

## Arts-Based Research in Health Care

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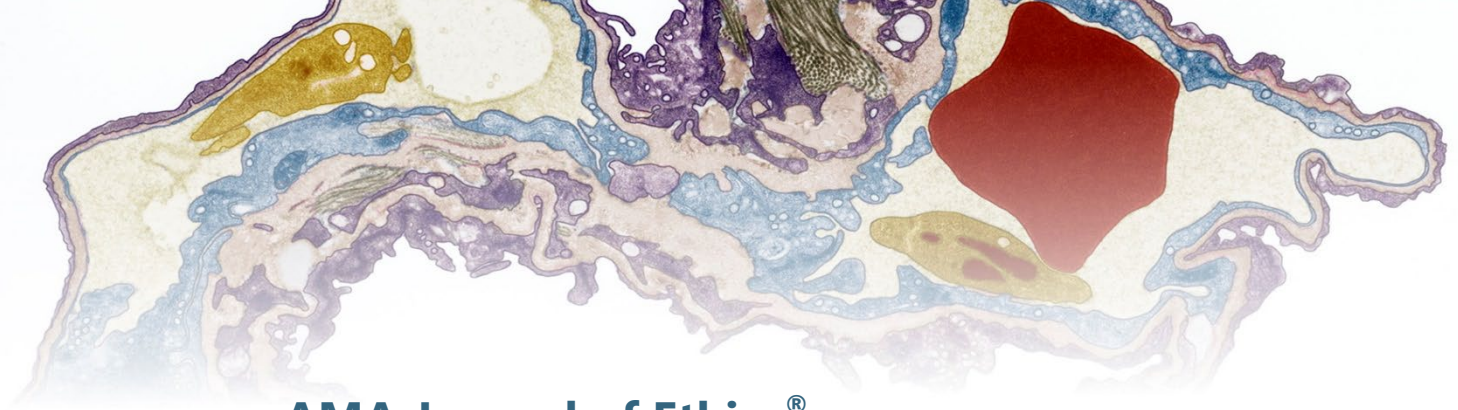
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## AMA Journal of Ethics®

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### FROM THE EDITOR

#### Arts-Based Research and Health Care

Mark Gilbert, PhD

Artistic or aesthetic ways of knowing have been embraced in many different cultures as forms of healing.<sup>1,2</sup> In health care and health professions education, there is increasing interest in the role of arts-based research or integrating the arts into a variety of clinical and community settings for therapeutic, educational, and expressive purposes.<sup>3,4</sup>

Arts-based researchers recognize that nondiscursive methods of inquiry (eg, pictures, music, dance, poetry) can, in their creation, be forms of research. The arts have the potential to generate statements and insights that cannot be expressed, documented, or shared in other forms.<sup>5,6</sup> They can provide a compelling means of engagement for multiple audiences, as they are capable of reframing our perspective and stimulating fresh thinking, dialogue, and connections. As such, the arts open spaces to challenge assumptions and call us to reconsider relationships and interactions that are fundamental in health care, research, and education.<sup>7</sup>

As an arts-based researcher and teacher, I have collaborated with caregivers, patients, and educators on numerous studies, including Portraits of Care at the University of Nebraska Medical Center (2006-2008).<sup>8</sup> Each of these projects explicitly draws on art forms' capacity to communicate relational, ethical, spiritual, and cultural aspects of medicine and care.<sup>9,10</sup> My initial skepticism about art having healing power was fueled by my ideas about art therapy, which I felt was not applicable to my remit or aims. However, my resistance diminished as I witnessed the **benefits experienced** by people whom I was privileged to work with and portray. Their responses to their portraits and the act of sitting deepened my understandings of art's potential function as a catalyst for connection and storytelling. The process of creating and engaging with art in research develops space for open communication, creativity, and imagination. It demands that we consider the relationships among the researcher, the researched, and the audience who engages with the resultant aesthetic forms. These relationships are themselves creative endeavors that parallel salient aspects of clinical interactions. The articles collected here invite us to further consider (1) the quality of the relationships between those who give and those who receive care; (2) how patients relate to their own illness; (3) the relationships we each have with our own self when we or loved ones fall ill; and (4) the relationships we have to **the challenges and life events** that we embrace and also resist.

This special issue of the *AMA Journal of Ethics* presents myriad ways that artistic expression as a primary mode of inquiry can be used to nurture an inspiring medical



education wherein creativity is embraced and can flourish.<sup>11</sup> The clinicians, educators, artists, researchers, and students who contributed to this issue make clear how much health professionals and students can learn from engaging with artistic ways of knowing. Moreover, they testify to how the arts can be enriched and informed by health care. My experience of working in clinical contexts has taught me more about communication and silence. We hope this special issue creates opportunities for readers to witness the relationships and interactions fundamental to medicine and to grasp the profound challenges and abundant rewards that await all who engage in arts-based research in clinical, public health, and community contexts.

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**CASE AND COMMENTARY: PEER-REVIEWED ARTICLE**

**Is a Video Worth a Thousand Words?**

Laura Kolbe, MD, MPhil, Ryan H. Nelson, PhD, Joelle Robertson-Preidler, PhD, Olivia Schuman, PhD, and Inmaculada de Melo-Martín, PhD, MS

**Abstract**

Bodily imagery elicits strong affective responses and is highly salient, potentially altering viewers' decision making. When clinicians engage surrogates in video calls showing the patient's body, several competing ethical issues must be considered. On the one hand, surrogates may require visual information to make informed decisions, and video technology closes crucial information gaps. On the other, video technology puts an increased amount of control in the hands of clinicians over how the patient's condition is perceived. This article explores some situations that can result in manipulation due to the affective impact of bodily images and the potential for selectivity and framing. Focusing on goals of care, the paper outlines the foremost ethical considerations for clinicians and provides recommendations for clinicians on how to reduce possible manipulation when making these video calls.

**Case**

Ms K is an 80-year-old woman initially hospitalized with sepsis. Multiple hospital setbacks include kidney injury, aspiration, and heart failure. She has been hospitalized for a month, with evidence of deconditioning, malnourishment, pressure injuries, anasarca, and delirium.

While previously cognitively unimpaired, she now fluctuates between agitation and somnolence. According to her family, she never discussed her critical illness or end-of-life care preferences. They consider her a “fighter” and therefore feel uncomfortable pursuing a palliative approach. Because of COVID-related visitor restrictions, they have not seen her in person. Her clinicians think she is unlikely to survive hospitalization. If she declines further, next steps could include a percutaneous endoscopic gastrostomy tube, hemodialysis, and intensive care unit (ICU) transfer. Thinking it best for the patient, her clinicians believe that Ms K's family should opt to stop aggressive treatments and focus on comfort, although family meetings have not produced this change.

Ms K's attending physician, Dr B, has told the team that one way to “change her family's mind” would be to increase video calls to the family during times when Ms K appears

uncomfortable or distressed and during activities such as wound care, so that the family “gets it” that Ms K is “in horrible shape.” Dr B advises against video calling the family when Ms K is asleep or relaxed, since “it paints too rosy a picture,” and “they’ll just cling to unreasonable hope.”

A resident feels uncomfortable but also thinks that knowledge is power and that providing this information can’t be wrong if it results in less suffering for the patient.

### Commentary

Clinician-initiated video calls to show surrogates aspects of the patient’s body raise ethical concerns about manipulation. Visual information may improve informed decision making by conveying additional nuance lacking in verbal communication. However, because of the **salience of bodily imagery** and its affective impact on viewers, as well as the special potential for clinician selectivity and framing, video calls can be manipulative. Here we discuss how manipulation can occur and offer some recommendations so that clinicians can reduce that possibility.

### Manipulation in Health Care Decisions

Informed consent, which is considered the **primary means of respecting autonomy** in clinical medicine, requires freedom of choice. Yet choosing freely cannot mean choosing absent any outside influence, since good decision making often demands others’ input. What forms of influence are acceptable? While coercion undermines autonomous decision making and rational persuasion is compatible with it, a range exists between these extremes involving varying degrees of manipulation. Generally speaking, A manipulates B when A intentionally subverts B’s rational capacity by employing trickery, deception, pressure, or a similar tactic to get B to do what A wants.<sup>1</sup>

Viewed through the lens of autonomy, manipulation is *prima facie* wrong—that is, manipulation has the morally bad feature of failing to respect autonomy and therefore should generally be avoided. It follows that clinicians ought to refrain from manipulating patients or surrogates in the absence of (sufficiently strong) countervailing ethical considerations. Whether a given act of manipulation is justified, all things considered, will depend on the particulars of the case. But the fact that an act or practice is *potentially* manipulative is enough to warrant scrutiny.

Dr B’s actions are arguably manipulative in 2 ways. First, Dr B proposes to share images via video call that support his favored outcome and to withhold images that might lead Ms K’s family to make decisions contrary to it—which involves a kind of trickery. By focusing on decisional outcome rather than the decision-making process, Dr B appears less concerned about providing information than about guiding Ms K’s family **towards a particular decision** that Dr B favors. Second, Dr B appears to be aware that the video calls, especially when timed and framed in a certain manner, are likely to have a special affective impact on Ms K’s family—which suggests a kind of pressure. Provoking family members’ strong affective responses, such as disgust and fear, risks undermining their rational deliberation rather than promoting it.

In the following sections, we consider video visits’ affective impact and selectivity in greater detail and argue that showing a patient’s body over video calls can manipulate surrogate decision makers. Potential for manipulation escalates in busy, stressful conditions that can limit clinicians’ abilities to evaluate specific features of a situation. While manipulation can certainly be present in traditional in-person visitation, already-

accepted standards of care help mitigate that outcome. However, the rapid rise in video communication and visitation may leave clinicians feeling particularly unprepared to manage these encounters ethically.

### **Relevance of Visual Information**

Visual information, particularly from observation of the body and about effects on the body, can be crucial for surrogates' ability to make decisions, especially when other sources of information are absent or unavailable. Whenever possible, surrogates' decisions should reflect a patient's values and preferences. To achieve this goal, clinicians should provide information about the patient's condition and prognosis so that surrogates can make a substituted judgment.

However, surrogates may lack knowledge of a patient's values and preferences or of how these accord with treatment options.<sup>2</sup> Additionally, factors other than medical information—eg, surrogates' beliefs about the patient's strength of character or their own observations of the patient's physical appearance—influence surrogates' understandings of prognosis.<sup>3,4,5</sup> Unconscious bias can also lead surrogates to underestimate pain, overestimate the patient's acceptance of risk,<sup>6,7</sup> choose options that require less knowledge,<sup>2</sup> or accept default options to reduce feelings of responsibility.<sup>8</sup> Consequently, patient-surrogate agreement on medical decisions is generally poor,<sup>9,10,11</sup> suggesting that new or additional modes of information might be valuable in improving concordance.

The case of Ms K illustrates the different views health care teams and families may have about a patient's interests. The family members' perception of the patient as a fighter and their inability to observe her deteriorating condition may hinder their appreciation of her prognosis. To circumvent these issues and ensure that decisions are truly informed, surrogates may require additional visual information. Absent in-person visitation, or when bedside visits are challenging to arrange, video calls can bridge this gap. In fact, audiovisual resources have been shown to improve informed decisions about cardiopulmonary resuscitation<sup>12</sup> and ICU procedures.<sup>13</sup>

### **Affective Responses to Bodily Imagery**

Although visual information can be helpful in decision making, how this visual information is provided has ethical relevance because of the salience and affective impact of such information. Bodily imagery, in particular, has been employed to discourage various health-related choices, including by placing warnings in the form of images of rotting teeth and blackened lungs on cigarette packages to decrease smoking<sup>14</sup> and requiring the viewing of fetal ultrasound images with the intent of reducing abortions.<sup>15</sup> Such strategies assume not only that there is a preferable choice but also that images are more compelling than other forms of persuasion, such as written or verbal communication.

This last assumption is supported by various types of evidence. Theories of visual attention recognize the salience of human images, ie, the degree to which the viewed object stands out from surroundings and attracts attention.<sup>16</sup> Human body postures, particularly when in motion rather than still, and when combined with emotional facial expressions, are especially salient to human observers.<sup>17</sup> Indeed, humans struggle with tasks that require looking away from images of other humans to focus on other kinds of information.<sup>18,19</sup> Neuroscience research reveals that there are biological underpinnings to our affective and empathic responses when viewing human pain or suffering.<sup>20</sup> Mirror

neurons become active both when individuals experience or perform a certain action and when they observe another person performing or responding to a similar act—suggesting that, from a functional standpoint, the brain processes experiences involving the self and the visually observed experiences of others similarly.<sup>20</sup> Viewing another’s body in pain activates brain areas that overlap considerably with those involved in perceiving one’s own pain,<sup>21</sup> as does viewing another person’s facial expressions.<sup>22</sup>

**Framing Images of a Patient’s Body**

The visual information in a video call has particular ethical relevance because of the degree of control that clinicians wield. Health care professionals serve as crucial intermediaries between patients and their surrogate decision makers, particularly when bedside visitation is limited and patients cannot communicate. Yet, unlike bedside visits, video calls enable clinicians to have greater control over viewing interpretations by determining when a video is used, what part of the patient’s body is visible or hidden, the incorporation or exclusion of surroundings, and the narrative that accompanies the visual transmission. As such, video calls have unique features that make it easy for them to be used in manipulative ways. A typical bedside visit, lasting several hours and involving interactions with several staff members, is a very different experience from a quick 10-minute video call that contains little contextual data and is restricted in its capacity for engagement. In addition, viewers exercise limited control over the interactive experience. Although visual imagery can activate emotion-driven decision making, visual imagery is not, as we have said, necessarily incompatible with good decision making.<sup>12,13</sup> Yet, in many cases, the control that the clinician exercises over how or when the body is shown is manipulative because a patient’s body is used as a means to the clinician’s preferred decisional outcome. In Ms K’s case, the clinical team believed her best interests were disregarded by her surrogates. However, the team’s proposed deployment of video calls was problematically selective and outcome driven. It failed to be transparent about the team’s motivation in initiating video calls and about the particular affective salience that viewing Ms K’s body might have on her family.

To avoid manipulation, we recommend that clinicians consider the following guidelines (see Table) when contemplating video calls to show the patient’s body in the context of surrogate decision making. Our practical recommendations are process focused, not outcome focused. As such, the team may never achieve the outcome that it believes is “best” for the patient, but these recommendations will help ensure that clinicians focus on upholding and promoting surrogates’ informed decision making, while avoiding some of the unique risks of video-call use.

Table. How to Avoid Manipulation in Video Calls for Surrogate Decision Making
<i>Normalization.</i> Clinicians and hospitals should standardize the use of video calls so that they provide many of the same benefits as in-person visitation. That is, video calls should be used on a regular basis in ethically uncomplicated decision making for patients who are not critically ill, as well as to support the psychosocial needs of patients and families in high-stakes, goals-of-care decision making.
<i>Process.</i> Clinicians should primarily use video calls to inform rather than influence a decision, with a focus on the process of informed decision making rather than outcome.



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*Patient assent.* Clinicians should obtain patient assent when possible and, when known, patients' wishes about displaying their bodies via video call or displaying particular wounds or bodily areas should be respected.

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*Transparency.* Clinicians should be transparent about the purpose of showing certain features of the body (eg, "We are very concerned about your loved one's wound and want to show you, so you understand its severity.") Clinicians should also be transparent about the salience and affective impact of bodily imagery (eg, "Seeing a loved one in a state of illness or suffering is an intense experience and weighs heavily on people's minds. We want to make sure it's one part of a well-rounded decision-making process for you.")

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*Substituted judgment.* Clinicians should explain how viewing the patient's body promotes substituted judgment in line with the patient's preferences.

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*Selectivity and framing.* Clinicians should reflect on the selective use and the framing of video visits, including their choice of narrative detail and the compositional arrangement of the images of the body.

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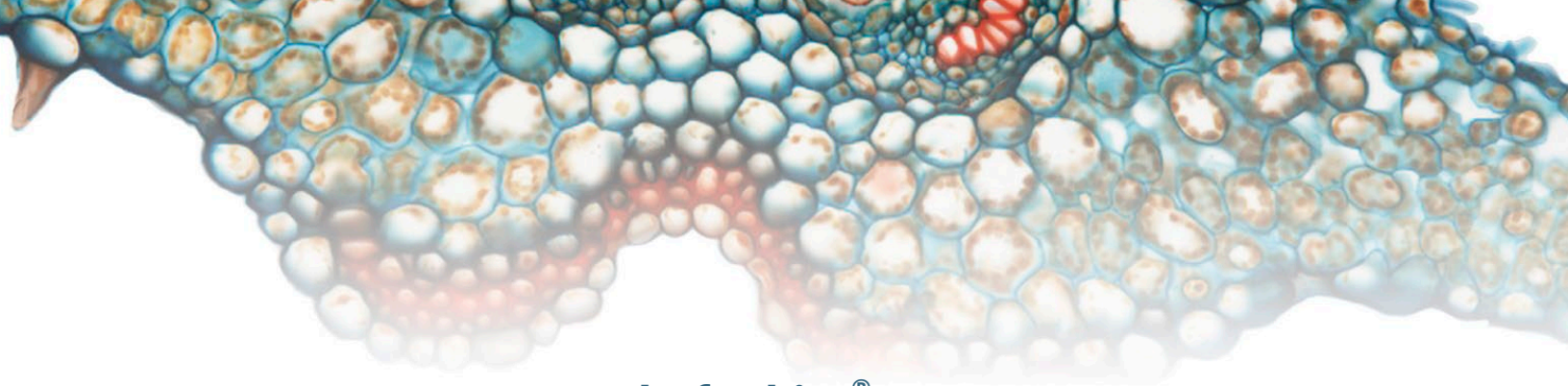
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*The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*



## AMA Journal of Ethics®

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### ORIGINAL RESEARCH: PEER-REVIEWED ARTICLE

#### How an Arts-Based Clinical Skills Set Can Be Assessed During OSCEs

Mark Gilbert, PhD, Leanne Picketts, MEd, Anna MacLeod, PhD, and Wendy A. Stewart, MD, MMed, PhD

##### Abstract

**Background:** Arts-based activities' roles in medical education is to challenge students to cultivate clinical skills using ART (aesthetics, reflection, time). ART activities offer opportunities for students to cultivate creative dimensions of their clinical skills and to reflect on their responses to uncertainty and ambiguity. Faculty, however, are challenged to structure these learning activities in diverse, sometimes unfamiliar, health care settings.

**Methods:** This study explored preclerkship medical students' responses to participating in ART activities presented in the common medical educational format of an objective structured clinical exam (OSCE). Activities included interpreting fine art (eg, images and poetry) and drawing a simulated patient. The discussion section transcript and student sketchbooks were analyzed to identify themes related to participating in the study.

**Results:** Use of arts-based activities elicited behaviors similar to those observed in students' responses to formal summative OSCEs, although students also wrestled with challenges and expressed their subjective impressions.

**Conclusions:** This study offers an arts-based tool set capable of being delivered within the familiar medical education setting and established structure of the OSCE.

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##### Introduction

It has been challenging for medical educators to devise and assess arts-based activities that medical students recognize as clinically relevant.<sup>1,2,3</sup> Arts-based activities in venues outside the student's traditional learning environment, such as a **museum** or **gallery**,

offer little contextual significance for learners. The importance of setting and environment in learning has gained growing recognition in medical education,<sup>4,5</sup> as learners are socialized to demonstrate requisite skills and model behaviors within the clinical and learning contexts.<sup>6,7</sup> It could be argued that, in order to pass standardized examinations, first- and second-year students adopt model behaviors that are without meaning for them and with no understanding of how the behaviors are relevant and critical to practice.

The objective structured clinical examination (OSCE) is an integral part of medical training and is regarded as an effective assessment instrument in terms of the types of skills and number of tasks that can be assessed.<sup>8</sup> Learners must demonstrate competence in a series of fixed-interval simulated scenarios with standardized patients (SPs), observed by an assessor. Although the OSCE is considered a standardized assessment of clinical interactions, some feel it is limited in its capacity to assess the cultural, subjective, and sociopolitical contexts that permeate clinical interactions.<sup>9</sup> The OSCE deconstructs the patient-physician interaction by assessing discrete and isolated aspects of a complete clinical encounter and is stressful for learners.<sup>10</sup>

The application of the arts in this setting could nurture fresh thinking, challenge assumptions, and engender critical reflection on socially relevant aspects of medicine and clinical care.<sup>11</sup> Previous studies have shown that spending time with works of art can cultivate students' critical thinking, identification of stories and narratives, emotional recognition, empathy, and awareness of multiple perspectives.<sup>12,13,14,15</sup> The journey of both the artist and the physician requires attention, reflection, critical questioning, and openness to the value of new and sometimes uncomfortable or unfamiliar perspectives or worldviews.<sup>16,17</sup> The Aesthetic Reflection Time (ART) of OSCE is a qualitative study using arts-based activities within an OSCE setting. We explored and observed participants' behaviors and responses to the different arts-based activities in the familiar clinical examination environment. The experiences were designed to promote participants' awareness of their thoughts and feelings related to the nature and demands of the OSCE process and space.

This innovative pilot study provides the basis for dialogue about implementing aesthetics—as an art-based tool set—in the established structure of the OSCE. This critical and transferable tool set could facilitate reflection on the nature of clinical interactions and decision making, thus contributing to a more holistic and reflective OSCE experience.

## **Methods**

*Participants.* We recruited a convenience sample of 8 preclerkship (first- and second-year) medical students attending Dalhousie University in Halifax, Nova Scotia, Canada. All activities took place at the Centre for Collaborative Clinical Learning and Research at Dalhousie University, a clinical skills and examination setting familiar to the students.

*Design.* The study consisted of 4, 1-hour sessions in a single day. Prior to starting the sessions, the first author (M.G.) introduced all 8 participants to the study activities. The session activities are outlined in Table 1.

**Table 1.** Description of the 4 Arts-Based Sessions

Session	Description
1	As a single group, M.G. and the students discussed and analyzed selected visual artworks, enabling participants to hear others' perspectives as well as articulate their own thoughts in response to each image.
2	Participants were given a sketchbook and drawing materials and made a series of short drawings of each SP. Participants were encouraged to work without the goal of getting the "right answer" to ensure their resultant pen drawings were rendered with acute observation and created with attention and feeling.
3	Participants were given a sketchbook and drawing materials and divided into 2 groups that rotated through a set of 4 OSCE stations. As in an actual OSCE, they spent 10 minutes at each station. Activities included reflecting on actual drawn and painted portraits hung on the walls of 2 stations, reflecting on a poem that was pinned on the wall of a third station, and, finally, drawing an SP who manifested a condition or ailment. Similar to a regular OSCE, students prepared themselves for each task beforehand by reading "candidate instructions" that were pinned on the door outside each station.
4	M.G. and the second author (L.P.) led a follow-up discussion with participants, which was recorded and transcribed.

Abbreviations: OSCE, objective structured clinical examination; SP, simulated patient.

*Analysis.* Qualitative analysis of the transcribed discussion section and of participants' sketchbooks, which consisted of their written reflections on the artworks and poem and their drawings of the SPs, was carried out by the authors. The analysis focused on what participants' drawings, interpretations, reflections, and written and verbal comments revealed about their experience of taking part in the study. In order to identify themes, the analysis team used an immersion-crystallization process in which reading and rereading the data was interspersed with ongoing iterative discussions of findings from multiple perspectives.<sup>18</sup>

## Results

The 3 main themes that emerged from the analysis and examples of each theme are shown in Table 2.

**Table 2.** Identified Themes Relating to Participation in the Study

Theme	Behaviors Exemplifying Theme
Participants adopted the same behavior they would have in an OSCE	<ul style="list-style-type: none"> <li>• Prior to entering the room, taking extensive notes about the task from the instructions pinned to the door</li> <li>• Knocking on the door, even when informed the room was empty</li> <li>• Trying to establish rapport with the SP, requesting permission to begin the drawing</li> </ul>
Participants were challenged by ambiguities, uncertainties, and silence	<ul style="list-style-type: none"> <li>• Voicing curiosity and skepticism</li> <li>• Expressing discomfort at sitting alone in silence with visual art, poem, or SP</li> </ul>

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Participants expressed their subjective impulses, reflections, interpretations, and imaginings

- Interpreting metaphors and imagery
  - Desire to know more about the individuals portrayed
- 

Abbreviations: OSCE, objective structured clinical examination; SP, simulated patient.

Exemplifying the first theme in table 2, the behaviors adopted by the participants mirrored those observed in their typical OSCE counterparts. In particular, when entering the fourth station with the SP, participants initially chose to try to establish rapport with the SP by requesting permission to begin the drawing. This behavior also parallels what would be expected from a clinician in a medical interaction when taking a history or carrying out a physical examination on a real patient. Because participants perceived the parallel between drawing the SP and their previous OSCE experience with SPs, they felt they could more readily “engage” with this station than others.

As an example of theme 2, participants wrestled with how the arts could inform their understanding of medicine. One participant stated: “I enjoy medicine and I enjoy art.... I wasn’t really sure how those could be collaborated together, other than just like drawing organs or whatever.” Another participant noted that, although “composing yourself is very valuable,” sitting in silence would be “a waste of time in a real OSCE.” Given their prior experience, sitting alone in silence was challenging. A third participant wrote: “I’m here, I need to say something soon or else I don’t know what. Or else it looks bad or something.” For others, drawing the SP felt like a distraction. A fourth participant reflected: “It was challenging ... trying to juggle the different things we were trying to do.” Yet another participant observed that drawing “seems like an intimate thing ... like you wouldn’t just start doing it. It’s too private.” In a regular OSCE, students must introduce themselves and explain the boundaries of the interaction. Receiving no verbal consent from the SP to be drawn was disconcerting to this participant: “So I just kind of tried to get comfortable with the silence.... One thing I’m working on even in med school is trying to not fill the void with my random rambling.”

As an example of the third theme, viewing the paintings and drawings prompted curiosity and a desire to know more about the individuals portrayed. One participant wrote: “I feel like I want to know each person’s story; they each look like they have interests unique to them.” The poem also encouraged participants to engage with the aesthetic values of rhythm and tone. Another participant reflected: “This is the only station that brought me out of the clinical setting and made me lose what I was doing and taking part in.”

## Discussion

Immersing oneself in works of art can develop emotional responses, provide alternative forms of representation, and promote dialogue and **sharing of stories** in ways that parallel the interpersonal and diagnostic challenges experienced in clinical interactions.<sup>14</sup> As medicine has become more collaborative and patient centered, greater appreciation of the patient’s subjective health and illness experience is required, yet is often secondary to the objective and clinical components of evidence-based medicine.<sup>19</sup> Arts-based activities have been shown to effectively address competencies related to a more patient-centered, empathic, and holistic approach to care.<sup>20,21</sup>

The ART of OSCE sought to develop a space for engendering more reflective and creative processes, where students could reflect not just on their interpretations of the SP or



artwork but on how these activities related to their prior OSCE experience. Learners used the familiar ritualized OSCE behaviors, such as knocking on the door and taking notes from the instructions, even when those behaviors did not apply in this study. They oscillated between what they had learned previously and the more improvisational and creative impulses they were being encouraged to act on during the study. They felt vulnerable outside the comfort zone of performing familiar tasks, yet the complexities of medicine require an openness to the unexpected, ambiguity, and uncertainty.

### Conclusions

The structure of the traditional OSCE may result in learners focusing on demonstrating competence rather than having an authentic connection to SPs and to clinical practice. This study provides the basis for developing an arts-based tool set that could be incorporated into clinical skills assessment. The study has several limitations, however. The number of students was small, but in an in-depth, qualitative exploratory study there is no defined number of participants. Moreover, only students from one campus participated due to timing. It is uncertain whether the results would have been similar with a second group of students at the same level of training. Future research could examine how this tool set could augment assessment of the relational, moral, and ethical aspects of medicine within the OSCE setting. The impact of the tool set on learners' ability to make relevant connections to critical aspects of their medical education could also be explored.

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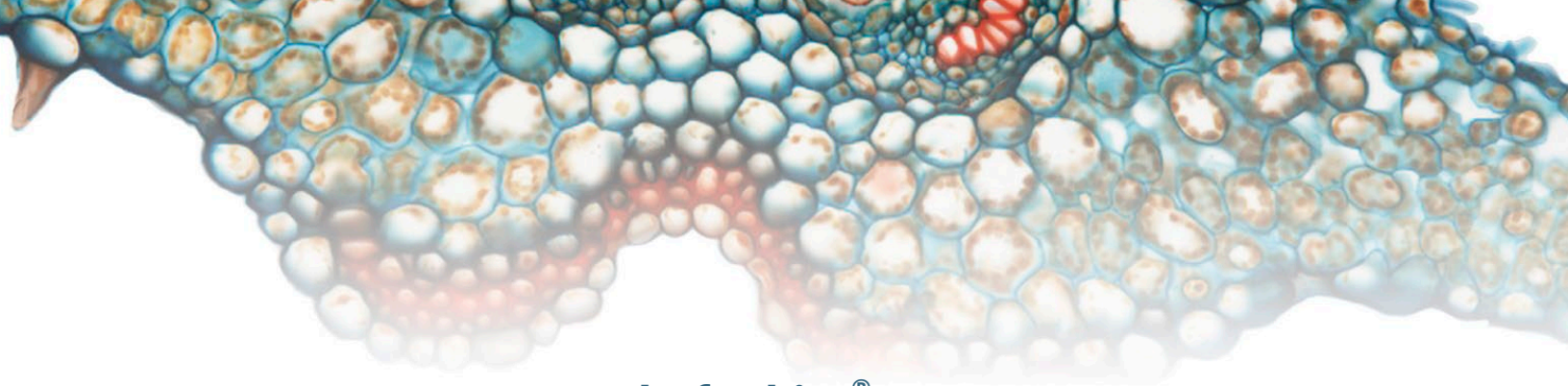
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### ORIGINAL RESEARCH: PEER-REVIEWED ARTICLE

#### Arts-Based Research Methods to Explore Cancer in Indigenous Communities

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##### Abstract

**Background:** Indigenous peoples experience an inequitable burden of cancer compared with other populations. The arts can serve as a culturally relevant cancer intervention and research method.

**Methods:** A scoping review was conducted to determine how arts-based research methods have been used to address cancer in Indigenous peoples. Literature searches identified 129 publications; 32 were selected for review. The following data were extracted: communities employing arts-based cancer research, cancer control continuum stages, cancer types, art forms, and methodologies.

**Results:** Most studies were conducted in the United States. Art as research and sound art forms were the most utilized arts-based methods. Cancer types and control continuum stages were not often specified.

**Conclusions:** Culturally responsive, arts-based methods can enhance research and education across the cancer-control continuum with Indigenous populations.

##### Art as Data Sources

The arts can serve as the core of an intervention (eg, art therapy, narrative medicine) and as a method of research (ie, arts-based research). There is a growing movement to diversify the academic research environment by treating the arts as an empirical source of information and to expand our understanding of what art *is* to include what art *does*.<sup>1</sup> Arts-based research (ABR), a method of inquiry that recognizes artistic expressions as ways of knowing, uses artistic expression and the artistic process as a primary mode of inquiry to understand and examine the experience of both researchers and research participants.<sup>1</sup> In particular, ABR has been used to explore, illustrate, define, treat, and explain cancer across the control continuum.<sup>2,3,4,5</sup>

In health research, ABR is commonly utilized with Indigenous populations as a culturally appropriate means of engagement.<sup>6,7,8</sup> A recent systematic review of Indigenous research methods (IRMs) found that the following most cited methods were general Indigenous frameworks: Western methods in an Indigenous context, community-based participatory research, storytelling, and culture-specific methods.<sup>9</sup> ABR was not explicitly identified as an IRM; presumably, it was included under storytelling and culture-specific methods.<sup>9</sup> Of the 47% of articles focused on health, one investigated cancer.<sup>9</sup>

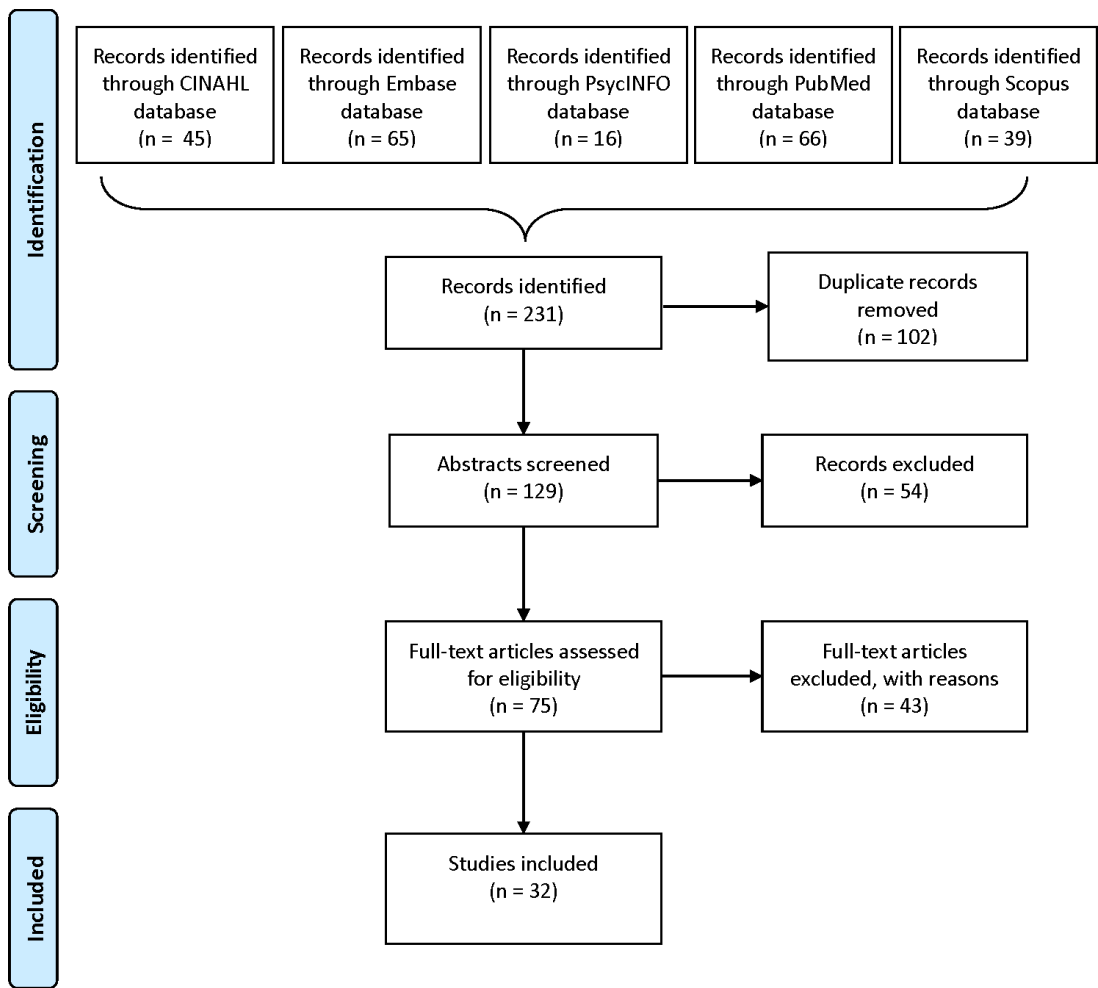
Although data are sparse, globally, some cancers, such as lung cancer and cervical cancer, disproportionately affect Indigenous populations.<sup>10,11</sup> Cancer is a leading cause of death for American Indian and Alaska Natives (AI/ANs).<sup>12</sup> Over the past 20 years, death rates for many cancers increased for AI/AN while decreasing for all other groups,<sup>12</sup> and gaps for many cancers continue to widen.<sup>13</sup> Despite the significance of this health disparity, there is a need for more community-focused and culturally appropriate cancer research and education specific to Indigenous communities.<sup>14,15,16</sup>

The objective of this scoping review was to identify literature reporting use of ABR methods with Indigenous populations to explore the ways that such methods are used across the cancer control continuum (CCC)—from cancer prevention through survivorship—in what we hereafter refer to as arts-based cancer research (ABCR).

