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An Online Photovoice Study Designed by Researchers from Art and Social Work to Better Understand the Experience of Chronic Pain by Women of Color

Abstract: In 1980s British feminist artist-photographer Jo Spence used phototherapy to challenge normative and medicalized constructions of the female cancer patient by documenting her illness and was then employed as a consultant by hospitals who, through her work, recognized the need to change physicians' practices and attitudes, which objectified patients. Photovoice, a Community Based Participatory Design method where participants take photographs and combine them with short text narratives, is similar to Spence's artistic method. It has been used widely in health and social work settings. Healthcare professionals are aware of the power of images as catalysts for meaning making in medical encounters with people in pain; as part of multidisciplinary analysis, because images can enhance a person's sense of agency in relation to their pain, especially in clinical contexts. Photographs can also establish a common ground for discussing meaning, therefore Photovoice can make the hidden experience of pain visible through collaborative photo-texts. These are subsequently shared with other patients and healthcare workers to aid them in specialist consultations. However, few studies have addressed gender and race-related health disparities in treating chronic pain. This paper draws on the authors' study with twenty women of color who created photo-text works about their experiences living with and being treated for chronic pain. In this novel online Photovoice study, participants engaged with asynchronous videos created by an artist-professor about the meanings viewers make of a photograph, including how perspective, angle, and lighting can affect the viewer's emotional response to photographs. Participants then deployed Photovoice through six synchronous sessions led by a social work professor with extensive experience designing and facilitating Photovoice studies. The resulting image-text works by study participants address health inequity and argue for health equity as a hallmark of social justice in healthcare by focusing on exposing and reducing healthcare disparities.

Keywords: Photovoice; arts-informed research; chronic pain; health equity.

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Chronic Pain in the US: Disparities and Inequities.

Over 100 million people in America experience chronic pain; more than one in every four Americans.[1] Evidence shows that pain is not experienced or treated equally across patients and communities, therefore understanding differences in an individual's experience and treatment is essential. Throughout this manuscript, Olivia Carter-Pokras's and Claudia Baquet's paper[2] guides our use of the contested terms 'disparity', 'inequality' and 'inequity'. The term 'health disparity' has been used in the literature to denote a simple population-specific *difference*[3]. WHO defines health inequities as "avoidable inequalities in health between groups of people within countries and between countries. These inequities arise from inequalities within and between societies. Social and economic conditions and their effects on people's lives determine their risk of illness and the actions taken to prevent them becoming ill or treat illness when it occurs."[4] When the term 'inequity' is used in this paper it indicates that the differences referred to are systemic and avoidable.

There are gender inequities in the experience of chronic pain, with more women than men experiencing chronic pain.[5] Clinical research suggests that women report more severe levels of pain, more frequent pain, and a longer duration of pain than men.[6] Women reporting pain are more frequently questioned than men, particularly by doctors, and told more often that they are either not sick or suffering from an imaginary illness.[7] A person's race and/or ethnicity also influence how their pain is

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[1] Lee S. Simon, "Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research," *Journal of Pain & Palliative Care Pharmacotherapy* 26, 2 (2012): 197–98.

[2] Olivia Carter-Pokras and Claudia Baquet, "What Is a 'Health Disparity'?" *Public Health Reports* 117, 5 (2002): 426.

[3] Paula Braveman, "What Are Health Disparities and Health Equity? We Need to Be Clear," *Public Health Reports* 129, 1_suppl2 (2014): 5–8.

[4] "Social Determinants of Health: Key Concepts," World Health Organization, https://www.who.int/newsroom/questions-and-answers/item/social-determinants-of-health-key-concepts, acc. April 24, 2023.

[5] Harald Breivik, Beverly Collett, Vittorio Ventafridda, Rob Cohen, Derek Gallacher, "Survey of Chronic Pain in Europe: Prevalence, Impact on Daily Life, and Treatment," *European Journal of Pain* 10, 4 (2006): 287–333; René Fejer, Kirsten Ohm Kyvik, and Jan Hartvigsen, "The Prevalence of Neck Pain in the World Population: A Systematic Critical Review of the Literature," *European Spine Journal* 15 (2006): 834–48; Inger Haukenes, Gunnel Hensing, Britt-Marie Stålnacke, Anne Hammarström, "Does Pain Severity Guide Selection to Multimodal Pain Rehabilitation across Gender?," *European Journal of Pain* 19, 6 (2015): 826–33; DaWana Stubbs, Erin Krebs, Matthew Bair, Teresa Damush, Jingwei Wu, Jason Sutherland, Kurt Kroenke, "Sex Differences in Pain and Pain-Related Disability among Primary Care Patients with Chronic Musculoskeletal Pain," *Pain Medicine* 11, 2 (2010): 232–39.

[6] Kelly M. Hoffman, Sophie Trawalter, Jordan R. Axt, M. Norman Oliver, "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 (2016): 4296–4301; Laura Kiesel, "Women and Pain: Disparities in Experience and Treatment," Harvard Health Blog, October 9, 2017, https://www.health.harvard.edu/blog/women-and-pain-disparities-in-experience-and-treatment-2017100912562, acc. April 24, 2023.

