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653. Design, Behaviour change and long term conditions: The impact of demonstrating design skills to adolescents with chronic pain

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This paper reports on part of a research-through-design PhD study. This study sought to understand if participatory workshops to share design skills and approaches with adolescents with chronic pain could have an impact on their management abilities and behaviours.

Academics have long sought to understand, define and articulate the skills that designers possess and how they 'do' designing. In recent literature there is increasing interest in how these skills might be shared and utilized outside of design professions in areas such as; education, business management, policy-making and as a means of empowering citizens. Supporters of this application of design typically associate the use of design practices and process to innovation, problem-solving, business strategy, behaviour change and resourcefulness.

There is an emergent precedent in health sectors to use design this way. Literature suggests it is a young field with scope to develop knowledge within it. Knowledge gaps include; developing an understanding of the impact of sharing design practices and approaches, exploring different types of engagement with a variety of stakeholders to identify how they might benefit from this approach, and to further develop methods and exemplars of delivery. Furthermore, a better understanding of healthcare contexts, languages, modes of operation and philosophical frames is required.

A mixed methods analysis was used to understand the impact of the workshops. Initial findings indicate positive changes in mind-sets associated with design approaches, greater understanding of design skills and subsequent application to management abilities and behaviours.

This paper will present the methods used in, and findings from, the research. It will also reflect on the complexities of conducting this type of design-led project in a healthcare context, where there can be conflicting worldviews on evidence and knowledge, and strict ethical procedures to adhere to.



Background

Recent years have seen an increased demand for design methods and approaches within healthcare development and research (Chamberlain, Wolstenholme and Dexter 2015; Horne 2013; Baeck 2013; Design Council 2004). This has been linked to a need for increased innovation, collaborative ways of working (Cottam and Leadbeater 2004), new ways of thinking on complex problems (Design council 2008) and better involvement of stakeholders (Wolstenholme et al 2014).

As a result, designers working in these cross-sector, interdisciplinary collaborations are often faced with a range of multifaceted issues. These 'wicked' problems can be open, complex and multi-dimensional, without a clear or optimal answer (Rittel and Webber 1973; Buchanan 1992). An area that demonstrates the potential of design's impact in relation to these types of problems, is behaviour change in long-term condition (LTC) management (Craig 2017).

An estimated 30% of the population live with a LTC. This has a large impact on the UK National Health Service (NHS) with 70% of the NHS spend, 80% of GP consultations and 60% of hospital bed days attributed to them (Ellins and Coulter 2005; Coulter, Robert and Dixon 2013). The support and management of those with a LTC is a priority for the NHS, who recognize that effective management of health and wellbeing results in better quality of life for patients, reduced use of NHS resources and in turn, reduced costs (Coulter, Robert and Dixon 2013).

The best way to support those with a LTC can be classed as a wicked problem; it is complex and multi-factorial and dependent on; age, the condition, physical and mental health and financial and social issues (Ellins and Coulter 2005; Lau-Walker and Thompson 2009). A review by the Health Foundation (2011) recognizes that certain behaviours improve health outcomes and therefore condition management programmes based upon changing behaviours are likely to have success.

There has been interest in recent years to understand how design can encourage this behaviour change in LTCs (Wolstenholme et al 2014; Craig and Chamberlain 2017). In 2009, the Royal Society for the encouragement of arts, manufactures and commerce (RSA) proposed that design is a form of resourcefulness. Believing that if other citizens had the skills to be resourceful (and designers shared their skills to support this) then it might impact upon their ability to create behaviour change and overcome challenges (Campbell 2009).

Consecutive studies by Craig et al. (2013) and Wolstenholme et al. (2014) have explored this hypothesis with patients who have a spinal cord injury. The first, in response to the RSA, undertook exploratory inpatient Design Thinking sessions at the Spinal injuries centre in Sheffield. The second, introduced Design Thinking sessions as part of inpatient rehabilitation offered at the same unit. Both developed activities that demonstrated design methods and designer's skills in areas such as; Creative thinking, communication, problem-solving and prototyping. They aimed to empower patients and give them confidence to take control of their environment and future plans as they learned to manage life with their injuries.



Results from the second study showed key themes of learning and experience. Quantitative data showed statistically significant, positive changes on self-efficacy measures. Participants enjoyed the sessions, changed their perspective on problems, reported better creative thinking skills and increased confidence to try new ideas. This suggests that design workshops as part of rehabilitation can support behaviour change and are a new, novel approach that needs further investigation, particularly to explore transferability to other areas of healthcare.