## Methods

This scoping review is reported in accordance with the preferred reporting items for systematic reviews and meta-analyses (PRISMA) guidelines. In October 2020, we used strategies designed by a medical librarian (ie, PRISMA) to search published literature for the concept of ABR in cancer research and health education with Indigenous peoples (see Figure). We limited our review to cancer, excluding other chronic illnesses, because cancer is a topic of interest to our local Indigenous community.<sup>17</sup> Using a combination of subject headings and keywords (see [Supplementary Appendix](#)), we searched MEDLINE via PubMed, Embase, Scopus, PsycINFO via EBSCO, and CINAHL via EBSCO. Language filters were applied to limit retrieval to English and Spanish language articles. Published letters, comments, and reviews were excluded. The results were exported to the citation manager RefWorks (legacy), where the automatic duplicate finder removed duplicates.

Figure. PRISMA Flow Diagram



Adapted from Tricco, Lillie, Zarin, et al.<sup>18</sup>

Literature selection was performed by 3 reviewers in 2 steps: (1) review of article title and abstract and (2) review of the full-article text. Each review required reviewer consensus meetings to resolve disagreements. Thirty-two of 129 articles screened were selected for inclusion in this review and evaluated by an analysis team to extract the following data: (1) communities employing ABCR, (2) stages in the CCC,<sup>19</sup> (3) cancer types, (4) art forms, and (5) methodologies employed. To classify ABR studies, we identified studies utilizing art as a method of inquiry as “art as research,” studies utilizing art to support qualitative inquiry as “art in research” and investigations of artistic topics as “research about art.”<sup>20</sup> Terms describing the data extracted are defined in Table 1.

**Table 1.** Description of Data Extracted

Data Extracted	Definition
<b>Demographics</b>	
Indigenous community	Who participated in the study
Country	Where the study took place
<b>Stages in CCC<sup>19</sup></b>	
Etiology	Includes gene-environment interactions, infectious agents, environmental factors
Prevention	Includes tobacco control, diet, physical activity, sun protection, HPV vaccine
Early detection	Includes screening and testing
Diagnosis, treatment <sup>a</sup>	Includes shared and informed decision making and treatment
Survivorship	Includes coping and health promotion for survivors
Nonspecific	Two or more CCC stages identified or discussed holistically
<b>Cancer types</b>	
Type of cancer	Specific type of cancer identified
Nonspecific	Two or more cancer types identified or discussed holistically
<b>Art forms<sup>20</sup></b>	
Visual	Includes 2- and 3-dimensional art forms
Sound	Includes radio, soundscape, and storytelling
Performing	Includes dance and theater
New media	Includes digital media, such as virtual reality
Literary	Includes poetry and short stories
Multiple	Two or more art forms identified
<b>ABR methods<sup>20</sup></b>	
Art as research	Art utilized as a method of qualitative inquiry
Art in research	Art to support qualitative inquiry
Research about art	Inquiry into art-related topics without (re)creating the object or installation under study

Abbreviations: ABR, arts-based research methods; CCC, cancer control continuum; HPV, human papillomavirus.

<sup>a</sup> Diagnosis and treatment were collapsed into one category, as literature that identified diagnosis also referenced treatment.

## Results

The majority of the articles (60%) did not specify the Indigenous communities the researchers were working with; therefore, we report our findings by the country in which the ABCR took place. Twenty-one publications (65.6%) reported on research conducted in the United States. Five publications (15.6%) were specific to Australia and 4 publications (12.5%) were specific to Canada. Our results also included one publication specific to New Zealand (3.1%) and one publication specific to Peru (3.1%).

Many publications were not specific to one stage of CCC or cancer type (see Table 2). Publications dealing with survivorship (18.8%) and early detection (15.6%) were the most frequent, followed by publications dealing with prevention (6.3%) and diagnosis and treatment (3.1%). Etiology was not identified in any publications. The most frequently identified cancer types were gynecological, breast, and colorectal cancer.

**Table 2.** Publications Categorized by Cancer Control Continuum Stage and Cancer Type

Publications	No. (%)
<b>CCC stage<sup>19</sup></b>	
Not specific	18 (56.3)
Survivorship	6 (18.8)
Early detection	5 (15.6)
Prevention	2 (6.3)
Diagnosis and treatment	1 (3.1)
Etiology	0 (0.0)
<b>Cancer type</b>	
Not specific	14 (43.8)
Gynecological	7 (21.9)
Breast	6 (18.8)
Colorectal	2 (6.3)
Head and neck	1 (3.1)
Lung	1 (3.1)
Skin	1 (3.1)

Abbreviation: CCC, cancer control continuum.

In Table 3, it can be seen that publications dealing with sound art forms, such as telling yarns or stories, were the most frequent (34.4%), followed by multiple forms (21.9%), visual form (18.8%), and new media (15.6%). Publications dealing with performing and literary forms were the least frequent. Over half of the publications utilized art as research (59.4%) as their methodology. In these publications, *portraiture*, storytelling, and theater served as the inquiry method itself. Research about art was identified in 9 of the selected publications (28.1%). Examples include investigations into the use of video vignettes and informational art cards in interventions. Four publications utilized art *in* research (12.5%), including drawing accompanied by qualitative inquiry.

**Table 3.** Publications Categorized by Art Forms and Arts-Based Research Methods

Publications	No. (%)
<b>Art forms<sup>20</sup></b>	
Sound	11 (34.4)
Multiple <sup>a</sup>	7 (21.9)
Visual	6 (18.8)
New media	5 (15.6)
Performing	2 (6.3)
Literary	1 (3.1)
<b>ABRMs<sup>20</sup></b>	
Art as research	19 (59.4)
Research about art	9 (28.1)
Art <i>in</i> research	4 (12.5)

Abbreviation: ABRM, arts-based research method.

<sup>a</sup> Not included in Wang et al.<sup>20</sup>

A detailed description of all data extracted from each article can be found in Table 4.



**Table 4.** Data Extracted From Literature Review

Country	Indigenous Community	CCC Stage <sup>19</sup>	Cancer Type	Art Form <sup>20</sup>	ABRM <sup>20</sup>	Reference
Australia	Aboriginal, Torres Strait Islander	Not specific	Not specific	New media	AAR	Ash 2010 <sup>21</sup>
Australia	Aboriginal	Not specific	Not specific	Multiple	AIR	Bernardes 2020 <sup>22</sup>
Canada	First Nations, Metis	Prevention	Breast	Visual	RAA	Bottomoff 2014 <sup>23</sup>
US	AI/AN	Not specific	Breast	Visual	AIR	Chilton 2013 <sup>24</sup>
Australia	Aboriginal	Not specific	Not specific	Literary	AAR	Clague 2010 <sup>25</sup>
US	AN	Not specific	Colorectal	New media	RAA	Cueva 2013 <sup>26</sup>
US	AN	Not specific	Colorectal	New media	RAA	Cueva 2014 <sup>27</sup>
US	AN	Not specific	Not specific	Multiple	AIR	Cueva 2014 <sup>28</sup>
US	AN	Not specific	Not specific	New media	RAA	Cueva 2015 <sup>29</sup>
US	AN	Not specific	Not specific	New media	RAA	Cueva 2016 <sup>30</sup>
US	AN	Not specific	Not specific	Performing	AAR	Cueva 2010 <sup>31</sup>
Peru	Shipibo	Not specific	Cervical	Multiple	AAR	Darivemula 2018 <sup>32</sup>
US	Chamorro	Survivorship	Breast	Sound	RAA	Duenas Manglona 2010 <sup>33</sup>
NZ	Māori, Tangata whenua, Pākehā	Survivorship	Not specific	Sound	AAR	Egan 2016 <sup>34</sup>
US	Winnebago Tribe of Nebraska	Diagnosis, treatment	Head, neck	Visual	AAR	Gilbert 2020 <sup>35</sup>
US	Comanche	Not specific	Breast	Sound	AAR	Haozous 2010 <sup>36</sup>
Canada	First Nations	Early detection	Cervical	Visual	RAA	Hislop 1996 <sup>37</sup>
US	AI/AN	Early detection	Cervical	Sound	AAR	Hodge 1996 <sup>38</sup>
US	AI/AN	Survivorship	Not specific	Sound	AAR	Hodge 2016 <sup>39</sup>
US	Native Hawaiian	Early detection	Breast	Sound	AAR	Ka'opua 2008 <sup>40</sup>
Canada	Mi'kmaq	Early detection	Cervical	Sound	AAR	MacDonald 2015 <sup>41</sup>
US	Lakota	Prevention	Lung	Sound	AAR	Margalit 2013 <sup>42</sup>
US	Osage	Not specific	Skin	Visual	AAR	McWilliams 2020 <sup>43</sup>
Australia	Aboriginal, Torres Strait Islander	Not specific	Not specific	Multiple	AAR	Meiklejohn 2019 <sup>44</sup>
US	AI/AN	Survivorship	Not specific	Sound	AAR	Pelusi 2005 <sup>45</sup>
Canada	Aboriginal	Not specific	Breast	Multiple	AAR	Poudrier 2008 <sup>46</sup>
US	AN	Survivorship	Not specific	Performing	RAA	Sharma 2016 <sup>47</sup>
US	Yakama	Early detection	Cervical	Sound	AAR	Strickland 1996 <sup>48</sup>
US	AI/AN	Not specific	Not specific	Multiple	RAA	Vogel 2013 <sup>49</sup>
US	Lumbee, Cherokee, Coharie, Waccamaw Siouan	Survivorship	Not specific	Visual	AAR	Warson 2012 <sup>50</sup>
US	Coharie, Waccamaw Siouan	Not specific	Breast	Multiple	AAR	Warson 2013 <sup>51</sup>
Australia	Indigenous	Not specific	Not specific	Sound	AIR	Yerrell 2016 <sup>52</sup>

Abbreviations: AAR, art as research; AI/AN, American Indian/Alaska Native; AIR, art in research; AN, Alaska Native; RAA, research about art.

## Discussion

Conducting health research and education in culturally relevant ways is vital to their success with Indigenous communities.<sup>53</sup> IRMs existed well before precolonization,<sup>54</sup> with their own theoretical constructs and protocols that should be respected and acknowledged in research conducted with Indigenous communities.<sup>55,56</sup> ABCR aligns with Indigenous knowledge systems in exploring and generating knowledge through painting, drawing, crafting, and storytelling.<sup>53</sup> We have identified 4 areas of opportunity to support ABCR with Indigenous populations based on the results of this review.

*Extension of ABCR to other Indigenous communities.* In the majority of publications in this review, ABCR was conducted in the United States. According to the United Nations,<sup>57</sup> Indigenous peoples account for 476 million individuals across 90 countries worldwide. There is an opportunity to apply ABCR methods in other American (eg, the Mayans in Guatemala) or European (eg, the Basque in Spain) communities not found in this review. Furthermore, many publications did not specify the Indigenous communities involved in the research but instead stated the countries where the research occurred. Identifying and acknowledging Indigenous communities not solely by the geographical boundaries created postcolonization but as their own sovereign units of identity would decolonize research and recognize ABCR as an IRM.<sup>58</sup>

*Extension of ABCR to other cancer types.* Over half of the articles reviewed were not specific to one cancer type. The conceptualization of cancer as a disease that can spread to many parts of the body is representative of Indigenous worldviews that we are all related.<sup>55,59,60,61</sup> This holistic perspective aligns with Indigenous **approaches to healing**, which include body, mind, and spirit.<sup>62,63</sup> There are more than 100 types of cancer,<sup>64</sup> yet only 5 cancer types were studied. These included most of the leading causes of cancer deaths in Native Americans. Prostate cancer, however—a leading cause of cancer death among AI/AN men<sup>12</sup>—was not mentioned and is arguably worth exploration.

*Extension of ABCR to all CCC stages.* No publications were identified that used ABCR methods to explore cancer etiology. ABCR (eg, art *in* research) could be integrated in research on cancer etiology examining environmental factors, genetic factors, gene-environment interactions, medication exposures, infectious agents, and health behaviors related to cancer.<sup>19</sup> Following the transtheoretical model of health behavior change,<sup>65</sup> arts could also be studied as a means to stimulate changes in health behaviors that could help prevent cancer. In this way, ABCR could support prevention efforts at this relatively uninvestigated CCC stage.

*Extension of ABCR to other artistic mediums.* Sound and multiple art forms were most often employed in ABCR projects with Indigenous populations. Only one article was found utilizing literary art forms. Poetry could be explored as a culturally responsive way to conduct literary-based research that honors Indigenous orality.<sup>66,67</sup> Two articles identified performing art forms. Theatre of the Oppressed, a methodology that explores non-oppressive experiences and discusses difficult social topics,<sup>68</sup> has been successfully employed with Indigenous populations<sup>69</sup> and could be utilized to address cancer. Tecno-sovereignty, an emerging ABR method that examines cross-cultural and intercultural Indigenous innovations from digital media, old electronic analog media, and traditional Indigenous media, is yet another possibility.<sup>70</sup> Integrating literary, performing, and media-based art forms into cancer research could create new methods that align with Indigenous values.<sup>70,71</sup>

## Limitations

Our search terms for ABR methods included prominent methodologies, such as photovoice and storytelling, and, for Indigenous populations, included common regional terms (see [Supplementary Appendix](#)). It is possible that not all publications were identified based on the search terms, as these terms are not standardized internationally. Similarly, publications in languages other than English or Spanish were excluded. The CCC model selected did not include end-of-life care and instead included noncurative care in the treatment stage. The literature could be further analyzed to determine ABCR uses in palliative care.

## Conclusion

This review details culturally responsive methods of cancer inquiry and education that can be employed with Indigenous populations to enhance research across the CCC. Understanding existing ABCR studies and their effectiveness can guide researchers in designing projects that acknowledge Indigenous knowledge systems and support more ethical ways of generating knowledge. Integrating ABCR can increase the cultural relevance of cancer research, education, and interventions for Indigenous communities. Future qualitative studies to address cancer in Indigenous populations should consider integrating ABCR.

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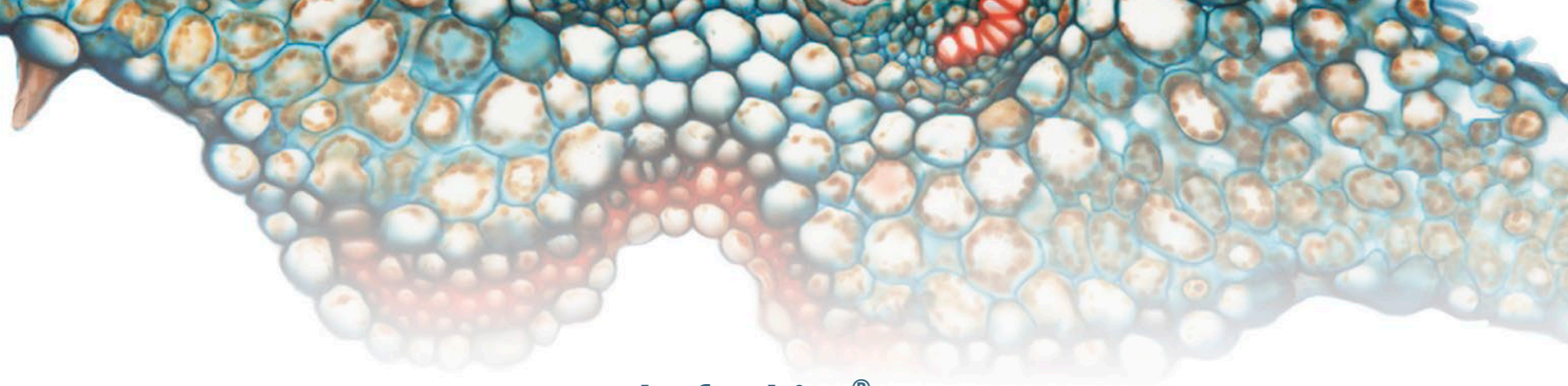
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### ORIGINAL RESEARCH: PEER-REVIEWED ARTICLE

#### Songwriting and Youth Self-Concept

Sophia Miao, MD and Wendy A. Stewart, MD, MMed, PhD

##### Abstract

**Background:** Current literature on the therapeutic outcomes of youth engagement in active music-based interventions is limited in terms of both the number of studies and methodology. This pilot study combined phenomenology and quantitative measures of self-esteem and self-efficacy to explore the impact of storytelling through lyrical and musical composition on youth self-concept.

**Methods:** Thirteen youth ages 12 to 16 engaged in a series of 5 consecutive daily music workshops, and themes related to participating in the workshop were identified. Participants also took the Rosenberg Self-Esteem Scale and Sherer General Self-Efficacy Scale before and after completing the workshops, and pre- and posttest scores were compared using *t*-tests.

**Results:** Key themes that emerged from the analysis were empowerment and accomplishment. Although the results of the *t*-tests were not significant, the qualitative data from this pilot study suggest that the workshops had a positive impact on participant self-concept.

**Conclusions:** These preliminary results could be used to inform further research and to plan active music interventions to positively impact youth mental health.

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##### Introduction

During the teen years, individuals develop a more distinct sense of personal identity and emotional and social independence.<sup>1</sup> However, many mental health disorders have their onset during this time.<sup>2</sup> Enhancing protective factors and resilience in this age group could **reduce the risk** for future mental illness.<sup>3</sup> Protective factors specific to mental health include physical activity, sleep, social connectedness, self-efficacy, self-esteem, confidence, and economic security.<sup>3,4</sup> Because leisure activities account for between

50% to 60% of youths' time, there is interest in how these activities could be used to protect mental health.<sup>5,6,7</sup>

Music-based interventions are of particular interest due to music's integral role in culture and its ability to facilitate reflection, personal expression, and emotional regulation.<sup>8</sup> Music therapy has been shown to be beneficial for mental health<sup>9</sup>; in particular, it has been shown to elicit positive mood changes in adolescent psychiatric inpatients, regardless of gender, diagnosis, or mental health acuity level.<sup>10</sup> Other therapeutic outcomes of engaging youth in active participatory music activity include enhanced self-expression and identity, self-concept and self-esteem, and decision-making ability.<sup>11,12,13</sup> Moreover, active **music-based therapeutic interventions** may have greater therapeutic effectiveness in reducing depressive symptoms than receptive methods.<sup>14</sup> Nevertheless, such studies are limited in number and focus on clinical settings.<sup>15,16</sup>

The authors conducted a pilot study that combined phenomenology and quantitative measures of self-esteem and self-efficacy to explore the impact of storytelling through lyrical and musical composition on youth self-concept in the setting of a youth center.

## Methods

*Participants.* Thirteen participants (5 females, 8 males) were recruited through social media and posters at KV Oasis Youth Centre, a local nonprofit organization for youth in Quispamsis, New Brunswick, Canada. All had an interest in music and 3 had songwriting experience: 2 with music and lyric composition and 1 with writing rap lyrics. Two individuals did not participate in postworkshop data collection. Consent was obtained prior to participation.

*Design.* A pretest-posttest design was used in which quantitative measures and qualitative focus group data were collected before the first workshop and after the last workshop.

*Intervention.* Participants took part in a series of 5 daily workshops between June and September of 2018 with the objective of composing a song centered on a lived experience, personal goal, or emotion. Group 1 (3 females, 4 males) participated in 4, 3-hour sessions (with a 30-minute break) over 4 consecutive days, with a final 1-hour session on day 5. Group 2 (2 females, 4 males) participated in 4, 2-hour sessions without breaks over 4 consecutive days, with a final 1-hour session on day 5. For both groups, the session on day 1 focused on formal music composition. The sessions on days 2 to 5 were focused on composing, with additional individual instruction on notation and composition as needed.

The workshop sessions were facilitated by a well-known local choir director, composer, and singer. During the workshops, participants selected a topic and brainstormed related ideas or experiences. The facilitator introduced structural elements of songs from various genres, basic lyrical and melodic concepts, and forms of musical notation. Participants were encouraged to work individually or in pairs to develop their compositions. The facilitator engaged the participants in conversation to encourage exploration of their life experiences, help them develop musical and lyrical ideas and choose instrumentation, and answer questions. Once the song was completed, an audio recording was made of each individual performing their composition, and a copy of the recording was given to the individual to keep. Lyrics, which were handwritten, were

photocopied, and original copies were kept by the songwriter. In the final session, participants were asked to describe their composition and the rationale behind it and then given the option to perform or play the recording for the rest of the group. *Data and measures.* Qualitative data comprised observational field notes kept during the workshops; transcripts from 60 to 90-minute pre- and postworkshop focus groups that were transcribed by a professional transcriptionist; audio recordings of participant compositions; and corresponding written lyrics and musical scores. (See [Supplementary Appendix](#) Figures 1 and 2 for focus group questions.) The Rosenberg Self-Esteem Scale and Sherer General Self-Efficacy Scale were used as quantitative measures.<sup>17,18</sup>

*Analysis.* Qualitative data were analyzed using a phenomenological approach<sup>19</sup> that centered on what the musical compositions revealed about the participants’ experience of the music-making process and how it affected their self-esteem and belief in themselves. Significant statements were identified from the focus groups to demonstrate the impact of expressing stories through music making. As patterns in the data emerged, they were coded as themes.<sup>20</sup> Quantitative data were analyzed using *t*-tests. To ensure the credibility and validity of the findings, triangulation (of quantitative and qualitative data, field notes, compositions, and lyrics) and peer review were used to confirm the interpretation of the narrative data.<sup>21,22</sup>

Results

*Qualitative.* The workshop themes and subthemes that were identified from the qualitative data, with supportive quotations, are shown in the Table. Participants agreed that receiving support from others, whether in the form of applause or praise, was empowering. In addition to receiving support, participants enjoyed the act of providing support to others and found that it helped boost the group’s morale. Working together built a sense of community in which shared goals and interests motivated and connected participants.

**Table.** Themes and Subthemes, With Representative Quotations, Identified From Workshop Qualitative Data

Themes and Subthemes	Supporting Quotations <sup>a</sup>
Empowerment	
Positive relationships and support from others	“It’s the people around you that support you and the support really encourages you to try harder.” (participant group 1B)  “I always point out the flaws and never really see the positives... When everyone was like, ‘No it sounds good.’” (participant group 2B)  “It’s great, it was like, ‘oh, okay, so it’s not as awful as I think it is.’” (participant group 2B)  “Everybody would congregate and we’d talk about what we were doing and everything and it kind of felt ... like a big group of people that we’re all working on one end goal, but we’re all going about it differently and it was cool to see how that changed from person to person until the endproduct.” (participant group 1B)
Self-expression	“An easier way to get my feelings out ... and it helps if you’re not feeling very good.” (participant group 2B)  “I feel like if it’s music, which I love, and writing, which I’m good at.... I feel like together it will make it a lot easier.” (participant group 2A)

	“With music, I can ... have a presence. And I can be myself. And not be afraid of others judging me.... I can feel like I exist.” (participant group 2A)
Feeling understood	<p>“And I never thought a song like that could like understand me so much. Like it could affect me so much.” (participant group 2A)</p> <p>“I might not understand what you’re going through, but I understood what the message was in your song.” (participant group 1B)</p>
Coping skills	<p>“So I started listening to music so I don’t have to punch a hole in the wall or someone’s face...” (participant group 2A)</p> <p>“Instead of doing self-harm, instead of hurting yourself ... like if I ever wanted to do that, I’d be like, ‘no, write some music.’” (participant group 2B)</p>
<b>Accomplishment</b>	
Overcoming barriers	<p>“I’m proud of myself for doing it, but not the song itself.” (participant group 1B)</p> <p>“It was difficult writing the lyrics and trying to learn the piano notes, [so I] decided to not do piano and just do beats with a metronome.” (participant group 1B)</p> <p>“I [made] my song. Like it empowers you and gives you a lot to [know] you done it yourself. And it makes you think that ‘I can do this.’” (participant group 1B)</p>
<b>Low mood/emotional dysregulation</b>	
Situational context	<p>“I get empowered in a way but in a way that I also get nervous because some people may make fun of me.” (participant group 1A)</p> <p>“Sometimes I like myself, sometimes I hate myself, sometimes I’m okay with myself.” (participant group 2A)</p>

<sup>a</sup> Participant groups 1A and 2A are pre-workshop groups; participant groups 1B and 2B are postworkshop groups.

Participants found it easier to express their thoughts and feelings through song, whether lyrical or musical. For many, it was the first time they had externalized a story they had repressed. One student was reserved, spoke softly and briefly only when spoken to directly, and was initially reluctant to engage in conversation. Throughout the workshops, this student made numerous drawings based on their traumatic experiences. These reflections allowed a narrative to emerge, which was expressed through the song lyrics and music. The student chose a topic they had not spoken of before, and the creative process allowed it to be externalized for the first time. More generally, the participants felt relieved and validated when understood through the music. After performing and sharing their compositions with one another in the final session, participants described feeling less alone.

Storytelling through music making also enhanced participant coping skills. Several participants considered music to be a “form of therapy” that was particularly helpful for managing anxious thoughts and destructive behaviors. One participant revealed that a song spoke to them when they were suicidal and likely saved their life. All participants reported a feeling of accomplishment after completing their musical composition and performing it or sharing it with others. Emotions such as relief, happiness, and pride were associated with the completion of the task. Participants emphasized that the positive feelings they experienced were derived from going through the motions of

songwriting and finishing the task rather than having a well-polished product. As one participant noted: “I’m proud of myself for doing it, but not the song itself.” This positive effect was particularly significant for participants who had never written a song before due to the combination of experiencing something new and making a successful first attempt.

Participants experienced a range of difficulties in the making of their songs, including lack of focus, inexperience, limited time, and lack of inspiration, yet they found creative solutions to these problems. It was evident from observations during the study that how youth felt on a particular day influenced their engagement, their feelings about the songwriting process, and their overall sense of well-being. One participant reported feeling an increased sense of self-confidence near the end of the program. The following day, this effect had diminished following an argument with their parents. The participant appeared downcast and less engaged in the workshop activities.

**Quantitative.** The mean posttest score on the Rosenberg Self-Esteem Scale (24.09, SD 7.3) did not differ significantly from the mean pretest score (22.55, SD 7.8;  $p = 0.11$ ). Six students’ scores increased between pretest and posttest, 2 students’ scores showed no difference, and 3 students’ scores decreased (see [Supplementary Appendix Figure 3](#)). The mean posttest score on the Sherer General Self-Efficacy Scale (74.55, SD 15.52) did not differ significantly from the mean pretest score (71.91, SD 15.63;  $p = 0.24$ ). Six students’ scores increased between pretest and posttest, 1 student’s scores showed no difference, and 4 students’ scores decreased (see [Supplementary Appendix Figure 4](#)). A decreasing level of commitment to the songwriting process may have contributed to the lack of significant differences in the quantitative measures.

## Discussion

Youth often associate music with emotional experiences.<sup>23</sup> While many use music to promote a positive state, those with mental health difficulties are more likely to use music that intensifies anger or sadness.<sup>24,25</sup> These data suggest that youth require guidance on how to use music effectively.

The qualitative data from this study strongly suggest that the workshops had a positive impact on participant self-concept. Individual data from the scales and compositions were consistent with the focus group data and researcher field notes. Although not statistically significant, the results of the *t*-tests reinforced the qualitative data, as students’ scores on self-esteem and self-efficacy scales increased slightly following their participation in the workshops. The study is limited by the small number of participants and short duration of the workshops. Combining qualitative methods with quantitative measures, however, provided a rich data set from which to draw conclusions and consider future research directions.

## Conclusions

This pilot study provides evidence that youths’ active engagement in music composition has a positive impact on their self-concept. The results provide the basis for planning further longitudinal studies examining the impact of songwriting on youth mental health. These studies could include examining correlations between music background and self-concept.

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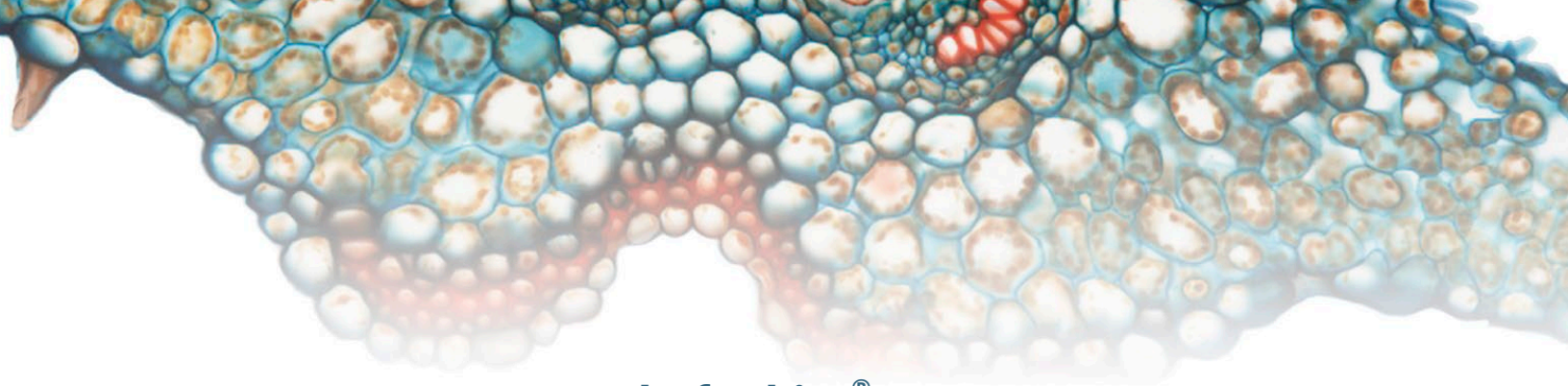
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## AMA Journal of Ethics®

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### ORIGINAL RESEARCH: PEER-REVIEWED ARTICLE

#### How a Medical Orchestra Cultivates Creativity, Joy, Empathy, and Connection

Roma Subramanian, PhD and Matthew J. Brooks, DMA

##### Abstract

**Background:** Inspired by research indicating that exposure to humanities correlates with reduced burnout, the Nebraska Medical Orchestra was founded in 2018 as a collaboration between the University of Nebraska Medical Center and the University of Nebraska at Omaha School of Music.

**Methods:** Semistructured interviews about orchestra participants' experiences were conducted with 9 musicians and recorded and transcribed. Transcripts were analyzed using the constant comparative method.

**Results:** The interviews suggested that participants are drawn to the orchestra to pursue a love of music, to be part of an ensemble, and to connect with others in an environment that provides a lighthearted, nonjudgmental, noncompetitive forum in which to create and enjoy music for its own sake.

**Conclusions:** This study has implications for designing arts-based wellness activities for clinicians and scaling them nationwide.

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##### Engaging Music

Burnout, a common phenomenon among medical students and clinicians, is associated with depression, a decline in job performance and empathy, and elevated levels of salivary cortisol, a stress hormone.<sup>1,2,3,4,5</sup> Engaging in music and other creative activities can help manage symptoms of burnout by reducing levels of cortisol and fostering social bonding.<sup>5,6,7,8</sup>

Inspired by research indicating that exposure to the humanities correlates with **reduced burnout**,<sup>9</sup> the Nebraska Medical Orchestra (NMO) was founded in 2018 with 55 members as a partnership between the University of Nebraska Medical Center and the

University of Nebraska at Omaha School of Music. The orchestra was conceived as a wellness initiative that would help alleviate symptoms of stress and burnout by providing health care professionals a space for creativity and engaging with a community.<sup>10</sup> This volunteer orchestra, specifically for health care professionals, is unique in that it is open to participants with varying skill levels—those with or without degrees in music, those with some or no experience performing, and even those who are novices or recently returning to their instruments.

