DESIGN4 HEALTH

Objects of desire and of disgust: Analysis and Design of Assistive Technologies

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ABSTRACT

Following the principle of 'one-size-fits-all', patients of different ages and socio-cultural backgrounds are often supplied with similar aids with little consideration for their personal preferences and socio-emotional needs. Assistive Technologies (ATs), specialist products for those with long and short-term conditions, are often being abandoned because of people's perception of themselves as disabled (Hocking 1999) and their fear of being stigmatised (Bright and Coventry 2013).

A pilot study was conducted to explore how ATs may become 'Objects of desire' through design interventions, affording a more positive sense of self. This in return may increase the rate of adoption of ATs in everyday life.

ATs are often invested by more positive personal meaning when supporting independent living. However, the ATs market is very underdeveloped, and limits individual choice. While older adults are resigned to use available products that, at best, match functionalities in order to compensate for their occurring physical deficiencies, they express a wish for personalised, elegant, discreet and at times bold artefacts matching their lifestyle and providing opportunities for self-expression.

This study provides insights into the design language of medicalised products and the need to rethink the current approach.

Keywords: Assistive Technologies, Older Adults, Design for Desire

Introduction

'Assistive Technologies' (ATs) is an umbrella term that includes devices to increase or maintain the functional capabilities of individuals with injuries or declining abilities and to enhance overall well-being[i]. Studies on ATs (Lewin et al. 2010) suggest that a priority of older and disabled people is to live independently for as long as possible and to be engaged in social activities to reduce the risk of loneliness and isolation. Research conducted with 3000 participants aged over 40 years[ii] identified key difficulties experienced, including getting out and about (23%), household chores (18%), DIY and gardening (11%), getting up from bed and getting ready for the day (9%), and preparing and cooking food (8%). As the world is ageing, the proportion of people who have difficulties with these activities of daily living (ADLs) is progressively increasing[iii]. In a recent report, Age UK[iv] stated that the percentage of people with at least one difficulty with an ADL increased from 16.4% when aged 65 years to around 50% over the age of 85 years. A wide range of independent living aids and products, many of which are relatively inexpensive, have therefore been designed to help improve people's health, safety and well-being (Consumer Focus 2010). However, in the UK, it is estimated more than 35% of ATs that are purchased are abandoned when they are still needed (Dawe 2006).

People are often supplied with standardized aids that tend to focus on the disability rather than the individual preferences and how physical needs change over time (Phillips and Zhao 1993). This has resulted in people who use ATs reporting an increased perception of themselves as disabled (Hocking 1999) and a fear of being stigmatised (Bright and Coventry 2013). These ATs whilst functional are rarely able to support complex rehabilitation trajectories as they are often not designed to evolve and are often rejected on the ground of aesthetics. There has also been less consideration about how ATs are in intimate proximity with the body and that they may be viewed as extensions of the embodied self. At the same time, these

objects can be permeated with stigma and negative emotions, such as dependence, disability, and disgust. In this context, a sense of 'psychological contamination' (Rozin and Fallon 1987) may occur due to the proximity of an object that is stigmatised but also imbued with negative connotations and acts as public and visual reminder of a disability or of declining abilities when doing everyday activities. While older adults may resign themselves to use available products that, at best, match functionalities to compensate for their physical deficiencies, they also express a wish for more personalised, discreet and at times bold artefacts that are flexible to fit with changing physical abilities (Parette and Scherer 2004).

Narratives of medicine, decline, and functionality around ATs therefore remain predominant, with minimal changes towards narratives of consumerism, flexibility, and style. Our premise is that a shift in narratives and language around assistive technologies may improve their effective use, as well as the ambiance and emotional connection to ATs. This paper presents the methodology and preliminary findings from a pilot study that explores how ATs are perceived and to provide insights into how ATs may become 'objects of desire'.

The Pilot Study

The pilot study was qualitative and participatory in order to understand and explore the issues from the perspectives of younger and older adults who have used ATs in the short or long term or who may be potential users of ATs. Ethical approval for the pilot study was gained from Brunel University London. The research involved six focus groups – 4 with older adults and 2 with younger adults in order to compare and explore different perspectives of ATs across the life course. During each focus group, we aimed to explore the perspectives and emotions that the participants held when they envisioned the use of ATs by themselves or others, and to excavate how perceptions changed when the age of the ATs users changed (from young children to older adults).

