Engaging Art, Science, and Empathy (ease): Lessons from interdisciplinary, care-centered research on the wicked problem chronic pain.

PROPHET, Jane, HASSETT, Afton and RAHMAN-TAHIR, Rahbel

This document is the Accepted Version [AM]

Citation:

PROPHET, Jane, HASSETT, Afton and RAHMAN-TAHIR, Rahbel (2025). Engaging Art, Science, and Empathy (ease): Lessons from interdisciplinary, care-centered research on the wicked problem chronic pain. In: SCOTT, Jillian, (ed.) Transdiscourse 3. Women in Art, Science and Body Politics. De Gruyter, 181-193. [Book Section]

ENGAGING ART, SCIENCE, AND EMPATHY (EASE): LESSONS FROM INTERDISCIPLINARY, CARE-CENTERED RESEARCH ON THE WICKED PROBLEM CHRONIC PAIN

Jane Prophet, Afton Hassett, Rahbel Rahman-Tahir

This chapter extends the authors' individual and collective research on interdisciplinary, community-engaged inquiry by examining how an Ethics of Care can shape collaborations across art, design, social work, and STEM fields. We share insights from a research initiative involving thirteen academic researchers and nine advisers, focused on the "wicked problem" of chronic pain and health inequities. Through six interdisciplinary teams, we co-designed arts-informed studies with over 100 participants living with chronic pain to support well-being, advocate for systemic change, and foster thriving. We examine the research that led to a Photovoice study co-developed with patients identifying as women of colour to illustrate how creative methods, relational accountability, and community engagement can challenge extractive research norms. Our findings underscore the importance of navigating disciplinary differences, building trust, and recognising lived experience as expertise. We propose that adopting an Ethics of Care approach to research design and team practices can lead to more inclusive, patient-centred inquiry. By reflecting on those approaches, we aim to promote equity in health research and support broader institutional transformation.

An Ethics of Care Approach to Chronic Pain

Chronic pain is an umbrella term that emerged in the 1970s to describe any pain that recurs or lasts longer than three months (Treede et al., 2015). Now classified as a separate condition, chronic pain is experienced by around 20% of adults globally, and by 100 million (over 20%) American adults (Dahlhamer et al., 2018; Simon, 2012). Unlike acute pain, which typically has a clear cause and resolution, chronic pain is highly individualised and there is no single practical standardised test or "cure." The need to balance evidence-based guidelines and patient-specific needs is now better understood. Still, diagnosis and treatment remain inequitable, with studies showing disparities in the experience and treatment of chronic pain, and age, race, gender, sexuality, and income linked to differences in the prevalence of pain (Breivik et al., 2006; Fejer, Kyvik, and Hartvigsen, 2006; Haukenes et al., 2015; Stubbs et al., 2010). Gender significantly influences how patients are treated in clinical settings, with those who identify as women or as gender-diverse individuals more likely to have their symptoms dismissed or pathologised as psychological or imagined (Johansson et al., 1996; Ware, 1992). A person's race and ethnicity significantly shape how their pain is interpreted by medical professionals (Edwards, Fillingim, and Keefe, 2001), with well-documented racial disparities in U.S. healthcare including the underdiagnosis of chronic pain and insufficient pain management among racially and ethnically minoritised patients (Hoffman et al., 2016; Wakefield et al., 2018). While patients presenting as White women are more likely than those from racially and ethnically minoritised groups to have their pain acknowledged by healthcare providers, they too are often subject to what has been termed the "gender pain gap" (eClinicalMedicine, 2024). These disparities underscore the urgent need for research that centres the voices of those most affected by chronic pain, particularly women or gender-diverse individuals from racially and ethnically minoritised backgrounds.

An Ethics of Care (EoC) approach is well-suited to understanding chronic pain health disparities and addressing treatment inequities because it emphasises attentiveness, responsiveness to lived experience, and relationality – principles frequently absent in biomedical models prioritising objectivity and standardisation. In her key work on the EoC in 1984, the American philosopher Nell Noddings described EoC as "rooted in receptivity, relatedness, and responsiveness" (Noddings, 1984, p.2). Noddings' focus was on relations between people, which is highly relevant to chronic pain and its treatment, where one group of people (medical professionals) has often treated people from another group (patients) differently depending on each patient's intersectional identity. Noddings was not using "relational" as Haraway does as a more-than-human relational network, which accounts for nonhumans such as plants, ecosystems, animals, technologies and immaterial entities such as ideas and practices. However, within a decade, Joan Tronto's definition of EoC came closer to Haraway's more-than-human relational network concept when Tronto described caring as "a species activity that includes everything we do to maintain, continue and repair our 'world' so that we can live in it as well as possible. That world includes our bodies, ourselves, and our environment, all of which we seek to interweave in a complex, life-sustaining web" (Tronto, 1993, p.103). Living with chronic pain unfolds within a more-than-human relational network in which the environment – both built and natural – can shape experiences of suffering and relief. Inaccessible architecture, noise pollution, or extreme weather can intensify pain or limit mobility. At the same time, elements such as soothing landscapes, animals, or adaptive technologies can offer comfort, mitigate symptoms, and foster a sense of connection beyond the human – contributions which point toward the need for more inclusive, patient-centred research and sustained advocacy, as evidenced in the image-text pieces produced by participants who identify as women of colour living with chronic pain, discussed later in the section on the Photovoice research study.

