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## REIMAGINING CANCER: AN ARTS BASED AUTOETHNOGRAPHY

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**ABSTRACT:** We interweave arts-based inquiry, painting, and autoethnography, to critically examine one researcher's fearful narratives around cancer, death, dying, and family myths. These methods give us the distance to deconstruct Christine's past schema in order to take away its powerful influence on her life. This destabilized illness narrative leads to a transformational narrative of peace. Arts-based inquiry invites the viewer/reader to engage in similar acts of deconstruction and transformation.

**KEYWORDS:** arts-based inquiry, painting, autoethnography, death and dying, transformation, illness narrative



*Figure 1. Carey*

I spent many years angry with God. I felt as though he allowed good people to get sick and die slow, humiliating deaths, while letting a lot of bad people live long, happy lives. In retrospect, I see this as my own inversion of the Protestant theologian Jonathan Edward's famous sermon, "Sinners in the hands of an angry God," (1741), which I transplanted to "God in the hands of an angry sinner." It was my rebellion against the punitive God that shaped my youthful worldview as a girl growing up in a Southern, and mostly Protestant small town.

One of my earliest memories is of visiting my Aunt Carey as a child. I remember her voice, which sounded like the actress Patricia Neal's<sup>1</sup> – deep, husky, and earthy. She joked and laughed a lot. She also made great blueberry muffins and was one of my grandmother's best friends. By the time I was ten she had breast cancer. I remember visiting her later when she was confined to a hospital bed, placed in her laundry room because the light and noise of her family disturbed her. Emaciated, pale, and mostly bald, her distinct voice and sarcasm

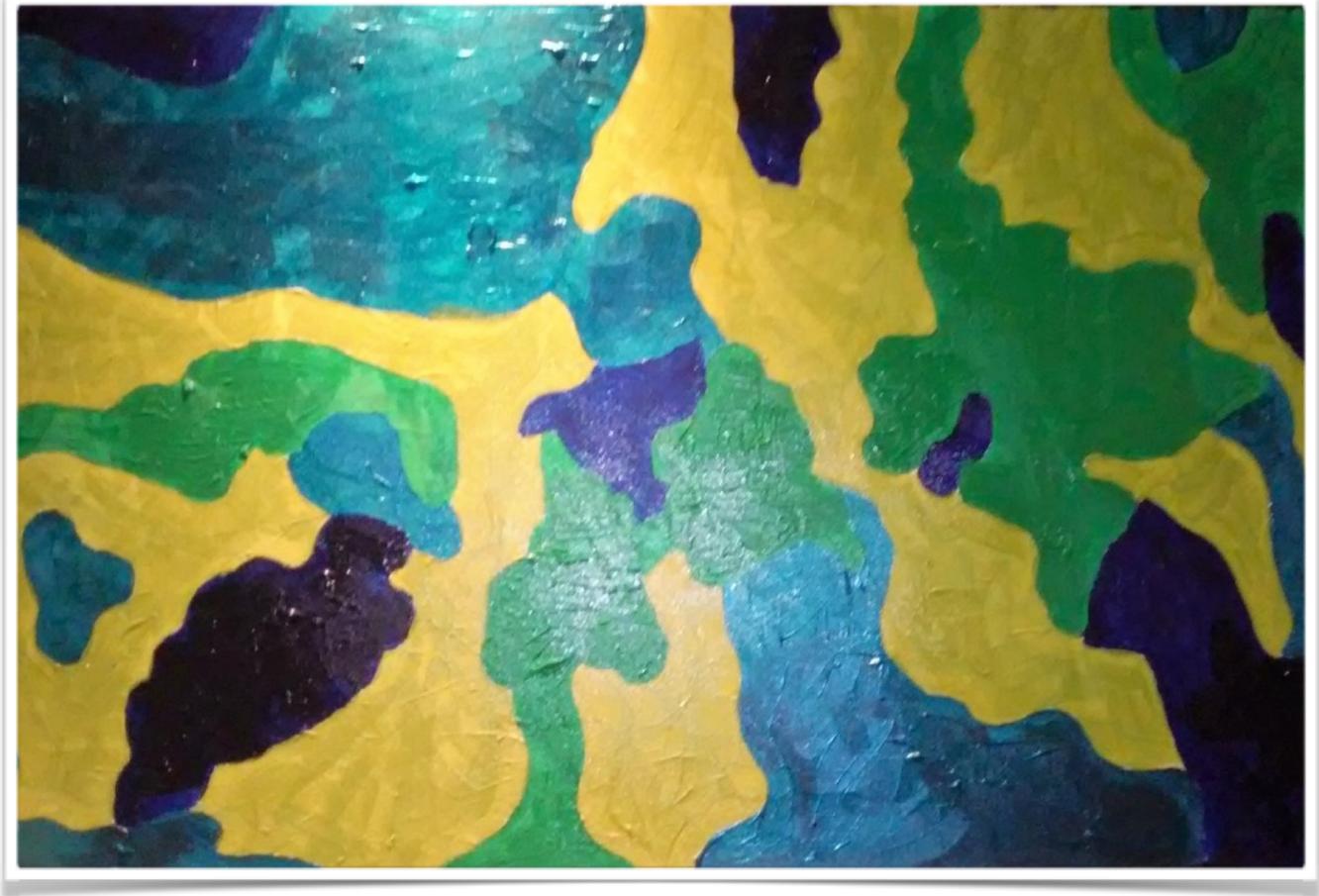
were my assurance that this Aunt Carey was still my Aunt Carey. Within a few years after Aunt Carey's death, my own father, his sister, and his dad, were all diagnosed with metastasized cancers. One by one, I lost my family. Grief pooled, and words failed to help me find peace. Years later, painting cancer into abstract forms gave me the distance I needed to release me from my pain and fear of an early cancer death. Autoethnography provided the framework to critically examine how my sociocultural context shaped my perceptions of my lived experiences and storied existence (Spry, 2001). My collaboration with Jodi helped me develop and realize my narrative as a published academic piece.

