RESEARCH EXPERIENCES BEYOND THE COMFORT ZONE

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ABSTRACT

The intersection between design and care is shaping new design fields that are both promising and challenging. Design for healthcare is one of these fields: it brings opportunities for improving people's experience of care through design research, but it takes designers out of their comfort zone. Scholars have reported success doing design for healthcare, but not much has been said about challenges, failures or confrontations found in this field. This paper argues that we should care more about discomforting aspects of design research to get a better understanding of what designing together involves. It presents a case of *care (in)action* and employs a personal approach to discuss challenges and confrontations that I faced doing research at the intersection of design, care and health.

INTRODUCTION

In the last four years, I have been involved in codesign research projects for healthcare. Apart from being rewarding, it has been a challenging experience where I have become aware of the commodification of care, have had difficulties taking care of others and myself, and have been questioned about the reliability of my findings.

As design incorporates co-creation paradigms we care more for final users and undertake new roles (Sanders & Stappers, 2008). However, traditional education – at least the one I received in Colombia in the 1990s – trained us to work in design studios, collaborate with creative professionals, and respond to commercial clients. Doing codesign for healthcare, I have had to learn new skills to work at hospitals and to collaborate with healthcare professionals and users to understand and improve experiences of care.

My work is far from unique. An increasing body of literature including books (e.g.Tsekleves & Cooper, 2017), journals (e.g.Chamberlain & Craig, 2017) and conferences (Christer et al., 2018; e.g.Seemann & Barron, 2017) demonstrates that design for healthcare is becoming a strong field of design research. These publications explain the joys of doing design for healthcare, but what most authors do not tell are the dramas of their practice.

What challenges and issues do we face when doing design for healthcare? Should we care about the commodification of care and the complicity of design in this process? How to take care of others if we are not able to take care of ourselves? Do our research findings really care if they contradict expected outcomes of industry partners and colleagues? This paper reflects on personal experiences doing codesign research in healthcare to explore these questions from a personal perspective. It aims to contribute to this conference and discussions about codesign in healthcare (Jakob & Manchester, 2017; Knutz, et al., 2017) by exploring challenges, sharing failures, and raising issues related to design, health and care.

CONTEXT, METHODOLOGY AND SCOPE

This paper discusses experiences from one of the first codesign for healthcare projects I conducted in collaboration with Australian cancer centres. I focus on this project because it was an experience that took me away from my comfort zone, where I had to face several challenges, and through these challenges gained important research skills.

This project, as others in this field, reflects increasing interest in bringing codesign and building design capability in hospitals. This interest is not fortuitous; it responds to new regulations that require healthcare organisations to involve users in the design and delivery of care services, which in turn has created opportunities and allocated budget for design research.

My design research is focused on the fuzzy-front-end: understanding patient experiences from a human-centred perspective and producing insights to inform subsequent projects to improve the delivery of care experience to users of healthcare services. On paper, the research project discussed here had a collaborative approach and a methodological framework based on co-design methods. However, since my objective is to discuss what happens out of the comfort zone, I must acknowledge the messy nature of the research process (Clark et al., 2007). In practice, due to logistics, costs and interests of industry partners a collaborative approach was difficult to maintain. The initial methodology had to be adjusted to ethical requirements, clinical restrictions and everyday circumstances, and the initial framework became an improvised mashup of tools and techniques.

This paper discusses three points. The first one relates to the commodification of care, and the role that designers are expected to play in the healthcare context. The second explores issues using codesign tools with cancer patients, and explains emotional issues faced by participants and myself as part of this process. The last part discusses tensions I experienced when my research findings were different to expected outcomes of industry partners and challenged results from previous research.

Following calls to engage with politics of representation (Light, 2018; Light et al., 2016), this discussion is written in first person. I have chosen this style as an attempt to capture elusive aspects of my practice and engage with politics of self-representation. In doing this I have deliberately decided to report not just success, but to critically reflect on discomforting and unresolved aspects of my practice.

BEYOND THE COMFORT ZONE

BRINGING DESIGN INTO HEALTHCARE: COMMODIFICATION AND DESIGN DIPLOMACY

The project discussed here had a multiple-stakeholder approach, where design researchers were embedded in hospitals to collaborate with providers and users of healthcare services. Bringing design to and embedding myself in a hospital made me aware of the commercial characteristics of healthcare, and the marketing processes that doing research in this context involve. In my experience, I found that I was coming into a highly corporatized environment and getting involved in bureaucratic and administrative activities.

The first issue I would like to raise is the commodification of care and the complicity of design in this process.