Carelessness in medical and academic research settings

At the British Pain Society's 2012 Special Interest Group for Philosophy and Ethics annual meeting, titled The Ethics of Care, participants analysed systemic failures in healthcare at the time. These shortcomings were attributed to a "loss of an ethos of care – not because their practitioners are essentially uncaring, but because of financial, organisational pressures, as well as the challenge of reconciling biomedical science with holistic approaches to healing and caring for the "whole person" ("The Ethics of Care," 2012, p. 3). Subsequent speakers reinforced the importance of treating the whole person, acknowledging their place within chronic pain's more-than-human relational network. One speaker noted that "Medicine's preoccupation with the biology of the disease risks distracting us from the biography of the person that is both the essential context of the biological problem and essential to its solution" ("The Ethics of Care," 2012, p.17). Care work extends beyond formalised tasks, encompassing institutional and everyday acts of care. Indeed, care work is broadly defined as the relational, emotional, and practical labour involved in supporting others, especially in contexts of vulnerability, dependence, or interdependence.

It would be disingenuous to discuss academic research and EoC without acknowledging what has been termed the "carelessness" of academic life. Like medical practitioners, academics operate under heavy institutional scrutiny, where auditing and organisational priorities frequently undermine genuine care despite pervasive rhetoric that superficially champions it. In academia, care is increasingly instrumentalised as a managerial tool, appearing in diversity statements, wellness programmes, and mentorship policies while being disconnected from lived, relational ethics. Applying an EoC lens to academic research practices reveals how institutional inequities shape who bears the burdens of care within research teams. These disparities span institutional hierarchies and career stages, with graduate students and early-career researchers often burdened by emotional, administrative, and relational labour with little recognition or support. This lack of care, or academia's broader "moral status" of carelessness, is especially prevalent in research-intensive universities, where Lynch (2010, p.59) argues that "the pursuit of unbridled self-interest (rationalised in terms of a "career") has not only been normalised, but it has also attained status and legitimacy."

To counter academia's pervasive carelessness, an EoC ought to be structurally embedded within institutional frameworks. This requires formally recognising and rewarding relational labour, such as mentoring, emotional support and collaborative work, through hiring practices, promotion criteria, and workload distribution changes. Key steps include fostering relational accountability through cooperative research models, implementing inclusive decision-making, and establishing mechanisms for repair when harm occurs. Care ethics should inform research practices, particularly in community-engaged or trauma-informed work, with deliberate attention to the well-being of both participants and researchers. Institutional success metrics should be redefined to prioritise equity, well-being, and collaboration over narrow productivity measures. Structural inequities, particularly across institutional types (e.g., research vs. teaching-focused) and career stages, must be addressed to ensure that care is not merely performative but systematically enacted. While institutional transformation remains inadequate, individual scholars and research teams can proactively model EoC principles through collaborative structures.

Care-full team building to solve wicked problems

Writing on EoC, Carol Bacchi reminds us that "how we talk about or theorise care means examining critically the concepts we use— asking what they allow us to see and what they (may) leave out" (Bacchi, 2024). How care is understood and applied in research (ie, by whom; whose voices are heard and whose are silenced) leads to partiality of knowledge and perpetuates inequities. It is therefore essential to critically examine how chronic pain research unfolds and to develop, test, and advance models of inquiry that intentionally amplify marginalised voices. Bringing together diverse perspectives is also central to studying "wicked problems," a class of complex, contentious problems that defy complete definition and resolution, and for which there is no single solution (Rittel and Webber, 1974). To solve them requires thinking beyond any one discipline, necessitating interdisciplinary teams of individuals with "interpersonal and professional skills that allow them to collaborate successfully within diverse teams of researchers and other stakeholders" (Kawa et al. 2021, 2). Chronic pain is known to be a wicked problem, and our approach was to build an interdisciplinary team to consider it from new angles and to ensure that perspectives of people living with chronic pain were central – not only as "subjects" to be studied but as participants in the research itself.

The overall project began after Dr Prophet, an interdisciplinary visual artist whose collaborations with scientists bridge art and science (Prophet, 2016; Prophet and d'Inverno, 2004), met with an anaesthesiologist and expert in translational science, Dr George Mashour, an advocate for team science (Kabo and Mashour, 2019) and for the contributions that the arts can make to the clinical science (Dittman Stanich and LaPensee, 2022). He introduced Prophet to Dr. Hassett, a pain researcher who develops tailored and innovative approaches to support people living with chronic pain in ways that enable them to thrive (Hassett and Gevirtz, 2009; Nicol et al., 2016). Dr. Mashour sourced funds for Drs. Hassett and Prophet to explore chronic pain using arts-informed methods through collaborations that adapted team science approaches ("Team Science," 2016) to a team art and science model. After a scoping review of artsinformed approaches to ameliorating chronic pain, they contacted colleagues to see who might be interested in joining the team. Our initial academic research team comprised twelve core individuals from the University of Michigan: six faculty members from art, design, and music; one from social work; two clinical researchers from pain research and psychology; and two paid graduate research assistants from design and social work. Later, Dr Rahbel Rahman-Tahir joined us, bringing her expertise in race and community-based participatory research (Rahman et al., 2023; Pinto et al., 2021). We began with in-person meetings to build trust and understanding among team members with different disciplinary backgrounds. Creating a safe space for team members to describe their situation, aspirations, and motivations was key. During these gatherings, team members described their professional roles and situations and revealed much about their personal lives as they built trust. Four team members disclosed that they had lived experience of chronic pain – slightly above the U.S. national prevalence of 21% – which aligns with expectations for a group self-selecting to engage in research on a personally relevant topic. All were committed to and had experience in community-engaged research using various methods. Our team brought a wide range of positionalities across race, ethnicity, gender, sexuality, and disability, shaping our intersectional perspective and informing our research approach.