[7] Eva E. Johansson, Katarina Hamberg, Gerd Lindgren, Göran Westman, "'I've Been Crying My Way' – Qualitative Analysis of a Group of Female Patients' Consultation Experiences," *Family Practice* 13, 6 (1996): 498–503; Norma C. Ware, "Suffering and the Social Construction of Illness: The Delegitimation of Illness Experience in Chronic Fatigue Syndrome," *Medical Anthropology Quarterly* 6, 4 (1992): 347–61.

perceived.[8] Racial disparities in healthcare delivery in America are well-documented[9] and extend to inequities such as an underdiagnosis of chronic pain and inadequate pain management for people of color.[10] White women are more likely to have their pain experience believed by healthcare providers than minoritized ethnic women. These gendered and racialized inequities in pain assessment and treatment are known to lead to suboptimal pain management for Black women, resulting in increased morbidity and mortality compared to White women.[11]

Such population-specific health differences in the experience of pain according to intersecting identities of gender, race and ethnicity result from systemic sexism, racism, and implicit bias in the healthcare system that disadvantages these groups, leading to well-documented health inequities. To create equitable healthcare, it is crucial to prioritize patient-centered and culturally responsive care by recognizing and challenging the gendered and racialized dimensions of chronic pain experience and treatment.[12] It is important to empower patients and promote awareness and education among healthcare providers through community-engaged research, where those affected by the problems document their experiences. This level of engagement has been shown to improve the health and health behaviors of those populations in 87% of cases.[13]

Community-Based Participatory Research (CBPR), a community-engaged approach to research, aims to increase understanding of social and economic complexities by disrupting the typical unequal power dynamics between researchers and subjects to enable a more equal collaboration. Photovoice is based on the foundation of Participatory Action Research (PAR), which aims to bring about social transformation. The participatory research framework involves participants as active research partners and ensures the research is relevant to their needs.[14] In PAR, community members affected by the issues under study are responsible for identifying the research questions and designing the study. Researchers and participants engage in

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[8] Christopher L. Edwards, Roger B. Fillingim, and Francis Keefe, “Race, Ethnicity and Pain,” *Pain* 94, 2 (2001): 133–37.

[9] Charles S. Cleeland, Rene Gonin, Luis Baez, Patrick Loehrer, and Kishan J. Pandya “Pain and Treatment of Pain in Minority Patients with Cancer: The Eastern Cooperative Oncology Group Minority Outpatient Pain Study,” *Annals of Internal Medicine* 127, 9 (1997): 813–16.

[10] Hoffman et al., “Racial Bias in Pain Assessment and Treatment Recommendations”; Cleeland et al., “Pain and Treatment of Pain in Minority Patients with Cancer.”

[11] Carmen R. Green, S Ndao-Brumblay, and M Miller, “Disparities in Chronic Pain Management upon Initial Assessment to a Tertiary Care Pain Center,” *The Journal of Pain* 6, 3 (2005): S42.

[12] Amy M. Kilbourne, Galen Switzer, Kelly Hyman, Megan Crowley-Matoka, Michael J. Fine, “Advancing Health Disparities Research within the Health Care System: A Conceptual Framework,” *American Journal of Public Health* 96, 12 (2006): 2113–21.

[13] Sheila Cyril, Ben J. Smith, Alphia Possamai-Inesedy, Andre M. N. Renzaho, “Exploring the Role of Community Engagement in Improving the Health of Disadvantaged Populations: A Systematic Review,” *Global Health Action* 8, 1 (2015): 29842.

[14] Gary Yu Hin Lam, Emily Holden, Megan Fitzpatrick, Linda Raffaele Mendez, Karen Berkman, “‘Different but Connected’: Participatory Action Research Using Photovoice to Explore Well-Being in Autistic Young Adults,” *Autism* 24, 5 (2020): 1246–59.

collaborative learning throughout the research process, with the ultimate goal of reducing power imbalances and sharing decision-making.[15]

Feminist Creative Approaches to Meaning-Making and Advocacy in Healthcare

Photovoice employs feminist theory to acknowledge that women are authorities on issues that affect them.[16] In the 1960s-70s second-wave feminists purported that "the personal is political" which resulted in numerous groundbreaking creative works where artists advocated for change in healthcare for women. Still, feminism continued to marginalize Black women[17] simplistically separating race from gender. In 1980 Audre Lorde wrote "The Cancer Journal"[18] which combined journal extracts, poetry, and critical writing. The title of the second and longest chapter "Breast Cancer: A Black Lesbian Feminist Experience" takes an intersectional approach to documenting health inequities, describing how her race, gender, and sexuality meant she was not treated equally. Lorde powerfully describes nurses' bias; they ignored her and then invalidated her by trying to silence her calls of pain rather than listen and give her pain relief after her mastectomy. Both the breast surgeon and his team repeated verbal microaggressions as they tried to make Lorde conform to heteronormative patriarchal ideals and wear a breast prosthesis to 'enhance' her appearance and femininity, going as far as stating that "it's bad for the morale of the [breast surgeon's] office"[19] that Lorde arrived without a breast prosthesis. Lorde describes her autoethnographic and creative writing about mastectomy, culture, and pain as both healing and a form of advocacy, "I am writing this now in a new year, recalling, trying to piece together that chunk of my recent past, so that I, or anyone else in need or desire, can dip into it at will if necessary to find the ingredients with which to build a wider construct. That is an important function of the telling of experience."[20]