This PhD study built on these recommendations and sought to develop further understanding by applying the concept to another clinical area. A scoping review identified that literature on LTCs suggests adolescents are an understudied population. An estimated 15-20% of adolescents have a significant ongoing healthcare need that relates to a LTC (Sawyer and Aroni 2005). Yet, of all age groups in the UK, it's the only one that had not seen significant health improvements over the past three decades, with LTC outcomes worse than in adults (DoH, 2012).

In 2012 the Department of Health recommended that children and young people (adolescents) should be equipped with skills and knowledge to support them to navigate the complexities of life, manage LTCs and improve future health outcomes (DoH, 2012). They recognize that this would support current health and provide an opportunity to invest in positively impacting on a generation. Health behaviours and patterns established during this time underpin a person's adult health and are likely to continue (Sawyer et al 2012; Lemer, Cheung and Davies 2014).

Through identification of this gap in the literature, this study sought to understand if workshops to share design skills with adolescents would impact on their behaviours and condition management.

Study Design

Building on the two previous studies, a programme of two workshops were designed and developed for adolescents who were receiving pain management (PM) through Sheffield Children's Hospital (SCH). Each workshop demonstrated design methods and practices and lasted three hours. Analysis sought to understand their impact on PM behaviours.

The aim was not to teach someone to be a designer or how to go through a design process. It was to introduce skills and build confidence to use them. It proposed that this might help them to approach the world like a designer would and apply those skills to challenges they might face.

Design techniques were used to illustrate and demonstrate these skills through experiential activities. Some were adapted and developed from various sources that included (Craig et al 2013; Campbell 2011; Wolstenholme et al 2014). In the interests of keeping the sessions interactive, the sessions focused around activities, video clips and short explanations. There was purposefully no PowerPoint, instead presentation and sharing by the participants was encouraged.



Figure 1: Participants during workshop one presenting their outputs from an activity on perspective.

The study recognized 10 key design skills from the literature (Cross 2006; 2007; Lawson 2004 and Dorst 2009). The focus of the first workshop was how designers see and experience things, with emphasis on; Observation, Perspective, Questioning, Knowledge and Understanding, and Opportunity. The focus of the second workshop was how designers imagine and create things, with emphasis on; Communication, Prototyping, Optimism/Creative Confidence, Experimenting, Learning through failure.



Figure 2: Participants during one of the second workshops.

The study was conducted as research and gained full NHS ethical approval on the 20th January 2017.

Analysis

A mixed-methods approach was used for analysis. A Qualitative Likert survey was used to compare abilities and confidences in design related tasks. Participants rated themselves from 'strongly



agree' to 'strongly disagree' across 12 statements. The survey was completed at the beginning of the first workshop and at end of the second.

Two qualitative measures were used. The first was a short questionnaire of eight questions. It enquired about their experience of the sessions and if they could see a change to any behaviours since. The second measure was a semi-structured interview. Both measures were subjected to a content analysis.

Findings

The workshops took place during the holidays, with two weeks between them. 15 adolescents were recruited, however four of these dropped out between workshops. Overall, there were 11 complete Likert scale data sets, 7 questionnaire responses and two interview transcripts for analysis.

Data from the Likert scale showed 12% negative responses, 64% positive responses and 24% had no change. Half of those negative responses can be attributed to one participant. Overall the average change for each statement was positive.

Qualitative data shows that the experience of attending was positive and engaging, it provided a unique approach to PM and has enabled them to develop new mind sets and skills.

Many of the participants gave examples of how these newly developed skills were being used, such as; in explaining their pain to others, within school or to consider new ways to get back to sport.

‘the whole time I’ve just been focused on my end goal..... but the workshop helps you kind of, not adapt but look at things from kind of hobbies that I’ve had and really enjoyed. From netball, I enjoyed the fitness aspect, I’m really competitive so I enjoyed that so then I’ve taken that and taken up other kind of sports an hobbies that I probably didn’t think about before’

Other less specific examples included; out-of-the-box PM techniques, developing confidence to give things a go and seeing things from another’s perspective.

Another finding is the positive aspect of being in a group with others who have the same experience. For many this was the first opportunity they had to meet someone with their condition. Finally, the adolescents enjoyed learning new skills and strategies without focusing specifically on their problems or practically applying the skills to themselves in the session.

