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Navigating the tensions of integrating lived experience in participatory healthcare design

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ABSTRACT
Despite growing interest in participatory approaches to healthcare design, the integration of people's lived experience—direct, first-hand understanding of a certain condition, situation, or identity—remains a key challenge to meaningful participation. Through an interview study with 23 patients, designers, family caregivers, and healthcare professionals involved in participatory healthcare design initiatives, the authors identify underlying tensions associated with leveraging lived experiences in healthcare design and investigate how existing strategies for integrating lived experience relate to these tensions. In doing so, this research offers insights for practitioners regarding ways of strategically navigating tensions when integrating people's lived experience through design in complex healthcare contexts.

Introduction

There is increasing recognition of the need for more participatory approaches to healthcare design that involve staff, patients, and families to co-create care (Cottam and Leadbeater 2004; World Health Organization 2018). Involving these various actors in healthcare design initiatives can improve treatment outcomes and healthcare experiences (Spanjol et al. 2015; Vahdat et al. 2014). It is considered a fundamental element of participatory healthcare design (Bate and Robert 2006). To co-create care that is inclusive and tailored to the needs of the affected people, purposefully

integrating their *lived experience* during participatory design efforts is a critical necessity (Berry 2019; Vink and Oertzen 2018). This research defines lived experience as a direct, first-hand understanding of a certain condition, situation, or identity. Lived experience is holistic, shaped by contextual factors, and unfolds over time (Gallan et al. 2019). For example, a person who has survived breast cancer has specific lived experiences that involve a deep, personal understanding of what it feels like to be diagnosed, receive treatment, and continue living after cancer (Williams and Jeanetta 2016). Their lived experience can inform the design of services others with breast cancer require, for instance by inviting this person to co-creation workshops to gather ideas, by asking them to provide feedback on early prototypes of a new service, or by investing resources for them to innovate for themself.

Despite considerable attention to the potential benefits of engaging different actors in healthcare design, little research details the approaches for meaningfully integrating lived experiences into design processes (Danaher and Gallan 2016). Without an in-depth understanding of the nature of leveraging lived experience in healthcare design, ill-informed efforts to involve staff, patients, and families create a risk of tokenizing those involved by marginalizing their contribution. This leads to establishing a participation façade, which (1) reinforces existing power imbalances as well as the pre-existing perspectives and strategies of people with dominant roles, (2) increases patient alienation and frustration, and (3) may even lead to serious healthcare failings (Farrington 2016; Ocloo and Matthews 2016). Therefore, the objectives of this research are to investigate the multifaceted elements involved in leveraging lived experience in healthcare design, and to develop strategies to support such integration in participatory healthcare design initiatives.

Background

In the past decade, healthcare organizations worldwide have invested more in design, in efforts to catalyse transformations that acknowledge the importance of the human experience (Hargraves 2018; Mager et al. 2017). This increasing interest in design is fuelled in part by the demand for significant changes to healthcare models, such as the World Health Organization advocating for a transition toward integrated, people-centred healthcare (World Health Organization 2018). Design promises a means to help healthcare systems transition from a biomedical model toward a people-centred care approach that emphasizes seeing the patient as a person in context (Malmberg et al. 2019). People-centred healthcare requires shifting from a narrow focus on a specific disease or body part toward active co-creation of healthcare experiences, including collaborative activities among patients,

their families, healthcare staff, and others (Danaher and Gallan 2016; McColl-Kennedy et al. 2012; Oertzen et al. 2018; World Health Organization 2018).

As design is positioned as a catalyst for this paradigmatic shift toward co-creation in healthcare, there has been a growing emphasis on participatory healthcare design processes (Cottam and Leadbeater 2004; Freire and Sangiorgi 2010). Participatory design is grounded in the fundamental notion that 'those affected by a design should have a say in the design process' (Ehn 2008, 94). Participatory healthcare design processes give staff, patients, and families opportunities to reflect on and shape their healthcare experiences and provide input into the redesign of the overall system (Donetto et al. 2015). The resulting range of processes might include inviting diverse people to workshops to inform the design of prosthetics (Hussain, Sanders, and Steinert 2012), or partnering with patients and staff to co-design a new service for people living with diabetes (Freire and Sangiorgi 2010). Thus, participatory healthcare design processes inherently rely on the lived experience of people, who have unique understanding of their own circumstances (Bate and Robert 2006).