In the 1980s, just after Lorde's journal was published, the working-class British feminist artist-photographer Jo Spence used phototherapy to challenge normative and medicalized constructions of the female cancer patient. She documented her experiences with breast cancer via photographs and accompanying texts in a project titled "The Picture of Health?"[21], which challenged medicalized constructions of ill-

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[15] Robin McTaggart, Rhonda Nixon, and Stephen Kemmis, "Critical Participatory Action Research," *The Palgrave International Handbook of Action Research*, 2017, 21–35.

[16] Linda Liebenberg, "Thinking Critically About Photovoice: Achieving Empowerment and Social Change," *International Journal of Qualitative Methods* 17, 1 (December 1, 2018): 1609406918757631.

[17] Kimberle Crenshaw, "Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics," *University of Chicago Legal Forum* 1989, 1 (1989).

[18] Audre Lorde, *The Cancer Journals* (San Francisco: Aunt Lute, 1980).

[19] Ibid., 87.

[20] Ibid., 53.

[21] Jo Spence and Terry Dennett, *Putting Myself in the Picture: A Political, Personal and Photographic Autobiography* (London: Camden Press, 1986).

ness and advocated for a change in how women patients were objectified in medical settings. Throughout her career, Spence was a vocal advocate for using photography as a tool for social and political change. She believed that photography could be used to challenge dominant narratives and expose the injustices and inequalities of society.[22] Lorde's writing and Spence's artwork go beyond therapy and are tools for advocacy. Spence's work is now used by the UK's National Health Service (NHS) during training for doctors to "help students to refine their judgments in the visual domain. An examination of medical photography itself sheds light on how a medical gaze has been constructed and reveals tensions in the doctor-patient relationship, especially in terms of power."[23]

Photovoice Method

Increasingly, healthcare professionals are aware of the power of images like Spence's, and autoethnographic writing like Lorde's, to catalyze meaning making in medical pain encounters. As the lens-based media artist researcher Deborah Padfield writes of her collaborative and interdisciplinary practice work with patients and clinicians "images can strengthen agency in the person with pain, particularly but not only in the clinical setting, and can create a shared space within which to negotiate meaning. [...] the invisible experience of pain was made visible in the form of co-created photographic images, which were then made available to other patients as a resource to use in specialist consultations."[24] Research has shown that art can be highly effective in educating medical professionals, communicating with healthcare staff and for patients to feel more ownership of their treatment.[25] While Padfield co-created work with patients, patients who are active participants in the Photovoice method create both the images and texts.

Photovoice is an approach used in CBPR and involves providing cameras to individuals who are typically left out of decision-making processes so that they can present their perspectives and experiences and influence the focus of the research so that it reflects their concerns about their lives and communities (rather than focusing on concerns predetermined by researchers). This PAR method,[26] in which individuals photograph their everyday health and work realities, was first developed in the 1990s by Caroline Wang and Mary Ann Burris at the University of Michigan and has

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[22] Suzy Willson, "Essay: What Can the Arts Bring to Medical Training?" *The Lancet* 368 (December 1, 2006): S15–16.

[23] Ibid., 515.

[24] Padfield et al., "Images as Catalysts for Meaning-Making in Medical Pain Encounters," 74.

[25] Arts Council of England, *The Power of Art: Visual Arts: Evidence of Impact: Regeneration, Health, Education and Learning* (London: Arts Council England, 2006); Marijana Braš, Veljko Đorđević, and Mladen Janjanin, "Person-Centered Pain Management–Science and Art," *Croatian Medical Journal* 54, 3 (2013): 296.

[26] Sara Louise Kindon, Rachel Pain, and Mike Kesby, eds., *Participatory Action Research Approaches and Methods* (London: Taylor & Francis, 2007).

been widely used in health and social work settings.[27] The design of Photovoice treats individual participants as experts in their own lives, supporting them to use images (photographs) and their voices (in facilitated discussions and the form of short texts) to create image-text works to inform individuals and to advocate when organizations make decisions, strategies, and policies.

Photovoice has been used extensively with under-represented and vulnerable populations because it is "relatively unobtrusive and has the capacity to be empowering"[28]. Participants are recruited to engage with a particular topic and typically meet as a group for multiple weekly or bi-weekly sessions. In their first group meeting participants discuss the topic they were recruited for, then they co-create an initial, more specific prompt and take photographs in response to it as 'homework', individually responding to the prompt before the next group session. This first set of photographs forms the basis for group discussions and critical dialogue about the photographs and their meanings in the next meeting. Participants then each write short text narratives to accompany the photographs they have selected. Photovoice is often used in participatory research with marginalized communities, it empowers participants to document their own experiences, challenge dominant narratives, raise awareness of social inequalities, and promote social justice. Given that Photovoice projects have successfully drawn attention to issues that require change[29] we selected it as our method and modified it for online as the study took place during the pandemic. Input was sought from stakeholders about how to make the study accessible to women of color experiencing chronic pain.