In a 2019 survey of this orchestra's participants conducted by the second author (M.J.B.), 78% (28 of 36 respondents) reported that participation in the orchestra was very or extremely beneficial for their sense of well-being.<sup>10,11</sup> However, this survey only asked about what aspects of the NMO were important to participants but not *why* they perceived the orchestra as having a positive impact. Moreover, the brief nature of the survey could not yield in-depth responses from participants about their experiences—for example, how and why does the orchestra positively impact well-being? Therefore, this study builds on this survey by investigating, via semistructured interviews, how participation in the NMO was beneficial for participant well-being.

## Methods

In spring 2021, participants were recruited from a pool of 18 of the total 55 members of the orchestra, as these 18 individuals were the only active members of the orchestra during the COVID-19 pandemic. Of these, 9 consented to participate in this study. These participants represented both string musicians (4 violinists and 1 double bassist) and wind musicians (3 flutists and 1 trumpeter) and the following health care professions: medicine (oncology, surgery), nursing, allied health (pharmacy, dietetics), patient care support, and medical research. Participants' years of experience playing their instrument ranged from about 15 to 40 years, but all were amateurs. Semistructured interviews were conducted with these 9 musicians and recorded and transcribed (see the [Supplementary Appendix](#) for a list of sample interview questions). Transcripts were analyzed using the constant comparative method, which involved an iterative process of reading the interview transcripts to understand the meaning of participants' responses, comparing and contrasting the responses, and then categorizing similar responses into themes.<sup>12</sup>

## Results

Analysis of the interview transcripts revealed 4 themes.

*Playing music is a chance to pursue a joyful and creative passion.* Most participants expressed a deep love for music that was an intrinsic part of their identity but for which there was no outlet in their professional life. Indeed, some had been music majors, and all had been playing their instrument since childhood. Some said that they were not able to pursue a career in music because of the demands of their health care jobs and, in 2 cases, because of an injury. Participants also alluded to how their work lives involved a focus on technical detail rather than creativity. The orchestra served as an outlet for both their passion for music and their desire to connect with the creative part of their identity. A quotation from one participant illustrates these points:

I have always loved flute.... As an adult having a super stressful professional life, having the luxury to practice just takes my mind away. I just love playing, and sometimes I think about what if I had pursued music instead of what I am doing. The reality is that I cannot change things, and I have a very rewarding professional life, but I would really feel like a part of me was missing if I was not able to play. (participant 6)

*Creating music in an ensemble is a uniquely joyful experience.* Participants said they were drawn to the orchestra because they had a particular interest in performing with others. Participants' reflections indicated that playing in a group was an ethereal, intangible experience, one that cultivates joy, community, humility, and purpose through members striving in unison to achieve a challenging goal, one that they couldn't achieve alone. Two participants expressed appreciation for different aspects of the orchestra experience.

When you're in an ensemble or in a full orchestra, you're able to play more difficult music and definitely recognize the talent of others.... I remember at one point I just kind of kept my violin up and stopped playing. I just was listening and I was like, this is so cool to be a part of and see all these other very talented people doing something they love. (participant 8)

There's something comforting about being in a large group of people who are all doing the same thing. They all have the same goal and so that's pretty nice. It's different than a sports team or something like that because you're not competing against anything. You're just trying to make something nice, and I really appreciate that. (participant 7)

*The empathetic atmosphere of the orchestra enhances enjoyment.* Participants described the orchestra as a safe, lighthearted, nonjudgmental, noncompetitive environment where they were able to play music for its own sake. They credited the conductor for playing a critical role in fostering this environment, especially given that participants are at different skill levels. As participant 6 put it:

[He tries] to select music that will be possible. It might be a bit of a reach for the least skilled, but not too tedious for skilled people. A lot of it is really thinking about the musical selection and trying to get a good mix of pieces.... I have been thinking back on other orchestras and other bands and situations [ensembles] where there was a lot of pressure in the conductors, and their purpose was to try to get perfection.... His [our conductor's] purpose is to make sure that people are enjoying it and that we do sound good. It is not going to be haranguing at an individual because they are out of tune or coming in late, which is what you get from top-notch conductors if you are in a serious musical ensemble. That is not the venue. That is not us. It is about creating a rewarding experience and making it worthwhile for us after a very long day. (participant 6)

This open, nonregimented atmosphere in turn heightened participants' enjoyment of playing because it gave them space to make mistakes, a welcome contrast from their health care professional lives. As participant 7 noted:

There's really no consequence if it goes poorly, right?... It's just the feeling of this is a pure artistic outlet. It doesn't matter how well I do. The stakes are so low, if I made a huge mistake during the performance, people seem to understand.... When you're working with reagents and samples that can cost you 1000s of dollars, there's a very large consequence if things go wrong. (participant 7)

The laid-back atmosphere of the orchestra, however, doesn't promote shoddy work. On the contrary, one participant commented on how members are intrinsically motivated to do good work:

The personalities of the group itself take care of holding the group to a high standard because everybody wants to be good. Everybody wants to do their best.... So, it all works out—being able to play at a pretty high level but we don't have to be pushed really hard by our conductor to do that. (participant 1)

*Playing with other health professionals fosters connection.* Participants said they appreciated that they shared with their orchestra colleagues an understanding of the stresses of working in the health care field. Participant 1 noted that this shared experience provided common ground for connection and commiseration outside of the

workplace and a chance to have open discussions about issues that work environments may not inspire:

Often the stress that comes with working in health care is something that's difficult to release.... But I think in a group that's all health care providers, where they're doing something creative, that's a very different setting. A different environment that's more welcoming to understanding what you're going through. So, it provides a whole network of people that you could talk to about things that are bothering you and also a whole group of people that you can just make music with. And I think that has huge role to play and positively impacting mental health. (participant 1)

## Discussion

Our findings indicate that the orchestra delivered on its wellness mission in 3 ways: (1) by harnessing participants' intrinsic motivation to pursue an artistic, creative passion; (2) by cultivating an empathetic, noncompetitive space to engage in this passion, wherein the focus is pleasure, not perfection; and (3) by fostering kinship and connection with other individuals who have dual identities as musician and health professional. Our findings suggest, as other research has noted,<sup>13</sup> that because wellness is a highly individualized process, **wellness programs** that are anchored in activities that participants find intrinsically joyful—in this case, making music—are more likely to be received enthusiastically. In other words, wellness programs that are tailored to the lived experiences of participants, instead of generic self-care skills (eg, exercise), may be more intrinsically engaging.

It's important to note that though individual-focused wellness promotion interventions, such as the NMO, are beneficial, they are unlikely to be effective in eliminating symptoms of burnout, especially if burnout results from systemic factors such as chronic imbalance between job demands (eg, excessive workload, administrative burden, moral distress) and job resources (eg, access to social support, meaningful work).<sup>14</sup> Having said that, the NMO does embody the guidelines proposed by the National Academies of Sciences, Engineering, and Medicine for designing well-being systems in health care organizations to combat burnout.<sup>14</sup> These recommendations, as embodied in the NMO, include university leadership commitment to the orchestra's mission of well-being and an orchestra culture that permits vulnerability and fosters peer support. Although there are roughly 35 medical orchestras across the United States,<sup>15</sup> few garner the same support as the NMO for financial and human resources from their affiliated institutions, and few have "wellness" as a primary goal.<sup>16</sup> The characteristics of the NMO would be worth taking into consideration if it were to serve as a foundation for other similar national or international arts-based initiatives. Future studies of medical orchestras should incorporate larger samples and a longitudinal approach for a more robust evaluation of the orchestra's impact.

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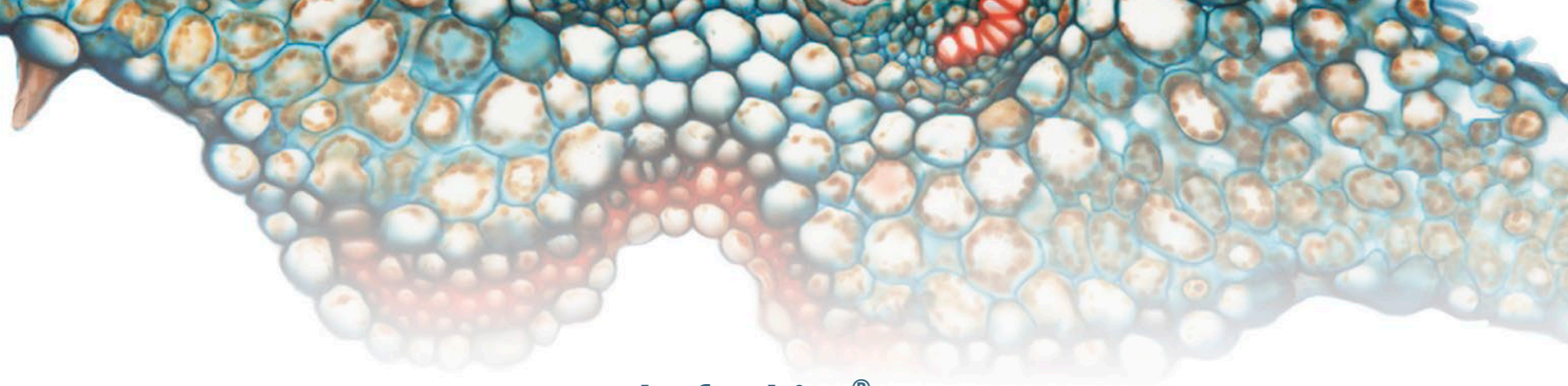
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## AMA Journal of Ethics®

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### ORIGINAL RESEARCH: PEER-REVIEWED ARTICLE

#### Activating Empathy Through Art in Cancer Communities

Megan Hildebrandt, MFA, Robin N. Richardson, MA, and Joy Scanlon

##### Abstract

**Background:** The Aesthetics of Health (AOH) undergraduate visual art studies course at the University of Texas at Austin aimed to enhance art students' awareness of cancer's impact not only medically but also socially, emotionally, financially, and spiritually and to examine how this experience might impact students' artwork, capacity for empathy, and connection to audience.

**Methods:** During the spring 2021 semester, the AOH course instructors employed assorted pedagogical methods, including art, illness narrative, and community engagement, in special sessions led by professors, community practice artists, and cancer experts, respectively, as well as oral storytelling by those with lived experience of cancer (ie, cancer patients, posttreatment survivors, and loved ones). For the course's final project, the 15 student-artists created self-selected media works combining health and activism and displayed them in public spaces, including online. Student-artists took the Toronto Empathy Questionnaire during the first and last weeks of the course and provided feedback. Two group interviews were also held with cancer storytellers following their participation.

**Results:** Student-artists' average score on the Toronto Empathy Questionnaire increased from 52.46 at pretest to 55.38 at posttest. Student-artists and storytelling participants also reported having positive experiences.

**Conclusions:** The AOH course's social practice approach encouraged student-artists to realize new ideas and relationships and modestly increased their capacity for empathy. The AOH framework demonstrates promise for increasing empathy through the arts in other educational, clinical, and artistic institutions. Further research is needed with larger sample sizes to measure the impact of the course and to demonstrate its potential for addressing burnout and moral distress.

*The American Medical Association designates this journal-based CME activity for a maximum of 1 AMA PRA Category 1 Credit™ available through the AMA Ed Hub™. Physicians should claim only the credit commensurate with the extent of their participation in the activity.*

## **Background**

In January 2021, the first author (M.H.), a young adult cancer survivor, artist, and professor, launched the Aesthetics of Health (AOH) course for 15 undergraduate visual art students at the University of Texas at Austin's College of Fine Arts in collaboration with Dell Medical School's Livestrong Cancer Institutes to enhance student-artists' awareness of cancer's impact on patients, survivors, and loved ones not only medically but also socially, emotionally, financially, and spiritually. The authors questioned how this experience might impact students' artwork, **capacity for empathy**, and connection to audience.

Guest lecturers introduced student-artists to the course's guiding theme, social practice art. According to social practice artist, author, and AOH guest lecturer, Ellen Mueller, social practice art is community-engaged, participatory, and activist art that exists in varying forms and on a spectrum of social engagement.<sup>1</sup> Ezra Benus, another social practice artist and guest lecturer, explored with the class how static understandings of health keep resources from those who do not fit into normative understandings of illness because of age, race, gender expression, or diagnosis.<sup>2</sup>

## **Methods**

*Course design.* The course enrolling 15 student-artists met for 3 hours, twice per week from January to May 2021. The multidisciplinary course focused on art, led by the professor; illness narrative and social practice, led by professional art activists; and community engagement methods, led by public health experts. Supplemental trainings were also offered, including patient privacy, provided by a legal expert, and palliative, supportive, and psychosocial care, provided by an oncology clinical social worker and a palliative physician. Professional mental health support was also offered throughout the semester.

Eight individuals who were actively in cancer treatment, were posttreatment survivors, or were loved ones of those with cancer joined the class over Zoom to participate in oral storytelling (one abridged session is on YouTube<sup>3</sup>). These **storytellers with diverse cancer experiences** work with the authors through the Livestrong Cancer Institutes' patient and family advisory boards, codesigning oncology support programs and clinical services.<sup>4,5</sup> Stories told to the student-artists included a Latinx patient's delayed breast cancer diagnosis, despite her family history of hereditary cancer; a patient with a rare blood cancer suffering through chemotherapy without access to pain management; and a young adult with colorectal cancer who worked throughout treatment due to opaque disability eligibility guidelines.

Throughout each of the 8 storytelling sessions, the 15 student-artists in the course engaged with the storytellers, asking questions, creating each storyteller's portrait in varying media, and sharing their in-process portraits. After conversing with those affected by cancer and gaining a foundational understanding of social practice art, student-artists were required for the course's final project to reflect on health and health care in their lives and to create a work that combined health and activism. Student-artists created pieces in the studio and installed them in public spaces, including online.

*Data collection and analysis.* A mixed-methods approach was used to evaluate the course's impact on student-artists and storytellers. The Toronto Empathy Questionnaire (TEQ), a validated self-reported 16-question tool with a 0 to 64 score range, was administered to student-artists in the first and last weeks of the course, and the average scores were compared to assess changes in empathy. Student-artists also provided written feedback to the professor about the course via a Likert scale and comments, and anonymous survey data were collected as part of a standard course evaluation, the results of which were shared with the professor following grade submissions. Two group interviews were held with storytellers following their participation.

## Results

*Student-artist projects.* The pandemic was both a subject of and context for projects. Project themes included personal approaches to audience connection; addressing heavy, complicated issues with compassion and lightness; and acknowledging the centrality of mental health to overall well-being. Returning to their pieces after installation required student-artists to observe public acceptance, indifference, or rejection. Below are 4 examples of student-artists' work.

**Figure 1.** *Mental Health Is Not Cosmetic*, 2021, by Bee Cortez



Courtesy of the artist.

## Media

Spray chalk on cement.

Bee Cortez approached their project through the lens of transgender rights, a movement to eliminate discrimination against the trans community. Leveraging the trans flag



colors, Cortez applied gradient spray chalk with a hand-made stencil that read “Mental Health Is Not Cosmetic.” This piece was created when the Texas legislature was actively considering transphobic legislation.<sup>6</sup> Cortez says: “This work is meant to be a blatant response: gender-affirming care is much more than cosmetic procedures. This care helps lower or eliminate dysphoria and plays a direct part in trans youths’ mental health.”

**Figure 2.** *You Are Loved*, 2021, by Elyse Garcia



Courtesy of the artist.

## Media Flier.

Exhibited during final exams, Elyse Garcia's flyer attempted to promote self-compassion among members of the higher education community. Figure 2 shows one example of her work on campus that she used to cover a White supremacy sticker made visible here by rain. Garcia says: "This assignment took place when my friends and I were experiencing

burnout from the pandemic. The work was intended to catch the eye and share affirmations that passersby can tear off and keep.”

**Figure 3.** *Open Field*, 2021, by Karina Teruya



Courtesy of the artist.

#### **Media**

Online game.

To support emotional well-being during the pandemic, Karina Teruya created a gaming platform, which she publicized on social media and which had 439 plays as of January 5, 2022. Hearing gentle music and seeing a calm animated outdoor scene, users can type worries or frustrations and watch their words slowly fade. The entered data is deleted and not accessible by the user, other users, or the artist. All users are anonymous, and the project is open media. Teruya says: “Nobody can read the messages so users can say what they want with no regrets and get weight off their chest.”

Figure 4. *On Being Whole*, 2021, by Nicholas Wong

# ON BEING

to be healthy means to be whole,  
to be whole means to be complete, lacking nothing  
to be



Courtesy of the artist.

**Media**  
Poster.



Using wobbly text to frame his piece, Nicholas Wong focused on overlapping bodies via contour lines depicting deep support and care. Wong, an art major and premed student, posted the image on his design studio’s Instagram account, @breather.studio, resulting in 66 likes and 37 comments as of January 5, 2022. He says: “Combining imagery from my studio practice with thoughts about health care, the piece considers what it means to be whole, what contributes to one’s well-being outside clinical spaces, and incorporating those qualities into health care infrastructure.”

*Student TEQ scores, ratings, and comments.* For the 13 student-artists who completed the TEQ twice, the average score increased by 2.92 from the semester’s beginning (52.46) and the end (55.38). Although this increase is modest, it should be noted that the average TEQ scores in validity studies range from 44.54 to 47.27,<sup>7</sup> so the class average was above this range before the course.

The 15 student-artists also anonymously rated both the instructor and course, unanimously providing a top rating for both on a 5-point Likert scale. Some opted to provide comments (see Table).

Table. Examples of Student Post-Course Comments
<p>“The strongest element of the class was the focus moving outside of the studio practice and showing where else art can and does exist.”</p>
<p>“I found this class to be very engaging and enriching, with a variety of projects and teachings that provided me with an array of tools to approach ethics and empathy.... Approaching vulnerable notions of wellness and personal health was daunting but gradually became more accessible as time went on.”</p>
<p>“Aesthetics of Health taught me that it’s valuable to be aware of who you are making work for, what physical space it will be in, and any implications.... But we should still be making work for us and not get hung up on what we expect others to want from the work.”</p>
<p>“I undoubtedly experienced an increase of empathy by taking this course. The most effective part of the learning experience was the class culture: collaborative and supportive—all seeking to heal and be healed.”</p>
<p>“It really showed me that art can be used to comfort and help those around you and the person inside you.”</p>
<p>“The viewer is more important for my work now than they used to be. Now when I create art I think about who it is for and how it will be perceived.”</p>
<p>“This class tangibly introduces art into real world circumstances and we are invited to see its impact. It was one of the first times art school didn’t feel self-contained in its own bubble of discourse.”</p>

*Storytellers’ comments.* Those with lived experience of cancer also overwhelmingly had a positive experience. One commented: “The emotional response [from the student-artists] was something I didn’t expect. Having a discussion [rather than sitting for a portrait in silence] was really important. You could totally see the empathy that these students had, just in the way they asked questions ... and processing it all on their end.”

Another shared: “I love the interpretations that they [the students] were able to grasp from this. It was really therapeutic.... It really helped me value it [my cancer story] more. For me, going through cancer didn’t feel like an important achievement ... but telling my story made me realize it is impactful.”

### Conclusions

There is evidence that the AOH course modestly increased student-artists’ empathy and encouraged student-artists to actualize new ideas and relationships. Student-artists judged the strengths of the course to be its variety of projects and approaches, its collaborative and supportive environment, and its real-world impact. However, the class size (15 students) was small, and the course was only one academic semester long. Nevertheless, the AOH course’s experiential framework demonstrates promise for other educational, clinical, and artistic institutions to weave lived experience of health and health care into humanities curricula, examine healing in new ways, and explore the impacts of curricula on participants, including on capacity for empathy. Further research is needed with larger samples to measure the AOH course’s impacts and to demonstrate its potential for addressing burnout and moral distress.

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**Joy Scanlon** is an MFA candidate in studio art at the University of Texas at Austin. An artist and educator, she uses pattern and its disruption to function as a stand-in for order and disorder more broadly. In reproducing and disordering pattern, Scanlon's paintings depict the tensions inherent in human attempts to structure life's chaos and make space for pleasure amidst these tensions.

#### Editor's Note

This human subjects research was reviewed and deemed exempt by the University of Texas at Austin's Institutional Review Board on August 3, 2020.

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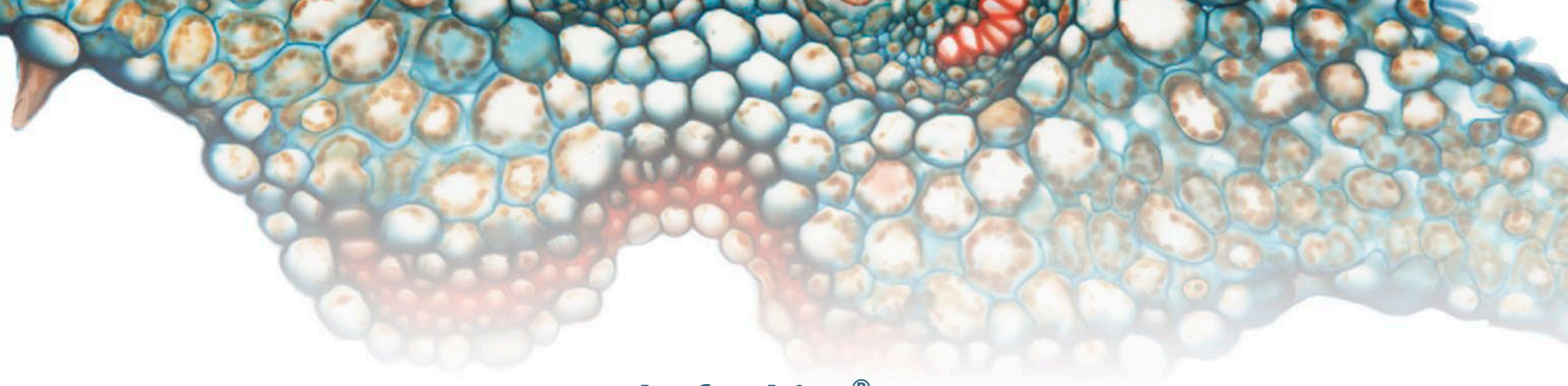
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The author(s) had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*



## AMA Journal of Ethics®

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### ORIGINAL RESEARCH: PEER-REVIEWED ARTICLE

#### Lead Toxicity and Environmental Health Justice Stories in Black and White Woodcut Portraits

Regina Idoate, PhD, Aislinn C. Rookwood, MPH, Sophia A. Quintero, MPH, Watie White, MFA, Shelby Larson, MPH, Arturo Aceves, MD, and Keyonna M. King, DrPH, MA

##### Abstract

**Background:** Omaha, Nebraska, has a lead-contaminated superfund site and substandard housing that pose risks for childhood lead exposure. Healthy Housing Omaha (formerly, Omaha Healthy Kids Alliance), an environmental health nonprofit, partnered with the fourth author, an artist, and a newspaper to raise awareness about lead poisoning by publishing portraits and stories of affected community members.

**Methods:** The authors analyzed an interview with the artist, photographs of portraits published in a local newspaper, and quotations from portrait sitters.

**Results:** Shared stories of lead exposure and poisoning conveyed in the portraiture and printmaking processes revealed structural racism as an emergent theme.

**Conclusions:** Arts-based research methods, such as portraiture, can be scaled and applied to support national and international community engagement efforts to advocate for environmental justice and public health.

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##### Introduction

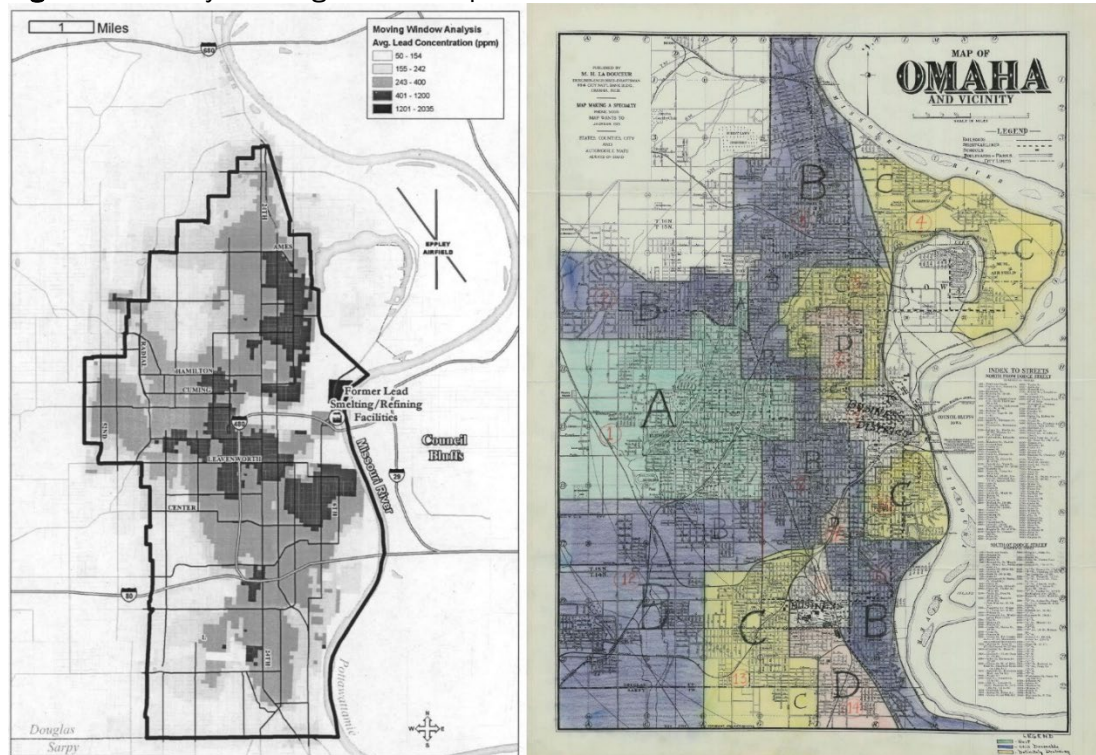
Lead poisoning is a major public health concern, with an estimated 3.6 million families in the United States at risk of lead poisoning from lead-based paint.<sup>1</sup> In addition to exposure through lead-based paint, lead exposures can occur through consumer products (eg, toys, glazes in ceramic pottery), foods (eg, spices, candy), [drinking water](#) (eg, through plumbing and utility service lines), occupation (eg, through contaminated



clothing, hair, and skin), and environmental contamination caused by industry (eg, mining and smelting).<sup>2</sup> **Lead poisoning in children** results in permanent neurocognitive impairments, increased risk of mental health disorders, delayed development, and kidney dysfunction.<sup>3,4,5</sup> Redlining, a form of structural racism characterized by exclusionary loan and zoning practices and disinvestment, has created inequities in housing and environmental pollution exposures that have resulted in lead poisoning disproportionately affecting Black children.<sup>6,7,8</sup>

Since 2003, Omaha, Nebraska, has had a designated superfund site, the Omaha Lead Superfund Site (OLS), encompassing 27 square miles radiating from downtown Omaha, where the surface soil is contaminated in concentrations that exceed 400 parts per million due to release of lead-containing particulates from the smokestacks of 2 former lead-processing facilities.<sup>9</sup> In the 1990s, approximately 25% of children aged 0 to 72 months in Douglas County (which includes Omaha) were found to have elevated blood lead levels above 10  $\mu\text{g}/\text{dL}$ .<sup>9</sup> In 1998, the Omaha City Council contacted the Environmental Protection Agency (EPA), which began an investigation in 1999.<sup>9</sup> The EPA found that residential yards in eastern Omaha, including the historically redlined and segregated Black community of North Omaha, had high concentrations of lead due to historic industrial air emissions (see Figure 1), and, as a result, this area was designated the OLS.<sup>10</sup> In 1999, the EPA began the process of lead remediation of sites in eastern Omaha,<sup>9,10</sup> and, in May 2015, the EPA entered into an agreement with the City of Omaha to conduct soil sampling and cleanup at the remaining properties.<sup>9</sup>

**Figure 1.** Healthy Housing Omaha Maps of Lead Concentration Areas in Omaha



Reproduced with permission of Healthy Housing Omaha.

A collaborative and interdisciplinary team analyzed an arts-based initiative developed to raise awareness of lead exposure and lead poisoning through local channels of

communication. The purpose of this evaluation was to better understand Omaha community members' experiences with lead exposure and lead poisoning.

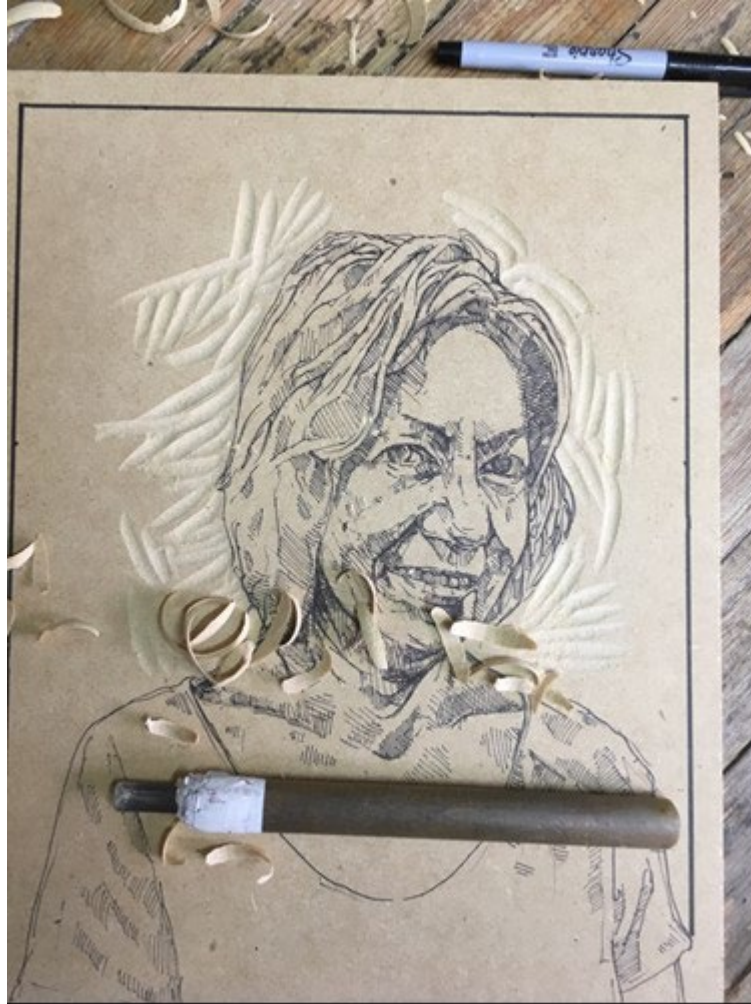
### **Healthy Housing Omaha LEAD Stories Collaboration**

Healthy Housing Omaha (HHO; formerly Omaha Healthy Kids Alliance), a nonprofit with the mission to improve children's health through healthy homes,<sup>11</sup> aims to raise awareness about environmental hazards in the home, such as lead.<sup>12,13</sup> HHO engaged in a collaborative effort with the fourth author, artist Watie White, and the *Omaha Star* to put a human face on the devastating effects of lead through a project called LEAD Stories. White is a painter, printmaker, and public artist in Omaha. The *Omaha Star*, founded by civil rights activist Mildred Brown, has earned critical acclaim for its editorials sharing Black perspectives on local and national news.<sup>14</sup> HHO leveraged the community-based participatory research approach<sup>15</sup> to engage these partners and investigate community experiences of lead exposure throughout this project.

LEAD Stories is a collection of portraits sharing the stories of people in Omaha, Nebraska, regarding their experiences of lead poisoning. HHO and White identified potential participants, and actual participants recommended additional potential participants to expand the recruitment pool through snowballing.<sup>16</sup> Individuals who identified as being affected by lead poisoning sat for a portrait; participants included caregivers of children who were poisoned by lead and the children themselves, adults living with the effects of lead poisoning, politicians legislating for policy changes to protect children from lead exposure, public health researchers studying the impact of lead exposure, and individuals who worked for the EPA or remediation services. Informed consent was obtained by all participants in this project; parents of child participants gave permission for their child's participation, and children gave assent to participate. Appropriate safeguards were put in place to protect confidentiality.

White created 13 portraits of 15 participants through woodcut, a form of a relief printmaking (see Figure 2). To create the proofs, White (1) gathered primary narrative accounts by taking photos of and conducting interviews with individuals who identified as being affected by lead poisoning; (2) created a woodcut portrait of each individual based on the primary data, drawing out the portraits on plywood and carving out the recess areas intended to be white; (3) analyzed all data as an aesthetic whole to create proofs of what was carved, rolling black ink onto a plate and running this plate through a printing press to create a black-and-white mirror image of the wood cut; and (4) shared his findings through the *Omaha Star*.

