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As the official journal of the AIA Academy of Architecture for Health (AAH), this publication explores subjects of interest to AAH members and others involved in the fields of health care architecture, planning, design, and construction. The goal is to promote awareness, educational exchange, and advancement of the overall project delivery process, building products, and medical progress that affect all involved in those fields.

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Co-Designing with Children: Innovating Patient Engagement and Participation in Pediatric Healthcare Design Research with Immersive Technology and Affective Interactions

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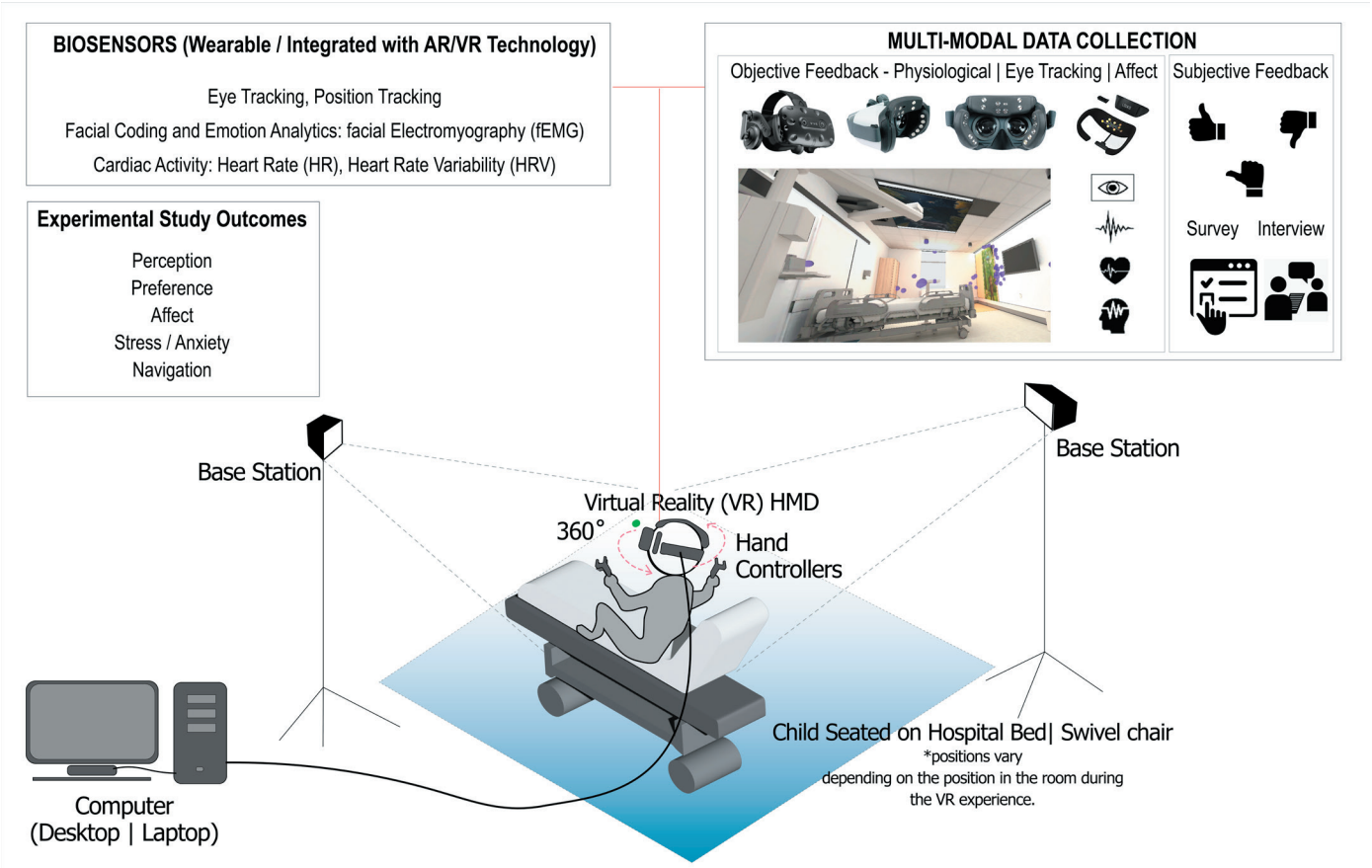
ABSTRACT

About 1.3 million children and adolescents are hospitalized yearly with a mean length of stay ranging from 4.2 to 5.3 days. Designing healthcare environments for young patients from different backgrounds is challenging due to the complex technology-intensive environments, interactions between people, and the diverse needs of hospitalized children from neonates to 21 years of age for supportive age-appropriate environments. Pediatric healthcare facilities have a crucial role in offering supportive healing environments to this vulnerable population. Considering the significant impact of the built environment on patient experience and health outcomes, partnership is important between hospital owners, doctors, nurses, administrators, architects, designers. It is particularly important for patients and family to include their unique and collective perspectives in the design of the healthcare environment. Evidence shows there is currently limited use of participatory research in pediatric health care built environments. This article outlines patient engagement methods in pediatric healthcare design research, along with unique challenges faced by researchers engaging with children in these settings. There is a need for innovation in the way children are meaningfully engaged and involved in research for patient-centered design. Our research explores innovative patient engagement methods and tools such as immersive technology and biometrics towards achieving a supportive pediatric built environment design.



