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IMAGES OF HEALING AND LEARNING

We Got Your Back: Patient Advocacy Through Art

Regina Holliday



Figure 1. Detail of "For Him" by Regina Holliday

I often paint pictures of patients facing away from the viewer with their johnny gowns open in the back. Nurses who watch me paint at conferences chuckle at this well-known reality of patient life; physicians often ask why I painted it that way. "Isn't that disempowering? Why do you paint patients like that?" They ask me this with a furrowed brow and quizzical frown. I glance up from my current canvas and respond with a wry smile, "We are all patients in the end."

Art can be a vibrant method of [advocating for the interests of patients](#). Those paintings of johnny gowns led to painting *on* business suit jackets. I founded a movement called the Walking Gallery of Healthcare [1], in which patients and clinicians don business suit jackets with personalized health care story paintings on the backs.



Figure 2. Detail of "Training the Brier," a jacket for Catherine Costa by Regina Holliday

LJ, a manager at a pharmaceutical company, wears the story of his brother on his back. LJ's brother died of AIDS prior to ready availability of the drug cocktail that has helped so many. He tells his jacket story while working in pharmaceuticals and hopes to save lives in so doing. CK wears her jacket story that depicts her childhood self receiving food from the free or reduced lunch program. Now she guides federal health policies that contribute to population health. There are currently 43 artists painting the images in the Walking Gallery, and close to 400 jackets are worn on five continents. Now when patients turn their backs on viewers, their stories are being seen and told, conveying that

they are human beings who have been affected by illness or injury experiences or lapses in health care service delivery.



Figure 3. Participants in the Walking Gallery of Healthcare at the conference: Cinderblocks2: The Partnership with Patients Continues on June 4, 2015.

When I dove into the world of health care in 2009, I was researching my husband's advanced kidney cancer. I would scroll through article after article looking for a study or clinical trial that could help him. The walls of text loomed large before me, and I was amazed that there weren't many pictures or any other kind of visual draw to the information. I was surprised that a digital age that thrived on viral images and videos would stick to dry and scholarly text when explaining disease. Occasionally I would see a stock photo of smiling people with the accompanying text praising a new cancer center on a medical website. Or an abstract smear of color maybe intended to be comforting—an image that could be interpreted as anything or nothing at all—would grace an article focused on end-stage options. Where was the message art? Where was the art that made an impression? Where was the art that inspired action?

In 2009, while my husband, Fred, was sick and we struggled to get access to his medical record, I began painting a series of murals focused on data transparency and patient rights. I called this the "Medical Advocacy Mural Project." The 17-by-70 foot mural "73 Cents" [2] was named for the average cost per page the hospital charged to patients for

their medical records (taking into account the first-page charge \$21.69 and the 69 cents charged for each subsequent page, which is the maximum allowed by Maryland State Law [3]). The painting depicts our family journey in a closed data loop: The computer the nurse uses in the painting is turned off. We are unable to access the record through technology. We only have access to a few papers the nurse hands to us behind her back. This painting is used in some communication studies curricula to explain meaningful use of electronic health records and patient rights as they relate to data access. Fred would die before the work was completed, but he had faith that "73 Cents" and the mural project would help other patients and families by changing health policy. These murals became part of the national patient rights debate in the US, helping support two pieces of legislation: the ACA [4] and the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009 [5]. Within weeks of beginning the painting, I was able to present our story at a US Senate press conference focusing on the Affordable Care Act [6]. Within the year I was able to testify to the Meaningful Use Work Group of the Health Information Technology Policy Committee at the Department of Health and Human Services [7].

After completing the murals, in 2010 I began painting about the relation between clinical scores and patient satisfaction levels measured by Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) scores. Using data sets hosted on the Center for Medicare and Medicaid Service's Hospital Compare website [8], I noted the very high clinical scores and the very low patient satisfaction scores at a local teaching hospital in Washington, DC. I painted the piece "Apples to Apples" [9] to explain to the average citizen that, although this hospital had great clinical scores, the patients inside the facility were not satisfied with their care. This painting was created *en plein air* in front of the facility, and throngs of passersby stopped to ask me where I got the data I was painting about. I responded that it was freely available online. I was very glad to inform patients that there were places they could look to find information about hospitals prior to admission. I entered this painting and a video of its creation in a competition hosted by the Sunlight Foundation, winning special honorable mention for best use of health data [10].

Next, I began live painting at medical conferences. Many concertgoers are familiar with live painting at musical venues, but medical conference attendees did not expect to see an artist painting about patient safety and data access at medical centers and hotel ballrooms. I would listen to the speakers throughout the day and paint an image based on their words from my worldview as patient and caregiver. Translating verbal messages into visual images is a skill set many graphic illustrators use to create illustrations that depict prominent themes of the day. Creating such images as a patient rights advocate combines a judicious depiction of the day's presentations with an underlying message of patient empowerment. Often the venue allows me to explain the painting at the close of the conference and thereby magnify its reach. The mirroring back of the day's themes in

both paint and story reaffirms the attendees' understanding of central themes. And the dual representation of information both verbally and visually allows a greater appreciation of it among attendees with a diverse range of learning styles. Finally, the painted image is more likely to live beyond the day of the event as visual images can be shared easily online.

I've suggested here that patient advocacy through art can be a vibrant method for creating positive change. I paint about health care, I blog about it, and I write poetry about this challenging time in health care. These poems often close speeches I give on the subject. Even though I am not the best singer, I wrote a song about being a widow, a health activist, and a mother. Two friends helped set it to music and we recorded it. I wrote a book revealing my entire life story in the hope that I could inspire others to fight for patients, too. I host medical conferences with fire dancers and doctors seated side by side, because [the arts united with medicine](#) is a mighty force for good. I hope that each of you who read this article is inspired to do the same—to use every talent and ability you have, medical or artistic, to make the world of health care a better place.

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