

Portraiture in Health Care

June 2020, Volume 22, Number 6: E465-570

From the Editor

- Portraiture and Health Care 467
Mark Gilbert, PhD

Case and Commentary

- Practicing Regard in Clinical Portraiture 470
Mark Gilbert, PhD

- William's Portrait and Community Narrative 476
Mark Gilbert, PhD

- A Permanent Lisa 482
Mark Gilbert, PhD

- Anthony and the Role of Silence in Portraiture in Clinical Settings 488
Mark Gilbert, PhD, Regina Idoate, PhD, Michele Marie Desmarais, PhD,
and William M. Lydiatt, MD, MBA

Medical Education

- Why Teachers and Learners of Medicine Need Portraiture 499
Maxwell F. Lydiatt and William M. Lydiatt, MD, MBA

- Health Care Professionals' Journeys of Caring Through Portraiture 505
Stacey Ocander, EdD, Lori Saville, MSN, Mark Gilbert, PhD, and Regina Idoate, PhD

Medicine and Society

- Neurofibromatosis and a Portrait of 1 in 3000 513
Rachel Mindrup, MFA and Regina Idoate, PhD

| | |
|--|-----|
| Should Art About Child Abuse Be Exhibited in Corridors of Health Professional Schools? | 525 |
| Paul R. Abramson, PhD and Tania L. Abramson, MFA | |
| Visual and Narrative Comprehension of Trauma | 535 |
| Paul R. Abramson, PhD and Tania L. Abramson, MFA | |
| Portraits of Children With Epilepsy | 544 |
| Wendy A. Stewart, MD, MMed, PhD | |
| Art of Medicine | |
| On Seeing and Being Seen in Dementia Care | 550 |
| Kathryn Hominick, MSW | |
| Personal Narrative | |
| Portraits of Suzanne, an Osage Woman's Story of Loving the Sun and Living With Skin Cancer | 557 |
| Bobbie McWilliams and Regina Idoate, PhD | |
| Portraiture Brought Introspection and Perspective | 565 |
| Mardi Denell | |
| CME Module | |
| How Portraiture Can Help Therapeutic Build Capacity in Patient-Clinician Relationships | 570 |
| Mark Gilbert, PhD | |
| Podcast | |
| Portraiture in Clinical Contexts: An Interview With Dr James Van Arsdall and Dr Mark Gilbert | |



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FROM THE EDITOR

Portraiture and Health Care

Mark Gilbert, PhD

Artistic representations of medicine and illness are present in anatomical and physiological illustrations of the human body, medical instruction manuals, treatment documentation, and aesthetic works that have, over the centuries, facilitated the discovery and understanding of various aspects of medicine, health, illness, and disability.¹ Portraits, in particular, have been instrumental in representing and explaining medical pathologies, pathopsychologies, and trauma.^{2,3,4,5} The term *medical portraiture* has been applied to depictions that commemorate and critique physicians and their practices.^{6,7}

Social psychologist Alan Radley called for greater use of images in research on illness and clinical practice, explaining that “pictures not only restore feeling but also the capacity to feel,” thereby transforming “what was previously a private experience of the patient to being a shared comprehension of illness by the group.”⁸ This theme issue on the intersection of the visual art form of portraiture and medicine considers multiple perspectives on **creating** and **viewing** portraits and how these processes can generate innovative strategies for perceiving and communicating ethical and aesthetic value; for fostering deeper and fuller understanding of patients’, clinicians’, and others’ **health care experiences**; and for teaching these **skill sets**.

As an artist, a researcher, and a teacher, I have spent the past 21 years creating portraits of patients and their caregivers in clinical settings. Creating these portraits relies on a series of intimate interactions that require space for open communication between artist and sitter as well as creativity and imagination. In my experience, these spaces engender powerful relationships that motivate consideration of important—yet often neglected—intersections of aesthetics and ethics in health care.^{9,10} A portrait is not just a picture of an individual but a picture of someone being looked at; fundamentally, it is a visual testament to a relationship. Portraits are potent sources of ethical, aesthetic, and clinically relevant analysis.¹¹ Tacit knowledge and behaviors residing in complex interactions that shape not only portraiture but also clinical practice can be illuminated by beholding and reflecting on expressive works about illness, recovery, and care.

The rich diversity of perspectives included in this issue testify to the multiple ways that portraiture invites **introspection** from viewers, artists, and those sitting for a portrait. This issue collects these perspectives with the aim of revealing how portraiture motivates

development of skill in analysis, interpretation, inference, imagination, and intuition, which are key features of **health care professionalism**. As health care moves towards more integrative, collaborative, and patient-centered models, portraiture can be a powerful resource in promoting public and professional understanding of relational and ethical aspects of medicine.

My collaborations with patients and caregivers demonstrate how portraiture in clinical settings engages participants in building trusting relationships, embracing uncertainty and ambiguity, exchanging stories, reflecting on experiences, and developing a sense of empowerment.¹² These 5 themes can inform clinical interactions between patients and caregivers and apply to any compassionate interaction. Just as in patient-clinician and student-teacher relationships, so in artist-sitter relationships ethical values such as mutuality and reciprocity are foundational to preserving respectful and healing interactions.

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CASE AND COMMENTARY

Practicing Regard in Clinical Portraiture

Mark Gilbert, PhD

Abstract

This article describes one collaborative arts-based research project. Portrait artist Mark Gilbert considers lessons for art and healing from one patient, John, whose cancer and portraiture experiences illuminate features of ethical and aesthetic significance about what it means to *witness*—to regard another’s difficult health and health care experiences.

Portraiture in Clinical Settings

As an artist-in-residence working with patients and caregivers, I became acutely aware of how relationships and interactions between subjects and me generated the process of making portraits. These relationships and interactions inspired me to further my arts-based research in another project, *The Experience of Portraiture in a Clinical Setting* (EPICS).¹ EPICS sought to explore artistic interactions and shared experiences of such interactions when I painted portraits of patients from the Head and Neck Cancer Clinic at the University of Nebraska Medical Center. The portrait, *John*, enables investigation of ethical and aesthetic roles of portraiture in John’s experiences of navigating depression and cancer.

Something Beneficial

From the beginning of the first session, John was demonstrative and spoke a great deal, especially during our breaks. He seemed enthusiastic: “I feel like we are doing something beneficial.” Yet, it seemed to take everything he had for him to show up. Often, he felt too depressed to sit for me in the studio. When he did, however, he was frank and open about his experiences. He told me he **suffered from depression**, which was exacerbated by the isolation he felt following his cancer diagnosis. He lamented that, even with a solid support system of family and caregivers, he often felt extremely alone. He described cancer as “a devious, insidious disease” and the radiation treatment as “a very difficult experience” of having teeth pulled, dry mouth, and “messed up” taste buds.

Figure. *John*, 2013



Courtesy of Mark Gilbert.

Media

Charcoal on paper, 40" x 26".

John had spent most of his life in the military. His promotion and status were something in which he took great pride. He brought a military bearing—decorum, discipline, and dignity—to many different roles he played in his life.

Sadness Evolving

During our studio sessions, John movingly spoke about being a son. He had, for example, transitioned his elderly father into a nursing home before his father died and had done the same for his mother, who was diagnosed with “awful” Alzheimer’s disease. John asked me about the EPICS study, my life, my family. The vibrancy of our dialogue was laced with sadness, as John repeatedly recounted the stresses of his illness and described physical effects of his treatments. These poignant moments were counterbalanced by John’s determination to regain the sense of physical integrity he felt he’d lost during his treatments. He was acutely aware that physical exercise enhanced his **emotional and spiritual health**. He described his need for control and how the lack of control he felt while being ill added to his stress. I was reassured when he said that choosing to participate in the EPICS study did not make him feel out of control and that he found the process purposeful, calming, and comforting. He explained: “I think it was a little bit of a healing process, because I went into this neutral and I started thinking about positive things, and I was not worried about my state of health or anything.”

My anxieties about exacerbating John’s unease were further assuaged by John’s curiosity about how he would be portrayed. This was a major factor in his decision to participate in the EPICS study. He considered what the portrait might communicate and sought to identify the difference between looking in a mirror and looking at a portrait of oneself. He acknowledged the subjective aspect of portrait making, saying he hoped to be able to—and anticipated being able to—see himself through my eyes: “What does John look like?” He added, “I am not expecting flattery.” He felt the portrait would have an “aura” that his reflection in a mirror didn’t have. On viewing his portrait at the end of his first sitting, he said forlornly, “I look sad.”

At our final meeting, John said that the portrait captured him as he is today, in a realistic manner. He no longer thought the portrait made him look sad. Instead, he said, “I think I look tired.” At the same time, he felt that the portrait “reinforces that I don’t feel like that. I feel better. I feel more alive. I feel more enthusiastic.” Referring specifically to his cancer treatment, John said, “I am through that. And, I am not dwelling on it.” John said he would like people to see his portrait and say to themselves, “That guy’s still alive, he survived, that guy.” Weaving John’s narrative together visually revealed meaning that might require pages of written material or hours of speech to convey.²

Ultimately, John stated that sitting for his portrait “helped” him with his depression. Reflecting on how he felt at the beginning of our sessions together, John acknowledged that sitting for his portrait diminished his feelings of isolation and engendered camaraderie with me and with others whose portraits hung in my studio at the time. He explained:

I have enjoyed it. It has been of value to me. Just like sitting in here today, seeing all these folks [the portraits] who have gone through something that might or might not have been as serious as mine. It gives you a little bit a feeling of fellowship. It gives me a broader perspective of what I have gone through.

Practicing Regard

When drawing John, I did not think in words. I thought in lines, smudges and tone, mass and volume. The charcoal I used gave form to abstract ideas, thoughts, emotions, tensions, associations, and reflections. In choosing to draw John instead of painting him, I immersed myself in an art practice that provided me more opportunity for self-reflection. That is, drawing allowed me to orient myself in the presence of John, which

brought me closer to him. Our unfolding relationship guided the marks I made on the paper, but it did not mean that every mark had to be perfect. It meant I strived for every mark to move the drawing closer to what it was becoming.

Prior to EPICS, I'd learned as an artist to detach and disengage from subjects. Drawing patients like John, however, required me to aspire to a participatory, empathetic approach to the portraiture process. I respected and had faith in John's and my other subjects' perspectives, and I allowed them to guide and support me as we created the portrait. Suggesting how portraiture can help us forge connections with each other, Sara Lawrence-Lightfoot and Jessica Hoffmann Davis state: "It is through relationships between the portraitist and the actors that access is sought and given, connections made, contracts of reciprocity and responsibility (both formal and informal) developed, trust built, intimacy negotiated, data collected, and knowledge constructed."³ Given John's experiences of depression and how hard it was for him to show up sometimes, this notion of reciprocity was particularly important in my relationship with him. That is, when he did show, I knew it took him courage and fortitude to do so; therefore, I needed to be present with him.

John Berger also offers a helpful description of artist-subject connections in portraiture. He suggests how each mark and accent one draws when making a portrait is like a "stepping-stone" across a river⁴; in working on John's portrait, I sometimes went sideways; sometimes, I backtracked. Every so often, I would step back and reflect on where I was and start again. I corrected and refined, the drawing would expand and contract, almost as if it were breathing. When I started the drawing of John, the early image looked almost like an exploded diagram. Features of John's head were there—his ear, nose, and mouth, for example—but they were not connected. The picture seemed awkward and flat. As I observed John over time, the drawing went through an iterative process of refinement: I encouraged the drawing to slowly fold in on itself, allowing the elements to float towards one and other. There then came a point at which the portrait and its tension with the background seemed to oscillate in such a way that the drawing came into its own as an independent form, generating its own space and reality.

In art research terms, Tom Barone and Elliot Eisner explain that meanings are derived from art's capacity to "adumbrate" rather than denote.⁵ The arts' usefulness comes not from their capacity to make propositional claims about events but rather from their capacity to invite audiences to experience aspects of the world that could otherwise remain unseen or beyond reach. *John* and the processes of creating it facilitated expressions, visual and verbal, that otherwise might not have been given space to breathe. The resultant image becomes a means for participant, artist, and viewer to reflect on, interpret, and behold our mutual witnessing. John's stories, through their telling, were interpreted and filtered through my perspectives and ultimately reshaped and reformed through my being with him, listening to him, and representing his story visually. His portrait is a tangible and permanent representation of our mutual witnessing of each other carrying out the project together.

The portraiture process, especially in a clinical context, involves ethical and aesthetic considerations. When I began working with patients and their families, sometimes during their most traumatic times, I was deeply nervous; I assumed their burdens would be exacerbated by my presence, that I might just make their experiences worse. My anxieties were compounded by my own fears of illness, disease, and mortality, which prompted me to call into question my capacity to function on a day-to-day basis, let

alone perform as an artist. I was dubious about whether it would be possible to nourish my capacity for expression and creativity while, at the same time, expressing appropriate regard, respect, and sensitivity for a subject's illness experiences. However, as my relationships with subjects strengthened, my anxieties diminished. John's and others' generosity and engagement freed me to focus on visually amplifying subjects' strengths while also wondering sometimes how they managed to face their illnesses' and treatments' demands.

Parallels Between Art and Medicine

The parallels between artistic practice and the humanistic practice of medicine are these: both entail relationships, integrity, compassion, altruism, empathy, and respect for others.⁶ The importance of entering into collaborative, reflexive relationships applies to both patient-clinician relationships and **subject-artist relationships**. Drawing John required me to act with purpose and care, much like an effective and efficient clinician. I listened to, witnessed, and respected John's stories. I paid close attention to innumerable details—some specific, others more nebulous—such as strands of hair; folds of his t-shirt; facial, vocal, or postural expression changes; the slope of his eyelids; and shadows under his chin. I tried to sustain a nonjudgmental stance and practice mindfulness when he spoke about his illness, treatment, recovery, parents, children, or puppy.

Just as clinicians delivering care in rooms adjacent to my studio listen to patients' stories, so John and I worked through the portraiture process attuned to John's story. In our own ways, John and I both experienced the tension between trying to control the process and trying to surrender to it and trust it. We approached portraiture much as I do an empty canvas, not knowing the end at the beginning.⁷ Although John initially felt unsure about sitting for his portrait, cancelled our first appointment, and sounded low, his voice trembling, when he called to cancel other appointments, he finally came often enough for us to create together, to complete his portrait. He sat before me to be drawn and I drew.

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CASE AND COMMENTARY

William's Portrait and Community Narrative

Mark Gilbert, PhD

Abstract

This article describes one collaborative arts-based research project. Portrait artist Mark Gilbert considers lessons for art and healing from one patient, William, whose cancer and portraiture experiences illuminate reflection as a critical component of both a sitter's and an artist's coassembly of visual narrative and community.

Portraiture in Clinical Settings

As an artist-in-residence working with patients and caregivers, I became acutely aware of how relationships and interactions between subjects and me were fundamental to the process of making portraits and the meanings those portraits generated. This experience inspired me to continue arts-based research through a project called *The Experience of Portraiture in a Clinical Setting* (EPICS), which sought to explore my artistic interactions and shared experiences with patients from the Head and Neck Cancer Clinic at the University of Nebraska Medical Center.¹ The following description of my interactions with William and reflections while drawing him enables investigation of the ethical and aesthetic dimensions of portraiture in clinical settings.

Hands

William was 82 years old when I met him. Two years previously, he had had a basal cell cancer removed from his upper lip. In January 2013, he found a lump under his nose; it was a squamous cell tumor that had driven itself into his mandible. He underwent 12 hours of surgery to remove his upper palate and teeth; part of his nose was also removed and reconstructed. This surgery was followed by 7 weeks of radiation. William had only recently completed his treatments and was just beginning to put on weight when I met him. His diet, he explained, was "just the same as before, only it's liquidized."

As we worked on his portrait together, William began to tell me his story, reminiscing about a long, productive life full of adventure, achievement, and global travel. A retired military physician and scientist, William had always been active. He stated, "I have always had a very busy, planned day, even in my retirement. I retired at age 50 from the Air Force. But I didn't retire from life!" When asked why he was initially interested in sitting for his portrait and being part of the EPICS study, he said with a laugh, "Actually I was interested, not because I was very interested in the arts, but the words *medical*

research turns me on. My connections with medical research have always been very positive.” He often spoke lovingly of his wife, who had resided in a care home for 6 years after a fall that left her a quadriplegic. William would visit her for 4 hours at a time, 6 days a week. He spoke movingly of losing his friends as they’d aged and of feeling more isolated. He poignantly wondered if he had “just lived too long.” He seemed to accept his illness and current challenges with a strong religious faith, stating over and over, “It is in God’s hands, when He’s ready for me, He’ll take me, and when He is not ready for me I will keep on plugging along.”

As we began working together on an initial charcoal drawing, I intended to focus on drawing his head and shoulders. However, as he sat, I was struck by William’s large, expressive, delicate hands. I was compelled to tentatively draw them first at the foot of the page.

Figure 1. *William*, 2013



Courtesy of Mark Gilbert.

Media

Charcoal on paper, 40" x 26".

Pastel of William

Each sitting with William took place in my studio, centrally situated within the Head and Neck Cancer Clinic. I would meet him in the waiting room, where he would be sitting reading. At my request, William would come wearing the same green shorts, exposing his thin legs and swollen knees. The shirt he wore was patterned with a maroon palm tree print. As it was a gift from one of his daughters, William was eager to have it included in his portrait. He also wore a flat Harris Tweed cap, of the type I had rarely seen in Nebraska (especially in July) but was used to seeing worn by older male adults in my native Scotland. When he sat down, William hung the cap on the arm of the chair. He walked with a slow, deliberate, lolloping gait and used a wooden walking stick that he told me had belonged to his father.

Figure 2: *William*, 2013



Courtesy of Mark Gilbert.

Media

Pastel on paper, 50" x 36".

William's generosity in sharing his reflections with me during our sessions was deeply reassuring and diminished my initial nervousness, which I always felt when first meeting EPICS participants. The role of reflection that is so fundamental to artistic practice proved also to be central to William's experience of the portraiture process. Like others in the EPICS study, sitting for his portrait gave William an **opportunity to reflect**, even when he was not inclined naturally to do so.

As an artist, I experienced 2 types of reflection in working on William's portrait: *experiential reflection* that focuses on the here and now, enabling a more intuitive, open monitoring of the present experience; and *narrative reflection* that focuses attention and effort on fitting the pieces of William's story and presence into a cohesive, believable whole. Through narrative reflection, I retrospectively analyzed and reconsidered formal elements of the portrait: the proportions, structure, and relationships of tone and color. As I familiarized myself with the materials, setting, and William, I also aspired to sustain a deep sense of curiosity fundamental to the iterative process of assessing the gradual evolution of the portrait while reflecting on my emerging relationship with William. By maintaining my curiosity and care, I **gained insights** about William—and about me—that were channeled into the portrait; with no set mission, we explored, improvised, played, and discovered.

