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HOLDING SPACE FOR WELLBEING: CARE AND ETHICS OF EXCLUSION

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ABSTRACT

In this exploratory paper, we consider how an ethics of care can be applied to designing for health and wellbeing. We start from defining design as a careful assembling around absences and attending to things that are excluded, with the explicit intent of finding alternatives to how bodies are made through design. We discuss the potentials and challenges of holding space for idiosyncratic practices of wellbeing. We show how an ethics of exclusion can be deployed to analyse how we hold space in our own design processes and propose future research pathways.

INTRODUCTION: DESIGNING WHICH BODIES?

Human bodies and practices have always been at the center of design research and human-computer interaction (HCI) (Loke & Schiphorst, 2018). But as researchers in HCI have pointed out (Homewood et al., 2021; Spiel, 2021), the somatic turn has more explicitly put bodies at the center of design. With wearable, implantable, ubiquitous technologies becoming smaller and more integrated in our bodies (Mueller et al., 2020), or in the environments around us (Howell et al., 2019), it matters to ask which bodies are being considered when we design, which ones are being invisibilized, and indeed which (cyborg) bodies are we making when we design technologies.

Design methodologies such as soma design (Höök, 2018) have been emerging to put at the centre how designers perceive to be their own bodies or somas, and how they get reconfigured, with new agencies and subjectivities, through engaging with technology as materials. Homewood et al. (Homewood et al., 2021) have suggested that instead of starting pre-defined categories and assumptions about bodies, designers should have them problematized. Design, through these developments, can be driven by ethico-onto-epistemic concerns, through which the designer is responsible for how the design process affects the world (ethics), types of bodies or bodily reactions (ontology) that are made tangible, or available to design through e.g. biosensing and datafication, and the research and design apparatus that is built (epistemology).

In this exploratory paper, we look at how design research around wellbeing can be informed by the notions of exclusion and absence, informed by a care ethics (de la Bellacasa, 2011; Hollin et al., 2017). This allows for addressing alternative bodily practices: the personal ways that we know and care for our own bodies, and how these may be incompatible with current technologies and ways of designing technology, therefore creating spaces where more diverse futures with technology can be imagined. Against success narratives of wellbeing, we pause and reflect on the limitations and failures of the design research process. The acknowledgement of failure within design research spurs new directions for challenging the current methodology and addressing researchers’ responsibility (Howell et al., 2021).

ASSEMBLING NEGLECTED THINGS

To guide our journey towards considering absences in design, we turn to scholarship in STS and feminist new materialism concerned with highlighting that which is invisible or excluded. There has been an abundance of work concerned with things that do not fit neatly into categories (Star, 1990; Lee, 2022). In particular, we bring to the fore the concept of matters of care (de la Bellacasa, 2011), as articulated by Puig de la Bellacasa, as a design ideal for considering absences.

Matters of Care in particular builds on the STS tradition of analysing technoscientific practices showing how facts are constructed and kept stable through networks of hybrid human and non-human agencies. These analyses have often served to shine light on the importance of subaltern (often invisible) humans behind decision makers (the scientists, or the managers). Taking a feminist perspective on these matters, Puig de la Bellacasa reminds us that the work of sustaining both
people and objects depends on those that clean, repair, and maintain these worlds as liveable. These are an “active doing”, a practice of caring. These “matters of care” have been historically overlooked, often invisible, gendered, subaltern. Puig dels Bellacasa invites us to engage with an ethics of care, to “assemble neglected things” (de la Bellacasa, 2011), to consider what is routinely excluded from being considered. Designing with care, therefore, should be done.

Below we present a design case study aimed at exploring practices of wellbeing for people with internal reproductive organs which was informed by an ethics of care. We show how an ethics of care and exclusion was used to hold space for idiosyncratic practices of wellbeing, but we also show the difficulties of doing so. These challenges illuminate research pathways for the future.

PROBES AS A WAY TO INQUIRE INTO LIVED EXPERIENCES

In this study, we sought to account for the complex and idiosyncratic wellbeing practices entangled in everyday life. To do so, we designed a protocol to engage in an intimate and long-term conversation around wellbeing with people with internal reproductive organs. This protocol included probes (Gaver et al., 1999), a soma design workshop (Höök et al., 2018), and interviews. The deployment of probes followed the design workshop. This paper unpacks the case of deploying probes to respond care-fully to the previously mentioned absences.

Probes, introduced by Gaver (Gaver et al., 1999), are a design-led approach that utilizes ambiguity to establish a reflective interpersonal multi-layered sense-making process. Their wide adoption in design research means that probes can take many forms combining conceptual interests, technological possibilities, and imaginary scenarios.