Graphical Abstract 1. Innovating Patient Engagement and Participation in Pediatric Healthcare Design Research with Immersive Technology and Affective Interactions.

1.3 million children and adolescents spend 4.2 to 5.3 days annually at hospitals. The pediatric world and children's hospitals, in particular, are special places hosting particularly vulnerable patients. The physical environment of these places has an enhanced role in addressing the pediatric patient experience by offering a welcoming and supportive environment. Hospitalizations cause specific difficulties for this vulnerable young population and adults, as they can involve short or long-term separation from peers, school, and family, leading to the perception of a loss of status within the peer group because of the physical absence (Hutton et al., 2021). Studies show racial disparities and equity issues in health outcomes for pediatric patients (KIDs Inpatient Database (KID), HCUP AHRQ, 2012). Pediatric healthcare facilities have a critical role in offering a supportive healing environment with age-appropriate environments that can address the unique needs and concerns of the diverse population group, while also addressing the unique needs of the parents and caregivers (Carrie Hill et al., 2018).

In pediatric healthcare research, there is a growing focus on special population groups with studies addressing adolescents and young adults (AYA), neurodivergent, ADA (Fekete & Lucero, 2019; Peditto et al., 2020; Poltronieri .L, & Freeman .K, 2021), care settings — mental and behavioral health (Shepley et al., 2017), study design — mixed methods and experimental studies (Creswell & Clark, 2017; Wingler et al., 2021) including innovative methods in environmental design research using immersive technology such as virtual reality (VR) (Jafarifiroozabadi et al., 2022; Joseph et al., 2020), and outcomes such as experience and human emotion (Bower et al., 2019). With recent studies addressing differences in the neurocognitive functioning of diverse groups, the need for inclusive design, and the benefits of codesigning with and for children to capture their unique needs, we understand that innovating the pediatric space to improve the patient experience requires a deeper understanding of multiple factors. Some of these factors include spatial and environmental design of the physical environment, to be able to accommodate operational and user-specific needs that can in turn adapt to the affordances (Choi & Bosch, 2013) of space.

Whilst studies indicate that children and young people are competent to talk about, and document their environment and experiences within it, in a capacity that is useful to designers, planners, and policymakers (Taylor et al., 2006), the use of participatory research with the general public and even more so with children is limited within healthcare research. We see a need for increased involvement of children as participants and co-researchers in various settings (Bishop & Corkery, 2017), and for targeted research to inform evidence-based design guidelines with an interdisciplinary approach through the use of novel methods for engagement with this vulnerable population. With the patients' voice required in design mock-ups, simulation, and feedback to address diversity and equity, and to meet functional and emotional affordances, meaningful engagement and collaboration will enable useful feedback for architects to design supportive environments, by improving the basic understanding of how design affects this group physiologically and psychologically across the breadth of the population. Immersive technology is showing promise as a tool for environmental design research and for its ability to elicit different emotional states as measured by neural and cardiac dynamics through integrated sensors (Higuera-Trujillo et al., 2020; Marín-Morales et al., 2018). This could have a significant impact with novel applications in fields as diverse as architecture, health, and education, as well as in design practice. In architecture, immersive technology ,such as VR in Evidence-Based Design (EBD), processes may improve participatory design strategies in the context of pediatric design projects.

This article takes the approach of a review paper to provide a brief overview of various themes related to pediatric healthcare design research.

1. Patient-and-family-centered-design and impact of the built environment on the Patient-and-Family-Experience in pediatric healthcare settings
2. A review of methods used for patient engagement and participation in pediatric healthcare design research
3. Immersive technology and affect studies in design research and application in healthcare design research
4. Challenges in participatory research with children in healthcare design research

In addition, we propose a methodology using immersive virtual environments integrated with biometrics to study affective interactions. The goal is to improve participatory design in the context of pediatric healthcare design projects for engagement with patients and families offering deeper insights and feedback loops for architects designing supportive environments in healthcare.

1. Patient-and-family-centered design and impact of the built environment on the patient-and-family-experience in pediatric healthcare settings

Growing evidence demonstrates the impact of the built environment linking favorable room design elements to patient satisfaction, stress, health, and outcomes (Gaminiesfahani et al., 2020; Jiang, 2020; Ulrich et al., 2008). Healthcare facilities and designers have a fundamental role in designing supportive environments for the health and well-being of their users. Designing healthcare environments for young patients is particularly challenging due to the complex technology-intensive environments, interactions between people from different backgrounds, and the diverse needs of hospitalized children from neonates to 21 years of age in terms of supportive age-appropriate environments. Pediatric hospitals lead the way in patient-and-family-centered care with families being involved in the care design process, but we can do more via innovative methods of patient engagement to improve the pediatric built environment design and the patient-and-family-experience with deeper engagement and insights. With the significant impact of built environment design on patient experience and health outcomes, more research is required in pediatric research through partnerships between children's hospitals, healthcare planners, and architects, and for methodological and technological innovation around patient engagement (Elf et al., 2020).