The portrait-making process required me, at times, to pause, be silent, step away from the easel, tilt my head, and halfway shut my eyes to gain perspective. These actions helped me alter my perspective enough to embrace the whole developing portrait and the sitter simultaneously, without a hyperfocus on details. Completion of my drawings of William relied on deep observation, mindful awareness, improvisation, and proactive problem solving.

Whether standing actively at the easel, drawing, or taking a break to quietly reflect, I was engaged in a constant process of drawing not only what I saw, but also what I felt as I sought to give expressive form to what I witnessed and shared with William. I acknowledged the centrality of my role as researcher and my perspective as painter in the portraiture process and in the final images. However, as an artist-researcher, I was vigilant during our sessions to allow space for William's voice and presence to predominate. The uncertainty that permeated the portrait-making process required me to divide my time between being and doing, to seek a balance between effort and surrender to the creative process. I tried to balance conscious acts of gathering fragments of information through observation with a passive stance of beholding to create a unified and credible aesthetic whole for each portrait or drawing of William.

William Sitting in Community

William considered his role in this study "in the same way" that his wife sees her role in the care home as an opportunity to be a "chief cheerleader" that keeps people in the care home "from just sitting in their rooms moping." He acknowledged that he looked quite different following his surgery yet was unconcerned that his portrait would present his postsurgical appearance to others.

Knowing that I have a different face and don't speak so clearly and so forth would tend to make me more want to stay more isolated, but I deliberately tried not to let that happen. I still go out to the store and do my own shopping. Try to keep my life as much as normal as I can. And not let the cancer mean I shouldn't go out and be seen like this. I haven't let that bother me at all. Should I go out? My answer is yeah, I am not going to change what I am going to do. I am not going to let it isolate me more than I already am isolated.

In later sessions, William commented on how looking at other participants' portraits on the studio walls helped him realize that everyone has their own unique stories and challenges. He pondered what other participants had been through.

Well, I look at all these faces there—including my own. Each of these people have that same life to look back over. They have all had things in their life. Some things have been very similar to what I have had, other things have been very different from what I have had. I wonder... I assume all these people have had some form of cancer or they wouldn't be in this clinic. I wonder how they did? How did it affect them? I had an advantage; I had been a doctor. I understood the cancer, I knew a lot of things, I didn't need to ask the questions because I knew the answer. I had a big advantage; it was not a big scary unknown.

On completion of his portrait, William described his experience of sitting. He said, "I enjoy it. I enjoy our talking back and forth. It has been a positive process, as far as I am concerned." He explained how participating prompted him to consider past events and relationships. He considered how his constant reflecting on the past differed from what he called the "forward thinking" of his younger days. William acknowledged that, as he gets further away from his cancer experiences, he sees the portrait as a kind of memorial to his cancer journey. Rather than focusing on his illness and health status, though, William expressed gratitude not only for the portrait itself, but also for the portrait sitting time, which he characterized as open-ended time that "made me look back over stories of my life ... and makes me think 'what happened in my life and why did it happen?'" He continued, "When I start looking back over stories of my life, I see patterns I didn't see before." In particular, William reflected on his ability to find solace in surrender, restating his religious faith when he shared that he looked at his cancer experience "as under God's control." When asked how he felt about people viewing his portrait and having their own interpretations in response to it, he stated, "They can interpret how they want to. It doesn't bother me, is my attitude. Yeah. I know the story of the picture. They can feel about it how they want to feel."

Finally, as he looked at his finished portrait propped on the easel before him, he made himself laugh, saying, "It's not very angelic, other than the fact it portrays a human, and a spiritual, being."

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Mark Gilbert, PhD is an artist and a research associate with the Faculty of Medicine at Dalhousie University in Halifax, Nova Scotia, Canada.

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CASE AND COMMENTARY

A Permanent Lisa

Mark Gilbert, PhD

Abstract

This article describes one collaborative arts-based research project. Portrait artist Mark Gilbert considers lessons for art and healing from one patient, Lisa. Lisa took comfort in the permanence of portraiture amidst the uncertainties of tongue cancer.

Arts-Based Research

The Experience of Portraiture in a Clinical Setting (EPICS) project sought to explore my artistic interactions and shared experiences with patients from the Head and Neck Cancer Clinic at the University of Nebraska Medical Center.¹ The following portraits of Lisa enable investigation of the ethical and aesthetic value of permanence in Lisa's illness and portraiture experiences.

Figure 1. *Lisa*, 2013



Courtesy of Mark Gilbert.

Media

Pastel on paper, 40" x 26".

Sit to Engage

Three years prior to sitting for her portrait, Lisa felt a small lump in the middle of her tongue. Six months later, a dentist urged her to see a specialist, and a biopsy confirmed cancer of the tongue. Pregnant, caring for a toddler, and working full time, Lisa felt that this diagnosis generated stress and uncertainty and even cast doubt on whether she and her husband should continue to expand their family. Despite feeling overwhelmed at times, Lisa agreed to sit for her portrait and be part of the EPICS study.

She welcomed the portraiture process as an opportunity to reflect on her illness and its influence on her family, especially her relationship with her husband. An important part of her portraiture experience was witnessing the development of other head and neck patients' portraits as she sat for her own portraits. For Lisa, this experience illuminated other subjects' resilience and brought about an evolution in her perspective of what was happening to her and her family: "Others had it worse," she remarked. When discussing other participants' portraits, she marveled at how they were all so different, despite each participant sharing similar experiences of enduring cancer and its treatment.

Portrait Making as Story Building

Portraiture in a clinical setting can create opportunities for subjects to build a narrative of self; at the same time, it can be a catalyst for sharing subjects' stories with others.² These two ethically and clinically relevant themes illuminate important dimensions of EPICS study patients' experiences. An important role of the portrait artist, then, is to enable emergence of new perspectives for the patient by generating new ways of thinking for the viewer.

Prior to painting in health care settings, my view of portraiture was traditional: portraits depict an individual and, more often than not, a great and good individual. Portraits hang in museums, separate from our everyday lives. My deep dissatisfaction with this narrow conception of what a portrait is was fueled partly by the richness of the relationships I developed with patients who sat for me. After witnessing how sitters found value in their portraits and in the process of making them with me, I discovered how portraiture could foster a relational aesthetic³ that was compassionate and healing, "inclusive rather than elitist,"⁴ and based on an ethics of care.

Once treatment is over, some patients find it challenging to create and sustain their own healing. Spiritual, intellectual, physical, and emotional healing is deeply personal, ever evolving, and continues even when interventions and drugs stop. When participants enter the studio space where I paint, they are invited to sit in an empty chair, a kind of blank slate, where they can initiate conversation with me, sit silently, or both. Over time, we typically navigate ways to weave past, present, and future experiences into an aesthetic whole to create and give shape to a story and portrait. For Lisa, sitting gave her an opportunity to engage with her own healing journey and to **communicate and connect** with others.

Figure 2. *Lisa*, 2013



Courtesy of Mark Gilbert.

Media

Pen and ink, 17" x 12".

Put on Hold

At our first meeting, I began working on quick pen and ink studies. Lisa described how insensitively she felt the news of her initial cancer diagnosis was given to her. She looked back with some amusement on how she perceived her clinicians as scrambling for an explanation of her cancer. She often found humor in episodes that were anything but humorous at the time. For example, Lisa went through multiple tests for other causes of her symptoms and other possible diseases, including syphilis, that might explain them. "I could have done without that [test]," she said wryly. The cause of her cancer remained a mystery.

I always met Lisa at 8 o'clock in the morning. I greeted her in the same waiting room where her surgeon met her. My studio was in the Head and Neck Cancer Clinic, a tiny windowless postal room containing only an easel and a chair. Since portraiture took place where patients came for clinic visits, this arrangement tended to encourage comparisons between patients' experiences of waiting in the clinic for portrait making and waiting in the clinic for appointments with clinicians. For Lisa, her attitude and approach to the portraiture process was a counterpoint to medical visits to the clinic. She contrasted feeling comfortable during portrait sessions with feeling anxious in the face of **persistent scanning** for clinical problems.

During her studio sittings, Lisa expressed how her diagnosis and treatment had put her and her husband's lives "on hold." However, at the time of her participation in the EPICS study, she celebrated her third year of being cancer free. She was optimistic, looking forward to a forthcoming holiday and to the birth of her second child and delighted that the portrait would depict her at this time in her life. Her pregnancy kept her awake at night, and she jokingly requested that I leave out the dark rings under her eyes. She recognized the potential for the portrait to visually draw focus to her pregnancy, to the imminent birth of her child, while simultaneously enabling reflection on her recovery from tongue cancer.

Lisa said she felt "honored" to have been asked to participate in the study.⁵ Overall, she found the process deeply reflective. She described sitting for a drawing as an opportunity to reminisce, contemplate, and sit quietly. She explained: "there were some empty moments" that were "a great break! to just sit here and be still.... It was still kind of refreshing." Lisa said that quieter times like this enabled her to "contemplate where I'd been and what the future may have." For Lisa, the tincture of time had been healing. As Lisa sat with her experiences, time and our connection folded them into her portrait. She noted that her identity was transformed, that she became stronger.

Finding Permanence

Lisa acknowledged how sitting for her portrait—and the portraits themselves—enabled her to prepare for dialogue with others that might not have otherwise occurred. Although she had addressed her illness and recovery process with family, friends, and coworkers, prior to participating in the EPICS study, she had not been given the time and space to share her whole story in free form. Lisa explained that she "loved" sharing pictures of her portraits because "it opened up discussion about how far I've come" and added that now "they know what I went through." It enabled her to share her **medical journey** and reflect on how her personal growth had changed her from who she was two-and-a-half years ago.

Lisa was an active participant in the portraiture process. As she sat, she saw finished and unfinished portraits of other cancer patients and survivors on the walls and easels around her and felt camaraderie with those patients and with me. Lisa often asked about the other subjects I'd painted and about how their feelings about their own portraits had changed over the course of my painting them. She considered, analyzed, and remarked on the progression of portraits of others with whom she sat in fellowship, as she shared with them a kind of collective experience of being a patient and of being painted as a member of that community of patients. Lisa described this community as having a collective story as head and neck cancer clinic patients: "We all overcame something.... Everyone kind of has that look that 'I did it ... I did overcome that!'" Lisa welcomed the fact that her portrait could serve as a medium by which viewers might

better understand and interpret lived experiences of cancer. Sharing her own lived experiences seemed particularly valuable to Lisa, as she felt “proud” to have the portraits displayed.

For Lisa, participation in the EPICS study offered a kind of permanence in portraiture. That is, her portrait could serve as a testament to her children of their mother’s life: “This is something that will be around, for hopefully for a very long time, and it is kind of neat like it captures this moment in my life.” Moreover, she realized the portraits’ potential to spread the message that she was not only a cancer survivor, but also a thriving, lively, active individual. Lisa pointed out that she was “strong for making it through” her cancer journey and affirmed, “If I can get through this, I can, you know, get through anything.” Lisa said, “Looking back ... I do think really positive about what we went through and I feel positive about the future.”

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CASE AND COMMENTARY

Anthony and the Role of Silence in Portraiture in Clinical Settings

Mark Gilbert, PhD, Regina Idoate, PhD, Michele Marie Desmarais, PhD, and William M. Lydiatt, MD, MBA

Abstract

This article describes one collaborative arts-based research project. Portrait artist Mark Gilbert and coinvestigators consider lessons for art and healing from one patient, Anthony, whose experience of head and neck cancer diagnosis, surgery, and recovery suggests how silence is ethically, artistically, and clinically significant.

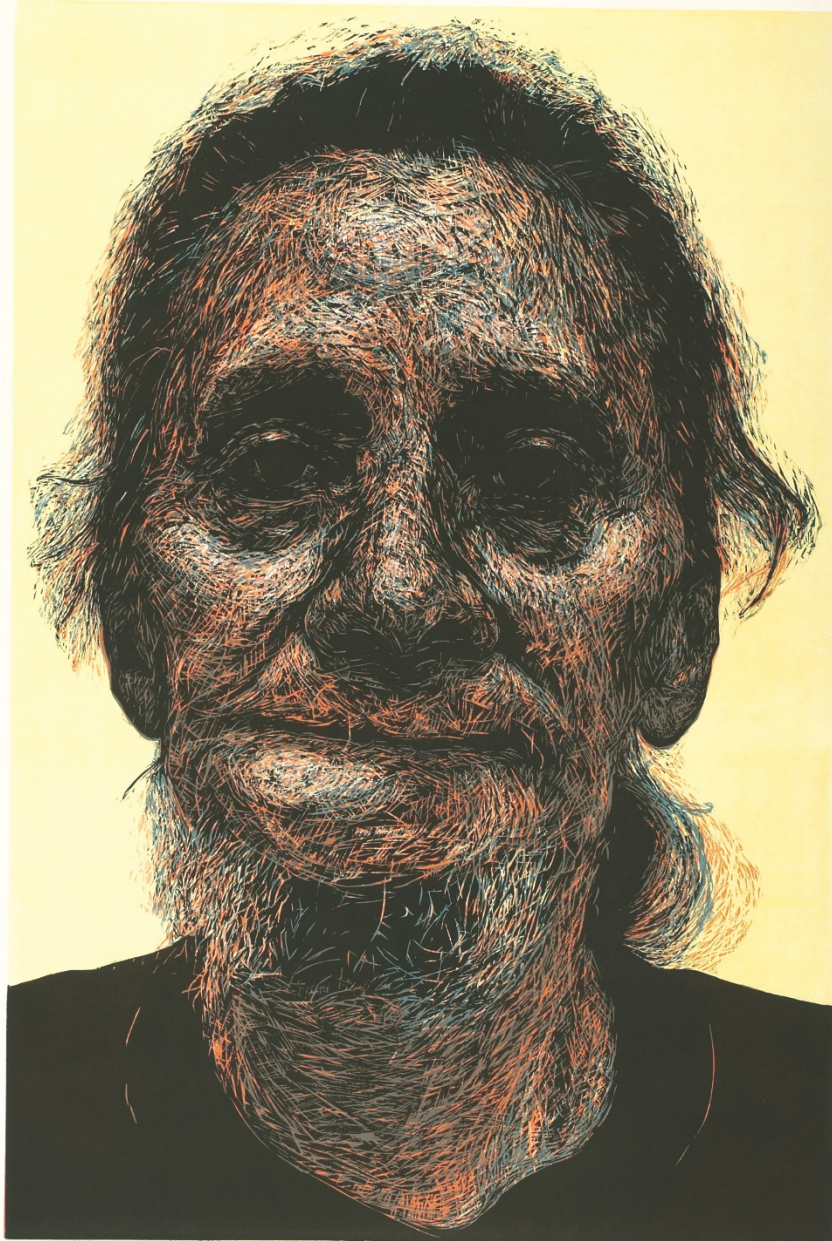
Portraits of Care

At the request of Virginia Aita and the fourth author (WL), the first author (MG) was invited to coconduct an arts-based research study using portraiture to investigate care and caregiving. In this mixed-methods study, MG drew and painted patients and their caregivers. The project culminated in an exhibit, *Here I Am and Nowhere Else: Portraits of Care* (POC) and was displayed at the Bemis Center for Contemporary Arts in 2008-2009.¹ This exhibit featured visual art as a means of cultivating deeper understanding of ethical and aesthetic values expressed in the experiences of patients, family caregivers, clinicians, and others—janitors, biomedical researchers, public health professionals, and policymakers, for example—working in health care. POC considered portraiture to be an untapped resource in health care that could be used to “imagine the humane dimensions, cultural frameworks and processes that shape human experiences of health and illness.”² The relationship that MG shared with one POC participant, Anthony, is especially illustrative of this purpose. Although this essay about Anthony is conveyed in MG’s voice, this work has been a collaboration among the 4 authors.

Anthony

I first met Anthony in the company of WL just prior to his tumor resection surgery. Anthony had graying hair tied back in a ponytail. His thin beard covered, but could not hide, a **protruding cancer** that enveloped most of his mandible, lower jaw, and tongue. When Anthony first noticed the tumor, he avoided treatment and traveled around the Midwest by himself. MG wondered why Anthony delayed seeking treatment and if his finally doing so was at the behest of his sister Gloria, who accompanied him that day to the clinic. Anthony was soft spoken, and his voice was somewhat muffled, as the tumor restricted movement of his tongue and jaw. His surgery that day would leave him unable to communicate verbally and therefore would illuminate the ethical and aesthetic roles of silence in MG’s subsequent interactions with him.

Figure 1. Anthony (Before Surgery), 2008



Courtesy of Mark Gilbert.

Media
Woodcut, 44" x 32".

Silence in Tumor Resection

Surgical removal of Anthony's larynx, tongue, and lower jaw left him unable to talk. A citizen of the Winnebago tribe of Eastern Nebraska, Anthony had misgivings about sitting for his portrait, and these misgivings were founded in his traditional belief that being drawn or photographed "toys with someone's spirits." MG was initially concerned that the verbal one-sidedness of the interactions would be awkward, but Anthony wrote short notes during his portrait sessions to communicate. MG learned that Anthony was also an artist who worked in traditional leather and beadwork. Many of MG's and Anthony's exchanges focused on their respective artistic practices. Anthony visited MG's studio weekly for 6 months.

Silently, together, MG and Anthony cocreated in multiple media and formats. Portraits of Anthony were drawn on canvas and paper and carved into wood for a relief print. MG used photography to record Anthony's time as an anesthetized patient. Anthony's resected tumor is shown below in a color monotype.

Figure 2. *Tumor (Anthony)*, 2006



Courtesy of Mark Gilbert.

Media
Monoprint, 40" x 26".

A photogravure of Anthony's tongue and lower jaw, suspended in WL's hands, was also made.

Figure 3. *Removed Cancer (Anthony)*, 2008



Removed Cancer

10/13

mark gilbert 2008

Courtesy of Mark Gilbert.