In early meetings, we showcased our research and creative work. We described our preferred research production and dissemination methods, which included deeper dives into methods that were arts-informed, such as Discursive Design (Tharp and Tharp, 2019), and those that had a creative component from social work, like Photovoice (Wang and Burris, 1997). The primary question guiding our discussions was, "How might creative practices with participants who live with chronic pain increase well-being, advocate for changes to healthcare, and enable those living with chronic pain to thrive?" In our first team meeting, we considered the different needs of team members, their individual goals, and how they were situated. This discussion was one we returned to repeatedly throughout our work together. By the end of our collaboration, we had identified ten significant differences that mattered to us as we scoped how we might work together and then embark on interdisciplinary research in an academic setting with an EoC. These are not exhaustive, but they were essential to our project. Intentionally discovering our differences helped us begin learning how to conduct caring research that divided effort more equitably and would enable us to advocate for institutional change whilst supporting one another.

We learned from first-hand accounts from our teammates that:
1. Allocated research time varies, with individuals on research contracts having more time than colleagues on research/teaching or teaching-only contracts.
2. There are significant differences in teaching loads between different schools/departments within a university and between research-intensive and teaching-intensive universities.
3. Remuneration varied based on colleagues' employers, contract type, rank and disciplines. 4. The pressure on STEMM colleagues and colleagues with research-only contracts to secure grants often exceeded the expectations placed on art colleagues. However, colleagues from art and design had fewer opportunities to access external funding, and that funding was of lesser amounts.
5. Access to university facilities differed significantly, with artists and designers frequently bearing personal expenses for external studio space. At the same time, STEMM and social science researchers often have space allocated by their universities. 6. The range of qualitative and quantitative research varied, with STEMM researchers generally being more familiar with quantitative methods than researchers from art and design backgrounds.
7. We had different traditions and norms associated with working with community participants.
8. There was a wide variety in accepted and preferred forms of dissemination, from exhibitions to papers.
9. Our team comprised people at all career stages, from graduate students to early career researchers to full professors, with associated hierarchies and power differentials.
10. Each team member's life situation and position affected the time and energy they had for research.

To foster a caring collaborative environment, we agreed that involvement would be voluntary, with members able to step back or leave anytime. Given the small grant, graduate students and community participants would be compensated, but salaried faculty and researchers would not. We co-designed clear objectives, in line with team effectiveness studies, showing that clear goals and committed individuals are critical for predicting the overall success of joint projects (Poulton and West, 1999).

Distributed leadership and co-designing research with community participants

In our large-group meetings, potential research projects emerged, with people drawn to specific methods and groups living with chronic pain. Instead of voting for the most popular, we formed smaller interdisciplinary teams, each co-researching with participants to help people thrive despite living with chronic pain. We disrupted the often-instrumentalist structures of STEAM collaborations (Halpern and Rogers, 2021), where artists frequently serve scientists. Each of our six research teams, consisting of 2-6 members led or co-led by art and design researchers, fostered an inclusive leadership structure, based on an EoC commitment of mutual respect and engagement. Periodic group meetings allowed discussion and sharing about practices that worked well, helping one another develop ways to overcome barriers, and reminding one another of how we could best balance individual interests and career goals throughout the research process.

Each project used arts-informed methodologies designed to centre participants whose expertise stemmed from living with chronic pain with intersecting health disparities. One team comprising two designers and a pain researcher developed reflective tools, including mindset collages and relationship maps, to empower chronic pain sufferers who identified a s w omen. Another team, consisting of a musician and a pain researcher, worked with African American elders to gather data and explore how music could soothe and express pain, then develop online "social prescription" playlists. An artist and pain researcher co-designed collage kits for patients to create layered translucent lightbox works to express their pain. Another team, composed of an artist and psychologist, codesigned an augmented reality app for youth living with sickle cell anaemia, enabling them to express their wishes for change in healthcare support. Through the collaboration of an artist-designer and psychologist, a team explored the integration of wearable technology for youth living with pain to help them self-soothe and distract from their pain. Lastly, through a partnership with an artist (Prophet), pain researcher (Hassett) and a Photovoice expert from the University of Michigan (Kattari) and a social work expert from Fordham University (Rahman-Tahir), we designed a Photovoice study that empowered participants identifying as women of colour living with chronic pain to share their perspectives and experiences through photos and texts.

