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I'm a PhD student, passionate about making healthcare more inclusive. My journey blends my academic approach with real-world design challenges, collaborating with Lund University, Mid Sweden University, and Sundsvall's Hospital on a project. Together, we're working closely with women dealing with pelvic floor injuries, co-creating solutions that prioritize their needs and autonomy.

My professional journey is diverse, ranging from being a senior lecturer on an artistic basis at Mid Sweden University to running my own company. My focus is on using design to drive positive change.

In essence, my work is about studying the grey area between design and healthcare, considering inclusion every step of the way. I'm committed to empowering those who need it most through collaboration, creativity, and a down-to-earth approach.

Åsa Wikberg Nilsson



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Åsa Wikberg Nilsson is a Chaired Professor in Design at Luleå University of Technology and a devoted advocate for using design as a transformative tool in both research and education. With robust academic and practice background in design, I use design to address complex social and environmental challenges in various contexts and areas.

My research focus spans all design areas of visual communication, physical products, interactions and services to places and systems, simply because of the need to integrate all these design orders in the exploratory design process. I have a strong belief in the power of design, the crucial need to work on inclusion, and design-for-change to achieve a sustainable social transformation.

Universal Design and Equitable Healthcare for Women – an overview of current literature and prospects

Semra Sahin Haglund and Åsa Wikberg Nilsson

Abstract

This paper presents an overview of the literature on universal design for equitable healthcare. The central inquiry in the current paper is a critical design-for-all challenge: how might universal design contribute to providing equitable healthcare for women suffering from pelvic floor injuries during birth? This study delves into some of the explicit and implicit needs of this deprioritized minority patient group and what the literature states in terms of how design might contribute to fostering patient engagement in their healthcare journey from pregnancy to after-birth care. The findings from the literature overview offer an understanding of the domain, elucidating some core concepts, and delineating existing and divergent scholarly perspectives. By exploring the intersection of universal design and healthcare, this paper contributes to the advancement of the design of equitable healthcare solutions for women.

Keywords: *Equity, universal design, co-design, design in healthcare, prototyping, literature overview*

Introduction

This paper outlines an overview of current literature as part of an ongoing PhD project with a focus on applying universal design principles in relation to equitable healthcare with a particular focus on women suffering from pelvic floor (PF) injuries after giving birth in Sweden. 'Equitable' is a concept used in this paper to cover both equal and impartial healthcare.

Generally, in healthcare there is a great deal of focus on the woman during pregnancy, but afterwards, the focus is mainly on the newborn child and there is less general knowledge about PF injuries that some women suffer from. If you on top of that come from another country and don't know the Swedish language, or from a culture with taboos about talking about these issues, the situation quickly gets complicated. The establishment of equitable healthcare can for this reason be seen as a societal challenge in which universal design could be one approach to find new ways forward.

The government of Sweden describes the objectives of health and medical care as being equitable, gender-equal and accessible (Swedish Government Office, 2014). However, more and more signals point toward unequal distributions of newly acquired wealth, with specific population groups being left behind. These disadvantaged groups present negative health outcomes at a stagnant high level, far more (23 percent) level 3 and 4 PF injuries depending on which country the women are born in (*Öppna Jämförelser Jämlig vård*, 2016). Social Determinants of Health (SDOH) is a concept that excludes medical care and defines the circumstances surrounding individuals from birth to aging, encompassing their upbringing, employment, environment, and broader societal influences shaping

their everyday life (Johnson & Wendland, 2022; Umstead et al., 2023). Thus, it has become clear that general economic development is not enough to improve health for all, but that policymakers and healthcare planners also need to consider the health of disadvantaged groups to ensure equitable healthcare. A driving force in the current PhD project is to let disadvantaged groups be part of the development process to increase equity and quality of care in its context.

The overall objective of this paper is to explore studies in design research used in healthcare primarily in maternal healthcare and PF injuries caused during birth. The review involves an exploration of relevant literature from various sources to provide a broad overview. The aim is to provide an overview of current literature about universal design and healthcare and provide some outlooks for future research possibilities about equitable healthcare for women's experiences of pelvic floor care. In this paper, we strive to answer the overall research question of what characterizes design practices in healthcare, with a special focus on equitable healthcare and concerning the lived experiences of women after giving birth.

Method

The core methodology of this paper is an overview of the literature, adhering to the approach established by Milton and Rogers (2013). This began with articulating the central research inquiry: in what ways can universal design contribute to equitable healthcare for women with birth injuries? The search for relevant literature spanned several databases, including Scopus, PubMed, Cinahl, and Web of Science, ensuring a wide-ranging collection of pertinent research. In addition to database searches, an exploration of foundational texts in design, universal design and co-design concerning healthcare,

equality and inclusion was conducted to enrich the context of the field's principles and applications. This dual-faceted approach allowed for the inclusion of seminal work in design literature but also the incorporation of emerging trends and methodologies.