Media

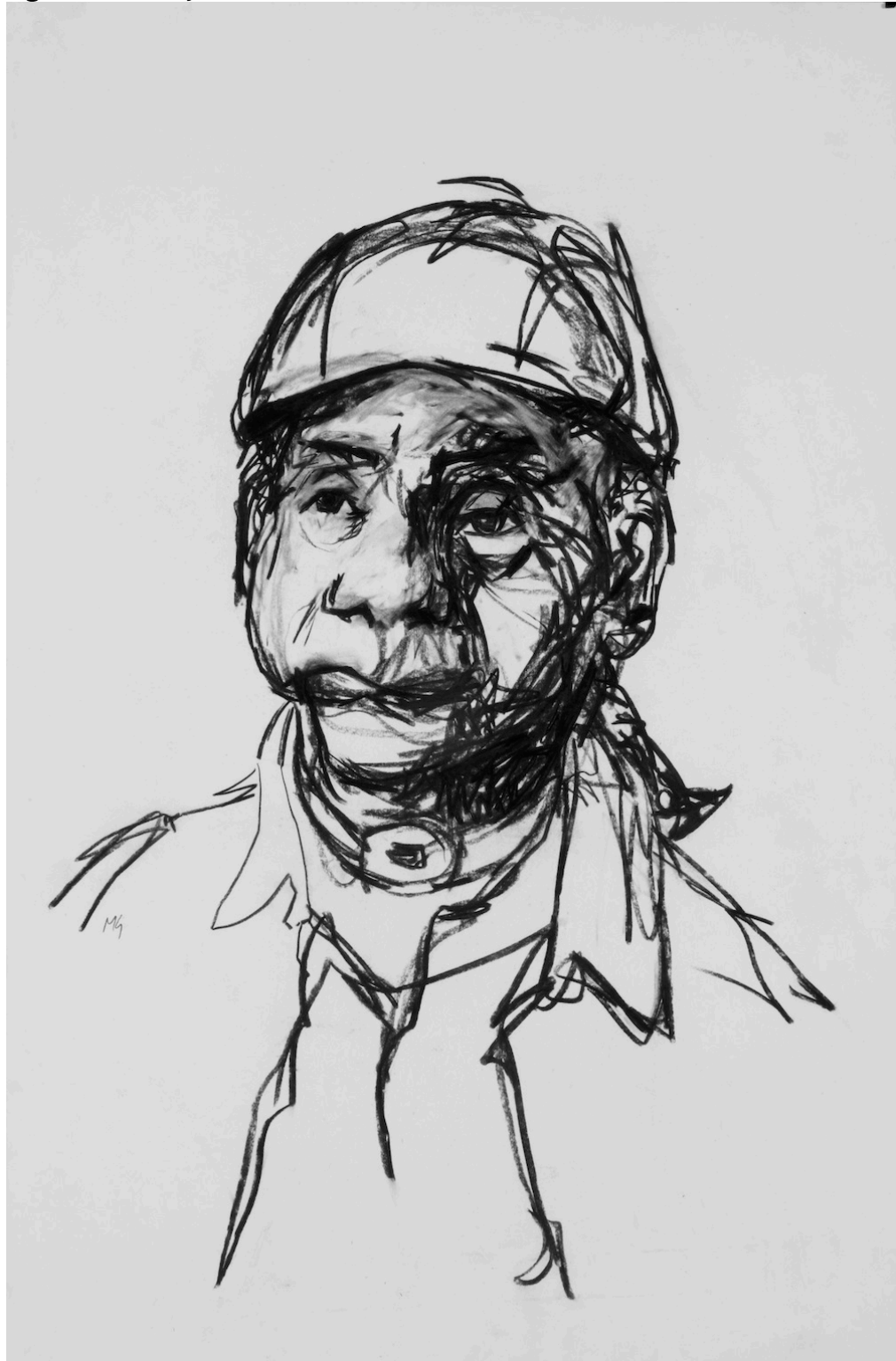
Copper photogravure, 20" x 15".

As WL and others worked to remove Anthony's jaw, tongue, and larynx, MG quietly sketched in pencil and photographed the specimen. Once removed, Anthony's jaw, voice box, and tongue were held by MG in his hand. MG still vividly remembers their weight.

Tumor, Body, and Story

In depicting the tumor, MG hoped to respectfully depict the mass and volume of what was removed from Anthony's body. Aesthetically, the cancer glistened and seemed bejeweled under the glare of the operating theater lights; ethically and clinically, however, the tumor specimen can be appreciated as being threatening and insidious. Elsewhere the third author (MMD) and her coauthor, 2 Indigenous scholars, explain how, "as part of the self-telling body that is the field of MH and NM [Medical Humanities and Narrative Medicine], we tell our stories ... because, like the parts of a body or the individual strands in a sweetgrass braid, our stories are connected to yours, irrevocably connected."³ In holding the tumor or even beholding the images made of the tumor, we might more fully recognize how the tumor, whether inside or outside Anthony's body, is an integral part of his story, a critical thread in his narrative. MG spent more time with Anthony than any other participant in POC. In the silence of the studio, Anthony and MG listened and responded to each other's curiosity and presence, drawing on portraiture to navigate different orientations to Anthony's life with the tumor and his life after its resection.

Figure 4. *Anthony*, 2007



Courtesy of Mark Gilbert.

Media

Charcoal on paper, 44" x 32".

Anthony let MG witness his responses to the demands of his recovery, his poise while adapting to his new postsurgery world and appearance, and his journey of learning to be composed despite being rendered nonverbal. Upon completion of his portraits, Anthony wrote of the role that his work with MG played in his recovery and of his adjustment to postresection life, describing the portraits as “*testimony of the struggle* that would follow to make life livable again with all of these changes.”

Silence-Stillness

In many portrait sessions, as the studio goes silent, the sounds of the first marks on the paper and those of the sitter settling into position accentuate both artist's and subject's embarking on an activity that generates an almost instant intimacy. Silence, deep looking, and curiosity emanate from both sides of the easel, sometimes creating an initial awkwardness. As the discomfort of those first moments dissipates, however, artist and sitter can interact and share to create a portrait that both testifies to their relationship and narrates the sitter's experiences.

As an artist, MG is acutely aware of the courage required to sit for one's portrait. In general, the silence in portraiture is often broken, punctuated with conversation. Although MG never regarded the silence as an empty void, Anthony helped him realize how much he'd initially assumed that verbal exchanges were the primary influence on the development of artist-sitter understanding, trust, and reciprocity during portrait sessions. That is, it is usually through talking that sitters and artists exchange stories; voice their passions, fears, and anxieties; and describe their responses to day-to-day happenings. These conversations, MG once thought, were the richest way to build relationships and create portraits.

Anthony's Teachings for Art and Healing

Silence and intimacy. It was not until MG worked with Anthony that he recognized silence as a deeply communicative act. Anthony lost his tongue and larynx, but he did not lose his voice. The silence that took its place became a profound form of expression. Anthony sensitized MG to the importance of silence and its salient role in portrait making. In Anthony's case, quiet was there to be discerned, just as noise might be. In silence, Anthony and MG gave earnest attention to *nonverbal communication cues* and were mutually committed to keeping, safeguarding, and stewarding silence. Neither sought to fill quiet with noise; Anthony's visual narrative of living with cancer and recovery was allowed to grow in—indeed, was enabled and enhanced by—the silence and in the space we inhabited together.

Silence and presence. In portraiture, both artist and sitter tend to be absorbed in the here and now. Silence is considered essential to developing full awareness of a present moment.³ Silence can be thought of as preparing a field for observing, for noticing. For artists and sitters alike, silence is to soundscape as space is to landscape, a state of receptivity, openness, and acceptance. Silence nurtures curiosity, stimulates interest, and frames the field in which thoughts, feelings, and sensations can be observed, interpreted, and visually recorded. Sitters often tell MG how they use the quiet of their sessions to reflect, meditate, or even pray. MG, too, uses the quiet to look, consider, and appreciate.

Silence and equality. Portrait making involves concentration, sustained focus, and astute attention to specific physical, mental, and sensory experiences. A productive portraiture process can be understood as occupying time and space for purposes of

telling and listening that inform the painting of an aesthetic and narrative whole. Although positioned differently, both artist and sitter are intentional, actively learning from one another, building trust, and recognizing each other's strengths, weaknesses, values, interests, and thoughts. As Back and colleagues explain, "While there are silences that feel awkward, indifferent, or even hostile, there are also silences that feel comforting, affirming, and safe."⁵ Occupying silence in comfort means sharing power—the power of disruptive potential, perhaps. One way to think of the ethical value of silence is in how artist and subject express respect for each other's equal potential to disrupt silence or stillness at any moment: painting and sitting demand that artist and subject embody that equality in their respective roles.

Silence and narrative. Learning to interpret what silence-stillness offers is also part of good portraiture practice. A portraitist's challenge is to be open not only to what is seen and heard but also to what is present and what is absent. Similarly, noticing and responding to space and negative space is vital to creating a narrative whole. As Buetow explains, "If we ignore the negative space, we risk seeing only the positive space we expect to see, rather than what is there."⁶ What is excluded is as important as what is included: blank space and silences shape the portrait as much as marks and layers of paint. For the portraitist, navigating the tension between documenting and creating, receiving and shaping, reflecting and imposing, and mirroring and improvising is a strategy for achieving visual narrative coherence and accuracy that flows organically from data offered by the subject and from the portraitist's interpretive witnessing.⁷ Artist and sitter cocreate visual narrative by inviting each other to fully engage with the potential of uncluttered space-time and silence-stillness to think and reflect and to see, feel, recognize, and generously acknowledge each other. Generosity is one thing creation and healing ask of us all. Anthony teaches us this.

Sharing Silence in Clinical Encounters

These elements of creating visual narrative in portraiture can also be useful in clinical practice. Anthony's portrait with the tumor, the painting of his resected tumor, and his portrait without the tumor form a series, enabled by his having shared silence with MG. Noises in clinical environments where health care is delivered tend to be distracting and to interfere with the attentiveness required for the artist's careful theme development and compositional decision making.⁸ But silence has its risks in both clinic-based and studio-based narrative inquiry. For a patient, silence can provoke anxiety, especially if someone disrupts a quiet space unilaterally. A mutually occupied silence, however, can nurture symmetrical connection, foster shared experience, and make collaboration and care palpable. Thus, in clinical settings as in studio settings, artists and subjects occupy silence together to enable cultivation of what Hart calls an "inner technology of knowing"⁹ that can engage stories and portraits of healing.

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MEDICAL EDUCATION

Why Teachers and Learners of Medicine Need Portraiture

Maxwell F. Lydiatt and William M. Lydiatt, MD, MBA

Abstract

Medical and especially surgical teaching stresses the importance of careful observation, developing tolerance for ambiguity, and cultivating empathy for patients' and colleagues' experiences of receiving and giving health care. Portraiture is defined by portraitist Mark Gilbert as a collaborative process between subject and artist; sitting is as critical to this process as painting or drawing. This article draws upon the second author's work with Gilbert to examine how portraiture can motivate key teaching and learning goals in health professions education by facilitating learners' explorations of their own and others' biases, limitations, and approaches to gathering information from and about a source (eg, a subject or a patient).

Practice Perceiving Detail

In an operating room, the rest of the world falls away. Minor details are magnified when a patient's life is in stasis, and each subtle variation in hue and texture can have significance. In this rarified space, it is a physician's duty to notice clinically, ethically, and aesthetically relevant tactile and visual details from a full range of visual cues in the sterile field and drape of a surgical site and to interpret them in ways that create a foundation for good decision making in real time. The muted sheen of a patient's superfluous fascia contrasts poorly with the thin lucency of that patient's distal nerve; the consequences of a surgeon's misjudgment about where to place a scalpel become magnified and intensified. Ideally, an experienced physician would have encountered this situation before and developed strategies for discerning color contrast among nerves and other tissues. Infinite variability persists, however, so it is impossible to offer a new physician in training a sufficient number of examples to lay the groundwork for confident, competent, and decisive action to proceed with an operation. Thus, curricula must nourish trainees' cultivation of perception and their capacity to notice—and skillfully interpret the meaning of—the most relevant among a vast array of compelling details under conditions of uncertainty. Responding carefully and competently to uncertainty is a key and meaningful part of the art of medicine, and those who practice medicine—like those who practice visual arts—benefit from a diverse range of perceptual **training experiences**. In this article, we promote the value of this modality of training and provide examples of portraiture's uses in health professions teaching and learning.

Practice Base-Coat Decision Making

Portraiture, like medicine, incorporates specific and concrete characteristics and imbues them with contextual depth. In viewing either a body intraoperatively or a painting, an observer is forced to confront not only ambiguous details obscured by pooled blood or smears of paint, but also multiple decisions they might have made that contribute to the view before them. Surgeons and artists both create outcomes built upon a base coat of prior choices. A surgeon commits to a plane of dissection that can have permanent consequences for a patient; a portrait artist chooses a perspective that renders indelible the orientation of a subject on a canvas. Final form is shaped by choice and action, and both portrait artists—with brush or medium—and surgical trainees—with a hemostat or cautery—must be able to conceive a realm of possibilities, adumbrate their consequences, and then choose among and commit to actions.

Lest the comparison end at the operating room door, relentless attention to detail must guide every interaction in which a physician presumes to manage another's life. By being trained with portraiture, learners can practice **discernment skills** before being called upon to serve the warm and breathing person who visits them in clinic.

Portraiture Parallels Medicine

Just as a clinician and a patient face each other in a clinical encounter, so a portrait artist and subject face each other in a sitting. Separating an artist and subject is a canvas on which an artist's marks express that artist's interpretation of a subject at a point in time; the canvas records the artist-subject relationship, influenced by the thoughts, personalities, and biases of both artist and subject. The portrait artist Mark Gilbert, with whom the second author worked on the *Portraits of Care* project,¹ hopes the canvas justly and accurately represents a subject's place on his or her journey during the time the two of them spent together doing portraiture (see Figure 1).

Figure 1. *Jim With Radiotherapy Mask*, by Mark Gilbert, 2014



Courtesy of Mark Gilbert.

Media

Pastel on paper, 40" by 26".

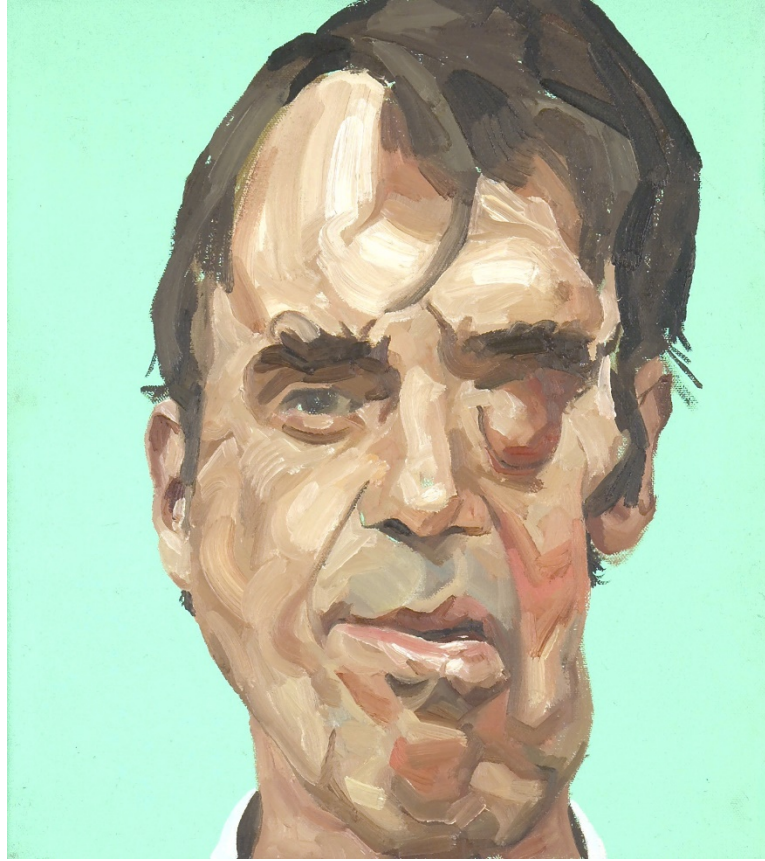
If an artist is tempted to create a “pretty” portrait, biases that shape his or her conception of what constitutes *pretty* will likely generate inaccuracy—and possibly unjust inaccuracy. Just as a portrait artist must guard against bias, so must a clinician guard against jumping to a diagnosis and then retrofitting observations to confirm an erroneous first impression. Clinicians can avoid this trap by cultivating the capacity to recognize how their own biases from prior experiences, prejudices about people with backgrounds that differ from their own, and tendency to neglect the real-world prevalence of occurrences (ie, base-rate neglect) influence their thinking, reasoning, and decision making. They must learn to observe themselves and to interrogate information sources about patients, such as history, physical examination, laboratory results, and radiographic findings, each of which must be carefully weighed to yield knowledge that informs medical decisions that help patients. Learning to observe oneself as a clinician in these ways can be practiced with portraiture.

Practicing Perception

A portrait is a physical manifestation of an artist with a subject (who is often but not always sitting); it is one model of a patient-clinician relationship and thus is a useful tool for training clinicians. Portraits provide a snapshot of a subject at one point in time with variations and nuances that are apparent to some viewers but hidden to others. Through engaging with portraiture, learners can practice navigating uncertainty and assuming a variety of perspectives, for example. A portrait of a subject can accommodate a variety of interpretations; learners can practice orienting themselves not only to a plurality of perspectives on the subject’s experience that might initially make them uncomfortable, but also to the experiences, backgrounds, and moods of different viewers of the same subject. Metacognition can take place when learners witness and process their biases and thought patterns, share them with colleagues, and participate in team-based distributed cognition, all while practicing collegiality. Educators can also prime learners with phrases that subconsciously prompt them to see a portrait differently.

For example, Mark Gilbert’s portrait, *Henry De L*, from the *Saving Faces: Art and Medicine* exhibit,² can motivate students’ and trainees’ explorations of their emotional responses to a portrait (see Figure 2). Questions can include these: How does disfigurement influence your perception of Henry? What do you think you can say you know about him from how this portrait represents him?

Figure 2. *Henry De L*, by Mark Gilbert, 1999



Courtesy of Mark Gilbert.

Media

Oil on canvas, 72" by 42".

Drawing can help sharpen observation and self-awareness. When performed with one's nondominant hand, the work does not depend on drawing skills so much as on observational skills. Students gain a reprieve from rendering a careful and detailed drawing, as they are forced to rely on observation rather than on dexterity and their preconceived notions of the subject. Comparing students' drawings allows class members to consider different attributes that each student noticed. Different students tend to focus on different features of a portrait; these differences can be launch points from which students can practice interrogating their biases and the habits of perceptions on which they typically rely.

