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NOW YOU SEE ME:  
A BLACK FEMINIST AUTOETHNOGRAPHIC POETIC POLEMIC OF  
RADICAL REFLEXIVITY AND CRITICAL ARTS-BASED INQUIRY

---

A Dissertation

Presented to

the Faculty of the Morgridge College of Education

University of Denver

---

In Partial Fulfillment

of the Requirements for the Degree

Doctor of Philosophy

---

by

Myntha Anthym

June 2018

Advisor: Dr. Bruce Uhrmacher

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Title: NOW YOU SEE ME: A BLACK FEMINIST AUTOETHNOGRAPHIC POETIC  
POLEMIC OF RADICAL REFLEXIVITY AND CRITICAL ARTS-BASED INQUIRY

Advisor: Dr. Bruce Uhrmacher

Degree Date: June 2018

### **Abstract**

This dissertation is an autoethnographic poetic illness narrative based on the author's year-long ordeal with unrelenting undertreated chronic pain. The project is grounded in the epistemological tradition of Black Feminist Thought and presented in alignment with the emergent methodological paradigm of critical arts-based inquiry. The purpose of the project is for the author to develop and articulate a radical reflexive praxis within the paradigm of critical arts-based inquiry while demonstrating the value of lived experience as a source of knowledge and poetry as a method of inquiry in revealing subjugated truths about the experiences of marginalized people. The dissertation lives into a tradition of Black Feminist autoethnography, and argues that the tradition offers insights for those seeking to operationalize the tenets of Black Feminist Thought as an intentional illustration of arts-based research.

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## **Foreshadowing**

1. The question is
2. The questions are
3. The problem.

I am here to talk about a problem (DuBois, 1903).

I am here to talk about a crisis.

(I am here).

I am here to talk about a problem, but before I talk about the problem, I need to talk about the way I have been trained to talk about the problem.

I am here to talk about a crisis, but first I have to talk about the crisis in my self.

The problem is that when Black women talk to trained medical professionals about their pain, the trained medical professionals do not believe them.

(This is an example of the crisis: that I say “they” when I mean “we”.)

When we, Black women, talk to medical professionals about our pain, they do not believe us.

When I talked to medical professionals about my pain, they did not believe me.

The crisis of representation is a crisis in the world that I experience in my self: Who am I speaking *for*? Who am I speaking *with*? Who am I speaking *as*? (Collins, 2016).

I am speaking “for” the other. Which is to say, as a social science scholar, as one who does research, I am speaking for people who are not (necessarily) my people. I am speaking for groups to which I do not belong. I am speaking for selves who are not my self. I am speaking for experiences that are not my experience.

Who am I speaking *with*?

(“with” in the sense of “alongside”, not  
“with” in the sense of “to”).

I am speaking with those who are like me: Black women. But this assertion is problematic. This assertion is emblematic.

I say *problematic* because there are differences within groups, despite any surface similarities. I cannot speak in concert with (all) Black women. We are Black, and we are women, but these similarities may only serve to disguise deeper differences. How do I guard against essentialism?

I say *emblematic* because this problem is the heart of the crisis of representation: Whom am I speaking for when I speak? How do I know if I got it right? What are the consequences if I get it wrong?

Who am I speaking *as*?

Do you assume that I am speaking as myself?

(Here, I am speaking as myself).

(Here I am, speaking as myself).

I am a trained social scientist. I am a trained research methodologist. In the context of the dissertation, I am expected to speak only as that version of myself: the academic, the scholar.

But I am also a poet, a life-long lover of language, in all its possibilities and limitations. And if I fail to speak as myself – if I fail to even attempt to represent myself – how I embody this crisis ...

This is the essence of my dissertation:

I was in pain, and they didn't believe me (Kleinman, 1988).

I am speaking as myself.

4. Social science as a second language.

I have learned social science as a second language. It has a rhythm and a structure, a way of personifying the research and absenting the self.

The *research* “seeks to”

The *research* “explores”

As if the research is agentic, absent human intervention.

The conventions of scholarly writing demand a disappearance of the self.

I am not one to disappear.

I tried.

In another version of this project, (the version that I tried, for the longest time, to write) I am entirely absent in the arguments I make. The voice is that of the scholar: detached, objective, and supposedly authoritative. I sounded like anyone. I sounded like everyone. I sounded like no one.

This intentional invisibility did not and does not come easily.

I struggled with an inherent contradiction: In a literature review, the researcher is expected to convey *established ideas* in *original language* while simultaneously erasing any reference to the self.

I set out to write about the crisis of representation.

I set out to write about the crisis of representation using the example of research about Black women who are disbelieved when talking about their pain.

The crisis of representation is a crisis of invisibility, a crisis of absence. The “subjects” of traditional research projects are absent in almost every aspect of the research process. They do not decide the research question. They do not decide the research method. They have no say in the interpretation of results. They are reduced to data. Nuance is lost. Outliers are literally deleted.

I was invisibilizing myself as I wrote about the dangers of invisibility.

The irony wasn't lost. I was.

I am found.

You will find me on every page.

I give myself permission to be myself, even here.

Especially here, in the pages of my dissertation.

I am in the text, in the subtext, and in the space between

Me, writing this, and

You, reading it.

## **Chapter One: Survivors**

### **Context**

Black women are dying.

Black women are dying due to complications with pregnancy (Creanga, Syverson, Seed, & Callaghan, 2017; Howell & Zeitlin, 2017; Moaddab, Dildy, Brown, Bateni, Belfort, et al, 2016).

Black women are dying from heart disease (Lu, Ezzati, Rimm, Hajifathlian, Ueda, & Danaei, 2016; Pool, Ning, Lloyd-Jones, & Allen, 2017; Smilowitz, Maduro Jr, Lobach, Chen, & Reynolds, 2016).

Black women are dying from cancer (DeSantis, Ma, Goding Sauer, Newman, & Jemal, 2017; Newman, 2017; Vidal, Miranda-Carboni, White-Means, & Starlard-Davenport, 2017).

Black women die violently (Koch, Rosenberg, & Geller, 2016; McFarlane, Campbell, Sharps, & Watson, 2002).

Black women die quietly (Katz, Holmes, Power, & Wise, 1995).

Across multiple categories, Black women are dying at significantly higher rates than female counterparts of other races.

And Black women are suffering (Taylor & Holden, 2001).

Black women are suffering from depression (Atkins, 2016; Carr, Szymanski, Taha, West, & Kaslow, 2014; Molina & Kiely, 2011; Watson & Hunter, 2015).

Black women are suffering under the dual oppression of racism and sexism (Ashley, 2014; Collins, 1986; Crenshaw, 1991; Davis, 1981).

Black women are over-represented in the criminal justice system (Baker, 2008; Richie, 2012).

And Black women are living with chronic pain (Baker, Buchanan, & Corson, 2008; Walker, Thorpe, Harrison, Baker, Cary, et al., 2016).

It is to this last problem that I turn my attention. I turn my attention to the problem of Black women's untreated chronic pain for two primary reasons:

There is a significant gap in the literature.

I have relevant lived experience.

### **Problem Statement**

Research has consistently revealed disparities in health that fall along racial and gender lines, as well as health disparities at the intersection of race and gender. However, the problem of nonmalignant chronic pain (NMCP) at the intersection of race and gender remains under-examined.

The Black Women's Health Imperative (BWHI) was founded in 1983 (Guy-Sheftall, 1995) with the purpose of increasing health equity for the estimated 21 million Black women and girls residing in the United States (Black Women's Health Imperative, 2018). As of 2018, the organization was working to effect change in seven key areas, including affordable health care, heart disease, breast cancer, HIV/AIDS, reproductive health, diabetes prevention, and emotional well-being. Even this organization does not specifically address the problem of pain for Black women.

Edwards, Fillingim and Keefe (2001) reviewed the history of research on the relationship between race, ethnicity, and pain. Their research describes the way that the civil rights era “led to an active minimization of the differences among races” which resulted in “medical research [that] primarily focused on Caucasians with little emphasis on representing minorities and their uniqueness” (p. 133). But “People of color are not white people with pigmented or colored skin” (Milner, 2007, p. 389). Real differences have been downplayed under the assumption that everyone should be treated equally: that is, everyone should be treated “the same”. In that view, equality is regarded as a reality instead of being regarded as a goal.

But the truth will out. A 2003 study concluded that “there is evidence supporting disparities in the health care experiences of racial and ethnic persons” even when controlling for socioeconomic status and health insurance (Green, Anderson, Baker, Campbell, Fillingim & Todd, pp.179-180). A separate review article revealed that “racial and ethnic disparities in pain perception, assessment and treatment were found in all settings” including post-operative and emergency room, “and across all pain types” including acute and chronic pain (Green, Baker, Sato, Washington & Smith, 2003, p.277).

Disparities also exist when the problem is considered in terms of gender (Hampton, Cavalier, & Langford, 2015; Hollingshead, Matthias, Bair, & Hirsch, 2015).

Missing in most analyses is specific attention to the compound effects of race and gender in pain management care when race = *Black* and gender = *woman*. In 2005, Ndao-Brumblay and Green published a study detailing the results of an investigation on the differences in the experience of chronic pain between Black women and white women.



Their literature review brought them to the conclusion that health disparities in access and care resulted in “suboptimal pain management for black women” (Ndao-Brumblay & Green, 2005, p.1370) as compared to white women. They investigated a retrospective selection of self-reports of chronic pain and comorbid conditions (post-traumatic stress disorder; depression) collected from 1993 to 2000 at specialty pain clinics. The 1,192 reports included in the sample represented the responses of 1,088 white women (91.3% of the sample) and 104 Black women (8.7% of the sample). The evidence indicated that inadequate pain management care resulted in increased physical disability and depression in Black women.

Since the 2003 publication of the Institute of Medicine (IOM) report on the unequal burden, there has been ongoing interest in studying racial and gender based disparities in health care and treatment outcomes. A variety of limitations, including sampling methods, homogeneity of samples, and sample size make it difficult to get a clear picture of these disparities, especially on the issue of disparities in pain management experiences (Hampton, Cavalier, &Langford, 2015).

The research results are not unanimous. For example, a 2003 study found that statistically significant differences in decisions related to pain management with analgesic medication were related to the gender of the physician rather than either the race or gender of the patient (Weisse, Sorum, & Dominguez, 2003). However, this same study “showed a significant interaction between patient race and patient gender” (p. 507), with black female patients receiving less medication overall than male patients or white female patients. The conclusion was that “gender differences were revealed only when patient race was considered, suggesting that decisions about pain treatment are subject to

subtle patient characteristics unrelated to medical condition and symptom presentation” (Weisse, Sorum, & Dominguez, 2003, p. 509).

Pain is one of the ultimate subjective experiences (Frank, 1991; Scarry, 1985; Sontag, 2003). It is notoriously difficult to describe, exposing the limitations of language. Poets do what they can with metaphor; philosophers wrestle with its metaphysical meaning. Indeed, the problem of pain makes philosophers of us all.

As difficult as pain is to describe, it can be equally tricky to treat, with options for alleviating it ranging from meditation to medication, from metaphysical to chemical (Day, Jensen, Ehde, & Thorn, 2014; Nahin et al., 2016; Tesarz et al., 2014; Wren, Wright, Carson, & Keefe, 2011).

“When choices are unclear ... there may be a tendency to use stereotypes to help with problem solving” (Hampton, Cavalier, & Langford, 2015, p. 969). I will return to a consideration of the stereotypes that constrain the experiences of Black women in Chapter 3. For now, I will focus on the fact that, despite the pro forma conclusion at the end of research reports stating that more research is needed in order to understand the prevalence of, and the functional and emotional cost to, Black women living with undertreated chronic pain (Ndao-Brumblay & Green, 2005; Weisse, Sorum, & Dominguez, 2003), not much research has been done.

### **Systematic Literature Review**

This systematic literature review was conducted in April 2017, and was informed by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist, available online at <http://www.prisma-statement.org/>

PRISMA, developed in 2009, provides guidelines for scholars who are preparing systematic reviews for publication, so that the systematic reviews are easier to classify and identify (Altman et al., 2009). It also offers guidelines for researchers who are conducting systematic reviews, so that they are able to capture relevant studies, or at least demonstrate that a thoughtful and thorough attempt was made to do so. PRISMA has been used for systematic reviews in social work, medicine, psychology, education and other disciplines, and has been endorsed by hundreds of peer-reviewed journals; a list of endorsers is available on the PRISMA website (<http://www.prisma-statement.org/Endorsement/PRISMAEndorsers>).

### **Search Term**

One of the challenges of a systematic literature review is developing a search term that will retrieve maximum relevant results across multiple databases. The search term for this review was created in consultation with an academic research librarian. We chose to use the Boolean operator of “or” rather than “and” in the hope of maximizing search results, while acknowledging that this choice would increase the return of false-positives. Inclusion criteria not included in the search term (see below) were indicated by use of drop-down menus in each database.

The search term was entered in Academic Search Complete, PsycINFO, and PubMed, which were chosen for their robust representation of research relevant to a variety of disciplines. The search term was also entered into the PRISMA database, as authors who use the protocol are encouraged to index their work with PRISMA so that other researchers do not produce redundant scholarship.

I used the following search term for this systematic review:

("Black women" OR "African American women" OR "women of color" OR race OR gender OR ethnicity OR "health disparities") AND ("chronic pain" OR "pain management" OR "pain treatment") AND ("systematic review" or qualitative)

### **Inclusion Criteria**

The following inclusion criteria were used to evaluate articles retrieved in the systematic review:

*The research centers the experiences of Black adult females suffering from non-malignant chronic pain (NMCP).* This population and problem were chosen for reasons indicated above.

*The research specifically addresses pharmacological treatment for NMCP.* A variety of alternative pain-management modalities are gaining attention in the scientific research community, including mindfulness meditation (Day, Jensen, Ehde, & Thorn, 2014), yoga (Wren, Wright, Carson, & Keefe, 2011), Eye Movement Desensitization and Reprocessing (EMDR) (Tesarz et al., 2014), and more (Nahin et al., 2016). But my particular interest is in the experiences of Black women seeking medical treatment, because these experiences can serve to illuminate bias that results in suboptimal outcomes where medical treatment is warranted, but is delayed or denied.

*The research took place in the United States and is published in English.* This criterion was included for practical reasons. Investigating multiple sociocultural contexts is impractical for me at this time.

***The research was published after 2007.*** Research indicates that systematic reviews tend to be out of date after six years (Shojania et al., 2007), with some suggesting that they are out of date within as little as two years (Elliott et al., 2014). What is meant by “out of date”? “SRs that have not been updated [within two years of publication] will have failed to incorporate new evidence that would substantively change conclusions about the effectiveness or harms of therapies” (Elliott et al., 2014, p.1). I used a 10-year timespan in the hope of capturing a snapshot of change (or lack of change) during the “Obama era” (Tesler, 2016).

***The research used qualitative methods and / or the research is a systematic review.*** For reasons I will detail in Chapter 2, I was -- and am -- particularly interested in research that captures nuance, lived experience, story. For those reasons, I focused on qualitative methods (Creswell, 2007). I included a search for systematic reviews in the hope of finding literature that could contextualize the problem and provide a sense of its scope.

**Table 1: Summary of Systematic Literature Review**

<b>Database</b>	<b>Articles identified</b>	<b>Articles retained after abstract review</b>	<b>Articles ultimately retained</b>
Academic Search Complete	78	0	0
PsycINFO	47	0	0
PubMed	157	21	0
PRISMA	0	0	0

## **Results**

After performing the search in each database, I scanned the titles of the articles that were retrieved and excluded the obvious false-positives, such as articles whose titles indicated that the research involved children or teens, or research on pain related to childbirth or cancer. I read through the abstracts of the remaining articles to determine whether they were relevant to my research questions. None of articles identified in this systematic review specifically addressed NMCP in Black women. Some of the research I reviewed considered either patients' gender or patients' race / ethnicity, and some studies did address gender-by-race. For example, a 2016 study described the experiences of 10 participants suffering from chronic musculoskeletal pain (Wiklund et al., 2016). The purpose of the study was to develop an "intersectional perspective" on access to specialty pain clinics. The study did not meet my inclusion criteria because it took place in Sweden, and because, while the authors made reference to ethnicity as a factor that combines with gender to reduce access to pain management care, they made no mention of the actual ethnic makeup of the study participants.

Other studies that considered gender-by-race/ethnicity in chronic pain care were ultimately excluded for similar reasons. Despite the inclusion of "United States" as a geographic limiter via dropdown menu, some of the articles described research that took place in other countries, including Sweden (Wiklund et al., 2016), Canada (Allen et al., 2015), and Norway (Nortvedt, Hansen, Kumar, & Lohne, 2015). Despite specifying that the studies should have Black female participants, some of the articles described research with immigrant or aboriginal women, or failed to provide details about the racial background of participants.

Do you see what I see?

Empty

Spaces

Where our stories

Should be.

### **Research Questions**

My research questions are explicitly epistemological and methodological (as are all research questions, even if only implicitly).

Epistemology begets methodology.

R1: What does the existing research literature say about Black women's experiences with medical treatment for chronic pain?

R2: What does the literature of critical theory say about understanding Black women's experiences?

R3: What methods in aligned with critical theory can be used to probe the experiences of Black women seeking medical treatment for chronic pain?

R4: What does the evidence of my own experience say about Black women seeking medical treatment for chronic pain?

The answers to these questions are iterative and interlocking. Lived experience drew me to the literature. My lived experience was not reflected in the literature, so I turned to critical theories that engage with the fact that a lot of lived experiences are not reflected in the literature.

## **Thesis**

Taking lived experience as a legitimate and meaningful source of knowledge (as critical theories insist we should), and poetry as method, reveals subjugated truths about the experiences of Black women in a way other epistemologies and methods cannot.

My research centers the voices and experiences of Black women -- my own not least.

## **Nature of the Study**

My dissertation is an autoethnographic poetic inquiry on the problem of suboptimal treatment of non-malignant chronic pain in Black women. Autoethnography is a method for the explication and exploration of personal experience (*auto*) in the context of a critical examination of cultural phenomenon (*ethno*) (Ellis, 2004). Poetic inquiry is part of the emerging body of scholarship described as “creative analytic practices” (Richardson, 1999) that complicate the dichotomy between social science and the arts.

I describe my project as autoethnographic (rather than simply describing it as an autoethnography) because, while it shares certain features and goals in common with autoethnography, my primary mode of expression is evocative rather than descriptive (Leggo, 2008; Prendergast, Leggo, & Sameshima, 2009), and my primary objective is that readers will “think with” (and feel with) my story, rather than “think about” it (Ellis & Bochner, 2000, p.735).

## **Reader, I Lived It.**

On October 31, 2014, I was in a car accident.



From October 31, 2014 to September 8, 2015, I lived with unrelieved pain. From the emergency room to urgent care, from my primary care physician to the night nurse who ignored me the night after I finally had surgery, I engaged with medical professionals who doubted my word when I told them that I hurt.

This experience, contextualized through the theoretical lens of Black Feminist Thought, and communicated in the form of poetry, is the subject of my dissertation. I will write a collection of autoethnographic poems detailing the year-long ordeal that began with the car accident on October 31, 2014, and reached its culmination nearly a year later in the form of emergency surgery. Some of these poems will be poetic representation of my writing from that time, and some will be new (“generated”) poems.

Using my own medical records, I will create a timeline of my quest for care. In my personal journal for the relevant time frame (beginning November 5, 2014 through October 31, 2015) there are 85 entries. On my personal blog there are 13 posts (November 4, 2014 through October 12, 2015). Not every journal entry or blog post specifically mentions my physical condition: using the timeline will help me to connect the emotional states recorded in my personal writing to my experiences with medical professionals and instances of intervention (or lack thereof).

### **Critical Theory (and the Problem that Has a Name)**

Critical theory, as it emerged from the Frankfurt School in the 1930s, was concerned with liberation from authoritarianism and hegemonic domination; criticism, particularly in philosophy and the social sciences, was seen as central to understanding and undoing “absolutist knowledge claims” (Wilkerson & Paris, 2001, p. 19). In general

terms, critical theory as a social science paradigm is concerned with reflexivity and transformation (Geuss, 1981; Guba & Lincoln, 1994).

The emergence of Critical Race Theory in the social sciences began with Critical Legal Studies in the 1970s as legal scholars were seeking a way to articulate the role of race in the justice system in the aftermath of the Civil Rights movement of the 1960s (Delgado & Stefancic, 2001; Solorzano & Yosso, 2002). Scholars in other fields, especially education, embraced Critical Race Theory (CRT) in the 1990s, and CRT has since evolved and been adapted to consider other marginalized statuses, such as disability (Critical Disability Studies; Goodley, Liddiard, & Cole, 2017), the Latinx experience (LatCrit; Solorzano & Yosso, 2001), indigenous scholarship (TribalCrit; Brayboy, 2005), and gender (Critical Race Feminism; Wing, 1997).

Critical Race and related theories provide researchers with tools to engage with the situated-ness of knowledge and knowledge production. “Critical theory is committed to unveiling the political stakes that anchor cultural practices – research and scholarly practices no less than the everyday” (Conquergood, 1991, p. 179).

Just as differences between races were minimized in research arising after the Civil Rights movement, differences within identity-based liberation movements have been minimized or overlooked as well: feminist movement and anti-racist struggle each attempt an essentialist synecdoche, wherein “woman” is coded as white, and “Black” is coded as male (Smith, Hull, & Scott, 1982). So it is that, in feminist movement, the interests of white women are predicated over and instead of the interests of women of color, and in anti-racist movement, the interests of Black men are predicated over and

instead of the interests of Black women (Collins, 1989). Black Feminist Thought is a response to the marginalization of Black women in those historic struggles for liberation.

Black Feminist Thought is a part of and apart from other critical theories, with some scholars identifying its origins as far back as the 1850s, when abolitionist Sojourner Truth insisted, “Ain’t I a woman?” (Guy-Sheftall, 1995). While sharing certain goals in common with feminist movement and the centuries-long struggle for racial equality, Black Feminist Thought specifically considers the interlocking oppressions of race, gender, and class experienced by Black women in the United States (Crenshaw, 1981; Davis, 1981; King, 1988), and rebukes both the sexism apparent in much race-centric liberation work and the racism apparent in mainstream feminism.

In 1963, Betty Friedan published *The Feminine Mystique*, describing the listless malaise of the educated woman in that era as “the problem that has no name”. In that seminal work of second-wave feminism, Friedan failed to consider the unique plight of those who shared her gender but not her race. The problem that is unique to Black women in the United States has a name -- more than one. It is double oppression, or, when class is entered into the equation, triple jeopardy (Davis, 1981; Guy-Sheftall, 1995; King, 1988). Crenshaw (2016) described the problem in terms of intersectionality (1991) and later said “we all know that, where there’s no name for a problem, you can’t see a problem, and when you can’t see a problem, you pretty much can’t solve it” (Crenshaw, 2016, transcript).

In addition to the emphasis on Black women’s unique social position and lived experiences, Black Feminist Thought centers alternative sources of knowledge, as well as alternative methods of knowledge validation (Collins, 2000). Black Feminist Thought

shares in common with Critical Race Theory the ultimate goal of dismantling all forms of oppression. To that end, Black Feminist Thought, like other critical theories that center identity, engages with the situated-ness of knowledge production at every stage of the research process. Critical theorists in academia are scholars who are “committed to a sustained critique of the pervasive assumptions that riddle academic research” (Vargas, 2003, p. 7).

Critical scholars critique the assumptions and, as a consequence, critique the methods. Critical scholars critique the methods and, as a consequence, critique the results and conclusions. Critical scholars reject the “difference as deficit” ideology that centers whiteness and marginalizes all “others”. They resist.

We resist.

And our resistance is fertile.

### **Health Disparities Research in a Critical Race Context.**

As noted earlier, one unintended consequence of the Civil Rights movement was the minimization of differences between the races (Edwards, Fillingim & Keefe, 2001), such that the experiences of white people were accepted as emblematic or representational of the experiences of *all* people. When evidence arises in contradiction to that assumption (or any dominant assumption), that evidence is contested. In social science, it is contested on the basis of epistemology. What we know is contested on the basis of how we know it: if we don’t “know” according to the standards set by a particular privileged worldview, our evidence is dismissed as inconclusive or insignificant.

Dominant narratives inform both the original assumptions and the methods employed to test those assumptions.

“What does it mean when the tools of a racist patriarchy are used to examine the fruits of that same patriarchy?” asked Audre Lorde (1984, p. 158). Engaging with that question from the lens of social psychology, Goff and Khan (2013) argued that preferences for unidimensional design (i.e., race OR gender) limit the credibility and utility of much social science research: “[S]tatistical methods that analyze each aspect of identity as unrelated and uncorrelated cannot draw meaningful conclusions about the ways in which identity is socially constructed” (p. 367) or the ways in which multidimensional identities manifest in lived experience. “The health of Black women is a subject of major importance for those of us who are committed to learning, teaching and writing about [Black women]” (Hull, Smith, & Scott, 1982, p.104). To honor that commitment and examine that issue, multidimensional research is necessary.

Audre Lorde’s question also resonates with scholars in the emerging field of critical quantitative methods (“QuantCrit”). QuantCrit expands upon the ongoing legacy of scholarship of CRT practitioners who, in the early 2000s, began exploring the ways in which CRT could be used in concert with qualitative methods on behalf of “racially stigmatized hypervisible minorities” in order to bring about changes in social policy arenas such as education, employment, and medical care (Garcia, López, & Vélez, 2018, p.150). Building on those efforts, QuantCrit scholars use CRT to critique and evaluate race-relevant research that relies on quantitative methods, arguing that “quantitative data is no less socially constructed than any other form of research material” (Gillborn, Warmington, & Demack, 2018, p. 158).

“Critical quantitative scholarship ... [questions] measures and analytic practices used in quantitative research, to ensure that they adequately represent circumstances and contexts, and do not themselves inadvertently perpetuate exclusion and hierarchy” (McClaren, 2017, p. 391).

The problem of disparities in pain management care is usually studied using quantitative methods (Anderson, Green, & Payne, 2009), often with physicians being asked to imagine their responses to hypothetical scenarios presented in a survey. Research based on this method is notoriously unreliable (Conrad & Schober, 2008), and a critical quantitative analysis of that approach would begin with the absence of context. Another approach is to compare physicians’ self-assessments of their own bias to patients’ perceptions of the patient-provider interaction, as survey respondents tend to underestimate their own bias (Jones, Gerrity, & Earp, 1990). Penner et al. (2010) used that method at an urban clinic in the Midwest, with inconclusive results. They speculated that a limitation of the study was that white physicians who chose to work in that particular setting, serving a 100% minority population, were likely individuals with low levels of implicit bias to begin with. Missing from their analysis was a consideration of the measure used to assess patient perceptions, a two-item self-report asking patients to indicate to what degree they felt that they were “on the same team” as the physician. Missing from their analysis were the voices of the patients.

Health researchers embracing CRT have proposed a variety of models to correct for racial bias in health disparities research (Aronson & Stephens, 2011; Ford & Airhihenbuwa, 2010; Graham, Brown-Jeffy). What their models have in common with other studies is an emphasis on understanding the persistent role of racism in health

disparities, and an interest in transforming systems and practices in order to not only reveal but also reduce health inequities. What sets the research apart, what marks it as “critical”, is an acknowledgement of the subjectivity inherent in knowledge production projects, and an insistence on the importance of finding culturally appropriate ways to access and understand the lived experiences of patients.

Research has not only results, but also consequences: “[W]hen researchers are not mindful of the enormous role of their own and others’ racialized positionality and cultural ways of knowing, the results can be dangerous to communities and individuals of color” (Milner, 2007, p.388). The consequences of research done at a distance are nonetheless felt at the most intimate level: “You must always remember that the sociology, the history, the economics, the graphs, the charts, the regressions all land, with great violence, upon the body” (Coates, 2015, p. 10).

Those who will live out the consequences of research should be involved in creating and judging that research (Milner, 2007; Wallerstein & Duran, 2006). Their lived experiences should be treated as essential – not anecdotal -- evidence. The stories of research participants are not extraneous variables; they are the most important unit of analysis. Treating lived experience as a legitimate source of knowledge requires thinking about the salience of identity in research design, program design, and program evaluation.

The fact that minority women suffer from the effects of multiple subordination, coupled with institutional expectations based on inappropriate non-intersectional contexts, shapes and ultimately limits the opportunities for meaningful intervention on their behalf” (Crenshaw, 1991, p.1245).

