

As education adapts to a post-COVID-19 world, photovoice and autoethnographic methods create flexible avenues for introspection and artistic meaning making.

Isolation and Empathy: Documenting Cancer Culture

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In this article, the author provides insight to a culture of cancer by describing a single day of chemotherapy treatment. The author and his caregiver document the process through photography. Wrapped in the context of a global pandemic, the author draws connections between life in cancer culture and broader cultural modifications created by COVID-19. Through this manuscript, the author shares a personal narrative with the hope of building empathy and community.

Keywords: cancer, photovoice, autoethnography

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Cancer impacts all of us. Nearly two out of five people will experience a cancer diagnosis during their lifetime (National Cancer Institute, 2020). As an art educator with cancer, I utilize photovoice (Wang & Burris, 1994; 1997) and autoethnographic (Adams et al., 2015; Ellis et al., 2011) methods to document and describe an aspect of my cancer culture: one day of chemotherapy infusion. Like other art educators who share narratives about experiences in cancer culture (Barrett et al., 2008), I anticipate that this “use of imagery helps...to confront and communicate the impact of cancer on our lives and on the lives of others” (p. 4). By sharing my story in the context of a global pandemic, I hope this photo essay fosters empathy and support for anyone who is isolated from family and friends because of their disease or medical needs.

In this project, my caregiver and I documented one day of chemotherapy infusion through photography. This cycle of my treatment involved seven hours at facilities, followed by another 46 hours of ‘take-home’ chemo via a mechanical pump. When creating these images, I received my 26th treatment, totaling more than 1300 hours of infusion over the course of a year. During this process, we became accustomed to a rhythm of procedures and the objects inherent in cancer treatment. However, each cycle presented new opportunities to live my cancer culture.

Cancer Culture

Living with cancer can make me feel like I am participating in a double existence. In the relatively normal aspects of my life, I spend time working at school and playing at home. In my cancer life, there are frequent doctor visits, scans, and treatment procedures. Over time, my family and I adapt to a culture of cancer. My use of the term cancer culture is intended to refer to both

the global culture of cancer survivorship, care giving, and support communities along with the microculture of an individual's experience and patients at their local medical facility. Therefore, I use cancer culture to connect broad similarities for what it can be like to experience any cancer diagnosis, while also recognizing that all journeys are unique and varied by factors such as an individual's type and stage of cancer; access to health care, age, and family history. In this article, I share my cancer cultures by describing what a day of chemotherapy treatment is like for me.

One Day of Chemotherapy

It is hard to describe the sensation of having cancer. Physically, I feel well—most of the time—but notice quicker fatigue, physical weakness, cognitive delays, and heightened emotions. I am lucky to have most of my hair; a consistent weight, and the ability to continue working. Outwardly, I do not look like what people expect to see from someone with cancer. I feel lucky to be as ‘healthy’ as I am.

At treatment, I regularly encounter people whose diseases appear more advanced than mine; their bodies seem ravaged by cancers. There is a shock to seeing people that I perceive as vulnerable and frail. What might other patients think when they see me? Then, I remember there are eight tumors lurking within me. I wonder if I may look that way soon.

In the public areas and waiting rooms of medical facilities, it is hard not to focus on my own health and mortality. Traversing these spaces, I do not pay much attention to people dressed in scrubs or white jackets. Rather, I want to bond with the people wearing medical wristbands, as we share a similar detour on our life journeys. Often, our eyes meet. We share an acknowledgment of membership in the same sorry fraternity. I try to smile and give them a

supportive nod. I regret that we rarely converse. It is not easy to get out of my own head when facing such consequential matters. In these passing moments, I attempt to connect with others, but our situations are inherently unique and can feel solitary to me. However, I find comfort in being part of a community of people who are also navigating life with cancer.

In my experience as a cancer patient, I control few things and there are many unknowns. However, the repetition of a treatment cycle provides some stability; I can anticipate how the day will go. For me, treatment days consist of two phases: screening and infusion.

Screening

We arrive at the oncologist's office around 8:00AM. Each cycle begins with a blood draw for laboratory work to see if my body can tolerate the medicine (see Figure 1). A three-fourths inch needle pierces my chest to access a catheter port used for infusion. It stings, even with a numbing product on my skin. A nurse collects three vials of blood for a complete blood count and comprehensive metabolic panel. These tests measure how my liver and immune systems are functioning. For me, unsatisfactory results delay treatment for at least a week. A hold back from treatment is when a patient is unable to receive medicine because their medical team deems that they are physically unable to tolerate the toll of treatment on their body. Benchmarks for treatment in my plan include the results of the blood draw and severity of side effects. Being held back is emotionally devastating for me because it means that my body is defenseless to the cancer until I can recuperate. I experienced this twice.

