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# Portrait of a process: arts-based research in a head and neck cancer clinic

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## **Abstract**

The role of art in medicine is complex, varied and uncertain. To examine one aspect of the relationship between art and medicine, investigators analysed the interactions between a professional artist and five adult patients with head and neck cancer as they cocreated portraits in a clinical setting. The artist and four members of an interdisciplinary team analysed the portraits as well as journal entries, transcripts of portrait sessions and semi-structured interviews. Over the course of 5 months, 24 artworks evolved from sittings that allowed both the patients and the artist to collaborate around stories of illness, suffering and recovery. Using narrative inquiry and qualitative arts-based research techniques five emergent themes were identified: embracing uncertainties; developing trusting relationships; engaging in reflective practices; creating shared stories; and empowerment. Similar themes are found in successful physician-patient relationships. This paper will discuss these findings and potential implications for healthcare and medical education.

#### INTRODUCTION

The Experience of Portraiture in a Clinical Setting (EPICS) explored the experience of participating in the process of portraiture for both an artist and patients in a Head and Neck Cancer Clinic at the University of Nebraska Medical Center (UNMC), Omaha, Nebraska, USA.

#### **BACKGROUND**

Art and medicine have historically informed one another. Artistic representations of medicine and illness are present in anatomical and physiological maps 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. Portraits, in particular, have been used to depict, illustrate and explain medical pathologies, pathopsychologies and trauma, <sup>2–5</sup> to commemorate and critique physicians and their practices<sup>6,7</sup> and to empower, inform and inspire patients, physicians and viewers alike. <sup>8–10</sup> Portraits have also been found to embody a metaphorical power that serves as a potent source for analysis. <sup>7,11</sup> The experience of the process of portraiture, however, has yet to be explored in a clinical setting.

#### **METHODS**

# Participant recruitment procedures

This study received full approval from the UNMC Institutional Review Board. Appropriate patient consent was also sought and received from all research participants (see online supplementary appendix 1). Those eligible to participate in the EPICS study were adults, ages 19 and older, undergoing cancer treatment or follow-up. WL, head and neck surgeon, used an opportunistic sampling strategy to identify and assess patients' suitability for the study. A total of seven patients were recruited into the study and five consented and participated in EPICS: 'Lisa', 'John', 'Jim', 'Judy' and 'William'. One patient elected not to participate because of time constraints and another passed away before consent was confirmed.

# **Participants**

Lisa was in her mid-20s. During her participation in EPICS, Lisa was pregnant with her second child and she celebrated the third anniversary of her surgery for oral tongue cancer. She is cancer free, doing well and continues to follow in the clinic.

John was in his 70s. Two years prior to his participation in EPICS, John received radiation and chemotherapy for cancer of the tonsil. John is cancer free and being monitored in the clinic.

Jim was in his 60s. Thirteen years prior to his participation in EPICS, Jim had surgery to remove a squamous cell carcinoma from his tongue and lymph nodes and underwent radiation therapy. During the study, he continued to attend the clinic to receive care for osteoradionecrosis. While cancer free, Jim continues to follow for management of the sequelae of therapy.

Judy was in her 70s. Fourteen years prior to her participation in EPICS, Judy had surgery to remove and reconstruct her mandible due to a squamous cell carcinoma of the mouth. Judy remains cancer free and under observation in the clinic.

William was in his 80s. William had a multiply recurrent basal cell cancer removed from his upper lip, nose and maxilla. William developed a recurrence of his cancer and succumbed a year following the project.

### Research setting

The Head and Neck Cancer Clinic at UNMC served as the research setting for the study. A small office located within the clinic, next door to patient rooms, was modified into an art studio. All study interactions with participants took place in the studio and the clinic's waiting-room; the waiting-room was familiar to participants as it was where they had, many times previously, waited to meet with their physician for check-ups, further treatment or diagnosis.

#### **Data collection**

Study data included a total of 24 artworks (pen and ink studies, charcoals and pastels), photographs of participants, artist and participants' journals, audio recordings and transcripts of portrait sessions, semistructured interviews and analysis team meeting transcripts.

The artworks recorded a visual narrative of the overall experience. Journal entries recorded reflections on the experience of the portraiture process and the portraits themselves. Audio recordings and transcripts of sittings provided further insight into the internal and external dialogue in the sittings. The artist conducted and recorded a 60–90 min semistructured interview with each participant, inquiring about the holistic experience of the artistic process. Interviews were completed in the presence of each participant's own and other participants' completed portraits (see online supplementary appendix 2). Analysis team meetings were also recorded and transcribed.

