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Communication system for persons with cerebral palsy: In situ observation of social interaction following assisted information request

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Abstract. People with disabilities may encounter many communication difficulties. Our main goal is to develop a communication system, called COMMOB, designed to assist people with cerebral palsy in different contexts: at home, at work and in public places. After a brief review of the different categories of assistive communication systems, our user-centered design approach is presented. COMMOB was tested in a public place in the context of a help request by a cerebral palsy person in a wheelchair. The result concerns particularly the response rate. The assistive power of COMMOB was rated from the respondents' and the user's point of view. The main lesson to be learned is that the most difficult was to attract the attention of people and to engage the interaction.

Keywords: Communication; mobility; cerebral palsy (CP); communication aid; COMMOB.

1 Introduction

People with disabilities are often marginalized, due to different processes of exclusion depending upon their physical, psychological, or cognitive functioning level. Restricted access to transportation works to isolation. Progress has been made in terms of accessibility due to architectural and technological improvements, but many individuals did not take advantage of these environments especially because of communication limitations. Fear to be unable to get information and/or help from others if they had to deal with an unforeseen situation may lead to feelings of generalized helplessness. The presence of an accompanying person (mostly usual family or professional careers) is thus often a *sine qua non* condition for travelling. However, this dependency can be seen by several disabled people as a limitation in both the development of an expected barrier-free living and their wish to have a meaningful role in the society. But requesting help from an unknown person is a challenge for many of them.

The first goal of the present research program is the development of a communication system designed to assist people with communication impairments not only at

home or at work with their relatives or colleagues, but also on the go with unknown individuals. This communication system also allows the communication with software applications (e.g., to write a document, to consult web sites, or to program), but the approach reported here does not exploit this potentiality. The specifications of this communication system, called COMMOB (COMmunication means for MOBility), have been published in [4] [5]. The second goal is to test the efficacy of this system in real setting for both the disabled requester and the information/help providers. This paper focuses on this goal and it begins with a brief state of the art about different categories of communication systems for people with cerebral palsy. Different communication needs of such people (considered here as users) are accordingly presented. Then, our current work on the COMMOB communication system is explained. The article concludes with a discussion and research perspectives.

2 State of the art

People with athetoid cerebral palsy (CP), i.e., multifaceted impairment syndrome secondary to lesions or anomalies of the brain arising in the early stages of development, often encounter difficulties to formulate understandable sentences due to dysarthria. They also frequently present difficulties in making gestures that prevent the production of written language with either pen or keyboard. No two patients are affected in the same way, including as for their intellectual abilities: despite mental retardation is frequent, many patients have a normal intelligence [6] allowing them to use rather sophisticated systems.

Several main categories of communication aids, more or less usable by people with cerebral palsy, can be identified in the literature: virtual keyboards (see several examples in [2] [5] [7]), physical aids (such as Guide finger [1] or EdgeWrite [12]), speech recognition system [11], brain-computer interface [13] (Please note that optical motion tracking is not considered in this study, due to the uncontrolled movements of many people with cerebral palsy). The time required for text entry using virtual keyboards is important for people with cerebral palsy; more, such devices require a significant physical effort over a long period (see an example of a study in [3]). The physical aids have the drawback that they must be used since childhood to be very effective [3]. Speech recognition is not yet effective for people suffering from dysarthria [11]. Brain-Computer Interfaces are not usable for complex tasks.

The state of the art of the different categories of communication systems for these people revealed that very few are designed for a mobile usage.

3 User-centered evaluation of COMMOB

A first prototype of the COMMOB communication system is available. COMMOB is part of the doctoral thesis of the first author. This system is based on pictograms that were chosen to allow quick text entry using virtual keyboards. The difficulty is not only to make the software easy to use from the user interface point of view; the users have also to be efficient in their communication tasks; too much involuntary move-

ments would temporarily or permanently reduce their accuracy in their actions through the user interface. The communication system is used on a tablet computer, which is installed directly on the wheelchair. We chose a tablet computer to make a compromise between the size and the display surface.

The Figure 1 shows page screens of the user interface, accessible through a joystick installed on the other side of the wheelchair: from the window #1, each module is accessible; for instance, the window #2 contains a module helping a computer scientist user to program (different pictograms helping to insert Java code are available); the window #3 shows a module supporting the generation of sentences from pictograms; the window #4 shows the virtual keyboard helping to generate words and sentences which are not represented by the available pictograms (e.g., names of cities).