13 British older adults (8 women and 5 men, ranging from 60 – 85 years old) were recruited though the Brunel Older People's Reference Group (BORG) and the Brunel University 50+

group from the Sports Centre took part, and 6 younger adults from Brunel University London (4 women and 2 men, ranging from 19-34 years old) also participated. Following a process of informed consent, ground rules for the activity were agreed, for example, consideration of all participants and for all discussions to remain confidential. Each focus group lasted between 70 to 90 minutes. To protect participants' anonymity and confidentiality names are fictitious.

The first part of the focus groups was dedicated to explore personal experiences and emotions encountered when using ATs. The activity was guided by displaying images portraying children, middle aged people and older adults using a wide range of mobility aids in the home environment, hospitals and in public areas. The second part of the focus group involved presenting the participants with a range of ATs which they could touch and interact with. The participants were asked to express thoughts and feelings around seven ATs namely, a pair of glasses, a hearing aid, a standard and a foldable walking cane, a wheelchair, a Zimmer frame, a motorised Scooter, and an Amazon Alexa (see figure 1). These ATs were chosen to explore a range of technologies and a variety of ATs that were highly visible, such as a Zimmer frame, and ATs that can be mostly hidden, such as a hearing aid.

Fig. 1 The seven prompts used in the focus groups divided for their visibility and level of technology embedded

A data-driven approach has guided a thematic analysis of transcripts with the intent to identify

descriptive codes and to cluster them into main 'themes'. The appropriateness of each theme identified has been considered upon the recurrence of the theme across the data set and its relevance to answer the research question. The analysis stopped when data saturation was achieved.

Preliminary Analysis from the Pilot Study

Two macro-themes emerged from the transcripts; the first from the analysis of the first exercise highlighting differences in use and adoption of ATs as the user evolves, while the second derived from the interaction with the provided devices clarifying the participants priorities and preferences when purchasing and using ATs.

1. Functional customisation of ATs

A view emerged that the role of ATs was to compensate for any loss of function and to limit the effect of deteriorating abilities across the life course. For some participants, despite needs for ATs, there was resistance in adopting ATs due to perceived negative connotations, for example, being seen as old: "my father wears hearing aids and he struggles because, I think, he is showing that he is old" or an increased sense of dependency: 'a Zimmer frame remind me when you are in a hospital and you are shuffling to the toilet' (both quotations from Sue, 61 years old). For most participants, the key parameters of ATs used in later life were functionality and product maintenance such as, 'the benefits [of using a device] overcome the visual disadvantages' (Sarah, 74 years old).

In contrast, when viewing the images of children, the functional dimensions of the mobility aids was interspersed with expressions of sadness for the children: 'it's good they've got them to go around' (Anna, 78 years old); for Louise (79 years old), 'you do feel sorry for the children but they [the devices] look stable, substantial'. Mike (76 years old) highlighted the possibility of enhancing their abilities as the children were growing up: 'the kid [using a mobility aid] might be learning to stand up straight, so you hold on to the frame so not to fall off, building up your strength […]. I am assuming his legs were the problem but this [device] gives him the chance'.

Two emerging sentiments were elicited focusing on image of decline in later life and relation to the use of ATs by older adults and children, that focussed on the predominant image of decline in old age and of playfulness in childhood: 'there is pretty much a fun element [in devices for children] and when you are 90-year-old you don't want fun on your appliances...' (Sue, 61 years old). Mobility aids were often associated with playfulness as well as functionality for the children: 'I think they should be more fun…I was going to say they should be red and jolly and cheerful' (Vic, 73 years old). The younger adult participants also made a similar distinction. Laura (28 years old) said: 'I think they look independent and I think it's good even though all these devices are not children friendly, but they give a sense of independence which is good' and Jillian (30 years old): 'if it is something more playful and colourful they will think it is something they can have fun with instead of struggling with'.

In contrast, when viewing people in mid to later life, the mobility aids were described in relation to what extent the person could continue their everyday activities. Jillian said: 'they look very functional and people are able to do what they want to do, and they are given the opportunity to do their normal daily activities […]. It gives a sense of normality - independence-.' Younger participants introduced the concept of functional customisation of devices; Laura (28 years old) said: 'since [older adults] are stuck with these products for long it's good if they support multiple activities. If it is a frame like this [Zimmer] they can do grocery just adding a basket and a seat that can be removed if they want to go for a walk. Otherwise the frame would be too heavy. All these activities can be done with different frames and it is good for them to have options'; and Jillian (30 years old) added: 'like an extension pack they can put it on'. The narratives around older people therefore assumed a trajectory of decline and a need to do everyday tasks and activities in order to maintain independent living.