The Study: Team and Collaborative Design Process

This study was approved in 2021 by the Institutional Review Board of the University of Michigan, Ann Arbor, MI, USA, HUM00166379, Study Title: Deepening Public Engagement with Chronic Pain Research: A Photovoice Project

A multidisciplinary advisory committee composed of eight specialists from various fields at the University of Michigan (UM): social work, pain research, psychology, art, design, and music, was formed in early 2019 to develop projects that use arts-informed creative approaches with participants to deepen knowledge about chronic pain and improve treatments and outcomes. Seven projects, funded by the Michigan Institute of Clinical Health Research (MICHR), emerged from this process including the study discussed here. The advisory group engaged in a collaborative design process led by two interdisciplinary researchers from UM: Dr Jane Prophet, an

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[27] Tamara A. Baker and Caroline C. Wang, "Photovoice: Use of a Participatory Action Research Method to Explore the Chronic Pain Experience in Older Adults," *Qualitative Health Research* 16, 10 (December 1, 2006): 1405–13; Caroline Wang and Mary Ann Burris, "Photovoice: Concept, Methodology, and Use for Participatory Needs Assessment," *Health Education & Behavior* 24, 3 (1997): 369–87.

[28] Alice Wilkin and Pranee Liamputtong, "The Photovoice Method: Researching the Experiences of Aboriginal Health Workers through Photographs," *Australian Journal of Primary Health* 16, 3 (2010): 231.

[29] Sarah E. Drew, Rony E. Duncan, and Susan M Sawyer, "Visual Storytelling: A Beneficial but Challenging Method for Health Research with Young People," *Qualitative Health Research* 20, 12 (2010): 1677–88.

artist from the Stamps School of Art and Design who collaborates with scientists[30] to create artworks that engage publics with science,[31] and Afton Hassett, PsyD, a clinical psychologist and pain researcher from the Department of Anesthesiology who examines cognitive,[32] affective,[33] and behavioral factors in chronic pain populations.[34] We altered the Photovoice facilitator team to be led by Dr Rahman, a woman of color, with extensive experience in CBPR[35] with a focus on improving the quality of patient care through the professional development of social and healthcare providers[36] and the relation between race/ethnicity and health.[37] Dr Prophet took the role of an assistant when the study was running. Both facilitators had experienced chronic pain at some point in their lives.

Participant Involvement in Study Design

A critical reflection on the Photovoice method urges researchers using Photovoice to find ways for communities to have a direct say in the study design.[38] Therefore, the research team worked with MICHR to run a two-hour interactive Engagement Studio (ES).[39] MICHR assembled a panel of nine stakeholders comprising women liv-

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[30] Jane Prophet and Mark d'Inverno, *Transdisciplinary Research in Cell*, (The MIT Press, 2006); Mark d'Inverno and Jane Prophet, "Designing Physical Artefacts from Computational Simulations and Building Computational Simulations of Physical Systems," in *Designing for the 21st Century Interdisciplinary Question and Insights*, ed. Tom Inns (Milton Park, Abingdon, Oxon; New York, NY: Routledge, 2007), 166–76.

[31] Jane Prophet, "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* (New York: Routledge, 2016), 482–503; Jane Prophet, Yong Ming Kow, and Mark Hurry, "Cultivating Environmental Awareness: Modeling Air Quality Data via Augmented Reality Miniature Trees," in *International Conference on Augmented Cognition* (Berlin and Heidelberg: Springer, 2018), 406–24.

[32] Afton L Hassett and Richard N Gevirtz, "Nonpharmacologic Treatment for Fibromyalgia: Patient Education, Cognitive-Behavioral Therapy, Relaxation Techniques, and Complementary and Alternative Medicine," *Rheumatic Disease Clinics* 35, 2 (2009): 393–407.

[33] Andrea L. Nicol, Christine B. Sieberg, Daniel J. Clauw, Afton L. Hassett, Stephanie E. Moser, Chad M. Brummett, "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 (2016): 1334–48.

[34] Afton L. Hassett, John D. Cone, Sondra J. Patella, Leonard H. Sigal, "The Role of Catastrophizing in the Pain and Depression of Women with Fibromyalgia Syndrome," *Arthritis & Rheumatism: Official Journal of the American College of Rheumatology* 43, 11 (2000): 2493–2500.

[35] Rahbel Rahman, Elizabeth B. Matthews, Alizeh Ahmad, Syeda Mahnoor Rizvi, Umme Salama, Lubna Samad, and Mansoor Khan, "Perceptions of Patient-centred Care among Providers and Patients in the Orthopaedic Department of a Tertiary Care Hospital in Karachi, Pakistan," *Journal of Evaluation in Clinical Practice* 25, 5 (2019): 1160–68.

[36] Rahbel Rahman, Rogério M Pinto, and Melanie M Wall. "HIV Education and Welfare Services in Primary Care: An Empirical Model of Integration in Brazil's Unified Health System," *International Journal of Environmental Research and Public Health* 14, 3 (2017): 294.

