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Behaviours: Design and behaviour change in health

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Design and behavior change (Dr Claire Craig & Prof Paul Chamberlain)

Abstract

This chapter explores the role of design in the context of behavior change for people living with long-term conditions. A series of short case studies illustrate how design can facilitate the development of products and interventions that better support the needs of individuals and how these can lead to positive coping behaviors. The chapter concludes with a broader discussion of the complexities and ethical issues that design in the context of behavior change promotes.

Introduction

Design and human behavior are integrally linked. The design of objects, the wider environment, way services are configured all elicit particular ways of responding and behaving (Fry 2008, Niedderer 2013). Interest in this relationship between design and behavior change has been growing particularly in the context of the broader health-care environment. This interest stems from an increasing recognition that when certain behaviors are adopted improvements in health outcomes and quality of life ensue (Alcorn and Broome 2014, Brady et al 2013, Rabe et al, 2007).

This chapter considers the role that design can play in promoting and facilitating these changes with a particular focus on individuals living with long-term conditions and begins by describing something of the wider context. It explores why an approach that focuses on behavioral change may be particularly relevant and of value to this population group. We then share three examples of research programs undertaken in Lab4Living at Sheffield Hallam University: these are, a product innovation focusing on the development of a neck collar for people living with motor-neurone disease; a research program focusing on design thinking in enabling individuals living with spinal cord injury to better manage their condition and an open-design research project which engaged young people with cystic fibrosis in the design of products to manage their medication. We share some of the findings of the research and suggest some of the principles that enabled positive behavior change

to occur. The chapter then turns to a critical discussion of the complexities of design in health-behavior change, ending with recommendations for future avenues for research and development.

The relationship between design and behavior change has been recognized for some time. Niedderer and colleagues (2014) suggest that its origins can be traced to design psychology or behavioral design (Norman 1988) which set out to understand the intuitive use of objects and our responses to them. Over time a shift in emphasis occurred and approaches developed with the express purpose of harnessing the potential of design to explicitly shape behavior as can be seen in the Loughborough model (Lilley 2009), the work of Lockton, Harrison and Stanton (2010) in the development of Design with Intent and the emergence of persuasive technology (Fogg, 2003).

Recently there has been increasing interest as to how these approaches might be applied to the emerging field of design for health, particularly in relation to supporting individuals living with long-term conditions.

Defining long-term conditions

The Department of Health defines a long-term condition as a '*health problem that cannot be cured but can be controlled by medication or other therapies*' (Department of Health, 2012, p.3). Long-term conditions can have a number of causes. Some are genetic in origin. For instance cystic fibrosis is a chronic, genetic condition that affects individuals from birth. Other long-term conditions may occur at a later point in the life-course and arise through a combination of biological vulnerability and environmental factors. For instance, the Stress Vulnerability model initially proposed by Zubin and Spring (1977) has been used to account for a number of chronic mental health conditions including bi-polar disorder, manic depression and schizophrenia. Some long-term conditions occur completely as the result of environmental factors including trauma and infection. Brain injury and spinal cord injury would be examples of this. Others such as heart disease, high-blood pressure and type two-diabetes have strong links to or may be exacerbated by unhealthy life-style choices.

At present it is estimated that long-term conditions affect over 15 million people in the United Kingdom (Department of Health 2012). The complexity of individuals' needs means that at present, people living which chronic conditions occupy 70% of all in-patient bed days, 50% of all GP appointments and 64% of all outpatient appointments. This amounts to approximately 70% of the total health and social care budget (Kingsfund, 2015). Future projections regarding this population are at present unclear. Recent reports by the Department of Health suggest that these figures will remain relatively stable until 2018 whilst other reports highlight the correlation between some long-term conditions and ageing and suggest that as the population ages that a further 5 billion pounds will be required to provide for care over the next ten years. There is however some consensus that the number of people with three or more long term conditions will rise to 2.9 million by 2018 (an increase in one million from 2008).