Pediatric facility design 'needs' include providing a positive, supportive healing environment that can offer cognitive stimulation, access to recreational and learning activities, social engagement, personal space, privacy, and control. While several theories have been applied to hospital settings for supportive design for patient care and delivery through human-centered design from the perspective of adult patients experiencing their hospital stay, there is a lack of studies with children. More research is required to address gaps with studies on affordances provided by the environment and perceptions that support an individual's actions e.g., a physical environment designed to offer better affordances for family presence and activities will increase family presence, and the extent a patient room provides affordances contributes to patient-and-family-centered care through design. Studies show some application of supportive design in palliative and end-of-care environments (Ghirotto et al., 2019) and a dearth of application in acute pediatric healthcare facilities. With findings that suggest correlations between social support and well-being, including the need for psychosocially supportive design within pediatric settings, there is a need for targeted research to inform evidence-based design guidelines that use a broad disciplinary approach, with age-appropriate support and empathy (Lambert et al., 2013, 2014; McLaughlan, 2018; Wiener et al., 2015). There is little high-quality quantitative research including randomized controlled trials (RCT) that include diverse groups and clinical settings. Evidence demonstrates the positive impact of the physical environment on family behavior along with interactions with hospitalized children and staff (Bosch & Lorusso, 2019), however, there are few empirical studies that show the effectiveness of patient-and-family-centered design on health outcomes.

2. Current methods used for Patient Engagement and Participation in Pediatric Healthcare Design Research

A review of studies on patient engagement methods in acute healthcare settings was conducted from 2000-2020 with the objective of understanding the methods used for patient engagement in acute care settings on spatial and environmental variables, related patient outcomes, methods, metrics, and tools for engagement. The search was conducted using the online database Google Scholar. Post-screening and evaluation of twenty-two publications, that included ten studies in pediatric settings, were selected to be studied. Only a summary of the studies with a focus on pediatric settings is presented in this article on trends.

There is a growing trend in research with 55% of the total studies conducted in the past five years focused on the built environments within healthcare. Figure 1 presents the distribution of the studies on the pediatric healthcare built environment comparing it to the total number of studies identified. Figure 2 presents the methods, tools, and measured outcomes in ten pediatric healthcare studies between 2000-2020. In pediatric settings, studies on the perceptions and needs of patients and families predominantly use qualitative methods (Lambert et al., 2013; Water et al., 2017) and theories were explicitly used in 42% of studies. The findings show a weak theoretical nature with 20% failing to apply any theory to justify findings. Ulrich's Theory of Supportive Design (Stress Reduction Theory) is the most popular theory followed by Psychosocially Supportive Design and Participatory Research. Most of the studies adopt quantitative or mixed methods design using an exploratory qualitative phase to inform survey questionnaire development or a preference study using

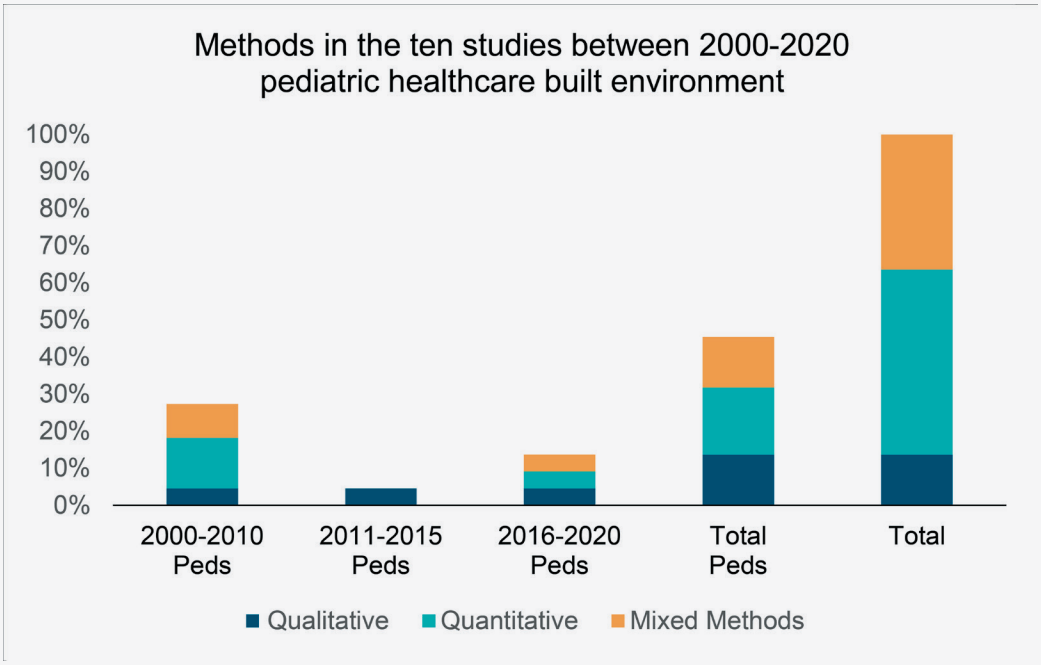


Figure 1. Summary of ten studies on the pediatric health care built environment conducted between 2000-2020 to the twenty-two studies identified in the review.