[37] Rahbel Rahman, Sameena Azhar, Laura J. Wernick, Debbie Huang, Tina Maschi, Cassidy Rosenblatt, and Rupal Patel. "COVID-19 Stigma and Depression across Race, Ethnicity and Residence," *Social Work in Health Care* 62, 2–4 (2023): 1–22.

[38] Liebenberg, "Thinking Critically About Photovoice," 2.

[39] "Community Engagement Studios," MICHR, https://michr.umich.edu/rdc/community-engagement-studios, acc. April 25, 2023.

ing with chronic pain via UM's Office of Patient Engagement from their pool of patient advisors. Each stakeholder was compensated with a $20 gift card and provided a light meal immediately after the session. The nine stakeholders were actively engaged in providing input and feedback on the research project's design: the informed consent development and the consent process; the incentives for research participation; the participant recruitment processes; how to develop culturally and linguistically appropriate study materials; understanding and interpreting research results; and sharing research results with the community. Dr Prophet briefly introduced her team and the proposed study to investigate the experience of chronic pain with a focus on gender and racial inequities. The research team were then directed to be active listeners and to answer questions, and the MICHR facilitator led a discussion with the participants.

One stakeholder suggested holding Photovoice sessions remotely as it could increase participation for those living with chronic pain, allowing them to join from their homes without the added difficulty of travel. Others emphasized the importance of physical comfort and the range of supports necessary to reduce attrition. Given the individualized nature of pain, the researchers were recommended to ask participants their preferred seating options during recruitment to ensure these supports were in place for future sessions. During a wider discussion, stakeholders expressed concerns about the physical limitations and exhaustion participants living with chronic pain were likely to feel and recommended alternative ways of attending, such as using Skype, for those unable to attend in person. While in-person attendance is ideal for the interactive group component[40] and conforms to the Photovoice protocol, the team recognized the reality of participants' needs. Coincidentally, the COVID-19 pandemic made it impossible to collect data in the traditional form.

The group reached a consensus that evenings or weekends were the optimal times for sessions, as early mornings were not ideal for this population. The stakeholders also discussed compensation for study participants and caregivers if caregivers were needed for a participant to attend. A level was set at $50/session to account for attending a one-on-one induction session, six sessions, and the time spent between sessions for a total of $350/participant. While there was consensus about compensating caregivers and participants, stakeholders also alerted the team to the challenges of caregivers being in attendance. One explained that she would be uncomfortable if her caregivers were present during sessions because she tries to shelter her caregivers from the pain that she endures, and if they were there, she felt that she could not be truthful.

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[40] David B. Nicholas, Lucy Lach, Gillian King, Marjorie Scott, Katherine Boydell, Bonita J. Sawatzky, Joe Reisman, Erika Schippel, Nancy L. Young, "Contrasting Internet and Face-to-Face Focus Groups for Children with Chronic Health Conditions: Outcomes and Participant Experiences," *International Journal of Qualitative Methods* 9, 1 (2010): 105–21.

The Structure of Asynchronous Materials and Sessions

COVID-19 and insight from stakeholders prompted us to deliver the study virtually using a hybrid synchronous/asynchronous model. The virtual delivery of this Photovoice project has been described elsewhere (*Rahman et al., forthcoming*). Brief videos introduced Photovoice, capturing and analyzing images, and various dissemination methods were provided asynchronously. The Photovoice principle of making research more accessible and equitable and promoting active engagement between researchers and participants guided the production of these captioned asynchronous videos. We also modified the Photovoice method to incorporate more arts-informed approaches, for example via our four-minute video entitled "The Art of Photography". This video, produced by Dr Prophet drew on her experience as an artist-professor and explored the meanings viewers can derive from a photograph. Specifically, the videos examined how the viewer's emotional response to a photograph can be influenced by perspective, angle, and lighting. We provided practical demonstrations of techniques such as lighting scenes using everyday household items like torches and table lamps and how camera angles, background colors, steam, and shadows can create different moods and meanings. This is not typically part of Photovoice sessions. We provided videos that included brief introductions to theories of representation and visual analysis of photography, concepts familiar to photography undergraduates[41] but not often explored in Photovoice sessions.

Synchronous Sessions

The live synchronous sessions were jointly remotely facilitated via our two institutions – Jane Prophet via the University of Michigan and Rahbel Rahman via Fordham University. No participants chose to request that caregivers attend the sessions. During these sessions, participants shared emotions, discussed photographs, explained image choices, participated in the collective analysis of their images and texts, and explored dissemination methods before deciding what forms of dissemination they wished to use. We used participatory visual analysis, pioneered by Wang and Burris[42] through which participants select and group together "photographs that most accurately reflect community needs and assets", they bring texts in to accompany the photographs "telling stories about what the photographs mean", and then codify the "issues, themes, or theories that emerge"[43]. We used the SHOWeD (What do you ***s***ee here? What is really ***h***appening here? How does this relate to ***o***ur lives? ***W***hy does this problem, concern, or strength exist? What can we ***d***o about it?)[44] and Objective,

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[41] Victor Burgin, ed., *Thinking Photography* (London: Macmillan Education, 1982).

[42] Wang and Burris, "Photovoice: Concept, Methodology, and Use for Participatory Needs Assessment."