Current policy directives therefore place emphasis on the prevention and management of multiple-morbidities rather than single diseases. Given the role that lifestyle plays in contributing to these morbidities (Mokdad et al 2004, Scarborough et al. 2011) the aim of health interventions currently revolves around enabling individuals to manage their condition in order to prevent deterioration of the original condition and the development of secondary problems. This is primarily achieved through a combination of education and practical support in terms of how to adjust behavior and routines in order to live with the condition (Welsh Assembly Government 2007).

This adjustment will occur throughout the life-course. Living with any long-term condition will require the individual to make changes in behavior at every level (Alcorn and Broome 2014). This may be relation to their day-to-day routines and the decisions they make. It may involve following a treatment regime, making changes in relation to how tasks and activities are undertaken, developing new habits and routines as well as avoiding certain behaviors known to exacerbate a condition (World Health Organisation, 2007, 2010). There will be an ongoing process of both

physical and psychological adjustment. The process can be complex and will be affected by a host of factors including: the individual's personality, coping mechanisms, physical and mental health, resilience, support networks and the nature of the condition (Schutzer and Graves, 2004). For example a person living with rheumatoid arthritis may have relatively long periods when this is stable interspaced by flare-ups where joint stability is particularly vulnerable and they will struggle to undertake activities of daily living. For a person living with a condition such as cystic fibrosis, treatment and care may be more intensive and ongoing. Each person's response will be unique. However it can be said that any long-term condition has the potential to impact on every aspect of a person's life including physical functioning, mental well-being, social relationships, self-perception and employment (Harris et al 2003).

Supporting the individual in adjusting their behavior and lifestyle to cope with the long-term condition is therefore an important area for consideration. At a recent design for healthcare event held at the Helen Hamlyn Centre it was highlighted that

'the first six months following diagnosis is a critically important time for chronic care patients to regain control of their lives. Yet almost 30% of post-surgical patients are back in hospital within 30 days because they have trouble adapting to new behaviors after they get home' (Helen Hamlyn Centre 2013).

What follows is a description of three research programs undertaken by researchers in Lab4Living. Lab4Living is an inter-disciplinary research cluster at Sheffield Hallam University drawing together a cohort of expertise in design, health-care, creative practice and engineering. The case studies have been chosen to reflect the diversity of approaches relating to a number of long-term conditions.

Three case studies

Case Study One: Head Up

Head Up is a research project led by Joseph Langley and Heath Reed. People with Motor Neurone Disease (MND) often develop weak neck muscles, leading to pain,

restricted movement and problems with swallowing, breathing and communication. Ideally, a neck collar would help alleviate these. However, neck collars currently available are of limited use for people with MND and are often rejected by patients. The same is true for patients with neck weakness due to other conditions.

The Head-Up research programme was a 2 year study funded by the National Institute for Health Research's Invention for Innovation, the principle aim of which was to develop a novel neck orthosis for neck weakness that offered the necessary support whilst allowing freedom to move without negatively impacting on quality of life.

The research represented a close collaboration between clinicians, engineers, creative designers, patients and carers. Individuals participated in a series of workshops where the emphasis was on developing solutions through a co-design methodology. Through this process end-users were able to highlight the strengths and limitations of existing products and to offer on-going feedback on the different iterations as the design of the neck orthosis evolved.

A series of comfort assessments offered the designers a first hand experience of how it felt to wear existing neck collars. In addition, the research included an engineering simulation of the neck and upper torso which enabled the designers to understand the nature of the contact between body and collar, and the pressure of that contact. Data of this experience was collected using the McGill pain Questionnaire and emotional responses to the impact of wearing the collars was documented.

The result of this process is the Sheffield support snood that consists of a lightweight snood that fits the back of the neck of the user allowing it to be worn under clothing. The snood functions as a scaffold for additional lightweight polymer support structures that can be added or removed according to the degree of support required by individual users.

