaborative sensors based on an instrumented wheelchair and humanoid robot (Figure 1).
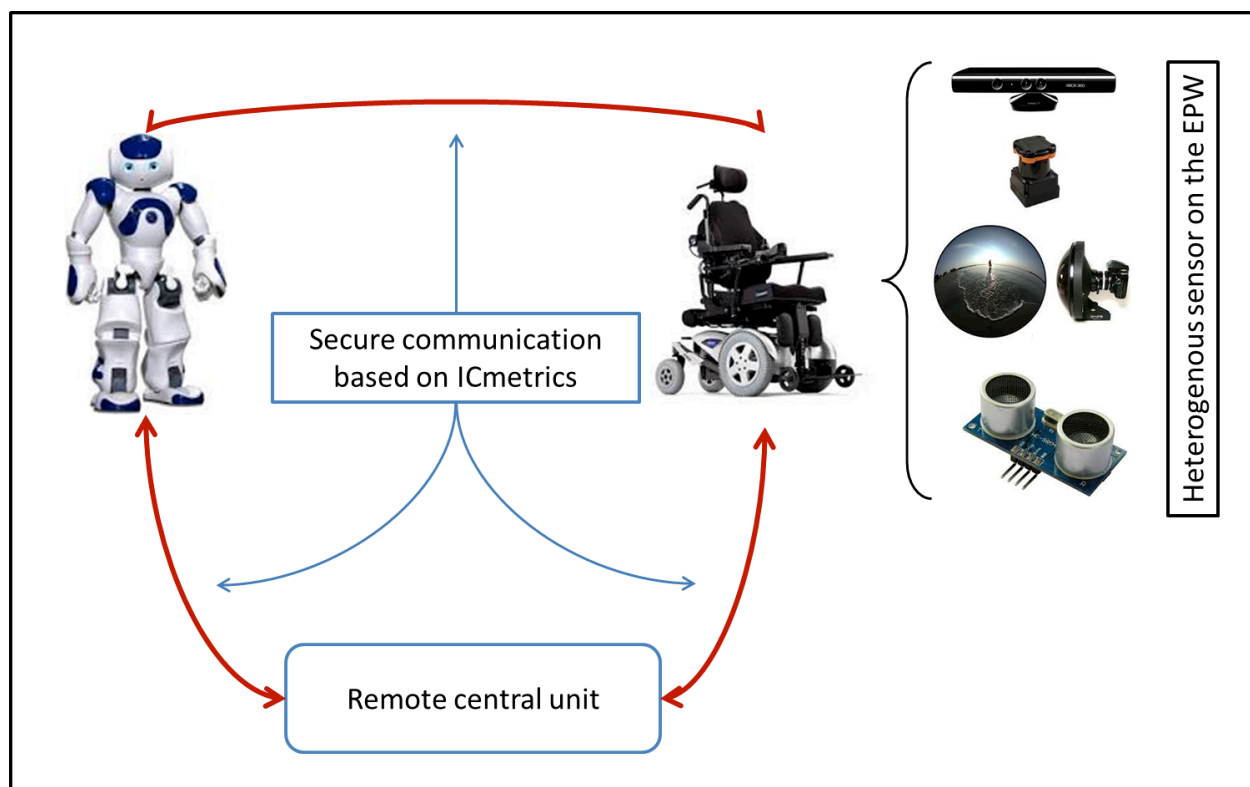

Figure 1. COALAS systems

By basing itself on an interdisciplinary approach (Engineering, Human and Social Sciences), this project aims to respond to new needs and uses by incorporating the expectations of the carers and users throughout the project. The COALAS project started in November 2012 and finishing in 2015 is divided into 3 phases: a) expectations and recommendations, b) technological

development, c) evaluation. This article presents the methodology and results of the "social acceptance" survey carried out in phase a) of the project.