Perception, Sitting, and Silence

Sitting for a portrait can also be instructive for trainees. Sitting helps one consider the anxiety a patient might feel when being observed by a clinician, perhaps watching for clues about what the physician is thinking (see Figure 3). During clinical encounters, two or more people are together in a room, facing each other with some level of anxiety about what the other is thinking and experiencing.

Figure 3. *Bill*, by Mark Gilbert, 2006



Courtesy of Mark Gilbert.

Media

Charcoal on paper, 72" by 42".

As discussed elsewhere in this issue of the *AMA Journal of Ethics*, accepting and acknowledging silence present in the room can nourish connection, and this **shared silence** is our best hope for a patient-clinician relationship rich in therapeutic capacity. Learning to become comfortable with silence can also help trainees navigate ambiguity and uncertainty during clinical encounters and experiences in which clinicians, patients, and their loved ones try to make sense of information on which to base important health decisions. Although double-blind, randomized controlled clinical trials are the gold standard for determining the safety and efficacy of new interventions or devices, the results—even if statistically and clinically significant—cannot tell us whether to apply a given therapy to individual patients. An evidence base still requires interpretation. This dimension of the art of medicine can be practiced when one is sitting for a portrait—particularly with focused attention to one's psychological reactions to silence,

uncertainty, and ambiguity—as such reactions persist in relationships between those who care and those who are cared for.

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MEDICAL EDUCATION

Health Care Professionals' Journeys of Caring Through Portraiture

Stacey Ocander, EdD, Lori Saville, MSN, Mark Gilbert, PhD, and Regina Idoate, PhD

Abstract

Metropolitan Community College, a comprehensive multicampus academic institution in Omaha, Nebraska, installed portraits by the third author (MG) in the Health Careers Building and integrated them into an associate degree nursing curriculum. One goal was to expose nursing students to patients' stories in ways that encourage them to look beyond pain rating scales and protocols to the many dimensions of patients as human beings. Using portraiture in this way could be applied to any health professions curriculum, as the intersections of humanities and health care prompted students and clinicians to look beyond science and into the emotional journeys of caring.

Portraiture in Nursing Curricula

In an effort to integrate portraiture into a nursing curriculum, Metropolitan Community College's Department of Nursing exhibited *Experience of Portraiture in a Clinical Setting* (EPICS). This collection of portraits by the third author (MG), an artist-researcher, resulted from his arts-based research with patients experiencing head and neck cancers. Patients participated in the portraiture process as part of their cancer clinic visits.¹

Students in an associate degree nursing program were exposed to EPICS' 24 drawings and paintings depicting 5 patients with head and neck cancers. In September 2017, the college hosted a formal public exhibition of EPICS and a discussion with Gilbert and his fellow researchers, health care professionals, and 4 of the 5 study participants who sat for their portraits. Gilbert and one EPICS study participant also delivered guest lectures in nursing classes about portraiture and EPICS, engaging students in classroom discussions about health, illness, and the nature of interactions among art, artists, and patients during portraiture sessions. A survey was conducted to examine nursing students' responses to being exposed to the patients' portraits. This article examines how integrating portraiture into nursing education can offer an opportunity for nursing educators and students to reflect on patients' and caregivers' **holistic human experience**. Below, we share educators' reflections on exhibiting EPICS in a college department of nursing, along with qualitative and quantitative analyses of students' perceptions of the educational experience.

What Students Reported

A total of 123 individuals, mostly nursing students, completed the survey after viewing the portraits. Respondents reported contemplating a range of caring traits. After observing the EPICS exhibition, attendees reported observing the following emotions in the portraits: fear, vulnerability, uncertainty, sadness, acceptance, comfort, resilience, strength, courage, hope, empathy and compassion. Respondents were presented with a list of potential responses to the portraits, and a majority reported that they agreed or strongly agreed that, when looking at the portraits, they developed a sense of compassion and empathy (93.4%), understanding (91%), awareness (88.6%), acceptance (87.8%), gratitude (87.7%), resilience (84.4%), and ethics (79.5%). A majority of respondents also reported that, when viewing the portraits, they thought about how health and illness affect identity (92.6%), the impact of caregivers on patients (87.7%), the psychology of bodily illness or health (87%), visual qualities of health and illness (86.2%), and the impact of illness on caregivers (85.4%).

In the survey, respondents were asked to describe both their initial thoughts when they first entered the portrait exhibition and their concluding thoughts when leaving. Some reported that they initially questioned the reasons for including portraiture in nursing education and wondered, “How do portraits relate to medicine?” However, in describing their thoughts after attending the exhibition, many noted the value of making human connections with patients and reported recognizing the uniqueness of patients’ stories, listening to and reflecting on patients’ stories, and embracing curiosity or avoiding assumptions about patients. Ultimately, participants reported that this exhibit opened their eyes, inspired a desire to learn more about cancer, strengthened their desire and need to help others, and reaffirmed why they were pursuing a nursing career. In response to the survey question, “What is the most important message you are taking away from this exhibition?”, participants recognized that humanity is key; art can be healing; medicine is an art; healing is a process; and there are different ways of healing.

Value of Portraiture

Exposure to portraiture can offer an opportunity for caregivers to reflect on personal experiences that have drawn them into a profession of caring and compassion and serve as a tangible way of acknowledging the lived experiences of patients. The second author (LS) reflected:

As I sat with my dying mother, a multitude of moments were instilled as mental portraitures in my mind, such as when my son stood still at her bedside with his 7-year-old eyes filled with not knowing that would be the last time he would be with her, my father relentlessly trying to get my mom to take a bite of the pureed beets as a desperate attempt to deny the dying process, the hospice nurse playing the health care worker’s role that is normally my job, standing at the foot of the bed with the look that told us what we didn’t want to acknowledge and my eyes focused on the desk that my mother so recently sat [at] and struggled to write letters on as the brain tumor took over her ability to write.... The desk stared at us during those long days as we sat watching her slip away. This was a mental portrait in my mind ... that desk has become a piece of the mental image of the experience as the grieving process continues.

Much like LS’s mother’s desk, images of the chair that participants sat in during the EPICS portraiture process (see Figure 1) became a means through which viewers engaged in deep reflection on the healing process. Physical objects can stimulate emotions that are felt during the portraiture experience and help construct meaning as the experiences are mentally processed and reflected upon. The same chair, which now sits in the office of the first author (SO)—the Dean’s Office at Metropolitan Community College—welcomes visitors as a continuation of the portraits now hung throughout the halls of the college. The ability to draw on **one’s own lived experiences** and emotions

through portraiture is one way to integrate medicine and the humanities, as evidenced by viewers' reactions to the portraits.

Figure 1. *The Empty Chair*, by Mark Gilbert



Courtesy of Mark Gilbert.

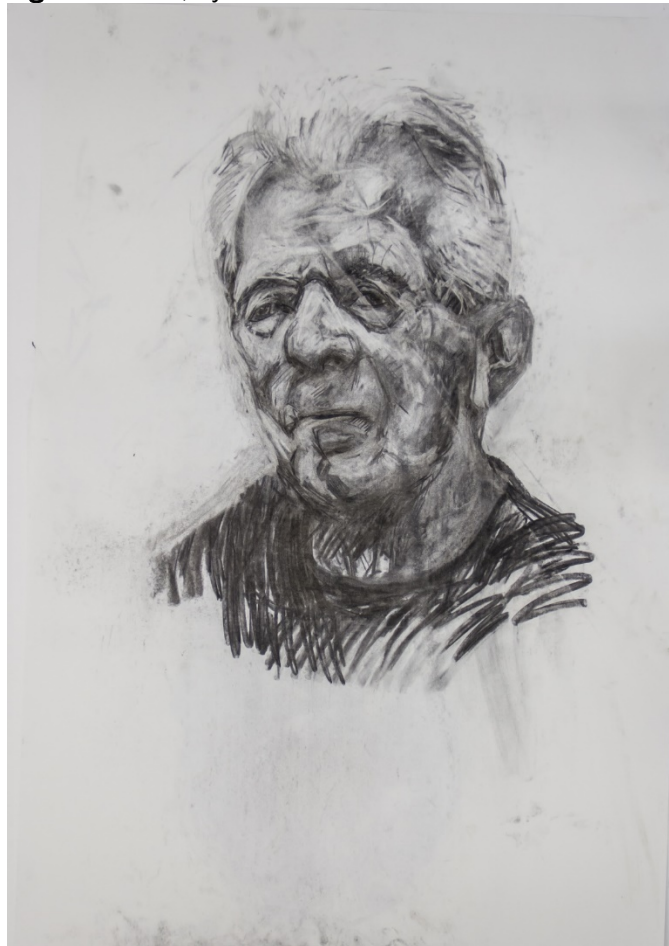
Media

Ink on paper.

The inaugural EPICS exhibit, which opened in 2017, provided the first public display of its 24 pictures and the first gathering of the participants who sat for those portraits, sans one, who had passed away. The event honored the participants in EPICS and gave the public its first opportunity to see the full collection of portraits. One family member was motivated to leave her residential care center for the first time since a catastrophic event had left her paralyzed.

The extent to which lived experiences of engagement with portraiture can affect one's life is often unexpected when the journey first begins. In particular, bringing together these individuals and their families led to unexpected connections. Marketing for the event led members of one family to find the portrait of their deceased loved one that they knew had been created but had since lost track of; that family came to the event and saw that portrait with great appreciation. Perhaps the most profound experience was the instant familiarity the participants had with each other. They had never met, but they felt a strong sense of fellowship through viewing each other's portraits during the study. One of the EPICS sitters, John (see Figure 2), said to another EPICS sitter whom he had not met in person before the exhibit opening, "I feel like I already know you because I saw your portrait and felt your story every day as I was being drawn. It helped me get through the rough times."

Figure 2. *John*, by Mark Gilbert



Courtesy of Mark Gilbert.

Media

Charcoal on paper.

Integrating EPICS Into the Curriculum

Integrating EPICS into the nursing curriculum at Metropolitan Community College has had unintentional effects, manifest in the reactions of both students outside nursing and staff to the portraits hung in the hallways. Prior to the titles and narratives associated with the EPICS collection being displayed, students routinely stopped and stared at the portraits, attempting to surmise the importance of these particular individuals. Although they had no concrete facts, they continued to visit, pause, and analyze the portraits. Students shared that they thought these portraits must be of important people, possibly large financial donors to the college or historians.

Slowly, the institution began to display pieces of information about the collection in a deliberate attempt to draw students into seeing the faces in the portraits: first, a patient's name; second, the artist's name; lastly, the story of the collection of EPICS. After the final piece of the narrative had been revealed, one would assume that the students and staff would be satisfied that they had found the answer to the mystery of the people in the portraits and grow tired of stopping to see them. Yet, what we found was an increase in visits to the portraits by the same students and staff. Students shared that they experienced a sense of peace and comfort in seeing the faces in EPICS each day. One student said, "It was like seeing a friend." One staff member stated, "I know when I walk in the door in the morning and see Judy's smile and her holding that cup, everything is going to be okay" (see Figure 3).

Figure 3. *Judy*



Courtesy of Mark Gilbert.

Media
Pastel on paper.

Listening to the artist and the study participants in the panel describe the impact of the portraiture experience on their own lives, members of the audience were moved to reflect on their own experiences and internal images of previous lived experiences that were “portraits” in their own mind. We believe reflection on these lived experiences, in conjunction with portraiture in nursing education, can enhance **soft skills** and the development of empathic nursing care.

Future Directions

To our knowledge, there has been no other comparable pedagogical experience offered in nursing curricula. Moreover, to our knowledge, there are no other existing studies of exposure to portraiture in nursing education with an accompanying quantitative analysis of students’ perceptions of the educational experience. Nevertheless, our research is only suggestive.

Future research could fruitfully examine the impact of educators’ personal encounters with health alterations on their teaching practices—specifically, on their training nurses to perceive the patient as a holistic being with depth rather than simply as an individual with a health ailment. Through the journey of portraiture, faculty members have the opportunity to share their own lived experiences of transitioning from a caregiver to a care receiver or a patient’s family member. Furthermore, the portraits create opportunities for students to reflect on the fluidity of these roles and how their actions in caring for others become the very portraits we draw inspiration from. We believe that it is through these shared stories that students, as future health care professionals, become aware of the impact they have on their **patients’ lived experience**.

In contrast to other more affordable and accessible types of art, such as poetry and literature, there are barriers to integrating original paintings into nursing curricula—namely, the cost, transportation, and care of originals.² These barriers often prevent the realization of the opportunity that we had here at Metropolitan Community College. We believe any exposure to MG’s work, whether viewed online or in person, is valuable for student learning and fosters caring when combined with the artist’s and patients’ narratives of the experience of portraiture. We remain committed to exposing students to original works of art and portraits of real patients.

Nonetheless, future research is needed to support the claim that original works of art and portraits of real patients are irreplaceable resources. We suspect that the specific nature of the paintings of real patients and the educational lecture and class discussions were important factors in students’ empathy-enhancing experience. Empirical support for this claim could aid in securing funding for institutions to integrate original works of art into curricula and to personally work with the artist, as was done at Metropolitan Community College.

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primary work includes developing programs and curricula that address the holistic approach to caring for others in a global society, and her contributions to this space address the cultural competency of students and their ability to recognize and resolve health disparities and their impact on the human condition.

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MEDICINE AND SOCIETY

Neurofibromatosis and a Portrait of 1 in 3000

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Abstract

Neurofibromatosis, a genetic disorder that occurs in 1 in 3000 births, can cause tumors to grow anywhere on or in the body. The first author (RM), an artist-researcher and mother of a son living with neurofibromatosis, has painted and exhibited more than 200 portraits of people living with neurofibromatosis to raise awareness of and resources for this little-known disorder. Among many stories shared through RM's works is the story of Ashok, a Nepali man who has undergone 3 surgeries to remove facially disfiguring tumors that developed as a result of neurofibromatosis. This article analyzes portraits of Ashok and interviews that the senior author (RI) conducted with Ashok and RM during each phase of his surgical process to present a case study of their lived experience at the intersection of art and medicine that illustrates the power of portraiture as medicine.

Painting a Picture of Neurofibromatosis

Neurofibromatosis (NF), a genetic disorder that occurs in 1 in 3000 births, can cause tumors to grow anywhere on or in the body.¹ NF can affect the development of bones and skin and can cause learning disabilities as well as vascular issues, deafness, paralysis, blindness, cancer, and even death.² The first author (RM), an artist, activist, researcher, and mother of a son living with NF, has painted and exhibited more than 200 portraits of people living with NF to raise awareness of and resources for this little-known genetic disorder.

Among the many stories shared through RM's works is the story of Ashok, a Nepali man living with NF who came to the United States for facial tumor removal and **reconstruction**. RM's body of work, including Ashok's biography and portraits, has been featured in multiple exhibits and installations: *Neurofibromatosis: The People*, at the Albrecht-Kemper Museum in St Joseph, Missouri³; *Many Faces of Neurofibromatosis*, at Washington University School of Medicine in St Louis, Missouri⁴; *Portrait of a Disorder: Neurofibromatosis*, at Creighton University's Lied Art Gallery, in Omaha, Nebraska⁵; and *Many Faces of Neurofibromatosis* at the Norfolk Arts Center in Norfolk, Nebraska.⁶ We analyze RM's portraits of Ashok and transcripts of 2 interviews conducted with both RM

and Ashok to present a case study of the lived experiences of Ashok and RM, which illustrates the power of portraiture as medicine in addressing NF.

Ashok's Story

The NF community is global and often stays connected through Facebook, where people share pictures and stories of diagnosis and management of, and life with, NF. When interviewed by the senior author (RI), Ashok explained, “many people know me ... all over in different countries ... from my story on Facebook.” In 2016, still in Nepal, Ashok uploaded his story on Facebook via video. RM saw it when a mutual friend posted it. With Ashok’s permission, RM painted his portrait by stopping the video at a certain point to clearly see his face. In an effort to promote awareness of his story and to support a United Kingdom-based GoFundMe campaign for Ashok, RM shared Ashok’s first portrait on Facebook (See Figure 1).⁷ Ashok **shared his story**, the campaign, and this portrait through Facebook with approximately 3000 friends across the globe. As a result, the GoFundMe campaign raised enough money for Ashok to obtain a medical visa to come to the United States in 2017.⁷

Figure 1. *Ashok Chatting With Friends*, by Rachel Mindrup, 2016



Courtesy of Rachel Mindrup.

Media

Oil on Canvas, 30" x 24".

In January 2018, RM met with Ashok and other friends in Omaha, Nebraska, to start a new campaign to raise funds for his medical bills.⁸ Since his arrival in the United States, Ashok has undergone 3 transformative surgeries performed in Chicago, Illinois, and RM has created portraits of Ashok after each of these surgeries. Ashok's first surgery in March 2018 removed over 80% of the tumors on his face, making it possible for him to

use his mouth to drink through a straw. Once he had recovered from the surgery, Ashok traveled back to Omaha, Nebraska, to meet RM in person and sit for a second portrait (See Figure 2).

Figure 2. *Ashok Visiting Creighton University*, by Rachel Mindrup, 2018



Courtesy of Rachel Mindrup.

Media

Oil on canvas, 30" x 24".

Both RM and Ashok were interviewed together by a journalist and RI with help from a Nepali friend and translator; RM's second portrait and insights gleaned from the interview were shared in the news media to continue raising funds in support of Ashok's second surgery.⁹ In the interview, Ashok described how even though the surgery made his face feel tighter and less natural, it helped him hear, eat, and breathe better. He also affirmed that he was "happy about what Rachel has done" in painting not only his portraits but also those of others. He explained that, in Nepal, NF has been considered a "sin" or a "curse extending through many lives" and that "people didn't know what it was." He said, "people would point at him and ask questions or laugh or make fun.... It was an unpleasant experience." His experience in the United States has been much different, and he recalled being recognized by people he had never met before but who had seen his portraits and who called him "like a brother" by his Nepalese name, saying "Ashok Dai." He explained that seeing his own image makes him "recognize" and "appreciate" how "the portraits played a big role in people knowing about my [his] case and raising funds."

Ashok underwent a second surgery in July 2018. Additional work was done on his cheek and mouth to continue to strive for more symmetry in his face. RM illustrated this facial alteration and Ashok's holidays spent with another couple (both of whom also have NF) in a subsequent portrait (See Figure 3).

Figure 3. *Ashok Playing Jenga*, by Rachel Mindrup, 2019



Courtesy of Rachel Mindrup.

Media

Oil on canvas, 30" x 24".

