

Design with Me: I Have Special Needs! The Case for Cerebral Palsy

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Abstract. The HCI community has an important task of bringing the requirements of people with special needs to the forefront. Thus, all involved can help inform the design of systems that promote quality of life, inclusion and citizenship for a large portion of individuals and groups. This article presents a process that draws from universal and participatory design, as well as intellectual tools, such as mental and empathy maps, to help designers to inform design of artifacts. As per the proposed framework, it also presents a set of suggestions of artifacts and systems to be built that are centered on persons with Cerebral Palsy.

Keywords: Cerebral palsy · Special needs · Universal and participatory design · Empathy map

1 Introduction

People with special needs have been excluded from society: they suffer daily through life-threatening situations that go unattended, mostly due to lack of awareness, proper practices and policies, tools and education, among others. People with special needs do not fulfill their human potential. This article follows the HCI community lead of designing for people with special needs to aid them in their social inclusion and citizenship. It presents an HCI process that relies on various theories, frameworks and tools with which to inform the design of artifacts. It also presents an initial set of artifacts needed that are centered on persons with Cerebral Palsy (CP).

CP can be described as a group of non-progressive motor syndromes, caused by injuries or abnormalities in the brain, which occur during birth or the first years of development. CP is not a disease to be removed: rather, one can think of people with CP as presented with a different way to experience human life. As such, families, healthcare personnel and those with the syndrome are in need of artifacts and educational tools - usually in the form of Assistive Technology (AT). AT are devices that enable people to perform tasks by providing enhancements and new interaction methods to accomplish such tasks. CP syndrome has a gamut of symptoms that range from low to high degree of motor and cognitive impairment. Thus, Universal Design (i.e. design of inclusive, accessible artifacts) should be used basically to generate initial ideas - and then the design should be tailored almost on an individual basis.

2 Related Works

Livox [1] is an App that enhances communication by using tablets. The proposed app can be seen as an improvement of the board of communications that up until now have been the most traditional way used by the CP community for their communication needs. But it still presents a series of challenges for the ones with severe motor impairments.

CP Family Network [2] Special Website aims to support and inform families about CP in general. However, there is little allowance for peer-to-peer information exchange.

Data about CP should be made visual – but to our knowledge there is little to no compilation of the existing graphics into information vectors. The CerebralPalsy site [3] makes extensive use of info graphs to explain CP causes, types, some treatments and data on daily life routines.

3 Design for CP

This article describes the requirement acquisition phase of a design process used by the research group in order to inform design of AT for several groups with specific needs. It has been used by Guimarães et al. [8] to design educational artifacts to teach Portuguese and Sign Language for Deaf children, among other uses. It vastly relies on the participation of members of the community as designers throughout the entire process, thus allowing for a more efficient process that yields better-designed systems (i.e. systems that correspond to the needs and expectations of the end user).

Figure 1 shows the proposed process to aid the design of Intellectual Interaction artifacts. Intellectual Artifacts can be defined as social interactions, mediated by

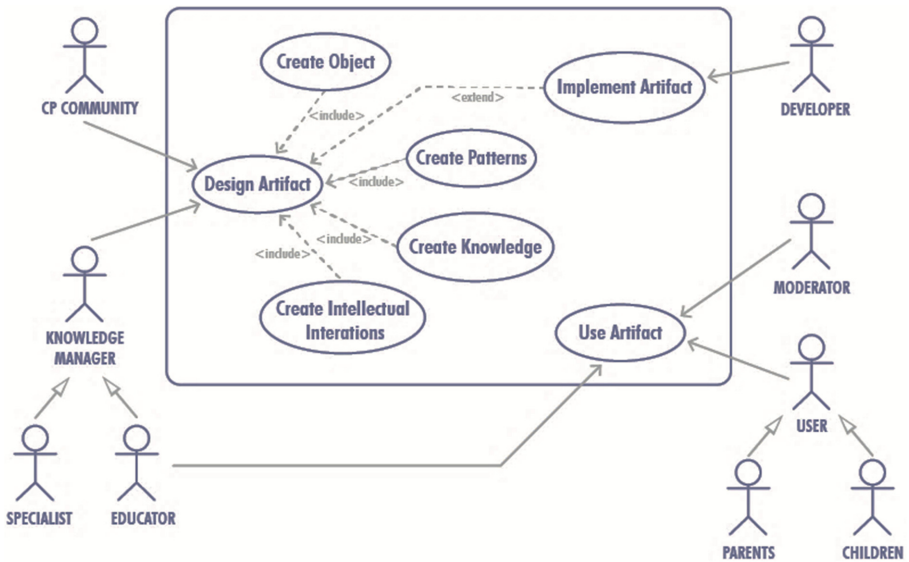


Fig. 1. Process to inform design for people with disability. Source [8]

computational artifacts that stimulate the use of intellectual processing for knowledge creation and overall development; the ensuing systems are based on cognitive theories for mind and physical development [8]:

As per the proposed process, in order to Design an artifact, the designer will use a series of cognitive and design tools (i.e. Empathy Map; Observation; Mental Map; Design of Service; Design Thinking, among others) to interact with the stakeholders (the user herself, educators, family members, specialists etc.) to better understand the person, her daily activities and her environment. These tools will help create knowledge, patterns and the design of the artifact.

In tandem with Human-Centered Design (HCD), designers must look at the individual person, and focus on her needs, identifying what she can or cannot do in her daily life. The process helps the designer to achieve such goal with the use of some cognitive and design tools.

Initially, the designer should follow the guidelines of the World Health Organization (WHO) [4], which provides the International Classification of Functioning, Disabilities and Health (ICF) that focus on the limitations for social participation in the environment where the person lives. The ICF broadens the designer's view beyond deficiency to inform design that promotes functional activities in all aspects of the individual's life in regards to her inclusion in her social context.

The use of simulations and ethnographic observation methods helped the researchers to understand the environment and its various aspects, such as human interactions, activities, and limitations, among others. The insight gained from the observation of the user in her environment proved valuable in understanding the actual features needed on the artifact [6]. The simulations and in situ observations carried out by the researchers provided a richer insight into the person's needs in her environment; researchers became more aware of the real, every day issues.

The use of Empathy Maps (EM) allows for better understanding of the stakeholders (their thoughts, needs and feelings). Additionally, EM provide insight into the features of the artifact being designed, according to Gray et al. [5].

The Empathy Map (EM) is a tool used to get to know the stakeholders, the way they think and feel. According to Gray et al. [5], EM aid in developing an agile profile of the users. EM centers on people (in our case, people with CO). Figure 2 shows the six different aspects:

- “Think and Feel” corresponds to dreams, ambitions, frustrations, motivations of the audience;
- “See” corresponds to how they contact to others, where do they work, how they experience things, how they see the others reactions, etc.;
- “Hear” corresponds to what do their friends say, what influences them, how they socialize, what they hear about yourselves, etc.;
- “Say and Do” corresponds to what kind of attitude do they have, what they talk about, what does their day look like, how does they react to some stimulus, etc.;
- “Gains” corresponds to what they want to reach: desires, needs, measure of success, etc.; and,
- “Pains” corresponds to what they face: fears, frustrations, obstacles, challenges, etc.

Figure 2 shows an Empathy Map complete, with actual needs, feelings and desired changes that were gathered by the research team with the community. The process of generating the EM was very helpful for the designers: real empathy was created for the everyday plight of people with CP that would otherwise be clouded by misinformation, lack of adequate communication and overall prejudice: a lot was learned about the syndrome and how it affects each individual differently that could not have been learned by literature review, or even by talking to family and professionals.

The use of EM allowed the designers to approach the requirements truly from the perspective of the person with CP – especially considering that most of them difficulties to communicate their thoughts and feelings. It became clear the need for AT, but also for technologies that would play into their sense of self, dignity, humanity and social inclusion.

Although it is very hard to determine the extent to which the cognitive functions of persons with CP are preserved, the EM revealed that, in most cases, those individuals were very aware of their condition, and were deeply affected by the misconceptions