The commodification of care is evident in the National Safety and Quality Health Service Standards (NSQHSS) (Australian Commission on Safety and Quality in Health Care, 2012), a document that regulates hospitals operations in Australia, where users of healthcare services are described as consumers. One of the standards requires healthcare organisations to ‘partner with consumers’ in the planning, design, delivery, measurement and evaluation of care – a role commonly assigned to designers working with hospitals.

As the project I was involved in progressed, I found myself facilitating consumer engagement, rather than collaboration with patients: having meetings with consumers, creating questionnaires, organising focus groups and using survey results in the design processes. Part of my academic background is in cultural studies, and I know that thinking of patients as consumers reflects the introduction of neoliberal paradigms in healthcare and suggests that hospitals are corporations, that patients are clients and that care has become a commodity.

The NSQHSS, in particular the ‘partnering with consumers’ standard, have created interest in design. Hospitals are opening ‘design centres’ and hiring designers to manage partnerships with committees of consumer representatives. Designers have made of codesign a buzzword to define any form of interaction with consumers and post-it notes have become a symbol of supposed empowerment and democratisation. However, codesign is not always about these attributes, but mainly – as in other industries – about attracting clients, selling services and improving feedback, as well as a ‘trojan horse for’ for getting grants and research contracts. Design scholars collaborating with communities have associated processes of readiness and infrastructuring with cultural awareness and social relationships (Akama & Light, 2018; Hillgren et al. 2011). In this context, however, these processes are more about ‘design diplomacy’, a term used to describe the work of ‘fixers’ and ‘spin doctors’ in charge of selling design as a corporate service. Overall, this is problematic because the work of designers is strengthening the commodification of care.

Commodification of healthcare is not new and has been studied in other fields (e.g.Lupton, 2014), but because design has become instrumental in this process, we should care about it. As Knutz et al. (2017) argue healthcare models introduced by neoliberalist politics are socially exclusive, fail to work and promise fantasies. We must remember that in this context we design *with* people in need of care, rather than *for* consumers of care commodities.

CODESIGN TOOLS IN HEALTHCARE: FROM PLAYFULNESS TO SORROW

Previous studies report on successful applications of codesign methods in healthcare. Less known, however, are the challenges involved in the use of these methods. I found that in this context, we need to adapt our ways for working to sensitive situations; and take care not just of participants, but also of ourselves. To illustrate this point, I share challenging experiences working with cancer patients facing difficult circumstances, and issues I had coping with my own emotions after being involved in sensitive situations.

Design literature emphasize the need for doing research in ethical ways and be sensitive of participants' circumstances (Kelly, 2018). Sometimes, however, we ignore the situations we will be exposed to, do not get prepared for them and consider institutional support irrelevant. As part of my research I collaborated with patients undergoing chemotherapy to understand their information needs and self-care practices. I designed a generative toolkit to facilitate conversations during chemotherapy sessions about information needs, and a probe about selfcare activities to be completed at home.

The initial design of these tools was problematic. Co-design tools are characterised for being playful, and my own research is inspired by playful triggers (Akama & Ivanka, 2010), and experiments and games (Brandt, 2006; Brandt et al. 2008). Consequently, the first prototypes of the tools were colourful and proposed ludic activities, but when testing the tools, patients and clinicians were uncomfortable with their format. I realised that a playful approach was inappropriate for this context and had to refine the tools through several iterations. The toolkit for these conversations started as a foldable with stickers and ended up as a moderate booklet with questions presented as visual icons.