2. Methodology

A. *Survey and sampling methods*

The social survey focuses on the place that COALAS's technologies can play a key role in the organization of social life of the disabled people. In this process of help, it is often mentioned the difficulties that face carers, sometimes overloaded by the amount of work to respond effectively to the expectations of the disabled persons. Thus, it requires taking into account the considerations of the carers whose role is very important in this process of help. We can consider that the machine enrolls to stimulation of the user rather than the substitution of its actions. That's why, we chose not to do a lot of interviews with involved people (elderly, disabled) but doing more with different care helpers around the same situation. To carry out the social survey, the semi-structured interview and direct observation were chosen as data gathering techniques. The interview guide aims to set the specific context for the assisted individuals: to observe the social inclusion (daily activities and occupations, trips, etc.); specify the current living environment (mobility and communication equipment, difficulties in the home with regard to housing, wishes, etc.) and to describe and hold discussions involving COALAS systems. This framework has enabled interviews to be carried out with disabled individuals and those around them as well as with the administrative and service managers. Regarding the make-up of the sample, we were interested in disability at two age ranges: young adults and elderly people. We also decided to target specific situations:

- Individuals in wheelchairs (electric or manual),

- Individuals who can only move with difficulty using a walking frame or support bars requiring the contribution of services for actions essential to daily life without being present permanently,

- Individuals with Alzheimer's disease or similar requiring regular surveillance.

We have thus put together a non-representative but characteristic sample. These three types were chosen as the establishments informed us that these were standard situations to which COALAS systems could be applied. They enable both the qualitative pluralities of the situations as well as the social dynamics to be recorded. The interviewees are old between 20 and 95 years. The majority of dependent persons live alone at home or in institutions. Our sample of dependent

persons (elderly, disabled) have different social backgrounds. It is made up of retirees, young students or not, and adults recognized as invalid persons. These people suffer from different types of disabilities or diseases: apparent (paralysis, vision problems, hearing problems) or other debilitating diseases (blood pressure problems, Alzheimer's, bedsores etc.).

B. *Data collection and processing*

This study is based on qualitative survey through the interviews. The interviews aim to highlight the representations that people may have about COALAS's technologies. The qualitative survey was carried out in March and April 2013 in Rouen and Le Havre. At Rouen, the survey was carried out within an Etablissement d'Hébergement pour Personnes Agées Dépendantes (E.H.P.A.D) (Elderly dependent persons' residential home) and with actors involved with disability working in public or private institutions. At Le Havre, we worked mainly with the Elderly Person's division of the Centre Communal d'Action Sociale du Havre (CCAS) (Le Havre communal social action centre), and a personal support association (Association d'Aide Familiale Populaire: AAFP) along with the University of Le Havre.

30 interviews were held concerning these three "mobility situations". The originality of the survey also comes from the desire to build the social system around the disabled individual. Four to five individuals (caregiver, nurse, academics, etc.) around the disabled individual were interviewed (see Figure 2). They constitute the social system within which the individual moves and are considered as an actor. Other interviews were held with the administrative and service managers. These people do not work directly with the ill or disabled individuals. They are considered as knowledge vectors, holding a certain level of expertise which they stated during the interviews. Moreover, they work directly in advising decision makers and in the design of tools and equipment provided to the professionals.
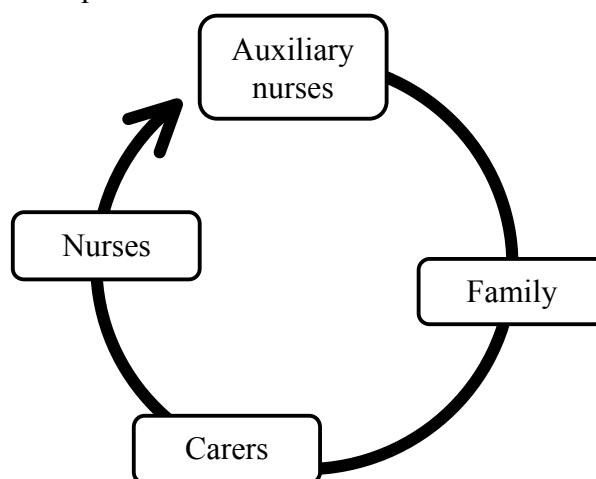

Figure 2: organisation of the interview for a given situation

3. Results

Regarding the analysis of results, this is done by integrating extracts from the interviews (as we have incorporated them below). To link with phase b) of the COALAS project, the interviews were analysed in order to feed into a technical specification split into two categories. Firstly, a list of the most often encountered daily situations was compiled. Secondly, recommendations were formulated in order to produce usage scenarios dealing with the major topics chosen by the COALAS partnership. These topics relate to the promotion of communication, mobility support, monitoring the state of health and detecting anomalies.