RCT. Interviews, focus groups, photo-elicitation, Delphi approach, art-based methods, observations, and surveys were the tools most widely used (Coad & Coad, 2008; Eisen et al., 2008; Felippe et al., 2017; Trzpuc et al., 2016; Ullán et al., 2012), with a couple of studies using physical or digital mock-ups using VR (McLaughlan, 2019). About 50% of the studies used validated tools to measure health-related quality of life (Mardelle McCuskey Shepley et al., 2012; Sherman et al., 2005), and 30% of the studies used qualitative findings to inform the development of the surveys. Two of the recent studies adopted a discrete choice experimental design (DCE) that is common in healthcare policy for a preference study. Both studies were not ranked high in terms of empirical evidence as they do not address rigor or share information on assumptions. Qualitative and quantitative methods of analysis include thematic analysis, descriptive statistics, t-tests, correlation, ANOVA, chi-square test, Fisher's exact test, and Mann-Whitney U test with two studies using structural equation modeling (SEM) with the exploratory and confirmatory factor analysis to study the latent built environment variables and the effect of mediators (perception). In pediatric settings, the sample size varies from n=37 to n=175, and includes children, adolescents, young adults, and parents responding as a proxy for children.

We present a summary of the built environment variables and the measured outcomes from the studies in Figure 3. Variables – Spatial, Positive Distraction, Social Support, Perceived Control and Comfort, and Outcomes – Perception, Satisfaction, Preference, Stress/Emotion, and Restorative/Healing. Some of the variables are not strictly as those presented in the paper, for example, "care for relationships" was included under social support and 'nature' was included in 'view'. Overall, we see that 'Positive Distraction' variables (window, view, nature) have received a lot of attention recently compared to perceived safety that is not directly addressed although it is seen in literature as a critical need for the pediatric population. Perception and Preference outcomes constitute 60% of all studies with 50% in peds- focused studies. Preference (42%) and Stress/Emotion (33%) are the common outcomes in pediatric studies. There is a lack of studies on healing environments within the pediatric group.

