

Applying Value Sensitive Design in Pervasive Brain-computer Interfaces

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ABSTRACT

Our paper investigates the values fostered and inhibited by current Brain-computer Interface systems for the physically disabled. We report on a study conducted among 12 physically disabled individuals by employing Value Sensitive Design, a tripartite methodology accounting for human values in the design process. Our study reveals that current systems restrict independence, articulation, recreation and customization. We also elicit values that we believe are important in designing Brain-computer Interfaces - family-centricity, a sense of community, altruism, intellectual involvement and autonomy. We discuss how Value Sensitive Design applies to the unexplored domain of Brain-computer Interfaces.

Author Keywords

User-centered Design, Value-sensitive Design, Brain-computer Interfaces, Pervasive Computing.

ACM Classification Keywords

H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

INTRODUCTION

Motor neuron diseases such as Amyotropic Lateral Sclerosis, stroke, brain injuries and cerebral palsy affect 60-70 people in every 100,000 [5]. These diseases cause severe paralysis, muteness but leave the person cognitively intact and alert [3]. Various techniques – invasive and non-invasive, convert a brain signal into a control signal to affect the movement of a cursor on the screen [4][8]. Unfortunately, apart from paralyzing a person progressively, these motor neuron diseases also cause

emotional and psychological damage. The onset of such a disease precipitates reverse parent-child roles, lowers self-esteem and increases dependence on others. Although research in Brain-computer Interfaces has come a long way in sensing and instrumentation, the current systems hardly support “regular” applications, such as reading e-books, social networking, gifting, customized for the paralyzed user[2] [6].

In our study, we investigated the value, habits and day-to-day activities of users of Brain-computer Interfaces. We employed the principles of Value Sensitive Design created by Friedman et al [1] to gain insight into the practices supported and inhibited by current systems. We discuss our salient findings and emergent values, and the appropriation of Value Sensitive Design in the design of Brain-computer Interfaces.

METHODOLOGY

Participants

Twelve participants across various stages of paralysis from twenty-one to sixty were recruited. There were equal numbers of males and females. The participants were recruited through ALS listservs, existing laboratory contacts and snow-balling.

Methods

Value Sensitive Design

People and social systems affect technological development and technologies shape individual behavior and social systems. This is an iterative tri-partite methodology, involving conceptual, empirical and technical investigations, which we describe below.

Empirical Investigation

The empirical investigation is applied to any human activity that can be observed, both qualitative and quantitative. Here, we tried to understand the social meaning of technology through interviews. We sought to understand the mundane activities and its context, to reveal the challenges faced by the community.

Conceptual Investigation

Here we tried to understand the direct and indirect stakeholders of the system, implied values and trade-offs between them.

Technical Investigation

In this stage, we analyzed how technological properties and underlying mechanisms inhibit and foster the values from the previous stages.

KEY FINDINGS

After conducting grounded theoretical analysis on the data sets from above, we obtained five overarching categories from open and selective coding. Briefly, *restricted independence* is dependence on others for basic activities, *restricted control* is the lack of control of multiple devices, *lack of articulation* is the inability to express oneself or the absence of a medium for doing so, *reduced recreation* is the limited creative and recreational venues, *lack of customization* is the lack of options to modify a system suitably. We shall discuss these findings in detail below.

Restricted Control

The clinical nature of Brain-computer Interfaces in laboratories has resulted in very few practical and useful applications for the user. With the bare minimum speller and e-mail, users found it hard to control appliances, web services and other gadgets. Participants responded:

I would want to Control entertainment devices, play games, live a life close to normal.

Basic communication and control of entertainment devices (TV, TIVO, DVD, Radio) would be at the top of my list to be able to control myself.

Restricted Independence

Since very little control is available to the user, there is increased dependence on others to get tasks done. Basic necessities such as tying shoe laces and brushing teeth cannot be meted out by the user, depending on the degree of paralysis. In addition, the lack of mobility has serious effects on the freedom of the user.

Lack of Articulation

With the current technology, it is hard to call for assistance or express oneself to someone not present in the same space. E-mails and IM's do not always seem to work, especially when the recipient is not present at the computer perpetually.

I ask (my care-giver for assistance) if she is within earshot. If not sometimes I use Instant Messenger on the computer from mine to hers. Sometimes I just have to wait until she comes back into my area.

Reduced Recreation

Since a lot of these applications have been focussed on

basic communication needs such as spellers and browsers, there is almost no medium to express oneself creatively and otherwise. One of our participants noted:

To be able to speak or write fast enough to participate in a normal conversation would be sheer joy. My wildly entertaining wit and humor could once again shine through!

Lack of Customization

Since these applications are still rudimentary, very few customization options exist. The user may want to change the font, color or preferences, but the dialogs are not suited for paralyzed users.

The emergent values from the above stages of the investigation are:

Family-centricity

We observe that the participants were tightly knit with families and friends. Families offer *moral support* as well as *physical assistance*. 86% of our participants noted that spending time with the family was recreational. A participant commented:

I have a terrific support network made up of family and extended family. I have a brother and 2 sisters that are all married with kids and my parents and we all live within 15 miles of each other. We get together regularly, whether it is a holiday or birthday, BBQ or watching football (in season).

Community

This is a conceptualization that we use to refer to a common interest and a drive to nurture the group. 80% of the participants spend majority of the whole day in front of the computer, checking e-mail and group messages. A participant commented:

I spend most of my day on the computer. I co-host MDA ALS chats that are held 3 days a week. I also compile the Will Hubben Research Digest that is hosted by the ALS TDI formerly the ALS TDF. I have fallen behind on some of that as I'm doing physical therapy 3x/week for rehab after the pump implant.

Altruism

This is a conceptualization that we use to refer to helping others without personal gain or benefit. In 66.6% of the cases, the families of the participants were also involved in spreading the word about motor neuron diseases. The contributions impacted a wide range of people in variety of ways, such as answering a question about local doctors, standing by a newly diagnosed patient, providing greetings and well-wishes. As noted by a participant:

I attend support groups hosted by MDA & ALSA. I am an active fund raiser for the MDA through the telethon and

Stride & Ride events. My sons are also active and my wife is on the board of directors of the local MDA chapter. I am involved in the Living-with-ALS Yahoo group. There are over 2500 members worldwide. It is an e-mail list that has wonderfully supportive folks. They share struggles and solutions to common problems that affect people LIVING with ALS. They are remarkable positive and upbeat. The evening before clinic visits there is a mixer for newly dx'd pts. I usually attend this and attempt to answer questions to keep fears at bay.

Intellectual Involvement

We define this conceptualization as activities that stimulate thinking and are enjoyable. About 33% of our participants commented on the inability to express creatively.

Autonomy

Finally, this conceptualization refers to the personal independence in carrying out (day-to-day) activities. this value overrides all other values and is prime to self-esteem.

VALUE SENSITIVE DESIGN IN BCIs

Since the problem at hand involves complex dimensions of psychological well-being, communication and control, Value Sensitive Design offers a rich set of human values supported and undermined by technology. One of the propositions of the theory is that certain values are universally held, such as autonomy and community. The methodology accounts for human values in a principled and comprehensive manner throughout the design process. Elsewhere we have published about a prototype pervasive Brain-computer Interface system and its evaluation results

[7]. The prototype was modeled on allowing articulation, communication, recreation and environmental control.

Sociological investigations are relatively new to the field of Brain-computer Interfaces. We conclude that Value Sensitive Design applied very well to the design of Brain-computer Interfaces. By combining moral standpoints with user experience, the methodology offers an unparalleled perspective into a domain as sensitive and multi-faceted as designing for motor neuron impediments.

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