Designing for The Subjective Experience of Wearable Assistive Devices

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Abstract: The paper addresses the challenge of balancing the tension between a problem solving attitude in the design of assistive devices, with an ethical, aesthetic and cultural approach to design for people living with a temporary or permanent impairment. The topic is developed presenting two design cases.
The first case is a suite of smart jewels tailored to the needs of people with hearing impairment (Marti & Recupero, 2019), (Quietude, 2019). The jewels sense environmental sounds (e.g. the doorbell, an alarm, someone calling, a car horn) and notify them to the wearer through different modalities (light patterns, vibrations, shape changes). An App completes the system allowing the deaf person to record personal meaningful sounds and set preferences for their notification.
The second case is an orthodontic facemask for children designed as a 3D printed super-hero mask made of biocompatible materials (Marti *et al.*, in press), (SuperPowerMe, 2019). It is associated to a game where a superhero avatar wearing a similar facemask gains power by progressing in an adventure.
The design cases represent examples of permanent and temporary impairment that share fundamental features of the user experience: the stigma associated to hearing aids and orthodontic facemasks alters self-image and self-esteem of people affecting all aspects of life. The cases show that design can promote a cultural shift by transforming assistive wearables into beautiful, playful, gender-appropriate accessories.
Keywords: Wearables, Assistive devices, Co-design, Disability, Impairment, Aesthetics

Introduction

There is a huge potential for innovation in the design of wearables for people with disability. Wearables are “any device worn or carried on the body capable of receiving input, processing information, and providing output to a user” (Gandy *et al*., 2008). Nowadays the spread of tiny sensors and microprocessors with increasing processing capabilities brings wearable computing closer to everyday use. Applications range from mobile communication devices, to physiological data monitoring systems (Majumder *et al.,* 2017), to sensing/perception devices of the surrounding environment (Mateevitsi *et al.*, 2013), to skin interfaces (Liu *et al.*, 2013); (Hsin-Liu Kao *et al.*, 2016) and smart textiles (Pailes-Friedman, 2016).
Unfortunately, many wearable assistive devices remain highly stigmatizing in nature due to their medical-looking, poor aesthetic and no gendered body design. Furthermore, these devices are usually framed in terms of solving problems of people with impairment. This is of course a valid and important perspective. Yet other more open-minded frames are necessary to address the

complexity of the lived experience of wearing assistive devices, which demands for sense of style, self-expression and social acceptance beyond the functional support.

Most commercial assistive devices overlook the gendered body and pay little attention to aesthetics, if any. A nuanced choice of materials and forms, chosen by the wearer according to personal preferences and creativity, contexts of usage, and cultural habits are nowadays made almost impossible by the unavailability of alternatives on the market. People who wear an assistive device to compensate a temporary or permanent impairment have basically two choices to downplay the negative impact of the device: either giving up accessorising the body with style or adapting the device to suit the desire for style and image. More often the device is concealed, selectively used, or completely abandoned.

Therefore, a critical design perspective in the development of assistive wearable technology is necessary to achieve a sustainable convergence of humanistic and technological approaches.

In what follows, we first review recent attempts to theorise design and disability as two dynamic, interacting disciplines, which can influence and inspire each other. We do this by describing projects with an explicit focus on designing assistive devices beyond a problem-solving mindset. Later we present two of our design cases: the first addresses the culture around Deafness with a capital D to mean a human condition that is more than just hearing impairment; the second regards the design of a facemask for the correction of maxillofacial disorders in children viewed from a playful perspective.

In the conclusions, we draw some lessons learned and reflections to help designers embrace a broader, socially inspired and participatory culture of design engaging people who are experts of their disability as active and creative participants.

Literature review

Recently, designers involved in the creation of assistive wearables have started experimenting with new approaches and solutions to counteract the stigma of disability.

Profita, Roseway, & Czerwinski (2016) developed Lightwear, a series of gender-oriented garment designed to administer light therapy for on-the-go treatment of Seasonal Affective Disorder. The project explores the integration of light into fashion-forward wearable textiles combining style and aesthetics with efficacy, usability, and convenience.

A similar approach was adopted in Flutter, a fashionable smart garment for sensory enrichment of individuals with hearing impairments (Profita, Farrow, & Correll, 2015); and Swarm, a fashion-driven actuated scarf aimed at mediating affect for individuals with difficulty in recognizing and regulating emotions (Williams et al., 2015).

