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“Livin’ the Dream?”

How Veterans of Operations Enduring Freedom and Iraqi Freedom Negotiate the Experience of Illness as They Transition from Healthy Warrior to Sick Veteran

by

Jodie L. Sweezey

A dissertation submitted in partial fulfillment
of the requirements for the degree of
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share such personal aspects of their lives but you did so as partners in this struggle for answers. May this be a first step for us in making a change in the lives of our brothers and sisters.

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LIST OF ABBREVIATIONS, ACRONYMS, INITIALISMS

AARDA: American Autoimmune Related Diseases Association
AVIP: Anthrax Vaccine Immunization Program
CDC: Center for Disease Control and Prevention
CEAUSSIC: Commission on Anthropology's Engagement with the Security and Intelligence Communities
DOD: United States Department of Defense
EPA: United States Environmental Protection Agency
FDA: U.S. Food and Drug Administration
GWS: Gulf War Syndrome
HQ USSOCOM: Headquarters United States Special Operations Command
HIPPA: Health Insurance Portability and Accountability Act of 1996
HTS: Human Terrain System
IED: Improvised Explosive Device
MD: Medical Doctor
MRI: Magnetic Resonance Imaging
OEF: Operation Enduring Freedom
OIF: Operation Iraqi Freedom
PTSD: Post Traumatic Stress Disorder
RAC: Research Advisory Committee
SA: Situational Awareness
SOF: Special Operations Forces
UV-B: Ultraviolet Light with Short Wave-length
VA: Department of Veterans Affairs
VHCN: Vaccine Healthcare Centers Network
TBI: Traumatic Brain Injury

ABSTRACT

As combat veterans returned from supporting the wars in Iraq and Afghanistan, questions over the safety of vaccinations as well as exposure to burn pit smoke and toxic metals lying dormant in the sand emerged. For many, returning home was marred by unexplained symptoms followed by diagnoses of autoimmune diseases and/or cancer. This research examines how these veterans negotiate this transition from healthy to sick struggling with the many forces that interact with this transition. I focused on the lived experience of their illness as it is non-verbally expressed through embodiment, verbally expressed through illness narratives, and negotiated to avoid stigma.

This research is situated in and through the body. It is based on assumptions, rooted in context, founded on theory, and framed by visual methodology. I utilized photo elicitation and photo voice in concert with open-ended interviews of 10 Operation Iraqi and/or Enduring Freedom veterans diagnosed with autoimmune diseases and/or cancer. I then created a digital story to give voice to these often overlooked veterans in hopes of educating not only clinicians but also a broader audience. It is also a call to other anthropologists to fill this most important qualitative research gap.

CHAPTER 1:

INTRODUCTION

At the national-level, the events of September 11, 2001 changed America profoundly. On an individual level, they transformed the lives of the millions of men and women deployed in support of Afghanistan's Operation Enduring Freedom (OEF; 2001-2014) and Iraq's Operation Iraqi Freedom (OIF; 2003-2011). On a personal level, after two deployments to Fallujah, Iraq, I had an adverse reaction to an anthrax vaccine and was eventually forced to resign my commission as my health deteriorated and my diagnoses increased.[1] As a United States Marine, I did not speak about my struggle to work and attend school. When I eventually did start to confide in other veterans, I was astonished at the number of them facing the same issues.

Almost from the start of OEF and OIF, controversies emerged over the safety of vaccinations, inhalation of burn pit smoke, and inhalation of toxic metals and other contaminates lying dormant in the sand. Yet despite lawsuits and news exposés, little is understood about the relationship between diagnosed cancers, autoimmune, and neurological diseases related to combat in Iraq and Afghanistan. Today, with a resurgence of global military actions and a catastrophically broken Department of Veterans Affairs (VA), studying the illnesses plaguing veterans is of vital importance. Feeling isolated in their struggle for health, veterans are affected on a very personal

[1] Despite having classic adverse reaction symptoms less than thirty days after my vaccination, the Vaccine Healthcare Clinic denied the link.

level. This isolation is compounded as they fight military cultures which still hold sway, as well as the power of the United States government, which controls the knowledge through funding. The information available from various government organizations, each with their own agenda, is conflicting, which leads to distrust.

The What and Why

The majority of current medical literature is focused on Traumatic Brain Injury (TBI) and Post Traumatic Stress Disorder (PTSD); each is of vital importance. However, there is a slowly growing body of literature examining other diagnoses and even questioning the existence of an Iraq War Syndrome similar to Gulf War Syndrome, identified after Operation Desert Shield/Desert Storm (Horn et al. 2006 and Research Advisory Committee 2008). Arguments for and against the existence of a Gulf War Syndrome lasted 17 years and although it was acknowledged by the VA, the syndrome continues to be contested (Friedl, Grate, and Proctor 2009; Patocka, Honegr, and Soukup 2014; and Research Advisory Committee 2008). Despite millions of dollars in medical research, mostly done in clinics and laboratories, there is still no known clear consensus on the cause of Gulf War Syndrome, let alone an understanding of the cause of diseases and unexplained symptoms plaguing Iraq and Afghanistan veterans (Friedl, Grate, and Proctor 2009; and Zavestoski et al. 2004). Additionally, there is a gap in the literature addressing veterans' day-to-day struggles in experiencing their new lives shaped by illness and disease characterized by debilitative and degenerative indications (Ware and Kleinman 1992).

It is for this reason I examined how veterans of OEF and OIF negotiate the transition from healthy warriors to sick veterans, struggling with multiple illnesses and

the many forces that interact with that transition. This is a transition poignantly described by Susan DiGiacomo as a form of culture shock, where we no longer know the world in which we live (in Singer and Baer 1995:82). More specifically, my research focuses on the lived experience of illness as it is non-verbally expressed through embodiment, verbally expressed through illness narratives, and negotiated to avoid stigma. This experience does not happen in a vacuum but within a context rooted in the Gulf War veterans' struggle and therefore must be included in the critique of the multiple institutions that further complicate this tenuous transition (Singer and Baer 1995).

This research, in line with Arthur Kleinman, divides illness (what is experienced) and disease (what is diagnosed), an approach that shines a light on the veteran's circumstances not often understood by those who do not share the same experiences (Kleinman 2013; and Wessely and Cohn 2008). My research resides at the intersection of the two; focused on the experience of illness within the context of the diagnosed disease (Kleinman and Benson 2006; and Kleinman 2013). I understand illness and disease as two sides of the same coin – equally important yet with different viewpoints and language. Each veteran experiences illness and the linked emotions differently, despite shared aspects that are culturally (civilian and military) framed and governed (Durodie 2006; Kleinman and Kleinman 1996; and Ware and Kleinman 1992). Even with the power of military culture, veterans have agency in how they make this transition and when and if they chose to question their diagnoses and seek answers.

My goal was to examine the experiences of sick veterans without reproducing a stereotyped image that military culture creates (Blais and Renshaw 2013; and Mittal et al. 2013). This requires setting the right tone that is one of empathy without pity and

truth without sniveling (Kirmayer 2008). The right tone is important in making government, military, and congressional leaders see the experience of illness from the veteran's perspective and then take it seriously (Kleinman 2013).

My research is intended to further expose Afghanistan and Iraq veterans' lived experience of illness while placing it within the historical and systemic context that interferes with this experience on multiple levels. Veterans spend years finding treatments through medical institutions that may alleviate their pain, but never provide true healing. Although many veterans' organizations are founded to fight for answers, most disband due to the failing health and the lack of success in moving their goals forward against deeply entrenched bureaucratic institutions.

This dissertation is research completed by a fellow sick veteran trying to provide understanding to other sick veterans in their health struggles (Kleinman 2013). I am under no illusion that I will change the bureaucracies that control the current narrative but only hope to provide sick combat veterans the ability to communicate broadly their invisible battles. My goal is for this research to bring a widespread awareness about what all sick veterans confront.

Despite an insider status, from the beginning I had concerns regarding knowledge production. There is much at risk for sick veterans whose participation may be affected by circumstances outside my control (Ceja-Zamarripa 2007, Hale 2008, Speed 2006, and Sherif 2001). I contemplated how I would treat the need to critique my own military Service and civilian work within the Department of Defense (DOD), while still maintaining devotion to the ideal (Ceja-Zamarripa 2007, Kempny 2012, and Zaman 2008). Additionally, I was aware that others who spoke out against these organizations

were censured. Although outspoken, would I be comfortable with my critique reaching beyond those I privately speak with?

The Rest of the Story

Just One of the Boys

The “insider/native” discussion emerged when anthropologists from societies where “the Other” was traditionally studied began to conduct their own research (Kempny 2012, Narayan 1993, Sherif 2001, and Zaman 2008). This created a back-and-forth dialogue over whether insiders could produce a more nuanced form of knowledge that drew out subtleties an outsider could not see (Kempny 2012 and Sherif 2001). Acknowledging this, I chose to position myself with my participants while balancing the existing inner tension between my two selves; a Marine and an anthropologist. This tension grows from the adversarial relationship between the military and anthropology, which evolved over the last few decades. From the anthropologist’s viewpoint, a genuine distrust grew out of real abuses of their research, resulting in harming their participants. From the military point of view, as one colonel once told me, “I will listen to an anthropologist until it interferes with completing my mission.” Outside opinions are often put aside or reshaped to fit the need.

Once accepted into the anthropology doctoral program, a new “self” formed which immediately defined me by the blurred line where these two peculiar personalities violently collide (Kempny 2012, Le Meur 2015, and Sherif 2001). Although all researchers have multiple identities, this messy relationship created a non-negotiable requirement for examining these statuses and their relationship to any future research (Chavez 2008, Kempny 2012, Le Meur 2015, Sherif 2001, and Zaman 2008). Because

research in particular grew out of these two identities, the last 26 years of my life, could be characterized as “one continuous participant-observation.” (Ceja-Zamarripa 2007:11) Planting one foot firmly in each side of my identity, I fully acknowledge that there are both advantages and limitations to this positionality.

Christina Chavez (2008:479) provided a thorough accounting for possible advantages and disadvantages to being an insider researcher. Table 1 will be

Advantages to Insider Status	Complications to Insider Status
Positionality •a nuanced perspective for observation, interpretation and representation •an equalized relationship between researcher and participants •expediency of rapport building •immediate legitimacy in the field •economy to acclimating to the field	*Positionality* •Insider status unchecked can complicate or overwhelm researcher role. •over-identification or over-reliance on status obscures researcher role or goal of research •social roles in group or community constrain researcher role and objectives •expectation to participant in community events or affairs •overload with exchange or reciprocity requests from participants •requests to take sides in community political and moral issues •the rise of value conflicts as a result of research and community member role •compromised professional ethics and/or research results •participants' perceptions and expectations co-opt researcher or constrain role
Access •expediency of access •access to more in-group activities	*Access* •bias in entering field and establishing rapport •limited access based on political climate
Data Collection/Interpretation/Representation •insight into the linguistic, cognitive, emotional, sensory and psychological principles of participants •knowledge of the historical and practical happenings of the field •stimulation of natural interaction and behavior •detection of participants' hidden behaviors and perceptions •detection of nonverbal gestures of embarrassment and discomfort •detection of informants' actual behavior versus their performed selves •identification of unusual and unfamiliar occurrences	*Data Collection/Interpretation/Representation* •observer and/or participant role may be culturally inappropriate •large amounts of impression management to maintain rapport and/or identity •selective reporting •difficulty with recognizing patterns due to familiarity with community •bias in selecting participants •breaking or maintaining relationships with participants when leaving the field •community interaction style compromises interview process or observation •insiderness obscures representation or implementation due to turbulent or changing political and historical climate of the field

Table 1 Methodological Advantages and Complications of Insider Positionality (Christina Chavez and NSUWorks © 2008)

addressed again in chapter five when compared to the actual experience in conducting my research.[2] Initially, some of Chavez's (2008) observations provided particular land mines for me. Having one foot in both worlds I must be careful not to assume that my insider status will provide immediate and unfettered access to this community (Kempny 2012, Sherif 2001, and Zaman 2008). In fact, I could be viewed as an outsider due to my status as a researcher. This standing could prove troubling to those participants hesitant to talk about their deployment-related health problems (Speed 2006). Additionally, researchers tend to be an outsider group that the military does not always trust. For the veterans who have studied OEF and OIF diseases, I assumed they could be highly skeptical of any researcher because of so much conflicting data (Zavestoski et al. 2004).

In the past I spoke often with other sick veterans. Now I am coming to them as a researcher, recognizing that I walk a fine line in exposing their experiences without reducing them to a stereotyped image of a sick veteran among communities where health and fitness are extremely important (Blais and Renshaw 2013). These participants could easily become "fodder," not only for academia but also for government entities like the VA, Center for Disease Control (CDC), Food and Drug Administration (FDA), and DOD (Ceja-Zamarripa 2007:12).

Although I am, in some respects, a participant in my own research, I had to be careful not to project myself onto my participants by assuming all of our experiences are the same (Gallinat 2010, Kempny 2012, and Robertson 2002). However, I do believe

[2] Table previously pushed in The Qualitative Report 13 (3): 474-494. Used with permission under Creative Commons Attribution-NonCommercial-ShareAlike (CC BY-NC-SA).

that there were great advantages to having an empathy and understanding that only comes from a shared experience (Kleinman 2013). In fact, I cannot say with any certainty that I would have learned of this unless I too battled it. I never heard anyone talk about being sick and was very reluctant to speak of my own issues to other military veterans. Remembering this struggle ensured that I respected my insider privilege and was careful not to portray participants in overly simplified terms but as complex people living in complex situations (McKee 2010 and Narayan 1993).