Figure 2: Researchers in Lab4Living assess the comfort of the snood

Key strengths of the design relate to its aesthetic qualities as well as to improved comfort as the following quotes by participants reflect:

"I love the way you can adjust it in lots of different ways"

"It looks like an item of clothing and you can wear a scarf over it"

Figure 3: The Sheffield Snood

Moreover, findings of a preliminary study to examine the efficacy of design has shown that the product has increased the amount of time users wear the support by up to 80% - a significant change in behavioral practices (Langley et al., 2014).

Case study two: design thinking and spinal cord injury

This first case study describes an enquiry focusing on individuals living with a degenerative long-term condition. This study turns now to the potential of design in behavior change for individuals living with a sudden on-set of a long-term condition acquired as a consequence of trauma or illness.

It is estimated that 40,000 people are currently living with spinal cord injury in the United Kingdom. The degree to which an individual's function and behavior is affected will very much depend on the nature of the injury. Broadly, spinal cord injuries are frequently categorized into complete or incomplete, depending on the level of damage to the spinal nerves. In complete injury the person will experience paralysis below the level of the injury. For people living with incomplete spinal cord

injury there will be some movement and sensation below the injury. Nonetheless, whether complete or incomplete a person experiencing this type of long-term condition will require a significant degree of physical, psychological and behavioral adjustment to cope with the impact of this on their everyday life.

The research program was part of The Royal Society of Arts (RSA) Design and Rehabilitation initiative and was a collaboration between designers and researchers in Lab4Living at Sheffield Hallam University, Princess Royal Spinal Injuries Centre and the RSA. The aim of the research, led by Professor Paul Chamberlain, was to evolve a co-productive process of discovery, enabling people with spinal cord injury to gain insight into and develop alternative ways of thinking about and taking control of their interactions with the environment. Underpinning the research was the question as to whether design-thinking could facilitate change through building self-efficacy for individuals learning to cope with the injury.

Initial results of the study were very promising and a number of the participants who took part in the research described how the experience had led to them to think very differently about their condition which, in turn, had shaped how they approached a number of aspects of their lives. These findings very much reflected Campbell's suggestion that '*if people and not just designers have tools available to be more resourceful then changes may be seen in their self-management ability*' (Campbell in Craig et al., 2013, p798).

Building on this work, Wolstenholme et al (2014) developed a series of workshops focusing on design thinking that were shared with twenty people with spinal cord injury on the unit in Sheffield. The results of this study were again very promising. Participants described how they had used the skills learned to change the way they approached aspects of their life, enabling individuals to make changes in their routines and how they adjusted to living with the injury. As one of the participants in the study described,

'*I used it when thinking around setting a routine at home, the activities give a framework*' (Wolstenholme et al., 2014).

Further research is clearly required. However from these two studies it is possible to see how such an approach may promote changes in social adjustment to the injury.

This chapter has to date described a potential role of design in supporting change and adjustment to living with a degenerative neurological long-term condition, a long-term condition arising more unexpectedly as a consequence of illness or trauma. How then might design support individuals who are living with a long-term condition that is genetic in origin and present from birth? This is the focus of our final case study.

Case study three

Cystic fibrosis is a genetic condition affecting the lungs and digestive system, which become clogged with a thick and sticky mucus. The condition has a significant impact on a person's quality of life since management of the condition requires adherence to a strict daily management regimen and periodic stays in hospital.

Matthew Dexter's (2013) research explored the potential of the open design process as a way of engaging with people living with cystic fibrosis to give individuals a chance to play an active role in the design of products to manage their condition through the process. If individuals living with long term conditions are required to use particular medical products and devices it seems important to involve them in the design of the products to ensure an optimum fit between the design of the product and their requirements.

Given that cystic fibrosis is a condition where compromised immunity can make it difficult for individuals living with the condition to engage in face-to-face collaborative design processes this research utilised Open Design to facilitate a design process with people living with the condition. Open Design was facilitated by the Internet and Distributed Digital Manufacturing (e.g. 3D Printing) and as such the participants did not need to travel - instead using bespoke online tools for collaboration in their own home.