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## **Methodology and Methods**

Autoethnography, a research methodology that examines self in culture (Reed-Danahay, 1997), forced me to reflect on my own contextuality and how this played a role in scripting narratives about my experiences. Autoethnography freed me from delimiting narrative cycles, pushing me beyond my bounds to a new, less burdened, way of being (Spry, 2001) as it compelled me to question my reliability as my own story teller. How much is real, authentic, and, how much is a reproduction of my own culture?

This autoethnography is an illness narrative. Richards (2008) defines and delineates three main types of autoethnographic illness narratives: testimony, emancipatory discourse, and the destabilized narrative. Testimony narratives can serve to help the writer work through an experience therapeutically while giving readers a first-hand experience of the phenomenon of an individual struggling with an illness within a particular context. The illness narrative as emancipatory discourse examines how a particular context intersects aspects of identity and experience for individuals struggling with an illness. These two types of narratives focus on how an individual understands their lived experience and attend to the disruptive force of illness. For Richards, disruption lacks the power to permanently transform the individual and often functions to serve normalized story arcs where the protagonist is a hero learning a lesson. The third type of autoethnographic illness narrative is the destabilized narrative. These narratives do not follow prescribed tropes, nor do they serve the dominant discourse on illness, which inclines towards a universal theme. Destabilizing illness narratives, as the one that follows, trouble hegemonic discourse about illness, context, perspective, and positionality in a postmodern world (Richards, 2008).



*Figure 2. Me*

Painting has long been a transformative art, and as this autoethnography illustrates, it served the same purpose for me. Painting as a research method affords the possibility of reconstructing the self for both the painter and the viewer as it becomes a social act (Sullivan, 2008). Painting as research embodies four aspects: theory, form, idea, and action. As theory, it has the capacity to look beyond what is known to seek the possibility of new understanding as it challenges comfortable, false binaries. When I am painting, my subject becomes objectified as I engage in the technical aspects of painting. My attention shifts to color, light reflection, pattern, and movement within my painting. The subject, whatever it is, becomes an object and, at that point, has no meaning. This gives me distance. As form, the painting is the beginning point of meaning, out of which comes conflict, confusion, and self-awareness. As the painting emerges, I move it around so that I can see it outside in the light and from different distances and perspectives. I refer back to the original images, the photographs of cancer cells, concerned about how my subject has been replicated visually. I am curious about what a viewer will see. That question, of course, will be answered by other viewers and is beyond my control. As idea, a painting used and shared as a research method becomes a social act, which alters how the painter constructs his or herself out in

the world. The act of painting and my own relationship to my work is one matter; however, the ensuing interaction between my work and its viewers creates another relationship, one in which I am vulnerable. And as action, the viewer is also subject to the same changes and challenges to self-awareness caused by this experience. Returning to the subject, cancer, while viewing these paintings and entering this dialogical space with you, the viewers, changes us, viewers and authors both (Spry, 2001). Each of these four aspects of painting as research method is embraced through this autoethnography. Painting is central, while writing is the reflexive mechanism in this autoethnography. The initial production of abstract

paintings as research is a relatively new way of producing art/research as something other than a replication of so-called reality. How I paint is embedded in my current context. Abstract art as a method would not have been available to me as a painter, or acceptable by you as viewer, in the not so distant past.