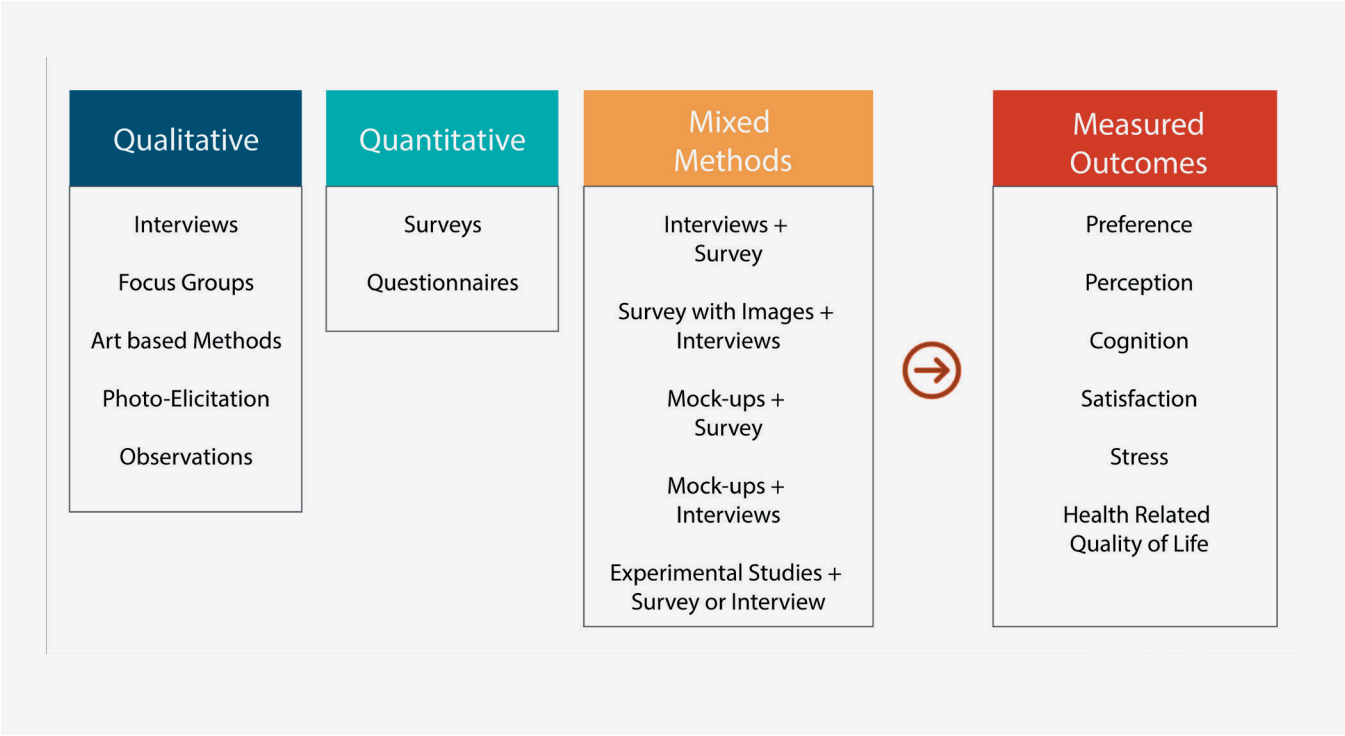


Figure 2. Methods, tools, and measured outcomes in ten pediatric healthcare studies between 2000-2020.

The studies reviewed present the need for objective measurements such as physiological and psychological responses rather than self-reports. Key challenges are in addressing covariates and confounders, and how to control for them. Existing research also highlights the need to include mediators and moderators for a holistic understanding of the impact. In the pediatric setting, early studies have focused on the ambient design features such as the color of the hospital environment and thematic design preferences such as nature and water using qualitative methods. Recent studies have focused on theoretical models such as supportive design with a new interest in addressing the age groups such as adolescent and young adults (AYA) population.

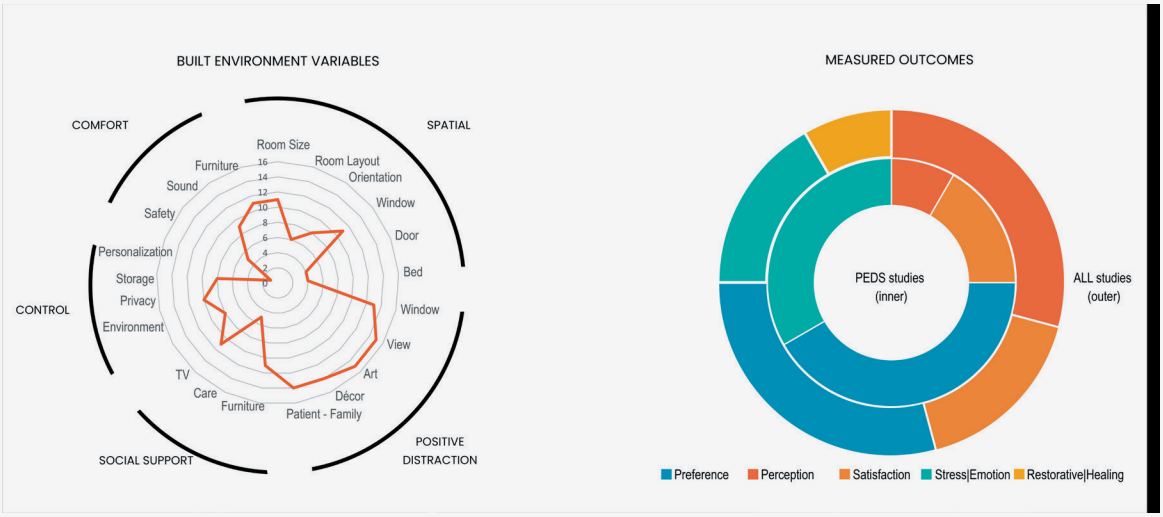


Figure 3. Summary of built environment variables and measured outcomes.

Recent research also questions the role that the physical environment's ambient features have on patient satisfaction (used as a proxy for patient experience), the increased role of spatial layouts and design features on health outcomes, and the need to include methods that can adequately measure objective qualities of the built environment that directly impact the patient experience for operationalization of the metric (Beattie et al., 2015). Study methods and metrics focus on the ambient environment and patient satisfaction while not adequately measuring the complex interactions within the physical environment for operationalization. There is a focus on single design features, lacking environmental sampling, and ignoring physiological mechanisms through which environments affect stress. Concepts are used interchangeably, with evidence showing patients tend to overrate satisfaction due to gratitude bias, and the need for measurement to focus on the experience in real-time (LaVela & Gallan, 2014). Patient experience, a multidimensional construct, needs to be re-conceptualized by identifying the constructs and variables for specific definitions and precise measurements, such as the independent room-level categories and variables, individual-level variables, mediators and moderators, and dependent variables. Strategies effective for operationalization of a multi-dimensional construct like patient experience include the following, all of which pose challenges described in a later section (1) involving the patient/end-users – here the hospitalized child and their parent (2) during active treatment (3) in a healthcare setting (4) using multi-methods of data collection for triangulation and validation of findings.