In June 2019, Ashok underwent what he hoped would be his last surgery. In this third surgery, the remaining tumor was removed; his lips, nose, and eye socket were resized; and a prosthetic eye was fixed into his eye socket. After his recovery from surgery, RM and RI visited Ashok in Chicago, where he sat for another portrait. At this time, RI conducted a second interview with RM and Ashok in which Ashok discussed how differently people treated him after he received the prosthetic eye. Ashok explained,

“People are looking at me. They had never looked at me before I received this eyeball. But, now ... everyone ... they look at my face. On the bus, in the road, everywhere ... they look at me.” Ashok’s portrait after his third surgery portrays his smiling face with 2 brown eyes and a mirror reflection behind him (See Figure 4).

Figure 4. *Ashok Holding up the Bean*, by Rachel Mindrup, 2019



Courtesy of Rachel Mindrup.

Media

Oil on canvas, 30" x 24".

Ashok and RM have worked together for more than 3 years to bring NF into view, creating portraits to **raise awareness** of NF and collecting resources to support NF education, treatment, and research. RM explained, “It’s my job to make sure that everybody knows about NF.” She added, “I think sometimes we don’t want to talk about it. With Ashok ... people see the tumors, so of course they know. But with my son, his tumors are internal. It’s hard to raise awareness about something unseen. And, at the same time, I can’t do portraits of just Ashok and tell everybody that’s what NF is.... I have to paint and draw as many portraits as possible to show you that there is actually no portrait to NF” (See Figure 5).

Figure 5. *Henry Checking the Weather*, by Rachel Mindrup, 2013



Courtesy of Rachel Mindrup.

Media

Oil on canvas, 40" x 30".

Ashok described the challenges of living with NF, explaining that most people with NF feel uncomfortable in society and face discrimination on many levels. He explained that “life is difficult” and that he hopes the portraits will encourage people to “be more caring.” Ashok is grateful that through the publicity inspired by his portraits, he has made thousands of friends, become a part of the NF community, and helped raise awareness of and support for NF. He said that people who see his portraits often befriend him, sending him messages of encouragement and donating to his cause.

Educational and Personal Value of Portraiture

Ashok and RM also have more specific goals. Ashok believes that his portraits, in serving to educate people about NF, “will help people understand ... that anyone can have a genetic disease,” and he hopes this understanding will promote “equality to all” and more opportunities for people with neurofibromatosis to enjoy living, learning, working, and playing in society. RM hopes for “a cure.” RM works with the Children’s Tumor Foundation, the Neurofibromatosis Network, and Neurofibromatosis Central Plains to share portraits of people with NF like Ashok with elected officials in Washington, DC, “so that they can see ... why it is important ... to let researchers do the important work they are doing” toward finding a cure for NF. Together, RM and Ashok have shared Ashok’s story, developed friendships and fellowship through NF advocacy, lobbied for policy changes, and raised over \$100 000 by sharing portraits of NF. Ashok explained that what they had accomplished was not done alone, and he added that he is incredibly thankful for his “friends and all of the donors from many countries, especially the people of Omaha” who “loved, donated, and inspired me along my medical journey.”

To date, RM has completed over 19 portraits of Ashok, including monotypes, charcoal drawings, and oil paintings, and shared them in a Facebook album titled “My friend, Ashok.” These portraits of Ashok, including a series of monotypes (See Figure 6), depict Ashok’s transformation and the power of art and medicine.

Figure 6. *Awaiting Donations, Surgery 1, After Surgery 1, Surgery 2, After Surgery 2, Surgery 3, After Surgery 3*, by Rachel Mindrup



Courtesy of Rachel Mindrup.

Media

Monotypes, 15" x 11".

When asked which image he liked the most, Ashok said, "I like the first one," adding that it holds a "memory" of the beginning of his relationship with RM and the first time in his life that anyone had drawn his picture. When asked how he felt about this portrait, he said, "from the heart ... it is extremely good." He is "content about the way it is," and commented that "the portrait has a positive impact on my [his] identity" and that when "someone who does not know me [him] sees that painting, they know about me [him]." That said, Ashok likes all of his portraits, and he explained that "art is something that attracts your attention. When you see it, you are taken, you are drawn to it," and "in this particular case, people come to see not just art, but they are aware of the presence of NF in the art, so people are left feeling something about this cause. It is very powerful, this art."

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Editor's Note

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MEDICINE AND SOCIETY

Should Art About Child Abuse Be Exhibited in Corridors of Health Professional Schools?

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Abstract

Imagine an exhibition—on a topic like child sexual abuse, dementia, or epilepsy, for example—not typically considered by museums or galleries. The question, then, is *Where might such an exhibit be displayed?* How about a medical school, for instance? An exhibition of this kind might include visceral psychological portraits and explanatory text tailored to the learning activities of medical students. This article examines these curatorial and ethical considerations.

Exhibitions on Sensitive Topics?

It was shop talk. Four people were sitting around a table at Leiden University in the Netherlands speaking earnestly about the psychological sequelae of child abuse—symptoms and their duration, the impact on brain structures, the deficiencies of treatment. The conversation then turned to the second author's new art book, *Shame and the Eternal Abyss*.¹ It features images of spinning outpourings of anguish that embody the perplexing sequelae of child sexual abuse.

"It's curious," one of our Dutch colleagues remarked; "I just had a conversation with a good friend who is a curator at the Stedelijk Museum Amsterdam. We came to the conclusion that the time might be right to create an exhibition about child abuse, one that incorporates visual artworks no less than research symposiums." Many delightful conversations ensued, although the exhibition has yet to materialize.

What would it take to bring to fruition an exhibition on a sensitive topic like this? The question is neither rhetorical nor specific to child abuse. Any medically relevant subject matter that's taboo for any reason, or that's overlaid with halting inhibitions, might suffice as a representative example: epilepsy, facial disfigurement, and dementia, to name a few. Although each topic has been profoundly represented through artworks, these categories nonetheless don't easily lend themselves to museums' and galleries' priorities, such as marketability. That caveat notwithstanding, how might an exhibition of this nature be made more feasible? And where might it best be displayed? Narrowing the focus of an exhibition to child sexual abuse, for instance, would make its implementation more practical because it would allow the subject matter to be rendered

more minutely, thereby facilitating greater viewer comprehension and increasing the subject matter's relevance to **social advocacy**.

Exhibiting Child Abuse

There are 4 categories of child abuse: physical abuse, sexual abuse, emotional abuse, and neglect. Each is further partitioned by intuited or factual differences. For example, child sexual abuse is subdivided into prepubertal and postpubertal classifications.^{2,3,4}

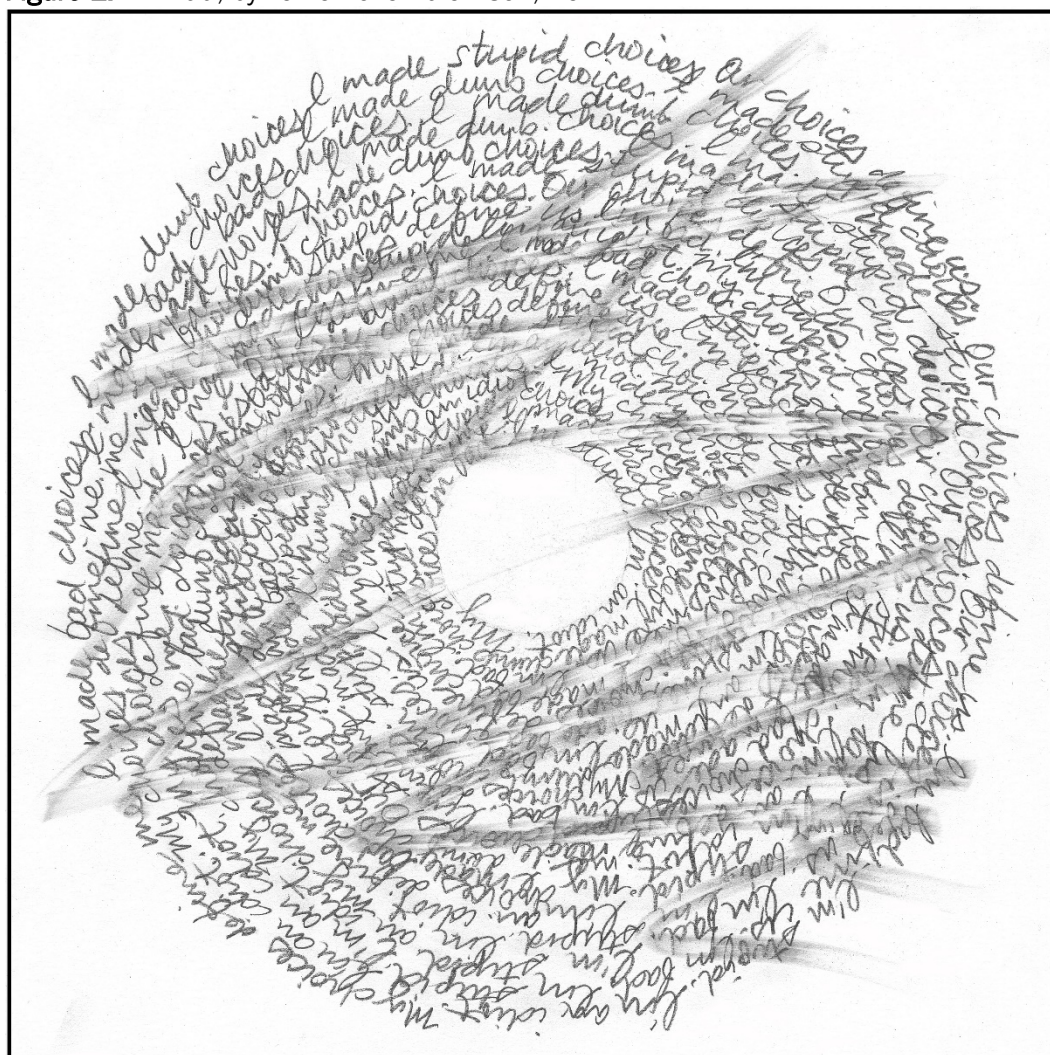
If, indeed, a more circumscribed exhibition on child abuse could be designed—again using the example of child sexual abuse—the more fundamental question is why would anyone want to feature an exhibit devoted to this issue? Sexual abuse is a crime that is an unfathomable harm to a child, and, although this point is clearly of justifiable concern given the potential for adverse viewer reactions, what poses a greater danger, we believe, is censorship. Child sexual abuse is unquestionably a pediatric and public health crisis of epidemic proportions.^{5,6,7,8,9} Finding an optimal place to display an exhibition of this scope that is informed by trauma more broadly is arguably also a public health priority. Such an exhibition would surely be a conspicuous health initiative if these artworks and their accompanying narration effectively increased emotional engagement with victims of this dreadful ordeal.

Sensitive Exhibitions in Medical Schools

What about medical schools? There is certainly precedent for bringing a topical exhibition to a professional audience; the photographer Richard Ross's assemblage of photographs, *Juvenile-in-Justice*, is a case in point. His depictions of incarcerated adolescents were exhibited in 2014 in the hallways of Harvard Law School.¹⁰ Immersive by default, the photographs were manifest declamations of injustice, especially befitting for law professors and their students. It should also be noted that displaying artworks in the corridors of medical schools is hardly original. The Harvey Cushing/Whitney Medical Library at Yale School of Medicine routinely hosts exhibitions, such as *The AIDS Suite*, *HIV-Positive Women in Prison and Other Works* by Artist/Activist Sue Coe in 2016-2017.^{11,12}

That said, it still might be useful to consider yet another departure from traditional curatorial norms, like a mixed-media exhibition on child sexual abuse—artworks, documentation, symposiums, and performances linked to learning activities created, choreographed, and performed by medical students. Students could wear surgical masks to class, for instance, emblazoned with the letters CSA (for child sexual abuse). Such an activity could serve as both a collective witnessing of **CSA survivors** who have been shamed into anonymity and a tribute to CSA victims pressured into silence. The corresponding dynamics of shame and silence are also represented in Figure 1, in the form of self-punitive introspections and their erasures.

Figure 1. *I'm Bad*, by Tania Love Abramson, 2017



Courtesy of the artist.

Media

Pencil, erased, on paper, 14" x 11".

Although this exhibition need not be limited to corridors, it is nonetheless important to keep in mind that these architectural spaces derive their psychological meaning from their ambiance as much as their structure—most notably, their potential for advancing communication and association among those who traverse them,¹³ like the proverbial gathering around the water cooler. The main instrument for engagement with an exhibition on child sexual abuse would be the alliance between the institutional setting and the fervent artworks themselves.

Why hasn't something of this scope been realized previously in a medical school? Why hasn't there been an exhibition of artworks—allegorical in character, for instance—of children in the aftermath of sexual abuse—visceral portraits of unrelenting torment no less than resolute courage? We envision something on the order of an exhibition titled

Portraits of Abiding Despair and Steadfast Determination. Assuredly, there's been no lack of attention from the media, which has vividly portrayed child sexual abuse scandals for decades. Perhaps the gatekeepers in the world of art have deemed child sexual abuse too offensive to the sensitivities of viewers—a synergistic repression of the unacceptable, as it were. That supposition, if true, is especially hard to reconcile with the curatorial practices of Holocaust memorials—for example, the Dachau Concentration Camp Memorial Site¹⁴ (see Figure 2). Challenging the amnesia around a vast, horrendous crime is the first priority in documenting, and thereby fully comprehending, the Nazi Final Solution.¹⁵ Piercing the veil of comforting illusions would serve the same function for child sexual abuse while also reinforcing Mohandas Gandhi's adage that "truth never damages a cause that is just."¹⁶

Figure 2. Crematorium Ovens, Dachau Concentration Camp Memorial Site



Photo by Paul R. Abramson, 2016.

Purpose of Child Sexual Abuse Exhibit

Although the alarming atrocities of child sexual abuse are bad enough, their concealment by the art world is even worse. It's imperative to stage exhibitions of this nature because their existence alone affirms the putative value of art in connecting dots, including its intrinsic power to rankle. Failing to exhibit artwork of child sexual abuse would also unduly constrict not only survivor narratives but also the language of art more generally—manifest in metaphor, allegory, storyline, and history—or of any linguistic form that can enlighten without constraint and educate without evasion, no matter how indirectly its subject matter is represented or chronicled.^{17,18,19, 20} One example of indirect representation is an image of a crashing helicopter decimated by a

spiraling abyss that is meant to symbolize the emotional tailspin experienced by victims of child sexual abuse (see Figure 3).

Figure 3. *Lapse of Consciousness*, by Tania Love Abramson, 2017



Courtesy of the artist.

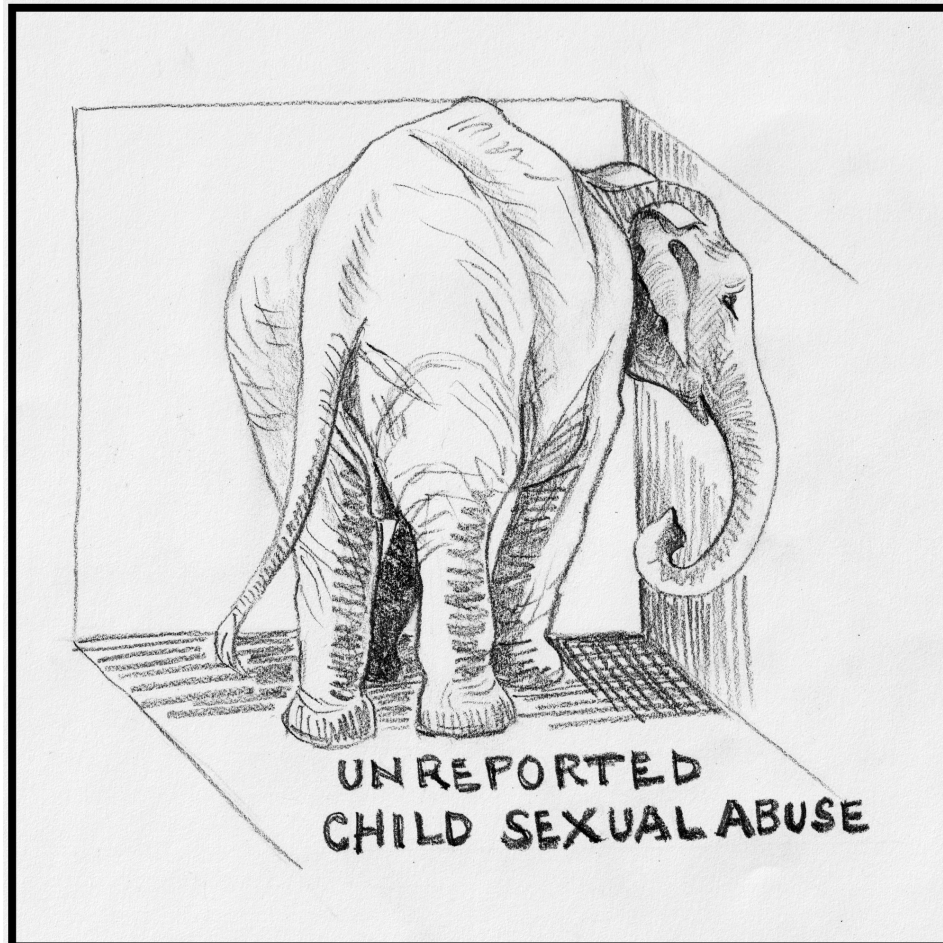
Media

Paint pen on found photograph, 16" x 20".

In the best-case scenario, one would want to create an exhibition capable of inducing a transcendent experience,^{21,22} whereby viewers recognize all of the ramifications of child sexual abuse. For this reason, we have suggested the need for active participation of viewers, symposia, performances, and catalogues in addition to static artworks. It's even possible to create a playlist of songs that reference child sexual abuse, such as the Girl Child Network Worldwide's *Avantwana-Children Being Abused (Tribute to Betty Makoni)*²³ and Crying 4 Kafka's *Fuck Mom/Fuck Dad*.²⁴

Only through identification can someone begin to understand and empathize with the fact that the sexual abuse of a child is an inconceivable trespass, an emotional annihilation in many respects.^{25,26} If adult women struggle to report a sexual assault to law enforcement and name their perpetrator, as the #MeToo movement has made abundantly clear, imagine how a child must agonize going through the same criminal process. What credibility does a child have when an adult perpetrator denies the charge? How does a child navigate the legal hurdles? The obstacles to disclosure and resolution are nearly insurmountable for a child (see Figure 4), which is why the crime of child sexual abuse so often goes unreported²⁷ and the psychological fallout, in combination with the long-term health consequences,²⁸ becomes so entrenched.