Photovoice is a well-established and rigorous "participatory action research method that involves placing cameras in the hands of participants so that they may visually represent and communicate to others their lived experiences" (Wang and Burris, 1997, p. 13). The Photovoice approach offers unique insights into patients' experiences living with chronic pain. During this process, participants respond to prompts by taking photographs and then reflect on and discuss these photos in a facilitated group setting. The structure offers opportunities for critical reflection on both individual and communal levels. This approach has been used to investigate the complexities of living with chronic pain (Wheeler and Early, 2018; Wallace et al., 2014). However, few studies have explicitly examined how gender, ethnicity, and race intersect to shape health disparities in chronic pain populations. Photovoice positions participants as experts in their lived experiences, empowering them to use photography and narrative to inform and advocate for changes in clinical practices, health strategies, and policy-making. This participatory approach has proven valuable for working with under-represented and vulnerable populations because it is "relatively unobtrusive and has the capacity to be empowering" (Wilkin and Liamputtong, 2010). Numerous Photovoice projects have effectively highlighted areas requiring systemic change (Drew, Duncan, and Sawyer, 2010), and align with our team's experience using art-based methods to bridge scientific research and patient experience. Their approach emphasises meaningful engagement with science rather than one-way dissemination (Gubrium, Hill, and Flicker 2014), a principle that underpins this project. Photovoice has been utilised in many studies to explore complex or sensitive topics, including intersectional healthcare disparities, while fostering collaborative knowledge production (Padgett et al., 2013; Wang, Cash, and Powers, 2000). Through the iterative process of taking photographs, group discussion, and narrative development, participants document, analyse and reflect upon their personal and collective experiences, captured in their visual representations that are accompanied by short texts.

Co-designing a Photovoice study

To improve our study design, we engaged in community feedback to refine our approach. The Michigan Institute for Clinical Health Research (MICHR) facilitated a 90-minute Community Engagement Studio, where two research team members presented proposals for the Photovoice study and related reflective tools study. Nine participants, all women with lived experience of chronic pain, recruited from MICHR's UMHealthResearch.org registry, provided input to improve the study's responsiveness to their needs. These participants were compensated with a meal and a $20 cash card for their advice. MICHR staff facilitated the session, and our role was to listen actively and answer questions concisely, reflecting EoC's principle of the wisdom of embodiment.

The Community Engagement Studio took place in 2019, before the COVID-19 pandemic. Initially, we planned in-person sessions. However, respondents suggested that the study be conducted via Skype or Blue Jeans due to concerns about exhaustion, pain, and stress. At the time, virtual Photovoice had no precedent, making it hard to get approval from the Institutional Review Board. However, after COVID-19 disrupted in-person plans, we secured ethics approval to conduct the study online, pioneering virtual Photovoice (Chen, 2022). One participant, who used art therapy for self-care, emphasised physical comfort and suggested flexible seating, movement breaks, and individual comfort preferences. We applied them to our virtual format, encouraging participants (n=20 across two groups) to prioritise their well-being (e.g., turning off the camera when needed). Remarkably, only one participant dropped out. The twenty who stayed were likely able to adjust more easily if they experienced pain or discomfort.

Other practical recommendations included scheduling sessions in the evening, as many pain sufferers need extra time in the morning to manage their condition. Expert opinions were divided on whether caregivers should be included in the sessions. Some felt uncomfortable with caregivers present, while others wanted them to be excluded in order to speak truthfully. We decided to offer caregivers a space with compensation, but no one took it up. Advisers also suggested broader recruitment criteria, so we used the clinical definition of chronic pain lasting more than three months and did not require a clinical diagnosis.

The financial burden of chronic pain is as high as $635 billion annually in the US (Muneer 2015). In addition to social costs, individuals and families face lost earnings and increased medical and self-care expenses. Given this, it was unsurprising that advisers questioned participant compensation, suggesting $25 to $50 per session. We settled on offering a $ 50 gift card per session. Advisers also inquired about the Photovoice approach, asking whether participants could take pictures of anything they chose. They believed this freedom could encourage creativity. We confirmed this, with the condition that participants could only photograph people if they obtained consent and signed permission forms. Some participants did take images of others with the necessary consent. The overall sentiment from the Engagement Studio was that "This [Photovoice] group could help others and empower them to express themselves and advocate and communicate using their art" (Anonymous participant).

Participants' insights into more-than-human suffering and thriving from our Photovoice study

Subsequently, our study "Deepening Public Engagement with Chronic Pain Research: A Photovoice Project: Using Art and Design for Translational Medical Research with Pain Researchers and Patients" received ethics approval from the University of Michigan Health Sciences and Behavioural Sciences Institutional Review Board (approval # HUM00166379). The study, which involved twenty people who self-identified as women of colour working in two groups, facilitated by Dr Rahman-Tahir with Dr. Prophet acting as technical assistant, was completed in the summer of 2021. We detail how we adapted Photovoice using arts-informed methods and incorporating asynchronous videos to introduce participants to foundational concepts from art and photography theory on interpreting images and image-text works, as well as explaining practical art-based techniques such as lighting, scene composition, and the intentional use of colour in a separate paper (Prophet, Rahman, and L. Hassett, 2023). In summary, the participants took photographs, created short narratives to accompany each photograph, and sorted that data into groups, defining categories. Each group reached a consensus about how to share the publications to advocate for change in healthcare. The two groups shared their connected publications as printed books and eBooks. One group chose the title "Journeying beyond pain: our truth as women of colour", and the title of the other group's work was "The Invisible Struggle" (20 Anonymous Participants, 2022).