3. Immersive technology and Affect Studies in design research and applicability in healthcare design

Immersive virtual environments in head-mounted displays (HMDs) are having a significant impact on architecture and research, including opportunities for environmental design studies in-vivo rather than in-situ (Stals & Caldas, 2022). These advancements have given researchers opportunities to increase stakeholder involvement and efficiency of the work processes. Immersive technology allows the creation of realistic virtual environments where users can be fully immersed and feel a similar sense of presence as physical environments (Chirico & Gaggioli, 2019), blurring the boundaries between the physical and virtual worlds by creating a sense of immersion and enhancing the realism of virtual experiences (Slater et al., 2009). Immersive environments provide the opportunity for designers to create virtual mock-ups of buildings where the stakeholders and users can be immersed in and interact with a variety of design features to evaluate alternatives and provide feedback during the design phase, but it has not matured or been integrated fully in AEC projects currently. (Caldas & Keshavarzi, 2019) discuss design immersion and virtual presence in AEC and the possibilities with VR to address both the individual and social presence for collaborative design processes.

Immersive Technology such as Virtual Reality (VR) has emerged as a well-established methodology in different domains and as an empirical research tool for training, simulation, medical simulation in healthcare, therapy, spatial cognition, and navigation. In architecture, it has seen applications in building evaluation, prototyping, environmental design, and pre- and post-occupancy building evaluation. Virtual reality offers the advantage of testing out incremental changes through simulation in VR of several design alternatives in the pre-design phase without disrupting the usage of a building. Virtual environments are being used to support pre-design and pre-occupancy evaluation from a user's perspective on environmental design and evaluation. With the rapid development of immersive technology in the past decade, we are seeing more use of immersive technology as an empirical research tool as studies use theoretical frameworks and experimental design to study responses to different environments comparing the response to stimuli with the real environments in the built environment. We also see the need to test the creative power of designing immersive virtual environments. Some of the key challenges in empirical research include methodological difficulties that require controlled settings, reproducibility, and inflexible stimuli that are lacking in real work settings, which can be addressed by virtual environments. With advancements in wearables and biosensor technology, we are seeing an uptick in research that include bio-analytic metrics and interpretation that include physiological and psychological responses to real and simulated (virtual) environments. These allow for feedback and evaluation of human behavior offering a layer of unbiased data, real-time feedback, and point-in-time analysis of design and impact mitigating actual problems in data collection and participatory design methods that focus more on subjective feedback. Some problems in traditional methods of data collection and participatory design methods can be mitigated through immersive technology such as virtual reality and bio-sensors that allow for replication of healthcare environments in a virtual medium and facilitate data collection from patients after their discharge. This allows researchers to

circumvent hospitals and restrictions including patients in environmental and healthcare design research.

A study on the state of the art of research in the built environment using immersive virtual environments (IVE) was conducted from review papers published between 2000-2020, with the objective of understanding the major focus areas and trends where immersive virtual environments were used, methods, research context, sample size and factors in terms of stimuli, reactions, and outcomes. The search was conducted using the online database Google Scholar. A summary of the 13 review papers includes 4 papers on the state of IVE research in the built environment (Ayoung Suh & Jane Prophet, 2018; Kalantari & Neo, 2020; Kim et al., 2013; Zhang et al., 2020), 2 papers on education, 6 papers on presence/perception/emotion, and 1 paper on occupant behavior, with 70% of the reviews conducted since 2015, demonstrating the rapid growth of research in this area. Studies conducted in 2015 and later show use of tracking data such as head tracking, eye-tracking, and the use of biosensors for physiological data on heart rate (HR), heart rate variability (HRV), electrodermal activity (EDA), skin conductance, electrocochleography (EEG), Electroencephalography (ECG) and Facial Electromyography (fEMG).

Most of the studies use convenience sampling of students, predominantly university students, mixed samples with age groups 20-50 years, and fewer studies with the pediatric and elderly population. IVE is becoming popular for the elderly population with both VR and AR being used in diverse applications such as mental health, well-being in older adults, pediatrics, physical activity, and psychological outcomes. The sample size has high variance from very small samples of 7 subjects to large samples of 120 subjects and an average sample size of 10 for healthcare-related studies. There is more diversity in healthcare with the inclusion of different stakeholders – clinicians, nurses, and patients – while other domains mainly used students. There are few empirical studies with the pediatric population using a fully immersive experience using a HMD and even fewer studies with children under the age of seven probably due to the cost, weight, and fit of the headset (Bailey & Bailenson, 2017, p. 9) that we address in the next section.

4. Challenges in participatory research with children in healthcare design research

Participatory research is predominantly conceived from an adult perspective, adult-designed, and adult-led. According to Kellett (2005), involving children in research raises methodological and theoretical issues, on the rationale of involving them, acknowledging their perspective, valuing their contribution, giving them a voice, and empowering them. I present some unique challenges faced by researchers involved in participatory human subject studies with hospitalized children. Figure 4 presents the broad categories of the challenges and Table 1 presents the details of specific challenges in the identified categories. The list is not exhaustive and is based on personal experiences with ongoing mixed methods PhD research.