Pen, paper, a number of prompts, and four vials to collect materials were in the individuals’ bags to explore everyday care and wellbeing. All materials were open-ended, carefully attending to the diversity of bodies and minds. Keeping the space intentionally open is a challenge imbued with sensitivity. Our design process draws upon feminist perspectives in design (Bardzell, 2010) and acknowledges the subjective and experiential knowledge of the designer as an affective way to understand and explore wellbeing. The probes included a pamphlet that introduced individuals to the design method (Figure 1), a set of vials for material collections and theme cards (Figure 3), and reflection cards (Figure 2). The kit included four themes: relaxation, comfort, nurture, and wakefulness. The themes, informed by the strong concept of somaesthetic appreciation (Höök et al., 2016), were designed to make space to fit individuals’ inward attention and perform outside corrective framings of wellbeing. Instead, they described situations in everyday life that are associated with intimate sensations and care practices. The kit was designed in a way that it could be reused or kept as a souvenir from the study.

Figure 1: The pamphlet of the probes that included instructions on their use and notes from the designer to the participants.

Figure 2: Cards with open-ended phrases addressed to one’s body, selected to prompt reflections on their intimate relation. The phrases were designed to feel like a whispering confession that takes place between partners.

Figure 3: Vials for material collections according to the themes annotated on the label cards.
CARE AS STAYING IN THE TROUBLE

The study protocol was designed care-fully in a way that the central definitions of wellbeing and everyday care were let intentionally blank to empower individuals to contribute with their own identities and definitions. Individuals were asked to collect materials relevant to four themes. Links between the purpose of the materials and the themes were left undefined to fit better into individual care practices. The reflection cards were open-ended phrases aiming to unpack the unspoken thoughts addressed to one’s body. The cards included the following phrases: You make me ..., I am confident that ..., I am afraid that you ..., You look ..., What if we ..., Are you ..., You feel like ..., I feel as if ....

The recruitment of individuals to use the probes in their everyday life took place in Sweden. The recruitment was addressed to people with internal reproductive organs due to their significant and symbolic position in narratives of invisibility and prolonged unwellness (Cleghorn, 2022). Matters of safe space and relatability of experiences were also considered during the decision-making process of the recruitment. The description of unwellness was left intentionally undefined to avoid labelling that might lead to exclusions. In the end, the study intends to explore practices of everyday care outside the medicalized understanding of wellbeing.

Three individuals responded to the call, ages 24-30, and they identified their cultural origins from US/Iceland, Sweden, and Croatia. They identify as Thorie, Alice, and Kylie. The involvement of individuals in participatory research requires a meticulous design to regulate the existence of power dynamics between researchers and participants and protect individuals from unintended exposure to sensitive topics. Prior to their engagement, individuals were informed about the study’s objective and the openness of the method. Informed consent was given in written and oral form. Part of the methodically chosen care-full practices in the design process was the establishment of the designer’s positionality and intentionality. Staying with the uncertainty of the design method and contributing to the process requires a level of trust between researchers and individuals involved.

RESULTS

The study allowed individuals to create narratives of “everyday care”. We were happy with how wellbeing was narrated through creating, establishing, and maintaining rituals of care. Wellbeing practices expand beyond the singularity of the body and the self and might even be a space to discuss the entanglements with more-than-human entities. The element of materiality was integrated into the design of probes as the transient space between the inward focusing of somaesthetic appreciation and the outward expression of sensations.

Figure 4: Materials extended the nature of reflections on wellbeing and everyday care practices. The emergence of water and soil as elements for nurture and awakening indicates the significance of co-existence with the surrounding environment to the conversation of wellbeing and care.

Our participants told stories about how healthy lifestyles were associated with exercising and remaining active during the day regardless of individual engagement in such practices. All individuals expressed the importance of self-check-in rituals at different parts of the day to set boundaries with the often-invasive rhythms of everyday life and respectfully set their limits according to the current state of their bodies. The ability to stay present in the moment and in connection to one’s body was identified as the ideal state of a holistic understanding of wellbeing.

Our aim in this paper is not to show these in depth, but rather to point at the difficulties of addressing wellbeing in a holistic sense, even with a small group of participants. To do so, we will now highlight some tensions and frictions that came up during the interviews that debriefed the probes study. One participant, Kylie, revealed two aspects of wellbeing that the probes did not allow for expressing.

CULTURAL UNDERSTANDINGS OF WELLBEING

The first one is about culturally specific ways of expressing oneself:
“I can describe my growing up. When I grew up, everything was maybe a little bit patriarchal. […] Now, what else I know is that we do not have a lot of culture in my country, but we have a culture of complaining. It’s very hard to come to someone and tell them something nice, immediately. […] So, if something nice happened to me, sometimes instead of saying, I found the job, I would say: Oh, my back hurts. I’m just getting this, probably not that. Oh, this is horrible, this is horrible, this is horrible. And then in some way, like on one line, I would add up, but I also got a job. And I’m really cool. We have a tendency to pile up on ourselves to disregard our success in this regard. Little bit like the good things, not be proud of them. And I don’t like that. When for instance, I’ve learned to do that a little on my own to accept my success, that was wellbeing for me, in a way.”