# Study analysis

Analysis began at the inception of the study. An interdisciplinary analysis team, including the artist, convened a total of five times in the studio, in the presence of the portraits. The images acted as a fulcrum around which the analysis team shared insights and interpretations. The analysis team systematically analysed visual portraits, journals, field notes and transcribed dialogue data qualitatively.

In the initial meetings, the analysis team discussed and interpreted the portraits through a holistic lens, noting the physical, social, intellectual, spiritual and emotional aspects of the participants' narratives (both visual and verbal). Further analysis centred on what the portraits and transcripts revealed about the portraiture process in the context of health and illness. The analysis team used an immersion and crystallisation organizing style, reading and rereading the data interspersed with ongoing iterative discussions of findings from multiple perspectives. 12–14 The team identified common threads, resonant metaphors and repetitive spoken refrains, as well as poetic, symbolic and cultural expressions. Inductive analysis enabled coding and identification of

patterns, categories and themes. Analysis results were gathered into a final narrative report that reconciled overall results and conveyed emergent themes.

More than one form of validation was employed in this study; both respondent validation and triangulation were used at different stages of the project. The analysis team used participants' comments as a check on the viability of the interpretations of both visual and verbal data. To determine truthfulness, the artist questioned participants to authenticate analysis results with participant responses to and feedback on the portraiture process. Cross-verification was sought as a means of increasing the credibility of the visual portraits and other data. The process of triangulation was applied to test and ensure the integrity of the data collection process and management.

#### **RESULTS**

#### Portraiture sessions

The artist worked on each portrait, on a one-to-one basis, with all five participants in the clinic for approximately 1.5 h per session. Participants averaged eight sessions over a 5-month period. Initial sessions included relatively quick charcoal or pen and ink studies (figure 1). For all but one participant, initial studies led to the development of a large (48×36 inches) fullength, coloured, pastel painting.



FIGURE 1: John, charcoal on paper

#### **Emergent themes**

The analysis team found that participants' portraiture experience in the clinical setting mirrored one another's and also paralleled the artist's experience. Ultimately, results suggested that over the course of the project, participants and artist:

embraced uncertainties

- developed trusting relationships
- engaged in reflective practices
- shared stories
- felt empowered.

#### Uncertainties embraced

In his study journal, the artist reflected a strong sense of unpredictability and commented on the tolerance for ambiguity that prevailed in the drawing and research processes:

...as I tentatively hover my pen above the blank paper, a large drop of ink falls right in the middle of the paper. I stop and wonder what to do. It seems to be a bad start but it would seem wrong not to continue regardless. By deciding to continue, the drawing in ink has already begun to teach me what I suspected it might. It has already made me...embrace the process-a process that is always a little out of control, and therefore susceptible to error, accident, mistake and 'failure'. The process is not/should not rely on a search for a finished object or perfection. The ink and pen as a medium/methodology have emphasized the importance of having faith in the process, seeing what happens and jettisoning all preconceptions. In doing this [I] dissolve a great deal of the fear and vulnerability and isolation. It is a skill to be learnt none the less. Even now I feel it [is] something I only achieve in flashes, but I know it to be fundamental to drawing...fundamental to my research, and care, compassion and living one's life well. The implications of a blob of ink are not to be understated (Journal entry 7/25/13).

Participants also expressed their uncertainties when speaking about their role in the study. William stated, "I am not sure why I am doing it" and Jim expressed how he felt puzzled and perplexed by the aims, stating, "I did not totally understand what it was all about." Jim further described, 'not knowing', 'questioning' and feeling 'inquisitive' and full of 'confusion' and 'doubt', while also 'curious' about 'how it all goes together'.

Due to the qualitative nature of the study, no one knew what to expect; yet, all parties continued in the project, demonstrating acceptance of the un certainties inherent in the process. Although John 'didn't fully understand' the project, he reportedly '...had no apprehension whatsoever'. In reference to her portrait, Judy expressed a similar sense of open-mindedness when she said, "If it is good, it is good. If it is bad, it is bad.... that is just how it comes out."

#### Trusting relationships developed

The portraiture process relied on the trust engendered in the studio space. As marks accrued and faded on sheets of paper, participants and artist grew to know one other and this created a sense of community that shaped the quality and development

of the portraits. Participants noted that the relationships that developed in the studio were collaborative and reciprocal. Lisa described the portraiture process as a 'collaboration', and explained that "you can have a bunch of people with photos, drawing what they see, but I think you have that aspect where, when you are working together with the artist that you get so much more coming through."