Berwick (2008) proposed that meaningful intervention could result from research with a broader definition of what “evidence” counts in “evidence-based” initiatives:

Four changes in the current approach to evidence in health care would help accelerate the improvement of systems of care and practice. First, embrace a wider range of scientific methodologies. ... Evaluators and medical journals will have to recognize that, by itself, the usual ... experimental paradigm is not up to this task. It is possible to rely on other methods without sacrificing rigor. Many assessment techniques ... have more power to inform about mechanisms and contexts than do [randomized controlled trials], [including] ethnography, anthropology, and other qualitative methods. For these specific applications, these methods are not compromises in learning how to improve; they are superior. (Berwick, 2008, p. 1183).

In health equity research “Description needs to precede explanation” (Forbes & Wainwright, 2001, p. 813).

This is where I’m going.

### **Significance of the Study: Style and / as Substance**

In addition to the value of my study in terms of topic, it is also significant in terms of style. The dissertation has long been a rite of passage, meant to make a contribution to a field of knowledge and to demonstrate proficiency in research (McCarthy, 2016). In the early years of the new millennium, the doctoral capstone project has evolved, becoming an opportunity for the emerging scholar to explore the process of knowledge production and to experiment with alternative forms of data representation and scholarly communication. Dissertations have started appearing in the form of comic books (Sousanis, 2014, as cited in Patel, 2016), YouTube videos (Zak, 2014) and other objects and artifacts. Projects like these expand notions of what constitutes a meaningful or significant contribution, and also expand notions of what “counts” as scholarly research.



In 2016, the Graduate School Council (GCS) convened a panel to discuss the future of the dissertation (the conversation continues on Twitter, under the hashtag #DissFwd). “There was general consensus among the discipline experts in the Social Sciences and Humanities that substantial widening of accepted dissertation types and formats should be the future” (McCarthy, 2016, p. 2). Reasons for embracing an expanded understanding of the dissertation included the democratization of knowledge, the increasingly collaborative nature of scholarship, social media innovations with implications for broad and rapid dissemination of research results, and alternative career trajectories for those completing doctoral programs.

### **Arts-Based Research: Pinpointing a Methodological Paradigm**

In a review of 30 arts-based research (ABR) dissertations, Sinner, Leggo, Irwin, Gouzouasis, and Grauer (2006) suggested “a shift is underway in the academy as more and more arts-based works are accepted as doctoral submissions” (p. 1225). The projects, disparate in form, have in common a goal “to evoke or provoke understandings that traditional research formats cannot provide” (p. 1225). My dissertation is part of that emerging tradition, and is distinct in foregrounding a Black Feminist standpoint: “Arts-based educational research dissertations are an opportunity to reconsider the imaginative possibilities between and within theory and practice” (p. 1253).

Eisner (2008) also imagines such possibilities, saying that in arts-informed research “[s]cholars can bring to bear under one collective umbrella ideas about matters of meaning and communication, matters of technique, and matters pertaining to theoretical knowledge that can enrich the environment and yield truly remarkable products” (Eisner, 2008, p. 10).

The majority of arts-based dissertations have taken literary forms (Sinner, Leggo, Irwin, Gouzouasis, & Grauer, 2006), including “poetry, fiction, drama, life-writing, and creative non-fiction” (p. 1232). The preference for literary forms has been a trend in arts-based research more generally, though the field includes work in dance, visual art, performance art, music, and other media: the final form of any arts-based inquiry is based on a number of factors, including the researcher’s interests, abilities, and preferences, the type of research questions and data sources, and the anticipated audience (Knowles & Cole, 2008).

Knowles and Cole (2008) chart the development of ABR and note a marked escalation of interest and projects in ABR in the 1990s, when “a wave of change began to swell particularly in the educational research community” (p. 58). They surmise that this change happened in educational research due to the inherently interdisciplinary nature of educational research, as well as the mandate in educational research to link theory to practice. Milestones in the formal development of arts-based research include Eliot Eisner’s 1993 Presidential Address at the Annual Meeting of the American Educational Research Association (AERA), the founding of the AERA Arts-Based Educational Research Special Interest Group, and the establishment of the Centre for Arts-Informed Research at the University of Toronto in 2000 (Knowles & Cole, 2008; Sinner, Leggo, Irwin, Gouzouasis, & Grauer, 2006).

As should be expected given the iconoclastic nature of the paradigm (Barone, 2006), there is divergence among ABR practitioners not only in method, but also with regard to defining the characteristics and aims of ABR (Denzin, 2000; Finley, 2011; Finley, 2003; Hanley, Noblit, Sheppard, & Barone, 2013; Springgay, Irwin, & Kind,

2005). Arts-based research is more than simply “a means of analyzing and presenting data” (Schedstead, 2012, p. 4); there is convergence around a number of larger themes:

*ABR as a way of knowing.* Arts-based researchers turn to art as a way of apprehending the ineffable aspects of human experience. We examine, we consider, we describe, but most especially, we evoke. We engage the imagination. We “linger in the liminal spaces ... to make sense and create meaning out of difficult and complex questions that cannot be answered in straightforward or linear tellings [sic]” (Springgay, Irwin, & Kind, 2005, p. 902). “Knowledge as a term is a noun. Knowing is a verb. And knowing may be a much more appropriate descriptor of the processes of inquiry made in pursuit of a problem that will not yield to a set of rigidified [sic] procedures” (Eisner, 2008).

*ABR as a way of being / ABR as living inquiry* (Leggo, 2008; Richardson, 1994; Springgay, Irwin, & Kind, 2005). Just as arts-based research is more than simply an alternative method for analyzing data and presenting research results, it is more than simply a method of conducting research. “Seeing methodology through an artful eye reflects a way of being in the world as a researcher that is paradigmatically different from other ways of thinking about and designing research” (Knowles & Cole, 2008, p. 1). The difference is an approach to research that is holistic, encompassing aspects of the researcher’s life beyond the context of activities that are typically considered to be part of a research endeavor (Leggo, 2008). ABR is “a methodology of embodiment, never isolated in its activity but always engaged with the world” (Springgay, Irwin, & Kind, 2005, p. 899).

***ABR as relational.*** Arts-based research is unique among social science research paradigms in that it is intentionally designed to evoke experience in order to inspire empathy (Eisner, 2008; Prendergast, 2014). “It is a research methodology premised on openness, listening, and being responsive and receptive ... [it] encourages and fosters ethical relations” (La Jevic & Springgay, 2008, p. 71) between researchers and participants as well as between researchers and audiences.

***ABR as transformational.*** Social scientists “are in the business of not just interpreting but of changing the world” (Denzin, 2000, p. 256). In ABR, “the world” being changed might be limited to the world of research practice, or it might be the wider sociopolitical world:

While ABR practices challenge the art-science divide and thus dominant approaches to research, this is not the equivalent of all ABR being informed by an anti-oppressive stance ... To engage in ABR practices that seek to advance social justice requires a commitment to research as resistance. (Osei-Kofi, 2013, p. 148).

“*Good* critical arts-based research grasps our imaginations, grabs ahold of our souls, and unabashedly strives to affect our very ways of living, being, and co-being, as researchers, as social scientists, as people ... [it] is deliberately transformative” (Finley, 2014, p. 531, emphasis original).

### **Black Feminism: Theory and / as Praxis**

In the introduction to the 2001 essay collection *Black Feminist Anthropology*, Irma McClaurin argues for Black Feminist research as “a conscious act of knowledge production and canon formation” (p. 1). Her point is that critiquing the hegemony of social science research is not enough: Black Feminist researchers need to create new exemplars. Her argument is echoed by contributors to a 2016 special issue of *Departures*

in *Critical Qualitative Research*; in the introduction to that issue, guest editor Rachel A. Griffin describes a research imperative that works against the “continued orchestrated absence” of research by and about Black women articulating a Black Feminist standpoint (Griffin, 2016, p. 3). In that same issue, Patricia Hill Collins reflects on writing the first edition of *Black Feminist Thought* (1990) and calls on contemporary Black Feminist scholars to continue in the “ongoing diagnostic project of analyzing socially unjust practices that confront Black women ... [and] to build new knowledge about the social world in order to stimulate new practices” (Collins, 2016, p. 135).

Black Feminist Thought influences my work in terms of both theory and style. I seek to participate in the rhetoric of resistance (Griffin, 2016; Stover, 2003) that characterizes writing produced in the Black Feminist tradition. My autoethnographic poetic inquiry centers my subjective self as well as an intuitive epistemology and mode of inquiry. I resist my own marginalization.

### **Onwards / On Words**

In *The Body in Pain* (1985) Elaine Scarry writes about the “unshareability” of pain: it resists language. It is internal and personal in nature, such that it can neither be denied by the person experiencing it, nor confirmed by any person not experiencing it. Pain is self-referential in a way that other interior states are not: If I say that *I am hungry for an apple*, or *annoyed by a sound*, I can point to an object in the material world that relates to my interiority, and in the act of naming that object, in anchoring the object with words, I can offer meaningful insight to the person I am engaging. Not so with pain. It is simultaneously urgent and unspeakable (Frank, 1991). And yet, if there is to come relief from persistent pain, pain must somehow be made known: character, location, cost.

“Autobiographical writing essentially legitimizes the personal experiences and perspectives of those who have been excluded from the dominant discourse” (Rodriguez, 2006, p. 1069-1070).

My dissertation is a story of a body in pain.

It is a story of a

Black

female

body

in pain.

But it is also the story of the ongoing process of developing a critical reflexive lens, one that gives me permission to value lived experience – my own and others – as a legitimate source of knowledge, and to share that knowledge in ways that are personally meaningful. It is the story of setting aside the master’s tools.

## Chapter Two: Sisterhood of Scholarship

Research is the SYSTEMATIC search for knowledge.

(Office of Research Integrity, 2018:  
emphasis added).

Once we've decided  
WHAT we want to know,  
(Need to know  
Is the basis)

The basics:  
(what gap  
to fill,

What empty space

With points of light) (Winterson, 1989)

We must next decide HOW

We intend  
to know.

The ontology of missingness demands

Epistemology

(for knowingness):

Silence into

Speech. (Anzaldúa, 1990; Lorde, 1984)

Ontology begets

Epistemology

begets: (Collins, 1989)

The beginning

of wisdom.

### **An Iconoclast's Considerations for a Theoretical Framework**

A theoretical framework provides a way “to systematically explain and validate ... beliefs about how the world works” (Brown, 1999, p. 359). I wrote in Chapter 1 that when I discovered that my lived experience was not reflected in scholarly literature, I turned to Critical Race Theory and Black Feminist Thought because they are theories that engage with the fact that many lived experiences are not reflected in peer-reviewed social science literature. Black Feminist Thought was of particular interest to me. “Unlike any other movement, Black feminism provides the theory that clarifies the nature of black women’s experience” (Smith, 1985, in Guy-Sheftall, 1995, p.262).

The theories I engage with in this chapter suggest a way forward in knowledge-production endeavors, a departure from the systems and sources utilized in typical academic research:

Investigating the subjugated knowledge of subordinate groups ... requires more ingenuity than that needed to examine the standpoints of dominant groups ... I found my training as a social scientist inadequate to the task of studying the subjugated knowledge of a Black women’s standpoint.  
(Collins, 2000, p. 270).



Collins is not alone in this assessment of the limits of social science training. In 1996, Villenas wrote about the contradictions inherent in her dual identity as both a member of a marginalized community on the one hand -- “the colonized” -- and as a university-trained ethnographer on the other -- “the colonizer” (p. 714). She had to abandon the framing her training had taught her in order to “[unveil] the ways in which the ethnographer is situated in oppressive structures” (p. 716). Without this unveiling, the researcher risks reproducing the systemic inequalities she seeks to understand.

(She had to abandon the framing  
Her training  
Had taught her.  
Even the unveiling,  
On its own,  
Is not enough).

As a student of research methods and statistics, in a doctoral program situated in a Western / “first world” context, I have been trained to value certain sources of knowledge, and certain knowledge-validation practices, over -- and to the exclusion of -- others. “Because elite White men control Western structures of knowledge validation, their interests pervade the themes, paradigms, and epistemologies of traditional scholarship” (Collins, 2000, p. 269).

Social science research privileges the paradigm adopted from the natural sciences (Lather, 2010), giving primacy to the epistemology and methodology of the dominant group – that is, white males (Allen & Chung, 2000). The scientific stance is coded as a

neutral one, denying and negating subjectivity. In an ironic reversal, the subjectivity of the scientist-as-seer dominates the objectivity of the object that is seen (Collins, 1989). A subject becomes an object via objectification. “This is the gaze that mythically inscribes all marked bodies, that makes the unmarked category claim the power to see and not be seen, to represent while escaping representation. This gaze signifies the unmarked positions of Man and White” (Haraway, 1988, p. 581).

The unmarked position has since been marked.

Throughout this chapter I engage in the *Vox Theoria* mode of poetic inquiry (Prendergast, 2009). A fuller, contextualized description of the method can be found in Chapter 3, but I introduce it briefly here.

*Vox Theoria* is the term Prendergast coined in 2009 to describe a mode of poetic inquiry that involves extracting and repurposing phrases in research literature to create poetic representations. Writing in 2006, prior to naming the method *Vox Theoria*, Prendergast described “found poetry as literature review” (p. 369) as a mode of inquiry “[offering] an alternative method for understanding and representing key theories and texts”. She provided an overview of her process:

All the words in these poems are to be found where cited in the original source texts. I have played with line breaks, patterns on the page, parentheses, and the occasional use of repetition for emphases. This present work is an attempt to capture a number of different, and valuable, voices and theoretical perspectives through the crystallizing and creative process of found poetry. (Prendergast, 2006, p. 372)

Lisa William-White’s (2011) autoethnographic poem presents another approach to literature-review-as poetry. Her piece is a poetic polemic, and while it is replete with references to scholarly work, it nevertheless reads as she intends it to, which is as a poem.

Both Prendergast (2006) and William-White (2011) use endnotes to cite the works they reference in their poems. The conventions of my doctoral program require me to adhere to the citation style described in the sixth edition of the *Publication Manual of the American Psychological Association* (APA), which does not allow footnotes or endnotes. I have attempted a compromise that streamlines the poetry for the reader while giving appropriate credit to the writers whose work I reference: direct quotations are indicated by page numbers, while paraphrasing and summarizing statements are indicated by the authors' last name and year. Rose (1996) noted, "feminist writers ... have exploited unconventional citation styles to signify their rejection of some traditional values in scholarly writing" (Rose, 1996, p. 43). I am in good company.

The poem *Inter-Textual*, below, is a conversation of sorts with and among feminist standpoint theorists (Haraway, 1988; Lather, 2007) who critique the dominant EuroAmerican epistemology and its "falsely universalizing methodologies" (Mohanty, 2003, p. 501). The poem is drawn in large part from the introduction to the 2006 monograph *Wild Profusion* by feminist environmentalist anthropologist Celia Lowe. I was introduced to that volume during an ethnography class, and subsequently borrowed the book from my professor. Because the book did not belong to me I could not underline passages of particular insight or eloquence; I chose to write them out by hand instead. Later, reviewing those notes, I realized that I had quite unintentionally created found poetry. I polished the poem over time, adding my own voice and commentary from other scholars. As a poem it is recursive and discursive. As a literature review, it is reflective and selective (Maxwell, 2006).

As presented here, left-justified lines denote references to the works of others, noted with APA-style citations. My words are centered for practical reasons, and for theoretical reasons that are revealed at the end of the poem.

**Inter-textual in-text conversation-as-poem:**

(With / from Celia Lowe in the introduction to her ethnographic monograph

*Wild Profusion*; among others)

Until the 1990s

Euro-American experts held the important positions of authority

In scientific

nature-making

projects.

(Lowe, 2006, p. 5)

And this is still the case:

Study

The idealist separation of “humans” from “nature”

Student from

Studied.

Coloniz-

*er*

From

coloniz-

*ed*

(Villenas, 1996)

[As] specific to the European

Enlightenment. (Lowe, 2006, p.5)

We resist through

*endarkenment*

(Dillard, 2000)

Any understanding of nature will always depend upon

Representation.

(Any understanding of nature

Will always depend

Upon

Re-

Presentation)

And the subjectivity of those claiming

To represent

Such a nature

(Lowe, 2006, p. 9)

The representer

Has power

Over

Science

remains a metonym

for EuroAmerican modernity

and rationality

(Lowe, 2006, p. 11)

“Science” as

Synecdoche.

Reason displays a self-interestedness

“Enlightened”

self-interested

-ness

That situates it within

A field of normalization

and social

Power

(Lowe, 2006, p.22)

The normal has power

Over

the norm.

They resist

We resist

I resist

through naming

Them | Our | My

Selves.

Resistance is

Norming

And naming

the Self

Moving the self

From margin

to center

(hooks, 2000)

Power *with*

Not power over.

Methods have both politics and power (Barone, 2006). They are an expression of axiology:

It is ... absurd to suggest that social research can be value-free because social research is *doubly value-laden* [emphasis original]. Not only is social research circumscribed by values that determine things such as funding and how research results should be used ... the very concepts social researchers employ are evaluative of human behavior. (Howe, 1985, p. 13).

The epistemology and concomitant methodology of the Global West fail to account for the axiology and many other realities of the lived experiences of marginalized people. “Although social scientists tell stories under the guise of ‘objective’ research, these stories actually uphold deficit, racialized notions about people of color” (Solorzano & Yosso, 2002, p. 23). The “innate superiority” (Smith, 1999, p. 56) of the social scientist’s position in relation to the subaltern “other” (Spivak, 2008) usurps the authority to make meaning. This problem is referred to as the “crisis of representation” (Finley, 2011). It is a crisis of both misrepresentation and underrepresentation. It has resulted in a

distortion of, or else complete discounting of, the experiences, knowledge, and values of marginalized people, including, of course, women of color (Wing, 1997).

Black Feminist scholars and others have written about distorted images of Black womanhood (Ashley, 2014; Collins, 2000; Harris-Perry, 2011) stereotypes that shape narratives in service to a status quo, which, even when it shifts, keeps Black women at the bottom. Because Black women have been historically excluded from the power structures that amass information about, and disseminate information to, the masses, distorted images of Black womanhood have continued to dominate in the popular imagination (Farrington, 2005). There is the Sapphire (also known as the Angry Black Woman): quick to anger, emasculating, with a lacerating tongue. There is the Mammy: soft, unsophisticated, eager-to-please, content with her subordination (King, 1988). There is the Jezebel: lascivious, selfish, wily and willful. “The [stereotypes] applied to Black women are so uniformly negative that they almost necessitate resistance” (Collins, 2000, p. 110).

The 1965 Moynihan Report on *The Negro Family* (Moynihan, 1965) is a seminal example of major work about Black women done by white male sociologists (Bell-Scott, 1992), and stands as an exemplar of the longstanding negative images of Black women to which resistance is necessary (Cooper, 2017; Farrington, 2005; Harris-Perry, 2016).

Black Feminist Thought is a theory of resistance (King, 1988). It explains and validates both the experiences of Black women, and the meanings that Black women make of those experiences (Collins, 2000). It challenges the narrative of Black female inferiority, and resists the marginalization of Black women in liberation movements that



center gender or race, but not both (Crenshaw, 1991). “The concept of the simultaneity of oppression is still the crux of a Black feminist understanding of political reality and one of the most significant ideological contributions of Black Feminist Thought” (Smith, 1985, in Guy-Sheftall, 1995, p. 260).

I came to Critical Race Theory and Black Feminist Thought late in my doctoral education. If not for the absence of my particular experience in social science research literature, I might not have come to them until much later. I had become accustomed to quelling my own questions, quashing my own doubts with regard to the preeminence of the Western social science research paradigm. The false promise of rigor is: *do what I did and you'll see what I saw* (Jackson, 2006). The prevailing assumption widely accepted and thus, widely unexamined, is: *This is how we know*. There is a false sense of security offered by the social-science knowledge-validation process, suggesting as it does that replicability and generalizability are proof enough of truth. I suspended disbelief, and chose to trust the process.

### **The Betrayal**

Every research endeavor ends in betrayal. Every research endeavor ends that way, and many of them begin that way too. South Asian feminist ethnographer Kamala Visweswaran writes: “Normative historical description [of a research project] shields those moments when a project is faced with its own impossibility ... this shielding is an actively sanctioned ignorance and a form of colonial domination” (Visweswaran, 1994, p. 98).

I have been complicit in this shielding, in the “invisible manipulation of data” (Lather, 2007, p. 29), and in the obfuscation that is framed as statistical correction (Richardson, Simmering, & Sturman, 2009).

I have been complicit in betrayal. It is an art, and my apprenticeship is almost complete.

The betrayal occurs on three levels.

**At the level of the emic.**

Definition:

Emic [anthropology]

*adjective*

1.

relating to or denoting an approach to the study or description of a particular language or culture in terms of its internal elements and their functioning rather than in terms of any existing external scheme.

*noun*

1.

study adopting this approach.

At the level of the emic is the ironic reversal: a presumption of objective understanding of subjective reality. Social scientists have been trained to deny [“bracket”] our own subjectivities (Tufford & Newman, 2010) in order to observe and report on the subjective reality of an Other. The fact that the social scientist is situated within a social context, himself subject to subjectivity, is treated as an obstacle to

overcome. Preference is given to those methods of investigation and explication that are supposedly value free (Jackson, 2006), methods that “deny practitioner subjectivity, social location and emotional involvement” (Gunaratnam, 2007, p. 278). But “cultural interpretation is power laden” (Visweswaran, 1994, p. 76), and to hand-wave the power at play, to deny the subjectivity brought to bear on the research endeavor, is a betrayal.

**At the level of the etic.**

Definition:

Etic [anthropology]

*adjective*

1.

relating to or denoting an approach to the study or description of a particular language or culture that is general, nonstructural, and objective in its perspective.

*noun*

1.

study adopting this approach.

Social scientists have been trained to categorize, simplify, reduce and generalize from a supposedly objective standpoint: research at a remove (England, 1994). But there is no remove, no standing apart because, “as researchers, we create the reality we seek to describe” (Jackson, 2006, p. 533; Ronai, 1995). The researcher tells a story that, like every story, “makes certain facts relevant and others not” (Delgado, 1989, p. 2428). The researcher as instrument is a filter (England, 1994). Objectivity is a false frame, and claiming objectivity is betrayal.

### **At the level of the epic.**

Definition:

Epic [in literature]

*noun*

1.

a long poem, typically one derived from ancient oral tradition, narrating the deeds and adventures of heroic or legendary figures or the history of a nation.

Or

1.

noting or pertaining to a long poetic composition, usually centered upon a hero, in which a series of great achievements or events is narrated in elevated style

My life is nothing if not an interconnected series of stories. It is a sequel to the stories of my ancestors, and a prequel to the stories of descendants yet to be. Betrayal at the level of the epic is a betrayal of context, a betrayal of story. Ignoring the context of knowledge production should call into question the knowledge produced, because “identity and community shape anthropological analysis” (Visweswaran, 1994, p. 13). It is in embracing, rather than erasing, our stories, that research becomes rich, meaningful, and powerful (England, 1994). To honor the epic is a practice of humility, cognizant of the researcher’s role, “That the powerful play goes on, and you may contribute a verse” (Whitman, 1900). “Betrayal does not end with the premise that we can never know

anything. It does presume that to confront the subaltern is not to represent them, but to learn to represent ourselves” (Visweswaran, 1994, p. 77).

The representor

has power.

Will it be power with

Or power over?

### **Representing Ourselves**

Writing in 1992, Bell-Scott asserted: “Until recently, most of the research related to Black women that has received any attention has been done by white male sociologists,” (Hull, Bell-Scott, & Smith, 1992, p. 86). Black women – academics, poets, artists, outsiders – have been doing the invaluable and undervalued work of re-presenting ourselves (Griffin, 2016; Pollard & Welch, 2006): presenting ourselves again, presenting ourselves anew, telling stories, crafting theory. “An alternative epistemology challenges all certified knowledge and opens up the question of whether what has been taken to be true can stand the test of alternative ways of validating truth” (Collins, 2000, p. 22). Black Feminist Thought “calls into question the content of what currently passes as truth and simultaneously challenges the process of arriving at that truth” (Collins, 2000 p. 22). Among the concerns centered in Black Feminist standpoint are “self-definition, self-valuation, self-determination, intersecting identities and overlapping oppressions” (Griffin, 2016, p. 4).

Methods have politics (Lather, 2010).

These are mine.

## **Theory and Poetry, and Theory as Poetry**

A literature review is an inherently intertextual endeavor: it is a close encounter between different texts. More than just juxtaposition, it is conversation. In the remainder of this chapter, I engage with Black Feminist Thought and Woman of Color Feminism as an ongoing conversation to which I wish to add my voice.

AUDRE LORDE:

... it is not difference which immobilizes us, but silence. And there are so many silences to be broken (Lorde, 1997, p. 22)

GLORIA ANZALDUA:

To trust ... [whites]... is hard when in the past they've betrayed us, and when our very lives have depended on not trusting... It's difficult for dialogue to occur among individuals of unequal power (Anzaldua, 1983, p. xxxvi).

bell hooks:

... Rather than encourage a diversity of voices, critical dialogue, and controversy, [some feminists, some white and some of color] seek to stifle dissent (hooks, 1984, p. 9).

PATRICIA HILL COLLINS:

While domination may be inevitable as social fact, it is unlikely to be hegemonic as an ideology within social spaces where Black women speak freely.

MYNTHA ANTHYM:

Here I am, speaking as myself.

The voices I present here do not speak with one accord, but they share a commitment to breaking chains of silence (Lorde, 1997), and to a feminist project

centered on ending oppression rather than simply infiltrating existing power structures (hooks, 1992). They are poets and academics, lawyers and theoreticians, educators, journalists: iconoclasts all.

The powerful play goes on. My contribution? A verse.

### **A Sisterhood of Scholarship**

1.

We started making poetry right here,

On the ground beneath our feet:

Location, location, location.

“We find our origins

in the historical reality

of Afro-American woman’s

continuous

life-and-death

struggle

for survival ”

(Combahee River Collective,  
in Guy-Sheftall, 1995, p. 232).

Vocation, vocation, vocation.

Feminists have stakes

in a successor science project

that offers

a more adequate,

richer,

better

account

of a world.

(Haraway, 1988, p. 579)

An accountable

world.

An argument

for politics and

epistemologies of

location,

positioning,

where partiality

and not

universality

is the condition of being

heard.

(Haraway, 1988, p. 589).

We started making theory right here.

(Here, we started making theory right,

on the ground

beneath our feet).



We assert the right to privilege

“contestation, deconstruction, passionate

obstruction,

webbed connections,

and hope

for transformation”

(Haraway, 1988, p. 585).

“The process of recognizing

as social and systemic

what was formerly perceived

as isolated and individual ...

has been a source of strength,

community,

and intellectual development”

(Crenshaw, 1991, p. 1241).

For people like us.

2.

We who have survived

Have those who have survived

To thank for our

Survival.

We were never meant to;

(Lorde, 1984)

And yet, we ring like

Bells.

(Clifton, 2012)

3.

I am a black woman.

That one thing

You must

remember

Or nothing that follows

will seem

wondrous.

I am a Black woman

A Black

Woman

Scholar

Poet

Storyteller

Fire-starter

Artist

Act

-ivist.

I am a Queer

(like Audre)

Black

(like Alice)

Woman

(like Maya).

I move

Between and within

Insider / outsider

Within and Between

Both / and

Nor / neither

(Noire, neither

Here, near there).

A daughter of

Diaspora.

Having found

Black Feminist

Thought.

In the company of

Women who are

Blacks

Blacks

Who are

Women

(Cho, Crenshaw, & McCall, 2013, p. 790)

And we have always been

Feminist.

(Guy-Sheftall, 1995, King, 1988)

We (who love our

Race

And our sisters

As ourselves

Who birth and bury

Black boys)

(Davis, 1981)

Have always been

Feminist.

We have always

Labored

(Under the lash)

Labored

(To bring forth fruit

from seed)

Worked as hard

As any man

(And twice as hard

as some)

Sweating side by

Side.

Dying

Side by

Side.

Watering soil

With blood and tears:

(Cooper, 1893)

Equal.

What could be more feminist

Than that?

4.

I have found

Black Feminist

Thought:

Framework

Theory

Meaning-making

Methodology

Way of knowing

Understanding and articulating

The ways of my world,

The ways

my identities

inform

my experience.

“Unlike any  
other movement,  
Black feminism provides  
the theory  
That clarifies  
the nature  
of Black women’s  
experience”

(Smith, 1985, in Guy-Sheftall, 1995, p. 262).

I have found

Myself

Full

of possibilities,

Potential

Futures

(Mohanty, 1984)

A cross

road.