For Kylie, it was important to describe her cultural context and her upbringings that influenced her relation to wellbeing and defined her path of self-consciousness and care. For the designer of the probes, it was important to understand how Kylie understands wellbeing and which values she considered while interacting with the probes. The open-endedness of the probes encouraged individuals to engage in their own sensemaking process – somewhere between art and design – and communicate with the designer. This assumes a shared context and communication channel among designers and participants. Kylie’s attempt to share her cultural context problematizes the use of probes for designing across cultures. However, the cultural framing provided by Kylie also revealed to us that the collection of materials, the stories and the notes would be empty and dangerously open to external interpretations. Pluralism of experiences and bodies requires flexible spaces that escape the northwestern universalist ways of designing and give the power to individuals to formally wrap design methods with their contexts.

WELLBEING IS OUT-OF-CONTROL

The second aspect of wellbeing stems from the interaction between the first author and Kylie after the end of the probes study. Informed consent was given to keep this event on record.

After the almost one-hour long interview with Kylie on the probes and her takeaways, the recording stops. At that moment, Kylie shared the difficulty that she is facing to engage with what she shared during her interview. Her difficulty summarizes in the following phrase.

“I need to find a job in order to be able to renew my visa. Then I can do everything.”

Yoga, mindfulness, rituals of care for her body but also interpersonal care were disregarded in the sight of stability and survival. Everyday struggles were found on the way of pursuing care practices and could not be ignored. Why did Kylie choose to express herself when the official recording was off? Kylie’s confession, outside of the framing of the probes and the interviews, highlighted that there were unspoken tensions that were perceived as outside the study frame – probably due to the prevalence of well prefix in wellbeing. Holding space for absences means considering the unexpected and curating the space in a way that individuals have the power to reject framings without being excluded. Kylie’s contribution was rich in narratives of care, however, there was no space to illustrate her primary needs for stability as part of what we might consider wellbeing. As designers conducting work in the area of health and wellbeing, this raises important questions.

DISCUSSION: CARE AND EXCLUSION

Health and wellbeing, grounded on the intimacy and subjectivity of experiences, evolve around dynamically changing enmeshments between humans and non-humans. Ambiguity as design tactic may inspire interventions that respect the pluriversality of individual experiences of wellbeing and create spaces that allow individuals to gain agency over the ontologies of their bodies and identities through technology-mediated practices (Sanches et al., 2022). Attending to absences through tactics that leave spaces intentionally blank means to also consider the histories of the concepts and materials that we bring to our design process (Giraud, 2019). Care-full designs for wellbeing demand flexibility of spaces and reflexivity of methods in order to move forward and away from one-dimensional stances to wellbeing.

Every research project has a framing, even in cases where the designers purposefully intended to work with open-ended definitions. Staying with the trouble is an evocative provocation for designers and practitioners, yet the explorative design iterations described in this paper revealed to us aspects that hinder the attempts to responsible interventions. There is an inevitable framing, an inescapable closure in staying with the trouble that we ought to acknowledge – the trouble that someone actively selects over other troubles. This paper calls attention to the things that escape the frame and to the tensions that emerge when such situations occur in design. Feminist perspectives in design impel us to consider whether the given methodological tools are truly available to all people or whether they permit appropriation. The subjectivity inherent in the notion of wellbeing demands design strategies that acknowledge the asymmetrical power relations and embrace pluralism to mitigate the risk of intentionally excluding individuals and experiences.

Our design attempt and partial failure to cultivate entire spaces that fit alternative interpretations of wellbeing and care in everyday life evidences the challenging nature of designing with ambiguity. Ambiguous spaces demand
well-designed, participatory processes and transdisciplinary stances in research. The suggestion of holding the design space for wellbeing open for alternative narratives does not reject the scientific discourses of wellbeing nor intends to put individuals under the spotlight without their will. An ethics of exclusion invites designers to question invisibility through responsible and care-full practices that hold the space open.

Our exploration of the potentials and problems of leaving the space blank is meant to encourage design researchers to keep working on engaging with exclusions that we, implicitly or explicitly, bring to our design processes.

CONCLUSION

Design research informed by an ethics of care/exclusion (Giraud, 2019), is meant to help navigate knowledge politics within design work around designing for the body, especially with regards to how body centric technologies have world-making effects (specifically body-forming effects (Homewood et al., 2021), whereby human bodies are made known through them). In this paper, we have reflected on caring and holding space for alternative conceptions of wellbeing, and how an ethics of care and exclusion can be fruitful in illuminating further absences. What we have hoped to show is that designing with care, and with attention to exclusions, is never a done deal, but it should be under constant problematization.

ACKNOWLEDGEMENTS

A heartfelt thank you to all the volunteers who participated in all phases of this work and shared their experiences and personal stories with generosity. This work is fully financed by WASP-HS, The Wallenberg AI, Autonomous Systems and Software Program – Humanities and Society.

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