To "Assume" Makes an…

From the outset, my own experiences provided me a foundation from which to begin. Initially, I wrote down all of my assumptions regarding sick veterans and how they experience illness. These hypotheses provided me a place to start and a set of hypotheses to prove or disprove. They were:

1. They have varying degrees of understanding about the possible service-connection of their diseases.
2. The negotiation between healthy and sick is exacerbated by military culture (Barrett 1996, Messinger 2013, and Moore 2004).
3. When veterans spend their time trying to prove they are sick, they have less time to focus on getting better; specifically when working through the VA and doctors with little or no knowledge of combat exposures (Zavestoski et al. 2004).
4. The illness narrative is an individually and highly personal creation used to make sense of deteriorating health (Kilshaw 2004 and Kilshaw 2006).
5. Unlike Kilshaw's (Kilshaw 2004 and Kilshaw 2006) premise that veterans are drawn to other sick veterans in order to *create* (emphasis mine) narratives, they do so in order to find help and hope in others who truly understand (Chalder et al. 2001; Greenberg and Wessely 2008; and Hotopf et al. 2000).
6. The addition of caregivers adds another layer of difficulty in managing the transition (Kleinman 2013).
7. That despite the VA's acceptance of Agent Orange and Gulf War Syndrome based on exposures, they do not acknowledge the same for OEF and OIF veterans.

These assumptions not only provided a point of departure but also serve as a means to gauge my own biases.

Commander's Intent

For a Marine, "commander's intent" is the foundation of every decision and movement forward. Prior to any mission a commander tells you what he wants you to accomplish, then allows you to figure out how it is to be done. For my research, this "intent" was shaped by three central questions:

1. How do veterans negotiate the lived experience of illness within the context of their diagnosed disease?
2. In what ways can visual methodology further the understanding of the lived experience of veteran illness?
3. How can this qualitative research contribute to practical ways to address veterans' health issues within a framework of applied anthropology?

To address these over-arching questions, I planned to address a series of specific questions through interviewing combat veterans during the course of my fieldwork.

These questions were:

1. What was the timeline and process in which the participants learned they were sick?
2. How do/did they learn about best medications or treatments?
3. How have their lives changed since getting sick?
4. How do they understand their illness?
5. Do they measure their changing conditions by military standards or by civilian standards (Kilshaw 2004)?
6. In what ways does military culture influence or shape the veteran's transition?
7. How have the media defined and/or shaped this issue?
8. In what ways does the illness narrative change depending on who the veteran is interacting with? Is this related to fighting stigma?
9. Do they use metaphors in speaking of their diseases? If so, which metaphors do they use? To what are they linked?
10. Do they know about other sick veterans (Kleinman and Benson 2006)?
11. Were there impediments or support during their transition from healthy warrior to sick veteran?
12. What are the impediments of those groups in supporting veterans and getting answers?
13. Do the sick veterans trust the government, military leadership, or the VA to do right by them? To tell them the truth? Do they resist the power dynamic? If so, how?
14. How have these illnesses changed perceptions of the veteran's service to this country?

15. How has the sick veteran community been created? With support from Gulf War groups? With support from other veteran groups? How has this community been received within the veteran community? The broader military community?

Conclusion

This research is rooted in historical context out of which the methodological and theoretical framework emerged. In the military, plans are problematized and revised before execution against the enemy, or “making contact.” In keeping with the military focus of this research, I examined this subject in two parts. I first set out my plan which is what I believed to be the way forward. Then I made contact which addressed what actually played out in the research and analysis.

CHAPTER 2:

A CONTROVERSY FOR EVERY GENERATION

Using historical documents and medical records, scholars have argued that service members with unexplained symptoms and diagnosed diseases were common after other wars (Greenberg and Wessely 2008; Hyams, Wignall, and Roswell 1996; Jones et al. 2002; Nisenbaum et al. 2004; Soetekow et al. 2000; Unwin et al. 1999; and Wessely and Freedman 2006). Conversely, critics of this theory claimed that gaps in available documents along with the conflation of diseases were the precursors to PTSD and nothing else; for example, “a soldier’s heart” or “shell shock.” (Haley 1997:696, Jones et al. 2002, and Research Advisory Committee 2008:1) As a historian, doctoral candidate, and combat veteran, I subscribe to the latter. Even current service members’ medical records are incomplete at best and nonexistent at worst. Because they are often lost, it is common knowledge in each of the Services that one must maintain a copy of one’s military medical records. Additionally, my Iraq experience and exposures cannot be compared to my father’s in Hue City, my grandfather’s at Luzon, or my great-great-great grandfather’s at Gettysburg because of difference in experiences and exposures.

Having said that, I do believe that the Vietnam War and Operations Desert Shield/Desert Storm provide key historical context for specific reasons. First, both Vietnam and the first Gulf War were within a generation of Iraq and Afghanistan. In fact,

I served with Vietnam veterans in Iraq. Next, veterans of both wars dealt with exposure-related diseases. Finally, Vietnam veterans also faced battles to get the VA to acknowledge a service-connection to Agent Orange-related cancers and then provide adequate healthcare.

Vietnam

Multiple operations during the Vietnam War exposed troops to defoliation sprays; most often "Agent Orange." (Palmer 2007) Despite exposure-connected diseases and/or symptoms never being called a "syndrome," the struggle to get recognition for these combat veterans was similar to the experiences of future generations struggling to get healthcare for combat-related diseases (Martini 2012, Palmer 2007, and Tickner 2002).

Surprisingly, the safety of the defoliation sprays was called into question during the war; even by those manufacturing them (Martini 2012, Stellman et al. 2003, and Tickner 2002). The concern for the welfare of combat troops played out in courtrooms and through media outlets, forcing the government to create a subcommittee to study the issue (Martini 2012 and Young 2002). The DOD and other government and medical institutions then conducted follow-up research. The studies produced mixed results; both confirming and denying a link between Agent Orange and specific diseases. Some of these studies claimed the diseases resulted from mental health issues following combat experiences (Martini 2012, Palmer 2007, Stellman et al. 2003, Tickner 2002, and Young 2002).

Eventually, the VA associated the toxin to a set of diseases and declared them presumptive for disability compensation and treatment (Martini 2012 and Stellman et al.

2003). Despite this, the VA denied the majority of disability claims, leaving veterans to care for their own health. This did not change until the Agent Orange Act of 1991 was passed (Martini 2012). Additionally, it was not until recently that the Environmental Protection Agency (EPA) stated that the dioxins found in Agent Orange had the ability to negatively impact human health (Palmer 2007 and Young 2002).

Desert Shield/Desert Storm

Although Vietnam veterans had an environmentally and geographically different experience, the same is not true of Operations Desert Shield/Desert Storm. Due to greater overlap – including combat locations, exposures, and symptoms – my research was primarily built upon Gulf War-era medical studies which provided vital historical context (Department of Veterans Affairs Public Health 2015; Greenberg and Wessely 2008; and Horn et al. 2006). Despite decades-long focus by the media and medical research, the Department of Veterans Affairs Research Advisory Committee (RAC) on Gulf War Veterans' Illnesses did not acknowledge a Gulf War-era syndrome until 2008 when it published its report (RAC 2008:4).

Immediately following Operation Desert Shield/Desert Storm in 1991, stories emerged of unexplained symptoms plaguing veterans, not only in the United States but also from partner nations including Great Britain, Australia, Canada, the Czech Republic, and France (Carnall 1996, Emmerova 2004, Gwini et al. 2016, Kerr 2015, McKenzie et al. 2015, Nettleman 2015, Reid et al. 2001, Richter et al. 2015, and Schumm 2004). Because there was no overarching diagnosis for these symptoms, an umbrella term was used for reference: *Gulf War Syndrome*. By the late 1990s, a new moniker was adopted in the research: *Gulf War Illness*. More recently, the VA referred

to it as "*chronic multi-symptom illness*," or "*undiagnosed illness*" due to the varied symptoms (Department of Veterans Affairs Public Health 2015). However, they now refer to it as "*medically unexplained illnesses (popularly known as Gulf War Syndrome)*." (Department of Veterans Affairs Public Health 2017) Because of the evolving terminology, for the purposes of this paper, I will refer to it as "Gulf War Syndrome" (GWS).

Gulf War Syndrome is defined by the following profile: memory and concentration problems, persistent headache, unexplained fatigue, and widespread pain. It also includes chronic digestive problems, respiratory symptoms, and skin rashes (RAC 2008 and Zavestoski et al. 2004). The official number of Desert Storm veterans sick with GWS is estimated between 175,000 and 260,000 (Bertell 2006 and RAC 2008:1). However, this number could be much higher as some veterans sought treatment outside VA facilities (Zakirova 2015).

Approximately one billion dollars was spent on studies ranging in focus and outcome in the decade after the Gulf War (Gray et al. 2004; also see Friedl, Grate, and Proctor 2009 and Zavestoski et al. 2004). This included sick veterans petitioning for funding in order to conduct their own research (Zavestoski et al. 2004). Many of the early studies expressed skepticism regarding GWS, while a few claimed it simply did not exist (Everitt et al. 2002; and Patocka, Honegr, and Soukup 2014). After the 2008 RAC report, most medical literature spoke to the certainty of the diagnosis while looking for a cause and treatment.

Cause

In a 2002 article, Dr. Simon Wessely admitted that despite no “smoking gun,” he believed, “that something did happen and attention must be paid.” (Calandra 2002:50) However, that same year he released an article claiming there was no such thing as GWS (Everitt et al. 2002). Conflicting medical research on the veracity of claims and possible causes provided unlimited frustration for Gulf War veterans. The majority of research eventually converged along two differing etiologies: exposure versus psychological.

Exposures. Dr. Robert Haley, an American internist and epidemiologist, began researching GWS in 1994, and with his colleagues, was the first to support it and focus on an exposure-related cause (Haley, Kurt and Hom 1997; Haley and Tuite 2013; and Wessely 2001). Haley’s biggest contribution to this research was, no doubt, the use of factor analysis to identify clusters of symptoms (Kang 2002:61). His first three clusters were referred to most often in the literature due to their, “strongly clustered symptoms.” These were:

1. Impaired cognition: Problems with attention, memory and reasoning, insomnia, depression, daytime sleepiness, and headaches.
2. Confusion-ataxia: Problems with thinking, disorientation, balance disturbances, vertigo, and impotence.
3. Arthro-myo-neuropathy: Problems with joint and muscle pains, muscle fatigue, difficulty lifting, and extremity paresthesia (Haley, Kurt and Hom 1997:215).

Even the VA’s current definition of *medically unexplained illness* contains these clustered symptoms (Kang 2002, Hallman et al. 2003, Department of Veterans Affairs Public Health 2017, and Young et al. 2003).

Haley's camp argued for an exposure-related link to GWS (Haley 2003; Kerr 2015, Ojo et al. 2014; Steele et al. 2012; Department of Veterans Affairs Public Health 2015; White et al. 2016, and Zakirova et al. 2015). The toxic exposures included vaccines, pyridostigmine bromide (PB) pills, pesticides, burning oil wells, biological agents, and chemical agents. These exposures were experienced either alone or in combinations by those in direct combat and supporting roles (Asa, Wilson, and Garry 2002; Bassi et al. 2012; Haley, Luk, and Petty 2001; Hotopf et al. 2004; Iannacchione et al. 2011; Koslik 2014; Research Advisory Committee Report 2008; Ojo et al. 2014; Roland et al. 2000; Soetekow et al. 2000; Steele 2012; and Zakirova et al. 2015).

An Ounce of Prevention. Some of the toxic exposures linked to GWS grew out of the military's attempt to safeguard personnel against possible threats. These included pesticides, prophylactics, and vaccinations. Pesticides, like permethrin and DEET, were applied to uniforms in order to guard against insects carrying diseases. Another toxic preventative was the pyridostigmine bromide (PB) pills taken to protect against nerve agents. The RAC report (2008:1) determined that the, "evidence strongly and consistently indicates that two Gulf War neurotoxic exposures are causally associated" with GWS: pyridostigmine bromide pills and pesticides. Both alone and combined with one another, they were eventually linked to symptoms of GWS and specifically to impaired neurological functions like learning and memory loss and central nervous symptom damage (Abdullah et al. 2016; Haley 2003; Lucas et al. 2007; Nutter, Johnson, and Cooper 2015; Ojo et al. 2014; Phillips 2016; Steele et al. 2012; and Zakirova et al. 2015) as well as chronic fatigue (Cooper, Johnson, and Nutter 2016; and Nutter, Johnson, Cooper 2015).

The preventative measure which created the greatest firestorm was (and continues to be) vaccinations. Although the RAC report (2008) did not link vaccinations to GWS, it also did not rule it out. Studies examined the receipt of multiple vaccinations at once (Hotopf et al. 2000 and Koslik 2014); however, most of the controversy focused specifically on the anthrax vaccine. At the onset of the Gulf War, the anthrax vaccines were still experimental and given to personnel once they arrived in Kuwait (Steele et al. 2012). These shots were mandatory for deploying personnel until December 1997 (Asa, Wilson, and Garry 2002; and Bacevich 2000).

The major argument against the safety of the anthrax vaccine was, and continues to be, related to the use of adjuvants or additives to increase efficacy (Alijotas-Reig 2015 and Pasquale et al. 2015). In the United States (U.S.), one such adjuvant is squalene. The FDA as well as the DOD denied squalene was added to the vaccines, but researchers found evidence of anti-squalene antibodies in the blood of veterans who received vaccines which tested positive for squalene (Asa, Cao, and Garry 2000; and Asa, Wilson, and Garry 2002). Additionally, squalene is listed in the anthrax vaccine patent (Ivins et al. 2002). A French study found vaccines for British troops contained the adjuvant pertussis which could cause neurodegeneration; a possible explanation for the multi-symptom footprint of GWS (Tournier et al. 2002). Additionally, researchers claimed that adjuvants are tied to an autoimmune illness called Autoimmune/ Inflammatory Syndrome, in which GWS was listed (Bassi et al. 2012; Cervera 2011; Israeli et al. 2009; Israeli 2012; and Shoenfeld and Agmon-Levin 2011). More recent research opposed the anti-squalene antibodies claim, arguing that

even if it were present, it would not cause GWS (Lippi, Targher, and Franchini 2010; and Pasquale et al. 2015).

