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CITIZEN-DESIGNERS MAKING WORLDS IN HEALTHCARE: A REFLECTIVE READING OF ANNA LOWENHAUPT TSING’S THE MUSHROOM AT THE END OF THE WORLD

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ABSTRACT

Design in health and care has rapidly expanded into service experiences, digital, and all things patient-centered. As healthcare designers, with curiosities and concerns about the future, we open up our evolving questions of care for designers, educators, and citizens. The book The Mushroom at the End of the World by Anna Lowenhaupt Tsing offers respite and reframe with its critical examination of the ruins and fringes of capitalism and learnings about ecosystems and relational concepts required for a liveable future. The metaphor of precious mushrooms that thrive in the ruins of a forest sparks our interest in alternative design narratives – complex, collective, diverse, intangible – to explore the fictions and frictions of healthcare and our conversations about design that cares. What is care that lives on the fringes of predictability, scale, efficiency, and profit? This paper offers our inquiries structured around four questions, or entanglements as inspired by Tsing.

INTRODUCTION

A lot is at stake in the worlds of health and care. The cruel pandemic laid bare the strengths and weaknesses of care when health is at a tipping point. Forces of digitalization, data, and market opportunity apply pressure to our experiences of healthcare. Design rapidly expands collaborations for service experiences, digital solutions, and strategies named patient-centered. Yet the business of healthcare all too often leaves design contributing to non-caring results, neglecting and erasing a wider range of care dimensions that Puig de la Bellacasa embraces as “matters of care” (2017, pp. 66-67).

We are two designers with different trajectories in healthcare, yet with harmonious curiosities and concerns about our “collaborative survival” (Tsing, 2015, p.19). What began as a series of transatlantic conversations through the waves of COVID-19 in 2022 evolved into a collective foraging of new worlds. As
colleagues, thought partners, and friends, we reflect upon our lived experiences and values, unraveling our careers in service and health, and exploring questions for designers, educators, and citizens today.

We seek perspectives that help us to act as “citizen-designers” (Heller and Vienne, 2003; Resnick, 2018) because health and care affect all aspects of our lives. Designing with care is “cultivating a commitment to living worlds” (Puig de la Bellacasa, 2017, p.67) with which we are intertwined.

In a lovingly chaotic exchange, the book *The Mushroom at the End of the World: On the Possibility of Life in the Capitalist Ruins* by Anna Lowenhaupt Tsing offers respite and reframe. Tsing’s book (published before the coronavirus) is a critical observation of life at the fringes of capitalism and its ruins. It offers imaginative learnings about ecosystems and economies through the collaboration required for livable futures.

Healthcare is occupied by scale, efficiency, consistency, and predefined outcomes. So much so that designers are unable to access Tsing’s “polyphonic assemblages” where “patterns of unintentional coordination develop” (2015, pp. 23-24) – the spaces-in-between where care happens. Tsing’s book unearths alternative narratives – honoring interdependencies, diversities, intangibilities that nurture health and care. Through the metaphor of a precious mushroom that thrives in the ruins of a forest (Figure 1), we find inspiration for design to challenge the fictions and frictions of care.

![Figure 1](image)

Figure 1 (Drawing by Miya Osaki): “Matsutake are the place to begin: however much I learn, they take me by surprise” (Tsing, 2015, p.6).

This exploratory paper reflects our conversations and pain points, illuminated by Tsing’s concepts that resonate with the current state of healthcare. The format is intentionally freeform and open (not final). We offer four “entanglements” (Tsing, 2015, p.5) inviting other citizen-designers to notice ways of embodying care that pop up in uncommon places.

**ENTANGLEMENT 1: HEALTHCARE IS AN ASSEMBLAGE, NOT A SYSTEM.**

As healthcare designers, we feel an underlying discomfort: a “yes, but” to a dominant, top-down, reductive view of care. Care is validated when commodified, compensated, and provided by approved sources: nursing homes, hospitals, hospices, and health providers. In reality, care is a relational “assemblage” (Tsing, 2015, p.22) – decentralized, generative, and intermingled. Adrienne maree brown’s fractal concept is helpful here because “emergence notices the way small actions and connections create complex systems, patterns that become ecosystems and societies” (brown, 2017, p.3).