[43] Ibid., 87.

[44] Caroline C. Wang and Cheri A Pies, "Family, Maternal, and Child Health through Photovoice," *Maternal and Child Health Journal* 8 (2004): 95–102.

Reflective, Interpretive, Decisional (ORID)[45] methods to prompt group discussions. SHOWeD focused on the photograph's content, such as what do you see, what is happening in this picture, how does it relate to your lives, why does this condition exist, what can be done about it? ORID prompts focus on the process of taking the picture, such as how many pictures did you take; how did it feel while taking the pictures. Dr Rahman was the lead facilitator of most sessions. Being a woman of color and having experienced chronic pain, a shared experience and identity of the focus group facilitator(s) with participants, offers an opportunity for authentic sharing among focus group participants.[46] In Session 3, Dr Rahman introduced the session, and then Dr Prophet facilitated the participants' discussion of the images they had selected.

Photovoice studies typically provide instructions for camera use and cameras, most commonly disposable film-loaded cameras but increasingly digital cameras.[47] Recently, the Photovoice method has been adapted so that participants use smartphones and social media.[48] We modified our method to use smartphones because they have become ubiquitous. We had digital cameras available, but only one participant used a camera. We gathered data in four distinct categories: visual data (participants' photographs); text-based data (captions provided by participants, the Zoom chat threads, and participants' reflections on their experience of the study submitted in week 5); video data (recordings of the synchronous discussions in Zoom that were later transcribed word for word); and survey data.

Findings

Participants in our study had the opportunity to consider how photography functions as a medium of representation and communication in contemporary society. In arts research and creative production, photographs are often analyzed as data. Given the importance of images to the Photovoice method it is surprising that associated literature focusing on textual analysis of Photovoice photographs is rare[49] and that adding introductions to textual analysis and art-informed photography is not a central part of more studies. Given that the power of images that are aesthetically pleasing and/or produced by creative professionals trained in visual culture and

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[45] Keneth H. Elison, *Technology of Participation (TOP): Basic Group Facilitation Methods Manual* (Manila, Philippines: ARD/Gold, 1997).

[46] Katrina L. Rodriguez, Jana L. Schwartz, Maria K. E. Lahman, Monica R. Geist, "Culturally Responsive Focus Groups: Reframing the Research Experience to Focus on Participants," *International Journal of Qualitative Methods* 10, 4 (2011): 400–417.

[47] Kenneth C. Hergenrather, Scott D. Rhodes, Chris A. Cowan, Gerta Bardhoshi, Sara Pula, "Photovoice as Community-Based Participatory Research: A Qualitative Review," *American Journal of Health Behavior* 33, 6 (2009): 686–98.

[48] Kirk A. Foster, Brittany Davis, and Andrew Foell, "Innovations to Photovoice: Using Smartphones & Social Media," *Urban Affairs Review* (2022): 10780874221100264.

[49] Moshoula Capous-Desyllas and Nicole F Bromfield, "Using an Arts-Informed Eclectic Approach to Photovoice Data Analysis," *International Journal of Qualitative Methods* 17, 1 (2018): 1609406917752189.

representation can accelerate or undermine inequalities,[50] as evidenced by artists' and photographers' role in producing propaganda[51] it is also notable that Photovoice does not usually aim to increase participants' skills as photographers.

In the discussion below pseudonyms are those requested by participants. The texts they wrote as part of the Photovoice image-text combinations they created are reproduced in full when shown with their partner photograph. Participants discussed how the color, composition, framing, and context of their photographs helped shape meaning. They intentionally used this awareness as they shot images and to help them select photographs. Discussions of the use of color revealed that several participants had contrasted color against a monotone background to express their experience of chronic pain: "what this picture signified is the butterfly is very vivid in this photo, and then the background is pretty dull in color, and so it reminded me that even when I have moments of pain [...] there's always bright spots." (Grace Lee)

For others color took on a different symbolism: "I saw that bluish hue when I was looking at myself on the Zoom conference [...] it's like I got the blues, it's Monday. I'm in pain, I'm trying to participate in this, but it's hard [...] If I had to put a color to my pain it's black and blue because I'm bruised [...] For me, pain is a color. [...] If I had to make my pain and give it an image, an embodiment, it would be the color blue [...] I had a, you know, the face of pain, I had the color of pain, and that was one of the things that stuck out to me, and the face is not necessarily a face as much as it is an image being reflected out." (Ms. Monica). The second part of this quote also draws attention to the participant's understanding that self-portrait photography is not simply representation: "the face is not necessarily a face as much as it is an image being reflected out". (Ms. Monica)

In the group discussion, participants noted how many of them had chosen objects to symbolize their experience of chronic pain. "A lot of people [...] took pictures that were [...] symbolic of their pain" (DK). This is evident in the discussion of GG's photograph of a pool ball: "I took a picture of the 8 ball like by itself in the pocket because the 8 ball is like the unlucky ball in pool or at the end it's like what you use to win, so I thought [...] the 8 ball just sitting by itself in the cup was just a representation to me of like my journey [...] some days it feels really, really bad, but there are also days that are really, really good. And I also liked how the cup for the pool where the ball is sitting [...] it looks kind of like trapped." (GG). Another participant noted that symbolic meaning is not universal but contingent and influenced by what each viewer brings to their interpretation: "You know, sometimes the 8 ball is an awful thing to have and then at the end it's a great thing to get it right in the pocket. So, some days are perfect. And some days are just downright horrible." (LD).