A. List of daily situations

1) The family and management of the disability

Caring for a disabled person, whether living at home or in an establishment, remains a family concern both financially and socially. The family is a central structure in this support process. It manages two activities at the same time: its own and that of the disabled person. This double management is often a heavy burden: "Yes, there is a home help who comes every morning 5 days a week, but I do the rest and it's quite difficult to manage in fact because I do the washing, shopping, deal with doctor's and chiropodist's appointments, then I deal with washing, I think we'll get someone in because it is a lot for me to do, I'm doing too many things at once, I have my own home to do" (retired woman, dealing with her mother aged 93 who walks with difficulty using a frame). Some families give up their jobs to dedicate themselves fully to support: "Before, I worked for an elderly person, when my mother had all her health problems, when she came back here, I stopped working for this person to care for my mother. So this became my job" (woman dealing with her elderly mother of 86 who uses a manual wheelchair and has Alzheimer's). Caring for a dependent person sometimes destabilises the family and can lead to disagreements both as to the methods to be used and the sharing of the consequent financial burden: "My sister wanted a patient lift because she thought she had back problems, while my mother did not want a patient lift [...], we're not the same type" (woman dealing with her elderly mother of 86 who uses a manual wheelchair and has Alzheimer's). In addition, an imbalance in the active participation by members of the family regularly occurs. We observed that most often the responsibilities were borne by those who lived closest. Also raised were the financial difficulties which arose as dependency increased.

2) "Galaxy" of disabled situations

The alteration in the state of health of an individual, particularly when elderly, often results from chronic illnesses, a weakening of physiological capacities, or multiple obvious disabilities: sight problems, motor problems, paralysis. In certain cases, the disability may come on top of another series of illnesses: "She's been here for 20 years. She has always had health problems, several operations, about thirty, neck, knees, and prostheses almost everywhere. In 2007, the two [epilepsy and CVA] combined together, in addition to the previous problems", (woman who cares for her mother aged 86, manual wheelchair user with Alzheimer's). Psychoaffective disorders (depression anxiety etc.) can add to this due to a variety of factors (solitude, isolation, suffering, loss of a loved one, etc.): "When you're in a wheelchair, you are cut off from the outside world. You become dependent. And lots of things have stopped me getting out. People I used to see I can no longer get in contact with. This disability is very difficult to handle both mentally and physically" (man, 76, living alone in elderly person's residential home, electric wheelchair user). Note that obvious disabilities can not only impede the general mobility of the body but also affect the so-called fine motor control which relates specifically to the hands. This poses problems for example in holding things for long periods in the hands or carrying out small manual tasks : "It can be difficult for me to get a drink for example when I am alone or little things like that. Because I cannot control my hand movements", (man, 35, disabled, electric wheelchair user). A major difficulty emphasized by most of our interviewees related to falls. The elderly were more affected. The case of falls occurring in the home, particularly in the bathroom and shower, is raised: "It's often falls, dizziness. It is generally the same things. Dizziness mostly. It is often in the apartment", (manager of an establishment for elderly people himself with elderly parents.); "I fell in the bathroom, [...] I had to crawl", (woman, 87, living alone in sheltered housing, moves around with difficulty using a walking frame). It came out from the interviews that a good number of the difficulties encountered were connected with the management of basic daily tasks: personal hygiene, brushing teeth, shaving, dressing, getting up or going to bed, opening and closing shutters, opening a door, going up and down the stairs, doing housework, preparing meals, heating food up in the microwave, feeding, taking medication, moving around without support, etc. These difficulties are generally the same both for disabled people (young people or adults) and elderly dependent people. There are many examples: "The only thing I have a slight difficulty with is shoes for example, this requires quite fine motor control, it's a bit complicated, nowadays my mother puts my shoes on", (man, 21, motor disability, uses electric wheelchair); "it's mostly shaving and looking after my nails that I can't do", (man, 35, motor disability in electric wheelchair). Disabled individuals generally suffer

from a lack of mobility both inside and outside their dwelling for various reasons which we have classified into three categories. We observed a loss of motor functions: they cannot or can hardly get around. This can also result from personal choice: they don't want to travel around due to disaffection or the disappearance of their usual social environment. They do not want to take part in meetings or activities offered to them. Finally, at other times the world comes to them: television, telephone, connected computers, etc. We also observed that in an establishment, activities and events are organised but movement over a short distance is still required.