Something this analysis highlights are the difficulties communicating this type of design practice to those outside the field. Participants’ were unsure exactly what to expect from the sessions (although they recognized that a degree of experiential knowledge was required to fully



understand) yet found it hard to articulate to friends and family exactly what had happened despite the positive experience.

Finally, the data shows no direct impact on pain levels but this is not surprising, as this was not the intention of the study.

Discussion

This study has demonstrated that this type of design workshop is transferrable to other clinical areas, and has a positive impact on adolescents' mindsets. Adolescents reported an increase in confidence, development of design mindsets, the ability to see things from new perspectives and saw areas where these skills had a direct impact on their PM behaviours. In discussion with the therapists, some linked the studies success to opening a young person's worldview, as many become 'stuck' or fixed in their ways of thinking.

Research by Sawyer (2012, 2005) and the Department of Health (2012) on the current understanding of how to best support adolescents to manage conditions presents a field where there is still much to be understood. This study adds to this discussion; the findings suggest that learning about design skills and practice can support condition management. It also supports the notion that peer support and group sessions are positive for those who have LTC's. In the current PM service, there are no group interventions. As an outcome of this work, the team are in talks to develop these.

Further novelty was that there was no focus on the participants' condition. The activities demonstrated and gave the participants an opportunity to learn the skills but did not directly relate them to their pain. The adolescents found this helpful. It demonstrated the benefit of allowing a safe space to master a skill before applying to one's own situation. Furthermore, as this application was not part of the workshop it suggests the transferability of the design skills learned, and potentially demonstrates that the methods transcend the ideas and that adolescents can make their own links. This learning fits nicely within therapy for PM, which does not focus on 'removing' pain, instead, it seeks to enable patients to continue to engage with normal life, cope with their pain and facilitate recovery to as high of a level as possible (Sheffield Children's Hospital, n.d).

However, running these workshops as a design researcher in a healthcare environment was not without difficulties. This study was run as a piece of research; therefore it was subject to the ethical procedures of research in the NHS, alongside University ethics and local site protocols at SCH. Gaining ethical approval for this study was a lengthy process. Differences in worldviews, approaches to research and language barriers proved to be difficult to navigate. There were difficulties in clearly articulating the study whilst ensuring that the research stayed true to design methods. Much of the documentation did not allow for the reflexive, iterative nature of design research, requiring exact information on the amount of sessions and what would happen at each. It took careful negotiation to write an application that satisfied both fields. Overall, including



amendments, ethical approval took 18 months. This had a drastic impact on the time to recruit and run the study, as a result, only one round of workshops was completed (the original study design included multiple rounds to explore various ways of running and implementing the methods).

Alongside ethics the researcher spent time conducting a period of design ethnography. The aim was to build a relationship with the PM team to understand the context that the workshops fit within. Furthermore, building a relationship with the team supported the sessions and recruitment. This was successful and led to a body of work with the team to develop the service. More information on this is written up elsewhere (Partridge 2017).

Something that spans the ethical procedures, design ethnography and the findings of the adolescent workshops, are the difficulties communicating this type of design practice within healthcare. Peoples experiences of the term design vary widely, and many have little to no understanding of the methods and skills that designers apply. Even those who have been through the workshops found it difficult to explain the sessions to others, suggesting there is a degree of tacit learning within them. The concern is that if not articulated correctly, in a way that can be comprehended by healthcare practitioners, the value of design methods and designers will not be understood. As a result, this sort of study will not reach those who would most benefit from it and design in healthcare will not reach its full potential.

Conclusions

This work has clearly demonstrated the benefits that learning through and about design practice can have on adolescents with a LTC. It adds to a growing body of knowledge on how best to support adolescents and suggests that this could be a new and novel approach. It aligns with previous research by Craig and Wolstenholme demonstrating that the theory can cross contexts, although more work is needed to look at wider populations and the potential to apply it across conditions.

However, delays to ethical approvals limited the scope of the study and the ability to follow up patients over longer time periods. Further effort needs to look at the longitudinal effects of this type of intervention and explore optimal delivery and integration into current management support. This is particularly important as with current financial pressures on the NHS, there is scope to understand how these sessions could be delivered that would reduce costs, but maintain the outputs.

Finally, this research has demonstrated the difficulties of trying to conduct this type of work in healthcare, particularly when classed as research. More needs to be done within wider design and healthcare research to support the understandings of design practice and demonstrate its value.

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