Figure 4. *It's Always the Elephant in the Room*, by Tania Love Abramson, 2019



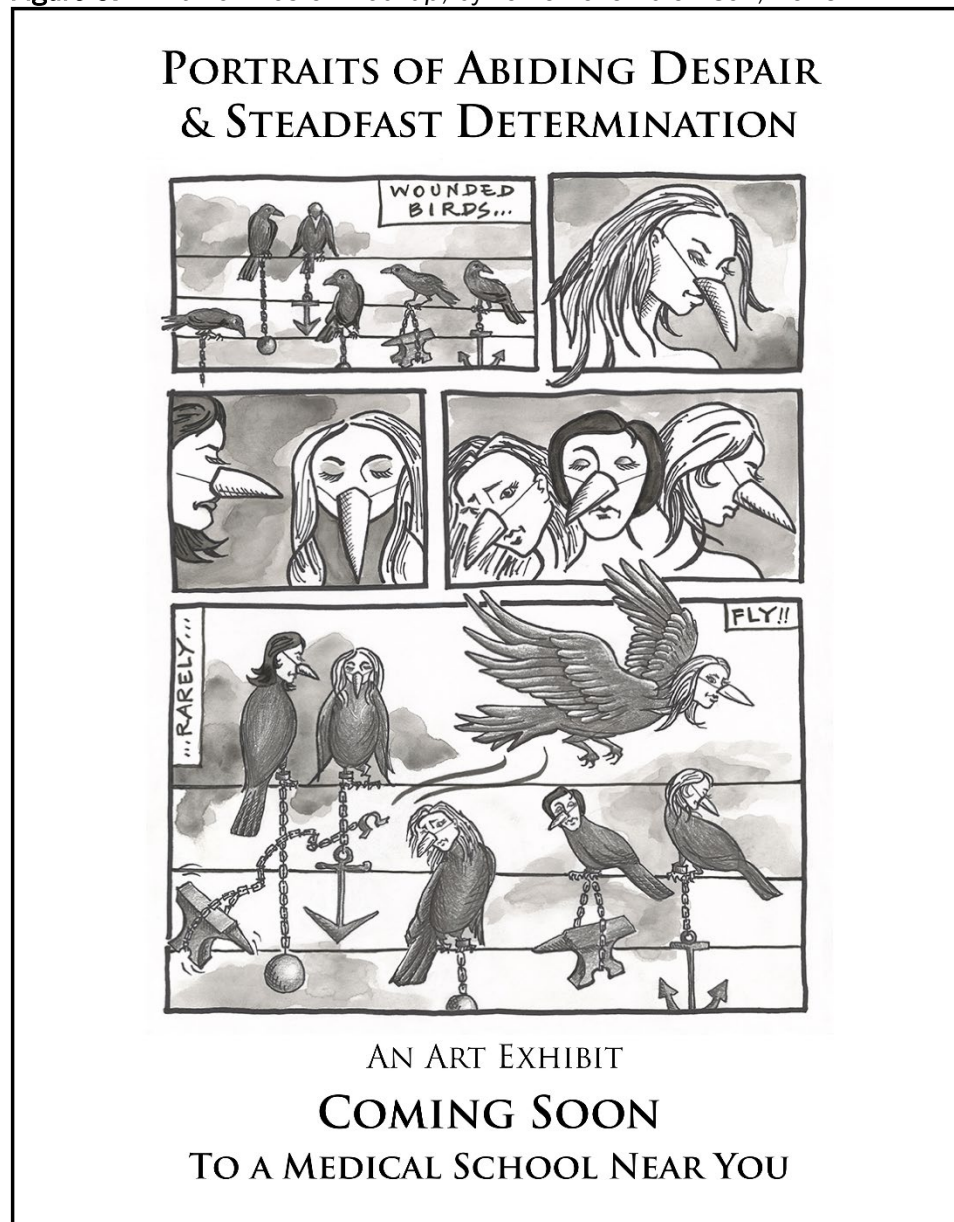
Courtesy of the artist.

Media

Pencil on paper, 10" x 10".

Although we have emphasized the need for this exhibition to be candid, we also believe that the curated artworks and the choreographed performances should be allusive enough to depict countervailing emotions—outrage and shame, vulnerability and courage or tenacity—as well as empathy and concern, all without ever being willfully antagonistic to viewers. While survivors' nightmares of abiding despair and their steadfast determination are obviously part of this picture (see Figure 5), so, too, are the stubbornly docile or actively conciliatory bystanders who unconsciously acquiesce to the reassurances of perpetrators of sexual abuse.

Figure 5. Exhibition Poster Mockup, by Tania Love Abramson, 2019



Courtesy of the artist.

Media

Ink on paper, 8.5" x 11".

If indeed an exhibition of this nature ever makes it past the customary barriers to whisper through the corridors of medical schools, the hope, ultimately, is that it propels physicians and their students to act upon what they have experienced. Child sexual abuse is an emotionally debilitating crime. Overcoming the **reluctance to report** suspected cases of child sexual abuse, particularly when the evidence is subtle, would be an especially significant outcome. Active involvement in organizations dedicated to

the prevention of child sexual abuse, such as *Darkness to Light*,²⁶ would be an equally meaningful consequence.

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MEDICINE AND SOCIETY

Visual and Narrative Comprehension of Trauma

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Abstract

How should we illuminate psychological sequelae of trauma? This article argues that though art is assumed to be useful as an intuitive means of representation, its usefulness in offering insight into trauma depends on accompanying narratives. Four artists' works considered herein illuminate how the synergistic interplay between art and expository input from personal narratives can augment comprehension of trauma.

Understanding Trauma Through Art

How should we illuminate psychological sequelae of trauma? Language is one way to express the inescapable pathos of tragedy. Another approach is to quantify the somber reach of misfortune through descriptive and inferential statistics. Neither approach, however, is without limitations. Psychological data are necessarily selective, sampling is often compromised, disclosure is constrained, and memory is constructive. If, indeed, our preferred methods for articulating and understanding the emotional impact of trauma are inherently circumscribed, it seems prudent to recommend alternative strategies that might also advance this goal. Although art is not usually associated with the inflections of tragedy, artistic imaginations charred by adversity can nonetheless affectingly illustrate how artworks animated by trauma can facilitate insight into and empathy with the trials and tribulations of others' suffering.^{1,2,3}

Trauma Aftermath

The Native American artist Luzene Hill's 2012 installation, *Retracing the Trace*, is a case in point.⁴ Hill uses numerous metaphors of rape to emphatically demonstrate how sexually victimized women are routinely shamed into obligatory silence by apathetic cultures. The ultimate power of Hill's artwork, however, is in its chronology. This installation reenacts Hill's own experience as a rape victim. She lays down on a gallery floor where blood-red, Khipu-style knots are scattered around her body. When Hill arises, she leaves an imprint comparable to the impression that her body made in the mud after she had been brutally sexually assaulted in a park. Viewer awareness of this accompanying narration—which we characterize as any input powerful enough to transform how artworks are perceived⁵—clearly impacts how Hill's installation is experienced.

Figure 1. *Retracing the Trace*, 2011-2015, by Luzene Hill (Eastern Band of Cherokee)



Courtesy of the artist.

Media

Cord, ink, and pastel; dimensions variable, performance view.

Narrative input is also critical for Holocaust memorials. It is the “unfathomable story lines” in conjunction with the “ghastly artifacts” that mobilize their didactic and “aesthetic power.”¹ One question, then, is how? We next consider how narration, or expository input more generally, can make a difference in our experience of artworks or memorials.

When looking at 2 paintings purportedly created by Rembrandt, Nelson Goodman asked, is there a difference in how they are experienced if we learn that one of them is a forgery? Absolutely, Goodman asserted, because information has the capacity to alter cognitive and perceptual judgment. Even a sliver of knowledge—the conveyance of a single word, for instance—had the power to modify and differentiate the experience of looking at Rembrandt’s paintings.^{1,6}

Consider David Wojnarowicz’s 1978-1979 series, *Arthur Rimbaud in New York*,^{7,8,9} which we have described elsewhere:

Wojnarowicz had photocopied the portrait of Arthur Rimbaud that appeared on the cover of Rimbaud’s book *Illuminations*. He then used the photocopied image to make a life-sized mask. Once the mask was created, Wojnarowicz photographed friends and lovers wearing the Rimbaud mask in various locations throughout New York City.

Does it matter whether the viewer knows anything about Arthur Rimbaud?... The mask itself is not distinctive. Rimbaud looks like almost any late 20th century white male New Yorker. What if the viewer knew that Rimbaud was a prominent French poet, who also happened to be gay? Would that effect how these artworks are encountered? What if the viewer finds out that Rimbaud died at 37 years of age, the same age at which David Wojnarowicz died? Or that Wojnarowicz and Rimbaud were born nearly 100 years apart, September 14th, 1954 and October 20th, 1854, respectively? Has the viewer’s aesthetic judgement been modified by any, or all of this knowledge...? If so, what are we to make of all of these nuances in how we perceive Wojnarowicz’s artwork?

To further this line of questioning, what if the viewer also knew that Wojnarowicz had created an artwork in 1982 titled *Peter Hujar Dreaming/Yukio Mishima: St. Sebastian....* Mishima’s breakout second novel was

Confessions of a Mask (1958), whose main character is gay, like its author.... Would any, or all of this information, influence how the informed viewer receives Wojnarowicz's *Arthur Rimbaud in New York*?¹

Figure 2. *Arthur Rimbaud in New York (Coney Island)*, 1978-1979, by David Wojnarowicz



Courtesy of the Estate of David Wojnarowicz and PPO-W, New York.

Media

Gelatin silver print on paper, 15 3/4" x 13 1/4".

The synergistic interplay between art and expository input is by no means limited to artistic visions of artists who have been shaped by tragedy or marginalization.⁷ Mark Gilbert's 2019 exhibition, *Seeing the Patient*, at the Nova Scotia Museum of Natural History¹⁰ is an equally striking example of this coactive blending. Gilbert's sheer talent for rendering portraits of **physical and psychological anguish**, combined with the deliberate shadings of his accompanying narrations on the reciprocity between patients and caregivers, adds immeasurably to how Gilbert's artworks are understood.

There is, however, an ostensible difference between artists who draw heavily from their own traumatic histories and those who document the trauma of others. Artists who create works about themselves must grapple with ethical issues—such as disclosure and its ramifications—and the vagaries of autobiographical memory. The question of consent, on the other hand, looms largest with artists who are depicting others. Perhaps the best framework for addressing this ethical concern is through the lens of consent as it applies to compromised populations.¹¹ In that regard, the collaboration between artists and their patient-subjects could ideally strive for consent that respects decision-making capacity, communication that is transparent and documented, and language that is forthright and accessible.

If we assume that narrative input is the conduit for illuminating the endemic but partly intangible psychological sequelae of trauma that reside within artworks that relate to

anguish, how, then, is this assumption relevant to a broadly conceived science of trauma? If the science of trauma was reducible to universal laws, qualitative knowledge emanating from artworks would be irrelevant, as would qualitative knowledge from individual psychological reactions to trauma and their quantitative measurement more generally. Value, however, is not necessarily synonymous with mathematical proof. The gathering of information and observations prior to the formulation of theories—inductive reasoning, as the case might be—is, one might argue, equally significant. The indubitable value of scrutinizing **artistic visions of survivors** and the compelling illustrations of **documentarian artists** thus rests largely on descriptive methodologies,¹² which could offset dependence on axiomatic thinking when theorizing about the psychology of trauma and its health care implications.

To further highlight this point, the remainder of this paper introduces how the artistic practice of the second author (TLA) embraces emotional unravelling to dramatize the experience of shame, using an analogy as the emblematic linkage between trauma and shame.

A Survivor's Art

Between the ages of 4 and 7, TLA was the victim of chronic sexual abuse by her father's close friend, Gene Hartman. As TLA recounts, "Several years later, Gene killed himself. Shortly after his death, I [TLA] received a call from his wife Eleanor. *He's dead*, she said, *and it's all your fault*. My [TLA's] troubled childhood got messier."¹³

This narrative input, like that introduced previously, surely modifies how TLA's artworks are now perceived. Her choice to name names (though both deceased) is no less calculated. Secrets, she believes, perpetuate crimes and protect perpetrators.

One way of interpreting the language of TLA's 2017 sculpture, *In Case of Shame*, is through the lens of analogical thinking. It takes a source—a locked red metal safety cabinet with a glass window that holds a fire extinguisher used in emergency situations to control small fires—and then translates it into a target—which, in this case, is a custom-fabricated locked safety cabinet holding a sledgehammer that has been repurposed for the abatement of shame. Markedly pronounced side effects are duly noted, and the cracked glass speaks for itself.

Figure 3. *In Case of Shame*, 2017, by Tania Love Abramson



Courtesy of the artist.

Media

Custom fabricated red-enameled safety cabinet, sledgehammer, broken glass, warning labels, 36" x 12" x 6".

The visceral impact of TLA's sculpture goes beyond merely perceiving its constituent parts. What's most striking about this piece is that viewers instantaneously grasp its meaning. A literal translation is unnecessary because the analogy works seamlessly. With an analogy, there is an intuitive disassembling and then an automatic reassembling. Here, what is disassembled—a safety cabinet holding a fire extinguisher—is recast as a safety cabinet holding a sledgehammer for rescinding shame. The cautionary label, "use may have unintended consequences," fortifies the sledgehammer's association with the destructive power of shame, often personalized as *I can relate to that*.¹⁴ This is not to imply, however, that the allegorical language of *In Case of Shame* is embedded solely in this analogy. The sledgehammer alone obviously has multiple connotations.

Approaching this theme from yet a different angle, TLA's *No Escape at All* is an evocative psychological "portrait" that is both annotated and metaphorical. It is constructed of words trapped in an abyss, spiraling simultaneously outward and inward. The inner text comprises tortuous outpourings of humiliation, while the outermost ring repeats the aphorism, "I can't escape this shame, which is no escape at all." These artworks, *In Case of Shame* and *No Escape at All*, are best conceptualized as integral components of an overarching tableau that intuitively rails against the imperious fortress of shame.^{13,14}

[illegible]

Media

What, then, is our take-home message? Artworks representing creative visions that emanated from trauma and thereupon were vitalized by narrative input have a special place in the medical humanities by virtue of their power to integrate traumatic

experiences and interpret them profoundly. For this reason, such artworks are especially critical to clinicians, because psychological traumas to patients can be deeply tumultuous but largely unarticulated.

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MEDICINE AND SOCIETY

Portraits of Children With Epilepsy

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Abstract

This article examines the challenges of raising a child with epilepsy and the role of portraiture in helping clinicians consider the impact of epilepsy not only on the patient but also on family caregivers. Portraiture facilitates the development of a visual narrative of how a child is seen by others, both figuratively and physically.

Seeing the Patient

Thirty percent of children with epilepsy have seizures that are challenging to control and often require multiple medications.¹ In the majority of these cases, the seizures cannot be stopped, which negatively affects both children's development and families' lives.^{2,3} Throughout my career as a pediatric neurologist, I have been moved and humbled by the many families I have met who care for children with a diagnosis of epilepsy. The portraiture study detailed here provided me with a way to honor what these families have faced, to allow others to "see" children with epilepsy in a different way, and to increase awareness of what these families live with.

This project was a collaboration between me and Mark Gilbert, a portrait artist and qualitative researcher. Children and their families were recruited from my pediatric neurology practice. I invited patients of a range of ages and their families to participate in order to document families' reflections on the challenges they face as a child gets older and transitions to adult care. The patients and their families attended multiple drawing sessions with Gilbert. During these sessions, informal dialogue was recorded and transcribed. The families shared what their lives have been like and the challenges they had faced. Gilbert also kept a diary of his own thoughts, observations, and perspectives. Following completion of the portraits, a semistructured interview with each family provided further understanding of the family's experiences living with epilepsy. The narrative data and portraits were analyzed using a phenomenological qualitative methodology.^{4,5} This approach provides an understanding of subjective experience^{6,7} and, in this specific instance, of what life is like for families living with a child diagnosed with intractable epilepsy.

What follows is the story of a single child and family from the study, yet his story represents that of all families living with the disorder. Although the specific challenges each family faces may vary, the unpredictability and stress of epilepsy impacts all

families in similar ways. The length of time this family has lived with epilepsy and the multiple challenges family members have faced provide a powerful example of the burden of epilepsy.

Figure. *Brad*, by Mark Gilbert, 2018



Courtesy of Mark Gilbert.

Media

Pastel on paper, 50.25" x 39.5".

Brad's Story

I met Brad when he was a teenager. In a rather convoluted set of circumstances following a car accident, I met the family soon after moving to New Brunswick in Canada to work as a pediatric neurologist. It was a low point for Brad and his family. He was having many tonic-clonic seizures and looked pale and unwell. His parents were feeling there was **little hope** for improvement in controlling his seizures. Since that time, I have provided neurological care to Brad even though he is now outside the pediatric age group. Through my many interactions with Brad and his family, I have seen his parents' high and lows, their feelings of helplessness at times, their frustrations with the health care system, and rewarding moments.

Brad is now 26 years old. He is a gentle young man who lights up the room when he smiles. He is nonverbal and yet can communicate with his parents, siblings, and friends in so many ways—by a gentle touch, the use of signs, and sometimes vocalizations. He understands more than he can express and is very demonstrative with his family and friends, giving them hugs and kisses. They have a very strong bond with him.

His seizures began at 1 year of age. The initial few accompanied a febrile illness, but they then continued without illnesses, and Brad developed multiple seizure types. His mother described the sense of fear, urgency, and desperation when the seizures first started. Although the epilepsy became a part of the family's life, the parents' immediate fear concerned the loss of who Brad might have become and their desire for a cure for his epilepsy. No etiology was ever found to explain his presentation. Over the years he has been on many different medications, the ketogenic diet, intravenous immunoglobulin, steroids, and he has had a vagal nerve stimulator inserted.⁸ Despite all these efforts, he has never remained seizure free for an extended length of time. As is common with many patients, he experienced periods of seizure freedom after starting a new medication, but the seizures always recurred.⁹

The seizures negatively impacted Brad's functioning and the family's functioning over time. The family was unable to take vacations and chose to create a positive space at their home on the river. In this way, Brad could—at any time—engage in family activities, such as riding on the personal watercraft with his dad, for example. The parents worked hard to have what they perceived as a normal family life but recognize it was not typical for the majority of people. It was challenging to do things as a family because of the seizures, and when Brad was young there was limited social support that would allow his parents to do things with the other 2 children. Brad's older and younger siblings recognized that Brad needed more support and have been changed by their experiences with him. His mother stated that his siblings "have great empathy for others" and are "kind and caring. It's beyond their years ... more from an experience point of view."

