

Judy

Mark Gilbert PhD

greeted Judy in the same waiting room at the Head and Neck Cancer Clinic where the physicians and nurses had met her as a patient. She arrived on time, as always. She collected up her bags and her cup of coffee from the vending machine. I showed her into the bare, windowless room adjacent to the clinic's examination bays. What was once a postal room was now transformed into an artist's studio, where Judy and other patients consented to engage in the process of sitting for their portrait.

The clinic was already full of memories and past experiences for patient participants in our study (Box 1), so it enabled Judy and the other participants to feel comfortable and free to be themselves. Except for the soft cushioned chair (brought in to enhance participants' comfort during portrait sittings) and the wooden easel, little stood out in the "studio's" design and function compared with other hospital rooms. The studio, much like the waiting room in the clinic, functioned as a social place to receive participants, observe, listen, and engage in the process of sitting for a portrait.

Box 1. Experience of Portraiture in a Clinical Setting

Experience of Portraiture in a Clinical Setting (EPICS) was an arts-based study in Omaha, Nebraska, that sought to explore the nature and shared experiences of artistic interactions between a professional artist and 5 adult patients with head and neck cancer as they sat for their portraits in a clinical setting. The 5-month study generated 24 works of art created from sittings that allowed both the patients and the artist to collaborate around stories of illness, suffering, and recovery.

The EPICS study recognized that artistic modes of representation have the potential to create statements and insights that cannot be expressed, documented, or shared in other forms of research. Here the artistresearcher, Dr Mark Gilbert, reflects on working with Judy, who was in her 70s. In 2000, she had surgery for a squamous cell carcinoma of the mouth. Her initial reaction to the project was one of curiosity.

Judy's portrait, along with the rest of the EPICS collection, is now being integrated into a teaching program in the Department of Health and Public Services at Metropolitan Community College in Omaha. The program uses the portraits and their accompanying participant narratives to promote reflection and ethical dialogue for allied health students to incorporate into their care planning assignments. Dr Gilbert, along with faculty and co-investigators, is currently evaluating educational outcomes of this program to inform and support future curriculum development using visual arts as a teaching resource.

Judy traveled about 100 km by bus for her portrait sitting. On her first visit she enthusiastically scheduled 4 more sittings. As we chatted and gossiped, she reminded me of her copious interactions with medicine. She told me, "My body is falling apart but my brain keeps going." Judy was tiny and looked frail, but was still vital and robust. Her legs were stick thin, with the left one even thinner, as bone and tissue had been harvested from it to help reconstruct her jaw. She reported that she'd had more than 40 operations, some in relation to the mandibulectomy she received to remove her cancer.

The follow-up jaw surgeries, including cadaver implants to restore her gums (which she said "worked real well"), and multiple back surgeries did not slow her down. She told me she still suffers from acute back pain. Her mouth was still dry with sore spots in it. She spoke almost incessantly, but at the same time was remarkably patient. When we worked on the portraits, she was obliging and still. During her second sitting, when reviewing the first charcoal portrait we had created the week before, she told me that I made her look mean and miserable, but then laughed it off and carried on into another conversation.

Recognition of a life

As we started the next portrait, Judy sat about 3 m away from me, and between us both stood the easel upon which was a large blank sheet of white paper. I paused, aware of the physical space. I could smell the turpentine and oil. I heard the crunch of the charcoal scraps underfoot.

Initially, I looked at Judy without making a mark. I looked again and again at her and then at the blank sheet of paper, hovering the charcoal over the surface, nervously considering choices in composition and where the first marks would take me. Although I looked at Judy objectively at the start, trying to see her as a jumble of abstract shapes and volumes in space, I was not oblivious to her. I appreciated the vulnerability of her situation; it takes a certain amount of courage at the best of times to have your portrait painted. The initial silence can generate an instant intimacy, one that some can find awkward.

Nonetheless, Judy sat quietly in front of me, allowing me to examine her and establish whatever I chose to on the page. When I begin a portrait, I am not simply copying or recording. Behind all the measuring of proportions, fracturing of the subject into shapes, bumps, hollows, lines, and tones, you hope the portrait is a recognition of a life. With each mark of the charcoal that scratches and squeaks across the page I am led on to

something else, another discovery, always on the brink of error and failure. Each mark helps me move further into the figure. Like an electric current, there is an exchange between Judy and myself that surely has to inform the marks I make in response to her.

The resultant portrait will be a culmination of a series of glances, thousands maybe, that guide my hand with the materials and inform my mind's eye constantly to assess and reassess what I am exploring, and the trail of marks I leave behind. The fact that the drawing is a culmination of innumerable corrections seems to run contrary to the more unconscious processes. Like the drawing, the mind is always changing, flowing like a river, leaving behind where it has been. The danger is I stop responding to Judy and resort to "picture making," embellishing what I think makes a good drawing instead of exploring what I don't know, caring more about the drawing than Judy, who continues to sit happily in front of me with a coffee in her hand, relaxing into the process.

Once completed, Judy sits looking at the portrait and tells me it makes her happy. Her participation required a considerable investment of time, money, and energy; she commented on how tired she felt the day after her visits to the studio, but she was glad to do it nonetheless.

Sense of fellowship

Judy found the process rewarding and hoped her participation and the resultant portraits might help others understand that many people with cancer are living their lives in a more or less normal fashion. She recognized that viewers of the portrait would want to know her medical history and learn that she is still alive despite it all. This reflects Judy's own interest and wish to hear about the other participants whose portraits hung on the walls. She often asked about the other people depicted and wanted to hear their

stories and related to their struggles with radiotherapy, denture problems, complications of treatment, dietary restrictions, and the recovery processes.

Judy reflected that sitting gave her the rare opportunity to think and to wonder about the people in the other portraits on the wall, as well as generating time to ruminate about her son in Oregon and her kids in Texas, or to reminisce about the beach in California she used to visit when younger. Judy's experience of viewing the other participants' portraits paralleled what others found—viewing the other portraits engendered a sense of fellowship that in itself diminished their sense of isolation and loneliness, which can be so prevalent for people living with cancer.

Although intellectually Judy was aware of the changes that were taking place in her body with age, she seemed to always find the silver lining and focus on the fact that she is still alive and can have cancer and still have fun. Judy believed the study and her portrait could help others: "If it can improve things later on, great."

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Competing interests None declared



Judy, pastel on paper, 40" x 26", 2013