(Anzaldúa, 1987)

Black Feminist

Thought

Can be likened to

And is distinguished from

Critical race

Feminist standpoint

Marxist critique.

(West, 1991)

It considers

Race | Gender | Class

Converges with other

Thought

Where interests

Align.

Diverges where single-

mindedness

Flails.

As long as Black women's

subordination

Within intersecting

Oppressions

Persists

(Crenshaw, 2016)

We will need

(We still need)

(Collins, 2016)

(I still need)

Black

Feminism.

“Intersectionality was necessary

(Intersection

ality  
is necessary)  
because the intersections of racial  
discrimination  
and gender  
discrimination  
were colliding  
in a way  
that needed  
to be named” (Martinez, 2017)

5.

The namer  
Has power  
Over  
The named.  
“This is the gaze  
that mythically inscribes  
all marked bodies,  
that makes the unmarked  
claim the power  
to see  
and not be



seen,

to represent

while escaping

(We are escaping

The master's house

(Lorde, 1984)

We are escaping

his mastering

naming

misrepresenting)

representation.

This gaze signifies

the unmarked positions

of Man

and White”

(Haraway, 1988, p. 581).

The namer has power

Over the named.

6.

The collision

needed

to be named.

(And some of us are

Black AND Woman

brave).

(Bell-Scott & Smith, 1992)

7.

Intersectionality turns

the academic eye

To “the vexed

Dynamics

Of difference

And the solidarities

Of sameness

In the context

Of anti-

discrimination

And social movement

politics”

(Cho, Crenshaw, & McCall, 2013, p. 787)

Intersectionality turns

The academic I

To “consideration of

Gender,

Race,

And other

Axes of power”

(Cho, Crenshaw, & McCall, 2013, p. 787)

Intersectionality as

Power analysis.

“Questions about

what intersectional analysis *is* (emphasis added)

Are answered by what people are

deploying it to do” (Cho, Crenshaw, & McCall, 2013, p. 788)

Intersectionality as

“A gathering place

For open-ended

Investigations

Of overlapping

And conflicting

Dynamics of

Race | Gender | Class ...

And other

Inequalities” (Lykke, 2011, in Cho, Crenshaw, & McCall 2013).

It is

What it does. (Lather, 2009)

“Influenced by intellectual

Traditions

Arising from

Black feminism

Ethnic studies

And community

Activism

Scholars took these

Intersectional sensibilities” (Cho, Crenshaw, & McCall, 2013, p. 790)

Out of the tower

And into the world

Where theory

Interrogation

And contestation

Live.

This work is

“grounded in the practice

of subjecting existing

doctrine

to trenchant critique,

a practice

predicated

on the belief

That uncovering”

The reinforcing

Rationalizations

Is a first step

Toward transformation.

The discursive terrain

Of the intersectional frame

Is the liberated

mind.

8.

We been sayin' it

In our own words

(but they don't hear it)

In their words

(but they still refute it)

And "it would

seem that

to continue to see race

of people,

any race of people,

as one single

personality

is an ignorance

of gothic

proportions"

(Morrison, 1975)

### Chapter Three: How and Where I Enter

A layered description begins (Ronai, 1995; Ronai, 1992)

With the history

of the universe. (Anthym, 2017; Geertz, 1973)

Epistemology

begets

methodology. (Tyson, 2003)

“Only the BLACK WOMAN can say

‘when and where I enter ...’ (Cooper, 1892)

This is how and where

I enter:

I enter

At the intersections.

I enter

Everywhere.

I wrote in Chapter 1 that Black Feminist Thought influences my work in terms of both theory and style. I said that I was setting aside the master’s tools. In this Chapter, I describe the tools I will use instead, tools better suited to the task of evoking this Black woman’s lived experience of a body in pain.

“Research is an extension of researchers’ lives” (Ngunjiri, Hernandez, & Chang, 2010. p. 2). The authors do not distinguish here between qualitative research and quantitative research. They describe the goal of separating one’s self from one’s research as “an impossible task”, and urge researchers to be unapologetic in naming their positionality as it pertains to their research endeavors. Other scholars express a similar sentiment: “I am arguing for politics and epistemologies of location, positioning, where partiality and not universality is the condition of being heard to make rational knowledge claims” (Haraway, 1988, p. 589). Politics of positioning can be a condition of making not only rational knowledge claims, but also a unique and meaningful contribution (Peshkin, 1988).

In 1998, some women of color social science researchers were invited to present a panel at the American Educational Research Association (AERA) Annual Conference. The scholars were asked to answer the question “How have you come to know what you know about research?” The papers presented for the panel were eventually collected in a volume titled *From Center to Margins: The Importance of Self-Definition in Research* (Pollard & Welch, 2006). The collected articles and essays argue against the invisibilizing of women of color in educational research. Invisibilizing happens when the work of women of color about women of color is marginalized. Invisibilizing also occurs when women of color downplay their own identities and “go along to get along” as the old adage says, depoliticizing their scholarship in order to establish academic careers (Collins, 2000). Pollard and Welch wonder whether women of color should “move to the center”, producing research in accordance with the prevailing white masculinist paradigm

in order to receive recognition, or should they – should we – “take researchers to the margins ... demonstrating the reality and validity of life in these spaces?” (Pollard & Welch, 2006, p. 9). The title of the volume – *From Center to Margins* -- provides the authors’ answer.

What does it mean to take research to the margins? It means rejecting the researcher-role of “detached observer” (Pollard & Welch, 2006, p. 15), and, instead, embracing and articulating positionality. They echo other feminist scholars, who “seek those ruled by partial sight and limited voice – not partiality for its own sake but, rather, for the sake of connections and unexpected openings [that] situated knowledge makes possible” (Haraway, 1988, p. 590).

I am a Black woman.

I am a queer Black woman.

I am queer

Black

Feminist

Woman.

I am a storyteller,

A statistician,

And a poet.

As a queer Black woman, a scholar and an activist, a storyteller and a poet, I move between and within insider and outsider statuses in the social and cultural spaces I inhabit. I have found in Black Feminist Thought a framework for understanding and



articulating the ways my identities inform my lived experiences. “Unlike any other movement, black feminism provides the theory that clarifies the nature of black women’s experience” (Smith, 1985, in Guy-Sheftall, 1995, p. 262).

That is the standpoint from which I make meaning.

That is the standpoint from which I conduct research.

This is the method chapter of a dissertation for a doctoral program in Research Methods and Statistics. It is worth noting here again that my dissertation is not “about” Black women receiving suboptimal treatment for non-malignant chronic pain. While my own experience with that phenomenon is the ordeal around which my argument is organized, my dissertation is about setting aside the master’s tools. I don’t share the master’s ontology, so why should I presume to share his epistemology and methodology (Guba & Lincoln, 1994)? Patricia Hill Collins (1989) wrote “... one cannot use the same techniques to study the knowledge of the dominated as one uses to study the knowledge of the powerful” (p. 751). I am situating myself in a tradition of Black Feminist and Critical Race scholarship, which means that the methods I use must align with those critical theoretical considerations.

### **Methods at the Margins**

A discussion of method is a discussion of the process of attaining and validating knowledge (Polkinghorne, 2007; Smith, 1999). The argument I am making when I say that epistemology begets methodology is the same one Carr (2000) makes: “the choice of a research methodology always implies a preference for the theory of human nature on which it is based” (Carr, 2000, p. 443-444).

In the Black Feminist tradition, "... personal expressiveness, emotions, and empathy are central to the knowledge validation process" (Collins, 1989, p. 766). Collins (2000) names six things that a Black Feminist methodology must do:

1. Embrace the Black woman standpoint as unique and inherently valuable (p. 39).
2. Accept responsibility for developing and moving forward with an agenda that centers Black women (p. 40).
3. Develop and articulate self-definition (p. 40).
4. Collaborate within and beyond Black Feminist intellectual spaces (p. 41).
5. Contextualize Black Feminist thought in the universal humanist struggle for liberation and an end to all forms of oppression (p. 46).
6. Remain dynamic, flexible, and open to change: "Neither Black feminist thought as a critical social theory nor Black feminist practice can be static; as social conditions change, so must the knowledge and practices designed to resist them" (p.43).

These articles of faith are echoed by other Black Feminist scholars. On the matter of self-definition, Audre Lorde said "For Black women ... it is axiomatic that if we do not define ourselves for ourselves, we will be defined by others – for their use and our detriment" (Lorde, 1984, p. 45). But such self-definition doesn't come easy: "The opportunities for Black women to carry out autonomously defined investigations of self in a society which through racial, sexual and class oppression systematically denies our

existence have been by definition limited,” (Hull, Bell-Scott, & Smith, 1992, p. xviii). In this dissertation, I attempt just such an investigation, recognizing that

“Seldom does defeat arrive in bullets, often in our acquiescing to see ourselves as others perceive us” (Hix, 2015, p. 40).

Black Feminist methodology does not acquiesce to false perceptions. Black Feminist methodology rises against “uncritical acceptance of distorted definitions” of Black womanhood (hooks, 1984, p. 22). Black Feminist methodology resists.

I resist.

Like Black Feminist Thought, Critical Race Theory emphasizes the value of the unique standpoint associated with positionality at the margins, and advocates an activist role for the researcher. Solorzano and Yosso (2002) identified the following characteristics of a Critical Race Methodology (CRM) based on Critical Race Theory:

- CRM foregrounds race and racism in all aspects of the research process.
- CRM challenges traditional research paradigms, texts, and theories.
- CRM focuses on racialized, gendered, and classed experiences of research participants.
- CRM offers a transformative solution to racial, gender, and class subordination.
- CRM is interdisciplinary, drawing from disciplines including ethnic studies, women’s studies, sociology, history, humanities, and the law.

Taken together, Black Feminist methodology and Critical Race Methodology outline a philosophy of research praxis, but they are short on specifics (Huber, 2008).

How are Black Feminist and Critical Race methodology operationalized?

Counter-storytelling, a tenet of Critical Race Theory, is at the center of Critical Race Methodology:

Critical race theory recognizes that the experiential knowledge of people of color is legitimate, appropriate, and critical to understanding, analyzing, and teaching about racial subordination ... Critical race theorists draw explicitly on the lived experiences of people of color by including such methods as storytelling, family histories, biographies, scenarios, parables, [and more]. (Solorzano & Yosso, 2002, p. 26).

Counter-storytelling is “a tool for exposing, analyzing, and challenging the majoritarian stories of racial privilege” (Solorzano and Yosso, 2002, p. 32). Counter-storytelling centers marginalized voices, honoring both alternate ways of knowing as well as alternative forms of knowledge production (Delgado, 1989). In that way, counter-storytelling can operationalize tenets of Critical Race Theory and Black Feminist Thought. “It is my contention that Black female scholars may know that something is true but be unwilling or unable to legitimate their claims using Eurocentric masculinist criteria” (Collins, 1989, p.753); those claims can be legitimated in via counter-storytelling.

While counter-stories challenge dominant narratives and offer an alternative approach to legitimating knowledge claims, they can serve additional purposes:

- They connect: “The attraction of stories for [outgroups] should come as no surprise. For stories create their own bonds, represent cohesion, shared understandings, and meanings ... The cohesiveness that stories bring is

part of the strength of the outgroup” Delgado, 1989, p. 2412). “[Stories] can show us the way out of the trap of unjustified exclusion” (p. 2415).

- They refine and redefine: “We sharpen self-definition by exposing the self in work” (Lorde, 1984, p. 291); self-definition is a liberating practice that is central to Black Feminist praxis (Collins, 2016; Griffin, 2016; Guy-Sheftall, 1995).
- They humanize: “Stories humanize us. They emphasize our differences in ways that can ultimately bring us closer together” (Delgado, 1989, p. 2440).
- They contextualize: “The radical empiricist’s response to the vulnerabilities of and vicissitudes of fieldwork is honesty, humility, self-reflexivity, and an acknowledgement of the interdependence and reciprocal role-playing between knower and known” (Conquergood, 1991, p. 182). “It is through [mutual storytelling] that we can overcome ethnocentrism and the unthinking conviction that our way of seeing the world is the only one” (Delgado, 1989, p. 2439).
- They transform:

Stories, parables, chronicles, and narratives are powerful means for destroying mindset – the bundle of presuppositions, received wisdoms, and shared understandings against a background of which legal and political discourse takes place ... Ideology – the received wisdom – makes current social arrangements seem fair and natural. Those in power sleep well at night – their conduct does not seem to them like oppression. The cure is storytelling. (Delgado, 1989, pp. 2413-2414)

Solorzano and Yosso (2002) describe three categories of counter-story:

1. *Personal stories and narratives* are “autobiographical reflections of the author, juxtaposed with ... critical race analysis ... within the context of a larger sociopolitical critique” (p. 32).
2. *Other people’s stories or narratives* “offer biographical analysis of the experiences of a person of color, again in relation to U.S. institutions and in a sociohistorical context” (p. 33).
3. *Composite stories or narratives* “draw on various forms of ‘data’ to recount the racialized, sexualized, and classed experiences of people of color” (p. 33).

Whether presented in the form of traditional narrative tales, poems, essays, performances, or via other means (Milner & Howard 2013), counter-narratives share certain features in common, including the goal of transformation: “Oppressed groups have known instinctively that stories are an essential tool to their own survival and liberation” (Delgado, 1989, p. 2436). “Master narratives are meta-stories that aim to bring final meaning to cultural phenomena” (Barone, 2006, p. 215). Counter-stories share a “challenge [to] the dominant narrative about race” (Williams, 2004, p. 167), a challenge to ascribed final meanings.

Here, in my dissertation, I challenge the dominant narrative that Black women are sneaky and devious, cheating the system for our own nefarious ends (i.e., the “welfare queen”, Collins, 2000, p. 273). This narrative of Black womanhood was most notably formally articulated in the 1965 Moynihan Report, and it has been marshalled against

Black women ever since (Harris-Perry, 2011). I am also challenging the narrative of Strong Black Womanhood, a narrative that portrays Black women as impervious to suffering (Harris-Perry, 2011; Scott, 2016).

I am not impervious to suffering. The suffering body finds expression in the illness narrative.

### **Illness Narrative as/and Counter-Story**

In the preface to the second edition of *The Wounded Storyteller* (2013), Arthur W. Frank describes illness narratives as stories that challenge the medicalization of illness and the objectification of the patient (patient as body; patient-qua-patient rather than patient-as-person). He posits the illness narrative as a corrective to “narratives [that] positioned the physician as protagonist and relegated me to being the object of that protagonist’s heroism” (p. xiv). His description suggests that illness narratives can serve a function in alignment with the role of the counter-narrative: “Telling stories of illness is the attempt ... to give voice to an experience that medicine cannot describe ... As a post-colonial voice, the storyteller seeks to reclaim her own experience of suffering” (p.18).

We experience the world through our bodies, through our five senses. In another way, we experience the world *as* our bodies: their capabilities and limitations, the way we move through the world, the way people react to us. We interpret this information through filters, and those interpretations become stories that we tell ourselves about the way the world works, stories we tell ourselves about our place in it. When we bring intentionality and reflexivity to the meaning-making process through storytelling,

“Stories become pedagogical and transformative ... opening a space for personal healing, public dialogue, and policy changes” (Spry, p. 56). Stories become counter-stories.

What are the consequences of being in a particular body? This black, queer, woman self. This black, queer, woman body. This researcher as instrument: these eyes, these hands, this mind, this body. This is the site where meaning is made. This is the means by which information is communicated. In the act of knowing, we cannot separate out the aspects of the self. Our bodies are inherently a part of the meaning making process (Spry, 2011). Illness narratives explicate that truth. “Narrative is a conduit for emotion and a means through which embodied distress is expressed” (Becker, 1997, p. 14).

Frank (2013) indicates that the “embodied stories” (p. 2) of illness narratives serve a dual purpose, both personal and social: “The ill body’s articulation in stories is a personal task, but the stories told by the ill are also *social* [emphasis original]” (Frank, 2013, p. 3). Frank describes the social aspect of illness narratives in terms of the culturally specific contexts in which stories arise, and the culturally specific ways in which stories are told. By this logic, illness narratives can be understood not only as counter-stories, but also as autoethnography.

### **Autoethnography: Writing Self as/and Culture**

In the preface to the 2013 *Handbook of Autoethnography*, Carolyn Ellis writes about the first time she ever wrote the word *autoethnography*. It was 1995. “I spelled it first with a hyphen, and then without” she recalls (Ellis, in Holman Jones, Adams, & Ellis, 2013, p. 9). She removed the hyphen to mark autoethnography as “a thing all on its



own, not just ‘auto’ linked to ‘ethnography’ ”. She describes the blossoming of autoethnography in the late 1990s – and its later eruption in the 2000s – as a reflection of the postmodern turn in social science, and the desire among scholars “to add to our canonical qualitative texts an evocative and vulnerable heart” (Ellis, in Holman Jones, Adams, & Ellis, 2013, p.10).

A literal definition of autoethnography can be derived from a simple parsing of the term: auto = self, ethno = culture, and graph = writing. But autoethnography is more than the sum of those parts. Buzard (2003), in an early critique of autoethnography, defines it as “the study, representation, or knowledge of a culture by one or more of its members” (p. 61). He goes on to describe it, rather disparagingly, as the inevitable marriage of “two trope clusters: those of ‘Letting the Silenced Speak,’ ‘Telling our Own Story,’ or ‘Speaking for Ourselves,’ on the one hand, and those of ‘Situated Knowledges,’ ‘the Politics of Location,’ or ‘Standpoint Epistemologies,’ on the other”. Autoethnography was still an emerging methodology at the time of his writing, but others have since made similar observations about the traditions from which the method emerged. Adams and Holman Jones (2011) see in autoethnography

...the confessional/ autobiographical embrace of subjectivity, contingency, and connection; the feminist insistence on historicized, strategic, politicized, and thoroughly lived standpoints; a commitment to theorizing how our work constitutes and traffics in knowledge production; and a deconstructive skepticism about the workings of reality, power, identity, and experience. (Adams & Holman Jones, 2011, p. 108).

Bochner (2013), too, describes autoethnography in terms of a constructivist context: “The *narrative turn* [emphasis original] provoked by poststructuralist, postmodernist, and feminist critics ... [cast] serious doubt on the sanctified scientific

doctrine of truth and method” (Bochner, in Holman Jones, Adams, & Ellis, 2013, p. 52); in that space of doubt about human science research, autoethnography has become “a rallying point for those who believe that the human sciences need to become more human” (Bochner, 2013, p. 53). The method appeals to those who “want to write stories with raw and naked emotion that investigate life’s messiness, including twists of fate and chance” (Bochner & Ellis, 2016, p. 10).

Autoethnography is a way to engage with complex questions of culture by writing about the self. Autoethnography “lets you use yourself to get to culture” (Pelias, 2003, p. 372). Autoethnographers engage in exposition of the situated self.

### *Autoethnographic Themes*

Recurring themes in autoethnography, and in writing about autoethnography, include resistance, bearing witness, and giving voice.

The theme of *resistance* has been emphasized by researchers producing scholarship at the margins (Barone, 2006; Pollard & Welch, 2006). “[Autoethnography] is a radical resistant democratic process” (Denzin, in Spry, 2011, p. 11-12). Chavez (2012) uses autoethnography (and, notably, Critical Race Theory) to contextualize her educational experiences as a Chicana in predominantly white institutions, and to articulate her resistance to certain norms of the academy: “I have found that when I write, I am unable and unwilling to create the traditional ‘academic distance’ between the papers I produce and the voices of my educational experiences” (p. 334). She goes on to say: “Producing autoethnographic research acknowledges and validates my Chicana

presence as well as draws attention to my marginal position inside dominant structures of education” (p. 335).

The resistance is fertile. Autoethnography has exploded in the last 20 years, and is a preferred method among scholars who are interested in “disrupting norms of research practice and representation” (Holman Jones, Adams, & Bochner, 2013, p. 32).

Lisa William-White (2011) expresses the theme of autoethnography as resistance in her poetic polemic *Dare I Write About Oppression on Sacred Ground [Emphasis Mine]*. She describes her piece this way:

[This] piece illustrates the conflicts inherent in Academic Freedom, perceptions of autoethnography, and the dilemma of representation in critical qualitative research traditions. Finally, this piece challenges the academy to consider the power of Spoken Word as a valuable method of storytelling; and, as an essential epistemology to enact and enliven representations of the self, and of others, with the greater purpose of engaging in activist scholarship. (William-White, 2011, p. 236).

Autoethnography resists the artifice of research-at-a-remove, reckoning with decision making as embodied theory, methodology as ideology.

Autoethnographers engage in the practice of -- and reflection on -- *bearing witness*: “autoethnography acts as a mirror or reflection of life and living in ways that are useful for contemplation as well as a mode of engagement with understanding” (Holman Jones, Adams, & Ellis, 2013, p. 38). Looking closely at our own lives, and inviting others to look, is humbling, disorientating and reorienting: “Maybe turning the gaze on myself is a way to avoid making Others out of others” (Shuler, 2007, p. 259).

Autoethnography makes a space in academia, and other corporatist cloisters, for the reclaiming of narrative through *giving voice*: “We are not alone in coming to the view

that it is understandings about the subjective dimensions of personal experience that are missing from many academic texts – subjective dimensions that are best expressed through personal voice” (Douglas & Carless, in Holman Jones, Adams, & Ellis, 2013, p.88). “I consider that all qualitative research accounts would benefit from the explicit and overt presence of the first-person ‘I’ of the researcher” (Humphreys, 2005, p. 853). The first-person ‘I’ inherent in autoethnography provides opportunity for reflexivity and humility through self-exploration, self-expression, and the explication of a partial perspective (Adams & Holman Jones, 2011; Bochner & Ellis, 2016).

The Combahee River Collective presaged the growing trend of Black Feminist autoethnography (Griffin, 2016) in 1977, stating “In the process of consciousness-raising, actually life-sharing, we began to recognize the commonality of our experiences and, from that sharing and growing consciousness, to build a politics that will change our lives and inevitably end our oppression” (Combahee River Collective, 1977, in Guy-Sheftall, 1995, p. 233). Autoethnography is a mode of life-sharing that makes space to recognize shared aspects of experience.

### ***Reliability and Validity in Autoethnography***

I argued in Chapter 2 that every research endeavor is informed by the unique positionality of the researcher, their metaphorical “location” in culture, including race, class, gender, sexual orientation, education level, and other demographic and situational variables. In autoethnography, this positionality is explicated and centered, with a recognition that “These qualities have the capacity to filter, skew, shape, block, transform, construe and misconstrue what transpires from the outset of a research project

to its culmination in a written statement” (Peshkin, 1988, p. 17). How can we (can we?) combat this skewness? In a research context in which the old centers cannot hold, how do we address the standards of “reliability” and “validity”? The answer lies, in part, in reflexivity.

Reflexivity is a process by which the researcher can explore and explicate positionality. Reflexivity increases accountability in research. It is “a guard against ... the assumption that there is an unproblematic relationship between the social scientific text and its valid and reliable representation of the ‘real’ world” (May & Perry, 2010, p.15).

Reflexivity is “a personal accounting of one’s social positioning in terms of race, class, gender, etc.” (Spry, 2011, p. 54). This accounting is undertaken because of an understanding that positionality shapes operations and observations (Crenshaw, 1991; Peshkin, 1988).

Humphreys (2005) argues “that the use of autoethnographic vignettes in a qualitative research account would enrich the story, ethnography, or case study and enhance the reflexivity of the methodology” (Humphreys, 2005, p. 853).

Collins (2000) identifies the community as a site for validating knowledge claims; and “... interpretive social scientists assert that our work has consequences for others and ourselves” (Richardson, in Ellis & Flaherty, 1992, p. 125). Again, this quote from Coates: “You must always remember that the sociology, the history, the economics, the graphs, the charts, the regressions all land, with great violence, upon the body” (Coates, 2015, p.10). Accountability to community is the benchmark for validity in critical and

interpretive research projects. It makes the research felt, and in so doing it empowers the researcher to become an empathetic advocate.

### ***Autoethnographic Analysis***

“Like evidence, experience means nothing until it is interpreted” (Spry, p. 19). “It is in this process of analysis of one’s own text that the [researcher] moves deeper into a critical understanding of the experience” (Spry, 2011, p. 190).

Data for autoethnography comes from a variety of sources, including. Approaches to data analysis in autoethnography vary.

As a storyteller, poet, Black feminist statistician, autoethnography as method appeals to me because it makes space for the voice and experience of the researcher as practitioner and as participant. Voice and experience are understood to be indispensable tools for understanding the world and the researcher’s place in it. Autoethnography provides an opportunity to meld the rigor of systematic inquiry with the resonance of the personal story, to meld cultural critique with subjective knowing, and to make a genuinely unique contribution: “Subjectivity can be seen as virtuous, for it is the basis of researchers making a distinctive contribution” (Peshkin, 1988, p. 18).

### ***Autoethnography and / as Counter-Narrative***

Chavez (2012) describes Critical Race Theory and autoethnography as “the perfect marriage” (p. 343), and she is not alone in her assessment: while a systematic literature review of this marriage is beyond the scope of this chapter, a cursory search for “critical race theory” and “autoethnography” in Academic Search Complete retrieved 22 records, including an April 2006 special issue of *Qualitative Inquiry* on Critical Race

Theory, autoethnography, and performance studies. (The same search in Google Scholar retrieved 1,820 records). Autoethnography as a method can meet some requirements of Black Feminist methodology and Critical Race methodology by giving voice to lived experience and connecting personal experiences to larger social concerns.

### ***In Brief: Critiques of Autoethnography***

Autoethnography has been criticized consistently since it emerged as a method unto itself under the broad umbrella of qualitative research. It has been dismissed as “being narcissistic, self-indulgent, simplistic, and just too personal” (Adams & Holman Jones, 2011, p. 111). But those criticisms seem to miss the point of autoethnography: “I have acknowledged that there are dangers arising from the charge of self-indulgence and narcissism but would argue strongly that this risk is outweighed by the potential in autoethnography for ... witnessing, empathy, and connection” (Humphreys, 2005, p. 853). Autoethnography does not do what other research methods do. It isn’t meant to (Chavez, 2012; Holman Jones, Adams, & Ellis, 2013).

When I describe my project as *autoethnographic*, I take the meaning articulated by Adams and Holman Jones (2011): “*The autoethnographic* [emphasis original] means sharing politicized, practical, and cultural stories that resonate with others and motivating these others to share theirs; bearing witness, together, to possibilities wrought in telling” (Adams & Holman Jones, 2011, p. 111). This is not so different from a vision of Black Feminist storytelling articulated by The Combahee River Collective in 1977: “Even our Black woman’s style of talking/testifying in Black language about what we have

experienced has a resonance that is both cultural and political” (The Combahee River Collective, 1977, in Guy-Sheftall, 1995, p. 235).

Autoethnography is a resonant reclamation, a way of being-and-doing a self in the world (Adams & Holman Jones, 2011; Ellis, 2004). My way of being-and-doing myself in the world is now and has always been through poetry; poetry can be a practice of resistance and reclamation: “As we reclaim our literature, poetry has been the major voice of poor, working-class, and colored women” (Lorde, 1984, p. 286).

Autoethnography is one way to “emphasize the complex relationships between the personal and political” (Chavez, 2012, p. 335) without letting the personal be subsumed by the political. It is one way to reclaim the narrative.

Poetry is another.

Shelley (1890) described a distinction between story and poetry: story is partial, he said, while poetry is universal. A story is beholden to the facts. A poem is beholden to the truth: “Poetry and narratives present multiple levels of the same phenomenon” (Gallardo, Furman, & Kulkarni, 2009, p. 290). Poetry is thus uniquely suited to the task of connecting the singular to the systemic, the personal to the political (Richardson, 1994). “Poetry is a way of knowing and living, a way of examining lived experiences by attending to issues of identity, relationship, and community” (Leggo, 2008, p. 171).

### **Poetic Inquiry: Poetry as Process and Product**

Poetic inquiry is “an umbrella [term] to cover the multiple terminologies ... in this field of arts-based inquiry practice” (Prendergast, 2009, p. 543). In her systematic meta-analysis of poetic inquiry, Prendergast identifies 40 terms describing the use of



poetry in social science research, including research poetry; poetic transcription; aesthetic social science; ethnopoetry; fieldnote poems; poetic portraits; and poetic reflection/resistance. The multitude of terms – a “heteroglossia” (Prendergast, 2009, p. 543) indicates the surge of interest in using poetry in the context of social science research, in disciplines as various as “psychology, sociology, anthropology, nursing, social work, geography, women’s/feminist studies and education” (p. 545).