Simultaneous rhythms of care emerge in different locations and times: at home, work, in communities. Multiple rhythms of care are essential, not circumstantial: between loved ones, neighbors, coworkers, carers, and healers. Care is a gathering, “a happening greater than the sum of its parts” (Tsing, 2015, p.27). In the spirit of polyphonic assemblages, every interaction, every collaboration is meaningful. Not all similar or replicable, care heals and nourishes the healthcare system. What are the benefits and challenges of embracing the fragmented nature of care?

**WE CAN PREPARE, BUT WE CANNOT PREDICT.**

“The farther we strive into the peripheries of capitalistic production, the more coordination between polyphonic assemblages and industrial processes becomes central to making a profit” (Tsing, 2015, p.24).

Design seeks iteration and inclusion, yet design structures are limited in practice. We define healthcare journeys in crisp linearity. Oh, the fantastic cleanness of blueprints! Designers dictate processes, players, interactions, mapping resources and measuring up to generalized outcomes and profit.

In checking the boxes, service design risks becoming transactional, even worse, burdensome, and disconnected. So much care happens outside of the lines anyway, every experience is adaptable by the very nature of the interaction. Service should be the in-the-moment performance of humans and non-humans, as much as it is a process. Care grows in this spontaneous exchange.

To unfold this complexity, Hakio, Mattelmäki and Vesselova’s “Lenses of Care” framework examines care as an “act, interconnection and presence” in the practice
of service design education (2019, p. 5). What lenses are required when care is also a design output?

EXPLORE THE KNOTS AND PULSES IN HEALTHCARE.

“Unencumbered by the simplification of progress narratives, the knots and pulses of patchiness are there to explore” (Tsing, 2015, p.6).

Humans are unpredictable, and there is value in this precarity. Tsing describes “precarity is the condition of being vulnerable to others. Unpredictable encounters transform us; we are not in control, even of ourselves” (2015, p. 20). We are all citizens needing care. Care embodies our lived experiences, intersectional connections, and positionality. Care extends beyond binaries of giving and receiving. It is the spaces in-between, not easily simplified or codified.

More may shift in healthcare if we explore all the complex knots and patchiness. How might design resist controlling or imposing power through neat boxes and over-planning? How would we invite more care if we allow for intentional gaps and blank spaces?

ENTANGLEMENT 2: CARE IS AN TRANSFORMATIVE ENCOUNTER – ALTERNATIVE NARRATIVES TO SCALING.

Design in healthcare serves entire populations and public health issues. Design is also in service of institutions and companies that shape the environment with their own commercial or political interests. Within this social, political, and financial force field, being able to scale healthcare experiences seems crucial for sustained impact. Scaling approaches derive from industrial mindsets that assume control of the value chain and efficiency gains by broad replication. Design tries to force-fit human-centric approaches into this linear framework of infinite growth.

All too often, when confronted with the complex and atomized field of humanity and care, dreams of efficient scaling collapse. No system readiness, lack of data continuum, regulatory barriers… multiple factors are to blame (Landers, et al., 2023). But beyond unquestionable inefficiencies, our approach to scaling care is reductive and fundamentally flawed. Tsing’s notions of “transformative encounter” and “translation” (2015, p. 28) are helpful to challenge assumptions about scale in a healthcare assemblage.

SCALING OR CARING: CONTAMINATION AND ENCOUNTERS OVER TRANSACTION.

“The important stuff in life on earth happens in those transformations, not in the decision trees of self-contained individuals” (Tsing, 2015, p. 29).