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## **Reimagining Cancer through Painting**

Experiences and imagination forge the family mythologies created to defend the group and build resilience (Ferreira, 1996). In my family, early cancer deaths have occurred in all the generations that I can remember. By early, I mean middle age. The middle space of life, where having left youthful foolishness behind, a person has settled into responsibilities and the busiest part of life. My family

mythologized cancer as the metaphorical tug on the rug holding a stable future. In this story, we were always working for a future something or other. These cancers undermined another family value, an enthusiastic embrace of Weber’s (2005) Protestant Work Ethic and belief in the myth that hard work and clean living would always be rewarded. It was also troubling against a backdrop of Southern Protestant faith in a punitive God. Perhaps this punitive, all knowing God detected some sort of secret sin or hubris.

My dad, his sister, and my grandfather were all diagnosed with cancer when I was 17 years old. I was angry for years; my dad had been so responsible for his family, pushing off plans for fun to a retirement that he would never enjoy. I never saw my dad angry about his cancer. He fought it in creative ways that pushed him out of his comfort zone. In addition to undergoing experimental treatments through the National Cancer Institute, he learned how to meditate, went to support groups, and ate a macrobiotic diet. None of this was a part of his milieu. He also stopped golfing and started fishing. He bought a couple of boats. In his truck, he carried his fishing gear because he crossed a river on his daily commute. On his

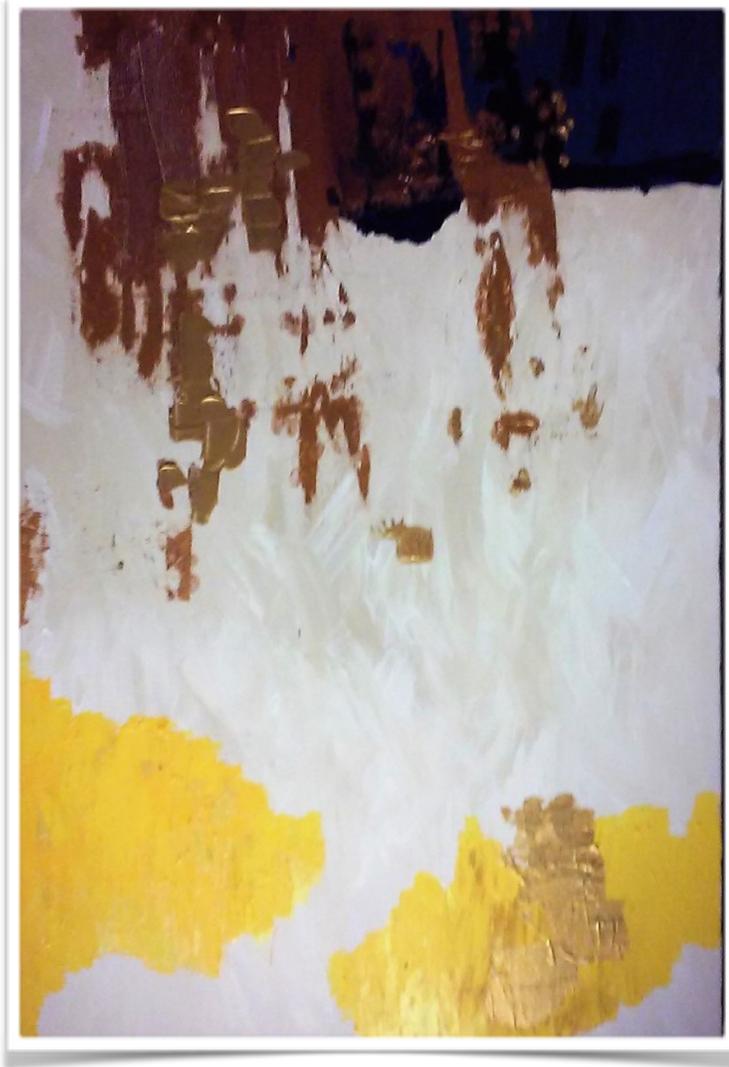
ride home in the evenings, it became common for him to stop at the landing and drop a line. He was a good old boy in South Georgia. My dad died after a 10-year battle.