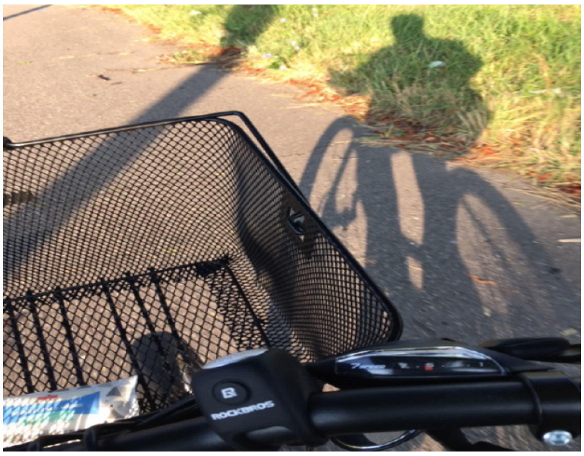

Figure 1: "This shows more of me on the bike. It's like proof of proof of life. It's like I'm really riding this bike. It's not me talking about riding the bike. The bike itself is not important. It's the process of riding it that's important, and so this is me, in flight." (Jan, Photovoice piece from the 2021 study). Reproduced with permission.

Pain is more than a physical sensation; it is becoming understood as a whole-person experience that can cause suffering (Siler, Borneman, and Ferrell, 2019). As a more-than-human relational network, the pain humans feel is not solely a human experience but a complex interplay of biological, psychological, and social factors extending beyond individual bodies and encompassing relationships with other beings and the environment. Studies that compare pain and suffering suggest thatsuffering is a separate but related experience thatcan be significantly impacted by the individual'sperception and coping mechanisms. Hassett's research explores the key role that the human brain plays in processing pain and how small, simple actions can make profound changes in how we experience chronic pain, showing that it is possible to find ways of thriving despite living with chronic pain (Hassett, 2023). Positioning humans as part of a more-than-human relational network invites a shift in perception that understands the environment, plants, and animals not as passive backdrops or resources, but as active participants in interconnected systems of meaning, care, and mutual influence.

Photo-text pairs and how each group categorised them reveal individuals' fluctuating movement across a spectrum of suffering and thriving, illustrating how seemingly simple environmental interactions can alleviate or intensify pain. In Figure 1, Jan depicts her embodied entanglement with the riverside landscape through cycling, describing it as liberating and affirming, "It's the process of riding that's important, and so this is me, in flight." In contrast, the interlacing staircases of a train station (Figure 2) were perceived as overwhelming. The group categorised them as an "everyday activity that can be difficult," under the broader theme of "obstacles."

These examples reflect an EoC orientation, where well-being is understood as emerging through relational, contextual, and embodied engagements with environments, objects, and nonhuman life. Many participants described their relationships with nonhuman animals and plants as sustaining, particularly through sensory encounters with plants. Shaima observed (Figure 3), "Sometimes you forget about those beautiful plants and then you see them... These are beautiful things that we should stop and look at. Just like pain, I guess—we have to accept it too." Here, care transcends instrumental acts; it is rooted in attentiveness to one's surroundings and an acceptance of embodied vulnerability. Practices like bringing flowers indoors, cultivating herbs, or tending to gardens emerged as acts of care toward self, space, and nonhuman others – as shown in Romona's contribution (Figure 4). These findings underscore the situated, relational, and more-than-human dimensions of care, challenging conventional framing within strictly clinical or interpersonal domains.

Figure 2: "This is a series of staircases that interlace through the middle of the station and feel never ending, especially if you are experiencing some kind of pain. I've seen plenty of people just stopped midway to catch their breath. My thoughts moved to how I would probably need to take the escalator. When you're catching the 2 train, you need to go up about three stories high which is broken up into half staircases, so there's really six levels of stairs which feel terrible, especially when you're in pain or it's too hot. So, I was actually at the bottom of that staircase and I took a photo as I was looking for the escalator. Just things that I didn't have to think about before. I'm not excited about the Michigan transportation system. It's made for cars, and so, if you have a car you're good to go, you can manage, you can get places sometimes that's the only way you can get places. So it makes me think about the infrastructure here, how that got put into place and who have the ability to own a car. It raised questions about managing transportation when you can't afford a car, or when you can't afford the gas for the car? All of those sort of considerations that you need to have, as you plot your life somewhere." (Doreen,