To reach more people, the logic of design and engineering impose necessary rationalizations: protocolization, metrics, blueprints, and business models for social, financial, and ecological sustainability. In these dimensions, even human-centric care operates differently. By reducing healthcare services to clean, replicable blueprints and KPI-driven protocols, service interactions become controlled transactions between “self-contained individuals”, (Tsing, 2015, p. 34), providers (resources) and users (clients). Once the opportunity to transform individuals is gone, so is the care. Tsing’s concepts of “contamination” and “transformative encounters” (2015, pp. 27-28) offer alternative views. Care is necessarily transformative. Care cannot emerge when interactions are fully siloed, coded, and transactional. Allowing contamination through encounters preserves humanity at scale.

By examining scaling closely, we are painfully aware of the frictions and contradictions of design in health. How (and why) would we codify the fear and disengagement of an individual (e.g., after a heart attack) into hardware requirements for a solution to help everyone? To what extent should we prescribe a choreography of interactions? Can we scale emotions, qualities, and mindsets?

ENABLING EMERGENCE REQUIRES TRUST.

“We are surrounded by many world-making projects” (Tsing, 2015, p.21).

This is not a call to let go of scientific approaches in healthcare design. Understanding the balance between process and emergence may be one of the keys to designing life-centered services that care for one and many. What is fixed, what is left open? A shift in design approaches is needed with new respect for all actors – their lived experiences and skills co-shape the design process. Caring design trusts them to bring experiences to life by enabling, not dictating. In this mindset, we necessarily depart from the industrial framework of scaling through Tsing’s idea of “translation” linking serendipitous patches of worlds together (2015, p. 62).

Cardiovascular health is a huge societal issue (over a million people die yearly in Europe after a heart attack). Health authorities aim at scaling initiatives to help people reduce cardiovascular risk. Yet cardiovascular care is not an abstract concept: a life-threatening event that leaves patients and loved ones riddled with fear, forced to change their lives, uncertain about the future.

The cardiac rehabilitation service in Alcorcón public hospital in Madrid, Spain, offers an example of design emergence and translation as an alternative to scaling. A rehabilitation team devoted years to developing a service supporting people post-heart attack. One highlight is the engagement of patient experts (people who suffered an acute cardiovascular event who receive training to support others) to help hospitalized patients. They collaborate with providers holding the patient’s
hand and offering a glimpse of a better future during a dark time.

The service has a stellar record of outcomes and patient satisfaction. It is also non-scalable by most definitions of the term. It could never happen without attention and involvement of the care team, who perform a myriad of tasks that cannot be captured in a protocol or a blueprint (last minute changes, finding the right expert for a patient, etc.) The commitment of the care team is essential and support for patient experts is understood, celebrated, and incentivized by the institution.

Indeed, the program is expanding, supported by the Spanish Heart Foundation. New relationships form as patient experts become active in other hospitals. The patient expert program is flourishing in some centers, not others, translated to a new context every time. Possibilities of adaptation and cross-pollination arise in this process of translation, rather than scaling.

A gem of emergence within the system, no designer was involved in creating this service. What if our role as healthcare designers involved the art of noticing care emergence, and helping it grow?

ENTANGLEMENT 3: FLYING SPORES OF CARE IN GRACEFUL ABUNDANCE.

Care is deep collaboration, embracing the messiness while recognizing that outcomes cannot always be controlled. So, we reduce harm, and recognize that designers cannot make all the choices. Care is pluriversal, vulnerable, and soft. Care work is liberatory by design, trauma-responsive, collective as informal, intersectional women-, QTBIPOC-, and disability-led “care webs” (Piepzna-Samarasinha, 2021, p. 32-68).

Social designer and doula, Michellina Ferrara centers abundance and joy as pedagogy, strategy, and ritual: “Design to sustain, heal, and empower our communities” (2022, p. 50). Ferrara’s social design experiment, Mama’s Care Mobile, repurposes a not-in-use ice cream truck as a care mobile for families in Crown Heights, Brooklyn. Volunteers circulate mutual care with community doula, diapers, formula, and ice cream (who doesn’t love ice cream?)

Care activates existing patches of infrastructure to grow assets in communities where they are. How can service design create abundant spaces for us to invent, thrive, live…and care more?

CIRCULATION FOR COLLECTIVE BENEFIT.

