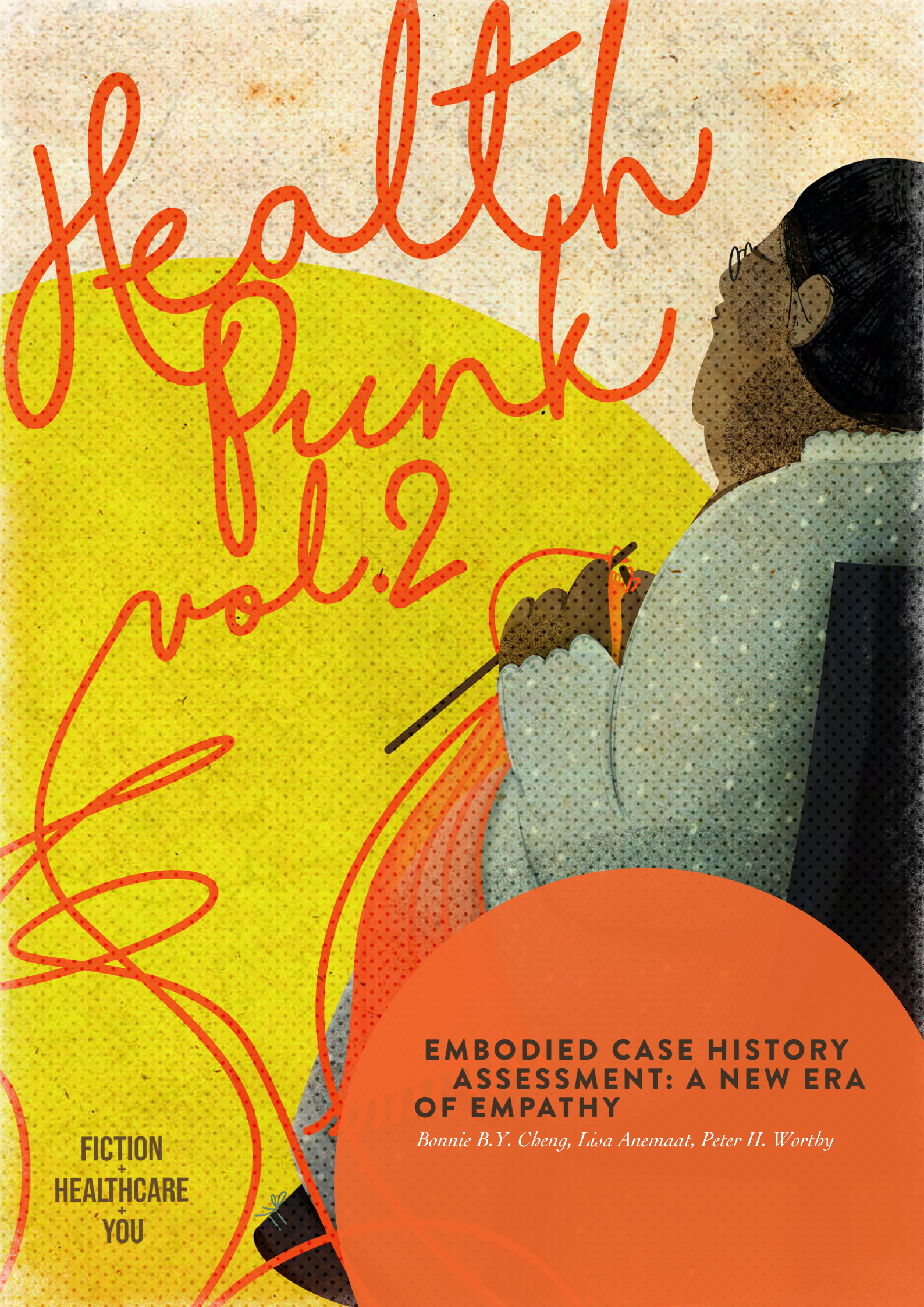

EMBODIED CASE HISTORY ASSESSMENT: A NEW ERA OF EMPATHY

Bonnie B.Y. Cheng, Lisa Anemaat, Peter H. Worthy

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"Why am I signing this?"

It had been 18 months since the EmCHAT was rolled out, and another six since the contentious and repeatedly-revised consenting process was finally deemed acceptable. To be fair, the whole idea of the Embodied Case History Assessment Tool was contentious from the beginning.

