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The Pavement and the Hospital Bed: Care Environments as Part of Everyday Life

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"The latest issue of [architecture journal] A+, which appears on September 20 [2021], is about architecture for children. The range of facilities for children - not only schools and nurseries but also sports halls, youth centers, playgrounds, and skate parks - largely determines the livability of a place. A+ issue 291 starts from the adage: if a city is 'kid proof', it is a good place to live for everyone. We look at the built environment through the eyes of the playing child and show projects that are stimulating and inspiring environments for growing youth"¹ (A+291 Kids: Let's Play!).

"Resources such as daylight, airflow, views, and overall structure are elements that have received much attention to support the healing process. A calming environment, which supports natural processes such as day-night rhythms, perception of the seasons and the weather, will also contribute to the wellbeing and recovery of the young patients. In addition, each age group has been given its own space, furnished according to their needs. This stimulates the social-emotional development optimally. Furthermore, LIAG has created spaces that, among other things, allow families to cook and eat together, attend class, or play with grandparents"² (Princess Máxima Pediatric Oncology Centre).

We start this invited perspective with two excerpts. The first is an advertisement for A+, a Belgian architecture journal, which devoted an issue to architecture for children to celebrate the 30th anniversary of the implementation of the Convention of the Rights of the Child. The second comes from the website of a Dutch architecture firm (LIAG) describing their acclaimed design of the Princess Máxima Pediatric Oncology Centre in Utrecht, Netherlands. For people engaging in design (research), these ordinary excerpts will not sound uncommon, and apart from the understandingly somewhat commercial tone, nothing written in them seems worrisome.³ The same may be true for people outside of design as they will not oppose the general idea that spaces for children or pediatric oncology wards are designed with young people's well-being and development in mind. Yet, as argued in this essay, contemporary discourse of children's spaces seems to be divided into two separate domains: on the one hand, everyday life and on the other hand, care environments, where children are seen as vulnerable and passive with an emphasis on a positivist approach to research. Our reflection on this distinction is rooted in lessons learned from a research project that fused empirical and theoretical work in a transdisciplinary way to explore how children affected by cancer actively use the hospital environment and emphasizes their agency in being space makers and everyday designers (Tutenel, 2021).

Words Matter: Questioning Assumptions Behind Everyday Language

Both excerpts above are similar: focused on children and the built environment. They are both written using phrases that are common nowadays, informed by (developmental) psychology that fits well with a biomedical paradigm. This is perhaps most clear in the second excerpt given the biomedical worldview of medical practitioners, researchers, and patients to whom such designs need to make sense. Typical expressions used include 'offering emotional support', 'contributing to well-being', 'accommodating children's needs in each age group', 'stimulating the social-emotional development optimally', 'creating stimulating environments', 'enabling interactions between children, their parents, and grandparents' (cf. Ramaekers & Suissa, 2012). In the A+ ad, this dialect is also evident in its mentioning of 'creating stimulating environments' for growing children (cf. Malinin & Parnell, 2012). This language has become part of our everyday speaking. We take it for granted to such an extent that it is difficult to find other words to talk and think about architecture and design for children without referring to these scientific disciplines.

Our concern is not that these excerpts or insights from these disciplines are wrong, nor that research findings should not be considered — although the predominantly positivist foundation of, for example, evidence-based design, drawing on the practices of evidence-based medicine, has proved difficult to integrate in design processes (Moore & Geboy, 2010; Rashid, 2013). *Our concern lies with the dominance of conceptualizing children and design through such vernaculars, downplaying other languages that may resonate with design processes and narrowing notions such as vulnerability, child(-hood), play, or care (cf. Ramaekers & Suissa, 2012). This is the case, as the excerpts show, in design practice, but also in research that aims to inform design.*

By way of illustration, we refer (amongst many we can choose from) to Carroll et al. (2017, p. 272) who, in line with contemporary discourses surrounding child-friendliness, stated that:

'ensuring the social sustainability requires 'child-friendly' cities, which take into account the rights and needs of the children who live in them to play and explore to ensure their present-day wellbeing and longer-term healthy development; and their rights, as citizens, to feel safe and welcome in public spaces and to participate in urban planning decisions affecting their use of the public realm'.