Much of the time, studio interactions were permeated with a purposeful silence that emphasised non-verbal communication; this created space for vulnerability, which allowed emotional states, personality traits, habits, values, comments, thoughts and feelings to surface. Tranquillity was punctuated by the sound of scratching charcoal and pastels on paper and the exchange of stories and observations. Participants reported that the studio became a comfortable place to reflect and contemplate, to express themselves and be heard. For example, in reference to how unusual it was to be able to share his story in the studio, Jim said, "I honestly haven't talked to many people about having gone through the long-term care that I have had, so that probably influenced (my healing process)." Participants' comments testified to trusting relationships and meaningful connections between the participants, the artist and the artworks.

Involvement in the portraiture process proved to facilitate a sense of community and inclusion, as participants spent time in the studio, in the presence of their portraits and in connection with the portraits of others. Although participants never actually met they got to know one another through each other's evolving portraits that hung on the studio walls. William explained, "the whole experience of walking in here...has brought me into contact with a whole new group of people." John expressed a "feeling of fellowship" while in the presence of the portraits. As John observed:

It has been of value to me...seeing all these folks (in their portraits) who have gone through something, that may or may not have been as serious, or not as serious as mine. It gives you a little bit a feeling of fellowship...It (participation) relieves the sense of isolation (John interview 10/23/13).

Jim similarly noted that the other portraits made him feel 'associated with the other people' and that he was 'not alone'. Jim elaborated, "it's given me a different attitude, I guess...to see the other portraits associated with the other people." As Lisa described, "we are all so different, yet we all kind of share a little bit of similarity with our diagnosis." In viewing other participants' portraits Lisa observed, "it just seems like behind the face of these ones you get the sense of 'I went through something or overcame something'." William, in particular, appreciated the fact that others would be introduced to his portrait and satisfactorily noted, "somebody is going to look at it in ten years from now and wonder who that guy is" (figure 2).

#### Reflection

Whether at the easel, drawing, or seated quietly in contemplation, the artist constantly sought to give expressive form to all that emerged from the process' exchange of narratives and shared experiences. The portrait-making process required

the artist to pause, be silent, step away from the easel, shift positions and angle his head or squint to gain perspective. The artist worked to balance the active stance of gathering fragments of information with the more passive position of creating a unity, a credible and believable aesthetic whole. As seen in the reflection below, the artist acknowledged the centrality of his role in the process and the importance of allowing space for the participants' experiences and perspectives to surface and be acknowledged:

Allowing the process [the drawing] to flow is what I attempt. It is done not without direction or purpose-it relies on being purposeful. Every now and then you have to come up for air and look around and reflect (Journal entry 7/25/13).

This reflection that was so fundamental to the artistic practice proved to also be central to the participants' portraiture experience. Participants described the studio as a peaceful place, wherein John described it as "very positive...to sit in here for an hour. There is no phones ringing, no TV, I am not watching FOX News...there [are] no demands. I just sat here and, you know, go from there." John revealed, "I know while I am here (in the studio), nothing is going to interfere with my thought process... it was actually a very calming, refreshing hour."



FIGURE 2: William, pastel on paper

According to participants, the studio created space to engage in reflection. Jim attested to being able to 'self-reflect' and contemplate on the past 13 years since his original diagnosis, which was something he had not done before. Comparing his studio experience to his clinical visits, Jim said:

Usually I come to these clinics for more treatment of some type, or follow ups, things like that. Nothing like this. I mean that (clinic visits) didn't involve self-

reflection or anything like that. It is a totally different reason for being in this clinic. (The portraiture) makes me think a lot more about me. It probably gives me more association with this clinic, than I have had in the past, in some ways, because it is more than just treatments...I keep saying self-reflection, because that is a lot about what it is...the project...making that available to more people (Jim interview 8/6/13).

At times, the studio was full of conversation and participants and artist engaged in more narrative reflection (re-counting what one knows, believes and values) and at other times, there were long periods of silence in which participants and artist engaged more in experiential reflection (contemplating what one knows, believes and values). Active dialogue and information sharing was balanced with the stillness and quiet of focused awareness. Lisa wrote about these different strands, 'we would chat, [and] then it would be quiet'. During periods of silence, Lisa would 'take some time and actually be quiet and still and think about it...what we went through'. Lisa claimed that the quiet time enabled her to 'contemplate where you've been and what the future may have' (figure 3).

Jim explained that his process of reflection came from 'looking at lots and lots of pictures of (himself)', saying, "Yeah, well part of it is simply that looking at a picture about yourself makes you think about yourself." John, too, commented, "it gives me a broader perspective of what I have went through." In reference to the sitting, William said, it "made me look back over stories of my life…and makes me think what happened in my life and why did it happen?"