**Figure 2.** Photograph of LEAD Stories Woodcut in Process, 2017

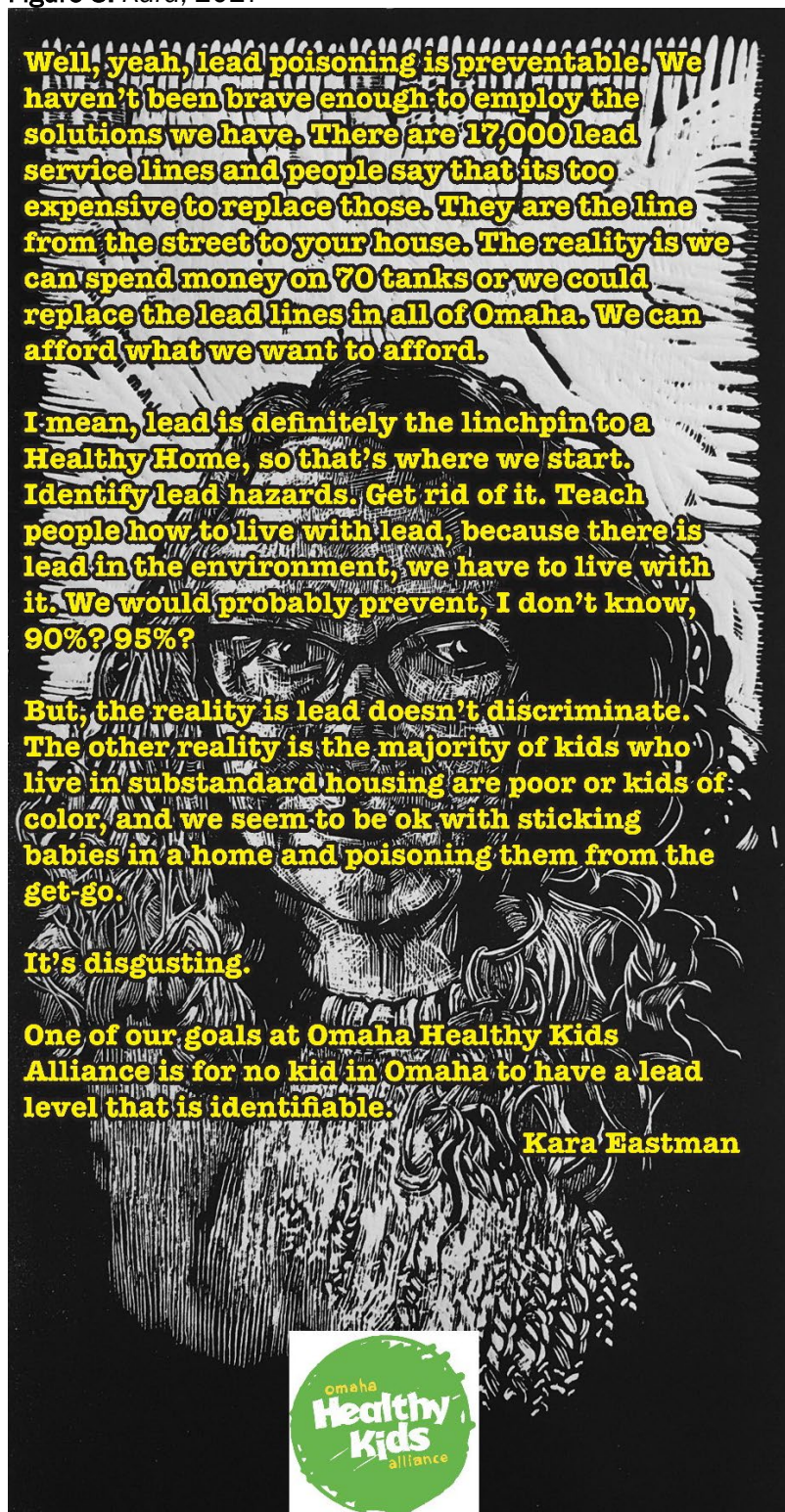


Photographer: Watie White. Reproduced with permission of Watie White and the participant.

From December 2016 to December 2017, the *Omaha Star* published one scanned proof each month (eg, see Figure 3, Figure 4, and Figure 5). The newspaper was distributed to over 50 000 residents in the area of the OLS.



Figure 3. Kara, 2017



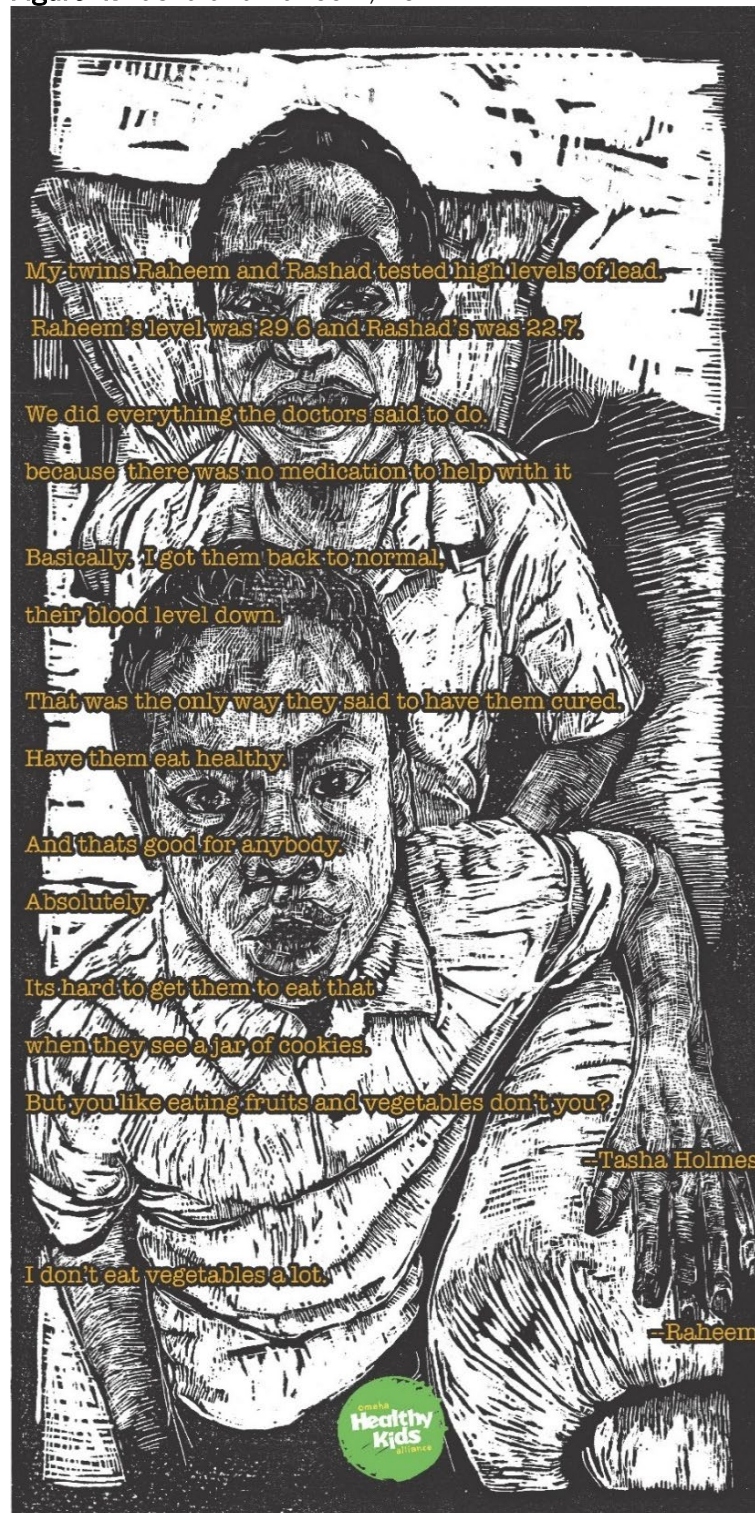
Reproduced with permission of Watie White and the participant.

#### Media

Woodcut with text overlay, 21" x 11".



Figure 4. *Tasha and Raheem*, 2017

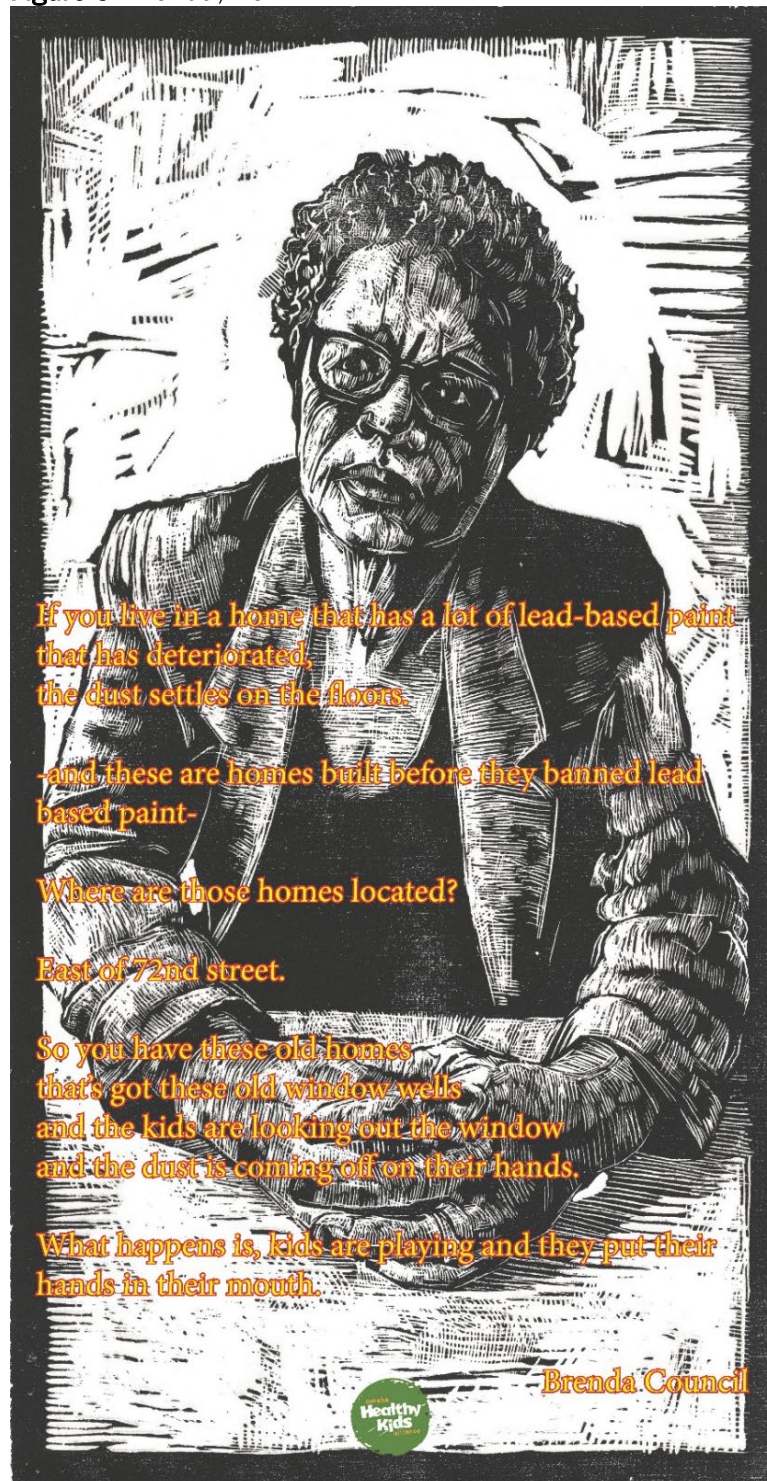


Reproduced with permission of Watie White and the participants.

#### Media

Woodcut with text overlay, 21" x11".

Figure 5. Brenda, 2017



Reproduced with permission of Watie White and the participant.

#### Media

Woodcut with text overlay 21" x11".



## Methods

**Data collection.** Public health researchers, including HHO staff, collected LEAD Stories portraits. The first author (R.E.I.) conducted an interview with White inquiring into the artistic process (from inception to exhibition) and the stories of each portrait participant, including participant background and other personal characteristics observed during the sitting. Data analyzed included photographs of 13 LEAD Stories portraits, quotations from 14 LEAD Stories participants, and a 75-minute interview with White that was digitally recorded and transcribed verbatim.

**Analysis.** Content analysis of the data sources to identify an overarching emergent theme and triangulation to validate the theme was conducted by R.E.I. and the second and third authors (A.C.R., S.A.Q.). The authors coined the term *proofing* to describe their arts-based method of evidence collection, analysis, and dissemination as applied to this public health issue. Analogous to the artist's process of creating proofs, *proofing* involves (1) gathering multiple narrative accounts of a public health issue (here, lead exposure or poisoning) through secondary artistic data (here, photographs of prints), (2) gathering primary data from the artist or researcher who documented this issue (here, by conducting an interview with White), (3) analyzing all data as an aesthetic whole (ie, using content analysis) to determine the root cause of the issue, and (4) sharing findings through relevant channels of communication. White and representatives of the HHO were consulted to confirm the accuracy of the results.

## Results

Analysis of the LEAD Stories artworks and the interview with White identified structural racism as a root cause of lead poisoning in Omaha. By sharing faces, names, and stories of people with real-life experience of lead exposure, White emphasized the history of racism that led to lead poisoning in Omaha's Black community. White described LEAD Stories as "a commonsense ... sort of approach." The portrait proofs published in the *Omaha Star* help deduce "the human impact" of lead. White explained: "in order to be able to even start to have the conversation about something practical that you can do to make this situation better, you have to be able to prove that causation [that structural racism has led to lead poisoning and related health disparities]." He said he did "all the legwork to see it, to look for it, and to find it" as he gathered, scrutinized, and organized data in LEAD Stories. As White explained, "it's like seeing ... discrimination. Once you see it, you can't not see it. Once you know it's there, you can't not know it's there. But you live in a world where it's invisible." The creation and dissemination of the proofs in LEAD Stories made structural racism identifiable as the root cause of lead contamination and exposure in Omaha (see Table).

**Table.** Descriptions of the Theme of Structural Racism

Data Source	Supporting Quotations
Artist's interview transcription	"You have to be so far in before you can see the problem. It's like seeing terrible things or seeing discrimination. What you see, you can't not see it ... you can't not know it's there.... You live in a world where it's invisible."
Portrait/narrative of HHO member working to reduce lead exposure	"The majority of kids who live in substandard housing are poor or kids of color" (see Figure 3).

Portrait/narrative of OLS community member with lived experience of lead poisoning	“My twins Raheem and Rashad tested high levels of lead. Raheem’s level was 29.6 and Rashad’s was 22.7” (see Figure 4).
Portrait/narrative of lawyer who established the OLS	“If you live in a home that has a lot of lead-based paint that has deteriorated, the dust settles on the floors.... What happens is kids are playing and they put their hands in their mouths. Where are these homes? East of 72nd Street” (see Figure 5).

Abbreviations: HHO, Healthy Housing Omaha; OLS, Omaha Lead Superfund Site.

## Discussion

We found that LEAD Stories made visible the power differential in Omaha communities that magnifies the White community’s lack of awareness of lead’s presence and long-term health impacts. This project transformed disconnect, uncertainties, confusion, and apathy into relationships, clarity, assurance, and concern by providing multiple proofs of the environmental injustices of lead poisoning, which has been called “a perpetual environmental justice issue.”<sup>17</sup> Redlining practices have resulted in Black communities living in segregated areas in older homes (built prior to 1955) with higher risk of lead exposure.<sup>18,19,20</sup> Middle-class Black children are 3 times more likely than middle-class White children to experience elevated blood lead levels.<sup>20</sup> Without LEAD Stories, the hundreds of OLS sites that still require remediation<sup>21</sup> and the Nebraskan families living in the state with the highest percentage of children with detectable blood lead levels would still remain largely unseen.<sup>22</sup> In October 2021, the Centers for Disease Control and Prevention recommended that the blood lead level limit be lowered from 5  $\mu\text{g}/\text{dl}$  to 3.5  $\mu\text{g}/\text{dl}$ .<sup>23</sup> These changes highlight the need to revisit the concerns of lead poisoning in Omaha, as well as nationally, through community-based efforts like LEAD Stories. Artists and researchers can serve as **public health advocates** who make visible the invisible determinants of health (eg, racism) and complex public health issues, such as environmental justice, through the art and science of proofing. Proof, in this case, illuminated the issue of lead as literally a black-and-white matter—in newspaper print, in woodcut portraits, and in all those affected, Black and White.

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**Editor's Note**

According to the Office of Regulatory Affairs at the University of Nebraska Medical Center, the program evaluation reported here does not constitute human subjects research as defined in 45 CFR §46.102.

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**Conflict of Interest Disclosure**

Dr Aceves is the manager of program services at Healthy Housing Omaha. The other authors had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*

**STATE OF THE ART AND SCIENCE: PEER-REVIEWED ARTICLE**

**Leveraging Cross-Campus Expertise to Contribute to Dementia Care Through Music**

Mary Perkinson, DMA, Vaishali Phatak, PhD, and Meghan K. Ramirez

**Abstract**

While there is evidence of the benefits of music for health and wellness, current US clinical practice does not commonly incorporate arts-based interventions, one drawback of which appears to be limited communication among practitioners within the arts, sciences, and health professions fields. This article shares a story of a 2-year multidisciplinary music in medicine program that aims to inspire joy and connection among people with dementia through interactive, creative musical experiences. The authors discuss the program from conception to pilot, canvass adaptations made to adhere to COVID-19 protocols, illuminate common themes of flexibility and curiosity, and share cross-campus, multidisciplinary collaboration experiences that guided the work.

**Benefits of Music**

Research demonstrates that participatory arts can enhance older adults' mood, enjoyment, memory, and overall well-being.<sup>1,2,3</sup> Music making inherently builds community, serves as an emotional and social outlet, and provides a space for creative expression. Unlike recorded music, live interactive music provides auditory, visual, and tactile-kinesthetic stimulation. More specifically, the sensory stimulation from music making has been shown to improve overall mood and sense of well-being in people with dementia (PWD).<sup>4,5</sup> Dowlen et al have shown that participatory music has 4 key benefits for PWD: taking part, being connected, affirming identity, and immersion “in the moment.”<sup>6</sup> Informed by application of Dowlen et al's research and models throughout the United Kingdom, Europe, and the United States,<sup>7,8,9,10,11,12,13,14,15,16,17,18</sup> the music in medicine program, Nebraska HeartBeats, at the University of Nebraska Medical Center (UNMC), founded in 2019, provides participant-centered, collaborative music interventions that inspire joy, reminiscing, and memory sharing through music making. In what follows, we present our motivation for developing this program as well as our experience in piloting the program with nursing home residents during the COVID-19 pandemic.

**Program Planning**

The Nebraska HeartBeats program curriculum at UNMC was developed by the Nebraska HeartBeats team—a group of experts from the fields of music, neuroscience, geriatric

psychiatry, dementia care, and music therapy—who teach, provide care, and conduct research. The program was later piloted at a regional memory care facility. The team selected musical genres and songs based on research that demonstrates that the musical memory of PWD remains relatively unaffected at all stages of dementia and that remote memories are more easily accessed by PWD than recent memories.<sup>19</sup> In this way, a beloved song from a person's youth can transport a person to a familiar place, eliciting happy or comforting thoughts. Musical selections, arranged for string quartet, were chosen to reflect popular music from the 1950s to the 1980s, or music that PWD would have enjoyed in their 20s or 30s.

Curricular goals for participants include making music in a variety of ways, engaging in meaningful ways with each other through musical collaboration, reminiscing, and sharing memories. The flexible in-person curriculum is adapted based on participant dementia stage (eg, mild, moderate, or severe) and offers music participation options that range from passive listening to active engagement, including music making with hand-held percussion instruments, improvisation, composition, singing, call and response, and dancing. The program thus provides a variety of engagement opportunities for PWD, many of whom experience a **loss of confidence** in themselves and their abilities as their disease progresses.

### **Modifications to the Program During COVID-19**

Due to COVID-19, the in-person pilot scheduled for fall 2020 was postponed, and the Nebraska HeartBeats team, of which we are a part, felt a heightened sense of urgency to provide PWD with programming that adhered to COVID-19 protocols recommended by the Centers for Disease Control and Prevention that included social distancing. During this time, PWD were negatively impacted by public health measures meant to protect them and experienced a loss of human connection and everyday social rhythms,<sup>20</sup> which may have accelerated their mental and physical decline. According to the Alzheimer's Association, there were an estimated 42 000 more deaths from Alzheimer's disease and related dementias in 2020 compared with the 5-year average from 2015 to 2019, representing a 16% increase in deaths attributable to Alzheimer's disease and related dementias in 2020.<sup>21</sup> Given the disproportionate and dangerous impact the COVID-19 pandemic was having on this vulnerable population, we worked to provide virtual programming that includes stimulation, engagement, connection, and socialization.

In spring 2021, the team modified the program to comply with COVID-19 protocols and implemented a virtual pilot with the following goals:

1. Improve the quality of life of PWD by providing a safe, supportive space to engage emotionally, socially, and musically.
2. Contribute to research on music and dementia care by adding to the literature on why music has a positive effect on the well-being of PWD.<sup>6</sup> Additionally, little research exists on the efficacy of virtual music interventions.<sup>22,23</sup>
3. Develop a best-practice model for musicians, arts organizations, and educational institutions to implement their own music in medicine programming.

### **Pilot**

Team members who are part of the University of Nebraska at Omaha Maverick Quartet used televisual technology (ie, Zoom), unmuted with video on, with 10 residents from a memory care facility. Participants, assisted by staff, remained muted but participated by watching and listening to the Zoom session of the quartet. Each of the 6, 30-minute

sessions began with quartet introductions followed by instrument introductions for participants (all of whom have an instrument pack with 6 unique instruments). Next, quartet members took turns guiding participants through 5 unique song cycles that included a song introduction, instrument demonstration, instrument modeling, participant instrument practice, and a performance of the song by the quartet while participants listened and took part with percussion instruments.

Seeking to understand the effects of loneliness and agitation among participants who engaged virtually in the program, we used the following for baseline measurements: the UCLA Loneliness Scale,<sup>24</sup> the Cohen-Mansfield Agitation Inventory,<sup>25</sup> the Montreal Cognitive Assessment,<sup>26</sup> and the Delis Kaplan Executive Function System Verbal Fluency Test.<sup>27</sup> The outcome of the interventions was assessed using the Observed Emotion Rating Scale.<sup>28</sup> Preliminary findings indicated that delivery of the music program was feasible for memory care residents. Residents were able to participate in the musical intervention delivered virtually, although there were challenges.

During the past 2 years, we faced and overcame challenges, including a lack of support staff, communication lapses, and limited campus infrastructure to facilitate and nurture cross-campus collaboration. Cross-campus collaboration would not have been possible without mentorship support and funding. Additionally, collaboration enabled us to gain valuable insight and knowledge about disciplines outside our areas of expertise. Currently, we seek funds to support continued virtual programing.

### **Authors' Perspectives**

MARY PERKINSON: As an artist, I've worked in the arts and health field for over a decade and care deeply about artist citizenry, or moving beyond the concert stage to contribute to human well-being and flourishing through reflective, empathetic, and intentional engagement with community partners.<sup>29,30</sup> This program allows us team members to contribute in meaningful, informed, and collaborative ways during a frightening and uncertain time while leveraging our expertise to contribute to research we could not pursue on our own. Mutual curiosity and flexibility contribute to the success of this collaboration.

VAISHALI PHATAK: Prescription of empirically validated treatments for conditions such as memory disorders, depression, or anxiety is the cornerstone of medical practice to protect individuals from ineffective care. Unfortunately, the current state of medicine still leaves PWD and their families facing an increased social cost. In the face of increased **risk of social isolation** and caregiver burden, there is an opportunity to bridge the gap by combining arts and science. Music is an important aspect of cultural experience as well as of every person's unique life story. Offering patients and families not just "traditional" medical prescriptions but the therapeutic benefits of music via research is an opportunity to provide greater personalized care.

MEGHAN RAMIREZ: Growing up in a home where music was ever present, it was heartbreaking for my family to know that my sister, who was born deaf, would never know music the way my family did. During one of my sister's school concerts, however, I learned to experience music in a new way. Before the concert began, hearing people were given ear plugs and informed that there would be loud music. My sister proceeded to sign the lyrics to *Fight Song* by Rachel Platten and did not miss a single word because she could feel the music. The therapeutic benefits of music became clear to me growing up with a sister who is deaf. As a first year PhD student in neuroscience, I was excited to

be a part of a program that brings neuroscience research and music together and seeks to share the therapeutic benefits of music with an underserved population.

## Conclusion

From conception to pilot, the Nebraska HeartBeats team worked collaboratively to complete a successful multidisciplinary research study. We gained new skills and knowledge outside our respective disciplines and engaged in a symbiotic relationship of give and take, listen and learn. Additionally, the team adapted to pandemic restrictions to create a pilot that adhered to COVID-19 protocols. In sum, we leveraged our cross-campus expertise to contribute in meaningful ways to the lives of PWD during a critical time.

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### STATE OF THE ART AND SCIENCE

#### What Are the Right Tools for Studying Arts in Health Interventions?

Miranda B. Olson, MSc, Stacey Springs, PhD, and Jay Baruch, MD

##### Abstract

The arts can touch places that are difficult to recognize and understand, capture in words, or measure by numbers—whether you're an artist, a patient, or an educator. This ineffability presents a dilemma for practitioners and researchers in arts in health when questions of legitimacy, efficacy, program implementation, and research funding are tied to outcomes-based research. Ethical tensions arise when traditional public health and clinical research methods are the wrong tools for capturing what's vital about the arts. This article argues that being a responsible arts in health researcher requires interrogating what counts as evidence, especially when the insistence on rigor risks oversimplifying and diminishing the power of the arts. It further argues for equity in arts in health research, including equity in investigative strategies that value both the arts and the research.

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##### What's Evidence?

Medicine aspires to be evidence based. As Guyatt et al summarized: “Evidence-based medicine de-emphasizes intuition, unsystematic clinical experience, and pathophysiologic rationale as sufficient grounds for clinical decision making and stresses the examination of evidence from clinical research.”<sup>1</sup> Evidence-based approaches require a significant investment in funding and human capital. Thinking about evidence—what counts as legitimate evidence, who decides what counts, and how we value certain types of evidence—ultimately influences which programs and research are considered worth funding. Consequently, absence of rigorous evidence, as defined by evidence-based medicine, can slow or shut down otherwise important research.

In the field of arts in health, researchers need to explore what counts as evidence and interrogate the validity of methods used to generate that evidence. According to Sackett, “the practice of evidence-based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research.”<sup>2</sup> The call for evidence all too often prioritizes results of randomized controlled trials (RCTs). However, evidence synthesis methods have expanded to include evidence generated from

observational and qualitative studies. This acknowledgement—that quality evidence for health care decision making can derive from many sources and through diverse methods—contextualizes the conversation of research in arts in health.

Rigor in research is characterized by the “strict application of the scientific method to ensure unbiased and well-controlled experimental design, methodology, analysis, interpretation and reporting of results.”<sup>3</sup> Insisting upon a framework of “rigor” without considering how this comports with arts practice, steeped in traditions and theories of its own, does not serve the purpose of generating rigorous evidence. This paper argues that authentic and equitable arts in health research requires expanding our understanding of acceptable research rigor to honor the art and the intentions of the artist.

### **Mystery of the Arts**

The creation of art is often mysterious, unpredictable, and difficult to put into words. The arts can touch places that are challenging to recognize and understand, whether you’re an artist, a patient, or an educator. Art has been called a “strange tool” that reveals what exists in the background.<sup>4</sup> It’s not a phenomenological process easily explained or measured. Art is a process that allows the art-maker and art-receiver to see themselves and the world anew. The **practice of art making** is just as much about the process as it is about the product. Art and research share the pursuit of what’s unknown, an investigation that takes us into ourselves and into the world.

The strength of arts-based interventions lies in this unmeasurable, malleable process. How do you measure meaning in a person’s life or the power of engagement, connection, and hope? By employing rigid objectives and methods in the service of rigorous outcome measures, we risk controlling for and rejecting elements of discovery in the arts. Thus, if we examine the arts through a clinical research paradigm, we risk losing the ability to identify what is vital. And if we lose what’s vital, is the evidence we pursue really evidence?

### **Mapping Evidence**

In 2016, the Rhode Island Arts in Health Advisory Group attempted to understand the evidence base in arts in health. Artists, clinicians, community members, patients, and researchers partnered to complete a scoping review and evidence map of arts-based health care interventions.<sup>5</sup> Our interdisciplinary research team focused on the importance of rigor in arts in health research in patient care and public health, noting that legitimacy, efficacy, and funding are tied to rigorous research. The scoping review allowed us to explore the existing research in arts in health; we screened over 6000 published studies employing various research methods—programmatic evaluation, qualitative methods, analysis of observational data, and RCTs. We identified 418 studies that described a population and intervention and measured at least one outcome, all characteristics of rigorous research design. The review indicated that arts-based interventions could be, and in fact had been, researched in health care and that their impacts were meaningful to patients and communities. However, this validation of arts in health research was felt by many on our team to be bittersweet.

Our discussions revealed previously unmapped ethical tensions about the relationship between methodological and statistical rigor and the mystery of the arts. In our scoping review, we excluded many fascinating studies as “research waste” because they did not

meet our criteria for rigorous research. What was lost by not including the other roughly 5500 studies in our scoping review?

Artists on our team prioritized community needs over all other aspects of our work, even over rigor. They pushed hard to have less rigorous studies included, such as work that focused on racism, social justice, recidivism and incarceration, and climate change, because studies on these topics aligned with artists' notions of individual and community health. In the end, these were excluded because they didn't fit strict definitions from public health and medicine. As a result, we discounted meaningful directions for arts in health inquiry. We ignored the artists and the artistic methods to the detriment of our research.

### **Navigating Rigor**

The arts have the power to make us uncomfortable, disrupting our world and pushing us to see in a new way. Arts in health research is challenging people in existing power structures to reconsider the definition of a valid health care intervention. However, in order for this work—which does not fit neatly within existing systems—to be valued, arts in health researchers must overcome hurdles that include negotiating both institutional forces and the unacknowledged assumptions embedded in currently accepted standards of rigorous research.

The assumptions embedded in “rigorous” research standards accommodate the needs of and benefit the academy. The artist's ethics of practice and personal ethos may not align with clinical research practices, but that doesn't mean the artist's practices are less rigorous. Yet innovative arts-based practices might be devalued in favor of less interesting work that is amenable to clinical research methods. Indiscriminate data-driven methods obscure the goals of arts in health research and perhaps distance it from the very human impact that makes arts-based work meaningful. Recognizable units of measurement that inadequately capture participant experiences risk generating evidence that is inauthentic at best and potentially unethical at its core. How should we negotiate this tension between research rigor and creative rigor?

### **An Agenda for Arts in Health Research**

To authentically capture the ineffability of arts-based interventions, research that seeks to employ methods for inquiry, discovery, and understanding must be valued. We have an obligation to pursue the best possible methods for generating evidence for arts in health. We must empower researchers to think more creatively about arts in health research rather than expecting the arts to comply with accepted standards of rigorous research. We must call for an expanded definition of research rigor—informed by respect for arts-based practices and their commitment to adaptability and iterative processes. If the arts are to be dignified and not just measured in research, we must respect the nonlinear processes critical to the arts experience, even going so far as to consider uncertainty and mystery as forms of knowledge, not as a failure of evidence.

We must **curate spaces** for interdisciplinary dialogue that explores research methodologies and challenges normative research standards. This dialogical process is only possible if funding mechanisms value meaningful evidence in nontraditional forms. Rigorous methods in arts in health research must be broadened and pluralized. However, for these valuable and deep explorations to take place, we must solidify opportunities for true interdisciplinary and inclusive dialogue that represents the rich arts in health community. We are not arguing for poor study design. Rather, we are

making space for evidence that honors the power and the mystery of the arts while demonstrating a commitment to authentic research.

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**MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE**

**Co-creating an Art Exhibition on Living Well With Dementia**

Gloria Puurveen, PhD, Susan M. Cox, PhD, Natasha Damiano, MA, Heather Neale Furneaux, MFA, and Samantha Pineda Sierra, MFA

**Abstract**

This article considers ethical questions raised during development of an online art exhibit for and with people with dementia and their care partners. This article also describes a participant engagement process emphasizing patient autonomy as a means of dismantling stigma, promoting personhood, and stimulating community engagement. This co-creative project suggests the potential for patients' art to spark attitude change and promote reciprocal, regenerative care practices.

**Including People With Dementia**

By 2030, Alzheimer's Disease International estimates that 74.7 million people will be living with dementia worldwide.<sup>1</sup> The illness is a major and increasing cause of disability associated with impairment and deterioration of memory and other mental abilities, communication and behavior disruptions, and decreased capacity for everyday activities.<sup>1</sup> With no known cure and limited efficacy of pharmacological treatments in ameliorating cognitive decline,<sup>2,3</sup> dementia significantly influences individuals', families', and communities' health and well-being. There is mounting interest in forms of psychosocial care, including arts-based interventions, which aim to facilitate "living well" with the dementia.<sup>4,5</sup> Moreover, there is now recognition that perspectives of people living with dementia should be included in effective care intervention development.<sup>6</sup>

Historically, this population has been omitted from conversations about care and from research owing to assumptions that they are unreliable narrators of their own stories.<sup>7</sup> Despite ethical and methodological challenges, the benefits of involving people with dementia in research far outweigh such challenges.<sup>8,9,10,11</sup> Participatory research, particularly qualitative and arts-based approaches, has demonstrated the efficacy of first-person perspectives in promoting agency and autonomy through aligning research methods with persons' capabilities and experiences,<sup>10,11</sup> which can help temper participants' feelings of shame, anxiety, and fear of being open about their condition. For the wider public, hearing the voices of those with lived experience of dementia can call into question false assumptions about what the diagnosis means and **diminish stigma** related to a fear of the unknown.

The commitment to more inclusive research practice is enhanced by a relational ethic of care that foregrounds real-life relationships between self and others. As such, the source of ethical commitments is located in everyday interactions, in affirming the particular over the universal and attending to the immediacy of the situation.<sup>12</sup> This orientation demands that researchers be reflective about their motivations and engage with participants’ stories in authentic ways, honoring the complexity and ambiguities of human life. In the context of research *with* (vs research *on*) people with dementia and their informal carers, relational care ethics is especially important in making space for narrative agency,<sup>13</sup> social citizenship,<sup>14</sup> and a strengths-based, person-centered approach to research ethics.<sup>15</sup> Relational understandings of persons’ agency, their human right to fully participate in society, and their capabilities, values, and preferences obligate researchers to adopt practices that support these elements of human flourishing throughout the research process.