*Figure 3. Daddy*

In the twenty years since he died, I married, had a family, and entered my own middle age full of work, kin-keeping responsibilities, and graduate school. Three years ago, I felt the tug. I had a full hysterectomy because I had some cells that were precancerous. I was relieved. My doctor assured me that I was mitigating my cancer risk by removing everything. I was proud to have broken the family myth. Unbeknown to me at the time, this pride was grounded in my cultural narratives: I had somehow appeased my punitive god, while working hard and living clean to stabilize the future. But, by the time my next mammogram appointment rolled around, I realized that I had forgotten about breast cancer. Of course, one cannot just stop there. Anything on the human body has cells, which can become cancerous. I found myself deferring checkups and mammograms, no news is good news, and then I felt guilty that this somehow made me an irresponsible parent. Guilt, like my pride, was grounded in narratives of a punitive god and a twisted protestant work ethic.

Last year, I got curious about what cancer cells look like; I Googled it, looking for images. I expected something dark, rough, and ugly. On the contrary, cancer cells are unique. Prostate cancer is distinct from ovarian cancer and so on. They are beautiful images. A key difference from a healthy cell is that healthy cells are more spread out. Cancer cells cluster as though they are unifying. I paint for a hobby and really enjoy working on large abstracts. I grabbed a canvas and began painting cancer cells. When I began painting, it did not occur to me that I was in fact, beginning to deconstruct a myth. Painting helped me understand and articulate my fears (Devlin, 2006).



*Figure 4. Sarah*

As I paint, I metaphorically take the cancer cells out of the human body. A cancer cell in itself is not a good or a bad thing: it simply is. It functions as it functions; When I paint cancer, I change the measuring apparatuses (Barad, 2007) – from high-content analysis to personal art; from cell biology, living cells, robotic hands, RNA interference, and high power microscopes to paint, brush, canvas, love, and me. In my measuring apparatus, the cancer cell loses its imagined signifying chain to a biomedical absolute, and emerges in an understood abstractness: it simply is. I no longer fear it. I think it looks like a landscape. I can also see how sometimes, in a biomedical context, it could look like a battlefield (Sontag, 1978).

The shifting perspective in painting pushes me to reflect on my own perspective of how these myths are products of my socio-cultural context (Spry, 2001). I see myself, my family, and our myths in the abstract as well. My family includes Scottish and Irish Protestants who settled in the Piedmont region of South Carolina where they took up farming. My grandparents also worked in construction and in textile mills as a move up out of solely relying on an insecure farm income. My dad was the first in his family to go to college,

where he studied Engineering. My grandparents were not particularly supportive of this because my dad had begun a high school apprenticeship with an electrician, which was considered to be a very good vocation. My dad had middle class ambitions.

After my dad died, I found a yellowed, folded up index card in his wallet. Back in college, Dad made his list of life goals, both personal and professional, and carried it with him always. It included the number of kids he wanted to have, 3 (check); and a timeline for what he wanted career-wise, beginning with engineering and finishing as Vice-President at a manufacturing company. By 40, Dad had become a plant manager at a company, which made bearings for automobiles. The stage 3 cancer diagnosis at 43 curtailed his career ambitions. Being ill also threatened his toehold into the middle class. After his initial illness, Dad worked hard to maintain an appearance of health and vigor so that his professionalism could not be questioned. The seriousness of his illness was kept as a family secret over the decade as the cancer spread. I wonder if my dad's apparent lack of anger had to do with a greater need to adhere to the Protestant Work Ethic in order to maintain normalcy, rather than to admit that he was dying. As a working adult with children of my own, I appreciate the financial insecurity caused by a serious illness. Employers may be sympathetic, but they have a greater responsibility to production, profits, and shareholders, than to their employees. I also wonder about the fact that my dad "defined" what success or a rewarding life would be at such a young age and kept hold of this idea throughout his life. It strikes me as rigid and narrow-minded. Reading my description of Dad through the eyes of an autoethnographer alerts me to how I make him into a Horatio Alger<sup>2</sup> hero, which limits him. With every word, I flatten him. My romanticism and Dad's stoic appearance are likely socially normed responses to the situation (Ellis, Adams, & Bochner, 2011).

This is one facet of a story. It is not my father's story. Would he agree with my account? Would he resent my talking about his class ambitions? It makes me feel gaudy to admit that I share these same ambitions for my children and me. Would he dismiss other parts as misty-eyed romance? My story now is that of a middle-aged woman who is fully aware that my perceptions were shaped by my youth and my socio-cultural context. Thanks to Dad's continued employment, I got to maintain my toehold into the middle class.