Why poetry? “[Poems] ... have the possibility of doing for ethnographic understanding what normative ethnographic writing cannot” (Richardson, 1994, p.12) That is, “to synthesize experience in a direct and affective way” (Prendergast, 2009, p. 545). Prendergast (2009) identifies three broad categories of poetic inquiry:

#### **Vox Autobiographica/Autoethnographia – Researcher-voiced poems**

The most common form of poetic inquiry identified in the meta-analysis, poems in this mode center the researcher’s experience, perspective, and voice. Gallardo, Furman, and Kulkarni (2009) exemplify this mode of poetic inquiry in their explorations of depression. Furman writes, from his own first-person perspective, about his struggle with non-clinical depression:

**The best years**  
And your [sic] sitting on your  
old filthy sofa chair,  
and the dogs  
watch you suspiciously,  
the raven outside  
watches you suspiciously,  
roaming through all the possibilities,  
all those things to do,  
that you won’t.

(Gallardo, Furman, & Kulkarni, 2009, p. 293).

Each of the eight poems in the article is framed with narrative and reflexive content. The interplay of evocation and analysis “provides an opportunity for the maker and the beholder to reflect upon ... life and what it means to be in the world [in a way that] can be transformative” (Glesne, 1997, p. 215). Gallardo, Furman, and Kulkarni (2009) conclude that work of this kind “provides perspectives that cannot be understood from more traditional social scientific methods” (p. 301).

**Vox Participare – Participant-voiced poems** feature the voices of research participants, on their own or in combination with the researcher’s voice. Poems in this mode are also described as “poetic transcription” (Glesne, 1997) as they are often based on interview transcripts, though they can also be co-constructed collaborative efforts. Laurel Richardson’s “Louisa May” (1992) is an exemplar of *Vox Participare*: Richardson used only “Louisa May’s” words, extracting them from interview transcripts and using poetic devices – line breaks, parallelism, repetition – to construct a poeticized life story (Richardson, in Ellis & Flaherty, 1992).

**Vox Theoria – Literature-voiced poems** are based on scholarly and other literature. They might be extractions from it, responses to it, or conversations with it. The poems in Chapter 2 of this dissertation are of the *Vox Theoria* type.

Poetry encourages an empathic relationship between the author and its audience...it helps to stimulate an empathic understanding in the reader; they are able to locate themselves in the poem, and when there is difference, they are able to transcend the poem and create that which is their own ... While a poem usually starts with one person’s experience, it attempts to move beyond the *N* of one to *N* of many. (Gallardo, Furman, & Kulkarni, 2009, p. 291).

The autoethnographer is

An *n* of 1, containing multitudes, (Brady, 2009)

An *n* of 1, whose name is Legion.

And unexplained

Variance is

Person-centered

Mystery.

(Unsolved,

Evolving

Mystery)

Sometimes the persons

At the center

Are the researchers

themselves.

### ***The Representational Turn***

“There is beauty in ruins ... transforming is what art does” (Sontag, 2003, p. 76).

We make art – I make art -- in part, to wrest meaning from experience. That is what poetic representation does: “Poetic representation plays with connotative structures and literary devices to convey meanings; poetry commends itself to multiple and open readings in ways conventional [social science] prose does not” (Richardson, in Ellis & Flaherty, 1992, p. 126).

Richardson turned to poetic representation in part because, when reading texts in her discipline (sociology) she found that “even when the topic was ostensibly riveting, the writing style and reporting conventions were deadening ... [containing] passive voice; absent narrator; long, inelegant, repetitive authorial statements and quotations; hordes of references; dead or dying metaphors ...” (Richardson, in Ellis & Flaherty, 1992, p. 131). Richardson describes herself as “clutching at [her] own throat at the thought of writing ‘straight’ sociological prose”.

I relate to Richardson’s reluctance to render without resonance; I share her dread of deadening prose. I have often said of my dissertation: This is the dissertation that only I could write, and this is the only dissertation I could write. But while the topic was consistently compelling to me, I didn’t know how to pursue it effectively. I didn’t know how to render it affectively. I was clutching at my own throat until I gave myself permission to pursue poetry. I gave myself permission for my dissertation to sound like me. I gave myself permission to appear on every page.

Richardson writes “[A] part of me that I had suppressed for more than eight years demanded attention: the part that writes poetry” (Richardson, in Ellis & Flaherty, 1992, p. 131). While I had not been entirely suppressing my poetic instinct over the course of my doctoral program, I had certainly been compartmentalizing it. Chavez (2012) says “I use critical race theory because I have no choice; it is what I know and how I come to know” (p. 343). Even more than Critical Race Theory or Black Feminist Thought, that is how I feel about poetry. It is both a way of knowing and a way of representing what I know.

In the social sciences, writing poetry becomes a practice of resistance. “I have breached sociological writing expectations by writing sociology as poetry” (Richardson, in Ellis & Flaherty, 1992, p. 126). If it is a breach of expectations to write sociology as poetry, how much more so to write a Research Methods and Statistics dissertation in that form.

The poems for this project are “found poems” (in the form of poetic representation of my journal and blog) as well as “generated poems”. Found poems are extracted from a variety of data sources and “crafted into poetic form” (Butler-Kisber & Stewart in Prendergast, Leggo, & Sameshima, 2009, p. 3), whereas “generated poems are created using words that come from within to express researchers’ understandings of their own and others’ experiences, or to explore and reflect upon research memories, roles, and assumptions” (p. 4).

Generated poems and found poems can each serve an evocative function: “...artistic expression can create opportunities for evoking and affirming some of the poetics of human experience” (Gunaratnam, 2007, p. 274).

Why poetry? “Given the reductionism of any method of inscription, choice of method reflects researchers’ deeper assumptions about social life and how to understand it” (Emerson, Fretz, & Shaw, 2011, p. 14).

My method of choice, my way of making meaning, is poetry.

### **Data**

Autoethnography “utilizes data about self and context to gain an understanding of the connectivity between self and others within the same context” (Ngunjiri, 2010, p. 1).

What counts as data in an autoethnographic account? Any artifact that provides information that the writer can draw upon to tell the tale. William-White (2012) used “journal entries, conversations, text messages, [and] emails” (p. 236); field notes and journal entries are often identified as the most common data sources for autoethnography and autoethnographic poetic inquiry (Ellis, 2004; Leggo, 2008; Prendergast, 2009).

My data sources are personal documents and medical records.

### ***Personal Documents***

There is a rich tradition of making use of personal documents in social science research. In *The Use of Personal Documents in History, Anthropology, and Sociology*, a personal document is defined as

one in which the human and personal characteristics of somebody who is in some sense the author of the document find expression, so that through its means the reader of the document comes to know the author and his views of events with which the document is concerned (Redfield, in Gottschalk, Kluckhohn, & Angell, 1945, p. vii).

Gottschalk, Kluckhohn and Angell (1945) each considered the value of using personal documents in research in their respective fields. Kluckhohn, the anthropologist, stated that “Life events have meaning only in their context” (Kluckhohn, in Gottschalk, Kluckhohn, & Angell, 1945, p. 112). His argument is that personal documents can be rich sources of meaningful information, but they are not research per se until they are analyzed and contextualized: “There is a sizeable bulk of biographical material available, but its significance – from either the cultural or personological angles – has not been expounded” (p. 133).

There is an even more “sizeable bulk of biographical material” available today, ripe for systematic introspective analysis:

We live in a world rich with personal documents that [chronicle] our lives, from college transcripts to medical reports to Facebook ‘likes’... The range of such materials that may be incorporated into autoethnographic inquiry seems limited only by researchers’ interests and imaginations. (Anderson & Glass-Coffin, in Holman Jones, Adams, & Ellis, 2013, p. 68).

The personal documents I rely on for my autoethnographic poetic inquiry include:

*Personal journal*

I have kept personal, handwritten journals since the early 1990s, and my journals serve as the major source of data for this autoethnography. Many autoethnographers rely on journals to track and reflect upon their experiences; researchers who are preparing to write autoethnography may begin keeping journals -- autoethnographic “field notes” -- specifically so that those documents can serve as a source of data (Ellis, 2004; Emerson, Fretz, & Shaw, 2011). In my case, the journals existed prior to my decision to write autoethnography. This means that my account is not curated or filtered in advance (though certainly curating and filtering are involved in creating my autoethnographic texts). Thought of another way, the “foundness” means that my journals lack explicit intention. This is true of all the personal documents I use for this project. The generated poems, based on intentional, directional reflection, are a necessary complement to the found poems based on personal documents.

In my journal for the relevant timeframe (Fall 2014 through Fall 2015) there are 85 entries. Not every journal entry specifically mentions my physical condition: using the timeline (see Medical Records, below) will help me to connect the emotional states

recorded in my personal writing to my experiences with medical professionals and instances of intervention (or lack thereof).

### *Personal blog*

On my personal blog for the relevant timeframe, there are 13 posts (November 4, 2014 through October 12, 2015). As with my journal, not every blog post addresses my ordeal. My blog posts, then and now, tend to have a more formal style than my journal entries. They are variations on the themes with which I was concerned when I started blogging: the craft of writing, my mental health, feminist critiques of popular culture, secular spirituality, queer relationships, and the like. When I was considering whether or not to use the blog as data for this project, I skimmed the entries for the year in question. There is a subtext present that I have been glad – even relieved – to explore in the context of this project.

### *Letters*

I have been a prolific if inconsistent letter-writer since my adolescence. I have continued to write letters by hand, on the computer, and in e-mail form. A friend to whom I addressed several letters during the year of my quest for care has graciously returned them to me for use in this project. I also have e-mails written to friends, family, professors, and employers.

During the year my ordeal, I did most of my communication about my ongoing situation via e-mail rather than by phone; I therefore have a written record of the ways I described my condition and my prognosis to friends, employers, and the faculty of my graduate program. These documents provide evidence of the ways in which I performed



“strong black womanhood” to an audience of people affected my situation, however peripherally.

### *Medical Records*

I have comprehensive records of my quest for care. These records begin with the emergency room visit on the night of the accident and also include multiple visits to urgent care, my primary care physician, physical therapists, chiropractors, radiology (x-rays and MRI) and a specialty pain clinic. I also have complete records from my surgery and hospital stay. These records are used to create a timeline of my experience, and as a memory aid. I also use them in conjunction with my journal entries, blog posts, and letters, in order to provide contextual information for the poetic constructions.

### *Speaking of / from Memory*

“All memory is individual, unreproducible-- it dies with each person” (Sontag, 2003, p. 86). I would argue that it dies before the person does, and becomes only a *representation* of a memory: whether written, recorded, or photographed, the essence of the moment is always already gone. “The life story becomes an invention, a re-presentation... In writing an autoethnographic life story, I create the conditions for rediscovering the meanings of a past sequence of events” (Denzin, in Holman Jones, Adams, & Ellis, 2013, p. 126).

Autoethnographers and other writers who write from life have wrestled with the question of credibility in relation to the imprecision of memory. What does it take to create a faithful account? Ellis (2004) discusses this question in terms of the situated-ness of memory: “My current frames of memory – and my need to have a coherent sense of

self – influenced what I remembered and what the memories meant to me... your current perspective always clouds your memory” (p. 117). I acknowledge this explicitly: my work references what really happened, but the emphasis is on the feelings as recorded in my personal writing and shaped by both memory and present perspective (Ellis, Adams, & Bochner, 2011). “... [Memory] is not remembering, but stipulating: that *this* is important, and *this* is the story about how it happened, with the pictures that lock away the story in our mind [sic]” (Sontag, 2003, p. 86).

My most vivid memory from the immediate aftermath of the accident is the feeling of a smile on my face. An emergency responder, checking for concussion, asked me “Who is the President of the United States?” I smiled as I answered: “Barack Obama.” The only record of this – until now, in this moment, this writing – is the impression of the moment on my mind.

Written words, and vivid images. The muted game show on the TV in the waiting room: “We don’t get to choose what we remember” (Hix, 2015, p. 38). We don’t remember only what’s worth remembering. We don’t remember all that’s worth remembering. This is the life-storyteller’s dilemma. The slipperiness of memory means that “Lived experiences cannot be studied directly. They are mediated through language” (Denzin, in Spry, 2011, pp. 11-12).

My solution is poetry, which never pretends to portray “the truth, the whole truth, and nothing but the truth”, but aims instead for verisimilitude, evocation, and resonance (Hetherington, 2012; Leggo, 2008; Pelias, 2004).

Analyzing the success of such aims is a complex process. After presenting the poems in Chapter 4, I take up that task in Chapter 5.

### **Forward with a Broken Heart**

What is missing  
from scholarly writing?

The heart. (Pelias, 2004)

Will I right  
These wrongs  
If I  
Write  
These wrongs?  
Will I break  
My heart  
If I  
Make this  
Art?

The way forward is with a broken heart. (Walker, 2000).

Early in the first chapter of *A Methodology of the Heart*, Ronald Pelias (2004) imagines a conversation between himself and a traditional social science scholar, a scholar skeptical about the value Pelias places on speaking from – researching from -- the heart:

Some would object: “To say all research is a first-person narrative is not to say that all research is about the heart. The heart pushes the self forward to places it doesn’t belong.”

And I would respond: “I don’t want to go to places where the heart is not welcome. Such places frighten me.”

“Are you frightened by the truth?” would come the rejoinder.

“No, I’m frightened by what poses as the truth.”

(Pelias, 2004, p.8)

I, too, am wary of places where the heart is unwelcome. I, too, am suspicious of what poses as the truth. Traditional social science methods of meaning-making too often leave the heart – emotion, intuition, personal perception – out of the equation (Collins, 2000; Holman Jones, Adams, & Ellis, 2013). As I resist the marginalization of scholarship by and about Black women, I also resist marginalization of matters of the heart.

It frightens me, to do this work, and yet I find I have no choice but to move through the fear: “[We] have been socialized to respect fear more than our own needs for language and definition, and while we wait in silence for that final luxury of fearlessness, the weight of that silence will choke us” (Lorde, 1984, p. 44).

The weight of that silence.

The wait, and the silence.

Holding silence, choking heart.

Broken silence, broken heart.

Forward with a broken heart.

I have always written for myself. Now, not without fear, I write myself for others (Lorde, 1997; Holman Jones, Adams, & Ellis, 2013, Prendergast, 2014).

## Chapter Four: Vivid Sections

### Epigraph 1

The story will write itself.  
Its preference is for the page, but,  
If denied the page,  
Then:  
on  
the body.

## Epigraph 2

“The doctor will see you now.”

No.

The doctor will see only

This

Black

Woman

Body.

**Now You See Me**

(Poems)

## **Timeline 1**

Accident.

Emergency room:

    X-ray.

Urgent Care.

Chiropractic adjustment.

Urgent Care.

Primary Care.

Chiropractic adjustment.

Primary Care.

Chiropractic adjustment.

Physical Therapy.

Physical Therapy.

Primary Care.

Urgent Care.

Pain Clinic.

Pain Clinic:

    Sacroiliac Joint Injection.

Primary Care.

Physical Therapy.

Physical Therapy.

Physical Therapy.

Primary Care.

Primary Care.

Primary Care.

Pain Clinic.

    Sacroiliac Joint Injection.

Primary Care.

Urgent Care.

Primary Care.

Urgent care.

Primary Care.

    X ray.

Pain Clinic.

    MRI.

    Surgery.

Recovery.

Recovery: Hope.



**Timeline 2**

I [redacted] suffered [redacted]  
[redacted] the accident [redacted]  
[redacted] injuries [redacted] stand [redacted] walk [redacted]  
questions [redacted]  
[redacted] emergency room [redacted] symptoms [redacted]  
[redacted] pain [redacted] grew worse. My neck grew stiff [redacted]  
[redacted] pain in my [redacted] back [redacted]  
emergency room.  
[redacted] emergency room, X-rays [redacted] No broken [redacted] fractured bones [redacted]  
[redacted] X-ray. [redacted] soft tissue damage [redacted]  
[redacted] whiplash [redacted] neck brace [redacted] pain  
[redacted] rest [redacted] ice.  
Throughout [redacted]  
[redacted] fatigued [redacted]  
[redacted] pain [redacted]

[redacted] exposed to cold [redacted] pain [redacted]  
[redacted] the pain [redacted] worse [redacted]  
[redacted] pain so severe [redacted] stand or walk [redacted]  
[redacted] urgent care [redacted]  
x-rays [redacted] pain specialists [redacted] physical therapists.  
[redacted] pain every day [redacted] sitting, standing, trying to sleep.

My symptoms [redacted] are consistent [redacted] caused by the accident on October 31, 2014.

Signed: \_\_\_\_\_

Date: \_\_\_\_\_

## **On Meaning**

Meaning is something we  
Make  
Not something we  
Remember.

And we have always  
Told stories.  
Which is to say,  
We have always  
Made meaning,  
or tried to.  
Found redemption  
In the telling  
(or tried to).

Will my words have weight  
Equal to the body?  
This page will burn  
As easily  
As I do.

But oh,  
The silk of it.  
My god!  
the flames.

## **What the Body Knows**

I believe in ghosts.  
Believer or not,  
I am haunted.

What the body knows  
It cannot forget.

Beloveds, believe:  
We are haunted.

(I am mostly  
ghost now).

## **Waiting Room**

Here is a  
Black woman  
In the ER  
Waiting room  
On Halloween night.  
See how she stares.  
What is she  
Waiting for?

Here is a Black  
Woman  
Not bleeding.  
Not bruised.  
Not broken.  
(Not yet).

What is she  
Waiting for?

Here is a Black woman  
On Halloween  
Night.  
Dressed to the  
Nines,  
Dressed to  
Kill.  
Dressed to  
Die.

What is she  
Waiting for.

**CRACK**

Broke back  
Black woman:  
Broke-ass  
Back.

*CRACK!*

\$60 later  
The same pain  
In my back.

## **Wind Chill (Kalanchoe)**

I count down the days  
To cold,  
To dark,  
But somehow I still  
Miss the signs,  
and the first frost finds me  
Unprepared.

My Kalanchoe is once again  
Robbed  
of opportunity to  
Thrive.

I pluck off her dying leaves,  
and wonder  
Is this resilience?  
The ability to  
Survive  
The coming of winter and  
Benevolent  
Neglect?

I pluck off  
Her wasted leaves,  
Try not to wish myself  
Out of this world.  
No more lamentations:  
They are wasted on the wind.

Wasted words and  
Wasted leaves,  
Lamentations  
On the wind.

## **Power(less)**

The only thing I can do is  
try not to burn down the world while  
I wait  
for my life  
to resolve.

If you had told me 20 years ago  
That nothing would be  
Worth it

I would not have believed you.  
But I  
Believe you now.

## What the Living Know

This too will pass.

(I crossed  
a line, I built  
a bridge)

This too  
Will pass.

And by “this” I mean:  
The endless hours *of*;  
And the bottomless longing *for*;  
And every stressor ever,  
And all of my time in the world.

(I think these things  
may take all year).



## **I'm Scared Tonight, and Cold**

I'm scared tonight, and cold.

I'm trying to shape a life  
worth living,  
trying to choose  
materials  
I can work with.  
Trying to see –  
and believe –  
that I have a lot  
to work with.

We want what we were promised.

But I'm scared tonight, and cold.

Pain –  
constant, sometimes  
severe –  
has defined my life  
for days.  
It's  
frightening and  
maddening  
to have my body  
betray me.

We want what we were promised.

I'm scared tonight,  
and cold.

## **It's Not Pain**

It's not pain.  
Not sharp like  
Pins,  
not sharp like  
Needles.

It's not  
Pain.  
It's an  
Aching,  
Resonant,  
Like the ringing  
of a bell, or  
the singing  
of a bowl.

It's not pain.  
It's an  
aesthetic:  
and I,  
not art,  
I, an aesthete.

## **One Good Reason**

I have one good reason  
to get up every morning.

This morning,

I've forgotten  
what it is.

## **How Far and How Fast**

I wonder how far  
and how fast  
I could run today  
If dared

(against medical advice)

to run  
away  
today?

## Seasons

I would gladly spend  
20 hours every day  
In a drug-induced  
Coma.

The sun sets,  
And the seasons  
Change.  
Nothing else does,  
and sometimes  
our friends  
Don't pick up  
the phone.

If I spent  
20 hours every day  
In a drug-induced  
goddamned  
Coma  
Who would miss me  
Besides my  
self? (And I  
already do).

## **One Question**

Here's the thing:  
if it doesn't break my heart,  
how will I  
recognize it?

My heart,  
is what I'm saying.  
Would I even recognize  
my own  
unbroken  
heart?

## **Light Snow (That Feels Heavy)**

It's snowing again.  
These days it is always  
Snowing  
Again.

Every day  
I claw my way  
Into dreaded  
wakefulness.

Every day  
I tell myself  
I have everything  
I need.

But what can I do  
in a world of such white?

It's snowing again.  
These days it is always  
Snowing.

## **Noah's Ark**

White Man.  
White Woman.

(This space  
intentionally  
left blank).

Man,  
man,

Black  
man.

Some woman.

Brown woman.

“Other” Woman,

“That” Woman,

Brown / Black /  
Queer  
Woman.

Female.  
Female.

7 Black  
Trans  
Woman.



## **X Rays**

Die,  
Agnostic imaging.

Die,  
Agnostic  
Tests.

Give me  
A god I can believe in,

A god who  
Answers prayer.

## **The Apostle**

I'm pretty sure it's how  
My mother  
Passed on:  
Waiting for God,  
Snow on the way,  
Reading the psalms of death.

It all came together in a  
Singularity:  
I am one  
who writes letters.

And I think I recall  
How her father  
Died too:  
Dreaming of God,  
A prayer  
(Or a poem)  
On his lips.

## **Gethsemane**

In Gethsemane,  
No one was  
an Apostle yet.  
There was still  
The crucifixion  
to get through.

Loneliness is knowing  
That you are going to die,  
And all of your friends are  
Fast asleep,  
And even your dog is  
Fast asleep,  
And only the new moon  
Keeps watch,  
And your secrets.

There are letters we write  
In the dirt of a tomb,  
Awaiting crucifixion or  
Resurrection.

(Tonight we turn the clocks  
Forward by one hour).

## **My Mind Breaks Up With My Body**

How does a self  
Become a body?

Accident:  
Injury.  
Suffering.  
Death.

Accident:  
Medicine.  
Overdose.  
Death.

Accident.  
Apathy.  
Entropy.  
Death.

And there is more  
To come.  
There is so much more  
to come.

## **Seven Veils**

The sun has moved past seven veils of cloud to show her face again, to show her face for the first time this week. I'm still describing my current condition as "moving towards health".

It's been six months since the accident, and I'm still fighting my way back to well, fighting my way past seven veils.

I am a promise worthy of keeping. My life is a song that begins with my name.

**Say Her Name (Women of the Charleston 9)**

I am a Black woman  
Just like Cynthia Hurd.

A Black woman like  
Sharonda Singleton,  
And the Reverend DePayne  
Middleton-Doctor.

I'm a Black woman  
Just like Susan Jackson:

A Black woman like  
Myra Thompson,  
and  
Just like Ethel  
Lance.

Invaluable,  
Undervalued:  
Just like them,  
Just like that, and

(don't we all feel  
a little bit  
tired  
too much of the time).

## **My Body Breaks Up With My Mind**

I've been  
napping during the day again:  
An attempt to fast forward  
Past tedium,  
To free my mind  
From my body, or  
my body  
From my mind.

Wake me up when night is over.  
Wake me up when winter ends.

I have hope. I really do.  
(I have hope – how about you?)

But I'm also weary  
of dreams deferred.

Weary  
Weary  
Weary.

## **Reading, Reading, Always Reading**

... And now, and before, and between: reading, reading, always reading. Bringing a book along, regretting when I don't, magazines I collect in waiting rooms, browsing the shelves at the library, tangents and Boolean searches and trying to find the way to say the words that will bring the next Best Book I Ever Read into my hands, into my head, and from my head into my heart.



## **I Want to Know**

1. Who I am, where I fit, what all of this means for me as an individual navigating this life.
2. What the weather is like, where you are.

## **The Body, Suspended**

What can it mean  
To move like this?

Supine,  
suspended,  
submerged.

Pulling myself  
through space,  
Or time.

Breathing  
In.

Breathing  
Out.

## **I Want I Need I've Tried**

The accident wasn't that bad.  
But I haven't recovered,  
and I don't know how.

I've tried to be:  
Brave,  
and consistent.  
Daring,  
and hopeful.  
The cold fingers of despair are always  
Reaching for my throat.

Anger. Jealousy. Bitterness. Fear.  
I want them gone.  
I protest: "*only love lives here!*"

BUT ...  
I NEED MY BODY BACK!  
I NEED MY HEALTH!  
I need sleeping through the night,  
and running every day,  
*free.*

I need it like  
air, like  
water.  
I need it  
right  
fucking  
now.

Because without it,  
I don't have any fucking hope  
for anything else.  
I don't even want  
anything else.  
Including –  
I'll say it –  
my life.

## **The Persistence of the Present Tense**

Memory happens in the present tense.  
Do you know what I mean?  
It is the sense – this sense –  
that everything that happened  
is happening now, or  
The only thing that ever  
Happens is  
Whatever is  
Happening  
Now.

What to do with memories  
That still don't feel like mine?  
And the bodies I have lived in  
That never feel like mine?

Pain traps us in the now.  
It will not be denied.  
It is so profound that we struggle  
to even remember  
its absence.

Pain forces mindfulness upon us,  
even as it makes us cry out  
for oblivion,  
Which is to say, for forgetting  
in the present,  
present tense.

## **Here on Earth**

The dreams I've had these past few nights are the best I've ever had: dreams of adventure in imaginary worlds, and one set here on earth, riding a broken bicycle home after a splendid evening with real-life friends. I awoke from the dream just as a stranger offered to fix the bicycle for me, and as hard as I fought to get back into that dream, it gave way to the others, which were wilder and more splendid by far than any others I've had for as long as I remember.

This is, I suppose, the most persistent form of hope.

## What the Living Do

(after Marie Howe)

First of all, remember,  
Or try to,  
How it felt, and how you  
Almost  
didn't make it.

Forget  
The stories that statistics tell,  
and the stories that we tell ourselves  
about statistics.

There are responsibilities  
that have their origins in dreams.

This is what the living do:  
put on socks when our feet get cold;  
take our medication;  
decide for ourselves when enough  
is enough.

Or, we wait.  
And live,  
And tell our stories.

On this cold clear morning  
I am among the living.  
This is what the living do.

I have escaped,  
and lived,  
to tell you.

So ask yourself what the living do  
When they are not afraid.  
And then ...

## Chapter Five: Ars Poetica

### a·nal·y·sis

(Definition):

*noun*

detailed examination of the elements or structure of something, typically as a basis for discussion or interpretation.

Or

violent extraction of meaning from a text (Anthym, circa 2001: Note to self during an undergraduate poetry seminar).

(End definition).

Modernist American poet Archibald MacLeish closes out his poem *Ars Poetica* with this couplet:

A poem should not mean,

But be.

(MacLeish, 1952, p. 41)

In the poem, MacLeish is writing against the tendency of scholars and critics to

“... tie the poem to a chair with rope

and torture a confession out of it” (Billy Collins, 2006, p. 58).

I am not against analysis. At its best, it can deepen the appreciation of the observer for the object of observation. However, at its worst, it can bypass the observer’s

intuitive understanding, substituting the ideas of the creator, or some other supposed expert, for the observer's visceral in-the-moment reaction.

I have attempted to have it both ways. The poems were presented in naked form in Chapter 4, leaving the reader free to engage with the work on its own terms, absent any additional contextual information or analysis. But because this is a dissertation, I am obliged to tie each poem in turn to Billy Collins' chair (2006). I can only hope I have not tied the knots too tight.

The analysis in this chapter is presented in three parts. First, I reflect on the process of creating the poems for this project. I discuss transcription, strengths and weaknesses of using my personal documents as data sources, and decision points about content, format, and flow. Next, I closely examine the individual poems. I describe the source material for each of them, comparing and contrasting source material to finished poem where appropriate. I discuss my use of poetic conventions and literary allusions. Finally, I analyze the collection of poems in relation to the literature of illness narratives, counter-narratives, autoethnography, and poetic inquiry.

### **Part 1: Process**

In some ways, I have been writing these poems for years. Poetry for me is not just something that I do; it's a way of being in the world (Leggo, 2008). Waking up at 3 a.m., in one kind of pain or another, thoughts racing, I often reached – reach -- for my journal. As I developed this dissertation, ideas for poems came to me, and I scribbled them down on whatever paper I had ready to hand. *Waiting Room* and *CRACK* are examples of poems written along the way.