This research project recruited individuals living with cystic fibrosis in the UK and the USA to a bespoke online social network, where they designed products from their own lived experience. These were prototyped and made using a MakerBot 3D Printer, at Sheffield Hallam University's workshop facilities (mimicking a Fab Lab). The participants that did not have access to a Fab Lab or 3D Printer themselves had prototypes posted to them by the project leader.

Further research in this area is required in order to determine whether this involvement was sufficient to trigger increased use of and compliance with treatment regimens. However it marked an important first step in demonstrating that the participants were able to conceive, design and develop complex devices that fitted needs based on their own lived experience.
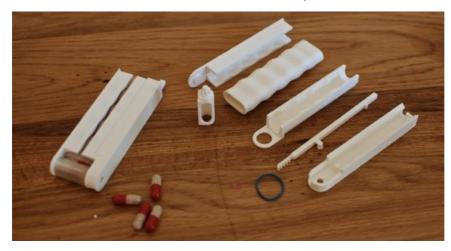
Figure 5: One of the designs generated through the Open Design process

The use of Open Design was fundamental for this process, as it allowed for the rapid development of the ideas, with less chance of duplicated work as everyone had access to the project files (Dexter et al., 2013).

Reflections

Whilst the above case studies describe work with very different groups of individuals managing quite distinct challenges we believe that they offer a number of useful insights in relation to design in the context and behavior change.

First and foremost they highlight the dangers of making assumptions as to why a person is behaving in a certain way. It would have been easy to assume, for instance,

that the primary reason why people living with motor neurone disease chose not wear a neck brace was due to discomfort. However it soon became apparent that the aesthetic of the orthosis and how it related to the person's self image was as important as the resolution of the current constricting nature of existing neck braces to the individuals we worked with.

The second insight was the importance of not just offering information but of also providing structures and frameworks to scaffold change or to focus and direct energies. The spinal cord project particularly illustrated the value providing a tangible illustration of how design thinking could provide an important set of tools to enable individuals to conceptualize their spinal injury in a different way and to adopt strategies to adapt to living and behaving with this.

There was great merit in bringing people together, both to share challenges but also to offer potential solutions and alternatives. This was true of all the projects cited and the final case study suggests that creating virtual meeting places is also a viable way forward.

The success of the projects we describe were underpinned by a number of key principles:

First and foremost each of the studies highlight the importance of working with people. We have already acknowledged that how a person experiences and manages their long-term condition is unique to the individual and the importance of spending time to understand these challenges is paramount. The level of participation and partnership was achieved through involving end users at each stage of the research, rather than just consulting at the beginning and the end of the process. Involvement was not confined to simply talking and commenting on issues but on photographing, drawing, responding to objects through active engagement, leading to the development of new and shared insights.

The second key principle we believe these case studies embody is that they draw on people's strengths, positioning individuals as experts because they are experts in living with their condition. At no point did the design process disempower the

participants. Rather it took as its starting point the strengths and the abilities of the person. We sought to challenge potential imbalances of power between the researcher and the researched and to work in partnership with individuals. Where new behaviors developed they did so as a consequence of people utilising their strengths and using these as a way of moving forward in a different way. This seems to be particularly important when designing for people with long-term conditions where so much of their self-efficacy and choice has been eroded. An approach that offers new possibilities, showing people what they are able to do feels to be of value.

The case studies also re-iterate the value of inter-disciplinarity. The research did not only rely on the extensive skills of designers but of engineers, health-care practitioners, of experts in manufacturing. This way expertise could be pooled in order to develop both potential and real solutions to meet the requirements of individuals participating in the studies.

The final principle to which we wish to allude is the importance of holism, of the and the need to understand the physical and psychological aspects of living with the condition, of recognizing the dimensions of work, home and community and of recognizing the importance of the aesthetic in challenging stigma and offering aspects of normalization.

