This forum is dedicated to personal health in all its many facets: decision making, goal setting, celebration, discovery, reflection, and coordination, among others. We look at innovations in interactive technologies and how they help address current critical healthcare challenges. **— Yunan Chen, Editor**

Co-Design in Health: What Can We Learn from Art Therapy?

Anne Marie Piper, Northwestern University, **Amanda Lazar,** University of Maryland

Driven by calls for democratizing design and empowering patients, researchers are turning to methods that involve users more directly in the design process. Methods such as participatory design and co-design provide a way of engaging individuals in the hands-on creation of their own health technologies. However, some of the ways in which we practice co-design in health are at odds with what the approach aims to achieve. We focus on our own ideas of success, such as improved health outcomes, treatment, or adherence, when the emergent nature of co-design often takes us in entirely new directions. We expect that participants will tell us their health-related needs and generate ideas alongside us, but health is highly personal, and talking about it with others can be emotionally distressing. For individuals with difficulty verbalizing their own experiences, we ask others, such as proxies, to fill in for them, even though this minimizes the role of those with health conditions, whom we most hope to engage through co-design.

To rethink co-design in health, we turn to a facet of the healthcare ecosystem that is not often studied by human-computer interaction or health-informatics researchers: the clinical practice of art therapy. Art therapy is a profession in which participants, guided by the art therapist, use art materials, the creative process, and the resulting artwork to express feelings, reconcile conflicts, foster self-awareness, and achieve other goals. As others have noted, most research in healthcare focuses on doctors and nurses; examining other perspectives, such as those of therapists, can provide new directions for research [1]. Art therapy services are situated within the broader healthcare landscape and alongside biomedical views of health. Yet art therapists approach clinical encounters in ways that are fundamentally different from those of other healthcare practitioners. This departure from mainstream biomedical thinking, while remaining situated within clinical contexts, makes art therapy a compelling site for inquiry.

Approximately five years ago, our research group began a fruitful partnership with an art therapy program in a skilled nursing facility. Through our fieldwork, we began to see the work of art therapists as a situated example of co-design involving people with diverse health experiences. Over the years, our fieldwork involved art therapists who work in varied settings (e.g., hospitals, private practice, residential communities) and with a range of populations, including individuals experiencing addiction, child-welfare recipients, immigrants, and domestic violence victims, as well as those with mental illness, traumatic brain injuries, physical disabilities, dementia, aphasia, and cancer. Based on our empirical work and long-term collaboration with practicing art therapists, we identify four ways in which art therapy has reshaped how we conceive of health-related, co-creative design engagements.

Insights

- → Art therapy provides a model of how researchers can approach co-design in health.
- → The process of creation and the resulting artifacts are equally as important as what people say.

FROM HEALTH OUTCOMES TO EXPERIENCE

The first way in which art therapy helps us rethink co-design is by changing how we view health conditions. Health-technology design often focuses on improving health status; we design technologies to help people exercise or remember to take medications. Art therapy offers another approach to understanding health. Often the goal of art therapy is to help people accept and live with varied health experiences throughout the course of life. In this way, art therapy is aligned with palliative care and wellness, with a focus on learning to live with symptoms and enhancing quality of life. For individuals in art therapy, this could be accepting a terminal diagnosis or dealing with anxiety or depression. Therapists describe the importance of viewing the patient as the expert in their own experience, though they acknowledge that their interactions occur within a larger context of care in which therapy recipients are positioned as in need of help and therapists as those providing help. Focusing on the individual's lived experience, rather than achieving health outcomes, helps empower the individual as an expert from whom the therapist can learn.