As I reimagine the cancer cells, I wonder how these paintings would be interpreted by a viewer who has had cancer. Would they think I was crazy for painting cancer? I have cancer paintings hanging up throughout my house now. If a visitor admires them, I rarely explain the subject. I haven't even told my own mother what they are despite the fact that she admires them and wants me to give her a painting for her home. My mother harbors her own grudge against God for taking my dad so young. In her mind, it is her story, not mine. I have a feeling the paintings would make her mad at me. Her anger may be a response to the confines put upon her by my parents' very traditional gendered roles. When Dad died in his early 50s, Mom lost her role as "the wife of . . .". In my own sneaky way, I feel like my

paintings have helped me beat cancer. Knowing what my paintings are and keeping it to myself, feels like my own sly joke.

As for my dad's young death by cancer, my reaction is more complicated. A young death is tragic in that it is an unfinished life. Of course, this is because I expect life to follow an arc of a predictable beginning, middle, and end. Death in the middle leaves loose ends for the survivors. I no longer consider it to be the large tragedy I once did. I now see how he gained things from his cancer. It created an urgency to drop the things from his life that were not authentic. He reconnected with friends he had lost touch with over the years. He had played golf because it is a social sport and good for business. Dad did not enjoy it, so he dropped it. He embraced fishing, which was his childhood passion. It was also for him a meditative and quiet pursuit. Would my dad have made these changes without the illness? Middle age has given me the wisdom to recognize that a too-short life is not the worst thing that can happen to a person (Halberstam, 1998). A short, meaningful life is a win. Or is it? Do I say this to make myself feel better? As I paint, I think about these things. I have no way of knowing if Dad would have considered this a win. I choose this narrative because it gives me peace to move past false binaries, which were never that comfortable after all.

## Conclusion

My narrative of peace emerges in the interaction of writing and painting. Writing a destabilizing illness narrative troubles my own hegemonic discourse about illness, context, perspective, and positionality (Richards, 2008). Writing about my painting helps me deconstruct and reconstruct my narratives through reading, writing, and reflecting. Writing made me think about my family myths – The Protestant Work Ethic and the Punitive God, and to understand why I have left behind the binary perspective and dogma found in the religion of my youth for a more flexible and imaginative faith. I now understand the Protestant Work Ethic as a myth. I think of God as not so much punitive as distanced from this broken world. Cancer and early deaths no longer inspire fear in me as a punishment. Experience has taught me that life is a random mix of both good and bad. Despite it all, I have the power of taking whatever happens and transforming into something meaningful.

***“My narrative of peace emerges in the interaction of writing and painting.”***

Without painting, this reconstruction would not have been possible. Had I just written it, this would have been a personal essay about my dad, cancer, or illness. The writing would have stayed at the level of navel gazing. Painting gave me distance and reconciliation. Applying Sullivan's (2008) rubric elevated and

expanded painting to a research tool and opened it up to all sorts of possibilities as it gained communicative power. Painting as theory separates the subject from the object, leaving open the meaning (Sullivan, 2008). As form, the painting itself became the starting point for inquiry as I physically moved the painting in space, reflecting on light, perspective, and meaning, outside my humanistic narratives of self in a small Southern town. As idea, painting allows me to separate my meaning of the family myth from my mother's meaning and cultural narratives. Painting reminds me that my dad had his own cultural scripts running as well. As a writer, I appreciate that cancer provides a lens for seeing many aspects of identity such as age, gender, social class, and religion. As human beings, all phenomena are at once individual and collective experiences. As action, using painting as a research tool changed my schema. Although, I may not publically share these meanings with those around me, my sly joke gives me strength and keeps me sane.

For the viewers and readers with whom I do share my paintings and autoethnographic writing, it is clear that we are engaged in a transactive process. Submitting to an academic journal necessitates that I directly respond to critical feedback which makes me dig deeper in order to justify and better articulate myself. It brings the intimate act of painting and writing into a social space wherein everyone comes away with their own constructed understanding. Viewers and readers have their own stories about illness, death, and family, which shape their perceptions as they look at my paintings or read my essay. My abstract paintings invite viewers to supplant their own meanings. Autoethnography and painting gave me the tools to become differently, to construct new narratives with beauty and distance in order to create a narrative of peace. It is my hope that others may use these paintings or this autoethnography as building blocks in their own transformations.

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## NOTES

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<sup>1</sup> Patricia Neal was a screen and film actress.

<sup>2</sup> Horatio Alger is known for his novels about poor young males who pulled themselves up by the bootstraps to gain access to middle-class lives.