Environmental Toxins. In addition to the "preventative" measures, there were also environmental toxins, in the form of chemical and biological agents, which were considered a possible cause. Environmental toxins included chemical/biological agents, smoke from oil fires, and depleted uranium found in armor-piercing rounds (Bertell 2006; Bleise, Danesi, and Burkart 2003; Duraković 2001; Jamal 1998; and Squibb and McDiarmid 2006). The RAC report (2008) did not link depleted uranium or the oil fires smoke to GWS; yet not all researchers agreed. Overall, few studies were done on these exposures as stand-alone culprits, while some researchers linked chemical exposures and preventative toxins to GWS (Iannacchione et al. 2011, Jamal 1998, and Roland et al. 2000).

One instance of chemical exposures occurred in Khamisiyah, a depot which, when destroyed, exposed military personnel to sarin gas. Initially, DOD claimed that those near the site received only minimal exposure (Tuite and Haley 2013). Research, mostly from the VA, claimed that troops within 50 kilometers of Khamisiyah, though exposed, did not show any different health outcomes than those further away (Bullman et al. 2005, Mahan et al. 2005, McCauley et al. 2002, and Page et al. 2005). It is important to note that some of the same researchers would later find links to cirrhosis of the liver (Barth, Kang, and Bullman 2016).

Further research, using meteorological data, determined that it was possible that sarin gas travelled much further and affected many more troops than originally thought (Tuite and Haley 2013). Building on this analysis, the authors compared the

Khamisiyah destruction with exposures during the initial air campaign. Though they believed it was the early bombing campaigns that were more closely linked to GWS, neither could be ruled out (Haley and Tuite 2013).

It is estimated that 350 metric tons of depleted uranium was used in Desert Storm (Duraković 2001). When an armor piercing round hit a hardened target it created uranium dust which was then inhaled (Bertell 2006; Bleise, Danesi, and Burkart 2003; Duraković 2001; Jamal 1998; and Squibb and McDiarmid 2006). Uranium is also found in trace amounts in the region's sand (Bleise, Danesi, and Burkart 2003; and Duraković 2001). During medical testing, depleted uranium was located in urine samples from Gulf War veterans but it was not evident that widespread testing was ever done (Duraković 2001; and Squibb and McDiarmid 2006). This is important because research showed that depleted uranium exposure was much more significant than reported and could negatively impact the immune, neurological, hormonal, and reproductive systems (Bertell 2006, Durakovic 2002, and Israeli 2012).

Smoke from millions of barrels of burning oil filled personnel's lungs with toxic chemicals (Hobbs and Radke 1992). The smoke clouds may (Emmerova 2004:212 and White et al. 2016) or may not (Smith et al. 2002) have resulted in GWS. Overall, the oil fires were not largely considered on their own to cause GWS but were often linked to asthma and other respiratory conditions (Blanck, Hiatt, and Kang 1995; Lange et al. 2002; Reid et al. 2001; and Smith et al. 2002).

Mental Health. Arguing against an exposure-related cause, the mental health proponents linked GWS with combat, PTSD, stress, and fear of vaccinations (Chalder et al. 2001; Greenberg and Wessely 2008; Ismail and Lewis 2006; Jones et al. 2002;

Unwin et al. 1999; and Wessely and Cohn 2008). The most prominent researcher supporting this association was Dr. Simon Wessely, a British psychiatric epidemiologist (Calandra 2002). Although he firmly believed in a psychological link, he did not completely reject possible toxic exposures affecting some Gulf War veterans (Chalder et al. 2001; Unwin et al. 1999; and Wessely and Cohn 2008).

Wessely and Cohn (2008:1656) cautioned the danger of, "disentangling 'real' risks from risk perception, not only because the relationship between the two is often subtle, complex and interlinked, but also because both can have significant impacts on people's lives and behaviors." So, a veteran's fear could escalate as he waited for the war to begin or was made aware of possible chemical or biological attacks. Then, despite never being exposed to toxins, he could develop GWS due to psychological distress (Wessely and Cohn 2008). Because this risk perception included very real threats, it would have "triggered entirely normal and understandable human responses" possibly leading to GWS (Wessely and Cohn 2008:1656; and Jones et al. 2002).

This same risk perception was applied to adverse vaccine reactions. Unwin et al. (1999) claimed that significant numbers of the cases of adverse vaccine reactions came from veterans who had "psychological distress" over what they only perceived to be a bad reaction. In fact, everyone had reactions in varying degrees (for example, everyone had some level of arm pain after getting the shot) and it was this perception that later caused the symptoms of GWS. These same authors stated that even if there was a link between these preventatives, then the risk must be weighed against protecting those in danger. However, most of this research was hard for them to codify, since veterans

were forced to remember their vaccine history due to a lack of documentation (Unwin 1999).

Although PTSD was diagnosed in the years following the Vietnam War, the effort to lift the stigma only came about after the wars in Iraq and Afghanistan. Proponents of the mental-health-link discussed PTSD in terms of its causing GWS, not in terms of stigma and treatment (Cohn, Dyson, and Wessely 2008; Greenberg and Wessely 2008; Iversen, Chalder, and Wessely 2007; Weiner et al. 2011; and Wessely and Freedman 2006). During this period, PTSD was more narrowly defined than it is today, which may have impeded this research (American Psychiatric Association 2013).

The evidence, much of which is contradictory, provided both the exposure and mental health proponents an abundance of ammunition to critique each other's line of reasoning. Haley (1997) believed studies that examined psychiatric causes used a standardized questionnaire instead of clinical psychiatric evaluations, leading to over-inflated numbers of veterans being diagnosed with PTSD. Conversely, Wessely and Cohn (2008:1655), believed that epidemiological studies could "only ever make assertions at the level of the population rather than the individual."

Despite studies calling for qualitative research to tease out issues surrounding the GWS debate, there remains a significant gap in the literature (Hotopf et al. 2004; Iversen et al. 2007; and Wessely and Cohn 2008). Of the few qualitative researchers, Dr. Susie Kilshaw made the greatest contribution to this effort. A medical anthropologist, her body of work showed strong leanings toward a psychological etiology (Kilshaw 2004, Kilshaw 2004, Kilshaw 2006, Kilshaw 2007, and Kilshaw 2008).

Her methodology included interviews and participant observation while working with veteran organizations.

Like other researchers on the mental-health side of the GWS debate, Kilshaw linked the growth of GWS to illness narratives (Greenberg and Wessely 2008; Kilshaw 2004; and Kilshaw 2006). Once created, one sick veteran's narrative convinced others that they too were sick (Chalder et al. 2001; Hotopf et al. 2000; Kilshaw 2004; Kilshaw 2006; and Greenberg and Wessely 2008). During visits to veteran organization meetings, she deduced that an, "inexperienced" veteran is taught to see their illness through other veterans' diagnoses (Kilshaw 2004:152). She also claimed that those who did not have symptoms decided they did have them after attending these meetings (Kilshaw 2006). Unfortunately, she produced an image of the sick combat veteran that was co-dependent and weak-minded (Bury 2001; Cohn, Dyson, and Wessely 2008; Kirmayer 1992; and Kilshaw 2006).

A Few More Points…

Other Theories. More than two decades later, there remains no consensus in the research regarding a cause – whether one or a combination. Although much of the earlier literature focused on the environmental versus psychological debate, a few researchers believed that exposure combined with mental health caused GWS (Hodgson and Kipen 1999; Moss 2013; O'Callaghan et al. 2015; Reid et al. 2001; Zavestoski et al. 2004). For example, Moss (2013) believed that GWS could be caused by a combination of the pyridostigmine bromide pills and the stress from combat, leading to autoimmune illnesses. Even Wessely conceded that, "Multiple vaccinations

in themselves do not seem to be harmful but combined with the “stress” of deployment … may be associated with adverse health outcomes.” (Calandra 2002:51)

To add a layer of complexity, there are researchers who argued that GWS could have been triggered by exposures in individuals genetically predisposed to be sensitive to them (Bassi et al. 2012; Georgopoulos et al. 2016; Haley, Luk, and Petty 2001; Kerr 2015; and Steele et al. 2015). So, in fact, the GWS “smoking gun” would be different for each veteran depending on the “gene-exposure interaction.” (Steele et al. 2015:16) This theory further complicates all of the exposure-related findings but would explain why *the* “smoking gun” has never been found.

The correlation between mental health and GWS in medical research predominately took place prior to the release of RAC (2008) report. This document made the official determination that GWS was not a psychiatric illness and, in fact, its veterans had lower rates of PTSD than other wars. After 2008, researchers on the mental-health side of the debate remained largely silent. In general, more recent medical studies moved beyond the underlying cause to focus on biological markers in order to find successful treatment (Johnson et al. 2016, Kearney et al. 2016, and Parkitny et al. 2015).

Veterans Administration. The Veterans Administration’s studies were most commonly linked to Dr. Han Kang and collaborating researchers. Their research was published both before and after the RAC (2008) report, and examined broader Gulf War veterans’ health (Barth, Kang, and Bullman 2016; Dursa et al. 2016; Eisen et al. 2005; Gray et al. 2004; Kang et al. 2000; Kang et al. 2009; and Li et al. 2011). Initially they questioned the existence of GWS, but also looked at symptom convergences (Eisen et

al. 2005, Hallman et al. 2003, and Young et al. 2003) as well as possible treatment options for those who were sick (Blanck, Hiatt, and Hyams 1995; Craddock et al. 2015; and Lincoln et al. 2006).

Additionally, the government sanctioned its own long-term studies using data from military and VA medical records, Defense Manpower Data Center, and Pre- and Post-Deployment Health Assessments (Phillips et al. 2009, Smith et al. 2014, and Teichman 2012). *The Millennium Cohort Study,* by the Department of Defense, is an ongoing data consortium originally started to address issues from the Gulf War but now also being used to look at OIF and OEF veteran's health issues (Millennium Cohort Study n.d.). The VA's epidemiologists continue to provide information and research on linked exposures and treatment options (Department of Veterans Affairs Public Health 2017).

"Illness of Modernity." Durodie (2006:689) stated that all previous GWS research was misplaced because it, "appears to have much in common with other 'illnesses of modernity.'" Although it is usually associated with unexplained and ill-defined symptoms, recent medical studies suggested that GWS may be diagnosed as chronic fatigue syndrome, fibromyalgia, lupus, and multiple sclerosis (Craddock et al. 2014; Dhillon and Boyd 2010; Durodie 2006; Hayer et al. 2015; Ismail et al. 2008; Khaiboulina et al. 2015; Lewis et al. 2012; Rayhan et al. 2013; Reid et al. 2001; and Skowera et al. 2002). The current illnesses specifically associated with "*medically unexplained illnesses (popularly known as Gulf War Syndrome)*," per the VA (Department of Veterans Affairs Public Health 2017), include both chronic fatigue syndrome and fibromyalgia.

Neither chronic fatigue syndrome nor fibromyalgia were widely understood in the early 1990s. In 1994 a group of international researchers provided a case definition for chronic fatigue syndrome (Fakuda et al. 1994 and Reeves et al. 2003) and the American College of Rheumatology published its list of criteria for fibromyalgia in 1990 (Inanici and Yunus 2004).[3] Fibromyalgia is listed on the American Autoimmune Related Diseases Association's (AARDA) list because it has "symptoms that mimic those of other disorders" and "accompanies other autoimmune diseases." (American Autoimmune Related Diseases Association 2017)

Operation Enduring Freedom and Operation Iraqi Freedom

The RAC report (2008:1) claimed that there were no similar unexplained illnesses after "current Middle East deployments." Data from the VA, released at the end of Fiscal Year 2011, stated that 1.4 million members of the military who served in Iraq and Afghanistan are now veterans (Teichman 2012). How many combat veterans are sick due to toxic exposure? Estimates are 35 percent, but close to 50 percent of veterans seek medical care outside the VA, so the true number may not be known (Teichman 2012).

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[3] Chronic Fatigue Syndrome is defined as "a clinically defined condition characterized by severe disabling fatigue and a combination of symptoms that prominently features self-reported impairments in concentration and short-term memory, sleep disturbances, and musculoskeletal pain." (Fakuda et al. 1994:953) The AARDA (American Autoimmune Related Diseases Association 2017) defines fibromyalgia as "a chronic disorder which is characterized by widespread pain, tenderness and fatigue. Persons with fibromyalgia may also experience sleep disturbances, morning stiffness, anxiety, and irritable bowel syndrome. Often it is also accompanied by depression. It is difficult to diagnose because most of the symptoms mimic those of other disorders. Fibromyalgia is NOT an autoimmune disease, however it does accompany other autoimmune rheumatic and endocrine diseases."

Most of the growing body of medical research on Iraq and Afghanistan is focused on PTSD, TBI, and general mental health issues (Betthauser et al. 2012; Collura and Lende 2012; Dursa et al. 2014; Fonda et al. 2017; Fulton et al. 2015; Kilmer et al. 2011; MacGregor et al. 2011; Martindale et al. 2016; O'Neil et al. 2017; Rosen 2012; Scholten et al. 2012; and Wilmoth et al. 2015). Due to the impact of mental health, TBI, and suicides within the military community, these studies play an important role. In fact, Greenberg and Wessely (2008) found that psychiatric illnesses being reported by Iraq veterans were much larger than Desert Storm veterans. However, this may be due to a more inclusive definition of PTSD (American Psychiatric Association 2013; and Collura and Lende 2012). In 2013, the American Psychiatric Association made changes to the PTSD profile opening the door for a more inclusive diagnosis and perhaps producing burgeoning numbers of "PTSD sufferers."