The analysis phase was implemented to dissect and synthesize the collected literature, identifying commonalities and disparities among studies, pivotal debates, trends, and methodological applications that have influenced the trajectory of design within healthcare. The gathered articles were categorized into six thematic areas: equity in healthcare, qualitative studies involving patients with PF injuries, co-design principles, universal design frameworks, service design, and other design frameworks, principles or methodologies that were considered relevant for this particular context. This categorization gave an understanding of the landscape of design-oriented healthcare research.

Further enriching the literature overview were some early interviews with patients with PF injuries. These interviews were semi-structured, allowing for a discussion in relation to the interview guide themes, aligning to the approach as presented by Clark et al. (2021). Some of the questions were about women's experiences of their PF injury and daily life struggles, their care journey before, during, and after injury, and their fears, wishes and dreams.

This additional layer of data collection was important in establishing an overview of the field, ensuring the historical underpinnings and contemporary shifts in design philosophy analyzed in relation to equitable healthcare practices.

Findings

This section outlines some of the current knowledge of what it means to be living with PF injuries, and what universal design and equitable healthcare means.

Pelvic floor injuries, universal design, equitable healthcare

Giving birth is a profound life event that often brings both physical and emotional changes. While the arrival of a new child is often celebrated, the impact of childbirth on a woman's body is traditionally less discussed but is a critically important issue. There are several specific types of injuries related to childbirth. The focus in this paper, however, is on PF disorders that tear the PF muscles and tissues, specifically grade three and four.

To provide some examples, the symptoms followed by PF injury can be urine, gas and spoil leakage problems. While some studies show that those problems may lead to long-term psychological problems and low quality of life (Espuña Pons & Puig Clota, 2008; Priddis et al., 2014) other studies state "varied results" depending on the individual (Elmir et al., 2010; Huber et al., 2022) and other studies claim little or no change in quality of life (Palm et al., 2013). The Swedish Government, for example, reports PF care as an area that needs to be prioritized and developed (Swedish Government Office, 2019), further considering the effects it causes on a woman's life such as social isolation and work and family-related problems. WHO defines health equity as health differences that are unnecessary and unavoidable (Whitehead, 1992). For this reason, a relevant question for further research is how universal design principles might help identify characteristics and patients' needs of PF care from patients' perspective.

Equitable healthcare

Using universal design to reduce inequities in health can be approached in many ways. One approach may be to strive for universal coverage of healthcare enhancements especially focusing on the most vulnerable groups. Secondly, targeted interventions can be applied directly to a marginalized population. Universal coverage of healthcare is a prerequisite for an equitable health system. Nevertheless, policies need to be modeled to proactively promote health for the disadvantaged with a clear understanding of the mechanisms causing inequity to override the structural drivers of inequity and ensure equal opportunity. Thus, universal implementations like free healthcare for all and the uniform geographical distribution of health facilities may need to be supported by targeted improvements. Such improvements should focus on special needs to overcome obstacles in delivering equitable care. Besides affirmative action, need-based support assessments are essential in these efforts.

Health literacy is a concept of an individual's understanding, drive, and abilities to obtain, appraise, evaluate, and utilize health-related information for making health decisions for their wellbeing (Meldgaard et al., 2022). How can a patient's PF health literacy be a vital factor motivating them to seek help? There is also the concept of organizational health literacy which is defined as how organizations provide health information and resources in line with individuals' health literacy capabilities (Meldgaard et al., 2022). This can be exemplified by how transparent and individually adapted the PF care information provided the women's clinic in Sundsvall is. Patients' and organizational health literacy are important measures in providing an equitable healthcare practice. Another related concept is 'Shared

decision making' where caregivers and patients decide together on the treatment options while aligning with the patient's goals, preferences, and values (Waddell et al., 2023). This concept differs from an informed consent concept where the flow of information is provided from clinician to patient making patients passive recipient of the care. This can be related to Arnstein (1969), who describes citizen participation on a ladder that ranges from manipulation to full citizen control of the process and its results. In the current research study, the participants are involved as active participants in the creation of possible design suggestions using the co-design method for the PF care within the women's clinic in Sundsvall's Hospital.

Equitable design

There has been a development of several different, targeted human-centric approaches. Universal design, for example, can be seen as a strategic approach aimed at making environments, products, and services accessible to all people regardless of age, disability, or other factors (Mace, 1998), and as such holds significant implications for improving women's healthcare. By incorporating universal design principles, healthcare providers, women and designers can collaborate so that medical facilities, products, and healthcare services are inclusive, addressing the diverse needs of women throughout pregnancy, birth and afterbirth. The importance of universal design, human dignity, and human rights in the case of healthcare and the current PhD project can, for example, contribute to ensuring that women have equal access to medical care, enhance communication in healthcare settings, and accommodate women with products or healthcare applications that are accessible regardless of language skills, body sizes, abilities, technical or medical proficiency or cognitive ability. The application of universal design in women's

healthcare not only has the possibility of enhancing accessibility but also promotes dignity, autonomy, and privacy, fundamental aspects of patient-centered care. Studies done by the World Health Organization highlight the necessity of accessible healthcare environments to reduce inequalities and improve health outcomes for women globally (World Health Organization & United Nations Population Fund, 2007).