Fig 1. Page-screens of the user interface of the COMMOB system.

By definition, the system must help the user to explicit a request or exchange information without ambiguity and with a sufficiently high production rate. The performance at this level can be quantified with a series of objective parameters, such as the time needed to create a sentence and to express it to somebody, or the number of words produced per minute.

In addition to its technical performance, the system is also expected to play a role in the social interaction between the requester and the information/help provider, who is latter called “the respondent”. As shown by [2], CP adults often report lower well-being than healthy controls and this seems to come from their life environment because of inconvenient life in their community and few opportunities to go out. However, many CP adults had self-esteem scores similar to those of the nondisabled groups [8]. The desire to be perceived as mentally competent to the greatest extent possible has also been reported [9]. Ordinary people in the street can be ignorant of the characteristics of the syndrome and its variability. The risk of failure in the information or help request is thus high, especially since uncertainty for the respondent as regards the requester can be a barrier to the social interaction. To see the technical equipment and its usage by the user will provide information about the intellectual ability of the disabled person. The respondent could thus adapt his/her behavior con-

sequently. The present study aimed at testing this assumption in a context of mobility, in a shopping mall (Fig. 2).

Fig 2. Cases of interaction using COMMOB in the context of mobility: information request concerning the location of the nearest station.

4 Study

The user who is the first author himself is a person with athetoid cerebral palsy. This 29-years old man presents communication difficulties as well as motor difficulties that require the use of an instrumented wheelchair (40% of the CP people are non-ambulatory patients [10]). With the help of COMMOB, the user tried to engage interactions with those who attend lonely this area. The scenario was standardized at its initial steps. The first sentence produced by using COMMOB was “Hello, I need help” in French language. If the pedestrian stopped, the following question was asked: “Where is the tram station?” The next exchanges were open. Two experimenters completed an observation grid, consisting mostly of check boxes, in order to collect data about every attempt of interaction, especially gender and approximate age-class of people contacted by the user, and the outcome of the attempt of interaction. The total length of the effective interaction was measured. During the observation phase, the experimenters were situated far enough from the user and the respondent for not interfering in the social contact. At the end of his/her attempt to help the user, the respondent was interviewed by a female experimenter who came to him/her for this purpose. Questions bore on the performance of COMMOB and on the opinion of the respondent about the system. The respondent’s knowledge of CP and any possible familiarity he/she might have with people suffering from CP or other disabilities were also rated. Responses were given on Likert scales or were notes between 0 and 10. Completing the questionnaire required no longer than 5 min per respondent but he/she was free to provide additional comments if he/she wished. Thereafter, the user rated the quality of the interaction from his point of view, with the possibility to add comments about his usage of COMMOB during this interaction.

Since most of the data related to the interactions presented a violation of normality conditions, non-parametric statistical analyses were performed

5 Results

Summary of the interactions. The requester performed 281 attempts to interact with mall customers (women: 66 %); 7.6% of these people were estimated between the ages of 18-25, 55.1% between the ages 26-45, 28% between the ages 46-60, and 9.3% over 60 years old, without gender difference. Among those approached, 214 people (76%; group A) showed no signs of attention to the requester, whereas 45 did (16%; group B) but without real interaction (e.g. some just said “Hello”). Only 22 customers (8%, group C) engaged themselves in a deeper exchange with the requester. Gender differentiated these three *a posteriori* groups ($\chi^2(2)=19.2$; $p<.001$), with a higher ratio of women in the group B (82% vs 58% in the group A, and 55% in the group C).

Ten respondents (group C) had a disabled person in their circle of acquaintances. Only one respondent knew what cerebral palsy is (just a little knowledge: 9; total ignorance: 12). The opinion the respondents had about the ability to get around alone people like the requester have ranged from a pessimistic view (0/10: “totally impossible to get around alone”) to a rather optimistic view (8/10, with 10 corresponding to “they can get around without any problem”; median note: 5/10); this note was not significantly related to the other data. The requested information about the station was clearly provided by 9 respondents and was given incompletely by 7 other ones. The duration of the interaction varied between 17 s to 90 s (median duration: 41.5 s) and was not related to the other data. The shortest durations were due either to the fact that the respondent did not know where is the tram station, or to the fact that they quickly offered to accompany the requester to the station, a proposal that was not accepted.