Even as the number of participatory healthcare design initiatives increases, meaningfully leveraging lived experiences in these design processes remains a challenge. First, though lived experience has immense value in terms of deepening understanding of people's needs and the context, it can be difficult to combine different knowledge sources and perspectives (Lehoux et al. 2011; Trischler et al. 2018). Conflict may arise across multiple truth regimes, such as when integrating the lived experience of patients with traditional sources of expertise, such as doctors' knowledge (Carr et al. 2009; Sellen 2018). Second, some people experience additional barriers to participation, such as patients with dementia, who require a thoughtful and sensitive approach to be able to collaborate (Tobiasson et al. 2015). Third, recruiting diverse patients to participate in lengthy healthcare design initiatives is difficult, such that design efforts often wind up relying on self-selecting, pre-existing patient groups with a narrow subset of lived experience (Farrington 2016). Fourth, many healthcare design initiatives fail to acknowledge the power dynamics related to leveraging lived experience in healthcare contexts, such that they risk reproducing oppressive, exclusive practices (Donetto et al. 2015).

Although there are various existing tools that evaluate participation (e.g. Arnstein 1969; IAP2 2018), they do not account for the specificities of integrating lived experiences. Determining how to leverage the lived experience of different people in participatory design processes is particularly important in healthcare contexts, in which others cannot gain an accurate, holistic understanding of what it feels like to have a certain condition or illness by using a product or service or even engaging in day-long simulations. That is,

an in-depth understanding of ways to integrate lived experience is critical for advancing healthcare design to support people's meaningful, authentic participation, which ultimately facilitates the transition toward integrated, people-centred healthcare.

Methodology

Noting the lack of in-depth insights into leveraging lived experience in healthcare design, this qualitative study, employing in-depth interviews, explores the multifaceted nature of this task and seeks to discover people's existing approaches for doing so in diverse situations.

Empirical context

The interviews were conducted in two contexts, at Experio Lab in Sweden and Patient Innovation in Portugal. Both initiatives represent examples of the growing global movement toward participatory approaches in healthcare design in Western healthcare cultures (Mager et al. 2017). Healthcare design in Experio Lab is initiated from inside the healthcare system by designers and healthcare professionals; in Patient Innovation, it is driven and initiated by patients and family caregivers. Conducting interviews across both contexts helps account for the different constellations by which lived experiences can be integrated.

The Experio Lab national initiative employs a service design approach to transform Swedish healthcare systems. Facilitated by designers and project managers employed within local healthcare systems, Experio Lab involves patients, families, healthcare providers, and other related actors in participatory service design processes. It was initiated in 2013 by the County Council of Värmland and has grown to seven labs in different regions across Sweden. The interviewed designers and healthcare staff have participated in healthcare design initiatives that focused on topics such as maternity care, mental health, recovery from a heart attack, and supporting family caregivers.

Patient Innovation is an international non-profit platform that connects patients, caregivers, and collaborators around the world to help them design and share their solutions for coping with health-related problems. At Patient Innovation, patients with rare diseases, who are often underserved by pharmaceutical firms and other medical suppliers due to the small market size, design healthcare services for themselves with support from others (Oliveira et al. 2015). Since being founded in 2014, its online platform has hosted more than 1000 innovative, shared solutions, sourced from approximately 80 countries (Patient Innovation 2022). We interviewed patients and family caregivers who led the designs of innovations focused on diverse

situations, such as bladder control, supporting breast cancer recovery, and helping people with visual impairments.

Data collection

Over a 12-week period, we conducted semi-structured interviews with 23 participants: 5 patients, 7 designers, 7 family caregivers, and 4 healthcare professionals (Table 1). We combined purposeful sampling and maximum variation sampling (Merriam and Tisdell 2015; Patton 2015) to recruit participants. To achieve maximum variation in the sense of information-rich, diverse cases relevant to the research objectives, as well as facilitate the interviews in terms of language proficiency, staff of Experio Lab and Patient Innovation suggested participants to interview. We took care to ensure that the interviewed participants represented both initiatives driven by designers and healthcare professionals and those driven mainly by patients and family caregivers. In addition to providing theoretical saturation for the specifically formulated objectives, the sample size reflects general recommendations for interview studies that suggest 12–20 participants for maximum variation (Kuzel 1992).