In this article, we draw upon relational care ethics to illuminate the ethical commitments inherent in 3 issues that arose during the development of a virtual art exhibition co-created with people with dementia and their carers. The exhibit was the final phase of a 3-phase qualitative, arts-based research project focusing on the meaning of living well with dementia at the end of life. We conclude with our thoughts on how the exhibition co-creation process embodied “taking and making care.”

**Development of the Virtual Art Exhibit**

The research proceeded in 3 phases. Phase 1 included 35 in-depth interviews with people with dementia and their carers. Of these, a total of 24 people (see Table) participated in phase 2, which included 4 in-person and 4 online artmaking workshops focused on what participants wanted others to know about living well with dementia. The autonomy of each participant in creating the art depended upon their individual capacity, although we were careful not to make presumptions about capacity. Indeed, both people with dementia and their carers held varying levels of comfort in creating art, and it was up to them to let us know if and when they wanted assistance. Follow-up interviews encouraged participants to jointly and individually reflect on the creative experience, what inspired or surprised them, what was most challenging, and what provided hope.

Table. Workshop Participant Demographics		
Characteristic	Persons Living With Dementia (n = 12)	Carers (n = 12)
Female, No. (%)	4 (33)	10 (83)
Age, range (mean), y	70-89 (75.4)	41-76 (67.7)
Caucasian, No. (%)	9 (75)	10 (83)
> High school education, No. (%)	7 (58)	10 (83)
Living alone, No. (%)	2 (17)	1 <sup>a</sup> (8)

<sup>a</sup> Carer’s relative with dementia moved into a tertiary care center at the time of the workshop.

In phase 3 (developing the online exhibition), 58 artworks were selected by participants from the works they created in the artmaking workshops. It is this process of co-creation we focus on here. Originally intended as an in-person installation, the exhibit shifted to a virtual format in response to the COVID-19 pandemic.<sup>16</sup> The exhibit was co-created over a 6-month period by study participants and the research team. It features painting, collage, poetry, sculpture, photography, and a short documentary, each piece accompanied by a brief artist's statement articulating salient aspects of the work.

From the beginning, it was important to center participant voices in the conversation about living well and to find ways to engage the wider community with the work in a positive way. In addition to soliciting individual participant feedback on the exhibit before its official launch, we held 3 group discussions with participants to collectively consider the exhibition's overall aesthetic, navigability, and accessibility and coordinated an online survey. We also asked participants how well these elements communicated key outcomes related to living well and caring well at the end of life. Our engagement process focused on 3 issues whose ethical connotations emerged through relational understandings of these issues.

### **Virtual Art Exhibit Design**

Co-creating the art exhibit required careful attention to decision-making processes to actively support participants' agency and personhood and to promote community engagement while still maintaining our commitment to respectful representation. While these 3 issues are interrelated, we discuss each in turn.

*Promoting power and agency.* Dementia researchers have a long history of exerting power by limiting options and information and not ensuring that circumstances uphold the moral agency of participants.<sup>17,18</sup> In contrast, relational understandings of autonomy encourage examination of inherent power dynamics and the tacit ways that the agency of people with dementia and their carers' is supported or undermined.

In order to represent participants' artwork and stories in an honest and respectful way and to prompt dialogue about what it means to live well with dementia, the layout of the art exhibition had to be simple, self-explanatory, and accessible. It was vital to meaningfully engage participants in decision making about the exhibition's design yet not to overwhelm them with continual requests for feedback or design questions that lacked context. Thus, we created a prototype based on website design principles developed for and by people with dementia<sup>19,20</sup> to give participants an idea of how the exhibit could look. We then provided opportunities for participants to share their opinions both individually and collectively. This iterative process allowed people to weigh in on the aesthetic aspects and navigability of the exhibit, as well as on how they were represented as individuals and as a group. The most common feedback was to increase the number of visual reminders about which webpage was open and to include clear instructions for where to click to move elsewhere on the site, access more information, or return to the homepage. In seeing their feedback incorporated in the exhibit design, several participants remarked that they "felt heard" (participants 2 and 4) and that their ideas "actually meant something" (participant 3). We took care to consult participants with dementia and their carers as equal agents by making space for them to voice concerns, opinions, and ideas to the extent they felt comfortable without putting anyone on the spot. Our understanding of participants' needs and concerns was central to ensuring that participants felt at ease showcasing their work. This was one of the major takeaways: living well with dementia means having a seat at the table.

Another relational aspect of power and autonomy is that people with dementia and their carers must have the ability to determine if and when they will reveal their own (or their partner's) diagnosis. Bearing in mind that labels can reify power imbalances, polarize relationships, and contribute to unfounded conclusions about the capacity of those with lived experience, we collectively decided to refrain from explicitly identifying each artist as either a person with dementia or a carer and instead made space for participants to self-identify if they chose. As shown in Figure 1, participant preferences regarding identification were sometimes explicit in the artwork and artist's statement.

**Figure 1.** *The Caregiver's Mask*, by Marilyn



### THE CAREGIVER'S MASK

by Marilyn

I wanted my mask to show strength and order amidst the chaos, so I divided it by colour. The row of "rhinestones" represents my need to be on the "straight and narrow", to be accepted by society, to do things right, to keep calm and patient, while struggling to balance the many times I was sidetracked by unforeseen events. The tentacles start out overwhelmingly heavy, moving "out there", eventually whittling away to nothing, much like my paths of awareness, adaption, and acceptance. The butterflies epitomize the dreams which I've had to give up, weighed down by heavy bells reaching for hell. This journey sometimes felt like it took blood, sweat (blue eyelashes) and tears (yellow triangles under the eyes) but I strive to concentrate on good things (the glitter flower) and hang on to them. The outside of our masks may be what we present to the world, but the inside is what I choose it to be. Is this my future? Can I paint it with fascinating allure and enchantment? This mask now is an effigy which always reminds me that there is always hope.

Courtesy of the participant.

Our collaborative work with participants was an enriching learning process that had a profound effect on the exhibition design, which further highlights the importance of co-construction—that is, centering the exhibit on the vision and priorities of people with lived experience. Maintaining an ethical commitment to attend closely to relationships in the myriad ways these can be expressed (eg, between care recipients and care givers, participants and their artwork, research team and participants, and caring and being cared for) reinforced our awareness of the overlapping nature of and intimate connections between these relationships. Moreover, the active engagement of participants illustrated how people might live well or even thrive with dementia. This emphasis on agency and voice and its importance as a social determinant of health is, however, neglected when the value of creative expression is reduced to a specific set of measurable health outcomes.<sup>21</sup> Beyond promoting autonomy, creativity plays a larger role in promoting the personhood of both persons with dementia and their carers.

*Personhood.* Smith et al assert that "an individuals' expressive capacity, or voice, is both an interactive link to others and a type of identity authentication. Without it, individuals lose their ability to participate in their environment and assert their autonomy."<sup>22</sup> That art making is an especially powerful vehicle for promoting self-expression and social participation in people with dementia is well documented.<sup>23,24,25</sup> In developing the exhibition, as a team, we reflected on how best to **honor the voices** of persons with dementia and their carers through co-creation of the exhibition design and careful curation of the artworks. Participants were also directly engaged in editing artist statements for 2 reasons. First, researchers' words and images could unintentionally portray persons with dementia in stereotyped or stigmatizing ways.<sup>26</sup> Second, presuming persons' incapacity to participate in decision making can quickly lead to deterioration of their standing and dignity.<sup>14,27</sup>

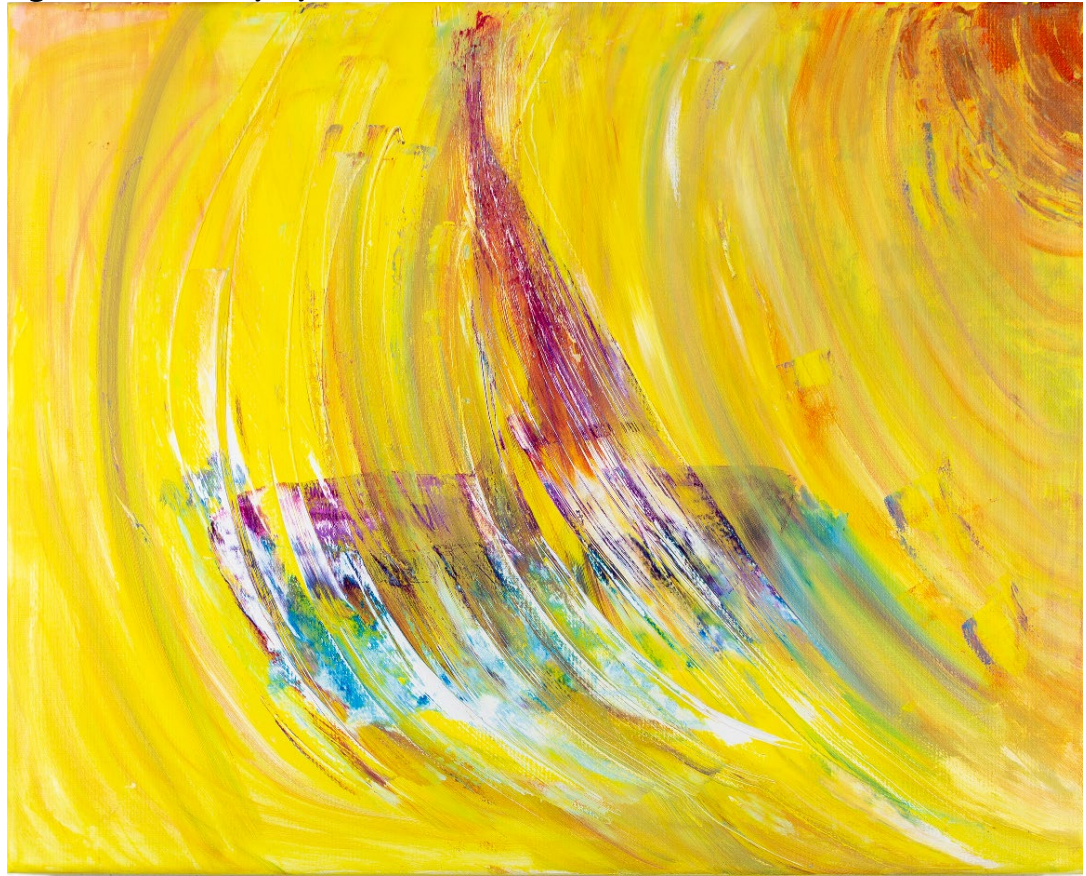
Working from a place of relational ethics enabled us to critically reflect on our own roles in “caring for” participants while promoting their personhood through actions such as not making assumptions about their preferences, supporting creative risk taking (eg, encouraging participants to use a new art form), being in the moment, and adapting the process to facilitate participation. However, what was at the forefront of our minds was striking a balance between hearing directly from people with dementia about their perspectives and hearing about their experiences through the voice of a carer. We accommodated this tension by coming at questions from several angles and engaging in an iterative process that ensured we listened to multiple perspectives and provided everyone with a chance to speak as authentically possible.

To support the ability of participants to exercise some control over the interpretation of their artworks, all were invited to write, or contribute to, a reflective statement about their creative work. However, many were hesitant to write the statement themselves, deferring to the research team for assistance. To foster a space of trust and to honor the priorities and values of each participant, it was essential to amplify participants’ voices rather than speak for them. Thus, in writing these statements, we employed multiple checks and balances. We wrote in the first person and used the participants’ own words available verbatim to us through interview transcripts and audio files. Listening to their voices and intonations and how they expressed themselves painted a picture of their personalities, values, and priorities. The words in each artist statement were arranged to reflect these unique voices and ideas.

Personhood was also reflected in the artwork itself. Each piece had a character and distinctive voice expressed through colors and shapes. Some were vibrant pieces in bright yellow and red (see Figure 2), and others were more quiet and subtle, using wood veneer in shades of brown (see Figure 3). Each piece and medium captured something unique about how the artist felt at that specific moment—and how they wanted to express it.



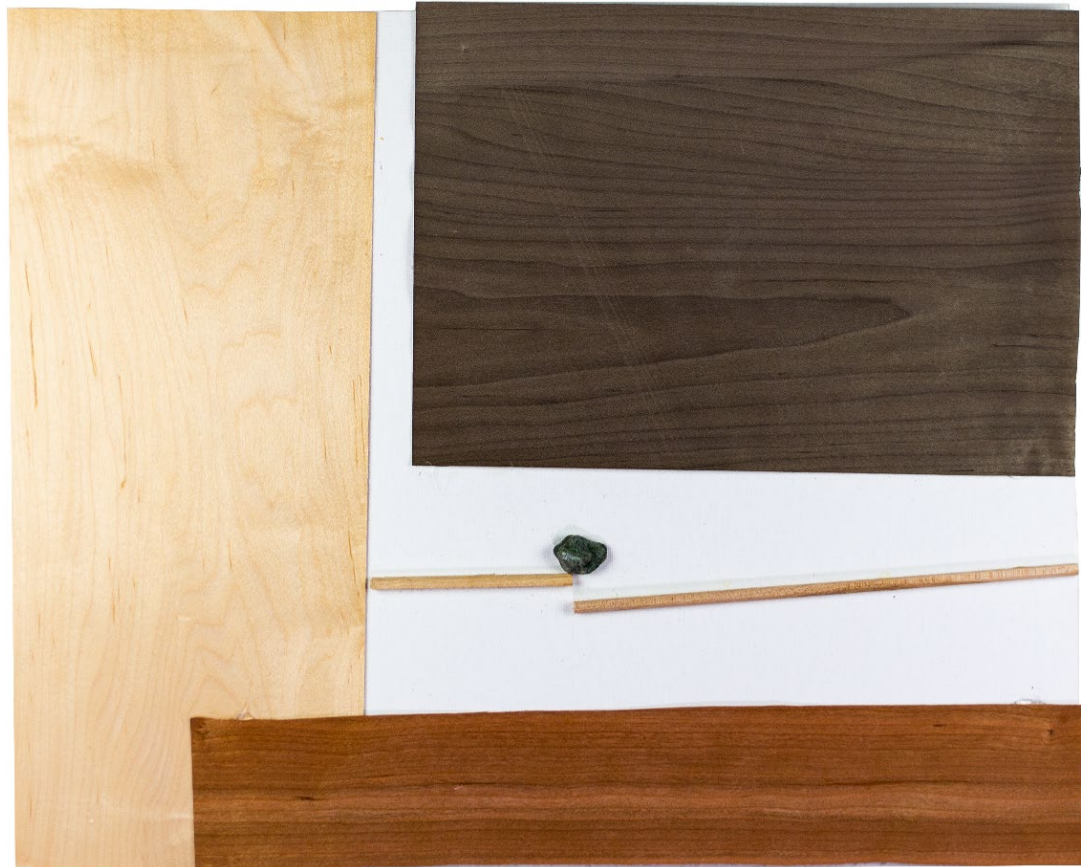
**Figure 2:** *Sailboat*, by Myrna



Courtesy of the participant.



**Figure 3** *Untitled*, by Jack



Courtesy of the participant.

*Stimulating community engagement.* With the shift from an in-person to an online exhibition, new avenues for community engagement emerged, enabling the project to reach a larger, more international audience. While exciting, this development also increased the importance of thinking carefully about intended and unintended audience impacts and their ethical implications.<sup>28</sup> Who might visit the exhibit and under what conditions? Was it likely someone with dementia or their carer would see aspects of themselves in the artwork and stories? Could the issues examined in the exhibit be triggering or seen as stigmatizing? What kinds of background information or design features would help ensure that viewers could both appreciate how the work was generated and have a safe and stimulating space in which to respond?

We developed 3 activities to encourage visitors to interact with the participants and one another. Once engaged, they could upload and share their own artwork, ask questions of the artists or comment on the art, or participate in writing a collaborative story. The goal was to provide a platform to connect people with similar experiences.

Since its launch in October 2020, the exhibition has attracted more than 2800 visitors from 38 different countries. This much-wider-than-anticipated reach allowed us to tap into a broader community perspective. To help us understand the exhibition's impact, a viewer survey was available directly from the website. As illustrated in Figure 4, a word cloud depicting the most commonly identified words used to describe the exhibit, responses to the exhibition from individual viewers were overwhelmingly positive.

beauty joy  
 inspiring colourful  
 life-giving hopeful powerful  
 insightful open collaboration brilliant  
 expression necessary living dynamic deep  
 community sharing wondering soul life  
 normalizing deeply wow talent  
 creative beautiful others  
 still peace humanity meaningful  
 awesome absolutely creativity touching  
 opportunity thoughtful honouring  
 values acceptance personal  
 challenging interpretations wonderful  
 nurturing emotions fulfillment  
 possibilities surprised  
 connection

Feedback on survey questions about possibilities for living well with dementia and how the viewer might subsequently respond to people with dementia attest to how the exhibition could also prompt change in viewers' attitudes. As one respondent noted, they now see people living with dementia "not as patients but as people first." Another respondent noted that the exhibit opens one "up to possibilities and the choice to not start with self-defeating assumptions based on what has been presented by others.... Quality of life is what you make of it as you proceed around, through, and over the potholes on the path."

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role in the exhibition on a popular radio program and at other community events; these activities showcased the power of arts-based research to convey and promote best practices in community engagement.

### Conclusion

The participant engagement processes used for both generating the artwork and procuring ongoing consent for the use of art, images, and story were strengths based and person centered. As an added measure to ethically safeguard and care well for all participants and relationships, we chose to foreground the art and artist statements that most reflected participants' relationships to the art itself, rather than delving into personal biographies. As a manifestation of an ethic of care, centering the artist statements on the art enabled us to emphasize the stories participants most wanted to share. It also framed an important space for critical reflection on our own practices of research and participant engagement, encouraging us to sit with questions of what it means to "be cared for" and to "care for well."

These 3 elements—power and autonomy, personhood, and community engagement—highlight the importance of situating ethics in the context of everyday interactions by attending closely to developing practices that support and sustain research as an act of both taking care and making care. This is a reciprocal co-creative process that asks nothing more and nothing less of us than to listen deeply and to respond with care.

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## AMA Journal of Ethics®

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### MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE

#### Wellness Through the Lens of a Medical Orchestra

Matthew J. Brooks, DMA

##### Abstract

Stress and burnout afflict medical students and professionals at alarming rates, which has led institutions to invest in counseling services and other traditional wellness programming. However, the stigma of utilizing these services permeates the medical community. This narrative explores the founding of the Nebraska Medical Orchestra—an orchestra created as a nontraditional antidote to reduce stress and burnout among health care students and professionals—and also examines the concept of wellness through interactions between the orchestra’s director and health care-related musicians.

##### Fostering Wellness

When the Nebraska Medical Orchestra was created in the summer of 2018, it was through a collaboration between the University of Nebraska at Omaha School of Music and the University of Nebraska Medical Center, facilitated by the assistant vice chancellor for campus wellness at both institutions. An amateur musician himself, the assistant vice chancellor was armed with research that showed how exposure to and participation in **arts and humanities**, such as **creative writing**, visual art, music, and dance, help to reduce symptoms of stress and burnout among medical students and professionals. Coping with a recent suicide on campus, he was focused on implementing new wellness initiatives, and the other partners at the University of Nebraska at Omaha School of Music and the University of Nebraska Medical Center were ready to make this new orchestra a reality.

As an academic conductor, I had never approached building an orchestra as a wellness initiative. My focus was always on building the finest ensemble by audition, careful repertoire selection, and high standards at each rehearsal. Yet I understood that the organization of this orchestra would prioritize accessibility and enjoyment. Therefore, I endeavored to include in the orchestra as many applicant musicians as possible without diminishing the experience of others by having too many musicians who played the same instrument, for example. I also strove to foster an environment that encouraged musical betterment instead of perfection.

In the early days of the orchestra, I spoke a lot about wellness, insofar as the orchestra was meant to benefit the musicians by giving them a creative, musical outlet that also enhanced community in a place where departmental silos and institutional ivory towers

exist. However, the musicians' eyes would roll, or their demeanor would shift, just at the mention of the word *wellness*. It made me wonder what is so taboo about wellness. I was aware of the stigma in the health care community about seeking help; could my referring to the orchestra as a "wellness activity" be triggering this concern among the musicians? I continued to ponder these questions as I rehearsed the group week after week.

### **Rewards**

I soon realized that the reward of this orchestra was threefold. First, the musicians would come to rehearsal after a long day of being in the laboratory, in the classroom, or at a clinical rotation or of providing patient care, teaching, or writing grants, among other activities. Many were racing in just at the 7:00 PM start time, others had a chance to go home and change out of scrubs, while some arrived late because that day's experiments, patient notes, or meetings took longer than expected. When the rehearsal started, though, their focus was on making music. Those tired, frazzled, and sometimes grumpy individuals were transformed into engaged, smiling instrumentalists, striving to shape the musical phrase together and working to make the swell of the crescendo just right. The hierarchies of the operating room were gone, as the respected surgeon gave way and followed the first-year medical student playing the principal part. The powerful department chair showed vulnerability by admitting that he did not know how to perform a passage and asked for help from those others around him. They were all there for music. They were, at least for the next 2 hours of rehearsal, not focusing on school or work; they were doing something that brought them joy and satisfaction.

The second rewarding aspect was something I noticed inside me, the conductor of the orchestra. Although I was working long hours outside of my regular work week to make this orchestra a possibility, I was finding great joy and satisfaction in it, even though the musical output was not equivalent to that of a highly refined orchestra. These musicians wanted to be there—there were no external forces requiring them to be there—and, in fact, it would probably be easier on their schedules for them *not* to be there. Seeing the transformation of these stressed and overworked individuals, seeing the hospital hierarchies disappear, and hearing the resulting music was a greater reward than I ever expected.

The third rewarding aspect was something organic that happens with all orchestras but was likely unique because we exist within a medical center. The community both on and off campus received the reward of live musical performance in the medical center. Our music was touching other staff, faculty, students, and even patients and families, and it brought enjoyment, artistic expression, and a unique sense of community to the medical campus. Those in academic and hospital administration were overwhelmingly present, which really demonstrated that support for this activity was sincere and the impact tangible.

### **Support**

While regular funding and support for arts and humanities initiatives on medical campuses may be slightly more common today than in the past, they are still likely an exception. However, from the initial organization of the medical orchestra, I received strong support from the highest office at both partner institutions. The chancellor—similar to a president at other universities—is an avid supporter of the arts. His support of this endeavor was unmatched. It is clear that strong leadership and institutional support are necessary for such endeavors to grow and succeed quickly. For instance,

when no rehearsal spaces were found on the medical campus, one email from the chancellor opened up spaces I never knew existed. When we needed funding for music stands and percussion equipment, he allocated the money. That said, it is important to note that gathering a small group of chamber musicians or a small, self-run orchestra can be accomplished creatively with limited or no funding. Folding music stands; free, public domain music; and empty lecture halls could make for a humble beginning to all of the positive benefits described herein.

Very quickly, I sensed that the campus community—including other administrators, faculty and staff, donors, and community arts leaders—recognized the rewards of this orchestra. While they may not have seen the individual transformations of the musicians at each rehearsal, they certainly saw the musicians' joy, felt the music's impact, and experienced a sense of community on campus while regularly attending our performances. I cannot remember any other artistic organization on either campus garnering such visible support at each performance. After one successful year of the orchestra, we received a significant operating budget from the university, which included funding for a graduate assistant in the School of Music to support the orchestra. At the end of the second year, we earned funding to create a tenure-track faculty position specifically to lead the medical orchestra, among other duties in music and medicine.

### **Reframing Wellness**

Having heard from some musicians about the stigma associated with wellness activities and the constant pressure they feel from the hospital administration to see more patients and bring in more revenue, there seems to be no simple fix for stress and burnout in the field of health care. One-size-fits-all initiatives, such as stress management training, presentations by employer counseling services, or other traditional mental health activities, might not resonate with all individuals and might carry stigma. A few musicians seemed to think that classifying the medical orchestra as a wellness initiative devalued it; "art for art's sake," they'd say.

I wonder if it is time to reframe the narrative of what is wellness and what activities can improve one's personal well-being. Exercise, knitting, journaling, painting, making music, and so many other activities can add happiness and positivity to one's life. The musicians' observed joy in rehearsals, the mental attention they needed to master new music on an instrument, and the sense of community they derived from the shared goal of ensemble music making all seem to enhance the participants' **state of well-being**. Some musicians understand this. They have shared that they enjoy the escape from routine that the orchestra brings, even if only for a few hours a week. Others simply express pure and sincere gratitude for the orchestra and the opportunity to make music each week. Even the critics of the orchestra as a wellness initiative express thanks for being able to have a musical outlet.

So, can wellness activities be things we already enjoy, which have intrinsic value of their own? Yes, they can. As we shift from the traditional narrative of wellness and learn from musicians in the Nebraska Medical Orchestra, we can see that an investment in more nontraditional arts- and humanities-based wellness activities can be integral to serving the health care community.

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**MEDICINE AND SOCIETY: PEER-REVIEWED ARTICLE**

**What Arts-and-Health Practices Teach Us About Participation, Representation, and Risk**

Sofie Layton, MRes, Jo Wray, PhD, Victoria Walsh, PhD, and Giovanni Biglino, PhD

**Abstract**

This article explores the implications of risk in arts-and-health collaborations that represent illness narratives for the purpose of engaging the public. Based on an artist's, bioengineer's, and health psychologist's reflections from pediatric and adult group workshop practice settings, this article canvasses 8 dimensions of risk that deserve ethical attention.

**Collaborative Arts-and-Health Projects**

Art in its myriad forms has the potential to bring a different perspective and language to the illness experience. Drawing on Virginia Woolf's meditation "On Being Ill," Rebecca Solnit reflects on her own experience of illness: "When you are well, your own body is a sealed country into which you need not explore far, but when you are unwell, there is no denying that you are made up of organs and fluids and chemistry and that the mechanisms by which your body operates are not invincible."<sup>1</sup> Artists, writers, and philosophers not only can draw on their creativity to articulate their own reflections on disease but also enable patients to articulate their particular experiences of disease.<sup>2,3,4</sup> These articulations often occur in a sensitive and vulnerable space—an interface between the "personal" and the "medical"—that can present risks and ethical issues requiring careful navigation.

From a theoretical standpoint, one model linking the arts with health has highlighted how different components of the artistic experience (eg, evoking emotions, stimulating the imagination, social interaction) can lead to psychological, physiological, behavioral, and social responses that are in turn linked to promotion of health and better prevention, management, or even treatment of disease.<sup>4</sup> To realize these benefits, artistic work requires careful attention to different relationships. Interdisciplinary collaborations can underpin new forms of problem solving and person-centered research and thereby an epistemological shift in arts-based research and arts-based interdisciplinary collaborations.<sup>5</sup> There is a growing evidence base of arts-based research and arts practices in a medical context.<sup>6</sup> As discussed elsewhere by 3 of the authors and colleagues,<sup>7</sup> this work must consider several important elements, including: (1) the health care setting itself, (2) aspects of production management, (3) relations



with cultural venues (when work is presented publicly) and (4) the public (patients in a health care context as well as public audiences). The authors view participatory arts-based research and **arts practices in a medical context** as a profoundly collaborative process, with participants at the core held together by a multidisciplinary team.<sup>7</sup>

**Risk in Arts-and-Health Projects**

The experiences of the authors in arts-based collaborations, particularly with regard to re-presentation of narratives of cardiovascular health and disease,<sup>8,9,10,11,12</sup> has led them to think carefully about the possible dimensions of risk and their associated ethical issues in collaborative, interdisciplinary, creative, and participant-centered work. These reflections take into account settings of engagement and art making (eg, hospital or arts studio workshop, one-on-one patient interactions), participants (eg, adult or pediatric patients with acquired or congenital heart disease, women with Takotsubo cardiomyopathy or “broken heart syndrome,” heart transplant patients), and different venues for public sharing (eg, installation in hospital settings, contribution to an externally curated group exhibition). Regardless of the specific setting or participants involved, we have highlighted 8 important considerations regarding sources of risk, their associated ethical issues, and mitigating factors, summarized in the Table.

**Table.** Dimensions of Risk, Ethical Issues, and Mitigating Factors in Participatory Arts-and-Health Practices

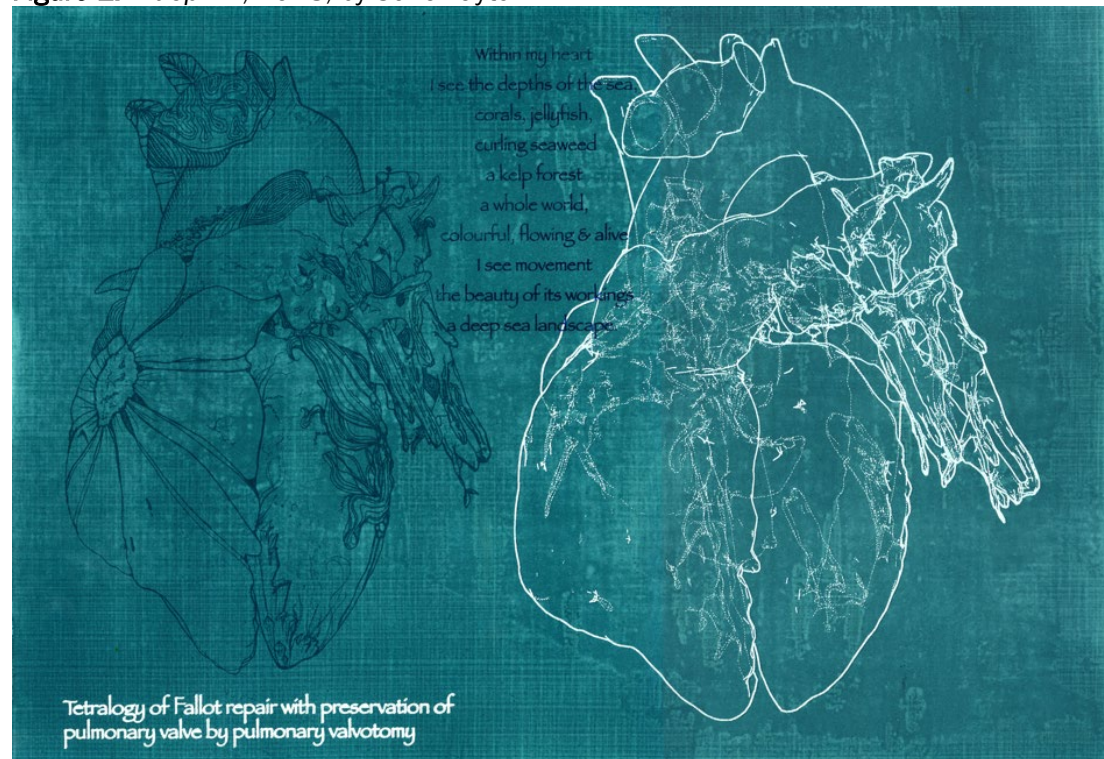
Dimension of Risk	Ethical Issues	Mitigating Factors
Using/presenting medical data <sup>a</sup>	<ul style="list-style-type: none"><li>• In rare cases, even appropriately anonymized data might be identifiable and have psychological implications for participants.</li></ul>	<ul style="list-style-type: none"><li>• Multidisciplinary team present to frame data appropriately, explain how imagery or 3D models are derived, and answer participants’ questions.</li><li>• Artist is mindful of symbolic and medical significance of imagery and models and of their value as a representation of someone’s illness narrative.</li></ul>
One-on-one interactions	<ul style="list-style-type: none"><li>• For participants, exploring concepts can be emotionally challenging.</li><li>• For the artist, lacking resources or stories on which to base the creation of artworks can risk “mining” patients for their narratives.</li></ul>	<ul style="list-style-type: none"><li>• Artist explores emotionally challenging concepts via creative activities that might generate metaphorical descriptions.</li><li>• Patients build trust with the artist while also trusting the complexity of the creative ideas that they are exploring.</li></ul>
Workshop methodologies	<ul style="list-style-type: none"><li>• The workshop should be accessible and not too strenuous or emotionally challenging for vulnerable patients.</li></ul>	<ul style="list-style-type: none"><li>• The artist should adapt the workshop methodology to accommodate participants’ needs (eg, physical disability)</li><li>• Psychologist or nurse, if appropriate, should be present.</li></ul>
Consenting	<ul style="list-style-type: none"><li>• Obtain informed consent from participants, including artists, prior to taking part in the work.</li></ul>	<ul style="list-style-type: none"><li>• Individual is told about the purpose, benefits, and potential risks of participation,<sup>13</sup> including</li></ul>

		how the workshop's content may be documented, interpreted, processed, and used by the artist and the team, and is given ample opportunity to discuss and ask questions.
Identifying suitable participants	<ul style="list-style-type: none"> <li>• Gauge individuals' emotional state and provide support.</li> </ul>	<ul style="list-style-type: none"> <li>• Ensure that the artist is aware of participants who may find the process challenging.</li> <li>• Ensure that suitable alternatives and signposting are in place.</li> </ul>
Workshop environment	<ul style="list-style-type: none"> <li>• Provide a safe environment that supports participants'—including the artist's— emotional and psychological needs.</li> </ul>	<ul style="list-style-type: none"> <li>• Provide clear communication not only during the workshop, but also before (workshop preparation) and afterwards (debriefing and reflection).</li> <li>• Facilitate open communication within the team, especially when dealing with challenging themes or potentially upsetting events (eg, death of a participant).</li> </ul>
Appropriation	<ul style="list-style-type: none"> <li>• Artist should reimagine and sensitively re-present someone's imagery or idea, without appropriation.</li> </ul>	<ul style="list-style-type: none"> <li>• Share and reexamine the narrative with participants to ensure that the artwork and subsequent exhibition reflect the individual and collective voices of those who shared their stories.</li> <li>• Make explicit from outset the authorship of the artworks developed through the workshop process and subsequent art making.</li> </ul>
Public presentation	<ul style="list-style-type: none"> <li>• Creating an artwork or a series of installations may trigger uncomfortable personal narratives.</li> <li>• Find a balance between artistic integrity and ethical appropriateness.</li> </ul>	<ul style="list-style-type: none"> <li>• Carefully consider the presentation of the artwork and the setting and how they may be interpreted.</li> </ul>

<sup>a</sup> Includes magnetic resonance imaging (MRI) and MRI-derived 3D printed anatomical models.