Concepts such as well-being and healthy development have become part of the description of childfriendliness or research connected to children more generally; the normative assumptions and values implied in these concepts, however, are presented as unquestionable. One of the risks is that this way of speaking entails a form of universalism and thus, leaves out **children's many different ways of being**-in-the-world. Another risk is that this language (implicitly) attributes full responsibility for positive or negative outcomes to design approaches (cf. Stam et al., 2020); e.g., this or that design-outcome will (not) stimulate the development of all children optimally. This to us seems in sharp contrast with the general understanding in design that there is no clear-cut causal relation between designers' activities and the eventual outcomes: design-use relations are very complex (Redström, 2008).

This dominance is apparent in language to legitimatize design research as well as in the understandings of what constitutes good or relevant research (Tutenel, 2021). Scholars tend to lean either towards a more positivist or

causal side of the research spectrum or towards a more interpretivist approach that attempts to legitimize research without necessarily linking it to a realist ontology and foundational epistemology (Bochner, 2018). By making explicit this continuum, we do not intend to value one side over the other. We do believe, however, that in research that connects design with the study of childhood, a positivist leaning is more dominant (for a recent review on design of built care environments, see Gaminiesfahani et al. (2020)). For example, the use of this vocabulary in research or ethics applications shows how seemingly innocent application forms shape a positivist research approach (cf. Tutenel et al., 2019a). If research does not want 'to suffocate and underrepresent a sizeable portion of the world' (Andrews et el., 2014, p. 211), it is important to consider the entire continuum. Being more sensitive to the assumptions behind the words we use, may encourage different approaches to design (and) research, and in doing so, help us see these words in a new light.

Children: Space-makers or/and Vulnerable Actors

As shown, both excerpts are similar (in language used and focus on children and design), but they are also different. In the A+ advertisement, one can read **examples of 'kid proof' spaces, spaces that are specifically designed** for the playing child; one speaks of schools and nurseries, but also sports halls, youth centers, playgrounds, and skate parks. Here children are active; looking through their eyes is valuable for design and research. On the other hand, *what apparently are not spaces for children are care environments such as the hospital*, and even less so, a pediatric oncology center like the one in the second excerpt (cf. Kraftl et al., 2007). In the latter, the building is understood as contributing to well-being, accommodating needs, and optimally stimulating **children's development**. It resembles a homelike environment, and much attention is given to daylight, airflow, views, and overall structure to support the healing process. Children appear as passive subjects: *in need of* stimulation, development, and recovery, waiting for these needs to be fulfilled. Children who are ill do not seem to be understood as actively contributing to the making of the world.

Designers and researchers of built environments commonly associated with children – as in the A+ ad – emphasize children's agency, e.g., their ability to 'unlock' the possibilities the built environment has to offer (cf. Hackett et al., 2015; Jelić et al., 2020). They consider children as social actors in their own right, who interpret, imagine, and use spaces, make and shape space for themselves, and reinvent settings adults made for them; they focus on how *children as space-makers* (e.g., Loxley et al., 2011; Orrmalm, 2020) creatively use, adapt, and appropriate the environment in orchestrated and more happenstance ways. Furthermore, for the past few decades, (design) researchers have also concentrated on non-designated spaces as opposed to official provisions for children (Hackett et al., 2015; Jelić et al., 2020; Pitsikali et al., 2020) (see Figure 1).



Figure 1 Colin Kennedy, switch backside 5-0, Milton Keynes Central Bus Station, 1994 (© Wig). The obstacle course skaters or parkour runners create when they draw their lines through a neighborhood is probably the most known example of young people as space-makers.