After we obtained approval for the research protocol from an ethical review committee, we conducted half the interviews face-to-face with participants in healthcare contexts and the other half through video calls with participants in their homes or offices. The same interview protocol guided the

Table 1. Interview participants involved in participatory healthcare design.

ID	Participant type	Healthcare domain
(P1)	Patient	Bladder control
(P2)	Patient	Arrhythmic heart monitoring
(P3)	Patient	Breast cancer support
(P4)	Patient	Visual impairment support
(P5)	Patient	Breast cancer support
(P6)	Designer	Maternity care
(P7)	Designer	Recovery after heart attack
(P8)	Designer	Dementia care
(P9)	Designer	Mental health care
(P10)	Designer	Client welfare
(P11)	Designer	Electroconvulsive therapy (ECT)
(P12)	Designer	Maternity care
(P13)	Family caregiver	Parkinson support
(P14)	Family caregiver	Autism care
(P15)	Family caregiver	Mobility support
(P16)	Family caregiver	Developing assistive products and services
(P17)	Family caregiver	Developing assistive products and services
(P18)	Family caregiver	Scoliosis support
(P19)	Family caregiver	Breast cancer support
(P20)	Healthcare professional	Supporting family caregivers
(P21)	Healthcare professional	Mental health care
(P22)	Healthcare professional	Electroconvulsive therapy (ECT)
(P23)	Healthcare professional	Recovery after heart attack

interviewers in both contexts. All participants received an informative letter, detailing the objectives of the research, and signed an informed consent form before answering any questions. The goals and progression of the interview were explained as part of the introduction of each interview. Participants were not provided with any monetary remuneration, and partaking in the study was voluntary; we found that participants were intrinsically motivated to share their stories. The interviews were audio recorded and lasted an average of 64 min. We asked participants to discuss the healthcare design initiative they participated in, the other people involved, how these collaborations took place, the role of lived experience in the process, the challenges they encountered in leveraging their lived experience, and lessons learned.

Phenomenology is well-suited to explore complex issues that necessitate deeper insights beyond surface responses (Goulding 2005), as it seeks to learn from people's lived experience based on the way a person describes their experience and perceives meaning in this experience (Bevan 2014). In phenomenological research, the sampling frame is purposive, as participants are selected based on their lived experience (Goulding 2005). To this end, the authors of this research immersed themselves in two healthcare organizations to gain a deeper meaning of the general context and the diverse spectrum of lived experience of different people. The active immersion lasted between five months to one year at the local premises of Experio Lab in Sweden and Patient Innovation in Portugal.

Data analysis

We analysed these collected data according to the general inductive approach of Thomas (2006), which aims to systematically condense raw data into summary themes, analyse relevant links between the research objectives and themes, and develop a framework from the underlying structures evident in the data. The general inductive approach is a well-established approach to addressing focused evaluation questions and identifying relevant themes, especially when not much is known about the research area (Crilly 2015; Thomas 2006; Yargin, Firth, and Crilly 2018). Table 2 illustrates the three stages of the data analysis process. First, we summarized the interviews upon their completion and the audio files were transcribed verbatim (321 single-spaced transcript pages). Second, we manually coded for the facets of and approaches to leveraging lived experience in participatory healthcare design initiatives. Third, we synthesized the findings, as reported in the subsequent sections. Note that all names used in examples below have been changed to ensure confidentiality.

Table 2. Stages of data analysis process.

Stages	Procedures
Stage 1: Summarizing the interviews	• Create detailed summaries of all interviews directly after completing it, by using handwritten notes taken during the interviews about the progression of the interview, notable quotations, and perceived feelings or emotions. • Transcribe audio files of interviews verbatim into 321 single-spaced transcript pages. • Revisit audio files and capture additional quotations and observations relevant to the research objectives.
Stage 2: Coding the interviews	• Manually code the *facets* of and *approaches* to leveraging lived experiences in participatory healthcare design initiatives; the members of the author team worked independently and iteratively to code the summaries and contrasted and complemented their findings for the analysis. • Code a text segment as a facet of leveraging lived experience if it included a particular characteristic of conveying or utilizing a first-hand understanding. • Code a text segment as an approach if participants discussed a way of dealing with the complexity of leveraging lived experience. • Obtain 116 text segments coded as facets of leveraging lived experience and 189 text segments coded as approaches to leveraging lived experience.
Stage 3: Synthesizing the findings	• Bridge the conflicting facets to derive six underlying tensions of leveraging lived experience in participatory healthcare design initiatives. • Develop seven strategies to leverage different degrees of lived experience in participatory healthcare design initiatives based on people's existing conscious and unconscious approaches. • Provide two detailed, empirical examples to illustrate some tensions and strategies of leveraging lived experience.