After the blood draw, we move to an exam room and wait for the lab results. We meet with our oncologist or their nurses for a consultation,

physical exam, and the opportunity to discuss side effect management (see Figure 2). If the consolation and lab results are acceptable, we proceed to a different facility to receive chemotherapy.

Infusion

Upon arrival at the infusion center, we sit in a waiting room surrounded by other cancer patients and their caretakers. Some are chatty; most are not. Nearly everyone in this space appears to be at least 25 years older than me. Cancer and treatment have ways of aging a person. Then, the staff move us to an infusion room where we prepare for treatment (see Figure 3).

The rooms are nice for privacy but can feel solitary. We wait for a pharmacist to prepare the chemotherapy. Guests help pass the time (see Figure 4). I try to eat lunch while still having an appetite. I receive several bags of chemotherapy and a few more bags of medicines that curb side effects of the toxins (see Figure 5). There are frequent trips to the bathroom to expel the fluids being pushed into my system.

Nurses and caregivers monitor me constantly, yet I cannot help but feel isolated by my circumstance. The physical toll of the medicines mount throughout the day (see Figure 6). I have hot flashes and chills. My eyes are sensitive to light. Loud noises hurt my head. It feels like my abdomen is rotting.

At the end of infusion, the nurse attaches a mechanical chemotherapy pump to my port (See Figure 7). Every 30 seconds, it makes a low humming sound while injecting me with more chemo. The device is about the size of a cassette player. I wear it around my waist for the next two days. By late afternoon, I am tired, weak, and ready to go home (see Figure 8). My spouse, son, and I exit the facility, saying 'goodbye' to

everyone we encounter. Fresh air fills my lungs and caresses my skin. The sun's warmth helps me feel alive and grateful to see another day.

Cancer + COVID-19

We created the photographs in this project in February 2020. Since that time, life around the globe dramatically changed. Through my reflexive thinking about the project, I could not help but to consider connections between my cancer culture and the broader world during a pandemic.

In these times, we may all feel sequestered by concerns for health and safety. There are modifications to the ways some go about daily activities and engage with the world. I have become more conscious of physical spaces and interpersonal exchanges. A heightened awareness of what and how I touch objects alters my interactions with the environment. Disruptions to the norm seem to affect all areas of my life. I am encountering the world in new and occasionally uncomfortable ways because of cancer and compounded by COVID-19.

Might these contexts have implications for art education? At schools, teachers and students face unprecedented challenges in managing health, safety, and instructional methods. Physical distancing, personal protective equipment, and remote learning environments modify the typically collaborative and social nature of art classrooms. Yet, the therapeutic potential of art making and empowering qualities of storytelling provide pathways to investigate our personal cultures, connect with others, and fight feelings of isolation by sharing our experience. As education adapts to a post-COVID-19 world, photovoice and autoethnographic methods create flexible avenues for introspection and artistic meaning making. I hope that in the uncertain times of a global pandemic, we facilitate the use of artistic

practices and narratives to communicate our experiences and combat isolation by building empathy to connect with others.

Conclusion

Cancer is an important—albeit challenging—topic to discuss. For individuals with my cancer diagnosis, approximately 14% survive beyond five years (National Cancer Institute, n.d.). A statistic that is difficult to face. Personally, this project helps me process feelings of isolation, vulnerability, and impermanence. Utilizing narrative to share my experiences with cancer provides a catharsis for the challenging realities of treatment (Barrett, 2011). By documenting a single day of treatment, I would like to help broach uncomfortable conversations, provide insight into my cancer culture, and transcend finite time by sharing my story. Beyond the images and narrative, I hope to confront feelings of isolation for others and inspire opportunities for connection and healing.

If you are affected by cancer or want to learn more visit the National Cancer Institute's website (www.cancer.gov) or contact the author at gartht@unk.edu to have a conversation and share your story. Through an informed community we can build awareness and facilitate empathy.