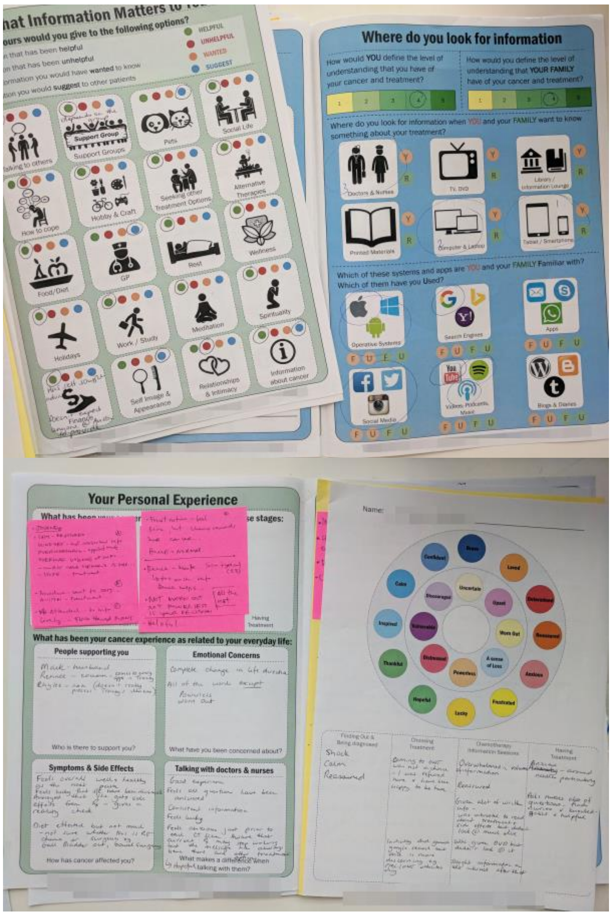

Figure 1: Example of final toolkit completed with participants

Being careful do not guarantee that things cannot go wrong for participants and researchers. The toolkit I designed was not focused enough on information needs and I ended up having personal conversations with patients about their emotional journeys – something clinicians warned me not to do. Patients told me more about sense of loss, anger, sadness, fear, and death, than about the information they needed.

The probe was also problematic. Although probes have been successful in other healthcare projects (e.g. Knutz et al., 2017), only two, out of our 15 participants, completed the activities. Those who did not complete the probe reported distress and anxiety when trying to do it.

Overall, the conversations immersed me in the drama of the oncology unit, and the probe brought the drama of cancer treatment into patients' homes.

Figure 2: Elements included in final version of the probe

I was completely unprepared for this experience and felt frustrated and guilty. Several months after these conversations I was afraid of the unknown, the randomness of cancer, and the fate of the people I worked with. At the time I did not mention anything. In design research 'care' is something we associate with others, not with us, and this has shaped a culture where being sensible can be considered as unprofessional.

THE PATIENT VOICE: RESEARCH FINDINGS VS. EXPECTED OUTCOMES

The project I was involved in, aimed to inform the design of healthcare services through a better understanding of information needs of cancer patients. The objective was to bring the 'patient voice' into the research process, which revealed perspectives considerably different to those of industry partners and scholars. My last point is about difficulties we face when our findings contradict expected outcomes and previous research.

The most problematic tensions I faced between expectations and findings are related to assumptions about the information patients need to know and their role in the delivery of care. One of the most common assumptions in the healthcare system is that patients want to take care of themselves. For instance, the NSQHSS expect that patients will become 'partners in their own care', and healthcare organisations promote selfcare practices through campaigns and publications. A common assumption in the literature is the belief that patients want to have power and participation. In cancer studies and participatory design (Andersen, 2010; Danholt, Bødker, Hertzum, & Simonsen, 2004), it is believed that if patients have their information needs satisfied, they gain an active role in decision making and get better treatment results. In this context, power and digital platforms are correlated; it is believed that digital health systems and social networking sites are shaping a new empowered subject: the patient 3.0 (Clemensen et al., 2016).

Expectations about selfcare, empowerment, participation and digital platforms have been demonstrated in previous research, but they are not a rule. Although some research findings coincided with these views, most patients were happy with the information provided and were not interested in receiving more than what oncologists considered necessary. It is true that many participants could be associated with an empowered patient: active information seekers, aware of information needs, able to formulate questions and find answers using their own sources. Some participants in this group where patients 3.0, they documented their cancer journey through social media and shared their experience with relatives and other patients.

However, many other patients did not fit in this pattern. They felt overwhelmed by the amount of information received and were not interested in getting more; other were not interested in selfcare and thought that health professionals were responsible for taking care of them. Some patients did not agree with the idea of empowerment, identified themselves as being vulnerable and preferred to delegate decisions to health professionals and relatives. And a few did not want information at all because they were afraid of hearing worst case scenarios. In terms of information sources, most patients preferred contact with doctors and nurses, and printed media; few saw benefits of digital systems or apps, but only as a complement to traditional systems.

Industry partners were disappointed and expressed disbelief when they knew of these findings and insisted on the idea of implementing digital health information systems, websites and social media platforms to deliver information and promote selfcare. Some of my own colleagues found these results controversial, considered them negative and questioned their relevance.

Despite the tensions they generated these findings are still important for design and healthcare because they point out contradictions in understandings of what care and being careful means. Introducing a human-centred perspective into healthcare is not just about caring for patients who confirm expectations of industry and designers, but also implies to care for the needs of patients who are not proactive, do not feel empowered, or prefer analogue over digital media.

CONCLUSION

This paper has used a personal approach to discuss challenges that take us out of the comfort zone when doing research at the intersection of design, health and care. Doing this I hope to shed light on some aspects of design research generally overlooked and raise questions about problematic aspects of the healthcare industry. Paying attention to our own dramas, and not just to the joys of our research, we can gain a better understanding of what we should care for when designing with people.

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