Findings

Based on experiences shared in the interviews, we identify six underlying tensions of integrating lived experience in participatory healthcare design initiatives. Furthermore, grounded in participants' conscious and unconscious approaches to dealing with the complexity of leveraging lived experience, we delineate seven strategies that respond to different tensions. In what follows, we detail these tensions and strategies, contextualizing them through empirical examples.

Six underlying tensions of leveraging lived experience

When scrutinizing the facets of leveraging lived experience in healthcare design, we encountered several contradicting patterns that we synthesized into six underlying tensions: in/ability, im/partiality, dis/connection, in/direct, dis/similarity, and mis/understanding. We use a slash to represent each tension, reflecting our recognition that the elements often are seen as opposing, yet they are not necessarily dichotomous. Nor are the tensions mutually exclusive, as they certainly may influence one another. Table 3 lists the six tensions, which we discuss in more detail next.

Table 3. Underlying tensions of leveraging lived experience.

Tension	Definition
In/ability	The contradiction between people being uniquely capable of leveraging their first-hand experience, but also facing significant barriers that limit their capacity to do so.
Im/partiality	The divide between using personal feelings and perspectives and the need for objectivity and acting based on facts.
Dis/connection	The push and pull between being too attached or too detached to the mission or context of the design effort as a result of a lived experience.
In/direct	Challenges related to having people with lived experience present to share their knowledge versus secondarily "presencing" them through empathic methods.
Dis/similarity	The contradiction between seeing someone's lived experience as related to someone else's experience versus recognizing that every experience is unique and different.
Mis/understanding	Being able to comprehend the lived experience of other people, but also considering it impossible to wholly know and comprehend someone else's experience.

Further supporting quotes for these tensions can be found in the Supplemental Online Material.

In/ability

A prominent tension that came forward in our analysis, 'in/ability', reflects the contradiction that people with lived experience are wholly and uniquely capable of sharing their direct knowledge in particular situations, but they also may face significant barriers that limit their ability to leverage their experience in participatory healthcare design initiatives. Some participants with lived experience were able to design for themselves with minimal outside resources. One patient (P2) had developed a device to measure his arrhythmic heartbeat. Notably, this patient encountered a need rooted in his own lived experience of having an arrhythmic heart, and also had a background of working in a field that allowed him to come up with a device to monitor it:

> I have the tools that allow me to do the job that the doctor recommended that I do. (P2)

But other participants mentioned various barriers to sharing their lived experience, such as sickness or stigma. In one of *Experio Lab's* healthcare design initiatives exploring maternity care, memory issues were highlighted:

> It is hard to remember what your concerns were when you were pregnant after you have your baby. (P6)

Im/partiality

Another emerging tension, 'im/partiality', pertains to the divide between the value of using personal feelings and perspectives and the need for objectivity in professional healthcare settings.

> I often struggle: what is personal and what's professional? And I often feel like, oh no, now I am unprofessional again because I am sharing too much. (P7)

Designers, in particular, found it challenging to deal with and leverage their own lived experience in participatory healthcare design, such that some argued their formal role as a designer requires suppressing their own experience:

> It's hard to put yourself aside, but that is what a designer has to do. (P8)

Dis/connection

The third tension that participants confronted, 'dis/connection', includes the push and pull between being too connected or too disconnected with the mission or context of a healthcare design initiative, due to one's lived experience. Some participants emphasized the importance of a close, personal connection to a healthcare design initiative and indicated that their lived experience drives their persistence and determination:

> The experience obviously makes it different. It makes it a mission. (P17)

Other patients and family caregivers who design solutions for their own well-being expressed feeling exhausted from the emotional investment of sacrificing themselves for the cause. They expressed their need for others with similar connections, for emotional and operational support, but worried that other people might not share the same level of connection. Designers also voiced an emotional toll of being too connected to a particular healthcare design initiative, because of their own lived experience as patients. In one case, the designer thus developed a desire to detach and not work on certain healthcare projects:

> I don't want to work with projects related to that because it's too close to heart. (P9)