COMMOB from the respondent’s point of view. To the question of how the assistive system (only labeled as the ‘system on the wheelchair’) is helpful to disabled people such as the requester for getting around alone, the median response was 8/10 (range 3-10; Fig. 3). To the question of whether the system can incite people to help the disabled requester, the median response was 7/10 (range 2-10, Fig. 3). The notes for these two items did not significantly differ ($W(22)=59$, ns) and they were positively correlated between each other ($\rho=0.69$, $p<.05$).

Fig 3. Respondents’ opinion (notes between 0 to 10) about the help the assistive system COMMOB can provide to disabled people, such as the requester, for getting around alone (left) and its incitative power for providing help (right).

Figure 4 showed the notes given by the respondents for the 3 items bearing on the quality of their own experience with COMMOB for reading the sentences on the tablet screen (median note: 10/10; 3 respondents were excluded since they did not look at the screen), for hearing the sentences produced by the speech synthesis (median note: 9/10), and for the communication rate allowed by COMMOB (median note: 6/10). Overall, these three notes significantly differed between themselves ($F(19,2)=6.14$, $p<.05$); the communication rate note was significantly smaller than both the reading note ($W(19)=16$, $p=.02$) and the hearing note ($W(22)=17.5$, $p<.01$), which did not significantly differed and were not significantly correlated between each other ($\rho=0.35$, ns). However, both the reading and the hearing notes were significantly related to the note provided for the communication rate (respectively, $\rho=0.49$, $p<.05$, and $\rho=0.56$, $p<.01$). The correlational approach did not significantly relate each of these three notes to the respondents' opinion about the help provided by COMMOB and about how it incites people to help the requester. However, the mean note for these three items significantly predicted the estimates of the helping power of COMMOB ($\rho=0.43$, $p<.05$, Fig. 5; for its incitative power: $\rho=.297$, ns).

Fig 4. Respondents' assessment of the quality of their experience with COMMOB (notes ranging between 0 and 10) for reading the sentences on the tablet screen (left side), for hearing the sentences produced by the speech synthesis (center), and for the communication rate (right).

Fig 5. Rating of amount of help the respondents thought that COMMOB provides to the requester (note between 0 “not at all” and 10 “extremely”) as a function of the mean evaluation of their own experience with COMMOB [(reading + hearing + communication rate)/3].

COMMOB from the requester's point of view. Difficulty in the access to the pictogram was reported only once by the requester ("quite a bit", due to reflection on the tablet screen). The ratings for the communication rate ("quite a bit" or "extremely" satisfactory in 81% of the cases) and for the speed of the joystick manipulation ("quite a bit" or "extremely" satisfactory in 95% of the cases) were not significantly correlated ($\rho=0.36$, ns), the lowest communication ratings given by the requester being mostly related to understanding difficulties he attributed to the respondent. Interestingly, these two ratings by the requester were far to correlate with the communication-rate note provided by the respondents (respectively, $\rho=.03$ and $\rho=.06$, ns).

As for the socio-behavioral components of the effective interactions, their initiation and the interactions themselves were rated by the requester as easy or very easy in respectively 95% and 86% of the cases, with a significant link between these two variables transformed into a 5-point scale ($\rho=.69$, $p<.01$). The correlational approach also revealed that the satisfaction of the requester with the interaction itself was significantly related to his satisfaction with the manipulation of the joystick ($\rho=.43$, $p<.05$), but not with the other factors including the communication rate ($\rho=0.34$, ns) as well as fatigue or pain (respectively, $\rho=-.17$ and $\rho=-.32$, ns). Pain was experienced during 7 interactions ("a little bit" for 6 interactions and "moderately" for another one), and fatigue occurred during 15 interactions ("a little bit" for 12 interactions and "quite a bit" for 3 interactions). Overall, pain and fatigue were significantly related ($\rho=.48$, $p<.05$), and the amount of fatigue was also negatively related to the satisfaction with the joystick manipulation ($\rho=-.53$, $p<.05$).

6 Conclusion

The study confirmed the usefulness of COMMOB for helping a cerebral palsy person with strong communication limitations to request information to unknown individuals. Some technical improvements are suggested, especially to the screen location that limited the requester's gazing toward the respondent, which is an important component of the social interactions. The engaged interactions were mostly a rewarding experience for the requester towards an expected barrier-free living. However, the more crucial point was the difficulty to engage the interactions. The short-term perspectives focus on the strategies aiming at increasing the response rate with the help of COMMOB.

Other perspectives are linked to (a) the development of the COMMOB system, about new functions which can be envisaged, especially for improving the communication flow, and to (b) different types of complementary evaluations in laboratory or in mobility contexts.

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