When designing or studying care environments, like a pediatric oncology ward, *children* tend to be understood *as vulnerable* or passive, e.g., subjected to the realities of illness and of the hospital. Many of these environments are assumed to lack possibilities for children because they are designed for safety and comfort (cf. **Boon et al., 2016). Birch et al.'s (2007) and Adams et al.'s (2010) studies were among the first** that explored how children experience hospital spaces with the aim to inform their design. These studies emphasized that **children's** care environments should have certain design characteristics that support individualization, customization, flexibility, sense of control, and autonomy. From architectural historians, we learn that throughout history designers have been trying to normalize and humanize **children's care environments** (e.g., Kozlovsky, 2020). Through (co-)design, designers want to bring everyday life into such environments by hiding medical machinery, integrating positive distractions (Jiang, 2020), striving to be unlike a hospital, optimizing the continuity between home and hospital, and designing a homelike atmosphere (Adams et al., 2010; Kearns & Barnett, 2000) (see Figure 2). What connects these different attempts is the tendency to locate, to assign/design particular spaces where children are allowed to act (e.g., the play room, the aquarium, a single or double bedroom, a decorated wall, age-specific care environments).

In short, in contemporary discourse surrounding spaces for children there seems to be a split between everyday life and care environments. It appears that care environments need to be designed *as if* these are spaces for children or everyday environments. While it might be important to convey the message, for example, through design 'children you are welcome here'; the risk is that such an understanding of children's care environments narrows their agency. In design (research), children in care environments tend to be considered as passive, acted on by these environments, while children outside of care contexts are considered as active, able to act with the environment (cf. Adams, 2017).



Figure 2 Integrated Field state they aimed to make the EKH Children's Hospital a fun place by incorporating playground features (© Ketsiree Wongwan). <u>https://www.dezeen.com/awards/2020/longlists/ekh-children-hospital/</u>

Learning from Children's Everyday Practices in the Hospital

Our reflection on this split is grounded in a research project on how children affected by cancer experience care environments with the aim to inform their design (Tutenel, 2021). We focused on everyday practices in a pediatric oncology ward by conducting fieldwork two days a week for over six months (cf. Buse et al., 2018; Shove et al., 2007). To do justice to the diversity and complexity of these everyday practices and to notice how artefacts are involved, we adopted an interpretivist approach that combined participant observation and video ethnography with concepts and

insights from childhood studies; theories on materiality; vulnerability scholarship in anthropology and philosophy; and design research.

In this invited perspective, we focus on what we learned from interweaving the latter two (Tutenel & Heylighen, 2021; Tutenel et al., 2019b). We connected two lines of thinking about vulnerability: one departing from Levinas' existential phenomenology, and one from Wittgenstein's ordinary language philosophy (Tutenel & Heylighen, 2021). Levinas understands vulnerability as a form of relationality and interdependency, as 'a general openness to the other' (cf. Petherbridge, 2016); as the ability that befalls humans to be touched (passivity) and to touch (potentiality) (Gilson, 2011). Inspired by Wittgenstein's ideas, some scholars broaden this general openness to also include other-than-humans, the world, our forms of life that are vulnerable and in need of constant support, protection, and repair (cf. Das, 2015; Laugier, 2016). This is not to be interpreted negatively: precisely because the world is vulnerable, because things can always go wrong or in different directions, 'the ordinary can function as a vehicle for change and transformation' (Lorenzini, 2018, p. 123).

The latter understanding of vulnerability has not found its entrance in design research – at least not explicitly (for an exception see Cipolla, 2018). We do, however, find researchers across different design fields who focus on the ordinary, the everyday, and understand actions like repair, support, revaluing, and maintenance as integral aspects of design (Graziano & Trogal, 2017). Rather than as finished artefacts, they conceptualize designed things as always **'open' to other things and processes (Pink et al., 2019).** These researchers emphasize design's contingency and indeterminacy (e.g., Sumartojo et al., 2020). Design does not stop when artefacts leave the drawing board, since every one of us designs in the course of living our lives (Wakkary & Maestri, 2008).

A concept like everyday design proved useful to untangle children's everyday practices in the hospital because it helped to 'see' children affected by cancer in a different light (Tutenel, 2021). These children tend to be considered as vulnerable or passive, when in fact, they are also active constituents of the world, even in a highly structured environment like a child oncology ward (Tutenel & Heylighen, 2021). Children affected by cancer often require repeated hospitalizations. As visits may extend over several months, the hospital becomes part of their and their families' everyday lives. We learned that, for these children, the pediatric hospital becomes an everyday environment, like the practices they participate in while being there (Tutenel et al., 2019ab).