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[50] David Freedberg, *The Power of Images: Studies in the History and Theory of Response* (Chicago: University of Chicago Press, 2013); Norman Bryson, Michael Ann Holly, and Keith Moxey, *Visual Culture: Images and Interpretations* (Middletown: Wesleyan University Press, 1994).

[51] Robert Jackall and Janice M Hirota, *Image Makers: Advertising, Public Relations, and the Ethos of Advocacy* (Chicago: University of Chicago Press, 2000).

Participants reported an increased understanding that the meaning of a photograph and that what it symbolizes is not fixed but emerges from the viewer's interpretation and is influenced by the social and cultural context in which the image is presented. The Photovoice process led to a greater understanding of how interpretation can be directed by adding captions: "She saw the 8 ball as trapped. I found it to be a beautiful lattice with this beautiful thing in the middle [...] I have my own reactions to the pictures – then I would read what people wrote about them." (DS).

After the image-text pairings were shared, participants drew attention to the impact of the text on interpretation: "Another member showed a photo reflection of herself through a magnifying mirror. I thought that was cute and unique. Never thought about the pain she must feel. [...] I was able to connect meaning because of discussions we have had." (LP). Participants gained a deeper understanding of the way that text, or captions, can direct the meaning made of images: "Here are some pictures that initially upon looking at them you wouldn't know that there's some connection to chronic pain. But after reading the commentary, you can make that connection quite easily." (Sarah).

The reflection homework in week 5 yielded some noteworthy insights into the Photovoice process. Participants commented on the importance of involvement in the analysis process: "We were extremely active in the process. We provided the data but also analyzed it as a group, which is not super common." (DK). Participants indicated that Photovoice facilitated dialogue using photos and by sharing how pain affected their daily lives. Three participants observed that art forms such as photography are better suited to capturing things that are difficult to talk about from people's everyday lives: "Telling stories through photos was such a different concept but I think allowed me to open up in a way that I haven't been able to before" (GG). It was also noted that the facilitated discussion about photographs created space for new sorts of conversations about their experience of chronic pain: "Some of the things I tried to portray in my photos were things that I have never really had the chance to speak about with others." (DK). Another participant noted that using photographs to tell their stories allowed them to be honest and gain a newfound respect for themselves and others living with chronic pain.

Participants expressed a strong sense of belonging and a culture of care within the group: "It's like this is the only place people see my real pain face, […] I felt very safe in this Zoom room where I could just kind of let my you know true pain self-show [...] as a woman and woman of color [...] I have the pressure of always [...] having to be a strong person [...] We're just expected to just grin and bear it." (Ms. Monica). The shared experience of chronic pain became more apparent as participants sorted their images into categories: "The different photos within the same category offered multiple perspectives [...] often when we experience pain, we kind of tend to think how it's affecting us and how our lives are affected, but just everyone else sharing their experiences helps build perspective." (Grace Lee). Realizing that they shared experiences was a key part of the support they received from one another, which improved their mental well-being, facilitated the sharing of remedies and adaptations for managing pain, and empowered them to schedule appointments with doctors and ask more questions.

Photovoice participants not only create images and texts individually, but they also then reduce them in number and sort them, through discussion, into categories that they define as a group, curating them to share publicly. Participants commented on the quality of their own images as they selected them, using language from the arts-informed videos and facilitated discussion, referring to framing, cropping, camera angle, and perspective. One participant commented that "The creativity of my colleagues was outstanding; I'm the art history visual culture professional [...] I'm used to thinking visually [...] I mean the shadow pictures, the 8 ball [...] they're just gorgeous [...] I've looked at a lot of art in the last 14 years [...] I am definitely in this mode of, you know, thinking critically about visual culture and visuality and this is just good [...] you guys have produced is like museum quality stuff." (DS) There is no doubt that in museum curation images are selected for aesthetic value. However, there has been a move away from affirming images and presentations and towards the curation of 'difficult knowledge'.[52] This often addresses trauma but does not necessarily explicitly show trauma to express it. The objective of curating exhibitions of difficult knowledge is to prompt viewers to feel empathy.[53] By making thoughts affective, the intention is to cause social change by triggering "ethical responsibility rooted in the physical response to the suffering of another."[54] Viewers experience 'empathic unsettlement', by bearing witness to trauma, in the case of this Photovoice study, chronic pain, by putting themselves "in the other's position while recognizing the difference of that position"[55]

This is "the aesthetic experience of simultaneously feeling for another and becoming aware of a distinction between one's own perceptions and the experience of the other."[56] Participants wanted to use their image-text to cause empathic unsettlement in order to advocate for employers to provide better support for employees living with chronic pain by making visible the hidden scale of the problem. "Everybody knows about the Americans with Disabilities Act [...] But much of what we discussed is invisible and there aren't a lot of accommodations that are made for the many who may be suffering invisible pain [...] I think [employers] need to be educated that the [...] people that they, you know, have provided, you know, physical accommodations for are just a fraction of the people who are in need of accommodations of some sort." (Jan)

Artists have long been engaged with political and social issues and have been vital members of grass-roots movements, using their work to advocate for and effect change.[57] Engagement with, and creation of, art has been shown to benefit health

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[52] Roger I. Simon, "A Shock to Thought: Curatorial Judgment and the Public Exhibition of 'Difficult Knowledge,'" *Memory Studies* 4, 4 (2011): 432–49.