FIGURE 3: Lisa, pastel on paper

Judy said, "when you sit, you can also think"; Lisa said, "I really don't talk about it (her cancer journey) a whole lot" but "it was interesting...revisiting our stories and, you

know, bringing it up again." She recognised, "if I hadn't have sat for this, I don't think I would have revisited going through that ('the whole cancer thing'), but I think it is good to revisit it and know what you overcame." Lisa described a salient aspect of being able to pose for one's portrait:

I mean how many times throughout the busy day do you get to just sit there, and really take a moment to think about you, about your family, about where you've come, and all this stuff... you just don't (Lisa interview 9/26/13).

John also described the studio as a peaceful place and explained, "I am not bored...I go neutral,.. it's all nice, it's good, it's a positive experience." John explained, "I went into neutral. I can remember looking at a spot up there (on the wall)."

For Jim, participation in the project involved being 'intensely more reflective' than ever before. Jim demonstrated a constant process of reflection as he consciously built his narrative and found purpose and meaning in his reflections. In fact, Jim described his portrait as a depiction of his 'self-analyses' and 'contemplation'. He recognised a 'mystery' within the project and within himself.

#### **Stories shared**

Participants had the space to figuratively stand at their own easel, to tell their own story and make their own marks. They shared their stories with themselves, with the artist, with each other and with other members of their community. William relished the other participants' portraits and intellectually engaged with them, stating, "they all have a story too. I would like to know what it is...I look at all these faces there, including my own and wonder how they did? How did it affect them?" Judy said that she would 'sit and look up' at the other portraits; this, she said, incited wonder and great 'curiosity' about the other participants.

All participants acknowledged that they were telling their stories through the portraiture process and that they were aware of the leverage they had in informing and shaping the pictures by telling their stories. Jim's radiotherapy mask symbolised his journey since his diagnosis. He felt that it was important to include the mask in his portrait, as it was an object imbued with significance; it was symbolic of his treatment and recovery (figure 4). In his exit interview, Jim described being aware that he could 'influence' the artist and recognised that he tacitly lobbied for the mask's inclusion in his portrait.

Jim said that 'as a result of the photographs' (of the artwork), he was able to reference and talk about his medical journey and explained how he had shared his portraiture experience with his wife and his colleagues at work:

I show pictures of what has been done so far to other people... they ask me questions about myself they would not have thought to ask me before. And it makes me answer them. A lot of people didn't know...didn't realize how long this process has taken until I talked about that as a result of the photographs (of the

artworks). It helps them, in some way, know a little more about me. (Jim interview 8/6/13).



FIGURE 4: Jim, pastel on paper

The artist and participants collaborated to tell each individual story and the aesthetic whole story of EPICS. The willingness of the participants to allow their stories to be told and to allow themselves to be seen in their portraits and as a group was fundamental to this collaborative process. The artist shared participants' developing stories as the portraits evolved and hung on the walls of the studio; each portrait communicated its own story. Lisa noted, "I loved hearing a little bit about their stories, I have such respect for everything they went through." Lisa explained that seeing other portraits 'developing over time', and observing what had been 'done with everyone's faces, and the body postures' makes the people 'really become real in your mind, so much more real'.

All participants noted the potential for their portraits to be seen as a testament to their lives as whole, past and present. Jim regarded his larger, more elaborate pastel portrait with his mask as more 'historical', explaining that it harbours more memories and 'tells more history of (his) treatments' and 'more of the steps [he'd] gone through', his own 'testimony'. Lisa, too, found that the pastel was more of a 'progression' that had 'more feeling' and 'more story behind it'. In fact, Lisa explained that she 'loved' being able to share pictures of her portraits with friends, family and coworkers; she said, 'it

opened up discussion about how far (she's) come' and recognised that, as a result, 'they know what (she) went through'.



FIGURE 5: Judy, pastel on paper

The artist had lived his own story in relation to EPICS. This project gave the artist the opportunity to investigate one role of art in medicine and analyse the process of portraiture to gain and share various understandings of the experience of portraiture.

Sharing a common interest in exploring opportunities to tell their stories beyond the clinic and beyond academic publications, both participants and the artist discussed and welcomed the possibility of a public exhibit of their portraits. Jim sought to exhibit the portraits at a local community college because he wanted to 'be involved in displaying the [study works] project'. He explained, "I obviously have an attachment to the project. I would like to see it, I mean, go beyond just what we have done here...I'd like to see it recorded."