Arts-and-health participatory work culminating in artistic re-presentations of illness narratives can provide new understanding and perspectives on illness, but it can also pose ethical dilemmas of working in partnership with patients, using patients' medical data or creative outputs in the art-making process (see Figure 1), or sharing artistic re-presentations with different audiences.

**Figure 1.** *Blueprint*, 2018, by Sofie Layton



Reproduced with permission of GOSH Arts from Layton S, Biglino G.<sup>14</sup> © 2018 Sophie Layton. Photographer: Stephen King. The patient whose narrative this artwork depicts agreed that her image could appear in the exhibition setting and the exhibition catalogue.

### Media

Screen print on fabric, 50 cm x 70 cm.

Arts-and-health participatory work is inherently multidisciplinary, and thus many of the identified risks can—at least in part—be mitigated by having a suitable team in place, supporting team members, ensuring regular and clear communication within the team, and—importantly—building trust with and meeting the needs of those taking part in the process. Unanticipated (and unintended) risks can be mitigated by comprehensive planning and preparation and having an appropriate **multidisciplinary team** in place. For example, a trained nurse or psychologist (with some experience in participatory practices) can support the artist facilitator by identifying subtle signs of discomfort in participants and signposting resources or following up with them after the workshop, if appropriate.

Other identified risks can be preempted by implementing appropriate good practice. Establishing ground rules is very important to ensure a safe space and clarity about the potential outcomes of the work and why any form of documentation (eg, audio recording, photography) is used. Ground rules include what these forms of documentation will be used for, what will happen to any creative output, how anonymity will be protected, and appropriately consenting participants on arrival. Also important are rules about sharing information or images. Participants must understand the need for confidentiality within the group—that they are not allowed to share outside the group anything about those in the group. The artist must ensure not only that appropriate

consent for use of images for research purposes was signed by the patient when the scan was acquired, but also that any identifiable information is erased from the metadata (ie, that the images are anonymized). Although the need for formal ethical approval for research activities is clear, similar approval for engagement activities is usually not required. However, independent review of the proposed processes for ensuring the safe use of patient data, such as by an external steering group that includes patient representatives, would provide important additional oversight.

### **Building Support for Arts-and-Health Projects**

The director of a local hospital arts program, if there is one, may be a key partner in supporting the work and facilitating local relationships. Three of the authors and colleagues have also discussed elsewhere the roles of a *relational producer*, including facilitating institutional relationships in this context, but this role may depend on the scale and budget of the project.<sup>7</sup> In other cases, the scientific or medical partner(s) in the collaboration may champion the work at an institutional level.

### **Other Contexts of Arts-and-Health Projects**

These reflections stem from the authors' own experiences in a high-income country, but it is worth mentioning that arts-based approaches have been deployed for the purpose of health promotion in other settings (eg, in response to HIV/AIDS in Sub-Saharan Africa).<sup>15</sup> Given the benefits of these practices in low-and middle-income countries, consideration should also be given to the specific context, which would likely result in a more nuanced set of recommendations. In addition to risk and risk mitigation, other considerations would include access to health care and power dynamics, as well as identifying culturally accepted artistic and creative processes that do not require specialized equipment and materials. For example, a body mapping exercise using basic art materials might lead to the participant's insightful and deep reflection on the body, which could be framed medically (see Figure 2).

**Figure 2.** Body Mapping Creative Activity in a Workshop Setting



Reproduced with permission of GOSH Arts from Layton S, Biglino G.<sup>14</sup> © 2018 GOSH Arts. The pictured participant consented to being photographed.

Finally, the COVID-19 pandemic leads to specific considerations of conducting this kind of work online. In a **virtual setting**, nonverbal reassurance is very limited (if not entirely absent) and group interactions are also limited. Simple actions, such as an introductory phone call to a potential participant, allow the workshop facilitator to become more familiar with an individual's narrative and to flag any accessibility needs. The authors acknowledge that the online workshop encounter merits its own discussion once more experience has been gathered in this setting.

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technologies and creative practices to represent health and disease in new ways and spark new conversations in society.

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**ART OF MEDICINE: PEER-REVIEWED ARTICLE**

**What Lawrence's Story Tells Health Researchers About Arts-Based Interactions**

Mark Gilbert, PhD, Regina Idoate, PhD, Anthony Ryan, MD, and Kenneth Rockwood, MD

**Abstract**

In arts-based-research, knowledge and meaning emerge from people's experiences of being in dynamic, ambiguous, intentional, and ethical relationships with each other and the arts. This case study draws on Launer's "7 C's" (context, conversations, curiosity, complexity, challenge, caution, and care) to understand the aesthetics (shape and form) and ethics of relationships between an artist-researcher and patient-sitter in portraiture-based medical research. This case supports the 7 C's being embodied in the art-making process, as the approach can usefully frame ethical challenges and rewards of portraiture-based health research for artist-researcher and patient-participant.

**Care**

Ethics of care (EoC) is a normative ethical framework that views moral action in terms of interpersonal relationships, with care and benevolence as core virtues. Because this ethical framework reflects the relationship between carers and patients, we decided to explore its usefulness for artist-sitter and researcher-participant relationships in a portraiture-based medical research (PBM) study.<sup>1</sup>

Launer has proposed that context, conversations, curiosity, complexity, challenge, caution, and care (the "7 C's") can help scholars understand the relationships between doctors and patients.<sup>2,3</sup> Since many of these themes overlap with EoC, we decided to use Launer's 7 C's to explore the EoC in the interactions and relationships between the first author—Scottish artist-researcher, Mark Gilbert (M.G.)—and sitter-participant, Lawrence. This case report was drawn from the Giving, Receiving, Observing and Witnessing Care (GROWing Care) Study, which investigated the experience of older adults and their partners in care.<sup>4</sup> We examined artworks, transcripts from conversations, and semi-structured interviews between artist-researcher and sitter-participant, as well as artist journal reflections.

**Meeting Lawrence Present**

M.G. met Lawrence, then 91 years old, after Lawrence's appointment at a memory clinic for subjective memory complaints. Although Lawrence's test results showed no sign of

dementia, his geriatrician asked him to consider participating in the GROWing Care Study.<sup>4</sup> Lawrence had painted with watercolors, was curious about the study, and consented. From 2018 to 2020, M.G. and Lawrence worked on a series of portraits recording Lawrence's life journey—from his leaving England (see Figure 1), to his immigration to Canada, through the emotional journey of grieving the unexpected deaths of his wife, Dorothy, and oldest daughter, Penny.

**Figure 1.** Lawrence in his 20s, as a Competitive Road Cyclist in England



Photographer unknown; courtesy of Lawrence.

**Media**  
Photograph.



Lawrence shared stories about his past, future, health, illnesses, loves, and losses. For example, M.G. learned that, following the deaths of Dorothy and Penny, Lawrence stayed with his younger daughter, Patricia, and her family. Patricia, as Lawrence's primary caregiver, also consented to participate in this study and sat for M.G. for her own portraits (see Figure 2).

**Figure 2.** *Patricia, Lawrence's Younger Daughter, 2018*



Courtesy of Mark Gilbert.

**Media**

Pastel on paper, 35" x 37".

**Getting to Know Each Other**

As Lawrence sat, his big hands nervously fiddled with his shirtsleeves (see Figure 3). The rapid intimacy engendered during the initial sitting might have felt somewhat awkward,



but it facilitated a more trusting relationship between artist and sitter, both of whom expressed themselves freely. Lawrence shared that Dorothy and Penny had each died of cancer within a few months of each other. Penny, Lawrence explained, following a difficult birth in England, was left with a severe cerebral palsy that prevented her from walking, despite her above-average intelligence. When Dorothy became a powerful campaigner for disability rights in the Canadian Maritimes, Lawrence maintained his primary role as caregiver to Penny.

**Figure 3.** *Portrait of Lawrence at Home, 2018*



Courtesy of Mark Gilbert.

**Media**

Pastel on paper, 63" x 53".

Lawrence often brought the conversation back to Penny. At times, M.G. observed him becoming quite emotional and visibly upset when talking about her. Lawrence's sorrow and grief seemed to be assuaged by a palpable pride in all that Penny had achieved. Penny lived life to the full, earning a university degree in commerce, getting married, and winning prizes for sports. Lawrence stated, Penny "could do anything ... she wanted to do."

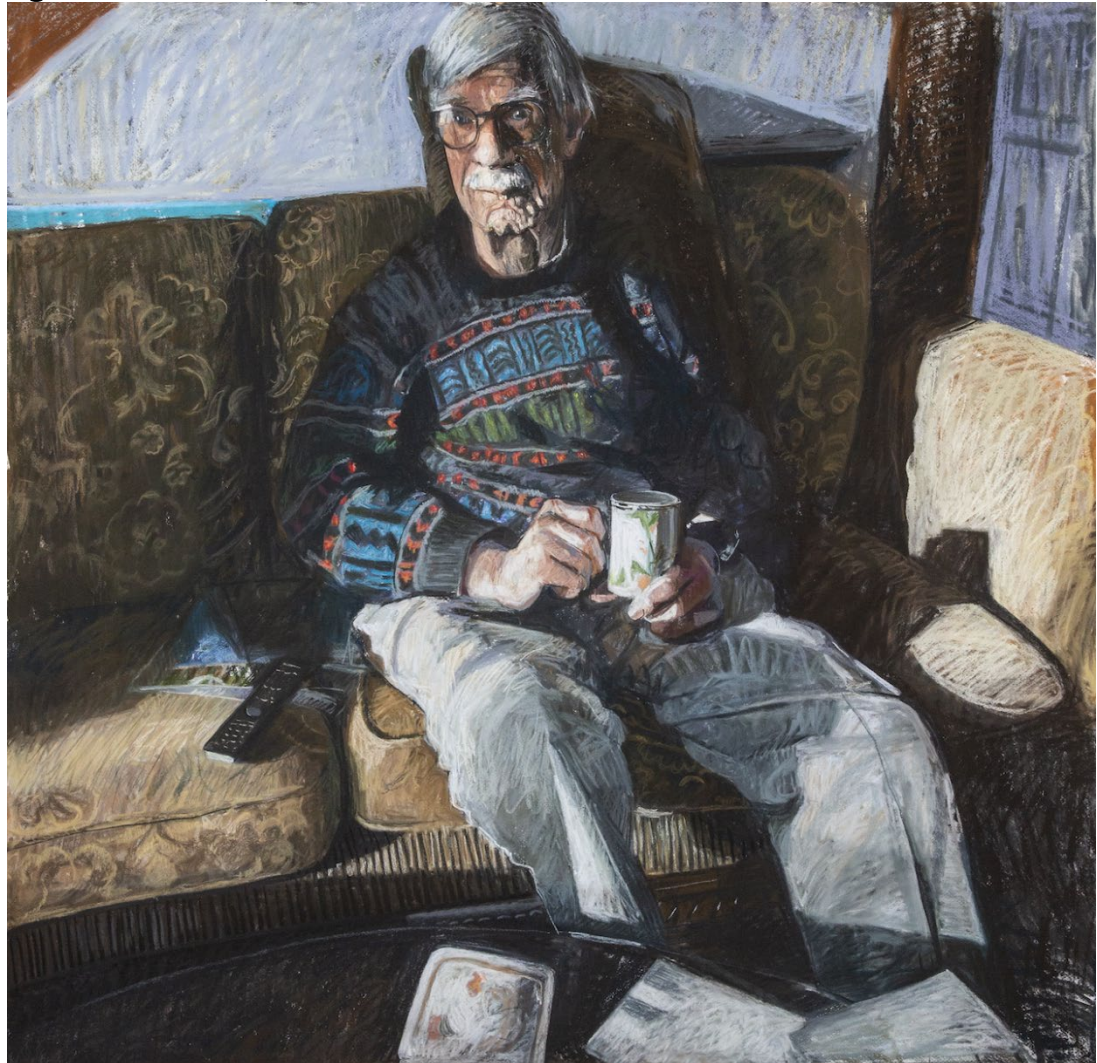
M.G. shared with Lawrence his own story of growing up in Scotland. During the study, M.G.'s father, Norman Gilbert, who was also an artist,<sup>5</sup> died, and M.G. often reflected on this loss with Lawrence. Lawrence was the same age as M.G.'s father. Despite the many years difference between Lawrence and M.G., they recognized their shared artistic and UK heritage and their recent bereavements. These conversations illuminated their shared interests and generated greater mutuality as they worked together to make portraits.

### **Following Lawrence's Story**

Launer described curiosity as "emotional engagement" in "a focused and committed interest in where the story might go."<sup>2</sup> Curiosity was critical to building the relationship between M.G. and Lawrence and to creating the portraits. M.G. noted in his journal: "I continue to measure, and try to maintain a 'searching' element to the marks I make, jettisoning all preconceptions ... trying to just respond to Lawrence and the pose."

Being positioned in the artistic research process invited Lawrence and M.G. to think about the portraits from different viewpoints. Lawrence noted: "My energy has got your portrait onto the paper ... it guides your hand" (see Figure 4). M.G. journaled: "I tell him [Lawrence] during the next break that I am having problems with the composition and proportions of his portrait. Lawrence seems to relate to my problem, and comes over to look at the drawing and offers me advice ... he suggests that the head is too big for the shoulders, and he feels 'it is a shame to change the head, because it is good.'" Inquisitively, he went on to say, "sometimes you have to make it wrong so that it looks right." Their mutual curiosity and openness facilitated co-creation of the portrait.

**Figure 4.** *Lawrence II*, 2019



Courtesy of Mark Gilbert.

#### **Media**

Pastel on paper, 53" x 51".

#### **Navigating Each Other's Boundaries**

Complexity engenders a "an infinite and unpredictable dance of interactions."<sup>2</sup> Both artist and sitter engaged in the process, not knowing the end at the beginning. M.G.'s choice to work in pastel allowed for experimentation and improvisation of a drawing with the color and richness of a painting. M.G. strived for every mark to be an authentic response to Lawrence. Lawrence remarked: "As an artist, I can leave out things that I don't like, and change things." However, he recognized that "if you're trying to do the portrait of my life then there's something missing." When M.G. nervously showed the drawings to Lawrence, he responded, "I look sick." However, M.G. was reassured when, at a later session, Lawrence viewed these portraits again and said, "the whole point ... is to be as honest as possible." Their honesty supported their relationship in co-creating portraits by establishing trust and acknowledging challenges.



### Story Evolution

Lawrence and M.G. had been working with each other for 9 months when M.G. received a call from Patricia, who said that Lawrence had fallen at home and broken his hip. Initially, Lawrence struggled physically to recover from hip surgery. As is not rare at his age, despite being in reasonably good health, Lawrence experienced early postoperative delirium. Lawrence described how frightening were the hallucinations he experienced and his frustration that nobody took him seriously when he tried to talk about them.

Lawrence felt “despondent” during the early days after the surgery. At times, although he grew tired of talking, he was still happy to be drawn (see Figure 5). As he lay in bed, looking frail and suffering from the effects of his medication, he communicated doubts: “Why do we go through all this.... What’s the point? Is it going to do any good?... Maybe it’s better to ignore it and just keep going. You keep going and then you’re not there, and then everything is just back to normal.” Nevertheless, Lawrence recognized the ever-evolving **nature of his story**, stating: “Tomorrow I’ll probably change and move on from this despondency.”

**Figure 5.** *Portrait of Lawrence in Hospital Following His Fall, Recovering From His Surgery, 2019*



Courtesy of Mark Gilbert.

**Media**

Pastel on paper, 63" x 53".



### Trusting the Process and Knowing When to Stop

In his journal, M.G. wrote: “even the challenges and discomfort I feel while making the drawing, are instilled with fears that I am able to share and overcome with Lawrence.” Practicing caution, M.G. monitored his own and Lawrence’s **emotional responses** and recognized when to stop questioning, stop probing, and stop analyzing.<sup>1</sup> Working in a clinical context required M.G. to practice reflexivity, sensitively reflecting on his role in his interactions with Lawrence, while maintaining a mindful awareness of Lawrence’s needs and willingness to continue to engage. M.G.’s fears as he started each portrait were tempered by the presence of Lawrence. Together, the two negotiated the boundaries of the research and the art.

### Relationship and Compassion

Launer wrote: “None of the ‘C’s’ will work in the way intended unless the person applying them is careful, attentive and kind.”<sup>1</sup> Care is at the heart of the practice of medicine and, in our opinion, was central to the interactions in this PBMR project. In his journal M.G. wrote: “I am sure that the sharing and collaboration in the [portrait] process is full of compassion.” For both artist and sitter, the portraiture process created a relationship in which care for one another and for the images themselves was foundational to their partnership. We subscribe to Lawrence-Lightfoot and Davis’ statement that “it is in the building of relationships that the portraitist experiences most pointedly the complex fusion of conceptual, methodological, emotional and ethical challenges.”<sup>6</sup>

### Conclusion

Attending carefully to relationships is foundational to EoC or any work of co-creation. EoC centers on clinical interactions, which can engender co-creation of knowledge, to improve outcomes and satisfaction with care.<sup>7</sup> Recognizing the 7 C’s not only in doctor-patient relationships in health care, but also in artist-sitter or researcher-participant relationships—particularly in **portraiture-based medical research**—can help those involved in the interactions to develop relationships that support a more ethical creative process and can lead to mutual understanding, richer findings, and more valuable outcomes.<sup>7,8,9</sup>

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**Editor's Note**

The Nova Scotia Health Authority Research Ethics Board approved this research in 2018.

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Dr Rockwood has asserted copyright of the Clinical Frailty Scale through Dalhousie University. He is president and chief science officer of Ardea Outcomes, which in the last 3 years has had contracts with pharmaceutical and device manufacturers (Hollister, INmune, Novartis, Nutricia, Roche, Takeda) on individualized outcome measurement. In 2020 he attended an advisory board meeting with Nutricia. He is also associate director of the Canadian Consortium on Neurodegeneration in Aging, which is funded by the Canadian Institutes of Health Research (CAN-137794), the Alzheimer Society of Canada, and several other charities. He receives research support through grants from the Canadian Institutes of Health Research, the Canadian Frailty Network, Research Nova Scotia Foundation, Nova Scotia Health Research Innovation, the Dalhousie Medical Research Foundation, the University Internal Medicine Research Fund, and the Fountain Family Innovation Fund of the QEII Health Science Centre Foundation. The other authors had no conflicts of interest to disclose.

*The viewpoints expressed in this article are those of the author(s) and do not necessarily reflect the views and policies of the AMA.*



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## ART OF MEDICINE: PEER-REVIEWED ARTICLE

### Art and Poetry in an NHS Hospital's Elevator Bank

Sue Ridge and John Davies

#### Abstract

*Our Storeys* is a “social wallpaper” installation combining poetry and visual art on 4 walls covering a 4-story elevator lobby in a hospital entrance. This article considers how the artists sought to create a work that connected with community members so that they, in turn, connected with their hospital. The installation is informed by “These Are the Hands,” Michael Rosen’s poem celebrating the 60th anniversary of the founding of the National Health Service, in which each line relates to all hospital workers.

#### Hospital Environments

Florence Nightingale improved the physical environment of Victorian hospitals through light and fresh air. In the same way today, artists can bring “the outside in” to freshen and reinvigorate the culture of health care institutions through empathetic engagement with patients, staff, and people who live locally.

Lead artist Sue Ridge and poet John Davies collaborated on a major arts project, *Our Storeys*, at North Middlesex University Hospital (NMUH), London, which was completed after 4 years in 2013 (see Figure 1) and is the basis of their book by that name.<sup>1</sup> The project sought to demonstrate the therapeutic, aesthetic, and **social impact of artists and their art** in a health care environment and on all the different people who move through it.

Figure 1. *Our Storeys* Book Cover

# Our Storeys

## Art and Poetry in Healthcare



Reproduced with permission of the authors from Ridge S, Davies J.<sup>1</sup> © 2014 Sue Ridge.



### The Brief

Part of the French-owned Bouygues Group that operates in over 90 countries, Bouygues UK built the new NNUH in Edmonton, London, between 2009 and 2013, reconstructing a hospital first built in 1842 as a workhouse for the local poor. Bouygues UK commissioned Sue Ridge to lead the creation and curation of artworks for the new hospital, and Sue invited poet John Davies (aka Shedman) to collaborate on an art and poetry project for the hospital's main atrium and waiting areas. The brief to John and Sue was to create a work that connected with local people so that they, in turn, connected with their hospital. Sue and John named the project *Our Storeys*, deliberately reflecting the objective to record and store stakeholder stories about the hospital in an artwork extending over 4 levels of the new hospital building.

### The Process

Sue and John had previously worked together on *From the Outside In*, a project that explored the physical, psychological, and emotional responses of patients and staff to navigating hospital sites in Sussex at Eastbourne and Hastings, with a focus on arrival, waiting, and departure. In his alter ego as Shedman, John used a simple wooden shed as the locus of positive research interaction with patients, staff, and visitors. He had honed this approach over numerous installations and residencies at literary festivals, events, and special projects.

For *Our Storeys*, Sue and John again used a simple wooden shed as the “strange attractor” for research engagement with stakeholder audiences. The material harvested provided inspiration and content for the visual and word-based artwork they subsequently developed, which featured the hospital's history, captured its day-to-day experience, and reflected the local communities it serves.

An exploration of the deep connections between community and hospital informed the artistic process, including the **hospital's history** and the structures that had filled its earlier place and space—from the Victorian workhouse to the 1960s tower block. Inspiration was also provided by the cluster of famous poets who had connections with the area, including John Keats as a young medical student, Thomas Hardy, concrete poetry pioneer Bob Cobbing, and Irish American Michael Donaghy.

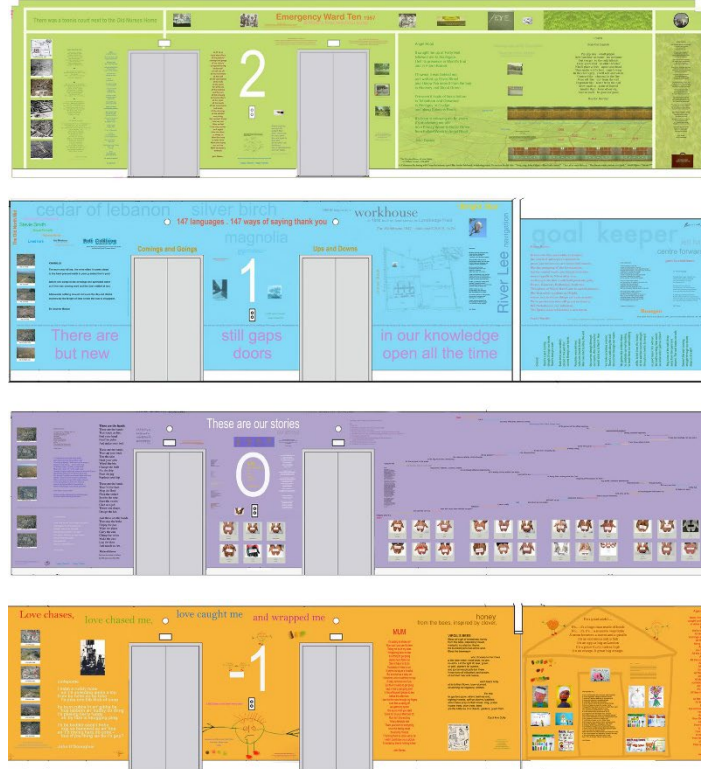
NNUH is a busy general hospital serving ethnically and linguistically diverse communities. John recommended that most of the verbal content be in English. This choice may seem strange, given the highly multicultural nature of London. But with more than 300 languages spoken in local schools,<sup>2</sup> the use of many different languages had the danger of being exclusive in itself. As the aspirational learner's language, English provided a connecting thread. And to overcome any language barriers for the largely transient population of ethnic minorities, Sue created patterns, shapes, and icons to convert the communities' stories—“our stories”—into “our storeys,” helping these patients to make the new hospital their own.

Completed in 2014, *Our Storeys* has 2 components. The first is a Poetry Wall, using digitally printed wallpaper, which rises up the lift lobby walls in the 4-storey entrance atrium. The second is a series of 5 photo-text images for the hospital waiting areas with specially written sonnets by John, alongside poems by other poets from the Poetry Wall and amplified by graphics and photographic images made by Sue.

## The Work

The Poetry Wall was installed over the lift lobby walls in the 4-storey entrance atrium (see Figures 2 and 3), papered with what we called “social wallpaper” that was printed with stories, poems, and texts collected in the shed and with Sue’s graphic artwork. The wallpaper represents a palimpsest of history, inspiration, and experience where, across the 4 levels, different elements interrelate and enrich one another. This richness is not meant to be transparent but to be lived with and absorbed over time, coexisting with the communities that gave rise to it. So, staff or visitors waiting for a lift may be drawn to one text or image on one day but to others when waiting at other times.

**Figure 2.** *Our Storeys*, Installation View of Elevator Banks 1



Reproduced with permission of the authors from Ridge S, Davies J.<sup>1</sup> © 2014 Sue Ridge.

**Figure 3.** *Our Storeys*, Installation View of Elevator Banks 2



Reproduced with permission of the authors from Ridge S, Davies J.<sup>1</sup> © 2014 Sue Ridge.

The Poetry Wall includes pictures of the design and construction of the new hospital, as well as references to the building's Victorian origins and décor, its stint as the first-ever British TV hospital (in *Emergency Ward Ten*, a soap that ran from 1957 to 1967), and a full-size tennis court next to the former nurses' home. The Children's Department lobby on the lower ground floor incorporates cartoon drawings from the community questionnaires.

To develop another language of engagement with NNUH staff, Sue used "These Are the Hands," a poem written by Michael Rosen to celebrate the 60th anniversary of the founding of the National Health Service (see Figure 5). The poem summarizes the many different types of people and jobs that contribute to a large hospital's day-to-day functioning, which, in these Covid times, has become even more poignant. Each line of the poem says what the hands are doing: hands that "find the pulse," "wheel the bin," "fill the bath," or "touch us last."<sup>3</sup>

**Figure 4.** “These Are the Hands”

These are the hands  
That touch us first  
Feel your head  
Find the pulse  
And make your bed.

These are the hands  
That tap your back  
Test the skin  
Hold your arm  
Wheel the bin  
Change the bulb  
Fix the drip  
Pour the jug  
Replace your hip.

These are the hands  
That fill the bath  
Mop the floor  
Flick the switch  
Soothe the sore  
Burn the swabs  
Give us a jab  
Throw out sharps  
Design the lab.

And these are the hands  
That stop the leaks  
Empty the pan  
Wipe the pipes  
Carry the can  
Clamp the veins  
Make the cast  
Log the dose  
And touch us last.

“These are the Hands” (© Michael Rosen, 2008) is printed by permission of United Agents ([www.unitedagents.co.uk](http://www.unitedagents.co.uk)) on behalf of Michael Rosen.

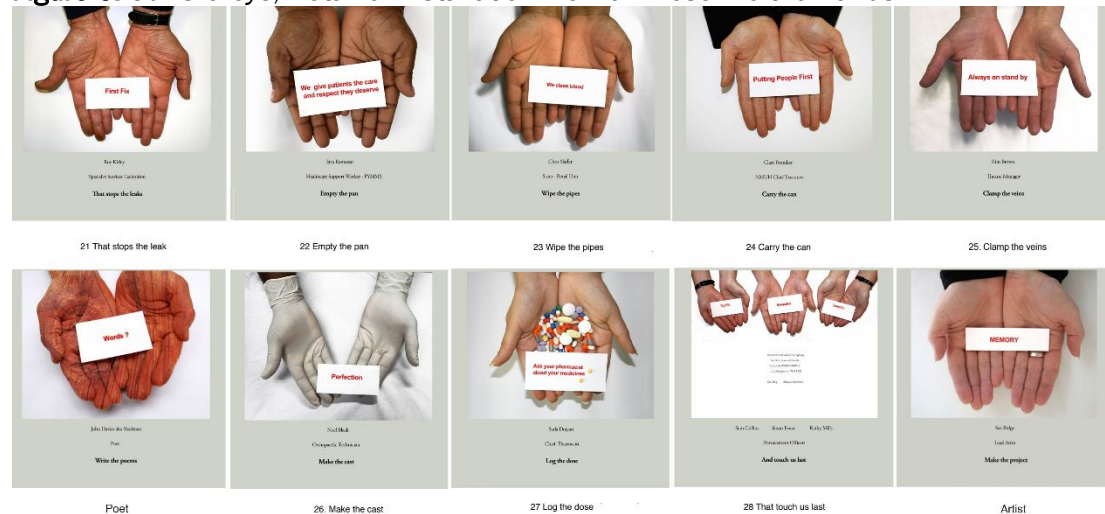
Sue photographed the hands of identified hospital workers holding a few words they wrote about their work. She then combined these images with the lines of Michael Rosen’s poem to create a memorable display (see Figure 6).



AMA Journal of Ethics, July 2022



**Figure 6. Our Storeys, Detail of Installation View of These Are the Hands**



Reproduced with permission of the authors from Ridge S, Davies J.<sup>1</sup> © 2014 Sue Ridge.

John Davies wrote a series of poems on a common theme (“the chase”) that rise across all 4 floors of the artwork in an interlinked stream. The common theme connects a number of facets: the local area Enfield Chase, once a royal hunting ground; the chase of everyday life at the hospital—the hunt for resources, time, staff, and the helter-skelter energy of hospital activity; the way the artworks are chased into the walls; and, ultimately, the way everyone in the hospital is chased or is chasing love, care, and goodwill. John invited other contemporary poets connected to the area to contribute work, including former poet laureates Carol Ann Duffy and Andrew Motion, as well as the Tottenham Hotspur football team’s poet in residence, Sarah Wardle.

For the hospital’s waiting areas, Sue prepared “visual musak” based on a series of sonnets John wrote about the seasons (partly because Vivaldi’s *Four Seasons* is often played in waiting areas or as “music on hold”). Sue included poems from the main Poetry Wall in the Children’s Department, such as Carol Ann Duffy’s poem, “Virgil’s Bees,” to create visual and verbal echoes for the Early Pregnancy Advice waiting area (see Figure 7).

**Figure 7.** *Our Storeys*, Installation View of the Early Pregnancy Advice Waiting Area



Reproduced with permission of the authors from Ridge S, Davies J.<sup>1</sup> © 2014 Sue Ridge.

Overall, the artist-poet collaboration was a highly successful process, but it relied on an empathetic engagement with people from all walks of life.

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**Sue Ridge** is a London-based artist whose practice often concerns expanding audiences in the arts. Many commissions have been situated in the public domain, particularly the hospital environment. Inspiration for her artwork is often evoked by playfully subverting the site, discovering patterns of the everyday, and mapping the overlooked and strangely familiar.

**John Davies** is a writer and poet whose work explores the changes that shape our lives. His alter ego, Shedman, is a literary funster, the original poet in a shed who uses sheds as the focus for a unique interaction with people of all ages, cultures, and backgrounds. He is also the author of *Nest: New and Selected Poems* (Red Hen Press, 2017).

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## AMA Journal of Ethics®

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### ART OF MEDICINE: PEER-REVIEWED ARTICLE

#### What Pandemic Portraits Illuminate About Balancing Vulnerability and Inurement

Brooklyn Larimore, Mark Gilbert, PhD, and William M. Lydiatt, MD, MBA

##### Abstract

Portraits of clinicians quickly became emblematic of what the COVID-19 pandemic has demanded of everyone, especially caregivers who witnessed deaths likely unprecedented in number during their careers. This article describes an arts-based research protocol exploring portraiture as a medium for representing and understanding clinicians' experiences, mostly during the first year of the pandemic. This article presents *Shadow of Corona*, a large oil on canvas portrait commissioned by the *AMA Journal of Ethics* to commemorate the American Medical Association's 175th year. The article also includes *Sarah*, a charcoal study drawing for that portrait, and *Front Lines of Care*, a 3 by 3 collection of 9 smaller oil on canvas portraits.

##### Arts-Based Health Research

The Covid-19 pandemic has shed a harsh light upon difficulties in health decision making. Science is necessary but not sufficient to address the complexity and nuance needed to navigate an ever-evolving and uncertain climate.

Arts-based research captures what science cannot, as it seeks to depict subtle yet complex interactions, ambiguities, and vulnerabilities in a perceptible way. Art's capacity to adumbrate—or faintly indicate, foreshadow, or symbolize—is what Barone and Eisner say allows meaning to be derived from art.<sup>1</sup> The nuance of art invites audiences to experience the world in ways unseen or previously inaccessible.<sup>2</sup> Portraiture, an emerging form of arts-based research, “bridge[s] the realms of science and art.”<sup>3</sup> It seeks to study relational and aesthetic aspects of clinical interactions in medicine, such as trust, vulnerability, and reflection—qualities required for successful artist-sitter and doctor-patient interactions.<sup>4</sup> Although portraiture is not intended as therapy, the relationship established **between artist and sitter** in portraiture allows the healing power of stories to be shaped and shared visually and verbally.

##### Sarah

Sarah was recruited as part of a convenience sample of 14 health care participants, including 5 nurses, 7 clinicians, a hospital chaplain, and a psychotherapist. Two

participants were based in New York; 1 in Houston; 1 in Washington, DC; 1 in Boston; and 9 in the Midwest.