Matters of care expose assets and strengths in our community structures to resist the extraction of
resources from the community. Care outside of healthcare settings offers potential for new models of care to circulate in unexpected places (Table 1).

Table 1: Circulating abundance in health and care.

During the pandemic lockdown, citizens spontaneously and simultaneously rang bells, clapping every evening in gratitude to healthcare workers. Care is shared through translation (circulating from building to building, across social media) for collective benefit.

When scarcity becomes dogma, care as abundance becomes subversive. If healthcare lets go of its authority, what will happen?

ENTANGLEMENT 4: CARE AT THE FRINGES OF CAPITALIST STRUCTURES.

Top-down efforts in healthcare innovation, under which most healthcare designers operate, often align with a capitalistic history of concentration of wealth. It turns humans and non-humans into resources for investment, in Tsing’s view, by imbuing “both people and things the alienation, that is, the ability to stand alone, as if entanglements of living did not matter” (2015, p. 5).

As a series of transformative encounters, care resists alienation and isolation. Tsing’s concept of “latent commons” offers “fugitive moments of entanglement in the midst of institutionalized alienation” (2015, p. 255). Caring connections occur in the wild even though healthcare services are being uber-optimized.

Inspired by Tsing’s research of matsutake and pickers’ precarious ways of life, we are curious about the interplay between structured healthcare services and the entanglement of care interactions that happen in the community, monetized and not. Extra dedication of unpaid care workers, informal networks, and support services in conversation with infra-resourced, structured health systems. Like pine trees and mushrooms in the ruined Oregon forest, they need each other to exist.

THE RIGHT TO CARE.

Paradoxically, healthcare invests in innovations that do not depend on a human genuinely connecting with others. Digital health promises greater efficiencies and cost savings, and now A.I. with speedy empathy and insight. Dreams of chatbots replacing connection with a trusted nurse, fantasies of not having to rely on a human conversation, and fictions of not needing trust are dystopian near-futures, underlying the capitalist discomfort with informal, unmonetized care. There is a drive to extract from the latent commons and turn it into profit for a few. Capitalism assimilates care, like matsutake, as a luxury good in salvage accumulation.

The urgency to protect care as a common good is apparent in perinatal care, where an interplay of formal and informal support is especially relevant. In the U.S. without universal healthcare, the business of birth prioritizes speed, efficiency, and control circumventing long laboring times, doula/midwifery, and perinatal care. The health and care of birthing people is unaffordable for many. Privatization and “luxuriation” of perinatal care turn birthing into privilege, widening health inequality, and worsening outcomes. U.S. maternal mortality is more than double of high-income countries, ten times bigger than New Zealand (Tikkanen et al, 2020).

Care as a protected right challenge a capitalist system – time, reimbursement, capacity, and profit at the expense of the latent commons. What if there was freedom for non-capitalist models of care?

As citizen-designers, we resist the system: scarcity is a fiction. Care abounds.

CONCLUSION

WHAT IS OUR MATSUTAKE AS HEALTHCARE DESIGNERS?

Surprisingly, our reflections help awaken us to the mindsets that we have been operating under in healthcare. The imposed scarcity of the healthcare business undermines our ability to thrive. Stepping to the side and looking through lenses of care frame a mosaic-like assemblage – many possibilities to care. Inspired by matsutake foraging and care workers, we view spaces of friction as opportunities.

Taking a pause, we also realize that a space for conversation helps us notice, and call out, fictions of care, in our own assumptions and systems. And care, gradually, becomes an act of resistance.
Care in resistance to:
… transactions over encounters.
… imposed scarcity over abundant worlds.
… alienation and isolation over interconnection.
… extraction over encounters.

MAKING WORLDS: IT’S A COLLABORATION.

We offer this piece as inspiration to pick up these conversation threads and create other ones. Mareis and Paim remind us that “[d]esign cannot change anything before it changes itself” (2021, p. 19).

Care allows us to juxtapose, notice, be abundant, find new models to build livable worlds together. In Tsing’s observation, matsutake cannot be cultivated or produced. It’s truly a collaboration.

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