The family had to deal with the stress of the epilepsy itself and the associated impact on Brad's cognitive and physical abilities. When Brad was younger, he loved to swim, ride horseback, and go skating. He would smile from ear to ear during these experiences. He is no longer able to do these things due to safety concerns. Now that he is in young adulthood, his parents fear for his future. They worry he will end up in an institutional or home setting with less care and support. Specifically, they are concerned he will lose his current quality of life. He goes out walking, goes to the mall, and goes to see hockey games, for example. He loves to sit in the garden and watch the birds or walk barefoot in the garden and at the beach. His parents have sought out daytime activities, but these often provide less stimulation than activities at home, making them feel uncertain about the future, particularly if they die before Brad.

What Does It Mean to Contribute?

When Brad was young, his parents were told by one physician that he would not be able to contribute to society and they should just let him be. His mother believes everyone brings something to society that does not have to be on an intellectual level. She shared an example of being at the grocery store. A woman was being mean to the cashiers, then Brad had a seizure. This woman completely changed, becoming gentle and supportive and doing whatever she could to assist Brad. His mother reflected: "Your contribution in life can be in various ways... I think how he [Brad] touches or changes people or makes them think differently about their life is ... more powerful than [what] most of us bring to society."

In society, we struggle with acceptance and tolerance of people who are different from ourselves, often due to fear of the unknown.¹⁰ Getting to know someone and being present with someone with epilepsy or cognitive delay can challenge and change our viewpoints. Brad's mother shared a perspective from someone she knew who got to

know Brad: “I’m not afraid anymore. I’m not afraid of somebody who doesn’t look like me or act like me or [if] cognitively they’re impaired. I’m not afraid of how somebody looks.” Children at school, family friends, and others who have gotten to know Brad are touched by his gentleness and his joy in the moment, noting that “sitting at a table, you can’t help but be drawn into his aura of pureness and goodness.”

Portrait Perceptions

Previous research has demonstrated that the creation of images humanizes and gives voice to the people and communities pictured. In Gilbert’s previous arts-based research, patients with cancer whose portraits he painted described feeling empowered—of not feeling alone—when they saw the other portraits and found it therapeutic to share their stories and feel heard.¹¹ There is, however, a vulnerability and risk in having a portrait painted. During this study, Brad’s mother was concerned that a portrait would not capture the “whole picture” and would be limited to a period in his life. She feared that people would only see one side of Brad, depending on the final image(s) used in the show. She hoped people would be able to see all of who he is and not just the physical impact of the seizures. The project tapped into all the different experiences and emotions she had had over the years. His mother shared with me: “When I ... let myself go to that place [the challenge of the initial diagnosis]. it’s still raw.... After 26 years, you would think it wouldn’t be. But I think everyone wants the best for their child.”

Nevertheless, Brad’s mother found the experience of sharing during the creation of the drawings and portraits therapeutic. To have someone listen allowed some of the hard moments from the past to be “washed away,” which she found freeing. When she saw the artwork displayed collectively and saw the portrait of Brad hung, she noted: “When I really stopped to look at it, I thought you [Gilbert] caught him, the essence of who he is, beautifully” (see Figure). Some friends accompanied her to the opening of the initial show, and they could not believe the detail of Brad’s portrait and the emotion they felt looking at it. She was moved by seeing the whole collection of portraits of my patients: “Every picture would capture an emotion within. And I think the emotion is different for everybody.... The artwork is kind of the vehicle that lets us see the emotion ... and gives people a glimpse of who that individual is without knowing the details of his life.”

Moving Forward

The project has had a profound effect on me and been a source of my reflections on care of children with chronic illnesses. Although I know these families well and understand many of their struggles, I am struck by how much more I have learned when the families were given time to share their stories. So often in medicine, we are constrained by time and focused on the medical issues at hand. Yet other issues are often more important for families, particularly if there is no cure. Families might need social, financial, or other support, and they need to know that someone is there for them.

Intractable epilepsy means there is no cure, and physicians must live with this uncertainty and lack of resolution. Walking with a family and **being willing to listen** is as important as the medical treatment. The portraiture study has affirmed my belief in the importance and value of being present to families, even when there is no cure. This trusting relationship can help them keep going and feel less alone and isolated.

In previous work, Gilbert identified themes that are common to the artist-sitter relationship and to the doctor-patient relationship: embracing uncertainties, developing

trusting relationships, engaging in reflective practices, telling a story (expression), and being empowered.¹² Portraiture provides a **forum for learners** and professionals to consider aspects of epilepsy care beyond medications, surgeries, or special diets. The portraits themselves provide a way of more wholly seeing patients and their families as individuals with struggles, resilience, and rewards and of understanding the impact of epilepsy on the family unit. The humanization of individuals has the potential to help health professionals find meaning at a time when burnout is a significant concern.^{13,14} The portraits created for this project are being used to educate the public, practitioners, and learners in health care about seizures and epilepsy and will have a role in advocating for families living with epilepsy.¹⁵

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ART OF MEDICINE

On Seeing and Being Seen in Dementia Care

Kathryn Hominick, MSW

Abstract

This article reflects on one health care professional's experience of sitting for Mark Gilbert's arts-based Patient and Caregiver Portraiture study. The author, a clinical social worker, discusses the roles of ageism, invisibility, and stigma in the lives of people with dementia. This article also explores the similarity between the process of an artist seeing the entirety of a scene and the process of a clinician assessing a patient; both artist and clinician are powerfully influential in their capacity to represent the personhood of a subject or patient.

Artist-in-Residence Program

When artist Mark Gilbert asked that I, a health care professional, reserve an hour in my workday to sit for a life-sized portrait as part of his art-based study on dementia and caregiving, it was not as unusual an "ask" as one might think. For the Geriatric Ambulatory Care/Memory Disability Clinic, part of the Nova Scotia Health Authority (formerly Capital Health), with which I am affiliated, is like a small gallery of local artists' large oil paintings and sculptures on themes of memory and dementia. This is the result of an artist-in-residence (AIR) program,¹ a scholarship program in which artists help assess patients' memory with families and clinicians and create works that represent what they saw, heard, and felt during that encounter.

The AIR program was inspired by a somber oil painting, *Ghost*, by Jennifer Hiscox, whose father had early onset dementia. This painting hangs outside my office door and is visited and discussed regularly by people passing by. *Ghost* is based on a photograph of Hiscox as a young girl; she is in a wading pool and a father figure is scratched out. The photo, taken prior to her father's diagnosis, shows him looking at Jennifer "like fathers should look at daughters." Hiscox, feeling not quite able to capture this moment, obscured his image to represent her father as a ghost.²

In what follows, I consider the roles of invisibility, ageism, and stigma in the lives of people with dementia and explore similarities between the process of an artist seeing the entirety of a scene and the process of a clinician assessing a patient.

Participating in Portraiture

I am fortunate to spend time outside of work with a social circle of filmmakers, writers, and musicians who identify as working artists. We have a complementary connection. An introvert by nature, I am relieved to sit back and take in all their fascinating discussions in the comfort of knowing that I will not be expected to start a conversation.

I recall one dinner party that changed everything. We were engaging in a typical roundtable discussion about inspiration, process, and grant deadlines, when one of the guests asked about my day. Being more listener than speaker and shy about interjecting myself into their conversation, I quietly offered that I made a home visit with a physician colleague to a retired man who was bedbound and experiencing the end stages of Lewy body dementia. While the physician examined him, I spoke with the patient's adult son about his conflicting feelings of grief and mixed relief at his father's imminent death. The disease had so altered his father's personality that he had not been recognizable for years.

The table fell silent for an uncomfortably long time until someone stated, "We make art about what you do!" Since that time, I have become more aware of "the art" in everyday interactions in my social work practice and have embraced how crucial creativity is when working in the area of memory and dementia care. Mark Gilbert's Patient and Caregiver Portraiture study has contributed to this awareness.

For more than 20 years, Gilbert has been using portraiture to investigate ideas about care and caregiving. According to Aita et al: "Portraits are introspective in nature implying the 'interior' of subject's experiences."³ **Caregiver portraits** in particular reveal the caregiver's "commitment to care." More generally, the portraits of patients and caregivers reveal "the centrality of the idea of mortality, the presence of hope despite adversity."³ Gilbert's project in the memory clinic is to use life-size pastel portraits of people living with dementia to better understand what they—and those who care for them—are going through.

Being Seen

Being the subject of a portrait was originally unsettling for me and made me feel vulnerable. It is uncommon to be looked at for long periods of time while remaining still. Yet Serbian performance artist Marina Abramović did just that, at a 2010 Museum of Modern Art performance, *The Artist Is Present*, which was in a sense a social experiment.

Seated silently at a wooden table across from an empty chair, she waited as people took turns sitting in the chair and locking eyes with her. Over the course of nearly three months, for eight hours a day, she met the gaze of 1,000 strangers, many of whom were moved to tears.⁴

Being seen can create a 2-way empathy connection. As Fogh writes, "being seen feels like unconditional acceptance and belonging," which "is ultimately *exactly* what most of us crave."⁵

Unfortunately, Western society's focus on youth means that older adults are underrepresented in mainstream media.⁶ When they are portrayed, it is most often negatively, as a generic stereotype or as a comic side gag.⁷ Older women, in particular,

report being unseen and undervalued in society.⁸ It is so much the case that the “invisible woman” can be anyone, even the famous.⁹

It wasn't until I entered the field of geriatrics that I became aware of the societal effects of ageism and was forced to confront ageist attitudes of my own. Even the social work curriculum, which emphasizes social justice for prejudice and discrimination on the basis of race and sex, barely addresses ageism and its potentially drastic effects on older people.¹⁰ A Canadian study found that ageism is the most tolerated form of social prejudice—more so than racism and sexism.¹¹ It noted that many well-intentioned people deprive older adults of the independence and choice that are crucial for aging well. In another Canadian study, the author of the present paper and colleagues found that staff members' low level of risk tolerance towards older adults resulted in older adults not returning home from the hospital as they wished but instead being funneled into nursing homes for their own safety.¹²

People with dementia must cope in addition with a negative label or **social stigma** associated with a dementia diagnosis. The general public and many health care professionals have little knowledge of dementia prevention and treatment until a family member develops its signs and symptoms.^{13,14,15} It is not widely understood that memory loss and other cognitive impairments become defining of a person when they interfere with a person's ability to function in everyday activities. In the memory clinic where I work, when a patient or family member first receives a diagnosis of dementia, it is common to notice fear and grief as the person's mind immediately jumps to the end stage of the disease. Many question the ability of persons diagnosed with dementia to care for themselves, make their own decisions, and lead a meaningful life. They are not people living with dementia but *demented*—labeled by the disease and possibly seen as incompetent, incapable, and a nonperson.

Seeing

The invisibility of the aged and people with dementia is the backdrop for Gilbert's Patient and Caregiver Portraiture study. Gilbert's portable art studio is old school—replete with canvas, easel, and pastels. The warmth of his Scottish burr conveys intimacy and encourages an unburdening of secrets. This artist is very much present, and his subjects feel that he captures their essence while creating their physical likeness.

It was not until my second portrait sitting that I considered the vulnerable position Mark was in, as I watched him in his intimate moment of creating. I immediately asked if I could capture this moment with my cell phone camera and created a photo I call “Me, Looking at You, Looking at Me.” I was pleased when Gilbert said that no one had taken his photo before.

Figure. *Kathryn*, by Mark Gilbert, 2019



Courtesy of Mark Gilbert.

Media

Pastel on paper.

Artists are thought to see the world differently than others because they can train their eye to **focus on the details** of the entire scene to reveal the person or object. They consider the white spaces and can break the image into a collection of lines, shadows,

shapes, and contours. Dingfelder notes: “As a result, artists can paint pictures that jar regular people out of our well-worn habits of seeing.”¹⁶ Gilbert’s portraits of patients are the result of multiple sittings in different settings. In addition, he reviews photos and audio tapes of the sessions to capture the essence of the person and the person’s interaction with the caregiver. This way of seeing is similar to that of clinicians working with people living with dementia.

Health care professionals’ work with people living with dementia is like creating portraits of people. For, in order to make a diagnosis of dementia, the clinician must assess the person by comparing what is known about the person in the present and in the past, prior to the illness. The clinician interviews the person and the caregiver separately, taking careful inventory of the person’s loss of function in key areas and documenting changes in personality and behavior. Timelines are measured in intervals to determine if this loss of function is an acute medical problem or sign of a progressive illness. Further complicating the diagnostic process is the fact that two-thirds of people with dementia lack insight that they have the disease.¹⁷ Therefore, they often do not recognize they have a problem, and clinicians must rely on information about changes from people around them to make the diagnosis. People’s lack of awareness of memory deficits affecting their function becomes the number one hurdle to their forming a therapeutic relationship and accepting a supportive care plan. It is here where the art happens.

How do you convey to persons with memory loss and other cognitive impairments that they have a problem when they do not believe they do? How can you be seen as a trusted ally with their best interests at heart? Such persons must know and feel that you see them.

To best accomplish this goal of *seeing* people who are living with dementia, the clinician must face the responsibility and challenge of seeing them in their entirety, both present and past, at a time when their ability to recall and express who they are begins to fade. It is often the unspoken hurts and disappointments of lived experience that form the person seated before the clinician. A key to this process of seeing is teasing out a detailed social history of the person, which considers intimate relationships and social supports while also noting the person’s level of risk tolerance and how they adjust to change.

Because people with dementia are often older and frail and do not recognize or have insight into their deficits, a home visit by geriatricians and other health care professionals often provides a true picture of how they are dealing with their memory and functional issues. At home, a shift in the power dynamic makes the person with dementia a comfortable host. With environmental clues, the clinician can prompt the person to share more of the richness of their life story. The clinician can also observe details of the person’s daily life, such as what food is in the refrigerator, if the person takes their medication, and their ability to access their bathroom and bedroom.

The clinician then creates an assessment report—similar to a portrait—of the person with dementia that records their life story, values, and wishes while the person can still express them. When the clinician next sees the person, the person might be unable to remember having met the clinician and the last encounter, but the clinician certainly remembers the person.

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PERSONAL NARRATIVE

Portraits of Suzanne, an Osage Woman's Story of Loving the Sun and Living With Skin Cancer

Bobbie McWilliams and Regina Idoate, PhD

Abstract

Suzanne, an elder of The Osage Nation, has been diagnosed with basal cell carcinoma, squamous cell carcinoma, and melanoma skin cancer. Her daughter, Bobbie, a cancer researcher working for the Youth Enjoy Science Research Education Program, conducted a case study to share Suzanne's story through written narrative and a series of images that present Suzanne's reflections on cancer prevention and treatment from a holistic perspective. Seven interview transcripts, as well as photographs, drawings, and paintings of Suzanne, were created and analyzed to explore Suzanne's lived experience of cancer. In her story of living with cancer, Suzanne shares an elder's love and wisdom that can inform cancer education and prevention efforts to help address Native American cancer disparities.

Native Americans Do Get Skin Cancer

Nearly 1 of 10 Native Americans (NAs) believe that Native peoples do not develop skin cancer, and nearly 9 of 10 have been sunburned at least once.¹ Melanoma skin cancer among NAs is less common than among whites²; however, only 1 of 10 NAs report using sunscreen regularly on their bodies,¹ and skin cancer among NAs often goes underdiagnosed until more advanced stages.² NAs' perceptions of their low risk of skin cancer, coupled with limited access to health care services, could contribute to the finding that, historically, NAs have made significantly fewer office visits to a dermatologist than whites.³ Scholars and practitioners recommend increasing public awareness and public health education and improving **screening and early detection** to prevent cancer.⁴ In an effort to raise the NA index of suspicion and increase efforts to prevent skin cancer among NAs, we share Suzanne's story through written narrative and portraits as a case study exploring one NA woman's lived experience of skin cancer.

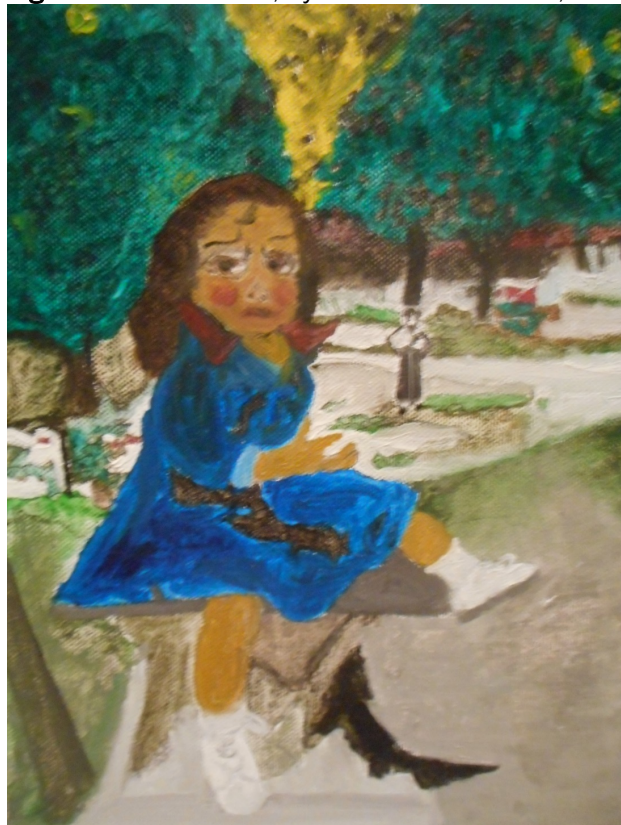
Suzanne, an elder of The Osage Nation who resides in Tulsa, Oklahoma, has spent the majority of her life outdoors, in the water and under the sun. Suzanne grew up in the Great Plains near the Osage ancestral lands, surrounded by rivers and lakes. She loved to swim and embodied the Osage sacred name "children of the middle waters." Suzanne's daughter, Bobbie McWilliams, citizen of The Osage Nation, an undergraduate fine arts major/Native American studies minor and a Youth Enjoy

Science (YES!) Research Education Program cancer research intern at the University of Nebraska Medical Center, and Regina Idoate, citizen of the Cherokee Nation of Oklahoma, conducted a case study to share Suzanne's story through written narrative and a series of images that can promote awareness of and reflection on cancer prevention and treatment from a holistic perspective. This article shares Suzanne's story, both verbally and visually, as analyzed through arts-based narrative inquiry. Bobbie conducted and transcribed 7 interviews and created several drawings and 5 portrait paintings of Suzanne that were qualitatively analyzed by the authors of this manuscript to share her story as an aesthetic whole.