Eone's founder, Hyungsoo Kim developed a stylish tactile watch for blind people.

Wear Sustain (2018) (Wearable technologists Engage with Artists for Responsible innovation) is a network funded by the European Commission Horizon 2020 Research and Innovation initiative, operating in 2017-2018. The network promoted collaborations between technologists and designers/artists to develop sustainable and ethic wearables. The network funded 46 projects in wearable technology design. 7 projects out of 46 specifically addressed disability and impairment with a focus on ethics, aesthetics and sustainability. More in detail, 5 projects developed assistive wearables for people with physical, cognitive or perceptual disability and 2 projects developed wearable designs for supporting rehabilitation (Wear Sustain, 2018): Quietude (interactive jewels for enriching the experience of sound of deaf people), Future

Jewels (responsive, wearable objects that create playful interactions with people with sensory impairments), Beneficial Works (haptic navigation device targeted to blind and visually impaired people), Sensewear (smart garments for autistic people to reduce anxiety, stress, and panic attack), Flexability (a kit to create made-to-measure e-textile for people with physical disabilities), Zish (garment designed to support posture monitoring for the purposes of rehabilitation training), Constructing Connectivity (a stroke rehabilitation method based on textile making).

Fashion-driven assistive wearables have also been developed following a consumer-driven endeavor in the beautification of assistive devices. For instance, Sophie de Oliveira Barata promoted the Alternative Limb Project (2011) where she created highly stylised prostheses as art pieces, involving clients in brainstorming sessions and fine-tuning prototypes throughout the design process.

A number of maker-focused initiatives have been emerging also from the DIY practice of developing or modifying artefacts. e-NABLE ("Enabling The Future," 2015), DIYAbility ("DIYAbility," 2016) and Hackability (2016) are notable instances.

The books Design Meets Disability (Pullin, 2009) and Rhetorical Accessability (Melancon, 2014) offer theoretical lenses to think about the complex and dynamic relationship between disability, design and accessibility. Both scholars envision a future where assistive devices are demedicalized and destigmatized as it happened to eyeglasses transformed from medical aids into fashion accessories. However, they develop this argument from different theoretical viewpoints.

Pullin uses critical theory as a framework to make designers think as opposed to design that solves problems or finds answers, and calls for a new approach to design in the context of disability based on a ''richer balance between problem solving and a more playful exploration'' (Pullin, 2009 p. 121). Meloncon (2014) uses phenomenology to connect theory to practice as a way of underlining the ethical need to better consider disability and to reframe, repurpose, or remake both technology and the human body. By using the term Accessability she means ''to emphasize the need to meet the abilities of users and audiences, no matter what those abilities are, while understanding the need to promote inclusive access for those same abilities'' (Pag. 10).

All projects and theoretical approaches described above promote a cultural shift through a change in discursive and design practices associated with disability. Some of them emphasize person over product approach grounded in disability studies; some others take a product-centred view grounded in design research and practice.

In what follows we present two design cases developed at the University of Siena, Italy, in partnership with other public and private organisations. The projects explore human-centred design from the lens of co-design and participatory design. This way the dichotomy person-centred vs product-centred design is overcame by practising co-design with disabled people who are not just consulted but actively engaged in the creative process. Both cases regard the design of assistive wearables for disability and rehabilitation support, and highlight the importance of putting the lived experience of people with impairment at the forefront of the design process.

Case Study 1: Quietude

Hearing aids are highly stigmatising. Size and visibility are the main features associated with the reluctance to use them and with the stigma associated with them. A recent survey showed that the most common stereotypes associated with hearing aids are that they make the wearer look older, less communicatively effective, less sociable/friendly, looking disabled, weak, feeble, embarrassing, lonely, and less confident (David & Werner 2015). The effect of stigma on self-perception and social identity of people with hearing impairment represent a major threat to social identity and threatens the stability of social interaction.

Quietude is an ongoing project developing aesthetically rich, socially sustaining wearables for deaf people to counteract the social stigma while providing functional support.