When it came time to devote my full attention to crafting Chapter 4, I began by creating a timeline of my quest for care. The timeline is based on the comprehensive medical records I had previously compiled in 2015 and 2016 in preparation for the lawsuit against the other driver's insurance company.

As I have indicated, the car accident took place on the evening of October 31, 2014. My first journal entry after the accident was written on November 5, 2014. Over the following year, I wrote in my journal on 84 additional dates, sometimes multiple times in a single day. Additionally, over the course of that same year, I wrote posts to my personal blog on 13 separate occasions, with the first post in that time period on November 24, 2014, and the last one on October 14, 2015. The surgery I underwent in September of 2015 was not the end of dealing with my injuries from the accident; it did not complete my healing. However, it represented a change in the care I received. After the surgery, medical professionals generally trusted my assessment of my pain, and I received adequate and appropriate care to alleviate my symptoms. So, for this project, I chose to transcribe journal entries beginning on November 5, 2014 and inclusive of entries through the one-year anniversary of the car accident.

I transcribed the entire year in one long day at the University of Denver Anderson Academic Commons. I propped my journal up between a computer monitor and keyboard, and typed it into a Word document, completing the task just 15 minutes before the building closed for the night. I had my research notebook at my side, the one I used throughout the dissertation for informal observations about the dissertation process,

reminders, and deeper thinking about the nature of the work. I occasionally paused while doing the transcription to write down impressions, reactions, and notes for poems.

I chose not to use software that is specifically designed for analyzing transcripts and organizing qualitative research, though this is what many others have done in the course of poetic inquiry (Glesne, 2007; Prendergast, 2009). In making that decision I went back to the purpose of the project, and the reason I chose poetic inquiry: I wanted to write my way into a deeper understanding of my experience, and create an evocative, impressionistic account (Faulkner, 2007; Leggo, 2008; Richardson, 1994). I wanted to attend to whatever themes arose intuitively. I have not ruled out the possibility of completing another project based on the same source material, using qualitative research software, counting what can be counted, weighting my words. But for now, for this, I chose a more personal approach.

This next admission might be controversial.

As I transcribed, I made the decision to omit certain entries, or parts of entries. I first made that decision when I came to entries written in December 2014, detailing my Christmas visit home. I asked myself, “Am I really going to transcribe ten pages of writing about shopping trips, Christmas cookies, my friends’ marital woes, and the funny things my nephew said?” That information is not necessarily entirely irrelevant: there is something to be said about how hard I worked to perform wellness over that holiday season (Frank, 1991). But to try to turn it into poetry for this project seemed like extra unnecessary work, a time-intensive tangent that I imagined would bear little if any fruit. The decision made, I jotted down criteria for moving forward with the transcription,

giving myself permission to omit entries, or parts of entries, that were mostly about goings-on in the lives of other people; monomaniacal rants about TV programs I was watching and books I was reading; or too private for even a project as personal as this one.

After transcribing the entries that fit my inclusion criteria, I had just over 5,000 words. I printed out the entire document, along with my 13 blog posts. I took them home, and started highlighting. Highlighting the transcripts started out as a kind of coding (Schenstead, 2012). I used a bright orange gel pen to highlight overt references to my physical condition, and a blue metallic gel pen for passages that seemed like poetry. I made annotations in the margins of the document, and wrote longer “memos” in my research journal (Emerson, Fretz, & Shaw, 2011, p. 185).

I read through the transcription several times, writing notes, crossing out certain lines, circling others. In my research notebook, I recorded the observation that “so much of this journal is about where I am and what the weather is.” That became a place to start. Weather became a metaphor and motif, a recurring theme that gave the collection continuity.

My method of data analysis has much in common in with Glaser’s (1965) constant comparative method of qualitative data analysis, a method which is particularly well suited to developing, rather than testing, hypotheses, and “plausibly suggesting” a variety of properties related to a phenomenon, including “conditions, consequences, dimensions, types, processes, etc.” (Glaser, 1965, p. 438). Glaser describes four steps of the constant comparative method (p. 439):

1. Comparing incidents applicable to each category.
2. Integrating categories and their properties.
3. Delimiting the theory.
4. Writing the theory.

I engaged in only the first two steps, as my purpose was making meaning rather than generating theory per se. The difference is subtle, but vital: evocation versus explanation.

After transcribing, coding, and annotating, I started writing. I wrote and revised the poems over the course of several days. The poems are, for the most part, quite short. This was not a surprise: it is consistent with my other poetic work.

The biggest surprise – and biggest potential limitation -- that came out of this process is that, over the course of that year, I wrote very little about my interactions with medical professionals, or trips to Urgent Care, or physical therapy sessions.

In a year of journal entries and blog posts, the following three references are the only references to medical intervention of any kind until after the surgery:

February 5, 2015 (journal): I wonder how far and how fast I could run today, if I dared – against medical advice – to run today.

May 12, 2015 (journal): ... Too sleepy to move pen across page ... the drugs are quick!

July 20, 2015 (journal): [I am] reading, reading, always reading: Bringing a book along, regretting when I don't, magazines I collect in waiting rooms ...

I was surprised by that because my memory of that year is dominated by the ordeal: not just the pain, but the fact that I could not get any significant lasting relief from it, no matter how many specialists I visited, or over-the-counter medications I took, or treatment protocols I followed. I wrote about the pain. I wrote a lot, about the pain. But until after the surgery, there is no mention of help-seeking behavior. Without my medical records, an outside observer would have no idea that I had dozens of visits to medical professionals that year, seeking a way to alleviate my own suffering. The subtext is there. I see it. I see it because I lived it, and because I have the medical records to prove it. For the purpose of this project, the availability of my medical records as an additional, supplemental source of data is a major strength. Ultimately, I relied as much on the medical records as I did on the journal and the blog in the writing of the poems.

In Chapter 3 I expressed my intention to use one additional data source: personal letters I wrote over the course of the relevant year. I reviewed several of those letters, both letters sent through the U.S. mail, and letters sent via e-mail. Ultimately, I decided not to use any of my personal letters for this project. I made that decision based on criteria similar to the criteria I used when making decisions about transcribing my journal. The letters are not on topic: they are about other people, or else they are reflections on popular culture, or they are written in response to received correspondence. I did make use of one letter, written to the Victim's Advocate who oversaw my case: its use is detailed in the discussion that follows in Part 2 of this chapter.

I expected to have a balance of "found" poems and "generated" poems (Prendergast, Leggo, & Sameshima, 2009), but most of the poems are hybrid. In some

cases, lines extracted from many different journal entries and blog posts serve as scaffolding for a single poem. In the end, I relied on my “headnotes” as much as I relied on my personal documents (Emerson, Fretz, & Shaw, 2011; Wall, 2008). The memories that were activated by looking through my medical records and transcribing my journal were vivid and productive. With Wall (2008) I have come to think that, when writing autoethnography, “It might be that headnotes are more important than field notes” (Wall, 2008, p. 45). I thought I would poetically rewrite my personal documents, and I did that, but mostly I wrote from memory, my personal documents serving as aide-mémoire.

### **Literary Influences and Allusions**

#### **American Sonnet**

Gwendolyn said “First fight, then fiddle.”  
Robert said “Just don’t call yourself “*Black*.”  
Sonia – go ’head sis – is holding the middle.  
Lucille reminds me: “Truth doesn’t mean fact.”

Mari regards herself past definition.  
Nikki calls poems empathic rendition.  
June names the poem political act.

Maya’s phenomenal,  
Langston’s adorable,  
Tolson to Hayden at Fisk was deplorable.

In whose mighty company do I belong?  
Can I commit to a lifetime of writing these wrongs?

Like Audre I’m lesbian, feminist, Black,  
A warrior poet developing craft,

But ...  
Is this still a sonnet  
If I put my own  
imprimatur  
on it?

There are works of literature and other art that I have internalized so completely that I sometimes all but forget that they aren't mine, that a rhythm or reference that appears in my work did not originate with me. I think of those works of literature and other art as "sponsors of [my] metaphorical habits" (Krieger, 1979, p. 600).

Despite my general awareness of the fact that I have been influenced by the work of others, it can be a challenge to point to clear one-to-one relationships between those sources and my own creative efforts unless there is a direct reference or allusion. All texts are layered; poetry is especially so (Watson, 2006).

Instead of attempting to name all, or most, or even many of the influences that hover at the edges of *Now You See Me*, I will limit my discussion to those that I deem most notable: Christian liturgy, former U.S. Poet Laureate Kay Ryan, and Audre Lorde.

### ***Liturgy***

Growing up as I did in a conservative evangelical church community, the Bible was a fixture of my childhood and my youth. I have read the Bible in its entirety multiple times. My youth group was competitive in "Bible Bowl" tournaments, where teams recited scripture from memory; there was a time when I could recite the first three chapters of the book of Genesis, and over two dozen Psalms, among many other championship feats. I recall handwriting practice that doubled as memorization drill: I would spend hours writing out a single verse in cursive, over and over.

Hymns were similarly a fixture of my childhood, and the influence of hymns on the canon of English-language poetry has been documented and theorized: "Central to the

poetic tastes and habits of the English people is the idiom – the poetic idiom – of ... many of the greatest hymns” (Holbrook, 1962, p. 386).

My first poetic publication was in the pages of the church newsletter. I was eight years old.

### ***Laureate***

I initially encountered Kay Ryan’s work during her tenure as United States Poet Laureate (2008-2010). When weather-as-motif emerged in my journal transcription, I recalled *Winter Fear*, one of my perennial favorites:

Is it just winter  
or is this worse.  
Is this the year  
when outer damp  
obscures a deeper curse  
that spring can’t fix,  
when gears that  
turn the earth  
won’t shift the view,  
when clouds won’t lift  
though all the skies  
go blue.  
(Ryan, 1999, p.18).

In just 43 words divided into 12 lines, Ryan evokes the creeping sense of despair that those of us who suffer from Seasonal Affective Disorder know all too well. I was inspired and encouraged by this example, not only for its content, but also for its brevity. Ryan’s poems are a surgical strike, a gut punch: she “packs more coherent argument into two dozen lines of verse than some poets manage in an entire book” (Yezzi, 2001, p. 103), and “her deceptive concision lends her lines a sly power” (Yezzi, 2001, p. 104). I aspire to a similar effect.



## *Lorde*

The influence of Audre Lorde on my life and my work cannot be overstated. In my early 20s, coming into feminism, coming out of Christianity, I received *The Marvelous Arithmetics of Distance* (1993) as a gift.

What a gift.

I discovered in its pages a Black woman with a poetic sensibility that called to my own. Her wit and anger, her inventive turns of phrase and references to West Indian heritage, her attention to the epic and the intimate, helped me to envision a way of being and doing in the world beyond what had been modeled in my cloistered Christian community. Some of Lorde's poems, like Ryan's, are fleeting and fierce:

### *Beverly's Poem*

I don't need to be rich  
just able  
to know how it feels  
to get bored  
with anemones.

(Lorde, 2000, p. 395).

In *Now You See Me* her influence is most obvious in the way I center the racial aspect of my identity (see Morris, 2002), and in the way I struggle to wrest meaning from a devastating bodily experience, as she does throughout *The Cancer Journals* (1997; 1980) and in much of the other work she created after her cancer diagnosis: "I am standing here as a black lesbian poet, and the meaning of all that waits upon the fact that I am still alive, and might not have been" (Lorde, 1997, p.17-18). Audre Lorde's work has

been and continues to be relevant for scholars across disciplines who are attempting to reckon with the intersections of race, gender, and physical ailment (Bolaki, 2011).

In her obituary for Audre Lorde, reprinted in the 1997 edition of *The Cancer Journals*, Adrienne Rich said “Poetry was at the core of Audre’s expressive life, her way of knowing” (Rich, in Lorde, 1997, p. 83). Those words are true of me as well.

I want to note that I intentionally chose not to read Audre Lorde while I was writing the poems for this project. Where her influence is obvious, as noted in the explication that follows, it is intuitive, not intentional.

## **Part 2: Product -- Explication**

### **How to Write a Poem**

First, wash your hands.  
You are doing  
Holy work,  
Performing  
Surgery,  
Going  
to War.

The poem is a prayer,  
is medicine  
is battle cry.

The poem is a  
Momentary truth:  
Speak it.

The poem is  
an inside  
Joke:  
Tell it.

Word.  
Sword.  
Wield.

Take up  
Your pen, or any  
Other weapon  
Suited to your hand.

Begin anywhere.

Use everything.

(How did I write this,  
Poem?  
I am asking you,  
Poem. How did I  
write you? Where did you  
Come from?  
And  
what do you  
mean?)

Take off your shoes.  
(And isn't it  
a beautiful obeisance,  
and also profane,  
To enter this space  
unshod?)

Feel the  
holy ground under your  
Feet:

Call  
and  
respond.

Say the same  
something several  
different ways.

Move the words  
Around  
In your mind,  
On the page,  
In your mouth.

Let the poem  
Come to you.

(I let the poems  
Come to me)

She is in the water  
You used to wash  
Your hands.

He is in your shoes  
Walking in  
The forest.  
They are in  
your hands.

How did I write this  
Poem?

One word  
at a time.

The process by which I write poems is always initially intuitive. Generally, I agree with Alice Walker, that “unlike ‘writing’, poetry chooses when it will be expressed, and under what circumstances” (Walker, 2003, p.xii). My responsibility as a poet is to be prepared, to “wash my hands”, as I say in the poem above, to call out to the muse, responding when she appears.

In this section, I discuss each of the poems presented in Chapter 4 in turn, in the order in which they appear. I considered organizing this discussion in terms of theme, or in “generated poems” and “found poems”, but ultimately I decided to offer the analysis in the order of appearance for the sake of simplicity, saving a discussion of themes for Part 3 of this chapter.

As I indicated earlier, in this project the distinction between “generated poems” and “found poems” is not always definitive. In the explication that follows, I note only when and how particular poems make use of source material; the reader can assume that a poem is “generated” unless otherwise specified.

### **Epigraph 1**

When talking about my dissertation, I have often said “This is the dissertation that only I could write, and this is the only dissertation I could write.” I did not mean that no other topic was feasible; I meant that no other topic was as compelling, as personal, as urgent as this one. Perhaps I should have said “This is the dissertation that I *have to* write”.

*Epigraph 1* is technically a generated poem, as it is not based on any of the source material I used for this project. It is based on my own reflection that there have been times in my writing life when the muse is heavy upon me, making it impossible to sleep, or to focus on anything else, until I have written what must be written. During such occurrences, I have often remarked, in the pages of my journal and elsewhere, that “the thing writes itself”. This poem is an attempt to capture my experience of that phenomenon.

The poem is also about the necessity of exorcism. Audre asked “What do you need to say? What are the tyrannies you swallow day by day and attempt to make your own, until you sicken and die of them, still in silence?” (Lorde, 1997; p. 19). There is an old axiom that says “you are only as sick as your secrets”. Expressive writing is an

exorcism, a process for purging the sources of existential ailment that manifest in flesh if not excised from the spirit.

### **Epigraph 2**

This poem is both accusation and lamentation. Doctors do not see people: they see patients (Frank, 2013). They see symptoms. They see bodies. *Epigraph 2* leads directly into the defiant title of the piece; in a way, the title is part of that poem. The doctors didn't see me. But you will.

### **Timeline 1**

This poem is a found poem based on my medical records. I wanted to offer an impressionistic overview of that devastating year. The title is somewhat ironic: the poem is not a timeline, per se: there are no dates, no times, just a creeping sense of futility and desperation. I don't know whether even a close reading makes it clear that my Primary Care Physician was of no help at all; that is one of the compromises involved in my decision to write poetry instead of narrative. It was a physician at Urgent Care who wrote me the referral to the pain clinic. It was a physician at the pain clinic who wrote me the referral for an MRI. The physician who read the results of my MRI was the same physician who performed my surgery 36 hours later.

### **Timeline 2**

This poem was created by redacting portions of a letter I wrote to the Victim's Advocate who oversaw my case in the county court. I was introduced to "blackout poetry" in the summer of 2017 at a workshop by Denver poet and self-described "living word architect" Molina Speaks.

The purpose of blackout poetry is to transform a text, either getting to the essence or changing the meaning altogether. In this poem, I use the technique for the former purpose. Taken together, the *Timeline* poems offer slightly different perspectives on the same series of events. While the first timeline is about “them” – the medical establishment – the second timeline is very much about me, beginning with a blunt, authoritative statement: “I suffered”.

Another version of this project could have been created entirely through blackout poetry: the full transcript of my journal; redacted. But I am not confident it would make for compelling reading. Using the blackout poetry process on the letter was effective in part because the letter is purposeful, a compact and intentional telling, staying on topic. The same cannot be said for most of my other personal documents.

### **On Meaning**

I wrote the first draft of this poem during the transcription process. It was a response to my own surprise that the meaning I’ve made of that year – the meaning it has in my mind, in this present tense -- isn’t immediately evident in the pages of my journal. I remember much about the experience, but I don’t remember exactly what the experience meant to me at the time; the meaning it has for me now is a construction.

When I say that the page “will burn / As easily / As I do”, I am attempting to denote the fact that meanings evolve and devolve over time (Schenstead, 2012). I am not now exactly the person who wrote the journal in 2014 and 2015; I am already not exactly the person who wrote the poem *On Meaning* for this dissertation. Nevertheless, I find

value and beauty in the meanings I made, then and now. Hence: “oh / The silk of it. / My god! / the flames”.

### **What the Body Knows**

This poem has multiple meanings. It is about the fact that, even after the surgery corrected the cause of my most painful symptoms, I had a long road of recovery ahead of me due to maladaptive movement patterns I had adopted over the course of the year in an attempt to alleviate the pain. That is what I am referring to when I say “What the body knows / It cannot forget”.

The poem is also about intergenerational trauma, particularly intergenerational trauma as embodied by Black people:

The body is the place of captivity. The Black body is situated as a sign of particular cultural and political meanings in the Diaspora ... as if those leaping bodies, those prostrate bodies, those bodies made to dance and then to work, those bodies curling under the singing of whips, those bodies cursed, those bodies valued, those bodies remain cursed in these attitudes. They remain fixed in the ether of history ... [cleaving] not only to the collective and acquired memories of their descendants but also to the collective and acquired memories of the other. We all enter those bodies. (Brand, 2001, p. 35)

Keeping with that theme of inherited, embodied trauma, the phrase “Beloveds, believe / we are haunted” refers to Toni Morrison’s Pulitzer Prize winning novel *Beloved* (1987), which deals with slavery as a “great and deep collective wound of a people” (Slattery, 2000, p. 207) as well as “freedom through the acts of remembering and imagining” (Slattery, 2000, p. 208).

Finally, the poem indirectly references the work of Bettina Judd. In her 2014 volume *Patient.*, Judd uses poetic narrative to contextualize an “ordeal with medicine” in relation to the history of gynecological experimentation on enslaved Black women. She



writes “verdicts come in a bloodline ... to recover / I learn why ghosts come to me” (Judd, 2014, p. 1).

I was introduced to Judd’s work in the winter of 2017, when I was writing my dissertation proposal. My project, an account of my own ordeal with medicine, is very much in conversation with hers, another example of the inherent intertextuality of Black women’s life writing (Perreault, 1995) that I referred to in Chapter 2.

### **Waiting Room**

I started writing this poem in May 2017; it is the first poem I wrote when I knew that I would be writing poems for my dissertation. In the poem I inhabit an alternate point of view, imagining others’ initial impression of me: “Human bodies are visually read, understood, and narrated by means of symbolic meanings and associations” (Omi & Winant, 2014, p. 13). In the poem I engage with the symbolic meanings of a visual reading of my body.

There is poetic license here (Cahnmann-Taylor, in Cahnmann-Taylor & Siegesmund, 2018; Faulkner, 2007; Hetherington, 2012): Though it was Halloween, I was not “dressed to kill” in the colloquial sense of “dressed up”. I used the term for the overlapping parallelisms of “dressed to the nines / dressed to kill” and “dressed to kill / dressed to die”. In the poem, “dressed to kill” refers to the pervasive, racist assumption that Black people are inherently criminal, inherently violent (Solórzano, 1997; Welch, 2007). In that sense, Black people are always perceived as dressed to kill. “Dressed to die” evokes the fact that Black people are so vulnerable in our daily lives that, in a sense,

we are always dressed to die. We are always simultaneously dressed to kill, and dressed to die.

*Waiting Room* foreshadows a poem that appears later in the collection, the poem about the women of the Charleston 9: dressed for church, they were dressed to die.

Finally, *Waiting Room* calls out the simultaneous hypervisibility and invisibility of Black women and girls (Collins, 2000; Griffin, 2016; Harris-Perry, 2011; Lorde, 1997). I was seen, but only in the most superficial sense. I could neither avoid being seen on a surface level, nor make myself truly seen in a deeper, metaphorical way.

Here is a Black woman.

What am I waiting for?

I am waiting to be seen.

### **CRACK**

In this poem, I intentionally conjure the “crack epidemic” of the 1970s and 1980s, not only to subvert the stereotype of the Black “crackhead” – the poem is about a different kind of crack -- but also to acknowledge and relate to the desperation and despair inherent in seeking solutions that cost much, but solve nothing, solutions that may serve only to make the problem that much worse.

### **Wind Chill (Kalanchoe)**

This poem is meant to be read on multiple levels. On the surface level, I really do have a “Fang” plant (*Kalanchoe beharensis*) that I sometimes forget to bring inside when the weather changes. Its survival has astonished me; its survival is as astonishing and dangerous as the survival of Black women, because surviving abuse and neglect means

that there is the danger that abuse and neglect can continue. That is the danger of embodying the Strong Black Woman stereotype (Harris-Perry, 2011): we are not gentle with that which we perceive to be impervious.

This is a hybrid poem (found and generated) built around fragments of blog posts, arising from reading and rereading the transcripts:

From November 4, 2014: “The shoulder is definitely worst first thing in the morning, and not running is driving me crazy, especially as **I count down the days to the cold and darkness of winter**, when running outside will be so unpleasant as to be well nigh impossible.”

From November 22, 2014: “Tell me what’s worth it, so I can go do that instead. I am struggling to muster energy enough to care enough to *do* something. I don’t have much fight left in me, so please, tell me what’s worth fighting for, so I can fight for that instead. I’m in a bad way. **No more lamentations. They are wasted on the wind.** And no more thinking about things I can do nothing about. No more asking for anything.

I underlined the lines indicated in bold (above) during my first read-through of the blog transcript. Days later, I wrote a first draft of the poem. Later still, I left my plant outside on a day that started sunny and warm but then ended with snow, as is typical of early spring in Denver. As I was trimming the leaves of my plant the next morning, I thought about how guilty I feel that it has weathered so much benevolent neglect. I asked myself if it would be better for the plant to just die already, instead of putting up with the poor treatment it receives at my hands. I was already unhappy with the first draft of *Wind*

*Chill*. It felt clunky, labored, and unfinished. The peril of my plant provided inspiration for revision:

*Wind Chill (first draft)*

I count down the days  
To cold,  
To dark.  
Trying not to wish myself  
Out of this world.  
No more lamentations:  
They are wasted on the wind.  
No more lamentations,  
They are  
Wasted  
on this world.

*Wind Chill (Kalanchoe)*

I count down the days  
To cold,  
To dark,  
But somehow I still  
Miss the signs,  
and the first frost finds me  
Unprepared.

My Kalanchoe is once again  
Robbed  
of opportunity to  
Thrive.

I pluck off her dying leaves,  
and wonder  
Is this resilience?  
The ability to  
Survive  
The coming of winter and  
Benevolent  
Neglect?

I pluck off  
Her wasted leaves,  
Try not to wish myself  
Out of this world.  
No more lamentations:  
They are wasted on the wind.

Wasted words and  
Wasted leaves,  
Lamentations  
On the wind.

Introducing the plight of my plant gave the poem a bit of breathing room between the sentiment of counting down the days, and lamentations on the wind. It also introduced an element of pseudo-personification (Bloomfield, 1963). The plant is both a plant, and a stand-in for Black women, a stand-in for me.

### **Power(less)**

This is a found poem that draws on fragments of a journal entry as well as fragments of a blog post. In it, I articulate both rage (“burn down the world”) and helplessness (“the only thing I can do is ... wait for my life to resolve”). In calling back to a time 20 years prior, I reflect on the futility of waiting, admitting to myself that I already don’t believe it will be worth it.

The journal entries I drew on for the poem are dated two weeks and three weeks after the accident. I don’t know what I would have done if I’d known how much worse things would get, or how long they would stay that way.

### **Sources**

November 13, 2014 (journal fragment)  
I feel – and have been feeling – powerless.  
The only thing I can do is try not to burn  
down the world while I wait for my life to  
resolve into something beautiful.

November 22, 2014 (blog post fragment)  
If you had told me twenty years ago that  
nothing would be worth it, I would not  
have believed you. But I believe you now.

### **Poetic Interpretation**

#### **Power(less)**

The only thing I can do, is  
try not to burn down the world, while  
I wait  
for my life  
to resolve.

If you had told me 20 years ago  
That nothing would be  
Worth it,  
I would not have believed you.

But I  
Believe you now.

## **What the Living Know**

This poem is an example of the way in which a poem is a multilayered text (Watson, 2008). It is based on journal fragments, and the fragments in turn are based on other fragments.

### ***First fragment:***

There is a story I tell my nieces and nephews when they are reacting to something, and I want to offer perspective. It is based on a story that my own aunt used to tell to me, for a similar purpose. Here is an abbreviated version:

*There was once a king who offered half his wealth and half his land and his daughter's hand in marriage to the sage who could tell him a single phrase that would always make him happy when he was sad, and always make him sad when he was happy. And the winning phrase was "This too will pass."*

When I wrote in my journal on November 15, 2014, "This too will pass", I was trying to give myself perspective, and patience. The reminder doesn't always make me sad when I'm happy, any more than it always makes me happy when I'm sad. But when I find myself feeling trapped in a desperate circumstance or despairing mental state, "This too will pass" can serve as a reminder that desperation isn't all there is. Whatever the present circumstance, good or ill: it hasn't always been this way, and it won't always be.

### ***Second fragment:***

As I articulated earlier in this chapter, I grew up in a religious tradition that emphasized memorizing the scriptures. One of the many verses that remain with me is "For the living know that they shall die, but the dead know not anything" (Ecclesiastes

9:5). It is another way to remind myself that no torment is eternal: even if nothing changes for the better, death puts an end to awareness, including the awareness of suffering. I reference it in this poem as a variation of “this too shall pass”, death being the ultimate passing. Using the phrase as I do in the poem, with the title of the poem as the implied first line, deploys the poetic device of parallelism: couplets that serve as “thought rhymes”, wherein the second line of the couplet echoes the sentiment of the first. This poetic device is evident in many of the biblical Psalms (Miller, 1984). Psalm 77 provides several exemplars of Hebraic poetic parallelisms:

I cried out to God for help;  
I cried out to God to hear me.

I remembered you, God, and I groaned;  
I meditated, and my spirit grew faint

I thought about the former days,  
the years of long ago;

Will the Lord reject forever?  
Will he never show favor again?

Has his unfailing love vanished forever?  
Has his promise failed for all time?

Psalm 77:1-8, New International Version

In *What the Living Know*, the implied parallelism is:

The living know that they shall die / The living know this too shall pass.

The journal entry from January 1, 2015 makes mention of a crossed line, a built bridge: these are also parallelisms, and references to passing, to crossing over. The poem ends with a (slightly modified) fragment also taken from January 1: “I think these things may take a year”. I changed “a year” to “all year” to disambiguate the perception of time:

“a year” has an implied foreshortening, as in, “a single year”, while “all year” implies something somewhat more daunting, as in “all the whole long year”.

Either way, the sentiment is apposite of a New Year’s entry, but it also serves as a final reference to things that pass: time, yes, but this time in terms of one full journey around the sun. The living know that time will pass and lives will end, whether or not we’ve made of them what we wanted. This year will pass, and next year too. The living know this all too well.

**Sources**

**Poetic Interpretation**

November 15, 2014 (journal fragment)

**What the Living Know**

This too will pass.  
 And by “this” I mean: this particular  
 combination of stressors,  
 As well as all my time in the world.

This too will pass.  
 (I crossed  
 a line, I built  
 a bridge)

January 1, 2015 (journal fragment)

This too  
 Will pass.

I crossed a line. I built a bridge. I am loved  
 and loved and loved.

And by “this” I mean:  
 The endless hours *of*;  
 And the bottomless longing *for*;  
 And every stressor ever,  
 As well as all of my time in the world.