In/direct

Another tension, which we named 'in/direct', relates to the struggle between having people with lived experience present to share their first-hand perspectives versus using representation and empathic approaches. The participants recognized the value of having people with lived experience participate directly in the co-creation process. In particular, they underscored the advantages of people's physical presence in participatory healthcare initiatives and the value of communicating through body language, in addition to spoken language:

> There is a huge benefit in being there in person. There is a lot of communication that happens through body language. (P16)

Yet in certain situations, including the patients' or family caregivers' experience was not possible, due to ethical considerations or sickness. At times, participants worked to 'presence' others through empathic methods and role-playing:

> Because we didn't have any patients in the room. I was both the patient and the moderator. (P11)

Dis/similarity

A considerable tension arose with regard to relating the lived experiences of different people in healthcare design initiatives, or what we refer to as 'dis/similarity.' Some participants proposed that their story was the same as the stories of many people with that particular illness or condition.

> My story is the same story of 85% of the … community. (P1)

Yet many participants highlighted the uniqueness of each person's experience and reflected on the risk of falsely assuming that someone else's experience was similar to their own:

> Everyone is really different. The issues experienced by one person are not necessarily the same as experienced by the next person. We would still need to go out and speak to a wider audience, even if we had one person [with lived experience in the team]. (P13)

Mis/understanding

Our analysis of the interviews revealed that participants were unsure whether it was possible to understand the lived experience of others, a tension we name 'mis/understanding.' Some patients and family caregivers consider it impossible for others to fully understand their lived experience, but others believe it is possible for others to gain some understanding, through their own related experience:

> There is no way somebody can understand. (P15)

Designers and healthcare professionals in particular reflected on identifying with the experience of others and understanding their experiences by using their own, albeit divergent, experiences:

> I haven't had that in my life, but I have had experiences of close relatives and families where the body has been affected a lot. … I feel like somehow, I have experienced the body being fragile. (P7)

Table 4. Strategies for integrating lived experience in participatory healthcare design.

Strategy	Definition	Practical example	Illustrative quotes
Simulating	Staging a temporary process of mimicking or replicating a particular lived experience	Role-playing a certain situation with people who have not experienced the situation	"Then we did role-playing, so one in each group was the patient and they did a scenario that they made up themselves." (P8)
Presencing	Sharing second-hand perspectives on lived experience in the absence of someone with relevant lived experience present	Drawing an empathy map of people with lived experience to make them "present" in the room	"We started with the empathy map, because we wanted to lift the target group into the room to have them present." (P21)
Templating	Creating a standardized procedure or format in which people can share their lived experience	Filling in the blank spaces in a provided document to template people's experience	"I felt the workshop was very controlled. It was even the start of a phrase, like the first words were set and then they were going to fill that in." (P7)
Sharing	A one-way process of directly communicating one's own lived experience, of value for others	Someone sharing their own lived experience through interviews	"I have this person that I call Lisa. ... She is telling the story and we listen to when she talked about how her life had been." (P10)
Exchanging	A multi-directional process of sharing and relating the lived experience of several people	Reciprocal dialogue among diverse people with similar and different lived experience to test and improve an innovation	"It's important that you get new people involved that have not been part of it before, because very soon you take something for granted." (P4)
Allying	On-going partnership and corresponding support between people with relevant lived experience and others	A collaboration between someone with lived experience and other people to develop an innovation	"We decided to do everything under equality. ... Our interests are perfectly aligned. ... We like to collaborate and we both don't like to fight." (P14)
Resourcing	Providing people with lived experience the assets they need to lead the design of the changes that affect them	Using resources from others to design for oneself as an entrepreneur	"They need to know what you want and they put it to work." (P1)

Strategies to leverage lived experience in healthcare design

During the interviews, many participants noted several conscious and unconscious approaches to dealing with the tensions they faced when integrating their own and others' lived experience. Grounded in these observations, we assembled seven strategies of integrating lived experience in participatory healthcare design initiatives. Table 4 provides an overview of these strategies, which are not mutually exclusive and can be combined, in ascending order from the lowest to the highest levels of autonomy that the strategy enables for the people that have lived experience relevant to the healthcare initiative.

Simulating

Integrating patients or family caregivers to leverage their first-hand experience in healthcare initiatives can be challenging for various reasons, such as memory loss or the pain of remembering (reflected in the in/ability tension). In these cases, designers or healthcare professionals may try to temporarily employ the 'simulating' strategy to replicate the lived experience of others, such as by role-playing a certain situation. Although a viable approach if the people that the healthcare initiative targets cannot be safely engaged, it runs the risk of falsely representing their lived experience or projecting other people's mental models onto their experience.