The responsive fashionable jewelry system recognises meaningful incoming sounds (e.g. wearer's name, the doorbell, a car horn, an alarm) and expressively notifies them to the wearer through light, vibration and shape change. The project received funding from the EU H2020 Wear Sustain Programme and was developed by an interdisciplinary team of deaf people, designers, technology experts, psychologists and an expert in ethics from the University of Siena, two private companies Glitch Factory and T4All, and Mason Perkins Deafness Funds Onlus specialised in providing services to the deaf community.

The jewels were designed to go beyond the functional goal of supporting hearing and aimed for fulfilment of emotional and sociocultural needs such as aesthetics, self-expression and identity of deaf persons. The system is modular to allow different types of formal configurations and personalisation of use (Figure 1). Modules embed sensors to detect specific sounds and actuators to notify sounds through light, vibration, and kinetic modifications (shape change). A video of the system's behaviour can be watched at: www.quietude.it .

Figure 1: A necklace of the Quietude collection

The jewels are connected to a smartphone application (Figure 2) that permits customisation of both input (sounds of interest to be filtered and recognised) and output (notification through light, vibration or shape change). The person can create a personal library of sounds of interest by recording meaningful sounds through the microphone embedded in the jewels. The recorded sounds are then labelled and stored in the app, and "translated" into vibrations, light patterns or subtle movements of the accessories to advise the wearer when they occur in the surrounding environment. Preferences related to kinetics, intensity of vibrations and light patterns can be set and fine-tuned through the app for different contexts, moods and bodily sensitivities.

Figure 2: Setting preferences through the app

Case Study 2: SuperPowerMe

SuperPoweMe is a research project developed by a multidisciplinary team of orthodontist doctors, designers, and technology experts from the University of Siena and the University of Firenze (Italy), with the involvement of children affected by Class III malocclusion and their families (Marti *et al.,* in press). Class III malocclusion is a craniofacial deformity characterized by concave profile that results from retrusion of the maxilla and prognathism of the mandible. At the dental level this skeletal relationship reflects into the prominence of the lower arch relative to the upper arch, or the inversion of the anterior bite. This type of malocclusion is treated using facemasks consisting of frontal and mental pads made from acrylic, connected by a midline stainless steel rod. In order to apply a forward traction to the maxilla, elastics are attached from an intraoral anchorage system to a cross bar extending in front of the mouth. The effectiveness of facemask therapy depends on patient's compliance with the recommended wear time, possibly ranging between 14 - 24 hours a day, over at least 9 months. Commercial facemasks are unaesthetic, uncomfortable and may cause skin irritations due to uneven pressure by the standard anchorage pads. In a survey assessing acceptability of orthodontic appliances, facemask was rated as the least acceptable device (Abu Alhaija & Karajeh, 2013). The facemasks are only available in standardized shapes and in two sizes. There is no gendered body design. Beside poor aesthetics and ergonomics, children often complain about facemask bulkiness and instability, which may compromise the treatment. The design of commercial facemasks is solely focused on the functionality of the device without paying attention to other aspects of the child experience like social acceptance and motivating factors, which are fundamental to make the therapy effective.

SuperPowerMe aims at developing facemasks using 3D printed biocompatible materials and customized design both in the appearance (form and colour are selected according to the child's preferences) and anatomy (the facemask is modelled following the child's face morphology). Decoration and embellishments are co-designed with the children.

In order to improve acceptability and collaboration of the patients, SuperPowerMe adopts a gamification approach. An interactive game for smartphone and tablet is connected to the facemask and can be played only when the mask is worn by the child (Figure 3). The game is conceived as an adventure game where a super-hero avatar wears a facemask akin to the child's one. The more the child wears the facemask, the more the super-hero avatar gains power and

progress in the adventure. The facemask wear time is monitored by pressure and temperature sensors embedded in the frontal and mental pads.

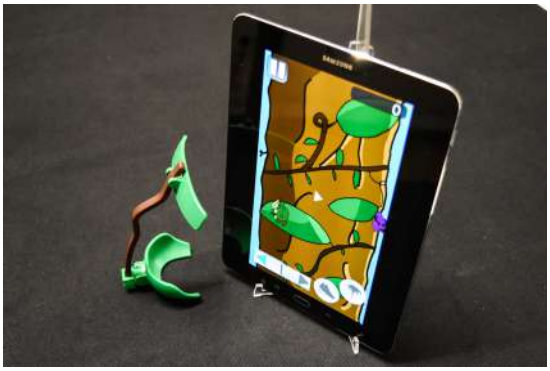

Figure 3: 3D printed customised facemask and the game app

A video concept of the project can be watched at https://vimeo.com/268795652.
Currently the project has developed the first customised facemasks realised with 3D printed bio-compatible materials that will soon undergo clinical trials. Embedded electronics and the video game are still at an early design stage. The customised facemask has been patented.