I think that’s enough to be getting on with. I  
 think these things may take a year

(I think these things  
 may take all year).

**I’m Scared Tonight, and Cold**

Frustration, fretfulness, and the sense of futility, as expressed in *Power(less)*, were also eventually accompanied by fear as I began to sense that there would not be a



timely resolution to my torment. “Afraid is a country with no exit visas” (Lorde, 2000, p. 383). I felt trapped – frozen, stuck -- and I was afraid.

### Sources

November 24, 2014 (blog post)

There are television shows that feature “working class” people. Usually they live in better houses and have better wardrobes than any person working a job like that would have in real life. Between these idealized imaginary worlds and the lies we were told about the value of a college education, it’s a wonder Occupy Wall Street was as short lived and ineffective as it was. **We want what we were promised.**

January 5, 2015 (journal)

I’m scared tonight, and cold. I’m trying to shape a life worth living, trying to choose materials I can work with. Trying to see – and believe – that I have a lot to work with.

January 22, 2015 (journal)

Back pain – constant, sometimes severe – has defined my life for the last several days. It’s frightening and maddening to have my body betray me.

### Poetic Interpretation

#### **I’m Scared Tonight, and Cold**

I’m scared tonight, and cold.

I’m trying to shape  
a life worth living,  
trying to choose  
materials  
I can work with.

Trying to see –  
and believe –  
that I have a lot  
to work with.

We want what we were promised.

But I’m scared tonight, and cold.

Pain –  
constant, sometimes  
severe –  
has defined my life  
for several days.

It’s  
frightening and  
maddening  
to have my body  
betray me.

We want what we were  
promised.

(I’m scared tonight,  
and cold).

There is anger mingled with the fear in this poem. I talk about betrayal, how I want what I was promised. I am referring to the fact that I worked hard to improve my health in the months leading up to the accident, exercising regularly, eating well. On the morning of the accident, I was the healthiest I have ever been in my adult life. While in the blog I am overtly writing about the American dream deferred (i.e., “lies we were told about the value of a college education”), the subtext is evident to me because I know what I was living through, what dreams of my own had been deferred. I was scared that I would never have the life I worked for, the life I was working toward.

Frozen. Trapped. Stuck. Repetition, an endless loop: I capture that feeling by making the title a repeating line throughout the poem, ending where I started.

In writing about a particular type of illness narrative, the “chaos” type, Frank (2013) says “The achievement of writing [this type of illness narrative] is to capture the claustrophobic terror” (p. 109) of the lived experience “in a way that gains the recognition of others”. That is the goal of *I’m Scared Tonight, and Cold*.

### **It’s not Pain**

Pain resists language, but we who suffer are obliged to try to language it (Frank, 2013; Scarry, 1985). This poem is based on one such attempt, as recorded in my journal on February 4, 2015:

## Sources

February 4, 2015 (journal)

It's not pain. It's an aching, resonant, like the ringing of a bell or the singing of a bowl. The ache that reminds me, again and again, of the power of telling our stories, the power of speaking the truth. I'm an aestheist: I believe only in art. Art is the only thing that has ever saved me. Art is the only thing that ever will.

## Poetic Interpretation

### It's Not Pain

It's not pain,  
Not sharp like  
Pins, not sharp like  
Needles.

It's not pain, it's an  
Aching,  
Resonant,  
Like the ringing  
of a bell, or  
The singing  
of a bowl.

It's not pain, it's an  
Aesthetic, and I  
(Not art),  
I,  
an aesthete.

In my journal, I aestheticized my pain, perhaps in an attempt to anesthetize it. In the journal, I describe “art” as the “the only thing that has ever saved me”; this is an appropriation of religious language. This appropriation is apparent in the poem also. Art replaces god (and I am not god: I cannot save myself). The analogy is that god is to the believer, or religious devotee, as art is to the aesthete. God saves the believer; art saves the aesthete. Sontag (2003) writes that art that takes suffering as its subject “evoke[s] the miracle of survival” (p. 87). In my case creating art about my own suffering did not only evoke that miracle; it was and is an attempt to make that miracle manifest.

The next three poems – *One Good Reason*, *How Far and How Fast*, and *Seasons*, are built around fragments of the journaling I did on February 5, 2015.

### **One Good Reason**

This poem begins with hope and ends with despair. In the original journal entry, I wrote “[My dog] Valentine continues to be one good reason to get up in the morning.” But I recognize this sentiment for what it was: a desperate attempt to put a bright face on dark feeling. What I didn’t write in the journal, but what would have been more honest is: “Valentine continues to be the only reason to get out of bed in the morning.” I certainly had that thought many times over the course of the year, particularly because mornings were always the most painful time of day.

### **How Far and How Fast**

This is a found poem, part of the February 5, 2015 journal entry. I added line breaks to the original statement, as well as a single, telling, word:

#### **Sources**

February 5, 2015 (journal fragment)

I wonder how fast and how far I could run today, if I dared – against medical advice – to run today.

#### **Poetic Interpretation**

##### **How Far and How Fast**

I wonder how far and how fast  
I could run today  
If I dared

(against medical advice)

To run  
away  
today?

The difference between simply running and running away is the difference between running for my life, and running from my life. Being unable to run for my life – in the best sense, in the sense of running for health, and for the joy of the breath in my lungs and the acceleration of my own heart – left me wanting to run from my life.

### **Seasons**

Claiming to want to spend “20 hours a day in a drug-induced coma”, as I did on February 5, 2015, was the closest I would let myself come to admitting in my journal that I was thinking about suicide. There is unconcealed bitterness in the statement that “The sun sets, and the seasons change, and sometimes our friends won’t pick up the phone”. In the poem, I connect those sentiments by asking who would miss me in my comatose state, besides “me, myself, and I”. It is very much the “who would even miss me if ...” thinking of a suicidal person.

What does not appear in any of the February 5 poems is the final contemplation in that day’s journal entry: “There’s a hole in the world. Not god-shaped. I wonder what shape it truly is.” I note that sentiment here in the analysis to lend credibility to my assertion that I am interpreting the February 5 text appropriately, not shading the past with the lens of the present. Despite the words on the page, I know that I did not feel I had any good reasons to get up in the morning. I know that I did not just want to run, I wanted to run away; I wanted a way out. I didn’t want to spend 20 hours a day in drug-induced coma; I wanted to die.

### **One Question**

This is another example of small changes that make a big impact, poetically speaking:

## Sources

February 4, 2015 (journal fragment)  
Here's the thing: if it doesn't break my heart, how will I recognize it? Art, is what I'm saying.

(Would I even recognize my own unbroken heart?)

## Poetic Interpretation

### One Question

Here's the thing:  
If it doesn't break my heart,  
how will I  
recognize it?

My heart,  
is what I'm saying.  
Would I even recognize  
My own unbroken heart?

In the journal, I was writing about art that moved me to the point of tears. The parenthetical aside was tangential, a phrase that came to mind that I liked enough to write down. In the poem, however, I am writing about how much I've changed in the months since the accident, how I hardly know myself anymore. My brokenness was so complete, my pain so overwhelming, that I could scarcely remember what my life felt like without it. The person I used to be was becoming unrecognizable to me.

### Light Snow (That Feels Heavy)

Weather as motif continues here. I was always in pain that year. It was not always severe, but it was always there. It covered over everything.

In the poetic interpretation, I left out the phrase "kicking and screaming", deciding that, despite its appearance in my journal, it was too much of a cliché to make for meaningful poetry. "I already have everything I need" is a reference to a mindfulness meditation mantra that I often repeated to myself. Like "this too will pass", it is meant to be perspective-shifting. At the time, it wasn't working. At the time, nothing was working.

I use the word “again” three times in 49 words; it is meant to conjure a feeling  
monotony: a world of such white, no differentiation, a blankness; snowblind:

**Sources**

February 16, 2015 (journal fragment)  
Light snow that feels heavy. Every day I  
claw my way, kicking and screaming,  
into wakefulness. Every day I tell  
myself, in an unconvincing voice, that I  
already have everything I need.

**Poetic Interpretation**

**Light Snow (That Feels Heavy)**

It’s snowing again.  
These days it is always  
Snowing  
Again.

Every day I claw my way  
Into dreaded wakefulness.

Every day I tell myself  
I have everything I need.

But what can I do  
in a world of such white?

It’s snowing again.  
These days it is always  
Snowing.

Kay Ryan’s *Winter Fear* (1999) is not the only winter poem that influenced me in  
writing *Now You See Me*. Allusions to the work of Robert Frost are evident in *Light Snow*  
(*That Feels Heavy*), notably, his poem *Desert Places*, the third stanza in particular:

And lonely as it is that loneliness  
Will be more lonely ere it will be less—  
A blanker whiteness of benighted snow  
With no expression, nothing to express.

(Frost, 1959, p. 296).

### **Noah's Ark**

On February 12, 2015, I wrote in my journal about the misappropriation of intersectionality, and the fact that seven black transgender women had been murdered in the first six weeks of 2015: “The murders of 7 black trans women this year alone already should remind us that the only statuses below ‘black woman’ are ‘black queer woman’ and ‘black trans woman’”.

There is a tension underlying the poem: While I am trying to evoke the hierarchy of the white supremacist capitalist patriarchy (hooks, 1992) and how it feels to be at the bottom of that hierarchy, I am also trying to avoid an uncomplicated “ranking” of oppression. I am attempting to comment on an observed reality, as interpreted through my positionality, without falling into essentialism; hence “This space / intentionally / left blank”.

### **X Rays**

On November 22, 2014, I wrote on my blog “If I should die before I wake, my last breath would be a fractured thank you to a god I don’t believe in.” Those words came back to mind as I was writing the *Timeline* poems, thinking about the fact that none of the X-rays I had after the accident showed the damage to my spine: diagnostic imaging failed me, just as surely as god did.

My atheism predates the accident by quite a few years, but the longing for something worth believing in – whether god or science – is still with me. Parsing “diagnostic” into “die, agnostic” is meant to be more than witty. I am writing about



longing for the death of my own doubt, the desire I have to suspend my disbelief, the yearning to pray to a god worth praying to.

### **The Apostle**

In this poem I am contemplating suffering and mortality and the way we live as we die. The positioning of *The Apostle* immediately after *X Rays* is intentional, as is the ‘small g’ god of *X Rays* and the ‘big G’ God of *The Apostle*. My mother, who died in my youth, believed in a ‘big G’ God all of her life, as did her father, who died in my childhood. In the poem I am connecting my mortality to theirs while contrasting their mode of facing mortality with my own way of contemplating that inevitable eventual occurrence.

In the poem *Legacy – Hers*, Audre Lorde writes about the death of her mother: “I learn how to die / from your many examples ... / constructing my own / book of your last hours” (Lorde, 1993, p. 4). Thinking about the example set in my own maternal line, I imagine that my mother and grandfather took comfort from their Christianity as they “read the psalms of death”. During my own ordeal, I had to look elsewhere for consolation. I did take comfort, sometimes, in writing. Writing a letter can be a type of prayer: it is an offering of self to another, hoping for a response that might or might not come. Letter writing can be “A prayer (Or a poem).”

My mother died on February 28, 1997. Every February, as the anniversary approaches, a cloud covers me. Sometimes I make the connection right away; sometimes it takes a while. In 2015, preoccupied with my physical pain, it took a while for me to connect my existential pain to its other perennial source. On February 23 I wrote “Last

night as I was going to sleep I thought about writing a letter.” What I don’t say in the journal I remember anyway, which is that suicide was very much on my mind.

When suicide is on my mind, I never want to say so in my journal. Somehow writing it down makes it serious, makes it seem like something more than a passing thought. In February 2015, it was something more than a passing thought. The letter I refer to in the February 23 journal entry, the letter I thought about writing, was a suicide letter.

If I say, “I am the only one who can read my journal”, I am not talking about permission; I am talking about what’s between the lines; I am talking about what’s underneath.

I am an apostle – a messenger, and one who writes letters – but my journal is not a book of revelations. It conceals as much as it reveals.

I conceal even here, in this telling. The concomitant counterstatement to “now you see me” is “now you don’t”. The title of the collection holds another implied parallelism, another multiple meaning.

*The Apostle* is about all of those things.

### **Gethsemane**

This poem engages with the trope of the suffering artist. I say “no one was an apostle *yet*”, that “there was still the crucifixion to get through.” In this poem, I suggest that the suffering artist trope offers some hope. There is loneliness in suffering, yes, and the certainty of death, but there is also the opportunity to make meaning: the “new moon keeps watch”; the writer awaits not only crucifixion, but also resurrection.

The closing couplet points to that hope: “Tonight we turn the clocks / Forward by one hour” is a fragment from the March 7, 2015 journal entry. Even the worst things, like winter, end eventually. Spring returns. Morning comes.

### **My Mind Breaks Up With My Body**

I wrote a lot in my journal and on my blog about what I was reading and watching that year. I sought out the kind of entertainment I had previously abjured: hyper-violent TV shows like *Sons of Anarchy*, gruesome murder mysteries by the likes of Karin Slaughter, boxing movies such as *Southpaw* and *Warrior* and *Million Dollar Baby*. I sought out visceral, immersive experiences that could take me out of my body and into my mind: stories that featured injury, suffering, agony, death. This poem is about rejecting the life of the body for a particular kind of life of the mind.

Scarry (1985) writes extensively about the relationship between pain and imagination – between body and mind -- in the second part of *The Body in Pain*. Because pain is “exceptional in the whole fabric of psychic, somatic, and perceptual states for being the only one that has no object ... no referential content ... [its presence] makes most pressing the urge to move out and away from the body” (p. 161; p.162).

There is an irony in my entertainment choices: while seeking escape from the vicissitudes of my body, I turned to stories that underscored the vulnerability of our mortal flesh. The conscious mind cannot make a clean break from the body.

I was awake at 2 a.m. on March 20, 2015. I wrote in my journal that I felt “pulled out of time, pulled out of my life. And there is more coming. There is so much more to come.”

This is the most terrifying thing about what happened to me: it could happen again. Accident, injury, illness, suffering: they are part and parcel of human existence. Even if no further significant accident or injury befalls me, someday something will kill me, even if only old age. This self will become a body for the final time.

### **Seven Veils**

This is a found poem, constructed from journal fragments.

#### **Sources**

Journal fragments:

March 21, 2015: The sun has moved past seven veils of cloud to show her face for the first time this week. I'm still describing my current condition as "moving towards health".

April 1, 2015: It's been six months since the accident, and I'm still fighting my way back to wellness.

May 1, 2015: Here it is: because it's not about beating anyone or competing with anyone, not even myself. It's about keeping a promise, a promise interrupted, but not broken. I am a promise worthy of keeping. My life is a song that begins with my name.

#### **Poetic interpretation**

##### **Seven Veils**

The sun has moved past seven veils of cloud to show her face for the first time this week. I'm still describing my current condition as "moving towards health."

It's been six months since the accident, and I'm still fighting my way back to well, fighting my way past seven veils.

I am a promise worthy of keeping. My life is a song that begins with my name.

Spring brought with it a measure of hope. That has always been true for me. In *Writing Selves: Contemporary Feminist Autography*, Jeanne Perreault (1995) describes autography – writing the self – as “the site of possibility ... whatever the dimensions of anguish” (Perreault, 1995, p. 62). There is something to be said for the fact of writing, regardless of content. Writing was a way of fighting for my life: the aesthetic reach in

*Seven Veils* is less obvious than in the poem *It's Not Pain*; less obvious in the poem and less apparent in the journal fragments which serve as scaffolding for the poem. But the impulse – aestheticize to anesthetize – is the same.

The “dance of seven veils” is a biblical reference that has found its way into the cultural lexicon. While it literally refers to the dance that ultimately culminated in the beheading of John the Baptist, the term is used more generally to invoke the inscrutability of the unattainable coquette. In the journal entry, I personify the sun as feminine, and by invoking “seven veils” I also personify the sun as a tease: having grown accustomed to 300 days of sunshine per annum in Denver, I lamented the long and unexplained absence of the sun. At the same time, I described myself as “moving towards health”; on March 21, 2015, health seemed as elusive and unattainable as the sun had been.

And yet, at last, the sun returned, and I needed to believe my health would too. In the journal, I am telling myself to have faith, to keep the promise I made to myself to stay alive long enough for things to get better. I am telling myself that it is worth it; I am worth it. I am singing the song that begins with my name.

And speaking of names:

### **Say Her Name (Women of the Charleston 9)**

On the evening of June 17, 2015, a white supremacist terrorist entered the Emanuel African Methodist Episcopal Church in Charleston, South Carolina and murdered nine African American congregants who had gathered for Bible study and prayer. Six Black women were among the massacred.

On June 30, 2015, I wrote in my journal:

“I’ve started a series of simple Facebook posts. ‘I am a Black woman, just like ...’ followed by the name of a Black woman who has recently been the victim of racist violence.” In my journal, I engaged with the question “Why the victims of violence, instead of poets, scholars, artists and activists?” I wrote: “[These women] were killed by people (racist white people) who saw them only as Black women. Which is to say, saw them as worthless. If Maya Angelou had still been living, and at Mother Emanuel that night, she would have been gunned down too, just like any other Black woman.”

I wrote what would become the coda for the poem on July 1, 2015: “I feel a little bit tired too much of the time.” The coda reflects the burden of performing Strong Black Womanhood (Harris-Perry, 2011; Scott, 2016).

There is not a lot of writing on race in my journal, then or now. There is not a lot of writing about gender, or sexual orientation. I don’t write a lot *about* those parts of myself, but I am always writing *as* that self, a self who is raced, gendered, sexed, oriented; I write an embodied self (Spry, 2011). Perreault (1995) wrote: “self writing [makes] the female body of she who says ‘I’ a site and source of written subjectivity, investing that individual body with the shifting ethics of political, racial, and sexual consciousness” (p. 2). Sometimes that consciousness is overt, as in the journal entry, and the Facebook posts referenced in the journal entry, and the poem I created for this project based on the reference, in the journal entry, to the Facebook posts. Writing – of myself and as myself -- is a way of living the intertextuality of Black Feminism. “... the writing

of self ... is central to the way in which feminism makes itself continuously meaningful” (Perreault, 1995, p. 2).

There are echoes of Audre’s work in *Say Her Name*. In the poem *Need: A Choral of Black Women’s Voices* she wrote

This woman is Black  
so her blood is shed into silence  
This woman is Black  
so her death falls to earth ...  
to be washed away with silence and rain ...

I do not even know all their names.  
My sisters [sic] deaths are not noteworthy  
nor threatening enough to decorate the evening news  
(Lorde, 2000, p. 350)

The “Say Her Name” initiative, as part of the larger Movement for Black Lives, began because the deaths of Black women who died due to racist violence were not garnering the same media attention as the deaths of Black men who died in similar circumstances (Crenshaw, 2016). Saying their names in this poem is a defense against invisibility—theirs and mine.

### **My Body Breaks Up With My Mind**

This poem indirectly references the adage that “the spirit is willing but the flesh is weak”. Those words don’t appear in my journal, but the sentiment is there. As the year progressed, it became obvious that I would not – could not – be running the way I longed to be, and likely would not be running at all for the foreseeable future. So, I tried other forms of exercise, including yoga and swimming. Nothing worked the way I wanted it to. I felt very much that my mind and body were at war. I wanted my body to do what it

could not. And my mind did not respond well to the things my body could do. Yoga was pleasant to my body, and a torment to my mind. The same was true of swimming.

I don't communicate all of that in the poem. I don't communicate any of that in the poem. What I communicate in the poem is the undercurrent of despair, the tedium, the weariness.

I constructed the poem from fragments of a July 5, 2015 journal entry:

<b>Sources</b>	<b>Poetic Interpretation</b>
July 5, 2015 (journal fragments) My sleeping is off. I've been napping during the day again. A part of me knows it for what it is: an attempt to fast forward through these tedious days... Wake me up when the long night is over. Wake me when the waiting ends and the living begins. What am I waiting for? Wellness. I've been wanting to say: People don't lack ambition. What people lack is hope. I have hope, I really do. (I have hope – how about you?) But I'm so weary of dreams deferred. Like, so fucking weary.	<b>My Body Breaks Up With My Mind</b>  I've been napping during the day again: An attempt to fast forward Past tedium, To free my mind From my body, or my body From my mind.  Wake me up when night is over. Wake me up when winter ends.  I have hope. I really do. (I have hope – how about you?)  But I'm also weary of dreams deferred.  Weary Weary. Weary.

### **Reading, Reading, Always Reading**

This is a found poem, a direct transcription of a journal fragment from July 20, 2015. I was frantic, desperate, looking for redemption, or solace, in the written words of



others. A part of the journal entry that did not make it into the poem reads: “I have always been a reader, but lately I have been consuming books with a ferocity that borders desperation.”

### **I Want to Know**

There is desperation in this poem also, and a hunger for meaning. Writing the poem as a list with multiple items tagged to each number is a way to portray my ineffective attempt to make order out of chaos.

#### **Sources**

July 27, 2015 (journal fragment)  
[redacted]

Who I am, what I want, where I fit,  
what all of this means for me as an  
individual navigating this world.

I’m curious. I want to know and  
understand myself and others. I want to  
protect myself and others. I want to free  
myself and others.

#### **Poetic Interpretation**

##### **I Want to Know**

1. Who I am, where I fit, what all of this means for me as an individual navigating this life.
2. What the weather is like, where you are.

In the poem, I changed “navigating this world” to “navigating this life”, in order to convey a more intimate specificity. I reordered the items, and brought the weather back in. What I say about the weather lets you know how I am. In the poem, I project that instinct outward.

### **The Body, Suspended**

The journal entry that served as scaffolding for this poem is actually about swimming. The entry, written on August 16, 2015, begins this way: “I don’t know what to do about how much I hate this.”

One of the things I love about running is progress, measured not only in literal miles, but in perceived distance traveled: from home to school, from the foothills to the summit. Swimming in a pool felt like the opposite: no matter how far I traveled, I ended up exactly where I began. That's one meaning of "What can it mean / to move like this?"

The poem is about a paradox of movement: time was passing, the world was changing all around me, and I was changing too, just by the fact of breathing in and breathing out, just by staying alive. But I felt keenly the lack of any really progress, the lack of any momentum, the lack of any forward movement. I was stuck, "supine, suspended, submerged".

### **I Want I Need I've Tried**

This is a found poem, a direct (though partially redacted) transcription of the journal entry in which I come closest to saying that I am thinking about suicide. It was written on August 20, 2015.

I don't know how long it had been since I slept through the night. I remember mornings so painful that I had to roll myself out of bed, half-falling onto the floor, so that I could crawl on my hands and knees to the door to let my dog out for her morning relief. I was never more grateful to have a fenced-in yard.

Rewind with me one year: In August 2014 I was accustomed to starting every day at dawn with an eight-mile run. In August 2015 the juxtaposition was devastating, crazy-making. And I wasn't getting better. I was getting worse.

I hadn't recovered, and I didn't know how. I had had months of physical therapy, multiple painful injections into my sacroiliac joints. I had tried swimming, yoga,

meditation, heat, ice. The pain was constant, often severe. Relief was always only partial, and temporary.

I knew I was coming to the end, one way or another.

### **The Persistence of the Present Tense**

Frank (2013) describes the chaos type of illness narrative as an “incessant present” (p. 99) “with ... no future worth anticipating”. On September 8, 2015, I wrote in my journal “Memory happens in the present tense. Do you know what I mean? It is the sense – this sense – that everything that happened is happening now”. Another way to say that is: the only thing that has ever happened is whatever is happening now.

I was reflecting on an “incessant present” that was already past when I wrote, on September 23, 2015 “Pain traps us in the now. It will not be denied. It is so profound that we struggle to even remember its absence. Pain forces mindfulness upon on, even as it makes us cry out for oblivion.”

Sontag describes memory this way: “[Memory is] individual, unreproducible; it dies with each person” (Sontag, 2003, p. 86). I would argue that our memories die before we do, becoming partial, representational. Even if written, recorded, or photographed, the essence of any given moment is always already gone.

When I wrote the journal entries that became scaffolding for *The Persistence of the Present Tense*, I was recovering from surgery. I was sleeping through the night. I wondered what to do with my memories, especially the memories of my alienating embodied experience. I was wrestling with what to do with the new version of me, a post-surgical self supremely conscious of the way I had been brought low by the

vulnerabilities of my own flesh. I was reckoning with the ways in which I was “who the world and I [had] never seen before” (Lorde, 1997, p. 48).

I was taking my memories, and starting to make meaning.

Meaning is something we make.

I ask with Audre: “How much of this pain / can I use?” (Lorde, 2000, p. 354).

### **Here on Earth**

This poem is a direct transcription of a journal entry written on October 1, 2015. I had been warned – or was it a promise? – that vivid dreaming was a potential side effect of my new medication.

The broken bicycle is such an obvious metaphor that I would never deign to make it up. It is also, improbably, an indirect reference to the closing passage of one of my favorite novels from childhood. Perhaps I shouldn’t call this fact improbable: I am a poet after all, even in my dreams.

### **What the Living Do**

When I tell people about this project, they give me an uncertain look. “But ... aren’t you getting a PhD in Statistics?” they ask.

I am.

And I tell them that the PhD is the beginning of something, not the end.

On October 31, 2015, I wrote in my journal: “It’s been one year since the accident. There are stories that statistics tell, and there are stories that we tell ourselves about statistics. There is the danger of a single story. And there are possibilities, responsibilities that have their origins in dreams.”

Inter-textual references abound in that entry, as they do throughout my journals, as they do throughout writing of all kinds. I had been thinking for some time about the limitations of statistics, beginning to envision a research agenda that took up the question of the crisis of representation, and offered reflexivity as an answer; I presented on the topic at a conference the year before the accident (Cuffy, 2013).

I will not bifurcate my life into “before” and “after”, or myself into “statistician” or “storyteller”. I am both / and. My life, my work, is both (Adams, St. Pierre, & Roulston, 2006). The title of the final poem, a phrase that recurs throughout the poem, is evidence of the impossibility of bifurcation. *What the Living Do* is the title and title poem of a 1999 collection by Marie Howe. I may have encountered the poem before, though I cannot recall when or where, or even if, not for sure. I stumbled upon her work during dissertation revisions, and wrote “after Marie Howe” as a subtitle with mixed feelings. I wrote the poem before I knew I was writing after Marie Howe.

In my dissertation research journal, during the transcription process, I wrote “I’ve been here for hours, and it’s night now. How will I write the poem of this moment?” I wrote about being cold, and sad, and scared. I made the choice to move through the fear. No other choice was feasible (Lorde, 1984; Lorde, 1997).

I close out this analysis with a reminder to myself, and to anyone else who dares to put themselves into their work, to make the invisible unavoidable, inviting others to serve as witnesses (Ellis, Adams, & Bochner, 2011), that this is how we change the world:

It is not my intention to judge the woman who has chosen ... silence and invisibility ... Each of us struggles daily with the pressures of conformity and the loneliness of difference from which those choices seem to offer escape. I only know that those choices do not work for me, nor for other women who, not without fear, have survived cancer by scrutinizing its meaning in their lives, and by attempting to integrate this crisis into useful strengths for change.

(Lorde, 1997, p. 8).

I ended my October 31, 2015 journal entry with these words:

“Ask yourself: What would I do if I was not afraid? And then? *Do that.*”

That is what I’ve done.

It is what the living do.

### **The Poems I Didn’t Write**

In the months leading up to formally sitting down to craft Chapter 4, I thought a lot about the poems I would write. I was curious to see what would emerge from a close reading of my personal documents, but there were two poems in particular that I was certain would be a part of the collection, and instead, are not.

The first of the two poems I didn’t write is about my final visit to the doctor who was my primary care practitioner in the months after the accident. The second is an epistolary poem, a thank you letter addressed to the doctor who ordered the MRI that led directly to the surgery that put an end to the worst of my pain. Which is to say: he ordered the MRI that saved my life.

I decided not to write those poems for this project because the healthcare professionals are not the protagonists of this story (Frank, 2013; Hawkins, 1999; Morris, 2017): I am. One purpose of this project is reclaiming narrative. “The new world of medical narrative is a site where patients no longer accept a passive, voiceless role”

(Morris, 2017, p. 109). My story is not about what the doctors did or did not do, did or did not say, or why. It is about what I lived through, what I survived, and the meaning I make (Frank, 2011; Kleinman, 1988; Sharf & Vanderford, 2003).

### **Part 3: Partitions**

#### **Now You See Me as Illness Narrative, Counter-Story, and Autoethnography**

##### **First Partition: Now You See Me as Illness Narrative**

Did I tell you a story? And if I did, what kind of story did I tell?