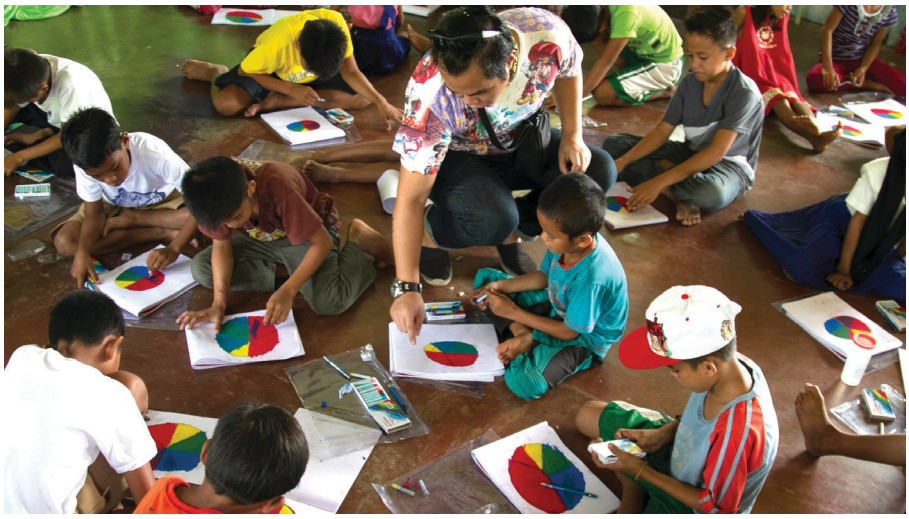
FROM PATIENTS TO ARTISTS

Prior work has identified the ways in which hierarchies and clearly demarcated roles in healthcare contexts (e.g., clinician, patient) affect the design process and reinforce power differentials [2]. The case of art therapy provides insights into how researchers can interact alongside participants and shift these power dynamics. Therapists carefully consider the language they use—some entirely eliminating the labels "patient" and "therapist"—in order to foster a collaborative relationship and mutual respect during the creative process. We observed therapists arranging material environments and configuring social interactions in order to position patients as artists and themselves as assistants and helpers. Most central to this analysis is the concept of the "third hand" from the field of art therapy, which describes the role of the therapist as a hand that supports the creative process without being intrusive or imposing their own goals [3]. Therapists describe learning to hone their third hand so that they become like machinery, invisible and fluid, and ultimately fade into the background of the creative process. For a woman who had difficulty doing the fine-motor movements required for a piece of needlework, the therapist fluidly came in to do the detail work, turning the piece back to the artist when she was finished. The therapist said, "It was always her process. I was the extra hand."

Art therapy, situated within the arts more broadly, teaches us that there is no one right way of engaging in co-creative practice. Instead, there is a multiplicity of ways of being for participants to explore together. While researchers may feel the need to take the lead during co-design sessions, therapists describe acting as a follower instead of a leader. Rather than imposing goals on the artist, they serve as a witness, as participants understand what their work means for them. As we and others have argued, instead of facilitating participants in responding to known issues or improving existing technology products (e.g., asking participants to design a better medication container), perhaps the role of the researcher is to provide an environment in which participants discover and respond to issues that matter to them [4,5].

FROM SELF-REPORT TO EMBODIED VISUAL EXPRESSIONS

The practice of art therapy also informs how we can view individual expressions. Specifically, art therapy offers a critique of the dominant and implicit role of verbalization in co-design. Collaborative design engagements often rely on participants' willingness and ability to verbalize alongside researchers, though this can be difficult for people with speech-language impairments (e.g., those



who recently experienced a stroke), memory impairments, or those dealing with sensitive, emotional, or stigmatizing health experiences. Within health-technology design, we often understand patient experiences through validated self-report scales (e.g., measures to assess depression such as the PHQ-9) or employ proxies to understand those who are unable to speak on their own. As we have argued [4], the implicit focus on verbalization can constrain involvement and limit what is achieved through co-design, in which the goal is to support participants' creative potential, enable a wide range of conversation topics, and envision new design futures.

Art therapy not only reframes how researchers can support co-creation but also shifts how we view the manifestation of health conditions and symptoms during the process of creation. Instead of viewing repetitive movements or disfluent speech as negative symptoms of disease, art therapists view these as expressions of the self to be engaged with playfully. For example, one therapist gave a paintbrush loaded with paint to an individual experiencing hand tremors and a rhythmic rocking motion. This individual then filled canvases with brushstrokes reflecting her movement. Rather than mitigating these behaviors, the therapist looked for creative ways to channel these movements as expressions that could then be shared with others in her life, such as her adult children.

What a participant does with art materials is more important than verbal self-report.

In art therapy, both the process of creation and the resulting artifacts imbue meaning. What a participant does with art materials is more important than verbal self-report. As one therapist explained, art materials are "the language of art—so they're like the verbs and nouns and things of visual art." Further, therapists observe and interpret the way a participant grips a paintbrush, glances at the color palette, shapes clay, or forms lines on paper. The art that is created gives the therapist insights into the thoughts, needs, and experiences of a participant that they could not or would not verbalize on their own. Relying on verbal language creates a barrier, and therapists use art materials to find a different way in. To be clear, the goal is not to deconstruct artwork to provide insight into symptoms and pathology; instead, the artwork tells us what is important to that person and provides points of connection.

FROM CLINICIAN TO ADVOCATE

In addition to the goals of empowerment and democratizing design, we engage participants in the design process in the hopes of creating better technologies, products, and services that align with their lived experience. Designing for health, however, raises special considerations

IMAGE BY CLUSTER MUNITION COALITION / FLICKR

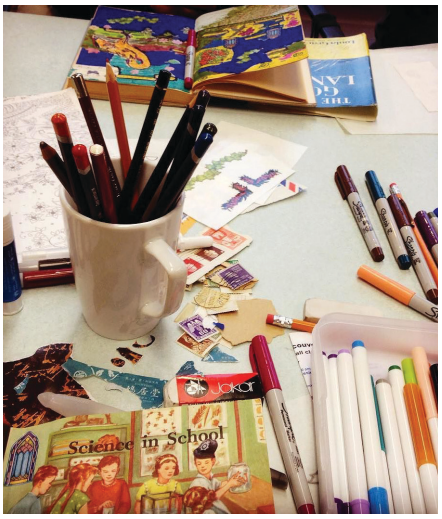


IMAGE BY VERONICA ROTH / FLICKR

for disseminating artifacts and insights that emerge through co-design. Co-creative design engagements within clinical contexts are often subject to information privacy laws (e.g., HIPAA [6]). Within art therapy, creative artifacts are part of the personal health record and expressions of the self, which expands our view of what we consider patient-generated data and how we treat resulting artifacts.