Sarah is an intensive care unit charge and rapid response nurse who has been working on the front lines of the Covid-19 pandemic in Nebraska since the beginning, all the while experiencing major life changes and caring for 4 small children. Sarah had a total of 9 portrait sessions from October 2020 to July 2021. The sessions took place in the second author's (M.G.'s) studio, located at the University of Nebraska at Omaha. The times of the sessions varied depending on Sarah's schedule. Portrait sittings ranged from 45 minutes to 2 hours, with most sessions lasting about an hour. Data were collected through initial interviews conducted by M.G., a final interview by the first author (B.L.), and audio recordings of all 9 portrait sessions between Sarah and M.G.

To analyze Sarah's experience of the pandemic and participating in the portraiture study, we conducted an in-depth analysis of the data and engaged in repeated discussions of findings from multiple perspectives, a strategy known as immersion and crystallization.<sup>5</sup> Qualitative analysis centered on Sarah's responses to her portraits and her verbal reflections on participation in the study and working during the pandemic. Three major themes emerged from Sarah's pandemic experiences and participation in our study: (1) confronting and overcoming uncertainty, (2) embracing vulnerability, and (3) assuaging feelings of burnout.

### **Overcoming Uncertainty**

*The COVID-19 pandemic.* In this study, Sarah found some certainty at a time when uncertainty permeated everything around her—from not knowing what would happen to her patients who were “so vulnerable ... and alone” to not knowing when the profound fatigue would settle in. Struggling with the lack of normal human contact and the ability to read the faces of patients, Sarah began to don the minimum required personal protective equipment (PPE) to facilitate more “human interaction vs the façade of all of the garb.” Just because patients are isolated from others does not mean they should feel isolated from their caretakers, who “become like their family,” or receive worse care. No matter the condition of patients, Sarah recognized that she has a specific “job and duty to perform care,” which drove her actions throughout the uncertainty of the pandemic. Sarah was able to confront and overcome this uncertainty because she is certain of what needs to be done as a caretaker.

*The portraiture process.* The creative process is inherently unpredictable for both artist and sitter. For the artist, working on the portrait is a practice of balancing observation and aesthetic striving, dialogue and silence, and uncertainty and trust.<sup>6</sup> Neither artist nor sitter knows how the process will resolve, and it is susceptible to error and mistake. For the artist, the struggle lies in trying to represent the sitter in an intimate and real way that allows the viewer to visualize the sitter's story. Sarah had no idea how she would be portrayed (see Figure 1) and no knowledge of arts-based research and its relation to medicine prior to this study. Sarah describes herself as “not artsy ... not a fluff and rainbow person,” yet willingly shared her story and engaged with the portraiture process. Sarah yielded to the ambiguous results of the study, just as she may have accepted the ambiguous outcomes of the care she delivered to her patients. When looking back at her decision to participate, Sarah stated: “I felt like it [participation] wasn't going to change anything because, you know, we were in the middle of the pandemic and it didn't feel like it was going away.” However, upon completion of her participation, Sarah stated: “when I reflect upon all of the discussions and sessions and think back to where



it started to where it is now, I honestly get ... emotional. Because I think about when it [the study] started.... I mean I was a little bit lost in that time. It was overwhelming and there were so many unknowns." Despite all of the unknowns she faced, Sarah surrendered to the portraiture process and was able to discover new meanings in relation to her experience, ultimately overcoming her uncertainty in a therapeutic manner.

**Figure 1.** Sarah, 2021



Courtesy of Mark Gilbert.

**Media**

Charcoal on paper, 44" x 30".

### **Embracing Vulnerability**

*The portraiture process.* Vulnerability is at the core of portraiture. The same is true in the medical setting when one is caring for or is a patient. Sarah was emotional in her interviews, which she described as “therapeutic,” because they allowed her time and space to reflect on her experiences critically and emotionally. Sarah stated that, without multiple sessions, the final portraits would “simply be a portrait and not a story to be told.” The portrait is a product of the relationship formed in the process of making it, and that relationship is simply underdeveloped after a single sitting because every interaction and connection between researcher and subject “makes the portrait come alive.” Sarah sees this depth and life in her own portrait portraying her in PPE (see Figure 2), saying:

When I look at it, and particularly my face and my eyes, I see a lot of really deep thought and like, I remember in that session I was reflecting on a lot, so as I see it progress, I think about how far it has come for me personally.... I see so many things with that picture. I see struggles and I see stress. I see that it is sad, but I also see strength with it as well, and perseverance—you know, you overcome it.... I see a lot of that in mine.

**Figure 2.** *Shadow of Corona*, 2020-2021



**Media**

Oil on Canvas, 58" x 56".

Moreover, Sarah stated that when she viewed other participants' portraits in the studio, she recognized their own sadness, experiences, and perspectives, which generated a sense of fellowship that assuaged her feelings of isolation.

*Burnout.* Sarah believes her participation in the study played a major role in avoiding burnout during the pandemic because it increased her capacity to consider her patients' and their families' perspectives throughout the period of isolation. Objectivity alone can close the door to vulnerability. Perhaps this is why **burnout among health care workers** is so great<sup>7</sup>; emotions are not black and white like traditional scientific thinking can be. It is easier to disengage from emotions completely than to become absorbed by them. However, vulnerability invites opportunities for growth, connection, and reflection not

otherwise possible. It demands a necessary balance between empathy and self-protection, which can only be achieved when invited to be practiced.

Sarah claims her participation set her apart from her coworkers in relation to burnout, saying: "I think that I am different than a lot of my peers in that [by] engaging in all of those conversations [with M.G.] ... I was able to then process more in real time and I also think it helped [me] ... learn how to better care for patients." Additionally, Sarah discussed the need to put up a wall for protection of herself and patients. However, too much self-protection—to the point of desensitization—poses a threat to medical professionals and patients because it may lead to burnout and to avoidance of the vulnerability that is indispensable to the patient-clinician relationship. Instead of putting up a wall, Sarah establishes a boundary that is permeable and flexible, one that exists because she is aware of—and that enables her to reflect on—her personal biases and her patients' wishes and beliefs. What maintains this boundary is Sarah's compassion, which balances the objective with the subjective, or detachment with empathy.



**Figure 3. Front Lines of Care**



**Media**

Oil on canvas, 18" x 18" each.

**Final Thoughts**

We will all experience what it means to be a patient and a caregiver at some points in our lives. The COVID-19 pandemic has required everyone, especially frontline health care workers, to reflect on their experiences of self-care and caring for others. There is potential for fear, distress, and dissatisfaction to thrive in the midst of suffering if these experiences go unaddressed. Arts-based research is a novel approach for investigating health practitioners' tolerance of ambiguity and the extent to which they embrace vulnerability to avoid desensitization. As discussed here, Sarah's and others' experiences illuminate the important role the arts can play in helping health care workers overcome uncertainty, embrace vulnerability, and assuage burnout by offering a way to better deal with ambiguity.<sup>8</sup>



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**Mark Gilbert, PhD** is an associate professor in the School of Art and Art History at the University of Nebraska at Omaha (UNO), where he is participating faculty member in UNO's Medical Humanities Program. He received a PhD from the Medical Sciences Interdepartmental Program at the University of Nebraska Medical Center. As an artist, teacher, and researcher, he has worked on a number of high-profile, art-based research projects using portraiture to illuminate patient and caregiver experience of illness, recovery, and care.

**William M. Lydiatt, MD, MBA** has more than 23 years practicing head and neck surgery and is vice president of medical affairs and chief medical officer of Methodist Hospital in Omaha, Nebraska. He is also a professor of surgery at Creighton University, a clinical professor of otolaryngology at the United States Naval Hospital, and a lecturer at the University of Nebraska Medical Center College of Medicine and Dentistry. At the University of Nebraska at Omaha, he also teaches an undergraduate and graduate course in the Department of Biology called “Art and Science of Medical Decision-Making.”

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# AMA Journal of Ethics®

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## ART OF MEDICINE

### Chinese Calligraphy and the Art of Writing

Audiey C. Kao, MD, PhD

#### Abstract

The popularity of portraits of clinicians during the COVID-19 pandemic suggested the importance of visual representation of what mass illness demands of us all—and particularly those on the front lines of health care. In addition to surges in variants of the SARS-CoV-2 virus, persons of Asian descent have endured waves of bigotry and violence. With the myriad of natural and man-made threats confronting the world today, an ancient Confucian proverb on the common good prompts us to recognize humanity's shared future. Although text-based, calligraphy is visually engaging and reminds us of the importance and poignancy of words that are well chosen and beautifully rendered. This article displays and describes Chinese calligraphies by Terry Zhizhong Yuan, commissioned by the *AMA Journal of Ethics*, to commemorate the American Medical Association's 175th anniversary and the extraordinary times in which we live.

*If I were born Chinese, I would not be a painter but a writer. I'd write my pictures.*

Pablo Picasso<sup>1</sup>

#### One World

Regardless of where you were born and with which ethnicity or nationality you identify, the COVID-19 pandemic has compelled all of us to face our interconnections and to recognize that individual well-being is invariably tied to collective welfare. More than 2500 years ago, Confucius professed that, with one world, people needed to work together and help each other if humanity is to secure a prosperous and healthy future. This ancient Confucian ideal of great harmony or *datong* (大同)<sup>2</sup> has contemporary relevance as we struggle to overcome ideologies of hate and planetary existential threats.

Chinese calligraphy is unique in that it is both a visual art form and a mode of written communication. This duality beckons us to contemplate where the boundaries are between functional writing and visual art.

### Three Styles

Chinese calligraphy includes 5 basic script styles.<sup>3</sup> Calligraphies in 3 of these styles were commissioned by the *AMA Journal of Ethics* to express the Confucian proverb 天下為公, 世界大同, which can be understood to mean *With one celestial home, we must live in harmony*. This proverb is artistically written in seal, cursive hand, and regular script styles by Terry Zhizhong Yuan.

Considered the first script style, seal script originated during the Qin Dynasty (221–206 BC). Rendered as pictographs, Chinese characters in seal style are, perhaps, the most difficult to decipher, so Yuan also depicted the Confucian proverb at the bottom of the scroll in a more readable and understandable style.

**Figure 1.** *Confucian Proverb in Seal Script, 2021*



### Media

Ink on paper, 13.25" by 54".

Originating during the Han Dynasty (206 BC–AD 220), the cursive hand script style is distinctive in that each character can be connected to its predecessor or be separate. Yuan incorporated both cursive script styles.

**Figure 2.** *Confucian Proverb in Cursive Hand Script, 2021*



**Media**

Ink on paper, 13.25" by 54".



Regular script is the style typically used in Chinese textbooks.

**Figure 3.** *Confucian Proverb in Regular Script, 2021*



**Media**

Ink on paper, 13.25" by 54".

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**Audley C. Kao, MD, PhD** is the editor in chief of the *AMA Journal of Ethics*.

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**PERSONAL NARRATIVE**

**How the Arts Help Us Hold Grief and Maintain Collective Care**

Tara Rynders, RN, MFA

**Abstract**

This first-person narrative illuminates how the author—a nurse, artist, and dancer—uses the arts and movement to help patients and clinicians process personal loss individually and collectively in the hospital setting. Through the arts, play, movement, and performance, the author raises awareness of and offers artistic practices to combat burnout, secondary traumatic stress, and moral injury. The author acknowledges that the stories of her patients have, in many ways, become her stories, and the reverse is true as well. These shared experiences remind us of the incredible impact that nurses have on patients—and patients, on nurses—every single day. Lastly, the author questions her understanding of resiliency and shares the ways the arts have helped her redefine its meaning.

**Nurse as Patient**

I have been a nurse for more than 19 years, and this was the first time I was a patient with a life-threatening experience in the hospital setting. I found myself alone, crying and waiting for a nurse to see me so I could get help. I knew this was one of those moments in life that I would never forget, a moment that would be with me and would change my life forever. I remember being admitted to the hospital with a tubal pregnancy and being transferred to a room when my fallopian tube burst. I remember my room being full of people, and though I was passed out, I could still hear everything that was being said. I remember my nurse grabbing my hand and telling me I was going to be okay, and I remember thanking her in my mind for remembering me because I was so scared, and I couldn't speak.

After my experience as a patient, I was reminded of the incredible honor and gift it is to be a nurse, to care so intimately for patients who are scared, and to stand witness for and support others during some of life's most difficult moments. As I reflected on the importance of creating this care with my patients so that they feel seen, heard, and truly cared for, I realized that the systems we work within do not readily allow for these connections to take place. Burnout, lack of support, secondary traumatic stress, moral injury, and many other factors in the nursing field contribute to inhibiting the experience of joy that can be found in a relationship as we care for another human being. In response, I founded The Clinic, an immersive theater company that creates artistic and play-based workshops and performances that take place in the hospital setting for

clinicians, patients, and the general public to raise awareness of, reflect upon, and challenge **inertia about burnout**, secondary traumatic stress, and moral injury.

### **The Clinic**

In October 2018, The Clinic premiered *First, Do No Harm*, an immersive theater performance open to clinicians and the general public that took place inside an active hospital. Through movement, art, music, and performance, *First Do No Harm* explored topics of grief, loss, compassion fatigue, and burnout from the **perspective of nurses** and patients' family members. Guests, including clinicians and members of the general public, were taken through the hospital to different locations, where they witnessed firsthand through performance vignettes what nurses and family members go through on a daily basis. This performance helped clinicians give voice to the grief they were experiencing and contributed to destigmatizing and calling attention to the importance of clinicians prioritizing their mental and emotional well-being. It also offered members of the general public empathy-fostering understanding of the complex work clinicians perform in their profession.

Through the arts and play, The Clinic is shifting cultures, behaviors, and beliefs. Collectively, workshop participants get curious, move their bodies, share stories, and partner with artists, empowering them to reimagine new and healthy ways of being and thriving in the health care profession. The arts and artists are crucial for this exchange and for healing and disrupting old—and creating new—pathways forward for themselves and patients. When clinicians are seen, heard, and cared for, I believe patients will experience this caring as well.

### **Witnessing and Experiencing Grief Alongside Patients**

I remember when I was working in the emergency room as the triage nurse. I had just returned from rooming a patient when a woman, crying, was wheeled into the triage bay. She was bleeding profusely, and she started screaming that she had lost her baby. As I wheeled her back into the emergency room, I saw a trail of blood behind us. When we arrived at her room, she was shaking, crying, and screaming. Her screams sounded like howls coming from the depth of her being. I hugged her as another nurse arrived to take over. As I walked back to the triage bay, tears formed in my eyes, as I could still feel the grief of this woman and hear her screaming for her child. In preparation to care for my next patient, I swallowed my tears. "You cannot cry." I said to myself, "You must be strong, Tara."

Only 2 days later, I see a trail of blood. I am losing my own baby, a baby I had just found out about earlier that morning. I remember this woman and how she held me as she cried and howled for her baby. I thought of how brave she was, and I chose in that moment not to swallow my tears but to allow myself to feel. This time I cried, screamed, and howled for her loss and for mine. I thanked her for teaching me that there's power and strength in feeling our own emotions and that healing can come from allowing our tears to fall, as they play an important part in our experiencing sadness and the depths of our grief.

### **Singing in the Suffering**

I remember when I heard her heart stop. It was 5:30 am and I was lying next to her in bed; all night I have been listening to her breath go in and out as the pauses between each breath got longer and longer until the next breath never came. I placed my ear to her heart and listened, but I heard nothing. This unconditional pulse of love that had

been beating my whole life—the unconditional love that had been guiding me, nurturing me, caring for me—had suddenly stopped. I gathered my brother and sisters, and we held my mother and sang her favorite song, together holding hands as she left her body.

After the death of my mother, I felt as if I could not bounce back, I could no longer be resilient, I was tapped out, I was done. I could not be strong any longer, and the flow of my tears began and did not stop for the next 3 years as I earned my master's degree in dance. Looking back, I wonder: *Is this what resiliency really is?* Up to this point, my definition of resiliency was to be strong—to bounce back quicker, harder, and stronger and be unchanged by my circumstances. I wonder now if the meaning of resiliency is to soften—to soften enough to feel and to find soft spaces of support to land. Softening also allows us a moment to slow down and reflect upon how self-care provides us an opportunity to see more clearly the injustices around us, which enables us to challenge harmful structures—including racism and other forms of discrimination—more effectively than someone who is burned out. It is in the softening, the *plié*, or the bending of our knees, that we are gathering the strength and support for ourselves to continue to grow.

### **COVID Stories and Resiliency Moments**

Alongside our own stories, our patients' stories can leave a lasting effect on us and, in some cases, even become part of our own story. In The Clinic, we create safe spaces where we can share these stories with one another and soften together, acknowledging the collective grief we carry in health care, and where we can create a mutual understanding that we are not alone in our suffering.

As COVID has ravaged an already-burned out profession, I have been honored to collectively create space for and access to the arts for health care professionals through our workshops, COVID Stories and Resiliency Moments. COVID Stories began during the pandemic and is a writing and movement series that offers time and space for nurses to journal and share their experiences during the COVID pandemic, both in person and virtually, through reading and responding to movement prompts with other nurses. Resiliency Moments is a virtual workshop that pairs health care professionals with **musicians**, dancers, and visual artists in one-on-one artistic experiences, offering health care professionals time to engage with artists through artistic prompts and offerings. Some participants receive a song that was created just for them, in the moment, based on personal preferences; others spend time in play and revisit memories of safe and calming spaces. In some cases, a visual art piece is created and mailed to the participant after the moment is over.

### **Listening to Ourselves**

Together, as we navigate the unknown continuation of COVID, grief, burnout, and fatigue, I urge everyone to put their ears to their hearts and listen to their own pulse, their own beat, and their own longings—to take a moment to connect to others through the arts, movement, and play. Once we are in connection with what we need in order to be cared for and take the necessary steps to care for ourselves, I wonder: *What would happen when we put our ears to the hearts of one another, hold one another's hand, and collectively care for one another?* I believe our hearts are urging us not to bounce back quickly from all we have experienced but to soften, to cry our tears, to listen, to slow down, to dance, to sing, to paint, to reflect, to grieve and, when ready, to use our soft landing, bend our knees, and wholeheartedly embrace the next leap that transpires.



**Tara Rynders RN, MFA** has been a registered nurse for more than 20 years. As a dancer, an artist, and an advanced grief recovery specialist, she specializes in movement and somatic practices and is the founding artistic director of **The Clinic**, an arts and play-based company that provides workshops and performances related to burnout and secondary traumatic stress. Rynders is an A Blade of Grass Fellow, a Nightingale Luminary, and a 2022 Fulbright Specialist.

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## AMA Journal of Ethics®

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### PERSONAL NARRATIVE: PEER-REVIEWED ARTICLE

#### Imprints of “Scanxiety”

Rachel Mindrup, MFA

##### Abstract

The days leading up to and waiting for the results of magnetic resonance imaging (MRI) sessions are anxiety inducing, and this anxiety has earned the moniker *scanxiety*. MRI images of the author’s son’s brain are used to track the progression and formation of tumors related to his neurofibromatosis (NF), a genetic disorder that occurs in 1 in 3000 births. NF can cause tumors to grow anywhere in or on the body. Analogous to pulling a print in art, the results of an MRI scan often have unexpected results. The author is an artist-researcher and mother who has painted, drawn, and pulled prints over the years about living with this disorder from a mother’s perspective. Throughout her son’s NF journey, she has found that life seems to happen “between the scans.”

##### Neurofibromatosis

According to the Children’s Tumor Foundation, which is the leading nonprofit organization dedicated to advancing research, knowledge, and care for the neurofibromatosis (NF) community, NF type 1 is a genetic disorder that occurs in 1 in 3000 births and can cause tumors to grow anywhere on or in the body at any time during an individual’s life.<sup>1</sup> NF can affect the development of bones and skin and can cause learning disabilities, vascular issues, deafness, paralysis, blindness, cancer, and even death.<sup>1</sup> My son was diagnosed with NF at 4 months old. He is currently a senior in high school and has had a lifetime of appointments, procedures, and navigating an uncertain terrain. My son’s NF has resulted in an optic glioma, which is a tumor that develops in the cells surrounding the optic nerve. He also has 4 other brain tumors, one of which was operated on with a risk of paralysis and blindness. He has some cognitive issues, fine motor skill deficiencies, and balance and coordination issues, as well as fibromas growing on his torso and back. Needless to say, *scanxiety*—the anxiety induced by waiting for the results of **magnetic resonance imaging** (MRI) sessions—contributes to the “what next” subcurrent of daily life with NF.

##### Printmaking

Printmaking is a process in which an artist transfers an image onto paper using plates or blocks. As an artist-researcher, the medium beckons me to savor details, texture, quality of paper, choice of ink, and the dexterity required. Unlike painting, in which I can step back and see the results and have some sort of control over the outcome, **printmaking** is a bit more intimate because every nuance on the plate will also transfer to the print.

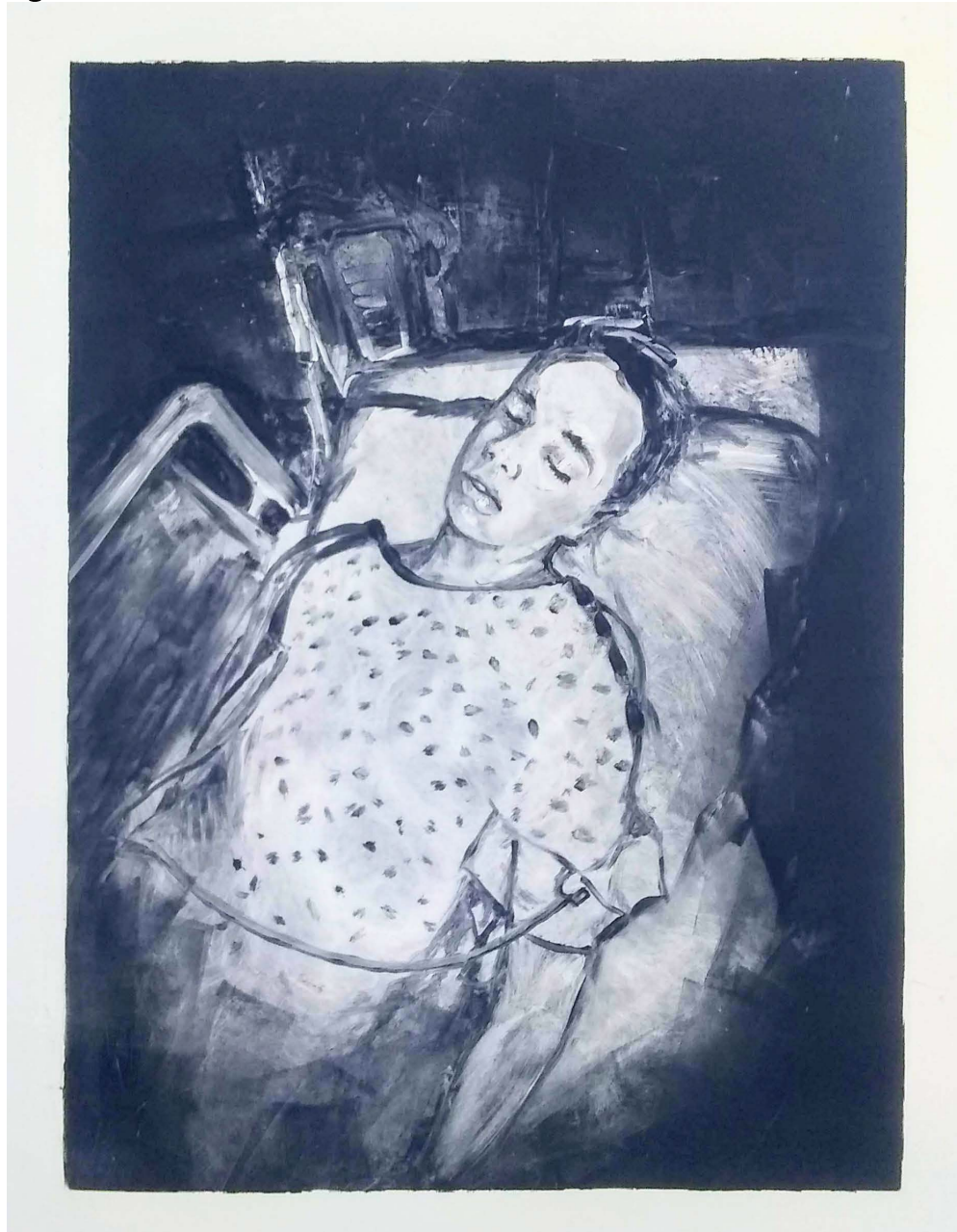
Sometimes this level of detail results in an exciting outcome; at other times it can be disheartening when unseen elements on the plate get printed. There is always a sense of a mystery until the print is pulled. As much as I believe I can control how a print will look, I am often surprised at what is revealed when I pull back the paper. The unfolding of the process evokes in me an emotion akin to scanxiety: What will be revealed? Over the years, I have chosen to make prints using etching and aquatint with zinc plates. Zinc produces a rough line and holds surface well.<sup>2</sup> I feel this rugged and durable metal is reminiscent of my son's body—rough and durable.

### **Brain Surgery**

When my son's deep thalamic brain tumor had not only grown internally but also changed structurally, the NF clinic decided it was time to intervene. I trust my son's team of clinicians and researchers. Without brain surgery, my son's right thalamic tumor would keep growing and eventually choke off important neural pathways affecting the use of the left side of his body. With brain surgery, he might have some temporary brain damage. *Temporary*. What an important word. We arrived at the hospital early, and, after all the preparatory measures, my son was wheeled away from me to go into surgery. Due to his NF, my son experiences a lot of anxiety. That morning, he held my hand. At the time, I thought he needed my reassurances due to his own anxiety. I later found out he held my hand to relieve me of mine. As his mother, I tend to wear that imprint of his anxiety as well.

Hours later, we were reunited on the seventh-floor pediatric intensive care unit recovery room. My son was not awake. My husband and I had no idea what to expect. There was talk of just temporary paralysis and temporary blindness. Would any of this come true? I just stared at him, waiting for him to awaken. After what seemed like a very long time, he awoke and could see and move his extremities. I could finally exhale.

**Figure 1.** *Uncertain Outcomes*, 2020



Courtesy of Rachel Mindrup.

**Media**

Monotype, 24" x 18".

I captured my anxiety after his brain tumor surgery by completing a monotype, *Uncertain Outcomes* (see Figure 1). A monotype is a unique process that combines printmaking and painting, resulting in a one-of-a-kind image that is developed on a flat plate with oil or water mediums and then transferred to paper.<sup>3</sup> This type of printmaking suited me well in processing my experience as a mother. I made one print. There will be no other prints. I do not want to repeat that experience multiple times. When I look at this image,

*I wonder: How many other parents and caregivers look down on their child who has also had life-changing surgery and are also feeling that general mood of passivity?*

**Figure 2.** *This Can't Be Good for me Long Term*, 2021

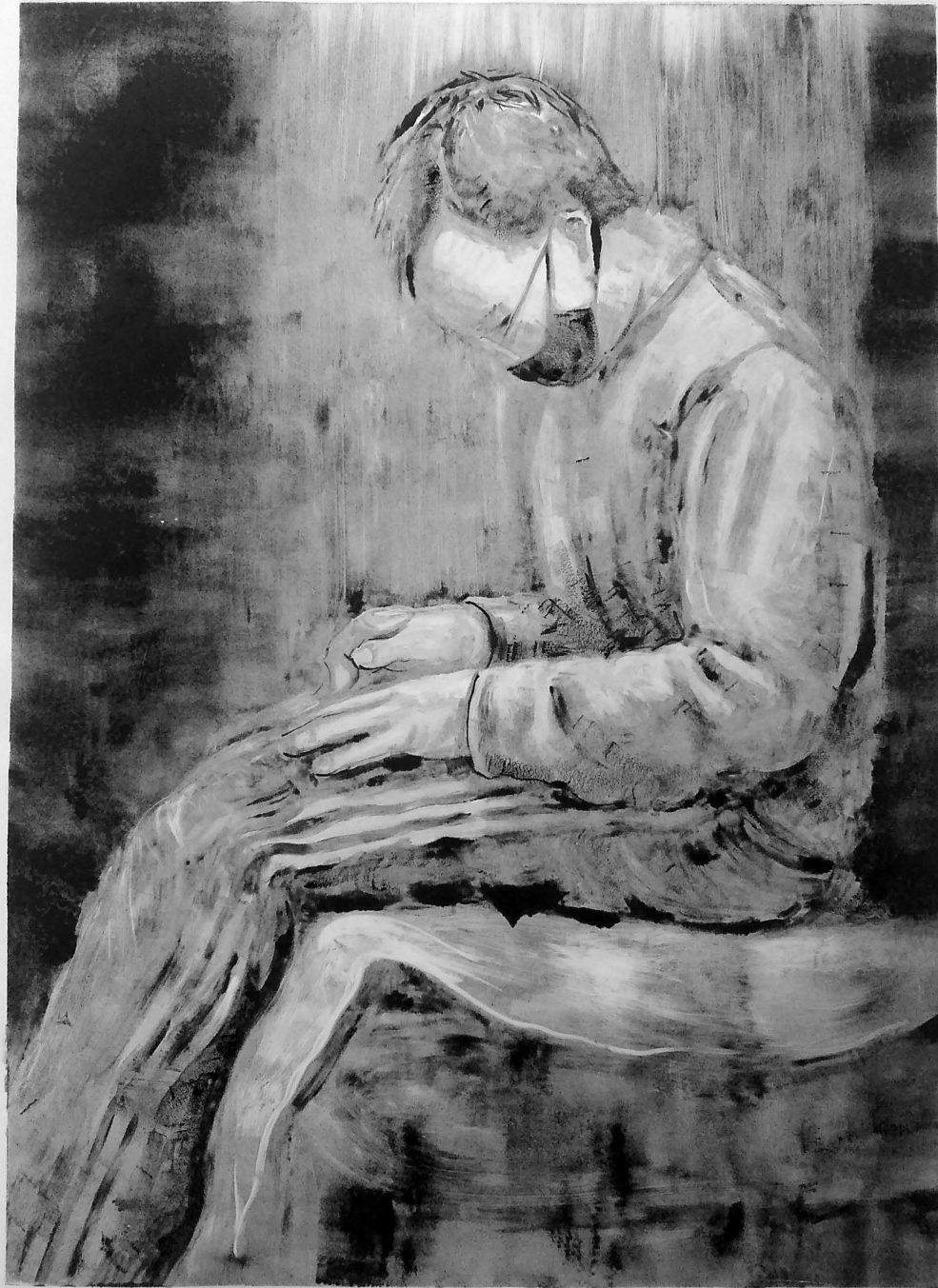


Courtesy of Rachel Mindrup.

**Media**  
Monotype, 30" x 24".



**Figure 3.** *This Can't Be Good for me Long Term (Ghost Print)*, 2021



Courtesy of Rachel Mindrup.

**Media**

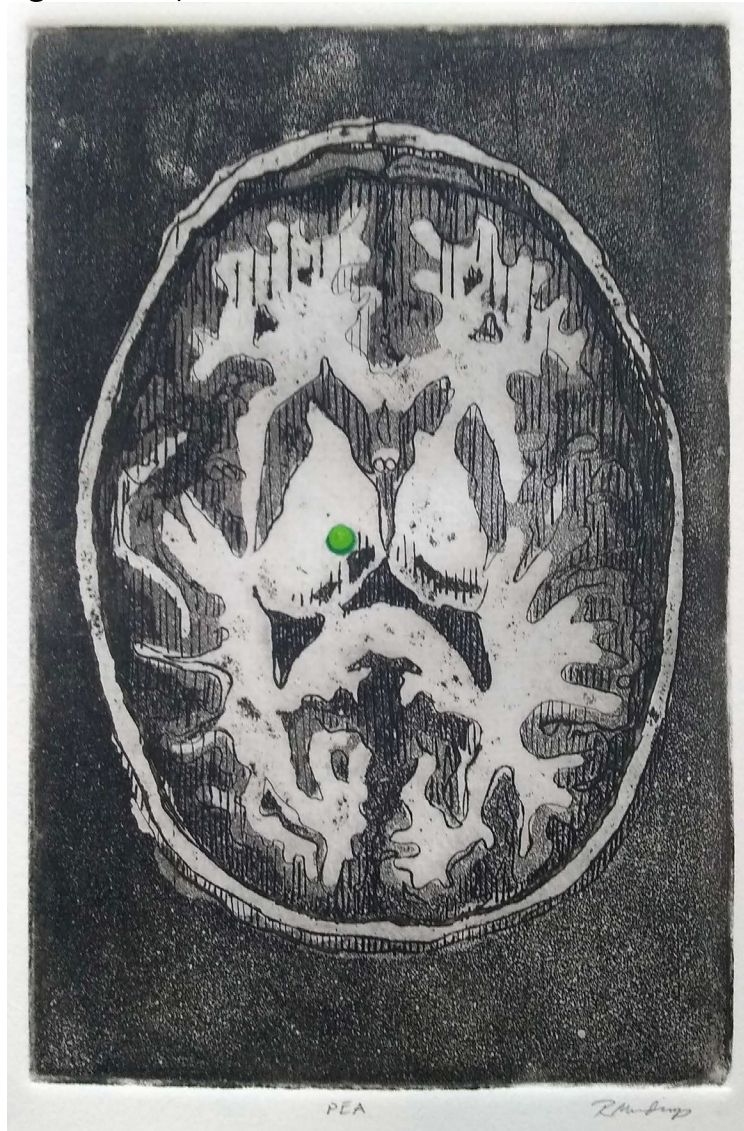
Monotype (ghost print), 30" x 24".