In *The Wounded Storyteller*, Frank (2013) describes three “narrative types” that give structure to illness narratives. The types are not mutually exclusive: “Actual tellings [sic] combine all three, each perpetually interrupting the other two” (Frank, 2013, p. 76). His argument is that thinking of illness narratives in terms of these three types can be an aid to bearing witness: “The advantage is to encourage closer attention to the stories ill persons tell; ultimately, to aid listening to the ill” (Frank, 2013, p. 76).

The restitution narrative, in Frank’s (2013) description, is the type of illness narrative that focuses on the return to baseline. It is the “all better now”, the “good as new”. The restitution narrative is ultimately a story about the return to health, rather than a story about illness. In “a modernist narrative of social control ... the sick person’s task is to get well and return to normal” (Frank, 2013, p. 81). The restitution narrative is a story of the triumph of modernity; specifically, modern medicine. It has a reassuring ending; the witness need not fear loss of sleep.

In contrast to the restitution narrative, the chaos type of illness narrative is “the most embodied form of story” (Frank, 2013, p. 101). Chaos resists narrative, in much the

same way that pain resists language (Scarry, 1985). Indeed, the chaos narrative is not really a narrative at all: it is cursedly recursive, lost in an “incessant present” (Frank, 2013, p. 99).

Frank says that “emotional battering is fundamental to chaos” (2013, p. 101). One of the poems I did not write is about my last trip to the Primary Care Physician who, with open contempt, expressed doubt about the veracity of my claim. “*I’m not going to give you pills*”. Those words, delivered with a smirk, were very nearly a death sentence for me. The Thursday prior to that appointment I wrote in my journal (as related in the poem *I Want I Need I’ve Tried*) “without [my health], I don’t have any fucking hope for anything else. I don’t even want anything else. Including – I’ll say it – my life.” Three days later, my doctor’s unfeeling dismissal ringing in my ears, I wept in the parking lot of the medical office, and seriously contemplated suicide for the first time in years.

That experience is the essence of emotional battering in chaos narrative. “Chaos is the opposite of restitution: its plot imagines life never getting better ... In these stories the modernist bulwark of remedy, progress, and professionalism cracks to reveal vulnerability, futility, and impotence” (Frank, 2013, p. 97).

The personal documents I used for this project were created in chaos, and the poems reflect the themes of that chaotic reality, the fog and despair of an “incessant present” (Frank, 2013, p. 99). If *Now You See Me* is an illness narrative – and it seems to me that it is – then it could be argued that it is the chaos type.

But my story does not end there.



The final of the three types of illness narrative that Frank (2013) describes is the quest. In explicating the differences between the three types, Frank writes: “Restitution stories attempt to outdistance mortality by rendering illness as transitory. Chaos stories are sucked into the undertow of illness and the disasters that attend it. Quest stories meet suffering head on; they accept illness and seek to *use* it” (Frank, 2013, p. 115, emphasis original).

I wanted a restitution narrative; that is clear when I wrote that “I want my life back” (November 5, 2014); that “this too will pass” (November 15, 2014); that I am “moving towards health” (March 21, 2015). Chaos reigns in much of *Now You See Me*. But in the telling, I transform my narrative from chaos to quest. “The quest narrative affords the ill their most distinctive voice” (Frank 2013, p. 115). The quest narrative is a process of intentional meaning making, as “memory is revised, interruption assimilated, and purpose grasped” (Frank, 2013, p. 131).

My work also moves into an empty space in the literature of illness narratives: Sontag (2003) asserts: “Suffering from natural causes ... is scantily represented in the history of art; that caused by accident, virtually not at all—as if there were not such thing as suffering by inadvertence or misadventure” (p. 40). In her overview of the landscape of what she termed autopathography, Hawkins (1999) had made a similar observation: physical suffering due to accident was underrepresented in illness narratives; that was still the case when Wilson wrote on the topic in 2016. I can only speculate on the causes of this particular dearth: there is a commonality to other categories of illness that is

missing in ailment caused by accident: cancer, AIDS, mental illness, and other conditions create community around similarity of experience.

In the introduction to her 2018 book about the consequences of sexism in the US healthcare system, Dusenbery writes “When you get diagnosed with an autoimmune disease, especially if you’re a woman of a certain age, it’s a lot like when you buy a new car and promptly start seeing the same make and model everywhere” (Dusenbery, 2018, p. 1). Her point is that there are multiple reflections of the lived experience of many illnesses and ailments.

But not mine.

Into the empty space, I place a point of light (Winterson, 1989).

### **Second Partition: Now You See Me as Counter-Story**

In Critical Race Theory the prevalence of race and racism is taken as a given: “[Race] is always already present in every social configuring in our lives” (Ladson-Billings, in Taylor, Gillborn, & Ladson-Billings, 2016, p. 17); “[racism] is so enmeshed in the fabric of our social order, it appears normal and natural to people in this culture” (p. 18). Rather than work to “prove” that racism exists, CRT scholars work to unmask it. This unmasking often takes the form of counter-storytelling. It is a form of resistance to “[a] majoritarian story [that] distorts and silences the experiences of people of color” (Solórzano & Yosso, 2002, p. 29).

“How does it feel to be a problem?” When W.E.B. DuBois posed that question in 1903 (p. 220), he was writing about the experience of “double consciousness” (p. 221), of being simultaneously aware of *who you are* and *how you are perceived*, and the

difference between the two. Counter-storytelling is the oppressed person's assertion of who they are in resistance to, and even in defiance of, false perceptions upheld by the dominant group. "...Personal counter-stories are autobiographical reflections of the author ... within the context of a larger sociopolitical critique" (Solórzano & Yosso, 2002, p. 32).

Ladson-Billings emphasizes the importance of connecting personal story to law and policy; in her estimation, a story that does not make those connections is not a counter-narrative (Ladson-Billings, 2013, in Taylor, Gillborn, & Ladson-Billings, 2016). Delgado (1989) outlined a broader perspective, suggesting that there are two main functions of counter-storytelling: "first, as a means of psychic self-preservation; and second, as a means of lessening ... subordination" (p. 2436).

Expounding on that first function of counter-storytelling, Delgado writes "stories about oppression, about victimization, about one's own brutalization - far from deepening the despair of the oppressed, lead to healing, liberation, mental health" (Delgado, 1989, p. 2437). The storyteller experiences this healing (Rodriguez, 2006) as do listeners who have had similar experiences, and through the story come to the realization "I am not alone".

In *Now You See Me*, race is present – always already present – but I name it only in selected poems (*Epigraph 2, Waiting Room; CRACK; Noah's Ark; Say Her Name*). I make no attempt to connect my story to law and policy; the individuals and institutions that left me in distress are not unmasked. They are not even named. The lawsuit I filed

was not against the doctor who laughed in my face while denying me medication; it was against the other driver's insurance company.

I am not here to “prove” that my story is a counter-story (though I think it is) any more than I am out to “prove” that racism explains the treatment I received (though there is reason to believe it was a factor). Delgado (1990) argued that “in writing and thought, particularly that related to racial justice ... inclusion, texture, and diversity of perspective -- in short, voice -- is everything” (p. 110).

Voice is everything (Perreault, 1988). I have offered mine.

### **Third Partition: Now You See Me as Autoethnographic Poetic Inquiry**

Like counter-story, autoethnography uses personal experience to engage with larger cultural concerns: “Autoethnographers ... must use personal experience to illustrate facets of cultural experience” (Ellis, Adams, & Bochner, 2011, p. 276). Leavy (2015) sees a similar function in poetic inquiry: “poems can capture intensely subjective ‘truths’ as well as their relation to the larger context” (Leavy, 2015, p. 91). In writing about the connection between autoethnography and poetry, Gallardo, Furman, and Kulkarni (2009) assert, “[poetry] has the capacity to meet the important qualitative aim of capturing the depth of human experience ... and encourages an empathic relationship between the author and its audience” (p. 290; p. 291). Those were among my goals in writing autoethnographic poetic inquiry.

Autoethnography exists on a continuum, varying in the balance of personal story and cultural context: some are more “auto”, others, more “ethno”. On the more “auto” end of the continuum “are stories about authors who view themselves as the phenomenon

and write evocative narratives specifically focused on their academic, research, and personal lives” (Ellis, Adams, & Bochner, 2011, p. 279).

In considering where – and whether – to place *Now You See Me* on such a continuum, I return to the idea of the unspeakable nature of pain and illness, as articulated by Scarry (1985) and Frank (2013); and the hypervisible / invisibility of Black women and girls, as articulated by Griffin (2016) Harris-Perry (2011); Collins (2000); and Lorde (1997) among others.

Stover (2003) argues that Black women’s autobiography is never only about the self; it is always also sociopolitical: “African American women autobiographers thwart attempts to keep [Black women] silent and invisible” (Stover, 2003, p. 6). “The literary rebellion, by its very nature, functions also as a sociopolitical rebellion” (Stover, 2003, p. 25). At the end of Chapter 3 I said, “I have always written for myself. Now, I write myself for others.” Like other contemporary Black poets, I “write self against the background of [my] community and its history” (Rowell, 2013, p. xlvi). I add my voice to the conversation. I contribute my verse, moving from silence into speech (Anzaldúa, 1990; Lorde, 1984).

Holman Jones (2005) describes “speaking in and through experiences that are unspeakable” as “a hallmark of autoethnography” (Holman Jones, 2005, p. 218). She suggests a guiding question for judging the merits of autoethnographic writing: “How well does the work present a partial, self-referential tale that connects with other stories, ideas, discourses, and contexts?” (Holman Jones, 2005, p. 219).

How well I have done it is for others to judge. That I have made the attempt cannot now be in doubt.

## **Chapter Six: Being / Doing / Making Meaning**

The next one will be about resilience.

I promise.

I swear to you.

The next one will be about

How poetry inspires.

The next one will be about

Love.

### **Denouement**

I am here to talk about a problem.

The problem is that when women and Black people tell doctors that they are in pain, doctors don't believe them.

Or, the problem is that we still say "women" and "Black people", as if there are no women who are also Black, no Black people who are also women (Smith, Hull, & Scott, 1982).

Or, the problem is that when Black women tell their doctors that they are in pain, their doctors don't believe them.

Or, the problem is that I say "they" when I mean "we".

Or, the problem is that I say "we", when I mean "me".

I am here to talk about a problem.

Remember?

I am here to talk about a crisis.

The research question is,

How does it feel to be a problem?

I am here.

Here we are.

The purpose of my project – introduced in Foreshadowing, reiterated in Chapter 1 – has been to describe and demonstrate a theoretically sound method of gaining access to and understanding subjugated experience, specifically, the experience of a Black female embodied self in pain. My thesis, implicit in much autoethnographic writing (Richards, 2008) was that taking lived experience as a source of knowledge and poetry as method reveals subjugated truths about the experiences of Black women in a way other epistemologies and methods cannot.

I had an experience that was not reflected in the research literature. Like Bettina Judd before me, and uncounted other Black women before us, “I had an ordeal with medicine” (Judd, 2013, p. 1). My ordeal was not reflected in the literature of social science research, and I turned to theories that explained the absence, particularly Critical Race Theory and Black Feminist Thought.

In Chapter 2, I engaged with Critical Race and Black Feminist critiques of the Euro-American mode of social scientific inquiry. I introduced the idea of research as betrayal – betrayal on three levels – and suggested critical inquiry and reflexivity as ways to honor the goals and ideals of research on those three levels. Ultimately, my argument



was for critical arts-based inquiry as a meaningful response to the crisis of representation, which has been defined as “the unsettling of the scholarly community in recognizing that we cannot really ‘know’ or ‘describe’ the other in an objective, unproblematic way” (Shuler, 2007, p. 258). The crisis is one of mis- and under- representation, hyper-visible invisibility, silencing, subjugation, bearing false witness (Few, Stephens, & Rouse-Arnett, 2003; Yosso, 2005).

The discourse on critical arts-based inquiry and the crisis of representation has been part of the conversation about emerging methods in qualitative research since as early as the 1990s (Conquergood, 1991; Denzin, 2000; Finley, 2003). In the second edition of *Method Meets Art* (2015) Patricia Leavy posits that the goals of critical race, feminist, and queer scholars – “unsettling stereotypes and challenging the dominant ideology” -- make arts-based research particularly appealing (p. 24) to scholars with those critical theoretical commitments. Arts-based research is well suited to the goal of exploring “micro-macro connections” (Leavy, 2015, p. 22): self and culture (Pelias, 2003); personal and political (Wall, 2008).

Part of my unique contribution has been to apply poetic inquiry across multiple modes of discourse, most notably in my use of *Vox Theoria* (in Chapter 2) to explicate the theoretical considerations that contextualize *Vox Autoethnographia* (Chapter 4) (Prendergast, 2009). I have chosen to merge a self that has too long been separated (Knowles & Cole, 2008; Perreault, 1988), to let the poet and the scholar speak in tandem.

In Chapter 3, I considered specific methodologies and methods. In the back of my mind was always Audre’s question: “What does it mean when the tools of a racist

patriarchy are used to examine the fruits of that same patriarchy?” (Lorde, 1984, p. 158). It means a crisis of representation. It means bias, subjugation, and betrayal (Lather, 2007; Madison, 2012; Milner, 2007; Solórzano & Yosso, 2002). Having decided to set aside the master’s tools, I sought tools better suited to my purpose, a methodology that I could justify in terms of my own ontology and epistemology. In keeping with the goals of Critical Race Methodology, and my own decision to explore a specific gap in the literature, I turned to modes of inquiry that elevate voice, lived experience, storytelling, creativity, and reclaiming narrative. I described the overlap and interconnections I saw between illness narratives, counter-narratives, autoethnography, and poetic inquiry. That last one was of special interest to me, with its emphasis on evocation and empathic connection (Gallardo, Furman, & Kulkarni, 2009; Leavy, 2015; Prendergast, 2009; Richardson, 1994).

The particular experience I wanted to articulate is embodied, unspeakable (Frank, 2013; Scarry, 1985). Sparkes (1996) asks “how might we write about biographical disruptions and interrupted body projects in ways that are themselves as disruptive, fragmented, and emotionally charged as the events they describe?” (Sparkes, 1996, p. 466). Poetry provided a path from silence to speech (Lorde, 1984), a way to “make another world accessible to the reader” as Richardson (1994) asserted, “[coming] closer to achieving that goal than other forms of ethnographic writing” (Richardson, 1994, pp.8-9).

In Chapter 4, I put the tool of autoethnographic poetic inquiry to use, writing my way into a deeper understanding of my experience, making new meanings, and inviting the reader to bear witness (Adams, Ellis, & Bochner, 2011; Frank, 1991; Frank, 2013). I followed that chapter with an explication of my process, and offered my own analysis of the poems, an articulation of the meaning that I made. I contextualized my tale, considering its merits as a critical-race counter-story, an illness narrative, and an autoethnography.

In this final chapter, I revisit each of my four original research questions. What does the existing literature say about Black women's experiences seeking medical care for pain management? What does the literature of critical theory say about understanding Black women's experiences? What does the evidence of my own experience say? I reflect on the evolution of my research questions over the course of the project, how using writing as a method of inquiry – iterative, reflexive -- has problematized my “research problem”.

In this chapter, I also reexamine the idea of research as betrayal. I said that every research project ends that way, that in research, betrayal is an art, and my apprenticeship, almost complete. Have I honored the emic, the etic, and the epic, or am I, too, guilty of betrayal? In connection to the three levels, I expound on the value I find in critical arts-based inquiry, and in poetry as my method of inquiry for this project. I reflect on the lessons I've learned by and about doing this work.

Finally, last as first, I turn back to Black women, situating my project in a tradition of Black feminist life-writing, reflecting on why we do this work, and imagining what comes next.

### **Research Questions Redux: Drive All Blames Into One**

Did I answer my research questions?

Does it matter?

“[I]t should be recognized that answers to questions and solutions to problems might not be arts-informed research’s long suit” (Eisner, 2008, p. 12). Part of the appeal of arts-based inquiry is fluidity and flexibility (Knowles & Cole, 2008). One of the contradictions inherent to this particular paradigm is that it engages the researcher in a systematic inquiry that nevertheless makes space for deviation and flux: “both the subject and the materialization of the research are open to perpetual reconfiguration” (Springgay, Irwin, & Kind, 2005, p. 902). Arts-based research is dynamic rather than static, expansive rather than reductive (Hanley, 2013).

Research questions by their very nature are reductive: they demand precision and specificity, a limiting of scope (Guba & Lincoln, 1994). In keeping with the conventions of a Research Methods and Statistics dissertation, I began this project by articulating specific research questions. In keeping with arts-based inquiry, I have ended somewhere unanticipated; in this paradigm “questions emerge over time” (Sinner, Leggo, Irwin, Gouzouasis, & Grauer, 2006, p. 1225). A mindset open to surprise and serendipity is appropriate – indeed, necessary -- for arts-based inquiry (Eisner, 2008).

American Buddhist Nun Pema Chödrön teaches a meditation practice called “Drive All Blames into One”. To drive all blames into one is to take a broad view of our reactions to circumstances that cause distress, looking for an overarching cause rather than focusing on a specific trigger (Chödrön, 2002).

An example: a woman is furious that her roommate finished the last of the milk; now she will have to drink her morning coffee black. The research question is, “Why are you mad at your roommate?” The answer is, “Because she drank all the milk, and now I will have to drink my coffee black”. But in Chödrön’s view (2002), there is a larger question, a cause of the woman’s suffering that goes beyond her dread at the prospect of imbibing a bitter brew. Meditation and probing might reveal that the woman worries about scarcity, about all the areas in her life in which she experiences a lack: she is running out of time, unlucky in love, underpaid and unappreciated at work. Her overarching sense is that her needs are never met, and never will be.

Is the research question still “Why are you mad at your roommate?” Yes and no. Is the answer still “Because she drank all the milk, and now I have to drink my coffee black”? Yes and no. There is something else, something deeper, with shading that is only apparent at a distance, from a wider lens with a longer view.

Without overextending the analogy, I can apply the example to my research questions to see what they have in common, how they brought me full circle to the crisis in the world that I embody in my self: the crisis of representation.

Sometimes the process of inquiry does not result in an answer to the research question; it results in a better understanding and articulation of the question (Eisner, 2008). Sometimes the process drives all blames into one in an ironic reversal: the process of inquiry reduces even as it expands. I started with four concrete research questions, and ended with one abstract one.

**R1:** What does the existing social science research literature say about Black women’s experiences seeking medical care for pain management?

The answer is, not much: The results of the systematic literature review I presented in Chapter 1 indicated a gap in the health disparities literature. While it is clear that Black women fare worse than their female counterparts of other races across a variety of health outcomes, the specific story of Black women’s experiences seeking medical treatment for non-malignant chronic pain is missing. “The consequences of undertreated or untreated chronic pain are severe and multifaceted and may cause permanent damage to the individual” (Greenberg, 2012, p. 66), including an exacerbation of conditions that already disproportionately impact Black women’s quality of life and life expectancy, such as diabetes, heart disease, and high blood pressure. Yet Black women’s experiences seeking care for chronic pain are missing in the scholarly research literature.

Greenberg (2012) also wrote, “Because there is no way to measure or quantify pain objectively, pain is subjective and a patient’s reports must be taken seriously” (p. 64).

Revealing and understanding subjective experience was at the heart of my research question. The query I developed for the systematic literature review was designed with that goal in mind, hence my focus on qualitative research (Creswell, 2007; Guba & Lincoln, 1994). I wanted to know, what does the literature have to say about experiences like mine, experiences that are often silent and silenced?

Considering the relationship between science, silence, and poetry, Leggo (2008) wrote “many human science researchers focus on research questions and methods, conclusions and implications, [but] as a poet I am often more intrigued with how language works to open possibilities for constructing understanding” (p. 166). What I called “the existing social science research literature” is certainly focused on the domains Leggo identified. Like Leggo, I was, and am, more interested in the possibility of poetry as a method of inquiry, in “exploring the lively intersections between critical discourse and creative discourse” (Leggo, 2008, p. 166), and making meaning in that in-between.

**R2:** What does the literature of critical theory say about understanding Black women’s experiences?

As I articulated in Chapter 2, critical social theories, including Critical Race Theory and Black Feminist Thought, take lived experience to be an essential source of knowledge (Taylor, 1998). Experiential knowledge is “legitimate, appropriate, and critical” for understanding the role of race and racism in systems and society (Yosso, 2006, p. 74). Black Feminist Thought (Collins, 2000; King, 1988), intersectionality (Crenshaw, 1991) and Critical Race Feminism (Simien, 2007; Smith, Yosso, & Solórzano, 2007; Wing, 1997; Yosso, 2005) further emphasize the value of experiential

knowledge of people with intersectional or multiply-oppressed identities, specifically, women of color.

Black Feminist Thought, in particular, “shapes, shades, changes, challenges, enlightens, and empowers as a critically conscious intellectual embodiment of resistance, humanization, and compassion” (Griffin, 2016, p. 3). A Black Feminist standpoint approach to understanding the lived experiences of Black women must exemplify those principles. But how?

In their influential work *Competing Paradigms in Qualitative Research*, Guba and Lincoln (1994) describe four broad paradigms of research inquiry, outlining the ontology, epistemology and methodological commitments of positivism, post-positivism, critical theory and constructivism. While their analysis continues to have meaningful implications for situating existing modes of inquiry, the work of operationalizing methodological commitments in post-positivist and constructivist paradigms still falls to those researchers who associate themselves with various critical positions. Even Critical Race Methodology (Solórzano & Yosso, 2002) is limited in that way.

**R3:** Considering the tenets of Critical Race Theory and Black Feminist Thought, what methods can be used to probe the experiences of Black women seeking medical treatment for chronic pain?

While both Critical Race Theory (Solórzano & Yosso, 2002) and Black Feminist Thought (Collins, 1989) describe values and suggest guidelines for researching marginalized experiences, they are sparse on specifics (Huber, 2008). In paradigmatic terms, qualitative methods have most often been deployed in a critical race framework



(Parker & Lynn, 2002), including such methods as case study and narrative research.

Critical Race Methodology gives primacy to lived experience as shared through counter-storytelling (Delgado, 1989; Parker & Lynn, 2002; Solórzano & Yosso, 2002).

In the most literal sense, then, the answer to Research Question #3 is that many methods “can be used” to investigate Black women’s experiences.

In sifting through scholarly literature of Black women writing from a Black Feminist standpoint about Black female experience, I found numerous examples of autoethnographic writing (Boylorn, 2013; Cozart, 2010; Griffin, 2012; Ngunjiri, Hernandez, & Chang, 2010; Pollard & Welch, 2006; William-White, 2011). Griffin goes so far as to specifically “advocate for Black feminist autoethnography (BFA) as a theoretical and methodological means for Black female academics to critically narrate the pride and pain of Black womanhood” (Griffin, 2012, p. 138). Writing about the connection between Black Feminist Thought and autoethnography, Boylorn (2013) reflected,

Black feminism ... gave me the framework to center and privilege my everyday lived experiences as useful, important, and relevant data for academic scholarship. When auto/ethnography [sic] came into the picture it made sense in the context of my black feminist politics (Boylorn, 2013, p. 74).

I was drawn to autoethnography for the same reasons, but the pull of poetic inquiry was even more insistent. I wanted to use self to get at culture (Pelias, 2004; Wall, 2008), yes, to connect the personal and the systemic, as autoethnographers do, but more than that, I wanted to use poetry to get at self (Leggo, 2008; Prendergast, 2014). I was drawn to poetic inquiry because it makes space to evoke (for the reader) and understand (for the self) one’s own subjective, subjugated, embodied experience (Leavy, 2015;

Prendergast, 2014; Spry, 2011) through writing it. It is not the only method that does those things, but for me it was the most intuitive, and certainly the most accessible.

**R4:** What does the evidence of my own experience say about Black women seeking medical treatment for chronic pain?

This question evolved over the course of transcribing my personal documents and writing the poems for the collection. The way I chose to write about my experience, as portrayed in the poetry of *Now You See Me*, ultimately says less about the seeking itself, and more about the emotional and existential consequences of the long delay in receiving the care I sought. In the poem *Waiting Room*, I write an “othered self” (Richards, 2008), using poetic repetition (What is she waiting for?) to evoke the longstanding futility of my quest for care, and connecting that futility directly to the fact of my Black woman body. Appearing as it does early in the collection, the poem foreshadows a narrative of mounting desperation and despair. *Epigraph 2*, *Timeline 1* and *Timeline 2* do similar work, but I would argue that *Waiting Room* most clearly engages the gaze(s) that marked me (Haraway, 1988; Tuck & Yang, 2014), and the consequences of being so marked.

I am here to talk about a problem.

I am here to talk about how it feels, to be a problem.

From four concrete questions to one abstract one:

How does it feel to be a problem?

It feels like having your experience unrepresented in the literature; it feels like being invisible, unvalued.

How does it feel to be a problem?

It feels like knowing that your way of knowing and validating knowledge places you on the fringes of your chosen profession (Bernal & Villapando, 2002; Collins, 2000), making you an outsider, marking you as marginalia.

How does it feel to be a problem?

It feels like

All of your friends are

Fast asleep,

And even your dog is

Fast asleep,

And only the new moon

Keeps watch,

And your secrets.

It feels like

Waiting for crucifixion or

Resurrection.

I was motivated to write about the personal cost of my experience because that story, that subjective voice, is missing in the social science literature on health disparities.

I asked in Chapter 1:

Do you see

What I see?

Empty

Spaces

Where our stories

Should be.

The research question is, how does it feel to be a problem?

The research method is poetic inquiry, a way of filling empty space with points of light (Winterson, 1989).

In the beginning, the body.

At the end, the word.

I wanted to write my way out of hyper-visible invisibility. I wanted to write my way out of silence. I wanted to write an absence into existence.

The absence of the voices and perspectives of the people who experience the impact of research – for good or ill -- is betrayal. It is the betrayal at the heart of the crisis of representation. It is the betrayal I want to address, and ultimately, redress, through critical arts-based inquiry.

### **Art Against a Sea**

I introduced the concept of the crisis of representation as a betrayal in Chapter 2. I described it as betrayal on three levels: the emic, the etic, and the epic. Is critical arts-based inquiry a meaningful response to that crisis?

Before I turn to that discussion, a clarification: the designation “critical” is, well, critical to the point I am making. While agreeing with Leavy (2015) that arts-based research can be especially valuable to scholars with an activist agenda, scholars such as Finley (2011) and Osei-Kofi (2013) caution against assuming that all arts-based research shares a social justice orientation:

While ABR practices challenge the art-science divide and thus dominant approaches to research, this is not the equivalent of all ABR being informed by an anti-oppressive stance ... To engage in ABR practices that seek to advance social justice requires a commitment to research as resistance. (Osei-Kofi, 2013, p. 148).

That commitment to a social justice agenda is what distinguishes critical arts-based inquiry from other arts-based research. Daring here to paraphrase the Bard, critical arts-based inquiry is a commitment to making art against a sea of injustices, with the ultimate goal of ending them. “Critical theory is committed to unveiling the political stakes that anchor cultural practices – research and scholarly practices no less than the everyday” (Conquergood, 1991, p. 179). What critical theory unveils, critical arts-based inquiry transforms. “[Art] is a form of social consciousness that can potentially awaken an urge in those affected by it to creatively transform their oppressive environments ... propelling people toward involvement in organized movements seeking to effect radical social change” (Davis, in Joy, 1998, p. 236).

What I am proposing is nothing less than a framework for radical reflexivity in the service of radical social change. It is a framework for researcher accountability regarding the obligations and ideals of a systematic search, not just for knowledge, but for meaning.

I see this framework as part of an ongoing conversation about established and emerging criteria for assessing what Lincoln, in 1995, called “new paradigm inquiry”:

The issues that scholars are proposing today make it clear that new paradigm inquiry is not, and never will be, second-rate conventional scientific inquiry. It is scientific inquiry that embraces a set of three new commitments: first, to new and emergent relations with respondents; second, to a set of stances—professional, personal, and political—toward the uses of inquiry and toward its ability to foster action; and finally, to a vision of research that enables and promotes social justice,

community, diversity, civic discourse, and caring. As a result, any discussion of standards today necessarily signifies a radical shift in the vision of what research is, what it is for, and who ought to have access to it. (Lincoln, 1995, p. 277-278).

Twenty-plus years after Lincoln, the question about standards for judging emerging forms of inquiry is far from settled. In 2015, Leavy wrote, “While I think it is more important to focus more heavily on building methodological principles and creating spaces to share new arts-based works, there is no question that we need ways to assess this work” (Leavy, 2015, p. 266).