As researchers, we can learn from the careful deliberation of art therapists in how they share products that emerge from art therapy sessions. We observed that sharing an individual's creative work involved a complex negotiation among multiple stakeholders, particularly for individuals with limited decisional capacity who have authorized representatives act on their behalf [7]. Therapists reflect on the different and sometimes conflicting preferences of individuals and caregivers, whether and how artifacts should be shared, the context in which the work is presented, and the information that is presented alongside the work.

Therapists attend to the intentions of the individual and are careful to present the work in ways that prevent others from taking the artwork out of context or that negatively affect the perception of the artist (e.g., highlighting a diagnosis). As part of this, therapists reflect on how sharing artwork affects the positioning of people with stigmatized conditions more broadly. The history of outsider art—which is art created by people considered "other" or with non-normative experiences—informs art therapists' contemporary practices [4]. In our fieldwork, therapists were well aware of the stigma associated with dementia. They intentionally created an art exhibit within the memory-care facility, explaining that this helped residents from independent living in "seeing the world through [art therapy participants'] eyes." Rather than the art further highlighting differences between individuals with and without cognitive impairment, the exhibit helped foster a sense of connection and empathy. Thus, sharing the products of co-design may be as much about advocacy and repositioning individuals in society as it is about informing the next steps in our own research agendas.

MOVING FORWARD

By learning from the practice of art therapy, we can begin to envision design engagements involving people with diverse health experiences in new ways. Viewing health as a range of human experiences, rather than problems that need solving, opens up new avenues for designing over the course of life and helps normalize experiences. Instead of using proxies, tapping into visual and non-verbal modalities can better support individuals with a limited ability or willingness to verbalize their experiences to researchers. We can learn to let participants lead while we follow and witness their unfolding work, rather than imposing our own goals and ideals on design sessions. We also need a renewed ethical sensitivity toward what emerges from co-design sessions. Resulting artifacts can be both protected health information and personal expressions. Our own interpretation, handling, and dissemination of what emerges from co-design can inadvertently reinforce stereotypes and stigma. At the same time, art therapists acknowledge that ongoing self-questioning and activism are inherent aspects of their work—these concerns are also central to our own design engagements. While the viewpoints we share here may initially seem distant from dominant views of health, integrating diverse perspectives not only helps us rethink accepted health concepts such as the value of self-report and what constitutes patient-generated data, but also provides new possibilities for how we design health technologies.

ENDNOTES

1. Fitzpatrick, G. and Ellingsen, G. A review of 25 years of CSCW research in healthcare: Contributions, challenges and future agendas. *Computer Supported Cooperative Work 22*, 4–6 (Aug. 2013), 609–665.
2. Donetto, S., Pierri, P., Tsianakas, V., and Robert, G. Experience-based co-design and healthcare improvement: Realizing participatory design in the public sector. *Design Journal 18*, 2 (2015), 227–248.
3. Lazar, A., Cornejo, R., Edasis, C., and Piper, A.M. Designing for the third hand: Empowering older adults with cognitive impairment through creating and sharing. *Proc. of ACM DIS 2016*, 1047–1058.
4. Lazar, A., Feuston, J.L., Edasis, C., and Piper, A.M. Making as expression: Informing design with people with complex communication needs through art therapy. *Proc. of ACM CHI 2018*, in press.
5. Le Dantec, C.A. and DiSalvo, C. Infrastructuring and the formation of publics in participatory design. *Social Studies of Science 43*, 2 (2013), 241–264.
6. HIPAA, which stands for the Health Insurance Portability and Accountability Act, is a U.S. law designed to provide privacy standards to protect patients' medical records and other health information provided to doctors, hospitals, and other healthcare providers.
7. Cornejo, R., Brewer, R., Edasis, C., and Piper, A.M. Vulnerability, sharing, and privacy: Analyzing art therapy for older adults with dementia. *Proc. of ACM CSCW 2016*, 1572–1583.

Anne Marie Piper is an assistant professor in communication studies at Northwestern University. Her research lies at the intersection of HCI, CSCW, and assistive technology. She designs and evaluates systems to support communication, social interaction, and learning across the lifespan with an emphasis on people with disabilities and older adults.
→ ampiper@northwestern.edu

Amanda Lazar is an assistant professor in the College of Information studies at the University of Maryland, College Park. Her research is in the areas of human-computer interaction and health informatics. She studies how technologies designed for health and well-being position and support marginalized populations.
→ lazar@umd.edu

DOI: 10.1145/3194353