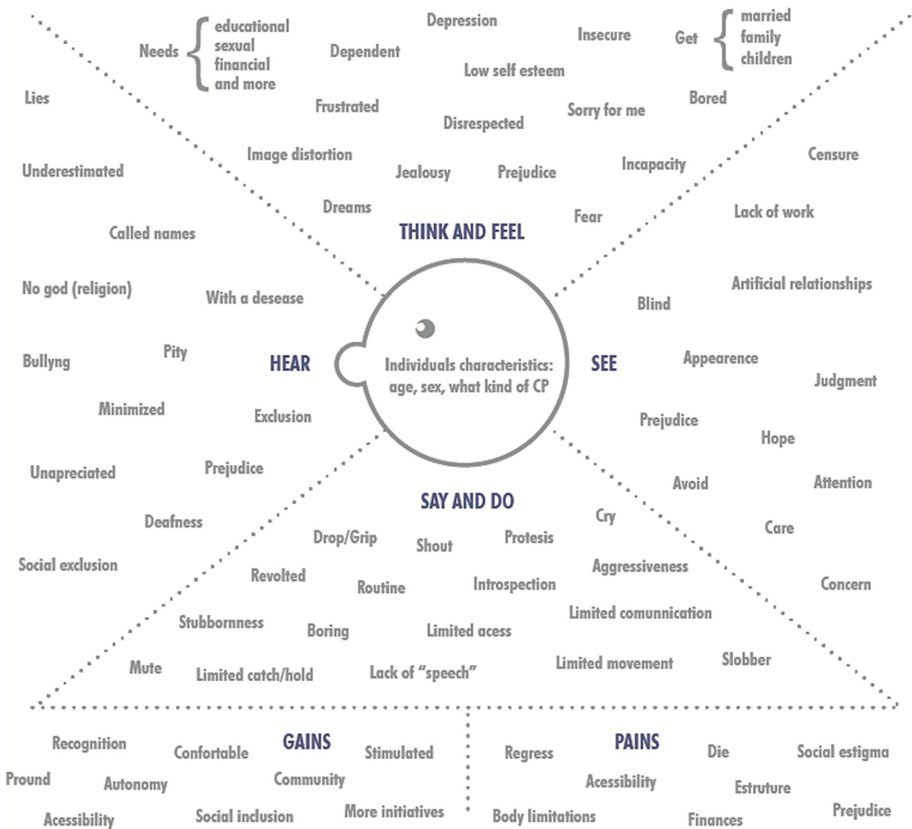


Fig. 2. Empathy map (based on what people with CP feel)

about them and the way they are treated by people who didn't understand them: there is no need for sympathy or patronizing.

This acknowledgement emphasized the general feeling that the first and foremost way designers can help people with specific needs is by providing educational tools about their conditions to the public in general, and to family and health care providers in particular.

Still on the requirements phase, and extending on the ideas of simulations and observations, designers should create Mental Maps (MP) with the aid of all involved. The use of MM allows for the generation, organization e mapping of ideas through synthesis and association of thoughts and experiences [7]. MM provide an approach and expansion of scope through various angles and interpretations that allow an easy visualization of the initial idea and its scenario in context.

Figure 3 shows part of the MM centered on the person with CP and its links with the CP environment. The resulting MM contains 8 main categories in which the aspects derived from the research were listed. This kind of organization allowed for deeper understanding of the types of systems that are needed.

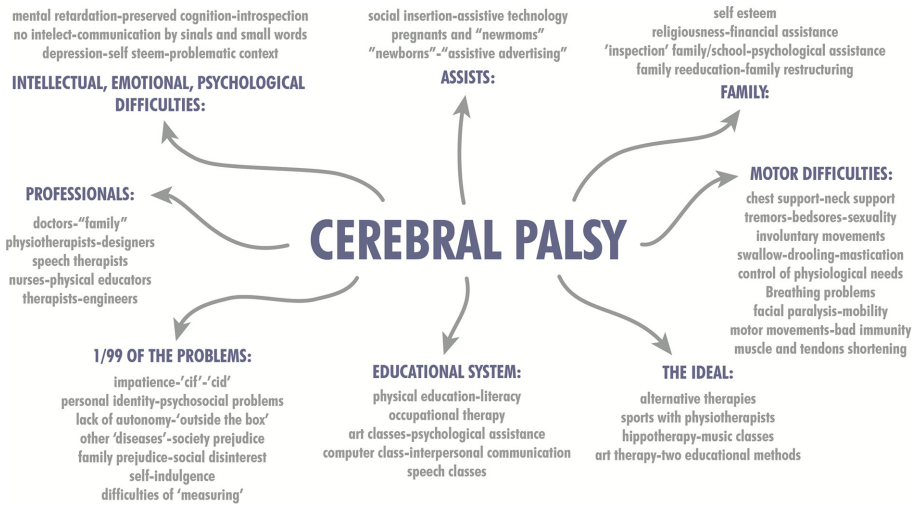


Fig. 3. Partial mental map

The use of MM and EM allowed for insights about the needs, scope and relations among the issues (i.e. how some of the issues were linked to one another, and how one issue would cause dire consequences on other issues). Thus informed, the designers were able to come up with high level suggestions of systems that would greatly improve the quality of life of all involved.

4 System's Suggestions for CP

Here are some examples of the needs for artifacts, processes and systems that came up in our research: a 3D process to get measurements to build prostheses and orthosis; virtual reality boards to enhance communications (the system would project objects within a category and the person would select her choice - e.g. food - apple, to convey that she wants to eat an apple); An information system to support the family - documentaries, educational videos, access to health care, support group etc.).