Gold standard care

There are also other approaches that do not originate in the field of design, such as *Gold Standard care*. Personalized care, team-oriented treatment and evidence-based diagnostics are highlighted as essential pillars for improved care after perineal tears (SBU, 2021). Research supporting multi-disciplinary collaborative specialist clinics that provide both physiological and psychological care in a perineal clinic setting suggests providing a smooth patient journey (Priddis et al., 2014). A pressing question here is how gold standard care can be described from a universal design perspective. Including a minority group of patient's experiences of care and their latent needs using co-design and including them in the development process of care may lead to the development of *Gold standard care* description for PF injuries.

Design Research Approaches

The design research approach in the current project draws inspiration mainly from universal design, co-design and health service design. Design research processes often span several years to allow for multiple iterations. They typically start with a design ethnography phase, followed by an ideation phase involving workshops for brainstorming and sketching. This is followed by developing

prototypes, which are evaluated in user test activities. This spiral runs several times to allow for continued learning as well as the maturing of the prototypes.

In tackling complex design challenges, a design can adopt a versatile and context-sensitive approach, one that allows for the application of diverse methodologies to fully understand and address intricate issues – what Rittel and Webber (1973) would term “wicked problems”. Experiences of symptoms such as leakage just after giving birth, pelvic floor injury health literacy to access need for professional help, and becoming a parent are some of the aspects of this complex, wicked problem. These are issues so multifaceted that they demand an exploration through various methodological lenses to unravel their complexity. While observations in the healthcare context, semi-structured interviews and several, iterative co-design workshops primarily with patients and healthcare staff are some of the planned activities, the project is open to changing its methods considering the human factor within the ethical framework. One does not rely solely on a universal design framework, instead, the approach is eclectic, borrowing and adapting techniques that suit the unique context of the problem at hand. Pragmatism recognizes the presence of consistent structural patterns influenced by the unpredictable nature of human behavior (Feilzer, 2010). Women’s narratives may show something new during the study that may need to be looked at through a new theory or a method. This author states that this abductive approach through its creative nature, leaves space for surprising events.

Nelson and Stolterman’s (2014) discourse on *The Design Way* highlights this necessity, emphasizing the development of design competence as a distinct mindset – a way of thinking that is both analytical and empathetic, ideal for navigating complex scenarios.

Universal design principles are instrumental not only in the backdrop of such a mindset but also in the methodology itself, ensuring inclusivity and accessibility at every step of the design process. Explaining universal design principles within this context means recognizing their role in guiding decisions that extend beyond physical accessibility, encompassing a broader spectrum of user experiences and interactions. This holistic approach ensures as many potential users as possible are considered in the creation of a solution, some are also seen as partners in the design process, thereby contributing to a more equitable and comprehensive understanding of the design space.

At its core, *universal design* is a concept that aims to create products, environments, services, and systems that are accessible to all individuals, regardless of their abilities, without the need for adaptation or specialized design (Hedvall et al., 2022). In this view, universal design principles are meant to emphasize flexibility, simplicity, and intuitive use. *Inclusive design*, similar to universal design, is another approach that aims to go beyond the principles of universal design to address the specific needs and preferences of marginalized or underrepresented groups, including people with disabilities, people from diverse cultural backgrounds, and those with low literacy or language skills (Clarkson & Coleman, 2015). Inclusive design involves engaging with and gathering input from these communities throughout the design process to create suggestions that are based on their needs and preferences.

Co-design is an approach that involves the active participation of users, relevant actors, and designers in the design process. Co-design aims to create products, services, and environments that are tailored to the needs and preferences of end-users, and that address their

specific challenges and needs (Sanders & Stappers, 2008). According to Sanders and Stappers, co-design involves three key principles: empathize, engage, and empower. *Empathize* involves developing an understanding of the users' needs, goals and motivations through observations, interviews, and other qualitative research methods. *Engage* means involving users and other relevant actors in the design process through workshops or other sessions and participatory activities. *Empower* involves giving users ownership in and through the design process and ensuring that their input and feedback are valued and acted upon (Sanders & Stappers, 2008).