'Presencing'

The second strategy, 'presencing', also does not directly include the active participation of the people with lived experience targeted by the respective healthcare initiative. With this approach, people use empathy and knowledge from their second-hand experience to represent others (often relating to the tension in/direct). Storytelling is commonly used to instil a sense of presence, which helps people understand and design for others and the situations they face. Although this strategy integrates the lived experience of others indirectly, it draws only on second-hand knowledge, which may still lead to false representations of people's lived experience.

'Templating'

'Templating' is the first strategy that directly integrates first-hand, lived experience in participatory healthcare design initiatives. It provides a structured procedure or format for documenting people's lived experience, such as a standardized form with blank spaces that encourages people to report their own experience. Such a strategy is often taken in response to the tensions of im/partiality or dis/similarity. This approach produces focused and structured data, but first-hand experience is often challenging to communicate in such a controlled and restricted format, and the data gathered inherently reflect the assumptions of the people who created the format for sharing.

Sharing

The fourth strategy, 'sharing', allows for the integration of first-hand knowledge in a less restricted and controlled format by asking people to directly communicate their lived experience, such as during interviews. This strategy is often brought forward in response to the tensions of mis/understanding and in/direct. The result is a more in-depth understanding of others' lived experiences. However, it still only offers a partial account of the first-hand perspective because such knowledge sharing generally is confined to a few

interviews, one-off storytelling, or one-time workshop participation. This strategy also creates a potential risk of misinterpretation, because of the lack of clarification and dialogue in a one-way sharing process.

Exchanging

'Exchanging' elevates the integration of lived experience from one-directional communication to a multi-directional process of reciprocal communication. It comprises dialogue among two or more people who share similar or different lived experiences. This strategy is often undertaken in response to the tensions of dis/similarity and mis/understanding. With this strategy, people can better understand the first-hand knowledge associated with multiple perspectives, and people with lived experience can contextualize their experience relative to those of others. For example, some patients described designing an initial prototype of a solution to meet their needs, then asking other people in a similar situation to try it and give feedback. However, the duration of this strategy is typically relatively short and allows for limited exchanges of other resources.

Allying

Unlike the prior strategies, the sixth strategy 'allying' is long-term in nature. People engage in continuous partnerships with others and receive on-going support. This strategy often is used as a way to relate to the tensions of dis/connection and mis/understanding. For example, those with first-hand knowledge might participate throughout the course of a healthcare initiative that is steered by a designer. As another example, people with lived experience could design for themselves and others, while closely partnering over the long-term with others to access the support, knowledge, tools, or funding that they lack. This form of partnering leads to continuous sharing of experience, but it can be slow and resource consuming, and power dynamics may continue to constrain how lived experience is integrated.

Resourcing

Finally, 'resourcing' comprises the highest level of liberty for people with lived experience who are the main beneficiaries of the healthcare initiative. This strategy provides people with lived experience with the assets they need to design the change they seek. This strategy reflects a response most prominently to the tensions of dis/similarity and in/ability. People might take control over designing an innovation that improves their well-being while co-creating with others. With this strategy, people with lived experience often become user innovators and entrepreneurs, who lead the development of the services and systems that affect them. In many cases, the adoption of this strategy was born out of necessity. Patients who need specific solutions

that are not readily available on the market may decide to develop them on their own, which usually requires resources from others. In some cases, though, resourcing is not possible or desirable, whether due to the graveness of patients' illness or policy barriers. Furthermore, providing resources without ongoing allyship and connections to larger networks limits the potential influence of such healthcare initiatives.

Examples of leveraging lived experience in healthcare design

To contextualize and illustrate the tensions and strategies of integrating lived experience, we provide two examples of participatory healthcare design initiatives.