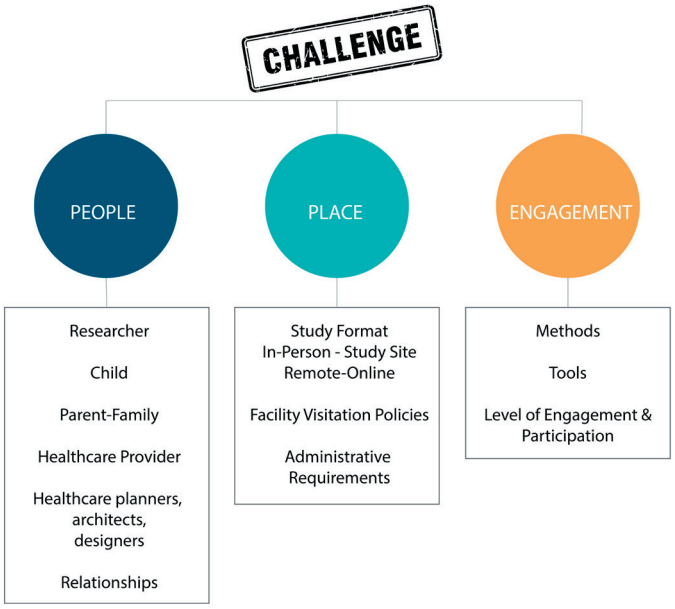


Figure 4. Challenges faced by researchers in pediatric healthcare research involving patient engagement.

Table 1 – Specific challenges in the identified categories in pediatric healthcare research

CATEGORY	CHALLENGES
People Access and Ethical Considerations	Access to the child – Navigating gate-keepers and healthcare mediators
	IRB and ethical approvals – Permissions/Consent/Assent for recruitment – Data privacy, confidentiality, and management in studies involving children – Strategies for approaching end-users responsibly, particularly in sensitive situations involving vulnerable populations (e.g., pediatrics, aged, mental and behavioral health)
	Logistical and child protection issues: Ensuring the presence of a trusted adult with the child
	Ensuring diversity in enrollment
	Child Health Status limiting participation during hospitalization – Challenges with proxy respondents and potential biases in self-reporting studies – Addressing biases in retrospective studies conducted during active hospitalization
Challenges for Researchers	Communication and articulation of ideas and opinions across different age groups and developmental factors
	Domain knowledge and skills for meaningful engagement, including patient education
	Parent-Family hesitancy and time commitment
	Perception of research as an unnecessary or unwanted disruption in a stressful period
	Time and commitment required for research
Challenges for Healthcare Planners, Architects, and Designers	Skepticism regarding children's engagement in research considering age and developmental factors
	Assessing children's competence and ability to engage in design
	Understanding complex visualizations and representations
	Allocation of personnel, time, resources, and cost
	Hesitancy to share project design and details for publications
	Empowering the child through co-design and addressing power dynamics
	Building trust and rapport with the research team
	Research agreements and approvals from hospitals – Navigating policies, permissions, IRB, and ethical approvals
	Commitment from the organization and healthcare providers to mediate between the researcher and the child/family
	Communicating the impact of design on care and patient outcomes
	Adapting research design during pandemics like COVID-19 – Addressing challenges posed by hospital visitation policies and finding creative solutions within pandemic constraints
Challenges in Relationships	Empowering the child in the research process
	Participation and engagement in ways that are meaningful to them
	Giving the child agency and control in the engagement process
	Providing the child with a safe inclusive environment, agency, and control
	Addressing power relations during engagement
	Building trust and rapport with the research team takes time, effort, and training
Place Field Research	Establishing expectations, possibilities, and agreements prior to research that impact time, resources, and cost
	Securing research agreements and approvals from hospitals
	Commitment from the organization and healthcare providers to act as mediators between the researcher and the child/family
	Communicating the impact of design on care and value to the experience and patient outcomes
	Hospital visitation policies and research during a pandemic like COVID-19 affecting the study design
Engagement Relationships	Challenges in Relationships (included under 'People'
Engagement Methods and Tools	Patient health status impacting active engagement, including physical and cognitive factors
	Frequency and duration of engagement depending on study design and tools
	Designing tools that value the child's worldview
	Need for simple, play-based, or art-based activities that children can trust and enjoy, keeping them motivated and interested