Co-design can have several benefits for designers, design researchers and users. For designers, co-design can lead to greater creativity, innovation, and problem-understanding, as well as increased empathy and understanding of users' needs and preferences. For design researchers, the process involves a deeper understanding of users' needs, preferences, experiences, fears and anxieties, visions and dreams. For users, co-design can lead to greater satisfaction, user experiences, and effectiveness of products and services, as well as greater empowerment and a sense of ownership of the design process and its outcomes.

Also, service healthcare design is a people-centered design approach that focuses on the design of services that meet the needs and expectations of patients, care providers and other relevant actors (Patrício et al., 2019). By using health service design methods, healthcare providers can gain a better understanding of patient's needs and preferences and develop services that are more responsive to these needs. Moreover, Vink and others (2021) emphasize the importance of how simple service design suggestions that neglect to encompass the entire system often fail and remain unused despite

proving beneficial for patients. PF care is a complex care and it is important to understand the underlying structures such as health guidelines, recommendations from health agencies and the practice of care. This can lead to improved patient satisfaction, greater patient engagement, and ultimately, better health and more inclusive outcomes.

Discussion

In this exploration of universal design for equitable PF care the aim has been to shed some light on the need for inclusive healthcare solutions that cater to women's journey of PF care. This paper, through its literature overview, illuminates some of the complexities of delivering equitable healthcare and the role that design – particularly universal design and co-design – can play in this endeavor. It reveals how traditional healthcare models often marginalize women with PF injuries, contributing to the stigmatization and under-prioritization of their care. Through universal design principles, in this study we propose a shift towards more inclusive healthcare approaches and environments that acknowledge and address the diversity of patient needs. Those deprioritized, minority group patients that have special needs from healthcare may as well be an inspiration in the development of care which may lead to solutions that are better for the majority.

By focusing on equity, the research aligns with global health directives that advocate for healthcare systems that eliminate unnecessary and avoidable health disparities. It leverages design as a strategic tool to foster patient engagement, ensuring that healthcare services are not only accessible but also resonate with the lived experience of women dealing with PF injuries. The study's

emphasis on co-design and patient involvement marks a departure from conventional healthcare paradigms, positioning patients not just as beneficiaries but as active participants in the design of their care.

The study is, however, limited to being a first literature overview and needs to be expanded to also be able to showcase good examples and practices of co-design methodologies in this context and hopefully also some universal design principles in this respect. The ethics surrounding this study are intertwined with its core objectives of promoting equitable healthcare and ensuring that design processes are inclusive, respectful, and sensitive to the needs of all women, particularly those with PF injuries. Ethical considerations in this research are manifold, reflecting the complexity of engaging vulnerable populations in healthcare design and research.

Future studies need to ensure informed consent, deal with language barriers, and cultural and other challenges in addressing stigmatizing issues. The ethical responsibility is therefore to ensure the participants' dignity and privacy throughout the research process, and that their experiences are represented with accuracy and sensitivity.

The transdisciplinary nature of the overall PhD study, bridging design and healthcare, introduces ethical considerations related to professional practices and collaboration. It necessitates mutual respect and understanding among disciplines, acknowledging the value of diverse perspectives while navigating the ethical implications of integrating design into healthcare solutions. The design approach might also challenge traditional power dynamics in healthcare. For these reasons, the PhD project has been ethically vetted and approved by the Swedish Ethical Review Authority.

The research done so far does, nevertheless, bridge the gap between design and healthcare by highlighting the potential of design to address the “wicked problems” within healthcare systems. A multidisciplinary approach is used, which here transcends the aesthetic and functional aspects of design and proposes services and solutions that uphold human dignity and rights. The exploration of universal design in healthcare systems alongside co-design methodologies underpin our vision for healthcare that is equitable, empathetic, and patient-centered.

Conclusions

This paper has outlined some of the arguments from research for the integration of universal design principles in healthcare to enhance accessibility and equity, in the current case with a focus on PF care for women postpartum. It critically assesses the existing literature, identifying a gap in the provision of care that respects the diversity and complexity of patient needs. Compared to women with lower or no tears during birth, patient groups with higher grades of PF injuries have more symptoms and therefore higher healthcare needs. At the same time, they can be an inspiration for creativity leading to suggestions that may be useful for a bigger patient group. Studying such a patient group may help identify the possible problems experienced with the PF health journey and provide alternative *Gold standard care* recommendations that may help other women going through the journey of pregnancy and giving birth. The application of design-for-all principles offers a transformative pathway toward healthcare that not only acknowledges but actively addresses the disparities in care experienced by women with PF injuries.

The paper's findings show the necessity of reimagining healthcare through the lens of design, where patient engagement, co-design, and empathy are foundational elements. It sets a precedent for future research and practice, calling for a collaborative, multidisciplinary approach to healthcare design that centers on the well-being and dignity of all patients. By utilizing universal design and co-design, the PhD project contributes to a growing body of knowledge that seeks to democratize healthcare, ensuring it is accessible, equitable, and responsive to the needs of diverse patient populations.

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