Interestingly our findings closely reflect the guidance suggested as best practice by the Department of Health, Social Services and Public Safety (2012) which are as follows:

Working in partnership: *The person, and the interests of the person, should be at the centre of all relationships. People, and where appropriate their carers, must be recognised as partners in the planning of services, which should be integrated and based on collaborative working across all sectors*

Supporting self management: *Self management should provide people with long term conditions with the knowledge and skills they need to manage their own condition more confidently and to make daily decisions which can maintain or enhance their health and well-being as well as their clinical, emotional and social*

outcomes.

Managing medicines: *Individualised support should be available for people with long term conditions to achieve the best possible outcome from their medicines.*
(Department of Health 2012, p.13)

Neidderer (2014, p.36) states, '*if in design for behavior change we understand design as a social process we can see that at its heart are people. Therefore at the most elementary level design for behavior change attempts to understand people, why they behave in the way they do and to use design to encourage them to 'do' or 'not do' something.*' In the examples we provide this understanding has led to better design of products, the application of design thinking as a way of claiming back and gaining control or the manifestation of products through a shared process of making in Open Design. This certainly sits well with the original conceptualization of behavioral design as expounded by Don Norman (1980s) with respect to product design.

However, the examples we have included all refer to positive changes, the adoption of new behaviors and ways of thinking. What about the role of design in inhibiting or changing unhelpful behavior? Poor lifestyle habits can play a significant contributing factor to many long-term conditions (Alcorn and Broome 2014). Poor diet, lack of exercise, smoking and the over-consumption of alcohol can significantly increase the risk of chronic disease including diabetes, cancer and heart disease (Hu et al 2001, Colaguiuri et al 2009, Rabe et al 2007). It can also exacerbate existing problems. For instance, according to Arthritis Research UK, for every pound a person is overweight three extra pounds of stress is placed on the knee joint and six pounds of excess stress is placed on the hip joint. For a person living with chronic arthritis this can significantly exacerbate the condition, leading to further joint instability and pain.

Dizzying arrays of approaches to behavior change exist including the Theory of Planned Behavior Model (Ajzen, 1991), the Health Belief Model (Rosenstock, 1988, Sharma and Romas, 2012) and the Stages of Change, also known as the Trans-

Theroetical model (Prochaska and Di Clemente, 1983, Prochaska et al., 1992). Designers have drawn on a number of models from psychology and the behavioral sciences. Lee et al. (2011) for instance have utilized behavioral economics in their design of interventions to reduce the consumption of unhealthy snacks in the workplace, '*presenting choices in a way that leverages people's decision processes and induces them to make self-beneficial choices*' (Neidderer et al. 2014, p.28).

Closely related to this is nudge: a concept in behavioural science that has been applied by designers (Sunstein and Reisch 2013). In a similar way to models based on behavioral economics the focus here is on shaping the decisions a person makes by making the healthy choice the default position. However the key component is that at each point a person has the freedom to opt out if they choose. For instance, in order to encourage its employees to drink more water the company Google placed bottled water on eye level shelves behind clear glass. Less healthy beverages were placed on the bottom shelves of refrigerators and behind frosted glass. Whilst at no point was the right of the employee not to drink sugary sodas removed, by making the drinking of water the easier position to take, the company increased water consumption by 47% and reduced the drinking of sugar laden sodas by 7% (Chang and Marsh 2013). Such is the potential of this approach in relation to behavior change that the 'Nudge Unit' (The Behavioral Insights Team) in the British Cabinet Office has been formed bringing together designers and behavioral scientists with the express purpose of finding ways to improve societies' behavior. These approaches are frequently categorized or described as 'libertarian paternalism', the idea being that rather than actively changing a person's behavior it is possible to simply 'design out' the problem.

These approaches however have been criticized on a number of accounts. First and foremost they raise a number of ethical concerns. Whilst acknowledging that at no point are people's choices taken away from them, the covert manipulation of behaviors, particularly when these occur at societal level raises questions as to the extent to which this impinge on human rights. The second main criticism is the failure of such approaches to result in any long-term behavior.