#### Feeling empowered

All participants attested to their desire to share their stories as well as spread the message that they were survivors, and thriving, lively, active individuals. Lisa pointed this out when she described how 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, in particular, saw an exhibit as an 'opportunity...to show people' something and was 'proud to have them displayed' as they tell the world, "we all overcame

something...everyone kind of has that look that 'I did it... I did overcome that! I was able to cope with what was thrown at me'." John expressed a similar sentiment:

I would be proud to be part of that (an exhibit). Because that in itself would present a story. People who have been through this... or people who have never had cancer...might see something in this in a positive way. And you can say, well that guy's still alive, he survived that guy....And people don't have to know, this is John from Omaha or anything else. It is just this is a guy and this is a lady, and the people went through some difficult times but they've all survived it (John interview 10/23/13).

Judy also placed significance on the role the portraits could play, saying, "If it can improve things later on, great!" Judy felt that the project could 'help (others) understand that if you get cancer it is not going to kill ya. You know, you are going to still go on'. She further affirmed, "they'd see that I am still alive, thank you!" When asked what she would like people to know or feel when they look at her portrait, Judy responded, "that you can survive after having something go messed up on you." Describing her portrait, Judy said, "This is a picture of how I am living my life... I'm sitting here for you" (figure 5).

Seated in the studio, contemplating other participants' portraits, John stated, "There is purpose for this. Maybe I am contributing a little bit. When all is said and done this may help other people." The participants, ultimately, also empowered the artist to tell this story and create and share the aesthetic whole of the EPICS project.

#### DISCUSSION

The study uncovered a number of dualities. The participants and artist each experienced emotions and feelings that spanned a wide arc: the threatening with the reassuring, the painful with the pleasant, what isolated with what became social, what was destructive with what was constructive, and what was damaging with what was healing. Drawing on experiences of the past, present and future projections, participants used the silence and dialogue, listening and questioning, reflecting and experiencing, analysing and imagining to construct the resultant narratives of EPICS.

While each individual involved in the EPICS study experienced illness, recovery and the portraiture process differently, each also found common meaning and purpose through the portraiture experience. The portraits validated aspects of participants' reality and provided them the opportunity to explicitly engage in their own healing journey. As Lisa said, "I don't think that I would have revisited going through that. I mean, push it off to the side, and it's behind us now. I think it is good to revisit it and know what you overcame. So I can see it (the portraiture process) being very therapeutic, very healing." While not all participants used the words 'healing' or 'therapeutic', they all found time to reflect upon, revisit and come to terms with aspects of illness and healing experiences.

The process of participating in the portraiture process granted all parties involved the permission, time and mechanism to reflect. When participants entered the studio space they were presented with a vacuum in which they were able to 'relax', 'reflect', 'take stock' and attend to aspects of their lives that were unpredictable, challenging, comforting and upsetting and weave them into their own narrative, both visual and verbal, which in itself was therapeutic. Participants and the artist engaged with one another and pondered the collection of portraits of cancer survivors on the walls around them; this generated fellowship. The physical presence of the collection of portraits appeared to link the participants into a larger whole. Participants were given opportunities to share their voices, individually and as a whole. The built-in dialogue and silence may have assisted in developing trusting relationships between the artist and participants. The tacit, quiet exchanges that occurred during the sittings created opportunities to continue to communicate with a profound purpose through the marks that accumulated as the portrait image expanded and contracted into life.

The way the artist and participants related to one another, either side of the easel, reinforced previously observed similarities between doctor patient and artist—sitter relationships.<sup>11</sup> The art and science of the practice of both portraiture and medicine requires practitioners to be productive and imaginative, to do and feel, and to care and to fix. Both practices necessitate the ability to listen, witness and share in the evolution of each other's stories.

The balance of art and science is a common theme in medical practice; physicians, much like artists, are often called to recognise, use, represent and unify the dualities that permeate human life. Lessons learned from this study can be applied to the work of physicians as well as artists. Emergent themes from this study may be relevant to the interactions between artists and participants and also physicians and patients as they face the healing process together. This study suggests that portraiture in a medical setting may offer therapeutic benefits to patients and valuable applications for teaching topics related to the delivery of clinical care and the nature of doctor—patient interactions.

Ultimately, the narratives and artworks created in this study can form a significant part of a text that can contribute to medical education. The data generated in EPICS may add to the collection of curricular tools to reinforce notions of holistic and humanistic medicine as an important aspect of healthcare.

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#### Contributors

Each of the six manuscript authors was deeply involved in all aspects of the study design, implementation, analysis and manuscript preparation.

# **Competing interests**

None declared.

#### Patient consent

Obtained.

# **Ethics approval**

This study was conducted with the approval of the University of Nebraska Medical Center Institutional Review Board.

## Provenance and peer review

Not commissioned; externally peer reviewed.

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