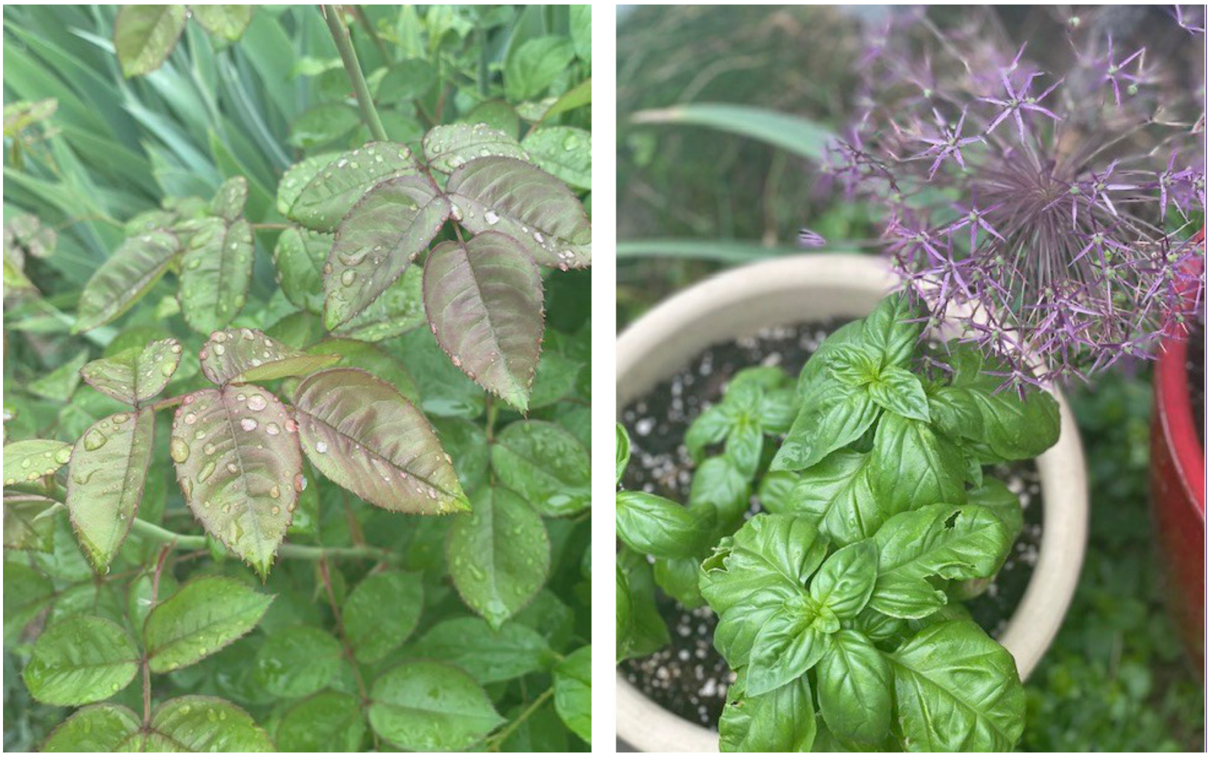

Figure 3: "And I was walking around it just poured rain and then stopped and the plants looked so fresh and so hydrated that I took my phone and I started taking pictures. Cause I really liked the moment, right after the rain. Just that pop of green and the smell, you know, earth. You're walking or just doing things, sometimes you forget about the pain. And sometimes you forget about those beautiful plants and then you see them, so I feel it's kind of the same thing, these are beautiful things that we should stop and look at. Just like pain, I guess, we have to accept it too. I used to paint and I know I see some purple in the left picture and you know the right, I feel both of them next to each other. Even though they're completely different plants but I feel both of them kind of complement each other." (Shaima, Photovoice piece from the 2021 study). Reproduced with permission.

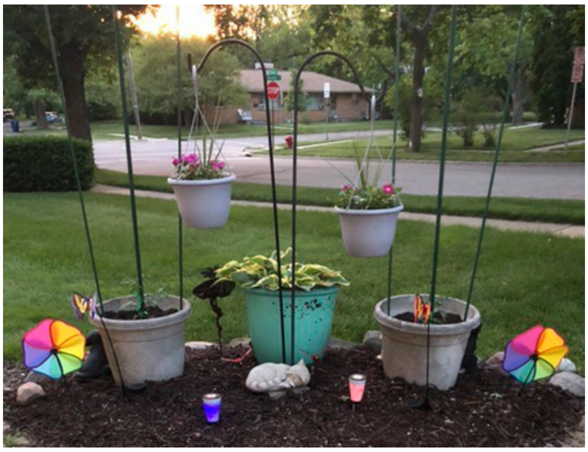

Figure 4: "My garden photo illustrates I enjoy from taking care of my garden and the peace and tranquility I get from watching the colors changes on my solar butterflies and stands." (Romona, Photovoice piece from the 2021 study). Reproduced with permission.

Conclusion

This paper demonstrates how an EoC approach – centred on relationality, attentiveness, and responsiveness – can meaningfully reshape research on chronic pain by addressing systemic inequities and valuing lived experience. Through arts-informed, interdisciplinary collaborations, we created a research environment where participants were engaged as co-creators of knowledge rather than passive subjects, and where self-care practices, suffering, and thriving were explored within a more-than-human relational framework. The Photovoice approach, adapted to reflect participants' embodied realities and cultural contexts, enabled nuanced expressions of pain and care, foregrounding the environmental, social, and structural conditions that shape chronic pain experiences.

We argue for increased institutional support for interdisciplinary collaborations that draw on the strengths of art and design, STEMM, and social work to confront complex, "wicked" problems like chronic pain. Building research teams grounded in an EoC requires time, reflexivity, and sustained attention to power dynamics, disciplinary norms, and differential access to institutional resources. By addressing these differences, research teams can become more inclusive, ethically grounded, and deliver innovative research. By revaluing relational labour, designing equitable structures, and amplifying marginalised voices, this project illustrates how careful research practices can generate deeper understanding and new pathways for advocacy, healing, and institutional change.

Acknowledgements

This study was funded by the University of Michigan's Michigan Institute of Clinical Health Research, The Institute of Research into Women and Gender, and Stamps School of Art and Design. We are especially grateful to George Mashour for his advice and support of the larger project. The Photovoice study is one of six arts-informed translational research projects. We thank Dr Shanna Kattari from UM's School of Social Work, who has experience designing and facilitating Photovoice studies and training facilitators, for advising us as we developed our draft design for this study. We also thank the team who worked hard to design the planned in-person study: Zahra Chevannes, Colleen Clark, Tricia Piechowski, Meghan Spiroff, and Ariel Mallett, who helped implement the virtual Photovoice.