Exposures

One of my service-connected disabilities, which is on the AARDA's list, per the Veteran's Administration, is "related to: environmental hazard in Gulf War." Like veterans of Desert Shield/Desert Storm, Iraq and Afghanistan veterans were exposed to environmental hazards and "preventative medicine" like burn pits, anthrax vaccines, waste in the soil, and permethrin-soaked uniforms (Riddle et al. 2008 and Quigley et al. 2012). Open-air burn pits exposed veterans to toxins like human waste, rubber, metal, and chemicals raising concerns over lung health and lung function (Abraham et al. 2012, Conlin et al. 2012, Jones et al. 2012, Powell et al. 2012, and Smith et al. 2012). Medical research predominately focused on links between the burn pits and chronic respiratory symptoms and diseases (Abraham et al. 2012, Abraham and Baird 2012,

Sharkey et al. 2016, Smith et al. 2012, and Soltis et al. 2009). Studies examining a possible link between other diseases and burn-pits used the DOD's *Millennium Cohort Study* data. These studies did not determine that burn-pits caused rheumatoid arthritis, lupus, chronic multi-symptom illness, birth defects, chronic bronchitis, emphysema, and new-onset asthma (Abraham et al. 2012, Conlin et al. 2012, Jones et al. 2012, Powell et al. 2012, and Smith et al. 2012).

In 2000, the Congressional Committee on Government Reform submitted a report that critiqued the DOD Anthrax Vaccine Immunization Program (AVIP) as "unproven force protection." [H.R. Rep. No. 106-556, at 7 (2000) (Comm. Rep.)] In 2001, DOD established the Vaccine Healthcare Centers Network (VHCN) in order to address congressional concern over this growing controversy (U.S. Government Accountability Office 2007). The VHCN worked with the CDC in order to oversee the military's vaccine program and address adverse reactions. Today they have, "expanded from its original site at Walter Reed to become an integrated specialized clinical program within the Military Health System. It has continued to expand its mission of improving vaccine safety, efficacy, and acceptability." (Vaccine Healthcare Centers Network n.d.)

Court cases, news stories, and congressional concerns over the anthrax vaccine only provided a short reprieve for deploying military personnel to Iraq and Afghanistan. Prior to my 2006 deployment, a raging legal battle halted the DOD's ability to require the anthrax vaccine while a court decision was pending. Previously, I received three of the six shots, so the questionable safety and painful side-effects made me more than willing

to sign a waiver. In the end, the program was reinstated and I received my fourth and fifth shots in theater (Beck 2006).

An OIF and OEF Syndrome?

Two British studies questioned whether or not there was an emerging “Iraq War Syndrome” by comparing data between Gulf War and Iraq veterans (Greenberg and Wessely 2008; and Horn et al. 2006). This research was done before the release of the RAC report (2008) acknowledging GWS. Both studies did not find an emerging Iraq Syndrome. However, after the VA report (2008), Lewis (et al. 2012) examined the overlap in symptoms found with current veterans and GWS. These symptoms overlapped with illnesses like fibromyalgia and chronic fatigue syndrome.

One study examined a small population of Iraq and Afghanistan veterans living in New York with combat-related illnesses (Amin et al. 2010). The researchers found that two-thirds of their participants were struggling with debilitating symptoms including pain, fatigue, and headaches. Additional research explored broadly defined symptoms like chronic pain and fatigue (Buis et al. 2011, Gironda et al. 2006, Jones et al. 2012, Matthias et al. 2014, and Powell et al. 2012). However, these studies overwhelmingly relied on statistical analysis and laboratory experiments for findings.

Considering there are so many veterans being diagnosed with autoimmune diseases and cancer, there is very little research available. I joined a group of concerned veterans several years ago called Team Archangel. We came together in an attempt to find answers regarding these diseases. As a starting point, we conducted a non-systematic survey which examined the symptoms associated with “*medically*

unexplained illnesses (popularly known as Gulf War Syndrome)" and discovered them in 81 percent of the 323 of the responding OEF and OIF veteran participants.

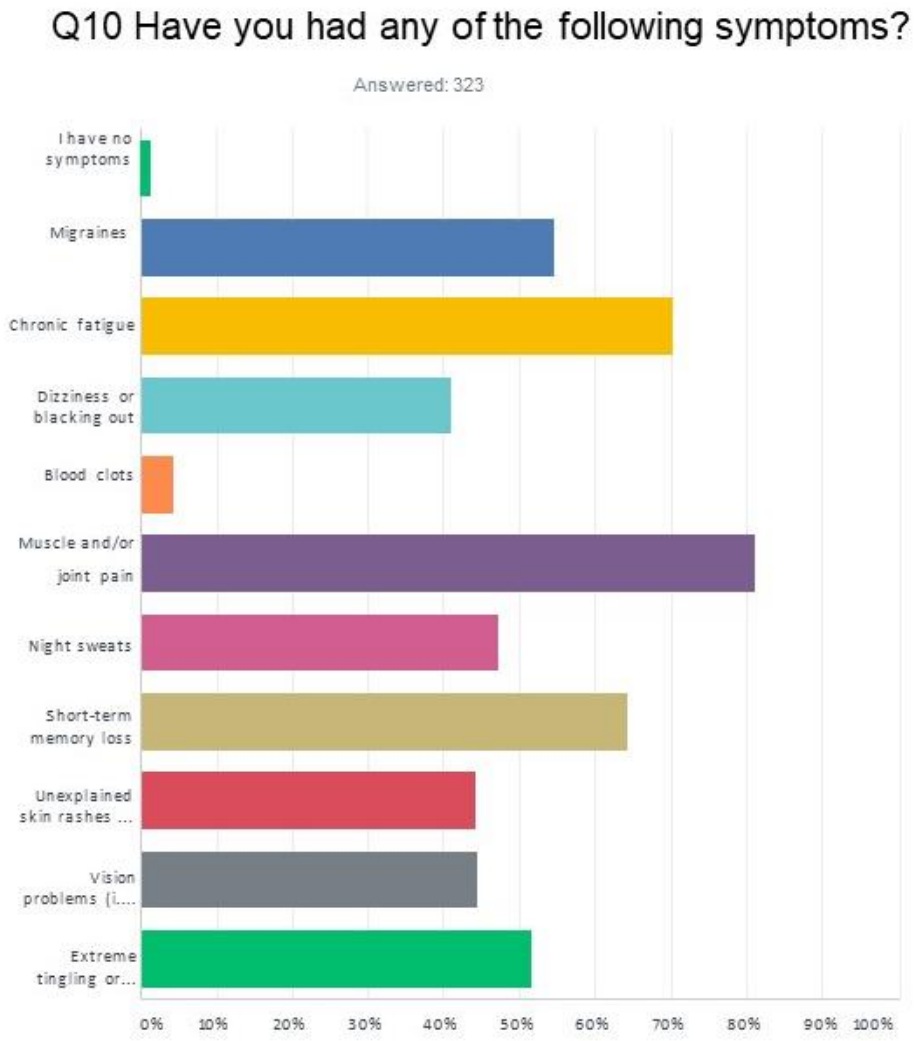

Table 2 Team Archangel Survey

The Department of Veterans Affairs website was updated regularly during my research. They are continually adding new research which provides hope that they are looking at these important issues.

An Anthropologist's Perspective

Anthropology of the Military. The American school of anthropology has a long and sometimes combative relationship with the military. From Franz Boas' censorship through the creation of the Human Terrain System (HTS), anthropologists' positionality with military/intelligence research moved back and forth across the spectrum (Albro 2010; González 2007; Gusterson 2003; McFate and Fondacaro 2011; and Price 2002). Over the decades, some anthropologists overtly, while some covertly, supported government operations around the globe stirring controversy along the way.

Once successes in Operations Enduring and Iraqi Freedom began to fade, military leaders looked to T.E. Lawrence as a model for counter insurgency doctrine. As they took on a greater role in civil engagements, they grasped for legitimate cross-cultural understanding putting anthropology square in their sites. I was both a civil affairs officer at the tactical-level and a government civilian at the strategic-level during this time providing me with a front row seat as it all played out.

After the death of three anthropologists in the combat zones and the American Anthropological Association's Commission on Anthropology's Engagement with the Security and Intelligence Communities (CEAUSSIC) report, those focused on military anthropology had to fight for control of their own narrative. Anthropologists provided a historical perspective of previous support to government operations but mostly focused on the debate over the HTS program. Those anthropologists willing to work with the military wrote articles supporting, and justifying, their work (Fosher 2007; McFate 2005; McFate and Jackson 2006; Selmeski 2007, and Simons et. al 2007). However, many

more anthropologists were vocal critics denouncing the program (Albro 2010, Forte 2011, González 2007, Gusterson, Price 2002, Price 2007, and Sluka 2010)

While anthropologists debated the role of the discipline in terms of ongoing combat operations, some looked at ways in which military anthropology might be useful. For example, Goldstein (2010) suggested a "critical anthropology of security" in order to examine a broader understanding of security praxis specifically as it relates to the individuals affected. Whereas Gusterson (2007 and Gusterson 2003) proposed the need to analyze and theorize militarism. He also suggests looking at our own military's cultures, practices, and policies. I too believe this is an important piece that is missing from the anthropological literature.

Medical Anthropology. Slowly, medical anthropologists are adding an important voice to veteran research. For example, qualitative research examining the on issues of opioids and pain management (Simmonds et al. 2015). There is also research to examine the healthcare needs of combat veterans returning from Iraq and Afghanistan (Finley 2010) or to means assess the care that is available (Finley et. al 2013). Although there is research regarding social integration it was, like most research, focused on mental health links (Finley et. al 2012).

Necessary Insight. What is most evident from the literature is the lack of wide-ranging qualitative research on quality of life issues for OIF and OEF veterans. I believe that we must begin with learning what exactly "quality of life" means for them. One anthropologist's study of OIF and OEF veterans provides a glimpse of the possibilities. Seth Messinger (2013) discussed combat veterans' experience with insights gained while working with amputees and those with mental health issues. Because of the

relationship he built with veterans recovering from traumatic injuries, he is able to get at nuances only evident to someone who is a combat veteran. In his study he used unstructured interviews to examine how vigilance is so ingrained in military culture that it could provide false PTSD diagnoses. Being vigilant, also called “Situational Awareness” or “SA” in military jargon, means always being aware of your surroundings in the broadest terms. While in combat, that vigilance becomes hypervigilance, necessary to keep you and others alive. We use other ways to describe it, for example, “Keep your head on a swivel.” When transitioning home this usually, gradually, fades. In some cases, it does not fade and can be diagnosed as PTSD. He is careful to clarify that hypervigilance is not PTSD but can become problematic if not addressed.

Messinger (2013:195) believes that, “the approach of anthropology is very useful for capturing the complexity of individual meaning and experiences.” He provided insights into how hypervigilance affects the veteran’s life after coming home. This qualitative study with unstructured interviews allowed the veterans to share openly and freely. This important research proved to me the vital role of a qualitative approach in understanding a combat veteran’s daily life experiences.

Conclusion

The qualitative research gap is even greater in examining OEF and OIF diseases than it is for Desert Shield/Desert Storm diseases. This is despite acknowledgment of its importance in providing added dimension to the overall research narrative. For example, when interviews were used to explore veterans diagnosed with chronic pain, researchers learned about the emotional toll and difficulty in sharing those struggles (Matthias et al. 2014). More qualitative research would help veterans who currently

must sift through volumes of medical studies, with hard-to-interpret data and conflicting results, in order to find answers.

CHAPTER 3:

LAYING THE FOUNDATION: THEORETICAL FRAMEWORK

My research examines how Afghanistan and Iraq veterans negotiate the transition from healthy warriors to sick combat veterans, often struggling with multiple illnesses, and the many forces that interact with that transition. Specifically, it is how illness is non-verbally masked through performance, verbally expressed through narratives, and negotiated in order to avoid the social consequences of stigma. This lived experience of illness is focused on the body.

Embodiment

The main character in this story *is* the body. It is as conspicuous as it is inconspicuous. It permeates every discussion, every question (Csordas 2005). Yet it is not just the biological self but a broader understanding of embodiment drawn from several definitions: the "body (as) an identity" (Barnard 2000:148), with "…social values and dispositions…anchored in and through the body" (Strathern and Stewart 1998:237), with "perceived experience" (Csordas 2005:182) and "…social or cultural categories… (which are) inseparable from the bod(y)..." (Barnard 2000:198) Nancy Scheper-Hughes and Margaret Lock (1987:7-8) argued for "three bodies" consisting of:

1. <u>The Individual body</u> is the, "lived experience of the body-self." (Scheper-Hughes and 1987:7) It is the subjective and fluid relationship between the various parts of the body and is where health and sickness reside.

2. The Social body is, “the representational uses of the body as a natural symbol.” (Scheper-Hughes and 1987:7) It includes the exchange of meaning between the body and its social context.
3. The Body politic is, “the regulation, surveillance, and control of bodies (individual and collective).” (Scheper-Hughes and 1987:7) It is also the determination of what constitutes a “good” or “bad” body.

The theoretical concepts for this research are situated within these three bodies. The battle against disease is a constant mediation between them as the illness experience goes beyond the individual to the collective of sick veterans as well as the power within society existing at multiple levels.