2. Permanent need for ATs and self-expression

A second theme that emerged from the exercise was the distinction between a permanent and a temporary need for a AT. If the need was viewed as temporary, participants expressed more acceptance of the ATs in their current design and function, for example, a standard, grey, metal walking cane was considered appropriate for orthopaedic rehabilitation from an operation or

a fracture. Aesthetic concerns however were voiced more significantly when the need of an AT was permanent: for Sue (61 years old): 'if you see it [a standard walking cane] to a younger person you associate it to injury and you don't worry because is a temporary thing, as it was for my husband. With my father, he was a bit shinier [to use it] and you think he is at another stage of life [because he needs it for a permanent condition]. It is a bit sad to see such a strong and fit man to depend on a stick and you don't think is a temporary thing'.

The permanence of the AT was not always associated with decline, but also to narrative of athleticism and sport, in particular the role of the Paralympics. As Sue said: 'I think is the association with sports…and Paralympic games…there is a new feeling… you feel very positive because you see this engineered frame [as an advanced design] and you are positive for future generations. New generations are embracing new prosthetic limbs and technologies'. The Paralympics was therefore seen as having brought to wide attention novel possibilities of design that could be personalised, flexible and customised for the user. The purpose, design and context of ATs was therefore significant. For example, whilst a standardised walking stick may be stigmatised, contemporary designs and activities are promoting new aesthetic dimensions: 'there was a period where gentleman used sticks […] - now we have trekkers with this Nordic style and I think that's the way they will become' (Marta, aged 60 years). As Marta further explained: being "trendy and young" was what made the difference.

Some ATs that are taken for granted, with less stigmatisation, in particular, glasses as a means to enhance vision were 'normalised' (Nas, aged 26 years). The extent to which an AT was not very noticeable, often due its size and close proximity to the body was also important. When an AT was less visible, there were, however, contrasting ideas; for example, Lucy (aged 34 years) said she preferred it when assistive devices, especially hearing aids, were invisible, as they are not as commonly used as glasses, and may be stigmatised. Nas introduced a more positive concept of 'cherishing the disability', by making devices fancier, visible, desirable. What made devices aesthetically less accepted was seen as 'the scale of the market' (Laura 28 years old) and because 'we don't see them around' (Bob, 34 years old).

Participants on the whole agreed that technology could be an effective enabler to enhance human activities and there were possibilities that ATs may be imbued with positive

connotations, as representations of the individual's dignity and self-respect, and by nurturing the functioning abilities of the user. However, if devices were seen to merely replace an activity that users could do for themselves, such as, the use of a scooter in large shopping malls or in holiday resorts and asking Amazon Alexa to do everyday activities, they were often associated with laziness by many participants, both younger and older, and therefore not always seen as useful for purposeful living.

Conclusions

The diffusion of ATs and the emerging use of consumer technologies for assistive purposes, has brought up a wide set of concerns and desires beyond the mere functionality of the product. The consumer products' market provides a great degree of choice to consumers; this is to cater for individual preferences, tastes, levels of usage, and personal requirements. The same choice does not extend to assistive products even though they are becoming increasingly prevalent for longer periods of time as we live longer. This is of significant concern as lack of choice may impact the adoption rate of assistive technologies. In the case of mobility aids the lack of adoption may result in falls, limited mobility and less engagement with social activities, that may compromise overall wellbeing. As for consumer products, older adults would like their choice to reflect their identities and as a form of self-expression. Therefore, in order to counteract the one-size-fits-all design of assistive aids towards a 'humanised' technology support, our preliminary findings suggest that functional customisation, by means of personalisation that allow products' changes so as to have multiple purposes and functions, can reflect the complex disability management of the users. A second theme emerged when assistive devices are seen as permanent and become central to the user's life and a bodily extension. The aesthetic importance of the device in terms of self-expression, with increased social acceptance, was considered significant. When devices embrace technical and futuristic features that empower the user, they are more likely to be enthusiastically accepted which has the potential to improve everyday life.

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