Addressing the need for bladder control

Paolo has an incurable illness that limits his daily life due to its symptoms, such as having to visit the bathroom unexpectedly and frequently. While on holidays with his family, he experienced a critical need for a toilet, and it took him over an hour to find one:

> We were in the line for Anne Frank's house and the line was around three hours waiting and I had a critical moment. I realised I had to go to the loo. (Paolo)

Paolo searched available products and services to find a solution. However, he could not find anything to help control his bladder, which prompted him to design a solution himself: an interactive app that could be used to predict the likelihood of critical moments. He needed further support to develop this solution. Specifically, Paolo required technical knowledge from developers, more in-depth knowledge about the target segment of people like himself, medical knowledge about how to predict critical moments, and financial insights regarding how to fund the undertaking:

> I had the sketch of the idea, but I have no knowledge of IT and all the dealings of the app. (Paolo)

While developing the solution, Paolo also encountered some contextual challenges, such as geographical distance from the software developers, located in Asia:

> For me its too difficult to manage the Skypes with [Asia]. We have a 5.5 hours time difference … I realize that for me as a … patient, I need to rest a lot. (Paolo)

His own experience enables Paolo to relate to and empathize with other patients suffering from the same symptoms, so he decided to make the app accessible for everyone in the community. As a result of Paolo's enduring efforts, he has been very emotionally and physically involved in the healthcare design initiative. Even though his experience with the illness motivates

and drives him, Paolo is exhausted from all the work, which he must perform even while still dealing with the symptoms:

> I'm too tired. I'm tired. I'm very tired, because I'm the ambassador of the project. (Paolo)

This example illustrates several tensions of leveraging one's lived experience as a patient while also innovating for oneself. First, Paolo experienced critical moments in his daily life, which made it necessary for him to look for a solution to control his bladder. He had knowledge of his own condition and experience, but he could not proceed with the design of the solution without more technical knowledge about how to develop the app. These conflicting forces—being wholly capable to design for oneself based on the lived experience but limited by a lack of technical knowledge—exemplifies the tension in/ability. Second, the software developers he found were located in Asia, and the time difference and virtual nature of their interaction challenged the collaboration. This complication reflects the in/direct tension, in that not being in physical proximity requires forgoing some of the value of being directly present in terms of body language and understanding one another. Third, Paolo was physically exhausted and so emotionally attached that he found it difficult to detach and relinquish some control over the initiative, reflecting the tension of dis/connection.

Paolo offers an example of a resourcing strategy, because he took the lead as an entrepreneur to design for his own well-being, while being supported by the resources of others, such as technical knowledge from app developers in Asia. Although he is designing a solution that truly matches his own needs and desires, he is restricted in his ability to develop a solution, due to his lack of expertise but also the symptoms of his illness. Allying with someone else could ease this burden, but it would denote a loss of control, which he feels increases the risk that the ultimate solution will not meet his needs as well. As this dilemma realistically illustrates, the tensions of leveraging lived experience cannot be resolved by a single, readily available strategy but instead must be navigated within the given context and evolving situation.

Improving the experience of electro-convulsive therapy
Electro-convulsive therapy (ECT) is treatment for patients with persistent mental health issues. It entails putting electrodes on the patient's head to stimulate seizure-like activity in the brain, creating substantial apprehension among patients and their families. The manager of a local ECT unit came to *Experio Lab* to get help with improving the experiences of patients and families. To better understand the experience, an *Experio Lab* designer, Nils, planned a re-enactment of the ECT patient journey process, in which doctors, nurses, managers, and operations staff would go through each step of the patient process, from the waiting room to departure. However, when the

ECT manager tried to recruit patients to join this re-enactment, none of the contacted patients were available and willing to join. During the re-enactment, one representative patient participated, but it was not a patient who had first-hand experience of the ECT process:

> The biggest problem was that we didn't have the real patient perspective. You can always feel and get empathy but it is not the same if you don't get them on board. (Nils)

The designer, managers, and healthcare staff involved recognized that with the stigma of mental illness, the unpleasantness of this process, and the current condition of patients, there were many barriers to their participation. Therefore, Nils played the role of the patient and asked the staff to reflect on what the patient experience might be like at every stage of the process. Lacking lived experience specific to this process, the *Experio Lab* team decided to reach out to ECT patients and conduct interviews, as another way to learn from their experience. However, Vera, a healthcare professional who conducted some of these interviews, noted some patients' inability to share their experiences in interviews:

> I almost immediately got the feeling that this woman is not well … She had difficulties explaining how it was and when it happened. She needed more help … She couldn't answer me clearly. (Vera)

Vera sensed that the patient did not remember her experience well and was not able to share it meaningfully. In another interview though, the patient was recovering well, and Vera, who interviewed the patient and his spouse at their home, related to and identified with his story:

> This was a man who had been healthy his whole life. It came from nowhere, like lightning. He looked normal. … It took me harder … that could have been me. Identification is always a strong instrument. (Vera)

After the interviews, the *Experio Lab* team compared what the patients said their experience was like against what the staff who re-enacted the journey believed the experience was:

> We saw a discrepancy between what the doctors think that the patients feel and what the nurse thought and the [patients]. … They always have this professional perspective with them. It is hard to twist in their head. (Nils)

Nils perceived that the professional roles of those who participated in the re-enactment and their distance from the lived experience of ECT patients created a misunderstanding about what the experience was really like. He also recognized the difficulties of leveraging lived experience in some situations, due to capacity and memory issues and the need for different strategies, reflecting the circumstances and conditions of the patients and their family members.