“The Individual Body”

It is necessary to examine the “body as self” (Csordas 2005; and Scheper-Hughes and Lock 1987) because each body experiences illness in different ways (Durodie 2006; Kleinman and Kleinman 1996; and Scheper-Hughes and Lock 1987). Even the emotions tied to a diagnosis – fear of the unknown, anger, frustration – are felt differently (Kleinman and Kleinman 1996; and Kleinman 2013). These varied emotions result from creating new meaning out of new circumstances; for instance, what could be accomplished yesterday may not be accomplished today (Kleinman 2013; and Ware and Kleinman 1992). These new circumstances come after a “biographical disruption” resulting from changes, usually significant, in a person’s life (Bury 1982:264). This *after* puts real things at risk; loss of job, loss of family, and perhaps even loss of life (Kleinman and Benson 2006; Kleinman 2013; and Scheper-Hughes and Lock 1987).

Illness as Lived Experience. In order to examine the lived experience of veterans’ illnesses, I used Arthur Kleinman’s body of work, the most significant for my research. He divided illness and disease in order to shine a light on the patient’s perspectives often obscured in the doctor’s office (Kleinman 2013). Indeed doctors diagnose the

disease despite patients living the illness (Kleinman 2013). Because disease cannot be separated from the illness experience, I chose to define illness and disease as two sides of the same coin (Wessely and Cohn 2008). This treats disease and illness as equally important, but with different vantage points. It does not divide them but also does not assume them to be the same. My research therefore is focused on the illness experience within the context of the broader disease diagnosis. The diagnosis is the first step on the path of the illness experience which may or may not be traversed easily (Zavestoski et al. 2004).

Kleinman's personal experience of becoming his wife's primary caregiver after her Alzheimer diagnosis reaffirmed his belief in the importance of the lived experience of illness (Kleinman 2013). He called this "transformative," providing a new and deeper understanding of his research on living with disease (Kleinman 2013:1376). This revisiting of research after a very personal experience brought to mind Renato Rosaldo's *Grief and a Headhunter's Rage* (1993). Like Kleinman, Rosaldo's personal experience illuminated what he originally failed to understand during his field work because, "life experience had not as yet provided the means to imagine." (Rosaldo 1993:4).

Both Kleinman and Rosaldo's insights underscored how nuances of this research could be unmasked with a firsthand knowledge of the experience. In fact, the experience of these veteran diagnoses may have been lost to me without my own struggle. I only became aware of this burgeoning health crisis after I got sick. It was then that a single conversation multiplied. I now saw what was not visible to most; the very personal and sometimes all-consuming struggle of the lived experience of illness.

> **Illness Narrative.** "Depicting illness in the form of narratives is a way of contextualizing illness events and illness symptoms by bringing them together within a biographical context. By *weaving the threads of illness events into the fabric of our personal lives, physical symptoms are transformed into aspects of our lives*, (emphasis mine) and diagnoses and prognoses attain meaning within the framework of personal life." (Hyden 1997:53)

Illness is verbally expressed through narratives that are shaped by our daily experiences (Kleinman and Kleinman 1991). The illness narrative allows us to share what we choose, to whom we choose. Illness narratives may be inflated to overemphasize experiences and get someone's attention, or be vague to hide the truth (Kirmayer 1992). It allows us to articulate the pain and the changes in our day-to-day lives (Hyden 1997). Illness narratives provide a medium with which to understand and negotiate illness and may be works of fiction or nonfiction (Bury 2001, Hyden 1997, Kilshaw 2004, and Kirmayer 1992). In fact, Cheryl Mattingly (2008:73) called them "half-told tales."

Mike Bury (2001) believed there were three types of narratives: contingent, moral, and core. The contingent narrative is shaped by the patient's understanding of their sickness and its effect on creating a new identity (Bury 2001; Kleinman and Kleinman 1991; and Kilshaw 2004). The moral narrative allows the sick to validate their changing lives (Bury 2001 and Hyden 1997). The core narrative brings order to chaos as a person transitions to a new normal (Bury 2001).

Laurence Kirmayer (1992:323) claimed that illness narratives relied on metaphors to make the irrational rational, allowing the sick to express their illness in words and/or ideas familiar to them (Bury 2001; Cohn, Dyson, and Wessely 2008; and Kilshaw 2006). *If* a common understanding exists, metaphors can increase the power

of the narrative, but if not they can lead to confusion (Jackson 2011). Additionally, metaphors are often in direct contrast to the scientific and technical language used in the medical literature (Good et al. 2010 and Kirmayer 1993) or the stories used between doctors (Mattingly 2008). So a doctor may have to translate an illness narrative, told in a different language, while trying to keep communications from breaking down (Good et al. 2010 and Hyden 1997). That different language is simply veterans using acronyms and combat metaphors when speaking with their doctors. These metaphors may have a different meaning to the physician (Cohn, Dyson, and Wessely 2008).

This language variation, or simply a lack of cultural understanding, may have led Kilshaw to credit the illness narrative for creating GWS. She claimed that sick veterans met with other sick veterans, discussed their symptoms, and GWS was born (Chalder et al. 2001; Kilshaw 2004; and Greenberg and Wessely 2008). Her research implied that these veterans also decided they had new symptoms only after speaking with other sick veterans (Kilshaw 2004 and Zavestoski et al. 2004). It was also suggested that illness narratives allowed the veterans to create a new identity as part of the GWS club; narratives created a label and the label created an identity (Kilshaw 2004).

What she did not ask was how many veterans wanted the identity of “sick.” No doubt it is possible for illness narratives to be leveraged for nefarious purposes (Bury 2001; and Cohn, Dyson, and Wessely 2008). Yet, by sharing, sick veterans could be simply finding social support (Bury 2001 and Zavestoski et al. 2004). Kleinman’s (2013:1377) example of “a gift exchange between individuals whose relationship to each other really matters,” makes this point. This “gift exchange” could be veterans

making sense of a shared diagnoses, finding the strength to cope, or finding solace in knowing someone else understands.

"The Social Body"

Scheper-Hughes and Lock's (1987) "social body" is how the body interacts with its social context to create meaning through what is shared. This ongoing reciprocity is in constant flux so that any conversation, interview, or picture is a single moment in time and may not reflect the body's truth tomorrow. In order to understand how veterans create individual meaning from their social world, we must understand that social world.

I Want You! Answering Uncle Sam's Call. During my first tour in Iraq, we had a U.S. Department of State official who lived with us in the city. He jokingly said that each night the Marines had to go plug into "the Matrix" in order to program our brains because of our group-think. Although a joke between friends, there was absolutely some truth in what he said. From the time we enter boot camp, we learn how to talk, how to walk…how to be members of our Service. This was never more evident than when contrasted with the culture of the State Department. My experience in the military over the past twenty-six years afforded me a broad perspective. I worked at every level from the smallest unit to Service higher headquarters located in the Pentagon. I was a U.S. Marine, a government civilian, and a contractor. I worked in/with both the conventional military and special operations forces.

The military, with its rigid rules and standards, is often thought of and treated as a collective body, yet it is made up of unique individuals. There are also significant differences among its many divisions. Although providing a comprehensive overview of military culture would be extremely useful, it is also impossible. However, I will provide

a broad synopsis while drilling down into key aspects important to understand this research. We will then be able to tease out the relationship between sick veterans and other actors at every level from peers to higher echelons. Highlighting specific aspects of military culture is in no way a denunciation of its practices. There are, however, aspects of the military which make seeking help difficult.

The Department of Defense is made up of both individual Service organizations and joint commands. It is led by a Service secretary who answers to and advises the president. The individual Services – Army, Air Force, Navy, and Marine Corps – each have their own mission. If looking at the Services in terms of a continuum, the Air Force is at one end, like corporate America, and the Marine Corps is at the other, unbendable and beholden to time-honored traditions. An Air Force colleague always joked that while the Marines dug in (fox holes to sleep outside) the Air Force checked in (to their hotels and white sheets). This continuum is further illustrated when visiting any base. The Air Force has beautiful golf courses and buildings and the Marine Corps deals with refurbished buildings from World War II. The branches of Service are further divided into self-imposed, and in some cases contested hierarchies: officer and enlisted; special operations and conventional; reserves and active duty; combat veteran and veteran; and job specialty. These hierarchies are reinforced differently in each Service.

Those Yellow Footprints and the Rites of Passage. From the moment a civilian steps off the bus at boot camp, their life is forever changed. For some it will be a one-tour adventure, while for others a lifelong career. When joining the military one becomes a member of another culture through a metaphorical rebirth, creating a new category of "the Other"-- civilians. It does not matter what branch of the military you join, each and

every person goes through boot camp. It is during this period of time that one is transformed from a civilian to a member of the Armed Services. It is a rite of passage, hence "a passage over a line…whereas the important thing is the line." (Bourdieu 1991:118) Crossing that line comes when one graduates boot camp and is given the title: soldier, sailor, airman, or Marine. It is through experiencing this rite of passage that one learns how to walk, talk, and think like a member of one's Service. It is these very things that will set them apart from civilians (Bourdieu 1991). This newly acquired identity stays with the service member after they leave the military (Barrett 1996 and Messinger 2013). For instance, there are no "ex-Marines" only "former Marines" because, "Once a Marine Always a Marine."

Second Lieutenant 101. As soon as we begin training for any leadership role we learn the importance of taking care of troops, the backbone of the military. This responsibility is so much more than civilian leadership in dealing with pay and safety. For military leaders it includes things like family well-being and financial security. At times this makes us more of a parent than a boss. A primary responsibility is medical readiness, so that if a mission emerges troops are prepared. Fitness is an extremely important part of readiness, although defined differently in each of the Services. Despite variations, there is a strong undercurrent within the military regarding "sickness," especially in poorly defined or newly emerging diseases.

A case in point is the attitude of Dr. Jeffery S. Sartin (2000), a former USAF medical officer, toward GWS from within the military's medical corps. Sartin claimed that it existed only because, "Non-physician scientists and nonscientist 'researchers' have promoted theories outside their area of expertise, without observing the principles

of controlled trials and statistical rigor." (Sartin 2000:815) He stated that those same non-academics, "Eschew peer-reviewed journals and the competitive funding process (in other words, government funded)…(and) have sought publicity and funding from activist groups and congressional sponsors, later posting their findings on the internet." (Sartin 2000:815) He goes on to claim that the, "Lack of *objective* (emphasis mine) findings and a suitable disease definition hamper the analysis of such conditions." (Sartin 2000:816)

Sartin only allowed for three options when it came to those claiming to have GWS: those with PTSD, those with an actual illness, or malingerers. Those with actual disease were, "small number of unusual cases (that) have objective findings that lack obvious explanations." (Sartin 2000:816) Sartin, I would argue, provided an example of military medical culture at its worst; that is, dismissive with little care shown to the well-being of the troops.

One very personal anecdote: As a second lieutenant I had a very aggressive form of endometriosis. When going to a Navy doctor for help in dealing with the symptoms, I was literally given "the hand." He did not want to hear about my issue. Not treating this disease, which required outpatient surgery, would eventually cost me the ability to have children. I share this extremely personal story because there are very real and very costly consequences to this dismissive mindset. This attitude is especially problematic in that it leads to troops not seeking necessary medical attention because they do not want to appear weak. And so we "suck it up."

Fitness and the Art of "Sucking It Up." Each of the Services has an annually required physical fitness test. Although there are significantly different prerequisites, low or

failing scores can hurt one for promotions or even retirement. The body's appearance is key to defining a "satisfactory" or "unsatisfactory" service member and therefore becomes closely tied to identity. Part of this focus on fitness is tied to another characteristic of military culture, "sucking it up." It is one of the first lessons learned and perhaps the most painful. In fact the Marines have a slogan, "Pain is weakness leaving the body." Regardless of how exhausted, or how much pain one is in, you can always push on, push through, go further than you thought possible – you just need to suck it up. This mantra, or as Pierre Bourdieu called it, the, "power of suggestion" (Bourdieu 1991:52), is conceivably one of the biggest impediments to service members and veterans seeking treatment.

Acknowledging you are sick, and then seeking medical help rarely happens when you "suck it up." In fact, I know Marines who trained and deployed with fractures or other significant injuries. Rhonda Moore (2004:182) wrote *Being Broken in the Marines*, where she examined what Marines call the sick or injured -- "broken." Moore found that regardless of why one is broken, Marines blame themselves so they are unlikely to get medical help (Moore 2004). I believe this self-blame is also why so many do not realize their diseases are linked to combat exposures.

Syndemics. S*yndemics* is focused on the, "…synergistic or intertwined and mutual enhancing health and social problems." (Singer 1994:933) Created by Merrill Singer, it argues for studying health within a broader historical and social context. Since disease is affected by other factors, a diagnosis could add emotional and/or mental stress to a person dealing with other issues, thereby creating additional medical complications (Gonzalez-Guarda, Florom-Smith, and Thomas 2011; Singer 2009; and Weaver and

Mendenhall 2014). Syndemics provides an important perspective for this research in examining both health and the military/medical culture as well as health and combat experience. As suggested in the medical literature, long-term stress created by multiple and lengthy deployments to a combat zone can lead to weakened or damaged immune systems. This, combined with environmental exposures, can result in disease (Bertell 2006, Duraković 2002, and Israeli 2012, and Singer 2009).

There is no part of the lived experience of illness that is not shaped by context, both past and present (Durodie 2006; and Kleinman and Kleinman 1991). We must see illness not just in the individual, but through the individual to the broader context that forms this experience. Arthur Kleinman and Joan Kleinman (1996:2) stated that suffering, is shaped by the socially acceptable rules of dealing with suffering in that it is both "taught and learned." (Fortenberry et al. 2002; Kendall-Taylor 2009; Lichtenstein 2003; Pelto and Pelto 1997; Macfarlane and Alpers 2009; and Plummer et al. 2006). It frames how we individually maneuver through this lived experience of illness. For veterans, we negotiate illness with the additional layer of military culture, where we struggle with being sick yet desire to "suck it up." We must bear in mind that this is individual-specific because some veterans, once they become "civilians" may shed more of the military culture than others (Durodie 2006; and Ware and Kleinman 1992).