Figure 1 0844 (Blood Draw)



Figure 2 0906 (Physical Check)





Figure 3
*1031 (Beginning
Infusion)*

Figure 4
1056 (Passing Time)



Figure 5
1215 (Toxic Medicine)

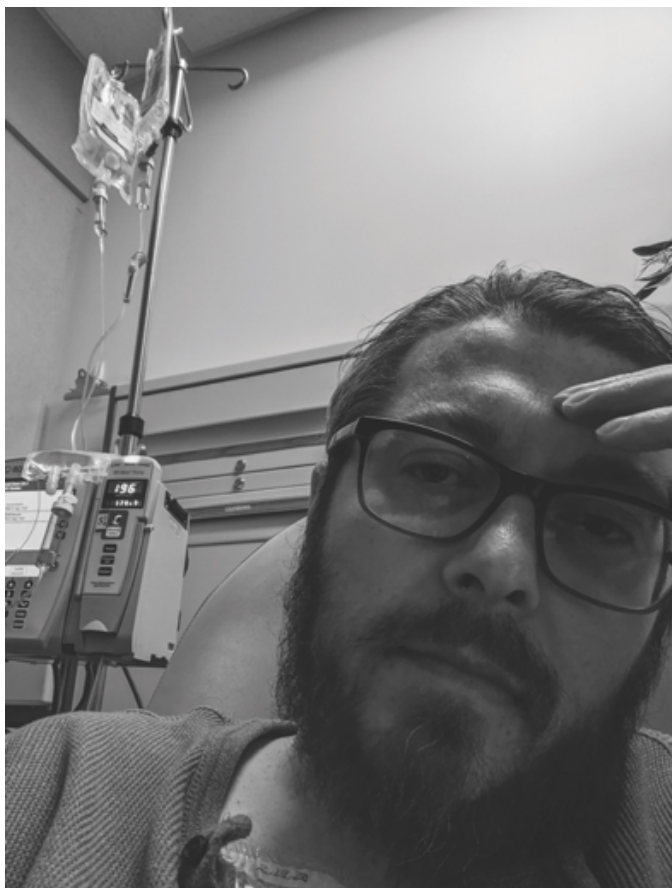
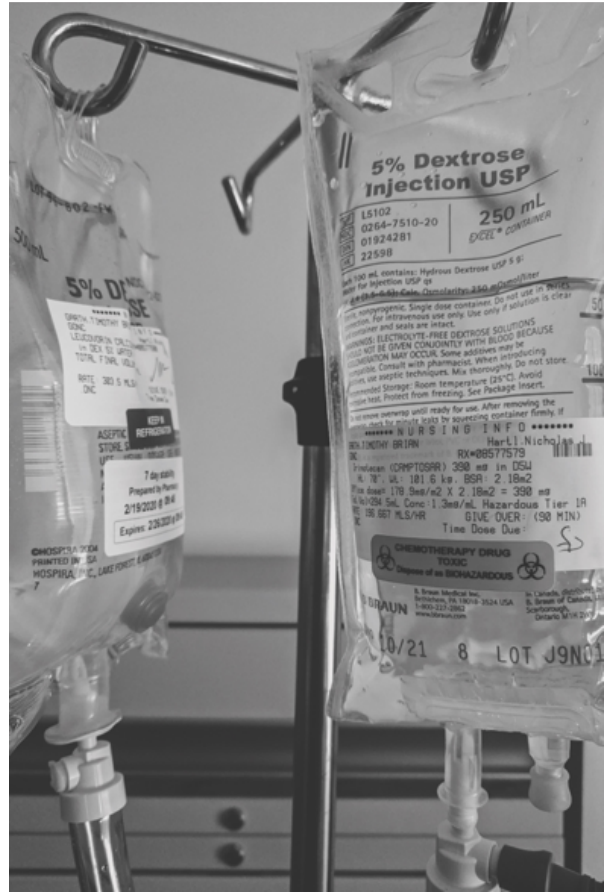


Figure 6
1322 (Tiring)



Figure 7
1444 (Check-out)



Figure 8
1456 (Homecoming)

References

- Adams, T. E., Holman Jones, S., & Ellis, C. (2015). *Autoethnography*. Oxford University Press.
- Barrett, T. (2011). Experiencing art with the ill, the elderly, and their caregivers. *Teaching Artist Journal*, 9(2), 90-100.
- Barrett, T., Smith-Shank, D. L., & Stuhr, P. (2008). Three art educators in cancerworld. *Journal of Cultural Research in Art Education*, 26, 3-23.
- Ellis, C., Adams, T. E., & Bochner, A. P. (2011). Autoethnography: An overview. *Historical Social Research*, 36(4), 273-290.
- National Cancer Institute. (2020, September 25). *Cancer statistics*. <https://www.cancer.gov/about-cancer/understanding/statistics>
- National Cancer Institute. (n.d.) *SEER cancer stat facts: Colorectal cancer*. <https://seer.cancer.gov/statfacts/html/colorect.html>
- Wang, C., & Burris, M. A. (1994). Empowerment through photo novella: Portraits of participation. *Health Education Quarterly*, 21(2), 171-186.
- Wang, C., & Burris, M. A. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behavior*, 24(3), 369-387