Suzanne's Story

Suzanne tells stories of being exposed to the sun even as a baby: "My mother had me in a buggy and ... my legs would turn black, just black." Growing up, Suzanne had a special relationship with the sun. She loved to swim and loved to be outdoors. Bobbie illustrated Suzanne's description of her childhood in a portrait that reflects her youthful unprotected exposure to the sun (See Figure 1). She swam outdoors so much as a child that she recalls wearing out the bottom of her bathing suit. When Suzanne was a teenager, she and her friends, wanting to be tan, "used baby oil and iodine and ... would actually almost fry in the sun." In college, too, Suzanne regularly sunbathed and spent hours in the pool performing synchronized swimming routines with her sisters. Suzanne says that, throughout her youth, she was never told to wear sunscreen and doesn't recall being aware that sunscreen lotion even existed. She's convinced that her family, teachers, and health care professionals didn't even know about skin cancer.

Figure 1. *Curious Sue*, by Bobbie McWilliams, 2018



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Media

Acrylic on canvas.

As a child, Suzanne does not remember ever thinking about protecting her skin from sun exposure. Although her mother's understanding of life and nature recognized dangers of the sun—and if her mother “happened to be in the sun, she'd have a great big hat on her head to cover up”—Suzanne never thought about the possibility of developing skin cancer. She spent most of her youth at the pool, training to be in the Olympics for diving, working as a lifeguard, and teaching swimming and lifesaving to both elders in her community and children at orphanages. She remembers “just like it was yesterday” teaching swim strokes under the sun on a grassy hill beside the pool.

After marrying and growing a family, Suzanne taught all 9 of her children how to swim and took them to the pool all summer long, every year. She describes swimming with her kids and living life at the pool as “a lot of fun!” Suzanne continued lifeguarding well into her 50s and is still swimming today.

In the summer of 1988, at age 56, Suzanne was diagnosed with skin cancer. She states, “It's just something that I got.” She explains, “I went to a skin doctor because I had different things on my arms and legs.” The doctor, however, found something on her back. Suzanne was shocked and “didn't know what it was.” She vividly recounts the doctor saying, “you have skin cancer.” She “was just flabbergasted, and ... just couldn't believe it!” Suzanne's first thought was that she would no longer be able to swim or be in the sun. She is happy to say, however, that she still visits the pool regularly and enjoys the sun in small amounts, wearing clothes, hats, and sunscreen to reduce her risk of skin cancer. She also visits the dermatologist regularly for screening.

Suzanne has had as many as 33 precancerous spots on her face and body treated and, according to her, she has been diagnosed with “every kind of skin cancer possible.” She calculates that, for her, “the cancer usually grows an inch apart from one another.” She describes a precancerous lesion as “a skin lesion that's formed before cancer.” She explains that screening is important because “the skin doctors can tell that it's a precancer ... and they treat them so they won't turn into cancer.” She has been diagnosed with basal cell carcinoma, which she describes as “more of a topical skin cancer,” squamous cell carcinoma, which she says “forms kind of a crust on your body,” and **melanoma**, which she refers to as “the bad one.” In Suzanne's words, “basal cell skin cancer is ... on top of your skin and it normally bleeds, and it is usually scraped off or burned off, preferably, rather than having it cut out.” She describes how basal cell carcinoma “won't stop bleeding until you have something done about it.” She says that squamous cell carcinoma “forms a very crusty top, and it's a bit painful, if you touch it ... and they have to get that out because that could spread, and get bigger and bigger, the crust part on top.” She warns, “what's ever on top of your skin is also underneath, so you have to be careful with that and be sure that you have it taken out.”

The type of skin cancer that Suzanne fears the most is the one she calls “the bad one,” melanoma. She learned from her dermatologist that melanoma “could spread through your entire body.” Suzanne describes noticing the melanoma on her body as “one very black spot.” She says, “it was extremely shiny, and very small, like a pencil head, and it just didn't look right.” The Skin Cancer Foundation urges people to examine their skin from head to toe on a monthly basis.⁵ Suzanne saved her own life by doing just that,

noticing the melanoma on her body and going to the doctor to ask, “What is this?” Suzanne says “I thought it might travel and I wouldn’t be alive today. I had to go to the hospital and they had to cut it out, I guess they did a good job because there’s only a dent in my arm from where they cut—that’s all, it’s fine.”

When discussing her experience with melanoma, she says, “I was glad that it hadn’t spread any further than my arm, very glad.... I’ve been very fortunate praying, and I have been very fortunate with cancer that it hasn’t gone any further.” Her joy, contentment, and gratitude are evident in her smile, her bare and relaxed arms, and the YES! t-shirt that she proudly wears in *Smiling Sue* (See Figure 2). At age 84, Suzanne lost her beloved husband, John, in 2015, but she still enjoys precious time with her 9 wonderful children and loves to make time for friends: “We try not to talk about illness when we’re together, we just want to have a good time.” She asserts, “I’m very happy that I’m able to do the things I like to do.... I feel like I survived very well the cancer that I’ve had, and I’m still getting it, and hopefully it won’t be the bad one.”

Figure 2. *Smiling Sue*, by Bobbie McWilliams, 2019



© 2020 B. McWilliams.

Media
Oil on canvas.

If you talk to Suzanne, she will tell you, “I still love the sun!” Observing the portraits, a viewer might notice not only Suzanne’s love for the sun but also her gratitude to be alive to share her story. Reflecting on one of her own portraits, Suzanne states, “It shows how my skin really is ... and I don’t think that my skin looks very good, and the truth is that it shows in the portrait what it really is!” (See Figure 2). She admits, “I know that I have a lot of skin cancer, my whole body is full of skin cancer.” Suzanne has new cancers and spots forming all the time. Every time she goes to the dermatologist, more cancers are removed. Suzanne affirms that “to survive all this, I’ve been very fortunate, extremely fortunate.... There are many people who have had cancer way worse.” In fact, she adds, “My sister had melanoma in her leg and it just wouldn’t heal, they tried and tried, and then it got infected and then it got worse, it was a contributing factor to her death at age 86 years old.” Ultimately, she says, “I hope others don’t get it” and “if it [Suzanne’s portraits and story] could help just one child or one person to be careful in the sun, it would be all worth it!” Suzanne is very proud of the cancer research and prevention work that her daughter, Bobbie, is doing with the YES! program, noting, “I feel very good about sharing my story, very good about it.” Suzanne wants to tell the youth “not to go to tanning beds and to be very careful.” She emphasizes, “I would like them to know that they should go out and have a good time, stay healthy, and be happy, but wear some sunscreen or a shirt or something over their skin so that they won’t get the skin cancer that I have had.”

Learning From Suzanne’s Story

Suzanne’s story can help promote cancer awareness, prevention, and control within Bobbie’s local urban NA community in the Northern Plains region of the Indian Health Service, as cancer is a leading cause of premature death among NAs, and NAs experience severe **health disparities** specific to cancer.⁶ Bobbie presented Suzanne’s story as a case study in a research poster at the 2019 Nebraska Science Festival in Omaha, Nebraska⁷; at the 2018 American Indian Health Research Conference in Grand Forks, North Dakota⁸; and at both the 2018 and 2019 Cancer Biology and You (CBY) workshop for NA students in South Sioux City, Nebraska.^{9,10,11} Participants in the 2019 CBY workshop reported that viewing and discussing the portraits of Suzanne was their favorite activity at the event. In this activity, the authors asked students entry-point questions to encourage them to observe and reflect on the portraits of Suzanne.¹² This approach can open up a dialogue around cancer, a topic often considered taboo in NA populations.¹³ Bobbie stresses that anyone can get skin cancer, even a citizen from The Osage Nation with a dark complexion. Suzanne reaffirms this fact, noting, “I do look very Indian, and I don’t think there’s a whole lot of us that really do have skin cancer, but I certainly do.”

CBY participants said that, in viewing Suzanne’s portraits, they hear Suzanne saying, “protect yourself,” and they see “joy” and an encouraging message to enjoy life and “live long” in her image. Wrapped in a quilt, Suzanne embodies a powerful message, reminding us all to cover up and protect our skin (see Figure 3).

Figure 3. *Suzanne's Wisdom*, by Bobbie McWilliams, 2019



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Media

Oil on canvas.

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Bobbie McWilliams, a citizen of The Osage Nation, is an undergraduate student at the University of Nebraska at Omaha who is studying fine arts and Native American Studies with a specific focus on Native American health and wellness. She also works as a cancer research intern at the University of Nebraska Medical Center for the Youth Enjoy Science Research Education Program.

Regina Idoate, PhD is a citizen of the Cherokee Nation of Oklahoma and an assistant professor of health promotion in the College of Public Health at the University of Nebraska Medical Center in Omaha. She is also a coinvestigator in the Youth Enjoy Science Research Education Program, which aims to increase diversity in cancer-related careers. Idoate's primary areas of specialization include medical humanities, preventive and societal medicine, spiritual wellness, and Native American health.

The Editor's Note

This human subjects research was reviewed by the University of Nebraska Medical Center Institutional Review Board in 2020

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All artists and subjects who participated in creating the Indigenous content analyzed herein contributed their perspectives and voices to all aspects of the research and the research analysis processes. Following Indigenous style, we formally use the names of Indigenous Peoples, and we recognize relationship and trust as the source of truthfulness, accuracy, and mindfulness about community impacts and continuity with history and heritage. This work is an expression of the individuals' and communities' rights and ownership of the research process and data. This project was sponsored by a Youth Enjoy Science Research Education Program grant (R25 CA221777) from the National Cancer Institute of the National Institutes of Health.

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PERSONAL NARRATIVE

Portraiture Brought Introspection and Perspective

Mardi Denell

Abstract

This article describes the perspectives of a scientist-patient and patient-caregiver when sitting for their portrait and also considers the value of this experience for facilitating healing and observation of patient-caregiver relationships.

Cancer Diagnosis

When my husband Rob was diagnosed with nasopharyngeal carcinoma, we researched the best National Cancer Institute-designated comprehensive cancer centers in the country with specific strength in head and neck cancers. We decided on the University of Nebraska Medical Center and made his treatment our priority. We put our life on hold and moved to Omaha, where we stayed in the hotel in the hospital complex for 10 months.

The rooms were set up for extended-stay care. I could cook in the limited kitchen, which allowed us to control Rob's exposure to potential infection from others while he was immunocompromised and weak. During this period, he underwent several rounds of chemotherapy and simultaneous radiation, and he was hospitalized briefly 3 times. We spent the Thanksgiving, Christmas, and Easter holidays in residence prior to the final neck dissection surgery in the spring.

Rob's diagnosis had come only 3 months after I completed treatment for breast cancer. My **breast cancer treatment** may have been considered more disfiguring than Rob's treatment. After a bilateral mastectomy and the administration of prescribed chemotherapy—which included doxorubicin, cyclophosphamide, and paclitaxel—I had 25 monthly intravenous infusions of pamidronate disodium (due to a questionable spot on my left calvarium). The chemotherapy was intense and not without complications. Yet, by comparison, Rob's treatment was far more complex and difficult.

Participating in Portraiture

Rob's diagnosis was a terrible blow; however, we were uniquely armed for this particular challenge. Rob was a researcher and professor of genetics. I had worked in several laboratories, so I shared his grounding in science. And, as a mother, I had years of practice being the observer and data collector for—and communicator to—the professional medical community. I had developed partnerships with physicians that

involved mutual understanding and appreciation. We felt that we had the advantage of feeling comfortable in the medical environment, and we each had medical teams who saw us as unique individuals. We planned to survive.

We were offered the opportunity to participate in the Portraits of Care study through William Lydiatt (a coinvestigator in the research). He introduced us to artist Mark Gilbert during one of our follow-up visits, which typically involved a few days of appointments with Rob's medical team. Mark's studio in a nearby lab allowed patient-subjects to conserve their energy and include convenient portrait "sitting time" in their clinic visits. Ours is the only canvas in the study that includes 2 subjects. It speaks to our partnership, reciprocal caregiving, and marriage. We took traditional wedding vows that hold "in sickness and in health" and "for better or for worse." And we certainly felt that we understood and had thoroughly tested the meaning of those promises. By the time of our first sitting for the portrait, Rob was 6 years into his recovery, and during that time we'd managed a few complications, including a mastoidectomy and a stroke. We were also experiencing more normalcy. Rob had resumed responsibility for his research program and accepted the position of director of the Johnson Cancer Research Center at Kansas State University. We were feeling fortunate to be entering this new stage of life.

I came to the initial portrait sitting fully prepared, with photos of both of us taken prior to and during treatment. Instead of using those materials, Mark helped us find a comfortable position and asked us to relax and simply focus on being present in the moment.

Having the portraits done in a laboratory at the medical center was particularly beneficial for us. Given our background, this was certainly a space we recognized and felt comfortable in! There were windows facing south, and the light was inviting for both the subject and the artist. The laboratory was filled with canvases and art supplies rather than the normal equipment and associated noise. There was charcoal dust on the floor and no lab glassware on the drying rack. On our first visit, those were the details we noticed and discussed with each other and with Mark. But, over time, sitting for the portrait in this space became a time of quiet reflection. We developed a camaraderie with other portraits progressing in the studio. We knew some of the other subjects from outside the context of the studio. Others became familiar through in-progress drawings of them, and, over the weeks of the study, some drawings clearly reflected subjects' improvement. In much the same spirit as a [gallery experience](#), I felt that the subjects, via the portraits, observed and connected with us. This connection seemed symbolic of humanity in the clinical setting.

This introspective time allowed Rob to focus on and internalize the magnitude of the impact of head and neck cancers on the individuals and their appearances. He became one of many who had undergone treatment. He was well aware of the discomforts, but he now fully realized that he had escaped disfigurement. The art allowed him to see the mass of patients as individuals and to connect as part of that community. All of these observations contributed to his feeling of well-being. Rob described this introspective time as a "bridge" during recovery for him.

It is vitally important for their survival that patients find methods to promote feelings of well-being and a positive self-image. As a life-long runner, my moments of meditation and self-awareness are associated with the repetitive aerobic exercise I enjoy. After my

own cancer treatment, I learned to employ new techniques, such as biofeedback and visualization, until I could safely return to a version of my preferred routine. Portraiture, a sensitive and innovative approach, provides a new lens and perspective for the patient-subject. The Portraits of Care study opened new dimensions of self-awareness for us as well as for several other participants.

We observed Gilbert's powerful ability to capture nuances in a subject's physical and emotional status as we compared notes after a sitting. Although the observational facts were present, the art brought the human condition to the science and the medical protocols. We had not anticipated Gilbert's sensitive insight. We discovered that our portrait enabled Rob and I to identify elements in each other that we had simply not been able to see in our daily life together. In the portrait, my strong public exterior was overshadowed by a waifish vulnerability, and Rob's face reflected a survivor's reconciliation of past hardships with the reality of life in the present. We realized that others could really see us. We also saw an affirmation of our partnership in life. We had a deep mutual understanding of each other and of the basic ways we addressed and handled both opportunities and adversities. The observations mirrored in the canvas were good predictors of our ability to enjoy the remaining years of Rob's life and to find unique solutions during challenging moments.

Figure. *Robin & Mardi*, by Mark Gilbert, 2007



Courtesy of Mark Gilbert.

Media

Oil on canvas.

Over the years, the portrait reminded us that life is finite. We were always cognizant of the importance of each of us caring for our joint physical and emotional health. We had each endured significant wear and tear, which was captured in our portrait. These realizations, combined with the loyalty of our relationship, helped us have frank and productive discussions with our legal, financial, and medical advisors as time went on and during the period of Rob's declining health. These conversations were not always easy for the professionals initially. However, they soon came to realize that we had a healthy respect for and comfort with our own mortality, which seemed a natural outcome of our many dress rehearsals with death. We eventually arrived at some innovative solutions in many areas that our aging population faces.

At the time of our participation in the Portraits of Care study, we had taken turns as patients and caregivers for a decade. In 2006, we had attended a prior exhibit of Gilbert's in Omaha called *Saving Faces: Art and Medicine*.² We found the images powerful, and we were impressed by the insights they communicated about the physical and emotional state of the subjects. When we were asked to participate in the art-based research study, we were honored and interested in the outcomes. We also had the feeling that we were participating in a project for the greater good in the same spirit as participating in a clinical trial. In particular, Rob appreciated that his medical team really treated him as a unique individual. His hope was that participation would further foster that value of patient centeredness in the **training of current students**. For him, this study seemed like an opportunity to embrace an enhanced level of care. I hoped that my participation in the study would benefit patients and their partners in care during their transition from clinical treatment to their "new life."

We would see our portrait where it was displayed for some years in the head and neck clinic. The canvas is life-size and always had an impact on me. At times, I felt very positive about and proud of our path and participation. This feeling was highlighted when the exhibit was displayed and used for studies at Interlochen Center for the Arts, one of top arts centers in this country.¹ On other visits, I appreciated that I had seen and accepted the vulnerability mirrored in our canvas, and I believe this acceptance of vulnerability had enabled me to know when to ask for help. To be fair, however, there were times when viewing our images reminded me of the anxiety and discomfort of the treatment experience. The vulnerabilities I could see in the art were simply an ongoing part of our physical lives. For Rob, long-term radiation damage resulted in balance and swallowing issues. My case would warrant surveillance for cancer metastasis or recurrence.

The "sitting experience" was insightful and expanded our coping skills. It added a depth and dimension to my life experience. The canvas provided a sensitive and revealing look at myself and my husband as individuals and as a couple. It had a lasting impact on our lives in reflecting the fact that we were united by 50 years of life together yet had individual needs. This visual reinforcement helped us to find creative solutions for appropriate residential options and end-of-life decisions. The piece that came from the project tells our story and helped us process our medical journey in a way that I believe only art can.

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Mardi Denell spent her early years working in different research laboratories with specialties in cytogenetics, population genetics, and mutation research. A lengthy “sabbatical” provided time to raise a family and serve on municipal boards, campaigns, and other community initiatives. Following that period, she returned to research with a focus on genetics and evolutionary developmental processes.

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CME MODULE

How Portraiture Can Help Therapeutic Build Capacity in Patient-Clinician Relationships

Mark Gilbert, PhD

Portraits are now commonly integrated into health humanities courses. They are often used to help health professions students cultivate their observation skills. The focus of this exploration, however, is how portraiture applies to health care ethics and professionalism, specifically, to nourishing therapeutic capacity in patient-clinician relationships.

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