In this example, we can identify several tensions of leveraging lived experience. First, the barriers related to memory, health, and stigma create a tension around the in/ability of patients to share their lived experience. Second, we note the push and pull between involving patients and families directly or indirectly, due to their circumstances. The emphasis on indirect sharing of lived experience led to various levels of misunderstanding between staff and patients and families. Furthermore, some patient experiences appear dissimilar from those of one interviewee, but another interview created a sense of identification that increased Vera's connection with the experiences shared, thereby reflecting the dis/similar tension.

For this example, the design team adopted a simulating strategy, in that Nils role-played the experience of patients in the ECT patient journey process to build empathy. However, recognizing the limitations of this approach, the team complemented the insights from the simulation with a sharing strategy, facilitated by the patient interviews. The team then used the insights from both approaches to compare findings and challenge existing assumptions about the lived experience of ECT patients and family members. However, there was palpable frustration about how the complexity of the situation limited the team's ability to integrate lived experiences through more dialectic approaches.

Discussion

Previous research highlights the importance of leveraging lived experience in participatory healthcare design initiatives (Cipolla and Bartholo 2014; Vink and Oertzen 2018). Existing literature also notes the challenge of doing so and the risk of tokenizing people with lived experience in the process (Farrington 2016). Despite this awareness, research to date offers limited insights into how practitioners can navigate these challenges and meaningfully integrate lived experience within the design process (Danaher and Gallan 2016; Sellen 2018; Tobiasson et al. 2015; Trischler et al. 2018). In response, this research identifies six underlying tensions of integrating lived experience in participatory healthcare design initiatives and assembles seven strategies that are often combined as responses to different tensions. Although the strategies used to integrate lived experience are influenced by different tensions, the strategies employed also affect the tensions present during participatory healthcare initiatives.

An understanding of these tensions helps explain the limitations of existing participatory design initiatives and contextualizes the key challenges of leveraging lived experience outlined in relevant prior literature. For example, Trischler et al. (2018) indicate the difficulty of combining different knowledge sources, and Sellen (2018) suggests that conflict might arise from working

with multiple truth regimes. These challenges reflect the mis/understanding tension, because different people struggle to comprehend and accept the lived experience of others. The im/partiality tension may add to this complexity, resulting from the contradiction between the acceptability of subjective perspectives and objective reasoning. Our findings further illustrate that these tensions influence the strategies used when co-creating in a particular healthcare context.

In outlining these strategies and concrete practices, such as role-playing, we identify existing practical ways of meaningfully integrating varying degrees of lived experience, for instance the lived experience of patients and family caregivers in healthcare innovation initiatives (Berry 2019; McColl-Kennedy et al. 2017; Ocloo and Matthews 2016). This research provides a basis on which practitioners can thoughtfully adapt and expand on the strategies for integrating lived experience in ways that best respond to the multiplicity of tensions within their context. With greater awareness of the contradictory forces at play, practitioners can be more intentional and preemptive in navigating the tensions through employed strategies. It is critical that practitioners do not assume generalized, simplistic solutions or rules exist; the tensions and appropriate strategies for integrating lived experience differ with the people involved and the context.

Further research is needed regarding the different strategies and emerging tensions. For example, research could help to shed light on how healthcare design initiatives might better support exchanging, allying, and resourcing when there are significant constraints on the integration of lived experience within a given healthcare context. Studies could also determine how to foster the integration of designers' own lived experience while ensuring that they remain open to the lived experience of other people. Additional research is needed on how the different strategies for leveraging lived experience employed resist or reproduce oppression in healthcare systems. It is our hope that the explication of these tensions and strategies provides a vocabulary for more nuanced discussion and thoughtful practice in relation to leveraging lived experience in participatory healthcare design.

Funding

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