Abstract: Online content produced by sick bodies, outside of clinical trials, is increasingly studied as real world evidence. US policy and biomedical companies are designing ways to make patient input legible and useful to their evidence-based medical system. My design study suggests an ethic of repair that might learn from the political agency of people with chronic autoimmune conditions. It brings feminist materialist studies into dialogue with two collective care groups who devise tools for reciprocal, collaborative *intra-action*. Their tools offer different ways to study illness online and negotiate boundaries (of bodies/expertise/space). Together they articulate the values and risks in generating embodied knowledge and redistributing data through digital communities.

Keywords: Precarious collectives, care, informed refusal, digital patient labor, boundary negotiating tools.

Reparative Design: Eine Studie kollektiver Praktiken zur Generierung und (Um-)Verteilung von Care im Internet


Introduction

I have been studying an image, an infusion selfie taken in December 2016 by a 28 year old Californian receiving medical treatment in Mexico intended to halt the progression of multiple sclerosis. The treatment she’s documenting is limited to exclusionary clinical trials in the US so, through the help of closed Facebook groups, she sought care elsewhere. I am struck by the selfie’s formal
similarities to Lynn Randolph’s painting “Cyborg” in constant dialogue with Donna Haraway’s writing (2004: 111). The selfie shows a smiling girl with piercings who is hooked up to machines and tubes, receiving medicines likely tested on or harvested from other species. Snapchat’s facial recognition program looks through her phone and places floppy ears on her bald head. The portrait articulates a kind of agency sick bodies experience online: negotiating boundaries of body, of technology, of place – while producing knowledge.

This study focuses on collective care groups – that mostly started in the US – who transgress the boundaries of the healthcare system. As a design researcher, I navigate healthcare data systems gathering material evidence that has cultural and political resonance.

The selfie comes from the subject’s blog, journaling her experience for other sick people or caregivers interested in learning the kinds of information medical experts don’t provide. This sort of photo is common and searchable online. But if her photo was a clinical record it could not be shared until 50 years after her death. Forms of regulation like ‘de-identify data’ policies1 are meant to protect patients’ privacy, but non-disclosure is not always an option for those seeking care. When people are performing and recording their sickness for each other online, privacy seems like a nostalgic value that historically has not protected marginalized people. The growing numbers communicating their felt experiences as patients and sick persons online has drawn the attention of the healthcare system that wants to enter their content into evidence. It’s what the medical industry calls ‘real world’ data.

I’ve been studying collective care groups with chronic autoimmune illnesses (AI) that disproportionally affect women, speaking with them about digital tools and labor that might undermine market logics by de-centering the expert and addressing what’s missing or biased in the system. These groups connecting online metabolize the politics of sick bodies, a kind of agency in dependency,2 where biological systems are said to malfunction and patients interface improperly (i.e. critically and politically) with corporate medical systems.3 Their work speaks to my central question: Rather than designing patient interfaces that allow sickness to appear in a recognizable format to normative healthcare, how might design make systems more intelligible as ‘made-up’ and in that sense repairable in multiple ways? In what follows I will define patients as digital laborers, forming precarious collectives. Real world data grounds the analysis in clinical discourse. It provides an understanding of the political forces within the healthcare system, ‘made-up’ of boundaries between patients and care.

Within this landscape, boundary negotiating tools are examples of collective repair that stake ethics of repair for design. Feminist physicist Karen Barad wrote, “reality is sedimented out of the process of making the world intelligible” (2007: 105). Barad offers the term ‘intra-action’ to describe how concepts and objects, humans and artifacts are ‘mutually constituted’ through encounter. Agency occurs and transfers in encounters like the practice of measuring. Measuring is an intra-action which gives a sense of realness to the thing measured and the tool of measurement. Artificial Intelligence in medicine reading and measuring medical imaging is humanly unfathomable (Brouillette 2017). Black