A Standing Ovation. Because there are socially acceptable ways to deal with disease, traversing the illness path can be difficult for an individual (Zavestoski et al. 2004). Three ways illness is masked and negotiated are through: performance, the looking-glass self, and stigma. These are all closely linked, subjective, and highly fluid.

They are a very powerful aspect of the lived experience of illness for veterans, because appearance, physical fitness, and maintaining the ideal are/were extremely important.

Performance. Like others who are sick, combat veterans mask illness through performance. Erving Goffman examined how we use our bodies through performance to exhibit only what we want others to see, while minimizing what we do not want them to see (Charmaz and Rosenfeld 2006; and Goffman 1959). He defined performance as, "all activity of a given participant on a given occasion which serves to influence in any way any of the other participants." (Goffman 1959:15) This "performance" is much like staging a play with costumes, makeup, and acting. Those who are sick perform to their social world, hoping that no one sees behind the curtain. Unfortunately for some, after disease manifests itself, the body projects the truth no matter how much we try to hide it (Charmaz and Rosenfeld 2006). These visible effects of disease cause a constant fear of losing control of what is presented on the body's stage (Charmaz and Rosenfeld 2006; and Goffman 1959).

"Through the Looking Glass." Kathy Charmaz and Dana Rosenfeld (2006:35-36) provided an extremely useful metaphor, tied to Goffman, to illustrate why people "perform" when they are sick (Scheff 2005). Through Charles Cooley's "the looking glass-self," created to examine the relationship between body/self/identity, the authors showed how those struggling with illness "see images of … themselves—in how other people respond to them." (Charmaz and Rosenfeld 2006:36) How others perceive us twists the image we see reflected in their eyes; removing reality and any previous image we had of ourselves (Kirmayer 1992; and Charmaz and Rosenfeld 2006). The image becomes distorted because this internalization of diseases is totally subjective

(Charmaz and Rosenfeld 2006; and Kirmayer 1992). Rarely do we understand or know what another is thinking yet somehow, we believe we can get inside another person's head. Despite this, it creates a desire to fabricate a façade projecting a healthy person.

When a veteran's appearance changes due to disease, they may see themselves as they believe others see them based on reactions and responses perceived from their past experiences (Charmaz and Rosenfeld 2006). Broken bodies go against what is acceptable in military culture and weakness equals incompetence, as we are so often told in boot camp (Moore 2004; and Charmaz and Rosenfeld 2006). This, in turn, may cause sick veterans additional pain in the twisted image they view through the eyes of fellow combat veterans (Goffman 1959; Kirmayer 1992; Kirmayer 2008; and Charmaz and Rosenfeld 2006). This forces sick service members and veterans to create a carefully-crafted performance which shows all is well instead of seeking help. In the end this could do more damage to their health (Goffman 1959).

Stigma. The lived experience of illness for veterans is negotiated in order to avoid stigma (Goffman 1963). Goffman stated that stigmatization occurred due to, "an attribute that makes him different from others in the category of persons available for him to be, and of a less desirable kind... (and it) can be born out of an illness." (Goffman 1963:3) Stigma's language demeans while categorizing a person in terms of pre-conceived notions; for example Marines being "broken" when sick or injured (Goffman 1963 and Moore 2004). When stigmatized, it affects every aspect of our identity – including things most important to us (Yang et al. 2007; and Kleinman and Hall-Clifford 2009).

This shift from healthy warrior to sick combat veteran is a shift in identity. Mattingly (2008:73) stated that, “a person’s very sense of self is lived in a special way through the body.” It restructures the way we see ourselves, the way we believe others see us. Illness can force a move to a stigmatized group. Understandably, the military must push those who would otherwise quit, because in combat we rely wholly on the person to our right and left. If anyone in your unit is a malingerer, then the consequences could be deadly. Yet whether or not a service member or veteran seeks treatment can be affected by a fear of stigma that impedes seeking treatment and getting help. It is a true conundrum.

Self-stigma. Stigma is not just imposed by others; it can also be self-imposed. Rebecca Blais and Keith Renshaw (2013) researched stigma and mental health issues among veterans. They highlighted a distinction which I believe is equally important to my research: *enacted stigma* versus *self-stigma*. Self-stigma requires three things: first, an awareness of the stereotypes associated with a stigmatized group; second, agreement with those stereotypes; and third, application of those stereotypes to one’s self. (Watson et al. 2007; see also Blais and Renshaw 2013; Kleinman and Hall-Clifford 2009; and Yang et al. 2007). Understanding how both enacted stigmas and self-stigmas are created and reproduced is a key component to fighting them (Kleinman and Hall-Clifford 2009; and Yang et al. 2007). By no means am I suggesting that sick veterans are helpless victims, because we are not (Link and Phelan 2001). I recognize that, as a researcher, I walk a fine line in sharing these important experiences without reproducing a stereotyped image of a sick veteran. But we must address this as part of

the lived experience of illness, especially in communities where health and fitness are so important, if we are ever going to make it better.

Within the Culture: "The Body Politic"

> "Without a historically deep and geographically broad analysis, one that takes into account political economy, we risk seeing only the *residue of meaning* (emphasis mine). We see the puddles, perhaps, but not the rainstorms and certainly not the gathering thunderclouds." (Farmer 2004:309)

Farmer's use of "the residue of meaning" impresses on us the importance of context in this research. I am already working with a vulnerable group that does not speak about disease. So to simply get the residue of their lived experience of illness provides a miniscule fragment of the totality of their struggle. The lived experience of illness, within the context of diagnosed diseases, must then be considered within the system with which it interacts -- the body politic (Scheper-Hughes and Lock 1987). When it comes to negotiating illness, the body politic examines "the regulation, surveillance, and control of bodies," as well as the overt and covert articulation of what constitutes a "good" body and "bad" body (Scheper-Hughes and Lock 1987:7-8).

Critical Medical Anthropology. Critical Medical Anthropology provides the mechanism with which to critique this political body. Defined as a top-down analysis of biomedicine both from within and without, it includes cultural differences, competing resources, and political tensions (Singer and Baer 1995:5-6). This approach allows us to consider the systemic failures within medicine where economics are often put above the health of veterans (Singer and Baer 1995:5-6). It provides a means to lay bare what is broken, starting at the top with the United States Government's health-related control over veterans' lives. Governmental agencies – like Department of Defense, Health and

Human Services, Veterans Administration, and the Food and Drug Administration – are the overarching health-related power mechanism that control the hospitals, clinics, doctors, medical research, and approved medications. This in short, controls all aspects of the veteran's transition from healthy to sick.

At the Macro-Social Level. Critical Medical Anthropology calls for a critique of biomedicine as not only a source of power, but also as a means of profits (Singer and Baer 1995; and Baer 1997). It is at the structural level that the authors examined how politics shape people's lives, both individually and collectively (Singer and Baer 1995). Therefore, they appropriately used the term *medical-industrial complex* (Singer and Baer 1995:5-6). The use of this term is not just fitting because it was borrowed from President Eisenhower's "military-industrial-complex," but also describes how the government's medical bureaucracy produces poor health-related results (Singer and Baer 1995; and Baer, Singer, and Johnsen 1986). Yet this is not just about the Veterans Administration's care for combat veterans, but includes burgeoning government contracts which are a component of the military-industrial-complex.

The medical-industrial-complex collides with the military-industrial-complex through the Anthrax Vaccine Immunization Program. This program requires every service member deploying overseas to get the vaccine; it is not an option. The vaccine is produced by BioPort through a sole source contract, or awarded without competition (Bacevich 2000). BioPort is a corporation originally owned by a retired admiral and former Chairman of the Joint Chiefs of Staff (Bacevich 2000 and DOD Subcommittee 2000). The ongoing incestuous relationship between the government and BioPort continues through current board members who are former members of the military and

the Department of Health and Human Services (Emergent Biosolutions n.d. and Lipton 2006). What makes this even more insidious is that the manufacturer was guaranteed immunity against all liability from adverse reactions and the overall failure of the vaccine to protect against anthrax (Department of Defense Subcommittee 2000:14 and Steele et al. 2012). This is particularly troublesome because medical research points to a link between vaccinations and GWS (Alijotas-Reig 2015; Asa, Cao, and Garry 2000; Asa, Wilson, and Garry 2002; Garry 2002; and Pasquale et al. 2015).

At the Intermediate-Social Level. At the "intermediate-social level," Critical Medical Anthropology is focused on the relationship within biomedicine, for example hospitals and clinics, as it relates to power and control (Baer, Singer, and Johnsen 1986; and Singer and Baer 1995). The need for scrutiny is evidenced by the stories of forgotten, sick veterans falling into a cavernous void. When whistleblowers come forward to bring attention to these issues there is unwanted scrutiny of a broken system. Steven Coughlin, a former Veterans Administration epidemiologist, came forward and then resigned when his leadership would not release information regarding possible links between GWS and service in the Gulf (Jordan 2013). I reached out to Dr. Coughlin and, after he had agreed to speak, I was unable to reach him again despite many attempts. He simply vanished. Whistleblowers must weigh the risk before speaking out, as it may very well be too high a price to pay (Zavestoski et al. 2004).

At the Micro-Social Level. At the "micro-social level," Critical Medical Anthropology focuses on the relationship between doctors and their patients, as well as how the sick understand their illness (Singer and Baer 1995; and Baer, Singer, and Johnsen 1986). Each combat veteran must decide how to interact with the power at the macro and

intermediate levels as well as how they see themselves fitting within the system (Ortner 2006; Knauft 1996; and Samuelsen and Steffen 2004). It is this personal struggle with a systemic power, made up of multiple layers of bureaucracy, which can overwhelm the individual. The Department of Veteran's Affairs and the Department of Defense are institutions rife with mismanagement that many veterans cannot get past (Heyman 2004, Martini 2012, and Zavestoski et al. 2004).

Power. Power gives itself an official tone. It is the expert. It creates the stigmatized groups by making determinations of who is acceptable and who is not (Pylypa 1998). Critical Medical Anthropology calls for changes in the "social alignment of power." (1997:1568) From the micro-social level, sick veterans are locked in a struggle with structural power, which is a David and Goliath battle. Critical Medical Anthropology scrutinizes power in relation to the medical and political systems regarding how decisions are made, characterizations are constructed, language is used, and contradictions are created (Singer and Baer 1995:62). Power is exuded both directly and indirectly from the macro to the micro. Singer and Baer (1995:62) believed that hegemony, how the powerful control and induce their will on others, was not only produced but also reproduced.

Pierre Bourdieu's *habitus* is where power is reproduced. The *habitus* is made up of *dispositions;* or the thoughts, actions, and words, which are trained or taught so that a person responds in a certain way without being told (Bourdieu 1991). We could say then, that service members are "predisposed" (Bourdieu 1991:17) to behave as service members based on what they were taught, what is emulated through leaders, and what is encouraged from their first day in boot camp. This is the unwilling to willing

internalization of performance; the “tell(ing) him what he is and thus lead(ing) him to become durably what he has to be...” (Bourdieu 1991:52 and Goffman 1959) Therefore, sick veterans move through a system without fighting because they are programed to do so.

Men, Men, Men, Men.

> “Militaries around the world have defined the soldier as an embodiment of traditional male sex role behaviors. From recruiting posters that seek ‘a few good men’ to popular media images of John Wayne fearlessly leading the troops in a World War II battle, Tom Cruise as a ‘top gun’ pilot, or Sylvester Stallone as Rambo single-handedly rescuing American prisoners of war, there has long been an association between the military and images of masculinity.” (Barrett 1996:129)

I remember sitting in the field as a lieutenant. It was after dark and we were wrapping up training for the night. The male Marines, who just learned they were to become infantry, began to chant, “Men, men, men, men.” Frank Barrett (1996:129 and Kilshaw 2008:223) used the term “hegemonic masculinity” to discuss this aspect of the military, or “a particular idealized image of masculinity in relation to which images of femininity and other masculinities are marginalized and subordinated.” (Barrett 1996:129) We are told stories of heroes and legends which become deeply embedded and are extremely powerful in shaping who we become. Military culture is built on a foundation of hegemonic masculinity, where weakness is unacceptable – the feminine is weak (Barrett 1996 and Kilshaw 2008). This masculine ideal is not just perpetuated by men, but also by women, who often use feminine slurs when referring to those who do not fit this ideal. This occurs because it is part of the culture: it is the language. The women admire “Wonder Woman” yet work and act like “Superman.”

It illuminates the rigidly prescribed model within the military, which does not include being “broken.” Hegemonic masculinity plays a role in why military personnel and veterans do not seek treatment. No one wants to be “broken,” no one wants to fall short of the masculine ideal, and no one wants to be a “girl” – even the girls. This decision to seek treatment is not a single decision made at one point in time, but made many times over; when a new symptom appears, each time a doctor requires a follow-up appointment, or in order to get medicine refilled (Kendall-Taylor 2009). This is why it was only through many whispered conversations at work with other sick veterans that I learned their stories. They wanted to protect their secret. It is also why it is very important not to treat sick veterans as faking malingerers, but to treat them with respect and empathy for an experience that matters.

Knowledge Production. Power is pervasive and can be subtle in its machinations for control (Foucault 1980). In part, those who wield it maintain control partially through the production of knowledge (Foucault 1980, Heyman 2004, Knauft 1996, Ortner 2006, and Pylypa 1998). The U.S. Government is the very definition of power. It too controls knowledge production including funding for medical research, medical care, and disability definitions. In this way, it is capable of squashing dissention and discrediting those who question them. Veterans continually express exasperation in fighting for information about their diseases within the shadow of the system.