### **Scanxiety**

Long before my son's brain tumor surgery, he had been receiving brain MRI scans. These started when he was 2 years old and are scheduled for several times a year. Each time, I wait patiently yet anxiously for the results. Recently, when my son was waiting for his umpteenth MRI scan, he turned to me and said, "This can't be good for me long term." I didn't know what he meant. I asked for clarification. He told me that a lifetime of brain MRIs could not be good for a person's brain. I have no idea if there is any literature on continual MRI brain scans, but I told him that there was no alternative because NF brain tumors need to be monitored. He thought about it and said, "I'm not going to live a long full life, am I?" I was mortified and speechless. He continued, "I probably only have less than a decade left." Moments later, the radiologist came out cheerfully. My son got up, smiled at me, and said, "It's all good; I'm happy, Mom." His words haunt me. Choosing the monoprint technique again, I did his portrait, hands folded in his lap, sitting on the examination table while he was waiting (see Figure 2). I also decided to run it again through the press, knowing that the resulting print would be a ghost image of the first print (see Figure 3). This fading-away image captured my fears of what the future may hold for him. It also reinforces what I know. I cannot control an unpredictable and progressive genetic disorder, but, more generally, How many of us have felt that way waiting on the examination table?

When I work on these prints, I always have nearby oil paintings of both my sons doing everyday activities. My youngest son once remarked that his friends' mothers blogged and took social media pictures of their kids, but his mom uses art. I think because of that, the series of prints I do of my son in a medical context do not bother him or cause him undue stress. Usually, quite the opposite happens, and the artwork is a catalyst for him and me to talk about what we are feeling, often creating a stronger bond between us and usually putting me at ease.

**Figure 4.** *Recipe for Brain Salad—Pea, 2021*



Courtesy of Rachel Mindrup.

**Media**

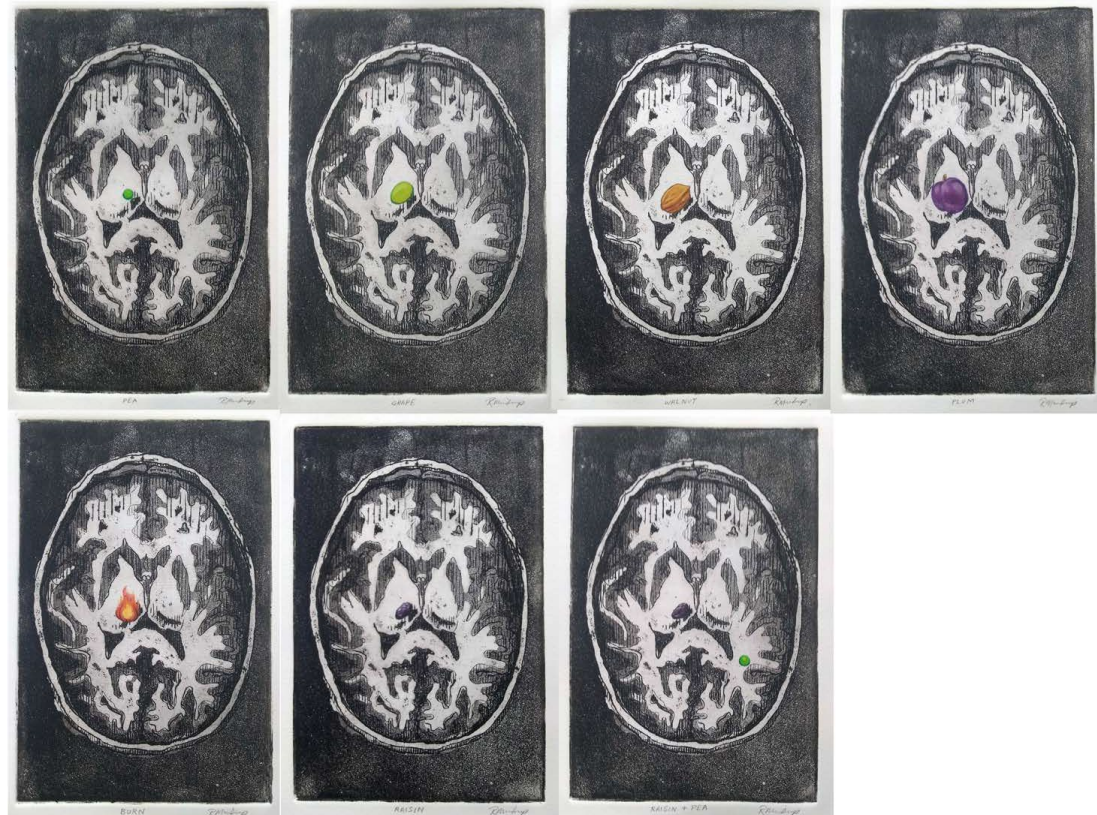
Aquatint and gouache, 9" x 6".

My scanxiety was heightened for me after my son's startling comment. His tumors sometimes go through a food analogy metamorphosis during the in-between times of MRI scans. A tumor that starts out the size of a pea can turn into a grape, then a walnut, but evidently the size of a plum is just too big for a tumor located in the thalamus. What would have happened with the new brain tumor they discovered if he had not had thalamic tumor surgery? Would it have grown to the size of a grape, or would it have been stable? What about the other brain tumors? Would they stay stable or decide to grow into new fruits or vegetables? Using the technique of aquatint, I printed my son's MRI brain scan to show the process of what had happened with his thalamic tumor. Unlike monoprints, etchings and aquatints are by nature made for multiples and printing



editions. Printmakers will often have a limited number in their edition, so collectors know how many prints were pulled, therefore making a limited-edition series more valuable than one that is not editioned. I have chosen not to edition the brain scan series in the typical printmaking tradition because I don't foresee an end to the scans. I wanted to alter each print with the analogy given to me by the NF team. I used gouache to paint the various nouns and verbs described to me during the growth of my son's thalamic brain tumor. The series starts with *Recipe for Brain Salad—Pea* (see Figure 4) and then goes through all the phases until the surgery, which I titled *Recipe for Brain Salad—Burn*, as depicted in the fifth panel in Figure 5.

**Figure 5.** *Recipe for Brain Salad—Pea, Grape, Walnut, Plum, Burn, Raisin, Raisin + Pea*, 2021



Courtesy of Rachel Mindrup.

### Media

Each panel is aquatint and gouache, 9" x 6".

The last panel in Figure 5 is *Recipe for Brain Salad—Raisin + Pea*, because this NF brain tumor cycle will continue, with other new brain tumors developing and growing in similar ways. The prints are displayed in an unsettling way (see Figure 5), leaving a space that is empty underneath. Many viewers would want to visually complete that space by having another image there to complete the box of images, but I do not. I do not necessarily want to know the results of the next scan, but perhaps I already know what is coming. That missing image is what fuels my scanxiety.

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**Letter to the Editor**

**Response to “Should Clinicians Be Activists?”**

Carmen Black, MD and Jessica Isom, MD, MPH

Kristen N. Pallok and David A. Ansell’s “Should Clinicians Be Activists?” highlights how physician activists risk retaliation from “economically and socially” privileged physician leaders and organizational leadership who “have been trained to comply” with structural inequity. We write as Black Yale medical faculty with personal and professional expertise in racial equity-focused advocacy. We reiterate the authors’ point: physician activists—skilled clinicians who challenge medical leadership and systems to dismantle racism—face retaliation because neither nondominant cultural authenticity nor equity-focused advocacy are systematically valued in, incorporated into, or safeguarded by current medical professionalism standards.

The Alpha Omega Alpha (AOA) Honor Society, medicine’s elitist society, membership in which is by nomination only, publishes a highly referenced monograph of medical professionalism standards.<sup>1</sup> Racism currently limits Black representation to 3.6% of medical school faculty members,<sup>2</sup> and AOA membership further limits Black representation by being preferentially offered to economically privileged, White physicians<sup>3,4,5</sup> who may be unattuned to and are invulnerable to racism. The monograph’s standards therefore center their dominant values and interests, even for minoritized and would-be activist physicians. For example, this 171-page monograph implores “a commitment to service, altruism, and advocacy”<sup>1</sup> yet never even mentions the words *race*, *racism*, *prejudice*, or *equity*. These standards generated by predominately White physicians vaguely praise advocacy while failing to intentionally and explicitly denounce health care’s own racism. Racial equity is literally omitted from medical professionalism, which places physicians who challenge health care’s **structural and cultural racism** outside the accepted boundaries of “professional” behavior.

Whiteness pressures racially minoritized physicians to “code-switch”<sup>6</sup> their mannerisms to minimize cultural deviations from White norms. Yet culturally authentic communication may explain the finding that Black men undergo more testing and preventive care when treated by another Black male doctor.<sup>7</sup> For instance, as Black female physicians, we build rapport with our Black patients simply by showing up authentically with them, including shamelessly using slang and references to pop culture, explicitly naming racism, and sharing personal experiences—whatever it takes to connect! However, White physicians witnessing or supervising us Black doctors being culturally authentic may devalue our clinical excellence and penalize the culturally informed rapport we build with fellow Black people across the diaspora: whiteness accepts code-switching while rejecting authenticity. Worse, any physician who **advocates for minoritized patients** against leadership’s racist policies, practices, and norms risks

retaliation by being labeled as “unprofessional.” Professionalism accusations against nonconforming physicians include being “resistant to feedback,” having “diminished capacity for self-improvement,” and being “unwilling to accept responsibility for their behavior and other’s perceptions of their behaviors.”<sup>1</sup> Personally speaking, the first author (C.B.) was remediated during her first residency program for claims levied against her “professionalism” using this exact coded language: resistance to feedback.<sup>8</sup>

Diverse, equity-minded faculty and trainees are recruited to dismantle racism. As Black faculty, we teach how adherence to the White normative professionalism standards that founded medical racism paradoxically stifles physician advocacy. To nonprivileged communities of color failed by medicine, perhaps physician activists are the truest medical professionals.

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# AMA Journal of Ethics®

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## ETHICS CLOSE UP

### What Is Represented “Worthily” in Luke Fildes’ *The Doctor*?

Audiey C. Kao, MD, PhD

#### Abstract

One of the most recognized paintings of Western medicine, Luke Fildes’ *The Doctor* aimed to represent a caring physician in a humble setting during an era when people living with poverty rarely had access to health care and nearly all physicians were White men. *The Doctor* challenges us to think about what good doctoring is.

One of the most recognized paintings of Western medicine, Luke Fildes’ *The Doctor* was hailed as an ideal representation of caring when it was first exhibited at the Royal Academy of Art in 1891. Henry Tate wanted an English painting worthy of a new gallery in his name, but he left the subject matter of his commission to Fildes.

**Figure 1.** *The Doctor*, 1891, by Luke Fildes



#### Media

Oil on canvas.



As witness to a doctor's care of his son who died of typhoid fever, Fildes wanted to "put on record the status of the doctor."<sup>1</sup> Fildes' surviving son wrote that his father "must have thought a great deal on the subject for.... it was the easiest and quickest painted of his big pictures."<sup>2</sup>

Light has long symbolized hope and wisdom and a table lamp provides the primary illumination in this otherwise dimly lit scene. At first glance, the doctor and his young patient seem to be the only figures present. Nearly centered in the painting, the child lies in a makeshift bed of 2 mismatched chairs. An outstretched left arm hangs over the pillow, signaling a certain precariousness of the moment. The doctor's presence signals some hope that the child will recover.

Not sitting tiredly despite a night vigil, the doctor is illuminated in a forward-leaning position, chin in his hand. His stare is not a casual gaze, but one that is intensely and diagnostically trained on the child.

A fisherman's net hardly visible in the rafters represents manual labor, presumably a means by which the father of the child supports his family. This labor is juxtaposed to the doctor's intellectual and professional work, which apparently supersedes the power of manual labor and that of the child's parents.

The child's parents recede into the background, reinforcing their helplessness to affect their child's fate. A dawn light filtering through the window reveals the father comforting the mother, casting further uncertainty on their child's immediate future.

Despite the painting's depiction, a doctor's presence in a working-class home is more idealized than reality. During the Victorian era, such house calls were generally afforded to those with wealth and power.

Prior paintings of the ill at home also never depicted a medical practitioner with a bottle of medicine, which was previously associated with only familial caregivers.<sup>3</sup> The content of this bottle is unknown, but it wasn't a typhoid vaccine, since none existed until 1896.<sup>4</sup> On the floor, 2 fragments of paper are probably the filled prescription for the medicine.<sup>5</sup> The torn and crumpled prescription suggests that the medicine has been dispensed, but its effect remains an open question.

It is notable that the stethoscope, thermometer, and other advances of medical science are nowhere to be seen. Instead, a cup and spoon are the instruments presumably used to deliver medicine to the sick child.<sup>6</sup> Fildes seemed more intent on focusing our attention on the art than the science of medicine.

Despite its idealized representation of doctoring or likely because of it, *The Doctor* struck a resonant chord with the public and profession alike. An engraved print of the painting sold more than 1 million copies in the United States. "A library of books written in your honour would not do what this picture has done and will do for the medical profession in making the hearts of our fellow men warm to us with confidence and affection," wrote a physician critic in 1892.<sup>7</sup>

Given its popular and professional appeal, *The Doctor* has been employed over the years to depict the practice of medicine in highly public and sometimes contradictory ways.



Raised by his grandmother, a supporter of the working-class Chartist movement, Fildes established his early reputation as an artistic champion of social realism. His works, including *Applicants for Admission to a Casual Ward* (1874), captured and drew attention to the harsh lived realities of the poor. Depicting a grim scene of families, homeless and hungry, which most well-off Londoners would have avoided in real life, *Applicants* attracted gallery patrons so numerous that police and barriers were needed to secure the painting.<sup>8</sup>

**Figure 2.** *Applicants for Admission to a Casual Ward*, 1874, by Luke Fildes



**Media**  
Oil on canvas.

Another of Fildes' popular social realist paintings was *The Widower* (1875). A father who labors to care for a sick child appears helpless, without either medicine to dispense or a doctor to tend to the child. The rest of his children carry on around him, seemingly oblivious to the gravity of the situation. While Fildes' works shone a spotlight on the desperate plight of too many in Victorian society, his conscience-raising and critical success did not afford him the material comforts of life. That would soon change.

**Figure 3.** *The Widower*, 1875, by Luke Fildes



**Media**  
Oil on canvas.

Fildes' works drew fashionable attention from those who desired to be lavishly showcased in self-portraits. He became one of the highest-paid portraitists in England and reached the heights of social and political circles, counting among his portrait subjects members of the British monarchy, including King George V. He was knighted by King Edward VII in 1906.<sup>9</sup>

**Figure 4.** *King George V, 1911*, by Luke Fildes



**Media**  
Oil on canvas.



Being paid handsomely to immortalize the powerful rich seems far from what a young Fildes could imagine, let alone accept, as an artist of the voiceless poor. So when Tate offered him *The Doctor* commission, Fildes jumped at the chance at some redemption by creating “something that would worthily represent me..... It is some time now since I painted an English subject of importance—a long time since the *Casual Ward*, *The Widower* and *The Return of the Penitent* series.”<sup>10</sup>

**Figure 5.** *The Return of the Penitent*, 1879, by Luke Fildes

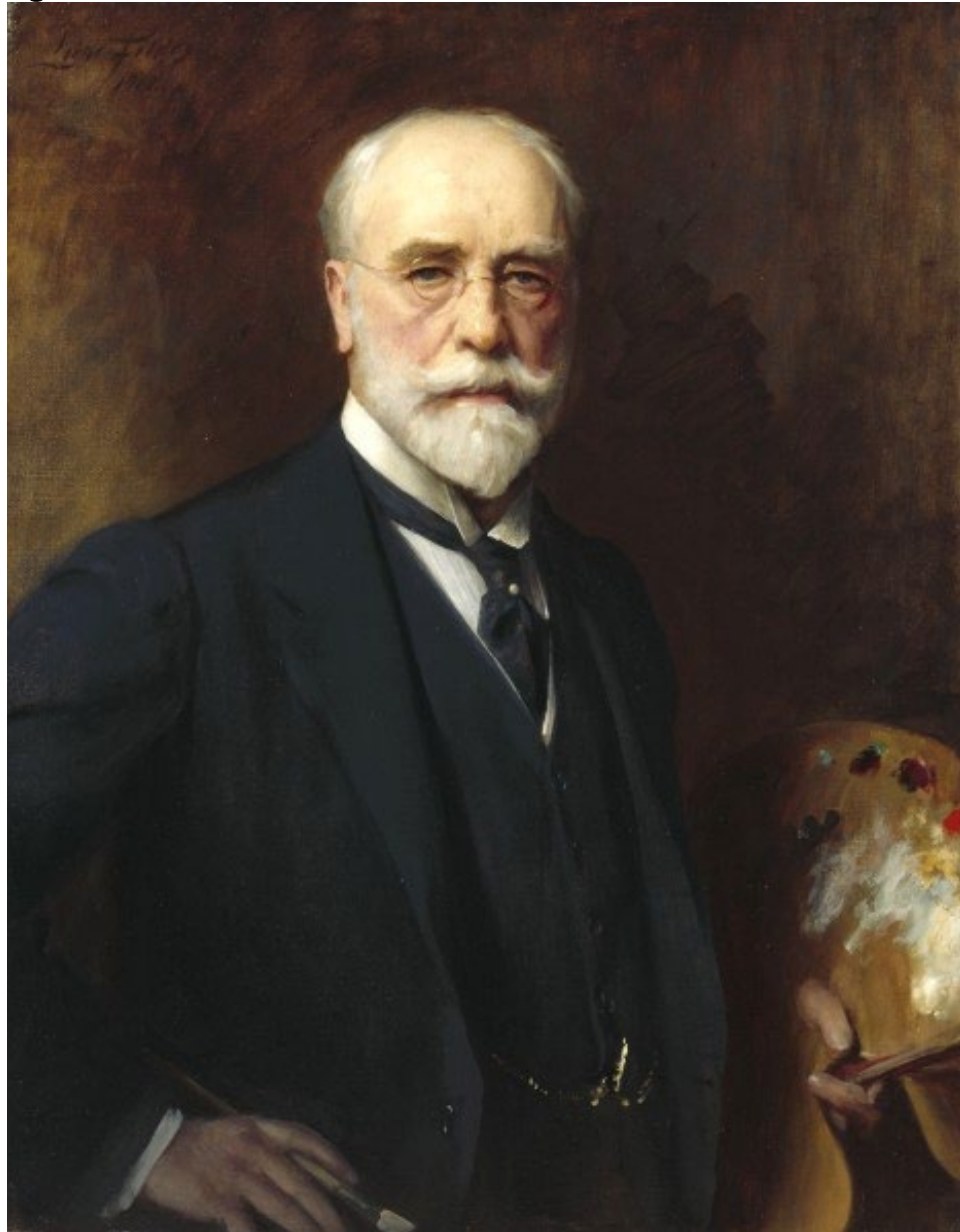


**Media**

Oil on canvas.

While the principal model was clean shaven, the painted doctor bore a striking resemblance to Fildes. Potentially casting himself as the dedicated professional tending to a sick child, Fildes captured the essence of a caring doctor that many patients apparently sought. “Many are the letter I have received asking for the name of ‘the doctor,’” said Fildes in 1893, “whilst one came from somebody who was ill, assuring me that she would be very thankful to have his address, for if she only had a doctor like *him* to attend her she felt sure she should soon get better!”<sup>11</sup>

**Figure 6.** *Sir Samuel Luke Fildes, 1911, Luke Fildes*



**Media**  
Oil on canvas.



The fanfare generated by *The Doctor* prompted many to leverage its visual potency to promote policies and market products. The painting was inspiration for a cartoon satirically critical of the National Insurance Act of 1911.<sup>12</sup> Given that this act eventually set the groundwork for a social welfare system in Great Britain, this cartoon would probably not have sat well with Fildes—or at least with his younger self.

**Figure 7.** *The Doctor*, 1911, by Bernard Partridge



### THE DOCTOR.

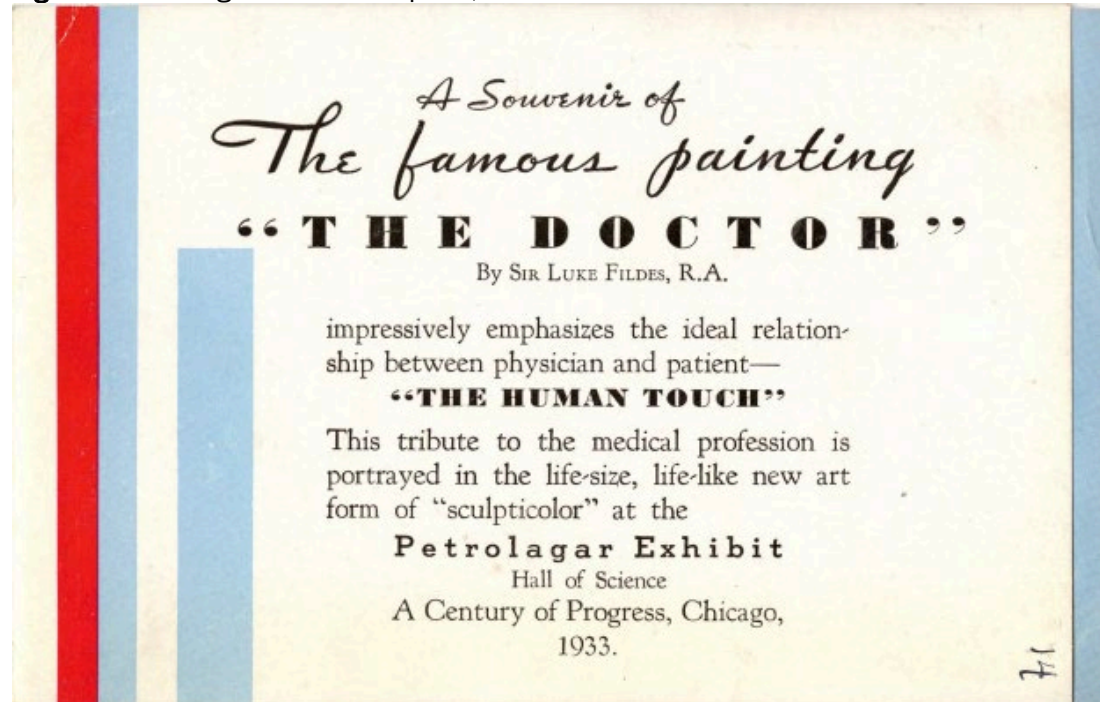
(With Apologies to Sir Luke Fildes, R.A.)

PATIENT (*General Practitioner*). "THIS TREATMENT WILL BE THE DEATH OF ME."

DOCTOR BILL. "I DARE SAY YOU KNOW BEST. STILL THERE'S ALWAYS A CHANCE."

At the 1933 Chicago World's Fair, Petrolagar Laboratories, makers of an emulsion to treat constipation, created a life-size, "sculpticolor" diorama of the scene depicted in *The Doctor*, celebrating the "human touch" and the "ideal relationship between physician and patient."

**Figure 8.** Petrolagar Exhibit Pamphlet, 1933



Special Collections Research Center, University of Chicago Library.

Joseph Tomanek was also commissioned to create a brighter reproduction of *The Doctor* for the Petrolager exhibit. Lest brightness be idealized, the faceless mother is now depicted in a pink garment, seeming to emphasize her emotional frailty in the face of her child's illness, while the men in the room remain calm and collected.

**Figure 9.** Reproduction of Luke Fildes' *The Doctor*, 1933, by Joseph Tomanek

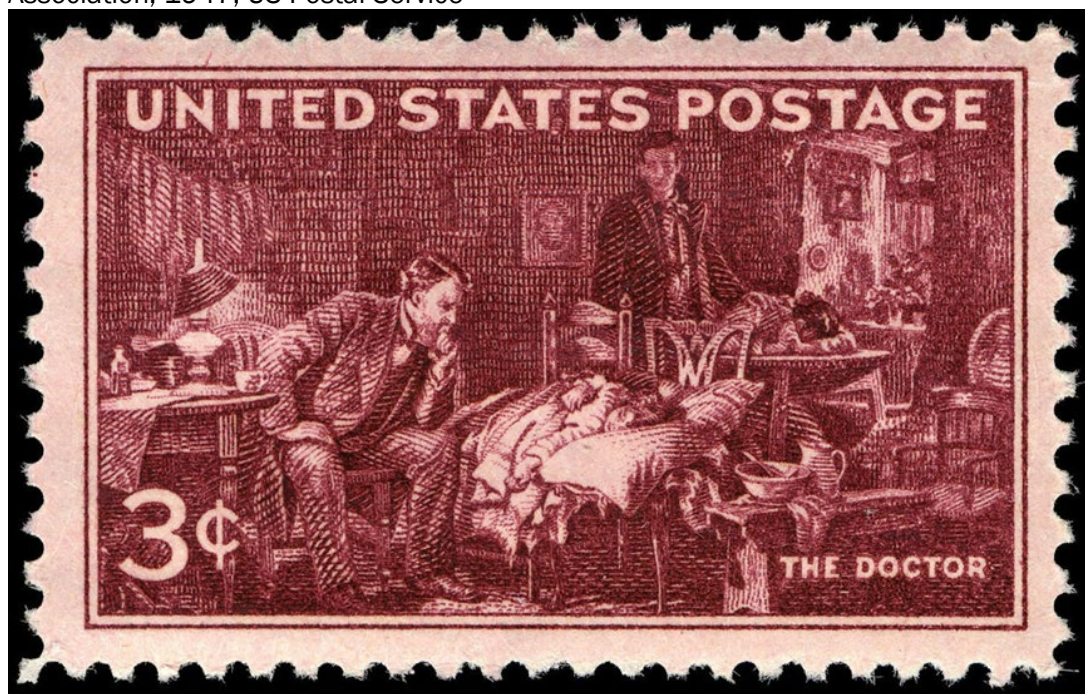


**Media**  
Oil on canvas.



In 1947, *The Doctor* was reproduced on a US postage stamp to celebrate the centennial of the American Medical Association (AMA).<sup>13</sup>

**Figure 10.** Stamp Commemorating the 100th Anniversary of the American Medical Association, 1947, US Postal Service



“Healthy citizens constitute our greatest natural resource, and prudence as well as justice demands that we husband that resource.... [A]s a nation we should not reserve good health and long productive life for the well-to-do, only, but should strive to make good health equally available to all citizens.”<sup>14</sup> Thus wrote President Harry S. Truman in a draft message to Congress in 1947, proposing a national health insurance plan.

**Figure 11.** Presidential Portrait of Harry Truman, 1945, by Greta Kempton

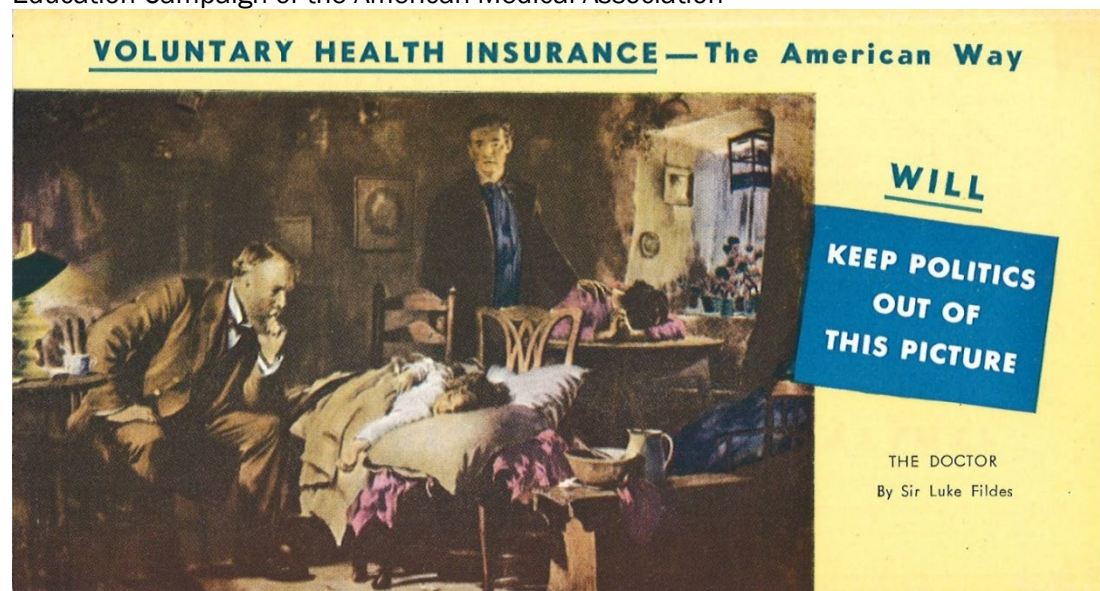


**Media**  
Oil on canvas.



In response to Truman's plan, which would have created a system similar to the United Kingdom's National Health Service (NHS), the AMA evoked the imagery of the dedicated and indefatigable doctor as the centerpiece of its campaign to defeat what it called "socialized medicine," whereby time spent with patients and medical decisions would be dictated by politicians and bureaucrats.<sup>15</sup> *The Doctor* was seen by millions on countless billboards, posters, and brochures with the slogan, "Keep Politics Out of This Picture."

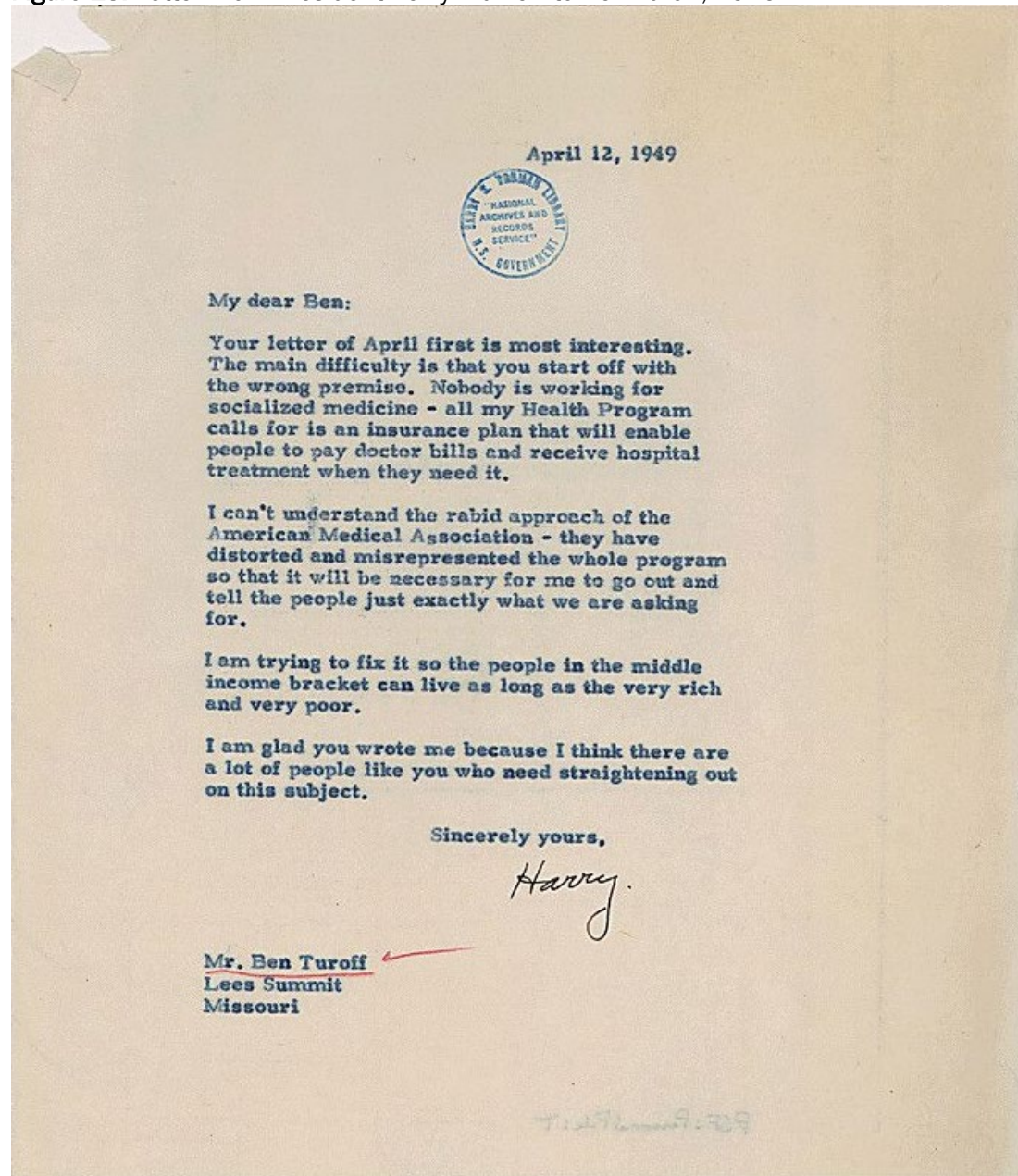
**Figure 12.** Voluntary Health Insurance—the American Way brochure, 1949, National Education Campaign of the American Medical Association



Courtesy of the American Medical Association Archives.

The AMA's campaign to defeat "socialized" medicine tapped into deep-seated reservations about government intrusion into what many considered to be personal affairs and matters of individual choice. Such vested concerns about the supposed ills of universal health coverage were even expressed by some of President Truman's friends, and universal coverage remains an elusive goal in the United States.

**Figure 13.** Letter From President Harry Truman to Ben Turoff, 1949



US National Archives and Records Administration.

Replace “compulsory health insurance” with “mandatory masking and vaccinations,” and this brochure produced more than 70 years ago can eerily speak to the views of millions of Americans today. But as the COVID-19 pandemic has shown, individual well-being is inextricably tied to the collective welfare. Even the most libertarian conception of freedom must recognize that no person is an island.

**Figure 14.** Voluntary Way Brochure With Eagle, 1949, National Education Campaign of the American Medical Association



Courtesy of the American Medical Association Archives.



Luke Fildes' *The Doctor* aimed to represent a caring physician at a time when only the rich had access to such care. Despite anachronistic uses to market health-related products, celebrate milestones in medicine, and advocate for and against universal health insurance, *The Doctor* challenges us to think about what good doctoring is. As humanity confronts a myriad of natural and man-made threats to its health and well-being, how physicians act individually and as a profession in combatting these threats will determine whether they are worthy of the public's trust.<sup>16</sup>

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