B. Recommendations for usage scenarios

From the knowledge of these daily situations, the second section of the study had the intention of bringing together the technical proposals produced in the COALAS project. Depending on the various facets selected from the scenarios to characterise the social relationship, the SHS team formulated the recommendations detailed in the following sections. Before giving the details of these recommendations, we would like to point out that the fact of being for or against the use of COALAS systems in everyday life emerged as a false problem. We will consider that, on the one hand, the development time of the system follows the distribution time of ICTs in society at large. On the other hand, from the demographic viewpoint, the low exposure of elderly people to the use of ICTs will gradually reduce.

1) Promotion of communication

Everyone was unanimous about household tasks being taken over by technical systems. But a human presence is wanted at meal time or when washing. These two moments are very important as they are occasions for talking with others. With regard to the use of ICTs in our samples, two positions emerged: for elderly people, using a landline telephone emerged as the most familiar. The systems should take this observation into account. With disabled people, we find more familiarity with technologies used in everyday life generally, and there is more openness towards computers and the new generation of ICTs.

2) Mobility aids

The wheelchair is considered as the main COALAS response to this objective. With regard to the technical characteristics, the stated requirement is for a wheelchair which is less conspicuous than what currently exists, lighter, using electric drive and able to extend the periods when the user is able to travel around outdoors (night for example). However, the representations of the wheelchair differ widely between the two categories of dependent person considered. Elderly people have a bad image of it as it appears degrading and is associated with a loss of autonomy.

They reject its use as far as possible. For younger disabled people, it is an everyday object. They are looking for any forms of aid which could improve their daily lives and adapt to the disability.

3) Monitoring the state of health

The principle of recording physiological data emerges as worthwhile input. The usage context would appear complicated insofar as monitoring is carried out via the wheelchair. Telemedicine would not seem plausible in the case of regular appointments for monitoring the state of health. In addition, the substitution of telemedicine for human contact is not wanted. On the other hand, emergency telemedicine is a scenario raised by various surveys in order to detect anomalies without symptoms perceived by the individual or to analyse anomalies with perceived symptoms triggering an emergency procedure to alert the medical profession.

4) Detecting other types of anomaly

According to the reasoning expressed by the interviewees during the interviews, detection by COALAS systems could be increased when the dependent individuals are alone. The "other" anomalies raised relate to unexpected events occurring during mobility. They thought that the COALAS systems could directly manage the presence of obstacles and discharged batteries. Or with remote assistance (both indoors and outdoors) coupled with the wheelchair, the systems could alert those around or professionals depending on the situation.

IV. Conclusion

The effect on social life expressed in the interviews related to the COALAS demonstrator confirms our hypothesis with regard to the importance of social relationships. Indeed, regarding the results of the survey, it emerges that the presence of the family or the carer must under no circumstances be called into question while at the same time hoping the systems do not cause inconvenience. Human contact, particularly with the doctor, is highlighted as being reassuring, an opinion which was emphasised both by the assisted people and the carers. We saw this for example when we dealt with the use of telemedicine, and even a robot, as a means of accessing this support process. From the point of view of the dependent individuals, family and medico-social carers, with the exception of housework, the COALAS demonstrator must not be a substitute for tasks involving human contact. A risk which was expressed was based on the reduction or even replacement of visits by the carer or the family. On the other hand, when no-one else is present, the COALAS systems may be present in the person's environment to help manage various types of unexpected event in place of the carer or the family. They can play a role in safety in the home. In the absence of the carer, the COALAS systems can contribute to the

safety of the individual by in particular analysing anomalies as well as supporting social relationships. Complementarity is, first and foremost, what is required. It is as if the help from the technology must not just be designed for the disabled individual, but for the benefit of the carer as well. It involves relieving the carer so that they can concentrate on the social relationship. Other questions are based around technical malfunctions, efficiency indeed the relevance of these systems. It is essential that the engineer and researcher goes beyond the mechanical approach to avoid the risk of thinking of the person as part of a machine. It's about adapting to the needs of the user, and above all adapting the design to the actual situation, in this case, the social reality (Scardigli V., 1992). Finally, the perception of the Technology, sometimes hostile often suspicious, is likely to gradually subside. Indeed, the natural demographic trends will gradually reduce the share of the population (the elderly) reluctant to use these technologies.

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