References

— Anonymous Participants, 2022. Journeying beyond Pain: Our Truth as Women of Color, and, The Invisible Struggle. Blurb Books. Available at: https://figshare.com/authors/ Jane_Prophet/20964686 [Accessed 28 April 2025].

— Bacchi, C., 2024. 'Care Ethics: The Feminist Ethic of Care (FEC) and WPR'. Carol Bacchi (blog), 30 March. Available at: https://carolbacchi.com/2024/03/30/care-ethics-thefeminist- ethic-of-care-fec-and-wpr/ [Accessed 28 April 2025].

— Breivik, H., Collett, B., Ventafridda, V., Cohen, R. and Gallacher, D., 2006. 'Survey of Chronic Pain in Europe: Prevalence, Impact on Daily Life, and Treatment'. European Journal of Pain, 10(4), pp. 287-333.

— Chen, J., 2022. 'Digitally Dispersed, Remotely Engaged: Interrogating Participation in Virtual Photovoice'. Qualitative Research, p. 14687941221110175.

— Dahlhamer, J., Lucas, J., Zelaya, C., Nahin, R., Mackey, S., DeBar, L., Kerns, R., Von Korff, M., Porter, L. and Helmick, C., 2018. 'Prevalence of Chronic Pain and High-Impact Chronic Pain among Adults—United States, 2016'. Morbidity and Mortality Weekly Report, 67(36), p. 1001.

— Dittman Stanich, V. and LaPensee, E., 2022. 'Supporting Artists on STEMM Research Teams: Why and How'. Insights. Ann Arbor, Michigan, US: The Alliance for the Arts in Research Universities (a2ru). Available at: https://a2ru.org/research/supporting-artists-on-stemmresearch- teams-why-and-how/ [Accessed 28 April 2025].

— Drew, S.E., Duncan, R.E. and Sawyer, S.M., 2010. 'Visual Storytelling: A Beneficial but Challenging Method for Health Research with Young People'. Qualitative Health Research, 20(12), pp. 1677–1688.

— eClinicalMedicine, 2024. 'Gendered Pain: A Call for Recognition and Health Equity'. eClinicalMedicine, 69 (March). Available at: https://doi.org/10.1016/j.eclinm.2024.102558 [Accessed 28 April 2025].

— Edwards, C.L., Fillingim, R.B. and Keefe, F., 2001. 'Race, Ethnicity and Pain'. Pain, 94(2), pp. 133–137. — Gubrium, A.C., Hill, A.L. and Flicker, S., 2014. 'A Situated Practice of Ethics for Participatory Visual and Digital Methods in Public Health Research and Practice: A Focus on Digital Storytelling'. American Journal of Public Health, 104(9), pp. 1606–1614.

— Halpern, M.K. and Rogers, H.S., 2021. 'Art–Science Collaborations, Complexities and Challenges'. In: Routledge Handbook of Public Communication of Science and Technology, pp. 214–237. Routledge.

— Hassett, A.L., 2023. Chronic Pain Reset: 30 Days of Activities, Practices and Skills to Help You Thrive. Hachette UK.

— Haukenes, I., Hensing, G., Stålnacke, B.-M. and Hammarström, A., 2015. 'Does Pain Severity Guide Selection to Multimodal Pain Rehabilitation across Gender?' European Journal of Pain, 19(6), pp. 826–833.

— Hoffman, K.M., Trawalter, S., Axt, J.R. and Oliver, M.N., 2016. 'Racial Bias in Pain Assessment and Treatment

— Hassett, A.L. and Gevirtz, R.N., 2009. 'Nonpharmacologic Treatment for Fibromyalgia: Patient Education, Cognitive- Behavioral Therapy, Relaxation Techniques, and Complementary and Alternative Medicine'. Rheumatic Disease Clinics, 35(2), pp. 393–407.

— Haukenes, I., Hensing, G., Stålnacke, B.-M. and Hammarström, A., 2015. 'Does Pain Severity Guide Selection to Multimodal Pain Rehabilitation across Gender?' European Journal of Pain, 19(6), pp. 826–833.

— Hoffman, K.M., Trawalter, S., Axt, J.R. and Oliver, M.N., 2016. 'Racial Bias in Pain Assessment and Treatment Recommendations, and False Beliefs about Biological Differences between Blacks and Whites'. Proceedings of the National Academy of Sciences, 113(16), pp. 4296–4301.

— Johansson, E.E., Hamberg, K., Lindgren, G. and Westman, G., 1996. '"I've Been Crying My Way"—Qualitative Analysis of a Group of Female Patients' Consultation Experiences'. Family Practice, 13(6), pp. 498–503.

— Kabo, F.W. and Mashour, G.A., 2019. 'Measuring Team Science: Associations between a Clinical-Translational Science Institute and Investigator Ego Networks'. Journal of Clinical and Translational Science, 2(6), pp. 363–370.

— Kawa, N.C., Arceño, M.A., Goeckner, R., Hunter, C.E., Rhue, S.J., Scaggs, S.A., Biwer, M.E., Downey, S.S., Field, J.S. and Gremillion, K., 2021. 'Training Wicked Scientists for a World of Wicked Problems'. Humanities and Social Sciences Communications, 8(1).