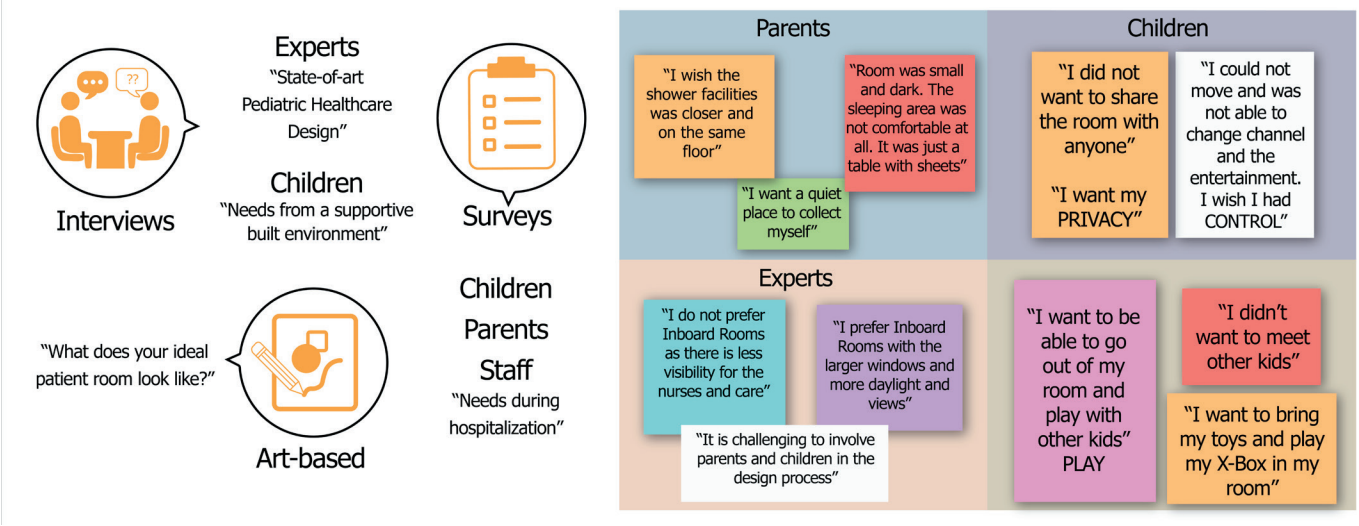


Figure 5. Preliminary Findings from Ongoing Exploratory Study using Art-Based Interviews and Surveys on the Needs of Child and Parent from the Pediatric Inpatient Room.

Improving Patient Engagement and Participation in Pediatric Healthcare Design Research through Immersive Technology and Affective Interactions

While there are numerous opportunities for using innovative digital technology in our research domain, there are also certain limitations that need to be addressed. These limitations include:

1. Limited focus on specific aspects of immersive technology in most studies.
2. Different conceptualizations of the concept of immersion.
3. Lack of empirical research explaining how and why technologies can improve or impair user performance.
4. Overreliance on student samples for data collection, potentially limiting generalizability.
5. Challenges in creating a sense of perceived realism and immersion.
6. Insufficient provision of sensory feedback in immersive experiences.
7. Time constraints impacting the depth of research.
8. Need for effective experimental design to ensure robust findings.
9. Selection and implementation of appropriate measurement techniques.
10. Development of comprehensive evaluation methods.
11. Importance of establishing feedback loops between end users and designers for design evaluation.

Considering both the opportunities and challenges, immersive environments show promise for research involving collaboration and engagement, providing valuable insights into human behavior to inform better design, particularly with the adult population.

Preliminary findings from our ongoing exploratory study reveal differences in the needs of children and parents regarding patient room design during hospitalization (Figure 5). Our study adopts a mixed methods approach, combining interviews with hospitalized children using art-based methods and an online survey to gather insights into their needs regarding the built environment of patient rooms. We are actively working on immersive experience studies to test incremental changes in patient room design (Figure 6), taking tangible steps to collect data from the child's perspective. These studies aim to evaluate the feasibility and effectiveness of the methodology with the pediatric population in healthcare settings.

Human experience within the built environment is closely tied to our physiological, psychological, and emotional responses, ultimately influencing our physical and cognitive states. Investigating emotions and physiological states can provide valuable insights into human behavior, serving as an unbiased layer of data for real-time feedback and analysis of design impact.

By addressing these challenges and leveraging the potential of immersive technology, we can enhance patient engagement and participation in pediatric healthcare design research, ultimately improving the overall well-being and experiences of patients in healthcare settings.

Figure 6. Testing incremental changes through simulation in VR of several room design alternatives in the pre-design phase.

Conclusion

Research on supportive design explores the impact of the healthcare physical-social environment on patients' well-being, including stress reduction. To gain a comprehensive understanding, more research is required in pediatric settings, considering the unique perspectives and preferences of children. Children are increasingly involved as study participants and active contributors in participatory research, highlighting the need for innovative approaches to meaningfully engage and involve them.

While it is widely accepted that the built environment significantly influences patient experience and health outcomes, there is a lack of validated data on children's emotional responses to pediatric healthcare environments. obtaining such data is essential to inform future design decisions. It is important to define key terms related to patient experience and satisfaction for a better understanding. Patient experience (PX) refers to the sum of all interactions that influence patient perceptions throughout the continuum of care, emphasizing the move toward patient-centered care (The Beryl Institute, 2010). Patient satisfaction, on the other hand, measures the extent to which a patient is content with the healthcare received and addresses whether their expectations were met (AHRQ, 2016).

As the use of immersive technologies is expected to increase, empirical studies are needed to examine their effects on user experience and performance, specifically in pediatric research settings. These studies should focus on measuring human responses and interactions in different environments and settings, taking into account the impact of immersive technology. By conducting further research and gathering empirical evidence, we can enhance our understanding of the impact of design on pediatric healthcare, ultimately improving the well-being and outcomes of young patients.

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