The framework I describe is as much about what the best critical arts-based inquiry *can* do as it is about what it “should” do, specifically in redressing the crisis of representation; Finley (2003) described this as “a parallel but related discourse” (p. 283) to the discourse on criteria for evaluating arts-based research. Other scholars have suggested criteria for assessing the quality of arts-based research as art, or assessing its quality as research (Barone & Eisner, 2011; Leavy, 2015). My primary interest is in assessing its potential for transformation:

I am wondering about the potential of a research approach that, boldly but not rudely, humbly and not arrogantly, intervenes in the current state of ... affairs, one that expands the reach of our scholarship because of (not despite) the fact that it is profoundly aesthetic, one that both finds its inspiration in the arts and leads to progressive forms of social awareness. (Barone, 2006, p. 218)

“The question – What does or can research do? – is not a cynical one, but one that tries to understand more about research as a human activity” (Tuck & Yang, 2014, p. 225).

I propose asking three questions at each of the levels I described when I conceptualized research as betrayal back in Chapter 2. The questions are:

What are my obligations?

How will I meet them?

How will I know I've met them?

### **Critical arts-based inquiry at the level of the emic**

The obligation of the researcher at the level of the emic is to portray a subjective reality, a local truth (Guba & Lincoln, 1994; Visweswaran, 1994). In order to accomplish that, the practitioner of critical arts-based inquiry seeks a “participatory understanding” (Conquergood, 2002, p. 152), developing and articulating co-constructed meanings, “shared understandings that emerge through artful displays and figurative language” (Finley, 2003, p. 286).

Essential to fulfilling the obligation at this level is respect for the epistemology of the people: what do they count as knowledge? How do they validate it? How do they disseminate it? “Different narrative strategies may be authorized at specific moments in history by complex negotiations of community, identity, and accountability” (Visweswaran, 1994, p. 15). The emic is honored through a collaborative process that makes the researcher a co-participant; power with, not power over.

The strength of critical arts-based inquiry at the level of the emic is exemplified by Estrella and Forinash’s (2007) use of multi-vocal narrative inquiry in their work on peace and reconciliation in the context of the Israeli-Palestinian conflict:

One can suggest using the arts to give voice to the various groups involved, hoping to provide a forum for those oppressed or marginalized, especially in the context of war. These multinarratives [sic] help us get to the level of unpacking or examining our concepts of what we mean by concepts such as “peace,” “conflict,” and “reconciliation.” How are these concepts embedded in culture? Do we have shared meanings of these words? How can we possibly work toward reconciliation until we understand the nuances of our experiences of these concepts?  
(Estrella & Forinash, 2007, p. 381).

Here, the expertise of the people takes precedence; the researchers understand that meaning is cultural, nuanced. “Situated knowledges require that the object of knowledge be pictured as an actor and agent, not as a screen or a ground or a resource ... the agency of people studied itself transforms the entire project of producing social theory”  
(Haraway, 1988, p. 592).

Agenda, agency, and agent are the same at the root, all having to do with *doing*. Honoring the agency of research participants means engaging them as co-constructors of the research agenda, co-constructors of meaning. “Indeed, coming to terms with the agency of the ‘objects’ studied is the only way to avoid gross error and false knowledge of many kinds in these sciences” (Haraway, 1988, pp. 592-593). Humility rather than ascribed expertise is taken as the first principle when approaching an Other.

### **Critical arts-based inquiry at the level of the etic**

The obligation of the researcher at the level of the etic is to name their location, and take ownership of the partiality of their perspective (Haraway, 1988; Lather, 2007; Visweswaran, 1994) in describing a supposedly objective reality. At issue here is not an argument about the facts of a given situation; the issue is that positionality influences what facts are considered noteworthy, what elements of a given context are considered



valuable. “[A] rigid epistemological distinction between facts and values is indefensible, and ... employing the fact-value distinction to avoid value bias instead exacerbates the danger of bias by cloaking value judgments with names such as ‘objectivity’, ‘truth’, and ‘science’” (Howe, 1985, p. 10).

At the level of the etic, the critical arts-based inquirer values “concentrated attention and contextualization as a way of knowing” (Conquergood, 2002, p. 152), while recognizing that “Identity, including self-identity, does not produce science; critical positioning does” (Haraway, 1988, p. 586). “It is important ... to name the perspective from which one constructs one’s analysis” (Crenshaw, 1991, p.1255).

An exemplar of the way critical arts-based inquiry functions at the level of the etic is a study published in 2007, in which a particular marginalized group of Bedouin women participated in an art-making and conversation group with the principle investigator and interpreters (Huss, 2007). The researcher, operating from an explicit feminist standpoint, allowed the women’s own interpretation and expression of the “lack” in their objective environment to emerge over the course of multiple sessions: “The data-analyzing strategy was first based on the women’s own explanations rather than on an external psychological metatheory” (Huss, 2007, p. 963); “we will see how the women describe the lack of elements that convey power: a house, a car or mobility, a man as protector, and a blonde thin body” (Huss, 2007, p. 964). The feminist standpoint informed the method that revealed a multifaceted interpretation of objective reality.

### **Critical arts-based inquiry at the level of the epic**

The obligation of the researcher at the level of the epic is to contextualize their work within and beyond its particular context, recognizing the role of research at the micro and macro level, “always [remembering] that the sociology, the history, the economics, the graphs, the charts, the regressions all land, with great violence, upon the body” (Coates, 2015, p. 10). It is the obligation of the researcher to reckon with the role of the research in an individual’s narrative as well as in the big picture, the long story, the powerful play. To honor the epic is to honor the n of 1 and the N of many. It is

“To see a world in a grain of sand ...

And eternity in an hour”

(William Blake, *Auguries of Innocence*, 1803 / 1863).

While the emic and etic consider the local context in which research takes place – the positioning of a particular partial perspective as it relates to either subjective or objective reality – the epic takes a longer view, positioning the research in a wider political context. At the level of the epic, the obligation for the practitioner of critical arts-based inquiry is to reject an apolitical or ambiguous stance: “[A]rtists and other researchers should not succumb to the pressure we might feel to depoliticize our work” (Finley, 2011, p. 571), but should rather embrace the potential for arts-based research to be “a transformative methodology” (Finley, 2011, p. 572).

Kidd (2009) offers a model of that potential for transformation. In his work with homeless street youth, he initially made use of a structured survey. He describes the progression to arts-based inquiry this way:

At the end of the survey, seemingly as an afterthought, I asked the kids, “Write or draw anything you want people to see” and gave kids a blank sheet of paper and some markers ... [I found] my passion was in the art and messages that I collected and in the time I spent with the youths after the “study” interactions were over. Somehow in these parts of this work, I was able to be myself and build on relationships formed through what were often intense and highly self-revelatory interviews about their lives... While starting as a group of people I worked with, out of curiosity and general sense of wanting to make a social contribution, insight into the issues faced by homeless persons has led it to become a driving force in my efforts at individual and social/policy levels to enact change. (Kidd, 2009, p. 346-347).

Kidd connected to the stories of the youth through the art that they shared, and those connections awakened his desire to make a difference in their individual stories, and in the larger story in which we all play a part.

In 2003, Finley argued that “Arts-based researchers need to move out of the crisis of representation to the new era of guerilla warfare” (p. 293), asserting independence from, and even creating art against, the status quo of social science research, committing to “research practice that is ethical, political, and culturally responsive” (Finley, 2003, p. 293). She echoes Denzin’s (2000) call for a “radical, ethical aesthetic” (p. 261).

“We are in the business of not just interpreting but changing the world” (Denzin, 2000, p. 256). And so to the emic, the etic, and the epic, I add one last level to the framework:

### **Critical arts-based inquiry at the level of the ethic**

The 1979 Belmont Report remains the standard of ethical requirements within guidelines for the Responsible Conduct of Research (RCR) at institutions and organizations in the United States. According to that report, ethical treatment of human subjects requires respect for persons, beneficence, and justice. Respect for persons

requires that research participants give free and informed consent. Beneficence means that the research should be of benefit to the participant, and that the researcher is responsible for minimizing and mitigating harm. Justice is closely related to beneficence; in RCR, justice means that risk should be commensurate with reward, and that participants should stand to gain as much or more from the research than non-participants: the distribution of benefits should be fair and equitable (Steneck, 2007, under the auspices of the Office of Research Integrity).

What does critical arts-based inquiry add at the level of the ethic? It adds an ethic of relationality (Bochner & Ellis, 2016; La Jevic & Springgay, 2008), which is to say, an ethic of care (Finley, 2014; Finley, 2011; Smith, 1999). “[C]ritical arts-based research ... [is] a means to a radical ethical aesthetic ... that is being established on the utopian ideal of an existential ethics of love and care” (Finley, 2014, p. 531).

Carol Gilligan (1982) developed her theory of the ethic of care in response to concerns, grounded in feminist epistemology, that women’s distinctive way of moral development was receiving short shrift in the theory and practice of psychology. The ethic of care underscores the way moral reasoning can find a foundation in the value that people place on relationship.

Applying an ethic of care elevates the standard of RCR:

The ethical standards of the academic industrial complex are a recent development, and like so many post-civil rights reforms, do not always do enough to ensure that social science research is deeply ethical, meaningful, or useful for the individual or community being researched (Tuck & Yang, 2014, p. 223).

That is perhaps especially true in qualitative research: “Most qualitative research raises ethical issues far more complicated than those covered by procedural rules” (Bochner & Ellis, 2016, p. 140). An ethic of care enters that gap.

Along the same lines as Gilligan’s 1982 articulation of an ethic of care, Cornel West (1991) argued for an ethics of “radical historicism ... *contingent, community-specific* agreements people make in relation to particular norms, aims, goals, and objectives” (West, 1991, p. 1; emphasis original). Both the ethic of care and the ethics of radical historicism accept contingency and relationships as meaningful factors in systems of ethics.

In an ethic of care, the principle of respect for persons requires not only informed consent; it requires the researcher to be a faithful witness (Gunaratnam, 2007) to the subjective reality of the research participant.

In an ethic of care, the principle of beneficence means that the researcher does not only mitigate risk; they also take responsibility for any harm caused, creating mechanisms for meaningful accountability and appropriate course correction (Smith, 1999). Interpreted that way, it is clear that beneficence is closely related to the value of justice, but in an ethic of care, justice has a more expansive definition: it is relational justice. It declares an intention: *I will do right by you.*

Critical arts-based inquiry engages the ethic of care. “Unique within the broader genre of arts-based research are critical researchers’ goals of using the arts in a project of social and political resistance to achieve social justice” (Finley, 2011, p. 561). “In this spirit of resistance to social injustice ... critical arts-based researchers perform inquiry

that is cutting edge and seeks to perform and inspire socially just, emancipatory, and transformative political acts” (p. 562).

A final, essential aspect of honoring the ethic of care in research methods is decolonizing dissemination of research results (Conquergood, 2002; Finley, 2011). “Dissemination of research results beyond scientific publication, specifically, to study participants and the general public, is an ethical responsibility of researchers” (Chen, Diaz, Lucas, & Rosenthal, 2010, p. 372). Dissemination is decolonized “by creating open spaces and multiple entrances to [the] work ... [enabling] participation by various and diverse members of the community the research serves” (Finley, 2003, p. 288).

What I have outlined is a framework for radical reflexivity as an ethical imperative; it requires us as researchers to consider the impact of our ontology, epistemology, and methodology (Guba & Lincoln, 1994) at every stage and every level of the research endeavor. “Researchers, notwithstanding their use of quantitative or qualitative methods, should systematically identify their subjectivity throughout the course of their research” (Peshkin, 1988, p. 17). And not only identify subjectivity, but interrogate the salience of that subjectivity. Doing so is an antidote to betrayal “through accountable positioning” (Visweswaran, 1994, p. 99).

Radical reflexivity is a bulwark against othering (Shuler, 2007) and essentialism. “The radical empiricist’s response to the vulnerabilities and vicissitudes of fieldwork is honesty, humility, self-reflexivity, and an acknowledgement of the interdependence and reciprocal role-playing between knower and known” (Conquergood, 1991, p. 182). A

commitment to radical reflexivity is a commitment to “transparency, accountability, and transformation” (Griffin, 2016, p. 6).

### **Practice / Praxis**

In this dissertation I have practiced writing as inquiry; it is a method emphasizing process as well as a product (Richardson & St. Pierre, 1997). It is a way of knowing as well as a way of sharing what I know. I am simultaneously developing and articulating a Black Feminist critical arts-based research praxis; it is an iterative endeavor (Leavy, 2015; Shuler, 2007). Elements of this emerging researcher self are intuitive, others are autodidactic.

Writing of her own early efforts to develop and articulate a scholarly identity, Shuler (2007) noted, “This paper is the result of . . .the intersection of personal and epistemological crisis and transformation” (Shuler, 2007, p. 259). My dissertation is based on an intersection of similar crises. It and I are both works of progress-in-process: I am making progress; this is that process. I remind myself of what my yoga instructor used to say when introducing an advanced pose: *That’s why it’s called yoga practice, not yoga perfect*. With Shuler, I acknowledge, “This is what it looks like from here, for now, toward the beginning” (Shuler, 2007, p. 259).

I aspire to arts-based inquiry as guerilla warfare, as Finley (2003) articulated; I aim to do as Denzin demands and “[make] qualitative research central to the workings of a free democratic society” (2000, p. 257). I seek to honor the highest ideals of research praxis at the levels of the emic, etic, epic, and ethic that I have outlined.

How have I fared?

At the level of the emic, have I made an honest effort to portray a subjective truth?

At the level of the etic, have I named the standpoint that informs my observations about objective or factual information?

At the level of the epic, have I contextualized my tale in a larger narrative?

At the level of the ethic, have I treated myself with respect, care and compassion?  
Have I made progress toward meaningful transformation?

### **Now You See Me at the level of the emic**

I have told a part of one of my stories. One of my stories is about the year in my life after a car accident, when I was in pain, and my doctors didn't seem to believe me. I have told a part of the story of that year. I have offered poetry, rather than narrative, in order to explore and evoke certain affective elements of my experience (Becker, 1997; Gallardo, Furman, & Kulkarni, 2009). There is much that I left out. For instance, I experienced extraordinary happiness and deep joy at times during that year: a visit from my sister and a road trip to New Mexico stand out in sharp contrast to the long nights of not sleeping, and the long days of wishing for relief. Is the fact that I left these elements out of the telling a betrayal of ideals at the emic level? Again with Shuler, I acknowledge that "I am still sorting out what part of my story is useful, compelling, and ripe for analysis" (Shuler, 2007, p. 277).

There is another consideration for my project at the level of the emic: I am part of a tradition of scholarship that is "so skewed toward texts that even when researchers do attend to extralinguistic human action and embodied events they construe them as texts to



be read” (Conquergood, 2002, p. 147). An autoethnography of the body presented only in text must necessarily be an autoethnography *about* the body (Spry, 2011). I must revise my claim that I have spoken what is unspeakable. I will say instead that I have spoken around a silence, evoking its contours through poetry, “a form that itself brings attention to silence” (Leavy, 2015, p. 79).

### **Now You See Me at the level of the etic**

At the level of the etic, I have provided little in terms of objective evidence or independently confirmable fact. I am not offering my medical records as inserts (Sparkes, 1996) or as an appendix for comparative analysis. I am not providing a transcript of my journal as proof of the veracity and validity of my claims.

And, which may be worst in terms of betrayal at this level, I have not interrogated certain subjectivities, namely my atheism and my queer identity. Despite references to Christian theology (in poems *The Apostle* and *Gethsemane*) and agnosticism (*X Rays*) my atheism is scarcely indicated and certainly not interrogated in the dissertation text. Yet my atheism is integral to the way I made meaning after the accident, and to the way I make meaning now. My atheism also sets me apart from certain structures of Black solidarity and validation (Lincoln & Mamiya, 1990), complicating my relationship with Black feminism (Collins, 1986).

My queerness is also almost entirely absent in the dissertation text. I left it out of the equation because it is generally invisible, and because it seemed to me to lack salience vis-à-vis the subject at hand.

Do my decisions about which parts of my identity to foreground undermine my claim to value radical reflexivity? What if I take the definition of reflexivity as “self-critical sympathetic introspection and the self-conscious analytical scrutiny of the self as researcher” (England, 1994, p. 82)? Does the fact that I thought about my multiple subjectivities (Peshkin, 1988), and wrote about them elsewhere (i.e., in my research journal), excuse their exclusion from the finished text? How much self-revelation is required for Visweswaran’s “accountable positioning” (1994, p. 99)?

Part of this process has been making decisions about what is analytically salient, and what fits the parameters of my stated objectives (Shuler, 2007). Though it pains me to parrot Pontius Pilate, his most famous words are doubly resonant here:

What I have written, I have written.

Readers will judge the verisimilitude. I own that I have offered a partial perspective and a partial account (Barone, 2009).

### **Now You See Me at the level of the epic**

Audre Lorde (*The Cancer Journals*) and Bettina Judd (*Patient.*), and now, another verse. Less assured, to be sure, less renowned (at least for now), but no less deeply felt. No less Black, no less woman: of, and from, *about* the body (Spry, 2011).

Theirs are not the only accounts worth considering in the context of the epic; I refer the reader to the discussion at the end of Chapter 5. I join and extend the literature of illness narratives, counter-storytelling, poetic inquiry, and, to use Griffin’s (2012) neologism, Black Feminist Autoethnography. Moving forward, (and I will move forward) I commit to a process of community validation (Collins, 2000) through performance and

participation in my local poetry scene. I will publish, so that the work does not perish, and so that others who may have had similar experiences will know that they are not alone (Delgado, 1989).

### **Now You See Me at the level of the ethic**

Much of the literature on ethics in autoethnography is centered on way the researcher portrays the other while writing the self (Chatham-Carpenter, 2010; Wall, 2008). Even Tullis (2016), while acknowledging that gap, offers little in the way of corrective in her ethics chapter in the *Handbook of Autoethnography*. Like Chatham-Carpenter (2010), she cautions autoethnographers to be mindful of the potential career consequences of publishing personal stories. She then shifts her attention back to the ethics involved in the portrayal of others (Tullis, in Adams, Bochner, & Ellis, 2016).

In any emotionally laborious research endeavor (Rager, 2005; Shuler, 2007) where the researcher is present, at whatever level of participation, it seems to me that an ethic of care must include an ethic of self-care. This is in keeping with the values of Black Feminist Thought: self-care “humanizes Black women” (Scott, 2016, p. 129) and should be “embraced and encouraged in the realm of praxis” (p. 130).

After reviewing my research proposal, the Institutional Review Board (IRB) at my university concluded that my project did not meet the classification of “Human Subjects Research” (personal communication, December 2017); others have reported similar responses when submitting proposals for autoethnographic to their IRBs (Bochner & Ellis, 2016). It was up to me and my committee to determine what would constitute

ethical treatment for this dissertation. I operationalized my ethic of self-care in three primary forms: journaling; expressive writing through poetic inquiry; and refusal.

### *Journaling*

In addition to maintaining my habit of personal journaling, I kept a research journal throughout the process of writing this dissertation. I used it to jot down reminders (“Find *Ars Poetica*”), start poems (“meaning is something we make not remember”), and to take notes during meetings, or when I was reading without a computer nearby (“hooks warns against ‘uncritical acceptance of distorted definitions’, 1990, p. 22”).

I also used my research journal to write about writing my autoethnography. Anger, trepidation, and anguish are acknowledged and interrogated. Surprise is noted. One of my favorite moments in the notebook is an observation about transcribing my February 26, 2015 journal entry: “The power of texts: they don’t change, but I do.”

Writing through emotion while conducting research can benefit both the researcher and the research (Boncori, 2018; Chatham-Carpenter, 2010; Rager, 2005). In addition to being part of a practice of reflexivity, it can be a way of establishing boundaries about what to share and what not to share. It served both of those functions for me.

Writing from the in-the-mist was valuable at the time, and it has value now, as I reflect on the project and think ahead to what I can offer others who are undertaking autoethnography. “Autoethnographies are often written without showing the struggles that took place during the writing itself ... More meta-autoethnographies are needed

which talk about the process of writing itself and how it affected the autoethnographer” (Chatham-Carpenter, 2010, p. 2; p. 10).

Chatham-Carpenter’s appeal to autoethnographers to write about the struggle reminds me of what I said in Chapter 3:

A layered account begins (Ronai, 1995; Ronai, 1992)

With a history

Of the universe. (Anthym, 2017; Geertz, 1973)

A text is never just a text, never entirely self-contained or self-referential. Our texts are inter- and meta- textual, emotional and relational, inherently multilayered (Watson, 2008). Excavating and explicating the strata of our writing can be a meaningful way to make a contribution to the scholarly work of and about emerging methodology. If the term “auto-archaeology” was not already taken (cf. Fox, 2010; Fox, 2014) I would offer it as an appropriate metaphor for the work of meta-autoethnography. Boncori (2018) echoes Chatham-Carpenter’s (2010) call for that effort, highlighting “the need for ethnography, especially in its more personal autoethnographic form, to explore and expose the emotional labour [sic] and emotional work embedded in its practice as a central component of academic scholarly production” (Boncori, 2018, p. 209). It is an area ripe for future research.

### ***Poetry as Inquiry***

In addition to the writing I did in my personal journal and in my research journal, there were aspects of self-care in the writing I did for the dissertation itself. Chatham-Carpenter (2010) describes finding a “new found freedom ... from writing through [her]

pain” (p. 7), and I found something similar, a kind of psychological release through the process of applying poetic aesthetics to my story. The poem *It's Not Pain* is a meta-textual example of that. The poem itself is based on a journal entry, yes, but in the poem I engage both the past and the present: as an aesthete, I can forge beauty from pain such that the beauty subsumes the pain. Transcribing my journals was difficult, emotionally exhausting. But writing the poems was not. It was rewarding, refreshing, a relief.

Poetry has been a mode of meaning-making for me for most of my life, as both reader and writer. Bibliotherapy and poetry-therapy have been informal modalities for psychological care since at least the 1930s, when librarians took it upon themselves to compile reading lists of items specifically selected for their potential to promote emotional wellbeing (Cornett & Cornett, 1980; Gladding & Gladding, 1991).

Bibliotherapy in the form of “expressive writing” has been demonstrated to have a number of therapeutic effects, both physically and psychologically (McArdle & Byrt, 2001).

Norman Denzin writes about autoethnography as a kind of time-travel: “In bringing the past into the autobiographical present, I insert myself into the past and create the conditions for rewriting and hence re-experiencing it” (Denzin, 2006, p. 334). As I prepared to write my autoethnographic account, I feared reliving the past. I did not know what the consequences might be of going back to that dismal and despairing epoch. I didn't count on being able to rewrite it. Having gone through this process, I won't remember that year in the same way ever again; I will experience the journal differently when I reread it. I will remember the poetry, and the meanings I've made. I haven't

erased the past: I don't take the Orwellian view of history as palimpsest (Orwell, 1949). I haven't written over it; I have written through it. That is one of the many gifts of writing as inquiry (Richardson & St. Pierre, 1997). Like Denzin, I found "in writing from the heart [a way to] learn how to love, to forgive, to heal, and to move forward" (Denzin, 2006, p. 334).

### ***Refusal***

In their 2014 article on refusing research, Tuck and Yang castigate the "academic industrial complex" (p. 223), and particularly the social sciences, for a preoccupation with "empirically substantiating the oppression and pain of...disenfranchised communities" and "eliciting pain stories from communities that are not White, not wealthy, and not straight" (pp. 226-227). They connect this critique to the history and ongoing legacy of settler-colonialism: subjugated knowledge, as championed by the academy, is knowledge of the suffering of the subjugated Other.

I acknowledge my own complicated complicity within this system, as reified in this project. But my resistance has also been reified, albeit in extra-textual fashion, through the strategic and self-protective deployment of what Tuck and Yang describe as refusal. "Not everything, or even most things, uncovered in a research process need to be reported in academic journals or settings" (Tuck & Yang, 2014, p. 233). Refusal respects the agency and protects the privacy of the person(s) portrayed in the research report. It is a powerful paradox within and against the academy, a stance that says that not everything worth knowing should be made known.

When I say, “now you see me”, I allow for a silence that is filled with what I previously referred to as the concomitant counterstatement “now you don’t”. That silence, that implicit counterstatement, is my refusal. It is my insistence that in my work against hyper-visible invisibility, I can insist that you see me, and I can also decide how you see me, and how much you see.

My nearly year-long quest for care was not only painful; it was also often humiliating. There are contexts in which I share those parts of my story. This dissertation is not one of them. “Although such knowledge is often a source of wisdom that informs the perspectives in our writing, we do not intend to share them as social science research. It is enough that we know them” (Tuck & Yang, 2014, p. 234). Though not naming it as such, Chatham-Carpenter is referring to refusal in her reflection about her decision not to write about her relationship with her husband in her autoethnographic account of life with an eating disorder. She writes: “Those are private boundaries that I did not want to cross, private information the world should not be privy to see or hear” (Chatham-Carpenter, 2010, p. 9).

Refusal played a part in my rationale for choosing poetry over narrative. Tuck and Yang are not referring to poetry when they describe “shadow curriculum” and “trickster knowledge” (2014, p. 235), but I find in poetry the same “play of shadows” they describe, in which “much meaning is made in silence surrounding the words, where memories are not simply reflections of a referent experience but dynamic in themselves” (Tuck & Yang, 2014, p. 235). Poetry gave me the freedom to evoke my experiences rather than describing them (Prendergast, 2014), to present my memories as mosaic



abstraction, re-creating instead of recreating, which is to say creating anew from memory, rather than attempting to recreate the memories themselves. Refusal, and in my project my poetic deployment of refusal, allows for “[portraying] the violations without reportraying the victimizations” (Tuck & Yang, 2014, p. 242). The scar is sufficient evidence of the wound that left it; scar is to wound as poetry is to narrative. “Poetry and narratives present multiple levels of the same phenomenon” (Gallardo, Furman, & Kulkarni, p. 290).

Refusal is a guard against doing research for the sake of research, a guard against unthinking exploitation, as well as more thoughtful varieties. Ultimately, Tuck and Yang propose refusal as a way to humanize research (2014, p. 223), which is to say, a way to make human subjects research more humane, more ethical: “Refusal challenges the individualizing discourse of IRB consent ... by highlighting the problems of collective harm, of representational harm, and of knowledge colonization” (2014, p. 242). Refusal recognizes informed consent as an ongoing and relational process, elevating the first principle of research ethics by expanding the discourse on doing no harm.

My ethical obligations encompass myself, but I am cognizant of the fact that they extend beyond, to the audiences who will engage with my work (Sinding, Gray, & Nisker, 2008; Tullis, 2016), and to the community I implicate as member-representative of a marginalized group. “To theorize *with* and *as* at the same time is a difficult yet fecund positionality” (Tuck & Yang, 2014, p. 243 [emphasis original]).

## **Forward / For Words**

It has been my intention to write myself for others, to offer a “for instance” of Black female embodiment and struggle in the context of an ongoing quest for the transformation that comes through and shows itself in self-definition (Collins, 1989) and re-presentation. Reflecting on the work Audre Lorde did in *The Cancer Journals*, Perreault observed “The writing of self ... is useful for knowing herself for herself, but the transformation of her experience into writing is to make it useful to other women as well” (1988, p. 10).

I am an *n* of 1, a part of and apart from an *N* of many, who “find our origins in the historical reality of Afro-American woman’s continuous life-and-death struggle for survival and liberation” (Combahee River Collective, 1977, in Guy-Sheftall, 1995, p. 232).

The struggle continues.

Audre asked “What do we want from each other / after we have told our stories” (Lorde, 2000, p. 409). And elsewhere, Audre answers the question. What we want when we tell our stories is “that the pain not be wasted” (Lorde, 1980, as cited in Perreault, 1988, p. 15).

When we bring intentionality and reflexivity to the meaning-making storytelling process, and share those stories with others, “stories become pedagogical and transformative ... opening a space for personal healing, public dialogue, and policy changes” (Spry, 2011, p. 56). That is my hope.

Writing the self “is an aspect of ... political life – the making of community through transforming what is usually seen as private experience into a public matter” (Perreault, 1988, p. 9). “[W]riting of self participates in the communal development of feminism” (Perreault, 1988, p. 14) and, in my case, particularly in the communal development of Black Feminist Praxis.

Questions about what Black Feminist critical arts-based praxis is can be answered by what people are deploying it to do (Cho, Crenshaw, & McCall, 2013).

Methods have politics, and these are mine.

This is who I am.

This is what I’ve done.

This is what the living do.

This is how we change the world.

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