Information Systems:

- Information System Vector/Portal for families and health care providers;
- Information System Vector/Portal with guidelines to educate society in general on how to interact with people with CP;
- Universal Design of communication devices;
- Forum and/or specific channel for open, peer-to-peer discussions about experiences, tips, feelings etc.;
- Virtual material to demystify CP and to prevent exclusion, with the participation of people with CP;
- App for connecting people with CP, your family's, institutions and promote integration, interaction, information exchange, etc.;

Educational Systems:

- Repository of information and communication (storage, retrieving and sharing); Economic and operational model for such repository;
- Repository of educational videos – along with its operational model (criteria for who can post; what can be posted; etc.) and generation and distribution of such videos;
- Alternative and extended communication via computer mediated Assistive Technology;
- Alternative and extended communication via other media (banners, posters etc.);
- Peer-to-peer online/virtual (computer mediated) discussion groups to promote support, experience exchange etc.;
- Development of Learning Objects to be made universally available;
- Development of awareness and simulation workshops.

Ideas for professionals:

- Universal Design of rehabilitation artifacts;
- Universal Design of artifacts for social integration;
- Universal Design of educational tools.

Ideas for families:

- Posters with support information;
- Digital information material;
- Call Center (and its business models) to provide information, support, assistance (psychological or social);

- Raise awareness and pride: events, social projects, socialization tools;
- National monitoring system to support families, educators and healthcare providers for newly born children with CP;
- Access to low-cost Assistive Technologies via new productions methods, research initiatives, operational material etc.;
- Webinars (online conferences) with specialized professionals;
- Artifacts that promote child's autonomy.

Ideas for help providers:

- Health care integration system to lower costs;
- Research into new born stimulation;
- Awareness and training for professional.

Ideas for general problems:

- General purpose artifacts to improve skills and promote physical and emotional independence;
- Enhance communication board;

Ideas for Intellectual, emotional, psychological difficulties:

- Artifacts to increase awareness within the family;
- Virtual reality tracking devices to activate digital systems for Internet access and other activities;
- Virtual reality for emotional education and life-enriching experiences;
- Virtual reality system to help access the cognitive level of the child;
- Assistive technology to stimulate intellectual development.

Ideas for motor deficiencies:

- Artifacts to help develop muscular strength;
- Health, balance, position sensors;
- Haptica devices for health monitoring and stimulation;
- Sensors for measuring and adjusting physical pressure in devices for facilitate movement;
- Exo-skeleton.

Considering that the support of the family is paramount for the child's development, priority was to develop an information system. Figure 4 is shown here as an example of one of the many research fronts that have to be addressed.

Figure 4 shows the prototype of a system that is being developed as per the process to provide families with information about CP, educational videos and to serve as a platform for support group, exchange of experiences, etc.

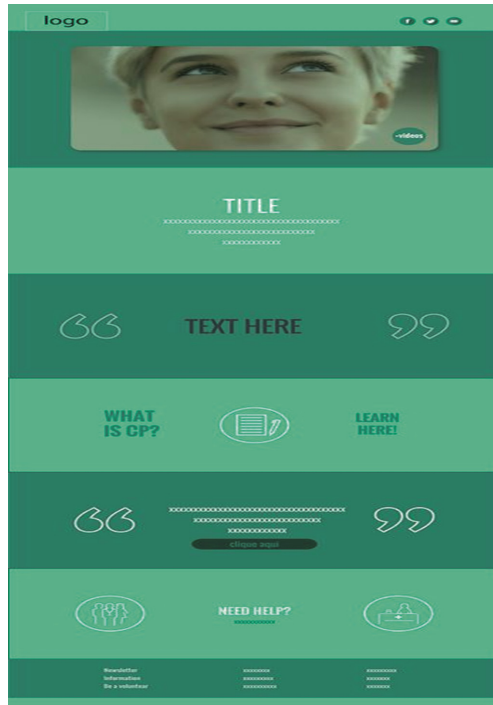


Fig. 4. Information system for the families

5 Conclusion (Discussions)

The proposed framework aims to help the HCI community to gather requirements to inform the design of systems with limited capacities (namely, in this article, people with Cerebral Palsy). It provides a sensible use of intellectual tools that help bridge the communication gap with members of the CP community. It has been extended to help design of artifacts for Deaf people also. In that regard, the proposed framework proved to be most valuable, as shown by the real insights that the researchers were able to get into the CP community. Those insights are here presented in the form of suggestions for system development.

One limitation is that this article does not provide enough solutions to the problems: rather, it presents the community with a series of suggestions of needed systems that were identified during the research. The important task of implementing, testing and validating of the suggestions is left to the community.

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