This was evident in how children waited or received treatment, reinvented an environment that was already finished, but also made everyday space in the hospital (cf. Duque et al., 2019). In the encounter between a boy with his matchbox car, the fish, and the aquarium, for **instance**, the latter became a racetrack and the parents' corner became a place to play (Tutenel & Heylighen, 2021). Or, the ward became a place to play soccer for a child and his dad (see Figure 3). Or, the side table became a place to park the matchbox car. Just as the cell phone charger

became a holder for a participant's phone in the hospital waiting place. And, the bed became a place to play the *Nachtwacht'* card game for another participant and her mom (Tutenel et al., 2019b) (see Figure 3).



Figure 3 Two pictures of children's everyday design practices. Left: An eight-year old boy, wearing an orange shirt, is attached to an IV-stand, kicks a ball in the corridor of the children's oncology ward. Right: A mother, wearing a red dress, and her daughter are sitting on a hospital bed. They are playing the Nachtwacht card game. (© Participants Room for Vulnerability)

By starting from children's everyday practices to understand their encounters with the hospital environment, we learned that medical machinery is mundane (Tutenel et al., 2019b). We noticed that for the children, parents, and staff, technological and medical materials like an alcohol gel dispenser, isolation gowns, or an intravenous-pump and stand are routine materials alongside (or in dialogue with) daily things like a book to study for a driver's license, a matchbox car, a bag of crisps, or a plastic box. For example, one of the participating children, when playing farmer in the hospital room, decorated a blood pressure monitor with pictures of horses. In a similar vein, another child, while waiting for treatment, used a waiting room chair as theatre stage.

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This way of seeing children might inspire professional designers to question the idea of designing 'homelike-' or 'child-friendliness' into care environments and researchers to search for more cross-pollination between studying children's care environments and other contexts (cf. Kraftl et al., 2007). It invites us to take everyday practices as a starting point to involve children as more equal stakeholders in design. It allows thinking differently about spaces for children in- and outside care contexts by understanding such spaces in other than categorical ways: spaces and artefacts cannot by themselves be child-friendly or not. Research with and about children and youth in general, and in the context of sickness and care in particular, is connected to the idea of vulnerability because of their assumed physical immaturity, limited life experience, and lack of knowledge (Morales, 2021). Unlike scholars in philosophy and anthropology, design researchers tend to understand vulnerability narrowly, as something negative or a problem to be solved (by design). Seeing children affected by cancer not only as vulnerable in this way but also as everyday designers invites professional designers to think differently about how to design in ways that support children as such. For example, what does it mean to focus on continuity between home and hospital if we start from the idea that the latter is part of these children and their families' everyday lives? Questioning the split between everyday life and care environments might help professional designers to move beyond designing these environments **'as if'** these are spaces commonly associated with children (e.g., a school, a home, a play space, a shopping mall) and reconsider what constitutes thoughtful care design (cf. Adams & Chivers, 2017). In the end, there is not such a big difference between a mundane piece of urban infrastructure, like the pavement (Kullman, 2014), inviting children to cultivate the caring potential of their city, whether this entails patting dogs, picking up empty bottles, or skateboarding as shown in Figure 1, and a hospital bed affording a stage for a child to practice playing the piano with the music therapist (see Figure 4).



Figure 4 An eight-year old girl plays 'the pirates of the Caribbean' theme on a hospital bed. She stutters and stumbles: she is practicing playing the piano. She is interrupted by bells and peeps of a finicky IV-pump and by the nurse who fixes the thing. The music therapist compliments and joins her in practice with her guitar; "Let us start over, with all these interruptions", she says; and so, they do (© participant Room for Vulnerability).

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Endnotes

¹ Authors' translation from <u>https://www.a-plus.be/nl/publicaties/redactioneel-beleid/</u> (access 26.02.2022)

² Authors' translation from <u>https://www.liag.nl/projecten/prinses-maxima-centrum-voor-kinderoncologie</u> (access 26.02.2022)

³ See, e.g., Dezeen for excerpts using similar language about designs for children.

https://www.dezeen.com/tag/children/ (access 24.02.2022)

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