Other methods utilised by designers have been more direct, focusing on triggers and prompts to encourage or discourage particular behaviors. For instance much of e-health is based on the potential of persuasive technology (Fogg 2003, 2014) to offer a medium, a conduit for change. This may be through raising awareness of the amount of exercise taken or the number of calories consumed, the delivery of motivating feedback messages, or more specific information such as heart rates, body posture, respiration or glucose levels. The utilization of such technologies has been a key component of enabling people to self-manage their long term condition and the design of tele-health and tele-care interventions has been based on a combination of enabling individuals to monitor their condition and to make small adjustments and changes to their behavior. Initial findings from the Whole Systems Demonstrator Programme, a government funded study that looked at the role of tele-health and tele-care in enabling people to manage their long-term condition was extremely promising. Initial figures indicated that this approach led to a reduction in mortality rates of 45% and cut hospital admissions by 25%. However more recent research has called into question these results, concluding that 'telehealth does not seem to be a cost effective addition to standard support and treatment.' (Henderson et al., 2013 p.2)

Further research is being undertaken to understand some of the mechanisms involved here. However an earlier European study undertaken by Domingo et al. (2012) offers us perhaps a hint of an explanation. This study evaluated a telemedicine intervention for heart failure patients. The study found that those who completed the study experienced a high degree of satisfaction leading to positive behavioral changes. However over half of those engaged in the research withdrew. The authors of this study concluded that more work was required in relation to understanding the factors that enable or prevent a person from accepting or rejecting the technology. This study underlines the challenges of scaling up any intervention focusing on behavior change because of the number of variables that are at play. This means that even when one can control some of these there are no guarantees that a specific response will occur. For instance, being able to see a reading of blood pressure does not automatically lead to a reduction in the amount

of salt a person consumes. A person's ability to change will depend on their understanding of the consequences of consuming the salt, on their value and belief systems, peer pressure from those around them and on their readiness to change. Equally there is an element of the unpredictability of how people will respond to or utilize a product and the unanticipated and unplanned for consequences of some designs.

Perhaps then it is necessary to look to other approaches and methodologies designers can take within this arena. One such approach is mindful design, a promising method expounded by Niedderer (2007, 2013, 2014). Drawing on the work of Langer (1989, 2010) mindful design works on the principle of achieving change through using design to '*disrupt the user's consciousness to raise their awareness*.' Examples of mindful design in the literature are limited at present although Neidderer (2014) cites an example from her own work whereby health-care practitioners were taught how to apply mindful design practices in their interactions with patients so that they began by asking questions regarding positive steps they had taken to manage their own health. The interesting aspect of this example is that amidst all the approaches that are currently expounded perhaps the task of the designer needs to extend to the potential of design on raising awareness, challenging stigma, changing attitudes to health-care and rather than focusing solely on the person living with the long-term condition to direct energies towards enabling the health professionals who work alongside them.

A number of examples regarding this approach exist in the literature. For instance SHIFT MS is an organization that seeks to support individuals living with the degenerative long-term neurological condition of multiple sclerosis (MS). In a recent piece of work people living with MS were invited to convey their experiences using visual media as a way of building understanding and challenging the stigma that is associated with this condition.

Similar research examples include Debra Padfield's work, which has explored the meaning of pain, again through visual media. Her face2face project focused on the development of a visual communication tool for clinical use, developed out of

photographs of the representation of pain, co-created with people experiencing pain. Findings from the research have been extremely positive with increased understanding of the consequences of pain and its impact on behavior.

Conclusion

In many ways, design for behavior change in the context of the health-care of people with long-term conditions is in its infancy and as we have shown, discussion around the role of design here raises more questions than it answers. For instance there are questions relating to how and when to offer interventions, potential ethical dilemmas, whether the focus should be on societal solutions or on approaches that place the onus on the individual. These issues still require further debate and discussion. However what is clear is that this area offers many possibilities. We have provided examples in this chapter where the design process has offered new insights, leading to the design of better products and hinted at other avenues for exploration where the focus of the designer turns to the health practitioners who work with individuals. Whatever the focus design for behavior change for individuals living with long-term conditions is an topic that requires further exploration.

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