Conclusions

The design cases described above represent the extremes of a continuum from permanent to temporary impairment. Notwithstanding the diversity of the cases, they share some important features of the user experience: the stigma associated to hearing aids and orthodontic facemasks currently available on the market considerably alters self-image and self-esteem of people affecting all aspects of life such as emotional and functional well-being, socialization and relationships in general. The design cannot ignore the potential psychological impact and social stigma associated to assistive wearables.
In designing aesthetically rich and socially sustaining solutions, we engaged disabled people as experts of their impairment in co-designing potential solutions, and actively and critically participate in the design process. As Balsamo (2011) argues, design involves not just the making of new products/services but also the creation of new cultural possibilities.
In our cases, people involved in the design of new assistive wearables were somehow also engaged in the process of designing and communicating a new culture of disability based on playfulness, gendered aesthetics, self-esteem and sense of style.
Through several iterative and incremental co-design sessions, cultural beliefs were materially reproduced, identities were negotiated, and social relations were codified (Mainsah, & Morrison 2014). In this process, design made possible the expression of new meanings related to the demand for destigmatisation and demedicalisation of the assistive devices.
In our projects, the co-design process took several forms from observation to interviews, and participatory design workshops (Marti & Recupero, 2019).
In the first design case, deaf people participated in two workshops. Workshop 1 lasted 6 days and involved 4 deaf people, 1 designer, 2 design researchers, 1 psychologist, 1 ethicist, 6 makers/engineers, and 2 Italian sign language interpreters. Day 1 focused on feelings deaf participants have about not hearing or being heard; Day 2 focused on creating forms and selecting materials; Day 3 focused on developing concepts; Days 4–5 were devoted to

materialising ideas and developing low-fidelity prototypes; Day 6 focused on testing the prototypes, reflecting on the achievements and planning the next steps. These activities disclosed a number of complex needs/requirements of deaf people ranging from functional needs like the awareness about meaningful personal sounds (e.g. pet, doorbell, name, etc.) and public notifications (e.g. train delay); safety in emergency situations (e.g. alarms, announcements in public spaces, police whistles etc.); to needs related to the possibility to express individual preferences and sense of style; aesthetics of hearing aids; curiosity about the quality of sounds that could be experienced through other senses, (e.g. sight, touch) or through on-body vibrations. The second workshop involved 5 Deaf participants and a group of hearing participants composed of 1 psychologist, 1 designer and 2 design researchers supported by an Italian sign language interpreter. The aim of the workshop was to reflect on the needs and desires emerged during the first workshop, and to engage the participants in evaluating the prototypes developed after the first workshop. The workshop was organised in two parts: a card sorting activity to reflect on needs and expectations and a testing session of the prototypes. The deaf participants were excited about the possibility to explore the sonic qualities of environmental sounds and experience them through different sensorial modalities like the visual (light and shape change) and tactile (vibration) perception. This functionality convincingly addressed the deaf people's curiosity about sound. The jewels were regarded as an example of universal design which does not stigmatize or define deafness in any negative way and scales the solution to a broader audience than deaf people.

In the second design cases, children were engaged in personalising the facemasks. The resulting prototypes highlighted that current facemasks are unattractive for both male and female targets. Gender appropriateness was clearly remarked as an issue.

In general, the participatory design activities carried out in the two case studies, made desires, uneasiness and disquiet emerge, pervading the entire design process. The activity was grounded in the lived experience of disable people and driven by their aspirations, beliefs and culture.

Results obtained so far show that individuals value participation in the design process and the opportunity of customising and transforming assistive devices. This is an important component to grant individuals' agency, ownership, and pride in wearing a device commonly fraught with marginalization. The practice of co-design has the potential to increase confidence in use and hopefully generate greater societal acceptance and awareness toward disability.

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