Resistance. Critical Medical Anthropology acknowledges where there is power, there is a struggle and there is resistance (Foucault 1980; and Singer and Baer 1995). There is a struggle against the disease, a struggle against those that control access to care, and a struggle against those who control medical knowledge. Individuals have the

agency to act against power although it is never easy (Knauft 1996; Ortner 2006; Rapport 2003; Rowe 2016; and Samuelsen and Steffen 2004). For example, those who took a stand over the safety of the anthrax vaccine by refusing to get inoculated were significantly maligned. They were given the choice to be discharged or get the vaccine. Gen (Retired) Charles Krulak, USMC stated that opponents of the vaccine program were people who “are petrified that their penis is going to fall off.” (Himmelspach 1999) This played into the masculine hegemony which permeates the military and made all of us afraid to question the vaccine for fear of being “girls.”

This struggle is a cacophony of emotions for veterans. It is complicated by pride in service and an unwillingness to doubt military leadership. This comes from a deeply rooted mindset that does not stand for questioning those in charge. Part of that adherence to the creed of obeying orders and not questioning authority is rooted in trust. Without trust the military would cease to exist. We trust each other and we trust our leaders to do right by us. But when faced with a life-changing diagnoses connected to service in Iraq and/or Afghanistan, it becomes hard not to question our leaders, or even our service.

Unfortunately there is a lack of trust in military leadership at every level of the government today. It is born of changing narratives and undisclosed information that cause veterans to re-consider what they believe. Veterans are, in small ways, taking back their narrative and creating their own knowledge, whether through their own research, emerging non-profits, or through social media.

Conclusion

It is easy to overlook the three bodies when focusing on the lived experience of

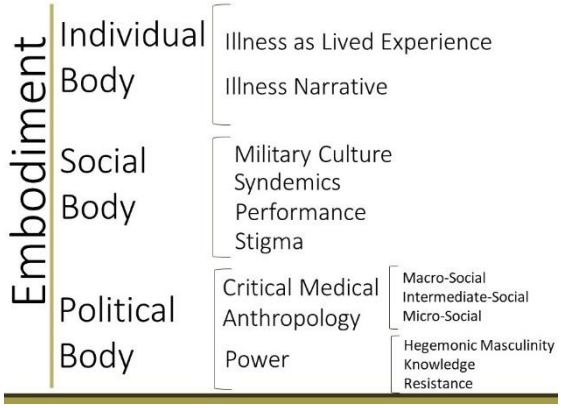

Table 3 Theoretical Framework

illness. We want to bury ourselves in the individual stories and ignore the social and political bodies which so often control the narrative. It is why, for this research, embodiment, with a focus on Sheper-Hughes and Lock's (1987) three bodies, was foundational in underpinning the theoretical framework. Embodiment was the point from which the others flowed.

This research is situated in the "location of sufferer experience within a framework of hegemony and resistance" and framed by the body's broader definition (Singer and Baer 1995:61). Remembering too that each of Scheper-Hughes and Lock's (1987) three bodies are equally important because context can change the narrative as the "body has a history (and) is in constant flux." (Csordas 1994:1-2 and Jackson 2011:371) This illness struggle happens against the backdrop of military culture and within the U.S. government. Most combat veterans are very proud of their service and battle the feelings of frustration over issues of health (Messinger 2013). This research is intended to turn the current debate on its head, let veterans take back their illness narratives, and in some small way control the knowledge (Hale 2008).

CHAPTER 4:

FRAMING THE HOUSE – METHODOLOGY

Context

The available medical research on veteran diagnosed diseases is focused on "the why" without providing a definitive cause. As observed in Gulf War, Iraq, and Afghanistan-related studies, medical doctors, epidemiologists, and psychiatrists each argue for their own, contradicting conclusions. The methodology used in this research varied widely, with much of it conducted in laboratories and clinics, and included: blood tests (Asa and Garry 2000; and Asa, Wilson, and Garry 2002), vestibular testing (Roland et al. 2000 and Skowera et al. 2002), electrocardiograms (Haley et al. 2004), psychological exams (Ferrari and Russel 2001; and Weiner et al. 2011), and neurological imaging (Bierer et al. 2015, Calley et al. 2010, Chao et al. 2014, Gopinath et al. 2012, Li et al. 2011, Odegard et al. 2013, and Rayhan et al. 2013) while other researchers utilized literature reviews (Greenberg and Wessely 2008; Haley 1997; Ismail and Lewis 2006; Reid et al. 2001; Sartin 2000; and Teichman 2012) and surveys (Dhillon and Boyd 2010; Jamil et al. 2011; McCauley et al. 2002; and Spencer et al. 1998). Some of the research leveraged veterans' data from pre- and post-deployment health assessments, VA medical records, and the Defense Manpower Data Center, allowing for widespread analysis of military medical diagnoses and health claims made

before and after deployments (Abraham et al. 2012, Conlin et al. 2012, Jones et al. 2012, Lewis et al. 2012, Phillips et al. 2009, Powell et al. 2012, Sharkey et al. 2016, Smith et al. 2014, Soltis et al. 2009, and Teichman 2012). Despite these variations, very few studies employed qualitative methods (Amin et al. 2010, Kilshaw 2004, Kilshaw 2006, Kilshaw 2007, Kilshaw 2008, and Messinger 2013) even though it was suggested that they could provide a deeper, more meaningful understanding of veteran diseases (Hotopf et al. 2004; Iversen et al. 2007; and Wessely and Cohn 2008).

Figure 1: Scott Peterson, US Marines Look After US-Funded Projects in Fallujah, Getty Image #72638577

A Case for Qualitative Methods with a Visual Approach

During my second tour to Iraq, an embedded reporter captured in this photograph (Figure 1) the moment my translator Salah and I walked toward a food distribution office.[4] It is my favorite picture because the strong emotions it evokes, ranging from pride to sadness. There is pride in what I accomplished, and sadness for what I now cannot. I keep it in a frame to remind me of how tough I once was, a

[4] Rights-managed license purchased for use in this document (usage type “editorial-magazine interior”).

reminder of a time now past. In exploring methods for this research, this picture played a significant role, specifically because of its power (Collier 1957). Although there are a number of qualitative methods available for uncovering combat veterans' negotiated health transitions, I believed not all were equally appropriate for my purposes.

Having conducted historical qualitative research in the past, I knew that interviews were foundational. However, despite focusing on the individual experiences, interviews alone would not be enough to accomplish my goals. As my research does not exist elsewhere and my participants are a small segment of the veteran population, an inductive approach was a necessary starting point (Clark-Ibáñez 2004; and Schensul, Schensul, and LeCompte 1997). Additionally, my subject matter is emotionally charged, requiring an individualized and partially participatory path. Access to data was further challenged by, "Confined spaces that are at once in (our midst) but also removed from it." (Bonifacio and Schillaci 2017:235).

In the end, visual methods provided me the means to meet these requirements, and thus became the centerpiece of my research. Visual methods allowed for the articulation of personal experiences when words fail. They afforded me a creative mechanism to listen to, discover, collect, and then share illness narratives (Banks 2013; Bonifacio and Schillaci 2017; Clark-Ibáñez 2004; Harper 1986; and Kleinman 2013). As they are inherently collaborative, visual methods offered a way to uncover hidden aspects of the illness experience and reduce my own voice in the process (Fultz 2010; Oliffe and Bottorff 2007; and Vila 2013). My research combined three visual methodologies in a two-phased approach which culminated in a final product. The first phase used photo elicitation, while the second applied photo voice, culminating in a

digital story drawing on the participant's open-ended interviews and photographs (Bernard 2006; and Schensul, Schensul, and LeCompte 1997). Although photo elicitation is part of photo voice, I chose to utilize it alone for the first phase of the interview process.

Photo Elicitation

> "Memory is a strange faculty. The sharper and more isolated the stimulus memory receives, the more it remembers; the more comprehensive the stimulus, the less it remembers." (Berger 1992:193)

Over the years I witnessed photographs reminding my father, a Vietnam veteran, of combat experiences long forgotten (Oliffe and Bottorff 2007). I am continually amazed at the new stories he tells each time we look through his album. His pictures stand as a record which connects him to his memories and the emotions tied to them. Most of the current generation of combat troops took pictures during their deployments. Just as the warriors before us, we too became experts at capturing key moments; records of what we survived and of our friends who did not. These photographs were the focus of the photo elicitation phase.

Photo elicitation uses photographs in the interview process to engender discussion; both about what is and is not in the frame. Douglas Harper wrote that photo elicitation provides the "interview a concrete point of reference" and "mines deeper shafts into a different part of human consciousness than do words-alone interviews." (Harper 1986:24 and Harper 2002:13, 22-23) This does not mean the information gained is more useful, but instead richer, deeper, and more meaningful because the pictures trigger forgotten memories (Harper 2002 and Vila 2013). Furthermore, it can turn assumptions on their head, making participants realize what the researcher does or

does not understand and allowing them to fill knowledge gaps. Photo elicitation creates empathy for researchers while putting participants at ease and opening dialogue (Epstein et al. 2006; Harper 1986; Lorenz 2011; and Oliffe and Bottorff 2007). It allows the researcher the ability to see inside the participant's world because it, "Illuminate(s) dynamics and insights not otherwise found through other methodological approaches." (Clark- Ibáñez 2004:1524)

Photo Voice

Photo voice, first used by Caroline Wang (1999), is participatory research in which the informants photograph their own world and their own experiences. These pictures are then used to generate discussions which deepen the understanding of that world. As she defined it, photo voice "enables people to identify, represent, and enhance their community through a specific picture technique." (Wang 1999:185) Additionally, Wang (1999) proposed that photo voice could be used in health-related research in order to:

1. Teach others about the illness experience through their own lens instead of someone else's lens
2. Influence policy
3. Empower through collaboration
4. Support activism

Each of these four proposals permeated my own research.

As stated, the main character in this story is the body so photo voice methods was a logical choice. It allows the participant to showcase the aspects of the individual, social, and political bodies which are most salient to their illness narrative (Scheper-Hughes and Lock 1987). Because photo voice data comes from the participants – their pictures, their understanding, and their viewpoint – they are joint producers of the

knowledge and must be respected as such (Johnson 2011). Photo voice allows participants to show researchers hidden aspects of their lives, providing a unique view of these usually imperceptible experiences (Bonifacio and Schillaci 2017; Mizock, Russinova, and Shani 2014; and Oliffe and Bottorff 2007).

It also allows participants to communicate struggles they may be uncomfortable verbalizing, which in turn can bring about healing (Mizock, Russinova, and Shani 2014; Oliffe and Bottorff 2007; and True, Rigg, and Butler 2014). John Oliffe and John Bottorff (2007:851) used photo methods in research with men diagnosed with prostate cancer. They claimed that men are complicit in sustaining masculine ideals that "men don't talk about health" and believed that photo methods could perhaps change this.

Making Contact in a Minefield

I chose this section title for a specific reason. The military has a saying, "no plan survives first contact (with the enemy)." For my purposes, I made contact the day my research began. The term "landmine" is often used metaphorically; for this research it is the *perfect* metaphor. Landmines are a military weapon once widely used around the globe. They are concealed and can explode when least expected. Even when a minefield is identified, there is the possibility of unintended detonation. Although I considered possible challenges, there were many that I did not foresee. I had a detailed plan for conducting research that conceded the participant's role, yet it still did not go as expected from the very moment I began execution.

Participants

After establishing a methodology, I struggled with, "who are my participants?" Combat veterans come from a vast and varied population with differences in diagnoses,

Services, ages, ranks, gender, status, and time in combat. My initial goal was 30 veterans; a mix of 15 active duty and 15 retired. I felt this was a manageable and achievable goal for qualitative research. I focused on veterans of Iraq and/or Afghanistan diagnosed with autoimmune diseases acknowledged by the AARDA (American Autoimmune Related Diseases Association 2017). When I began my research, the AARDA's list included chronic fatigue syndrome and fibromyalgia because they have closely linked etiologies (American Autoimmune Related Diseases Association 2015). However, within the last year, chronic fatigue syndrome was removed (American Autoimmune Related Diseases Association 2017).

I further narrowed my participant criteria to Special Operations Forces (SOF), a segment of the population most often deployed globally. They are in the best physical shape, psychologically evaluated prior to being selected for training, and the biggest believers in "sucking it up." Additionally, each Service has special operations units. Headquarters, United States Special Operations Command (HQ USSOCOM), oversees special operations, broadly speaking. Within the headquarters is the Care Coalition, the office directly responsible for all things related to the care of sick and grievously injured operators. I worked closely with members of this office, while I was a government civilian in the headquarters, so I knew they were logical gatekeepers. They are passionate about sick operators and work tirelessly on their behalf. After coordination, I obtained a letter of support signed by their commanding officer. It clearly states that I own the data and the rights to the final products (See Appendix A). Per our agreement, the Care Coalition will have access to the digital story for its own educational purposes. The support of the Care Coalition is further cemented by a Memorandum of

Understanding which exists between the University of South Florida and HQ USSOCOM to conduct research (See Appendix B).

The Care Coalition maintains a database of all sick and/or injured operators. After I completed the necessary Health Insurance Portability and Accountability Act (HIPPA) training, they ran a query isolating all operators meeting my criteria. Although I wished to focus on veterans living in Florida, the initial query only identified nine with autoimmune diseases. After speaking with the Care Coalition's commander, who was dealing with unprecedented numbers sick with cancer, I amended my IRB to include it in the participant criteria. The next query identified an additional 21 operators with cancer living in Florida. I was still not comfortable with this number so I requested a third query.

The third query identified 225 operators with autoimmune diseases and/or cancer, located across the United States. Each of them was assigned to one of 37 care coordinators located at commands around the country. I reached out to the appropriate coordinators to explain the purpose of my research while requesting their help. We discussed good candidates for this research as I wanted to ensure we carefully screened the operators to determine who was healthy enough to contact. I provided each coordinator an email and phone script for recruiting participants (See Appendix C). I worked through them until the operators agreed to participate. Those willing to support my research were instructed to contact me directly.