[53] Jill Bennett, *Empathic Vision: Affect, Trauma, and Contemporary Art* (Stanford: Stanford University Press, 2005).

[54] Simon, "A Shock to Thought: Curatorial Judgment and the Public Exhibition of 'Difficult Knowledge,'" 435.

[55] Dominick LaCapra, *Writing History, Writing Trauma* (Baltimore: Johns Hopkins University Press, 2014), 78.

[56] Bennett, *Empathic Vision*, 8.

[57] Claudia Mesch, *Art and Politics: A Small History of Art for Social Change since 1945* (London: Bloomsbury Publishing, 2014).

outcomes[58] and improve healthcare delivery and policy.[59] Social art, created to effect change, can "create positive changes in society and [...] artists are often unusually well-placed to highlight and challenge unjust systems that continue to exclude too many people."[60] Much social art, including that which advocates for policy change, involves community participants at the ideation stage who are not professional artists or is co-created with non-professional artist participants. By contrast, professional artists rarely facilitate Photovoice, which is not classified as an art-making method. In Photovoice all the images and texts are created by the participants, some of whom may coincidentally be artists, but if so, this is usually not specified in reports. Our arts-informed modifications to Photovoice did not dilute its use as a tool for advocacy and in the final group sessions, participants felt empowered to engage in community dialogues and change public perceptions about chronic pain. Both groups felt that sharing their work as a PDF booklet that could be emailed to many people was their preferred way to raise awareness. As well as directing the PDF and advocacy towards employers and healthcare practitioners, another community that participants thought about as they curated their materials was other people living with chronic pain. "I see these influencing patients who are dealing with pain as an ongoing issue, showing them a positive image [...] that they can still lead a productive life while still dealing with the pain." (Romona)

Conclusions

An arts-informed modification of Photovoice by adding asynchronous videos that introduce i) art-based practices such as how to light objects, frame scenes, and use color internationally, and ii) art-based and photography theories about how we 'read' images and image-text works does not over-burden participants. The artistic quality of the resulting images is rewarding for participants who feel a sense of pride in their works. Referring to arts-informed frameworks can lead to the production or selection of more powerful images. A facilitated discussion that includes art-informed frameworks does not detract from the participants' core focus; on the contrary, it can lead to further insights and result in more powerful images that enhance advocacy. Revealing the processes that researchers use to categorize data, including images, enables participants to better understand research. These modifications help participants advocate for health equity, a hallmark of social justice in healthcare, more effectively. It was effective to approach this as a process of 'curation' of image-text works, arranged and disseminated in forms designed for particular audiences.

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[58] Daisy Fancourt and Saoirse Finn, *What Is the Evidence on the Role of the Arts in Improving Health and Well-Being? A Scoping Review* (World Health Organization, Regional Office for Europe, 2019).

[59] Rosie Dow, Katey Warran, Pilar Letrondo, Daisy Fancourt, "The Arts in Public Health Policy: Progress and Opportunities," *The Lancet Public Health* 8, 2 (2023): e155–60.

[60] Lucy Wright, "Social Works? Journals Are like Buses. You Wait for Years for a New One to Be Published and Then Two Come along in Just over 12 Months.," ed. Lucy Wright and R. M. Sanchez-Camus, *Social Works? EDI* 3 (Spring 2023): 3, https://www.axisweb.org/article/social-works-edi-issue-3-spring-2023/, acc. September 5, 2023

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Figure 1. "I came across this butterfly while hiking with my dog. I initially observed it from a distance, wondering if it was in distress as it flapped its wings slowly. A nearby gentleman informed me that the butterfly's behavior was normal and sure enough, moments later, it gracefully flew away. I later learned that butterflies lack pain receptors and therefore do not feel pain. Despite its small size, I appreciated its rich colors and intricate detail. The butterfly's vibrance in contrast with the surrounding dullness was something I would categorize as being a 'bright spot' amidst pain." (Grace Lee). *Reproduced with permission.*

Figure 2. "Me and my dad, we play a lot of pool. On my good days me and my dad play pool, and I just really like our pool table, but I took a picture of the 8 ball by itself in the pocket because the 8 ball is like the unlucky ball in pool, or at the end it's like what you use to win. So, I thought, to me, the eight ball just sitting by itself in the cup was just a representation to me of my journey where some days it feels really, really bad, but there are also days that are really, really good. And I also liked how the cup for the pool where the ball is sitting looks trapped. But it's just kind of how you view it – it's the 8 ball by itself in the cup, but again, it could be something you see as discouraging or something that could be used for winning." (GG). *Reproduced with permission.*

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