Since the early consultation phase of our co-design project, people were not receptive to the idea of letting their doctor have an embodied experience of their disability using DETech. Our vision for this new approach to conducting case history assessment was to challenge the notion that one can have empathy for another without first walking a mile in their shoes, so to speak. For centuries, clinicians have relied on soft skills to breach this divide: fostering rapport with each individual patient as well as their significant others; treating not just the impairment but its unique impact on someone's capacity to function and participate in a way that's meaningful to them. Still, study after study has continued to uncover people feeling that the healthcare they received, whilst medically sound, missed seemingly innocuous, health-related changes that disabled them in their life. The socially ubiquitous Digitised Embodiment Technology, paired with the momentum of the anti-ableism movement, presented a promising solution.

We had anticipated that people would endorse, even embrace, the use of DETech in a healthcare context. But, this was not the case – a surprise exceeded only by the unexpectedness of my own unease with using EmCHAT when our team resorted to self-piloting the tool after a fruitless effort to recruit volunteers. It wasn't until I used the EmCHAT myself that I felt, rather than just understood in principle, the invasion of privacy, the vulnerability, and the loss of agency in letting an unfamiliar other live your life; to let them be in your body and in your mind so that they can see what you see and feel what you feel in order to know, if only momentarily, what it's like to live as you. The irony was not lost on us that it was an embodied experience of using the EmCHAT that gave us a vivid and holistic appre-

ciation of using the tool that promises to give patients a way for others to vividly and holistically appreciate their lived experience of disability. Yes, I had consented, and it was undeniably informed, yet I felt violated.

The other surprise – after we had successfully demonstrated that the benefits of embodied assessment outweigh the risks – was that instead of doctors, allied health professionals were the ones who patients and families felt comfortable trialling EmCHAT with. There is no doubt that doctors are respected, and for good reason they are also trusted by many patients and families desperate for a lifeline out of illness. But, in the days, weeks, months after a doctor has treated a patient, it's an allied health professional who journeys with the patient through their losses, big and small, their gains and setbacks. It's an allied health professional who grieves with the patient and their family, who celebrates with them, and who offers the right words to the right person when they need it most. This is what makes their rapport, unquantifiable as it is, therapeutic. A doctor may be a beacon of knowledge, but an allied health professional can be a beacon of hope.

EmCHAT is amazing technology. By occupying the gamut of rooms and alcoves of a person's mind, you suddenly see and feel their shape-shifting but ever-present collision of anger, sadness, shame, triumph, joy, and yearning for belonging. By experiencing someone else's experience as your own, your reality is altered and so too are your filters and interpretations of what, why, and how. In this way, EmCHAT is more than just a window into someone's lived experience. It's scary. And to be honest, each time I witness a consent signing, I wonder whether the patient can fully understand what the most carefully written form could not convey.

There have been times with a patient when I've transiently and subtly felt feelings and sensations that I know aren't mine but theirs. The trace effect, as we call it. Even though EmCHAT operates strictly on the basis that experiential knowledge is erased from the clinician's mind as soon as a management plan is determined, traces of psycho-emotional or sensory impressions can remain in the clinician and be spontaneously triggered.

In these moments, I know the parts of the patient's experience they've left unspoken. That knowledge gives me confidence in making their treatment more personalised, but it also gives me pause about an ethical conundrum that can neither be solved nor dismissed. That is, how should I use this knowledge… or, should I? My legal and professional responsibility tells me to use this knowledge in the patient's best interest, but who's to say what the patient's best interest is? Who's

to say why they left these parts of their lived experience unspoken? Maybe, the same technology that offers clinicians a means to more comprehensively know, robs patients of their right to voluntarily disclose.

"It says here, in the event of an emergency we can instantly terminate EmCHAT," my patient announces, her furrowed gaze and finger hovering over that line on the consent form, askance.

"That's correct." I feel a sharp pinch in my lumbar spine, a trace effect from a patient who had a slipped disc. Today, this pain makes me flinch at the thought of administering the EmCHAT again. Though it's not explicated in the patient consent form, the emergency termination function was designed as much to protect patients as it was to be a safety measure against the occupational health and safety hazards of administering the EmCHAT.

"Right, so if you had a heart attack during this thing, I won't have to suffer with you. No offense."

"None taken," I assure her, knowing that the EmCHAT poses a statistically higher risk of harm for the clinician than it does for the patient.

We knew these solutions weren't perfect. No solution ever would be. But we hoped that our team of lived experience and design experts would be up to the task of ongoing project development and evaluation. We hoped that our iterative work would continue to grant us insights not just to make EmCHAT better and safer, but to inform the development of ShCHAT. The ShCHAT would enable a clinician to virtually shadow a patient, as an alternative to embodying them. It was a brilliant idea generated by our lived experience reference group. Granted, having heard clinicians awkwardly pronounce the abbreviation, we might need to come up with a less crude sounding name.

"Ok, let's do it," my patient said. Let's do it, I thought.

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