— Nicol, A.L., Sieberg, C.B., Clauw, D.J., Hassett, A.L., Moser, S.E. and Brummett, C.M., 2016. 'The Association between a History of Lifetime Traumatic Events and Pain Severity, Physical Function, and Affective Distress in Patients with Chronic Pain'. The Journal of Pain, 17(12), pp. 1334–1348.

— Noddings, N., 1984. Caring: A Feminine Approach to Ethics and Moral Education.

— Padgett, D.K., Smith, B.T., Derejko, K.-S., Henwood, B.F. and Tiderington, E., 2013. 'A Picture Is Worth...? Photo Elicitation Interviewing with Formerly Homeless Adults'. Qualitative Health Research, 23(11), pp. 1435–1444.

— Pinto, R.M., Rahman, R., Zanchetta, M.S. and Galhego- Garcia, W., 2021. 'Brazil's Community Health Workers Practicing Narrative Medicine: Patients' Perspectives'. Journal of General Internal Medicine, pp. 1–9.

— Prophet, J., 2016. 'Self-Portrait of the Artist Meditating on Death: A Feminist Technoscience Reading of the Apparatus of Contemporary Neuroscience Experiments'. In: The Routledge Companion to Biology in Art and Architecture, pp. 482–503. Milton Park, Abingdon, Oxon; New York, NY: Routledge.

— Prophet, J. and d'Inverno, M., 2004. 'Creative Conflict in Interdisciplinary Collaboration: Interpretation, Scale and Emergence'. In: Interaction: Systems, Theory and Practice, pp. 251–270. Creativity and Cognition Studios.

— Prophet, J., Rahman, R. and Hassett, A.L., 2023. 'An Online Photovoice Study Designed by Researchers from Art and Social Work to Better Understand the Experience of Chronic Pain by Women of Color'. AM Journal of Art and Media Studies, (32), pp. 69–89.

— Rahman, R., Azhar, S., Wernick, L.J., DeVylder, J.E., Maschi, T., Cohen, M. and Hopwood, S., 2023. 'Mask Mandates, Race, and Protests of Summer 2020'. In: Dual Pandemics, pp. 154–165. Routledge.

— Rittel, H.W. and Webber, M.M., 1974. 'Wicked Problems'. Man-Made Futures, 26(1), pp. 272–280.

— Siler, S., Borneman, T. and Ferrell, B., 2019. ‘Pain and Suffering’. In: 35, pp. 310–314. Elsevier. — Team Science, 2016. Team Science. The Academy of Medical Sciences. Available at: https://acmedsci.ac.uk/policy/ policy-projects/team-science [Accessed 28 April 2025].
— Tharp, B.M. and Tharp, S.M., 2019. Discursive Design: Critical, Speculative, and Alternative Things. MIT Press.
— The Ethics of Care, 2012. Transcript. Special Interest Group for Philosophy and Ethics. Ambleside, UK: The British Pain Society. Available at: https://www.britishpainsociety.org/ static/uploads/resources/files/2012_The_Ethics_of_Care. pdf [Accessed 28 April 2025].
— Treede, R.D., Rief, W., Barke, A., Aziz, Q., Bennett, M.I., Benoliel, R., Cohen, M. et al., 2015. ‘A Classification of Chronic Pain for ICD-11’. Pain, 156(6), pp.1003–1007. Available at: https://doi.org/10.1097/j.pain.0000000000000160 [Accessed 28 April 2025].
— Tronto, J., 1993. Moral Boundaries: Towards a Political Ethic of Care.
— Wakefield, E.O., Pantaleao, A., Popp, J.M., Dale, L.P., Santanelli, J.P., Litt, M.D. and Zempsky, W.T., 2018. ‘Describing Perceived Racial Bias Among Youth with Sickle Cell Disease’. Journal of Pediatric Psychology, 43(7), pp. 779–788. Available at: https://doi.org/10.1093/jpepsy/jsy015 [Accessed 28 April 2025].
— Wallace, L.S., Wexler, R.K., McDougle, L., Miser, W.F. and Haddox, J.D., 2014. ‘Voices That May Not Otherwise Be Heard: A Qualitative Exploration into the Perspectives of Primary Care Patients Living with Chronic Pain’. Journal of Pain Research, 7, pp. 291-. Available at: http://link.galegroup. com/apps/doc/A400956167/HRCA?u=umuser&sid=H RCA&xid=4004ef1e [Accessed 28 April 2025].
— Wang, C., and Burris, M.A., 1997. ‘Photovoice: Concept, Methodology, and Use for Participatory Needs Assessment’. Health Education & Behavior, 24(3), pp. 369–387.
— Wang, C.C., Cash, J.L. and Powers, L.S., 2000. ‘Who Knows Streets as Well as the Homeless? Promoting Personal and Community Action through Photovoice’. Health Promotion Practice, 1(1), pp. 81–89.
— Ware, N.C., 1992. ‘Suffering and the Social Construction of Illness: The Delegitimation of Illness Experience in Chronic Fatigue Syndrome’. Medical Anthropology Quarterly, 6(4), pp. 347–361.
— Wilkin, A. and Liamputtong, P., 2010. ‘The Photovoice Method: Researching the Experiences of Aboriginal Health Workers through Photographs’. Australian Journal of Primary Health, 16(3), pp. 231–239.