After months of conversations, 15 operators agreed to participate. I provided them informed consent forms and discussed in detail the research process (See Appendix D). While getting the informed consent forms signed and setting up the first

interviews, all but one participant dropped out. In order to cast a wider net, I submitted a second IRB amendment which included conventional forces with the same service and diagnosis criteria. I kept the criteria of "male veteran" as a conscious choice for ease of transition. From the outset, this was not to avoid female veterans but because women are not operators.[5] While awaiting approval from the IRB, the last special operator withdrew because he thought the approval process took too long.

Using participant information from the Team Archangel survey, I contacted 276 veterans fitting my adjusted criteria.[6] With the IRB-approved email (Appendix E), I asked for voluntary participation. Thirty veterans responded expressing an interest; in the end, eleven participated and of those eight completed the entire interview process. One of the participants was diagnosed with liver cancer after his first interview so I encouraged him to focus on treatment and not my research. Despite repeated emails and voice messages, two participants did not contact me to complete the second interview. One of the eleven participants was diagnosed with Chronic Fatigue Syndrome (American Autoimmune Related Diseases Association 2015) and other diagnoses co-morbid with autoimmune diseases, common among Iraq and Afghanistan veterans, exposure-linked (Chiaramonte 2018), and identified with GWS (VA Website 2018). Because of the challenge of getting participants and his willingness to participate in my research, I included him.

I allowed the participants to choose the date and time for their interviews. I anticipated it would change often but also knew that each veteran had important

[5] During this research period, restrictions for women in SOF were lifted. However, this was after OEF or OIF ended.

[6] Participants were not required to leave an email address in order to take the survey.

information to share and their time was valuable. Prior to the first interview, I discussed my research with each of them and provided the informed consent form containing my research plan. I went over the informed consent, discussed the interview process, and answered any questions they had. Finally, I explained how the digital story, photographs, and interviews would be or could be used in future support of veteran illness awareness. I explained the challenges of confidentiality in photo methods research; anonymity was difficult but not impossible.

I originally planned to interview the veterans in a location most convenient for them. However, with eight participants located in other states it was financially impossible. The three veterans in Florida were interviewed face-to-face while the rest were interviewed telephonically. Although I originally planned to photograph the participants with their favorite deployment picture, due to anonymity concerns and the veteran's physical locations, I chose not to include this in the interview process. I do not feel that my research in any way suffered without these pictures.

The Interviews

Despite careful explanation of the interview process, none of the 10 participants were prepared for the first interview with deployment or transition photographs. One participant did not take photographs during his deployments so we had none to discuss. Only one participant provided photographs from their health transition period. Because the open-ended interview format allowed for flexibility, we were able to make adjustments. Due to the challenges in getting interviews scheduled, I continued with the first interview and focused on the questions which were not part of the photo elicitation and photo voice process. This reworked interview protocol changed the order of

questions but not the overall goals and outcomes. The photo methods questions were then addressed in the second interview along with any unasked questions. I used a checklist to ensure that each of the questions was answered by the participants.

For those concerned with anonymity, we discussed ways they could limit their visibility. For example, the combat photographs for the first interview could show the veteran posing with sunglasses and helmet. Additionally, they did not need to be in the frame of the photo voice pictures. I advised them the interview was recorded and transcribed but I was in sole possession of the recordings and transcripts. I also promised to use pseudonyms in the written documents and digital story.

Interview 1. Despite the lack of pictures, each participant discussed their lives as a "healthy warrior" as well as the transition to "sick veteran" when asked the interview questions. The pictures from this period were still addressed during the second interview which allowed for insight into what mattered most to them. The first interview questions included:

1. Can you provide me an overview of your service? Branch, MOS, years served, deployments, etc.?
2. At what point did you first start to notice you were sick?
3. What did you think was happening?
4. How did you learn you were sick?
5. How long did it take to get answers and/or a diagnosis?
6. Did you think your changing condition was physical, mental, or emotional?
7. Did you do research about your illness?
8. How do you continue to learn about your illness?
9. Do you talk about your illness with other veterans?
10. If so, how do they receive it?
11. Were there barriers in getting answers about your illness?
12. Were there barriers as you sought treatment for your illness?
13. Where have you found help and support?
14. Was your experience different for benefits and healthcare?
15. Do you trust the government to do right by you and tell you the truth?

16. Do you know other sick veterans?
17. Do you belong to any veteran organizations?
18. Has your illness changed your perceptions of your service to this country?

Before concluding the first interview, I asked the veteran to spend the next several weeks taking pictures of what defined their lives since their diagnoses. They were free to photograph anything they chose and I let them decide the number of pictures to take. I only provided instructions regarding informed consent and answered any questions. I made sure they all understood that if others appeared in the pictures they would be required to get a signed copy of the photo release form (See Appendix F). To allay concerns, I told them they did not have to appear in their pictures thus providing a level of anonymity (Mizock, Russinova, and Shani 2014). They were also reminded to bring their deployment photographs.

Interview 2. Although a photo elicitation interview may include any pictures, my participants were again asked to provide their favorites taken while deployed as well as from the time in which they were diagnosed. Although only 1 provided a picture from their transition period, all discussed this time in detail. The pictures that were provided allowed them to mentally target a very specific period of time taking them back and then bringing them forward during the photo voice portion (Harper 2002). We discussed who they were before their diagnoses as well as details of their own "biographical disruption." (Bury 1982:264 and Harper 2002)

This exercise focused the veterans on the emotional toll of this transition, which is not easy for men or veterans to share (Oliffe and Bottorff 2007). During the interview we addressed each photograph in turn with the aid of previously determined questions. These were:

1. Why did you chose this photo?
2. Who is in the picture with you? (If anyone else is)
3. What is happening in this picture?
4. When was this picture taken?
5. How does this photograph make you feel?

Additional questions were created through the discussions surrounding their photographs; this took the interviews in multiple directions. Because these photographs were chosen by the participants, they controlled a portion of the interview. I believe the participants' ability to choose the photographs created a level of comfort with the interview process and with sharing (Epstein et al. 2006; and Oliffe and Bottorff 2007). It allowed me to gain insight into what mattered most to them, and, "capture the tangible and intangible aspects" of their illness experience (Clark-Ibáñez 2004:1509 and Harper 1986).

We then turned to the photo voice portion and the pictures they took that defined their own illness experience. When looking at their pictures, I asked each of them the following questions (Bernard 2006; and Schensul, Schensul, and LeCompte 1997):

1. What is this picture of? Tell me about it.
2. What does this picture mean to you?
3. Why does this picture define your life now?

The content within the frame was important whether or not it was visually appealing (Harper 1986; Radley and Taylor 2003; and Shankar 2016). There was also the "meaning embedded in photograph(s)," which our discussions extracted (Oliffe and Bottorff 2007:853). I believe the photo voice interviews also empowered the participants, thereby creating an atmosphere in which they could speak freely without appearing weak (Goffman 1959; Charmaz and Rosenfeld 2006; Oliffe and Bottorff 2007; and Spradley 1979). The photo voice interview further highlighted participants'

experiences, especially their perspective of negotiating illness while overcoming roadblocks (Banks 2013). It helped me to understand their view of their world and their relationship to the macro-social and the intermediate-social levels as they negotiated and struggled within them (Singer and Baer 1995; and Wang 1999).

The culmination of this research, the digital story, incorporated selected pictures and quotes from the combined interviews that I drafted into a script. I utilized the pictures and script to create a short video in order to provide a window into the effects of diseases on veterans' daily lives to use as an educational tool (Charmaz and Rosenfeld 2006; Goffman 1959; and Oliffe and Bottorff 2007). I hope this digital story will pull back the curtain on veterans' illness struggle living with disease for wide-ranging audiences.

Analyzing the Data. Each of the interviews were digitally recorded and then transcribed. It was important to record the interviews so I could use the veterans own words. I began by reading and re-reading the transcripts while highlighting key quotes. I eventually relied on these highlights when it came time to incorporate quotes into the digital story or include in the written document. I manually coded the transcripts, using an excel spreadsheet, in two ways. First, I located the answers to each of the interview questions. I then placed those answers to each veteran's interview question together and compared them to each other in order to find commonalities. I then went through and identified common themes.

An Insider's Success?

I learned almost immediately that my binary status as both an insider AND an outsider did not guarantee success. In fact, this status created a tension in the "AND" (Glenn 2017) being a landmine AND an advantage. Despite knowing the danger of

assuming, I believed my status as a sick veteran would provide me the credibility to recruit participants. As an “insider” at Special Operations Command, I mistakenly thought that relying on them as a gatekeeper would help gain the additional rapport needed to recruit participants. However, it took relationships forged in combat for half of the participants to trust me enough to speak about their very personal experiences (Oliffe and Bottorff 2007; and Mathias 2010). In fact, eight out of the 11 knew me prior to this research and were contacted because they took part in the survey. Five of those eight deployed with me to Iraq. I cannot overemphasize the necessary strength of those relationships. Although I grappled with the idea that perhaps my insider status was actually a hindrance in getting participants, in the end I believe that it took the highest level of trust to get the participation for this research.

I will always be concerned that these participants will be stigmatized for discussing their illnesses experience publicly (Oliffe and Bottorff 2007). Upon joining the military, a body becomes symbolic of what is most important to that Service. In return, the individual is afforded membership and their body becomes a billboard, of sorts, to advertise belonging. This exchange creates a pride in service as well as a useful mechanism for recruiting. Once broken, that same person can become an outcast – the antithesis of what is good in their military branch. Stigmatization is even a risk for combat veterans who retired or were discharged (Kleinman and Benson 2006; Kleinman 2013; and Scheper-Hughes and Lock 1987). By publically shining a light on their own broken status, these veterans could be shunned by other veterans.

Two participants were particularly concerned that their identity would be revealed so I worked with them to mitigate this issue. One of the participants wanted to ensure

that his children would not be able to Google his name in the future and find it in my dissertation. They were unaware of his struggles and he wanted to make sure that it stayed that way. This was a concern that I never thought of when problematizing my research. I vowed to make every effort to ensure his privacy and he agreed with my approach.

As I wrote, I realized that I too was about to publicly share this incredibly personal side of my own life. I thought through how others might respond when they read my research. I grew increasingly uncomfortable with my own story being made public, and then became aware of my hypocrisy. I did not understand how uncomfortable this could make a veteran, despite my own status, until I thought about people reading my story. I immediately thought, “Will I be considered a malingerer?”

Understanding that photo methods make participants much more vulnerable than doing a survey, getting participants was still much harder than I anticipated. I believe there were a number of factors working against me. Despite being transparent in order to ensure there were no surprises, I truly understand why they would hesitate to participate. Appearing weak before others is paramount in the minds of those who served. I also believe that medical conditions created a challenge. I know what it is to be overwhelmed and not have time to participate. I had to remind myself that some days I feel better than others and know the pressure to keep commitments when my health is bad.

Regarding those identified by the Care Coalition, despite their backing, I am not an operator but former conventional military. This makes me an outsider to the special operations community and much like Marines, they trust their own more than anyone

else. I must also remember that I am a researcher in their eyes and perhaps was not trusted simply for my veteran status. After considering these possibilities, my frustration over recruiting challenges melted away.

I was also confident that I tried everything to mitigate concerns with open and transparent communication about shared goals and possible challenges along the way (Anderson-Lazo 2009 and Speed 2006). I explained to the participants the possible ways in which the data will be used in the future. The only way I would use this data is in the direct support creating an awareness of combat veteran illnesses. I was clear that not only am I a veteran but I also have a shared goal of getting answers and seeking accountability (Anderson-Lazo 2009).

I was always cognizant that my own experience of illness could create assumptions on my part resulting in inserting myself into this research or omitting information. This was much harder to do than I anticipated. I found that I would start speaking more in the interviews than I wanted to by injecting my own experiences. I wanted to create rapport based on common struggles but not overshadow the veteran. This included situations that were a challenge for me but positive experiences for other sick veterans. I made sure that their victories were shared despite my own biases.

Conclusion

Images are powerful tools to both elicit and dispense information yet they have inherent limitations. The boundedness of a photograph crops the context, leaving it open to broad interpretation (Banks 2013, Kleinman 2013, and Vila 2013). The experiences, and the photographs of them, have inferred context which is limited to what the participant shares and the viewer sees (Montgomery 2017). During the

interview, as the participants translated their photographs, the context became validated despite being incomplete (Vila 2013). Missing or partial narratives are not necessarily due to nefarious means, but they existed for a number of reasons including: faulty memory, discomfort with the truth, and fear of reprisals. We must consider that there is some disparity between the actual illness experience and what the veterans presented in the photographs and interview narratives (Shankar 2016).

Regardless of methods, this is a politically charged subject. Countless lawsuits, exposes, whistle blowers, briefings, debates, and congressional testimony followed the fallout of Agent Orange and the existence of GWS. Current health outcomes are questioned at the highest levels of our own government as well as our Partner Nations. The leadership's legacy, desired promotions, big government contracts, and union jobs all fight against finding answers. Through this research, I laid claim to a very small piece of what I hope will be ongoing and tireless research seeking the truth. I believe it is fitting to use visual methods because they originated within applied anthropology as a means to find solutions to societal problems (Chalfen and Rich 2007). Through visual methods we can get at both the visible and the invisible, raising awareness of the lived experience of illness and creating conversations about what is happening to combat veterans who served their country honorably (Chalfen and Rich 2004; and Kleinman 2013).

It is my goal for the digital story to bring sick veterans and their doctors together in new and different ways allowing them to better understand one another (Alexandra 2008; Chalfen and Rich 2004; Gubrium 2009; and Rich and Chalfen 1999). Using visual methods to educate doctors of patient's experiences outside the clinic is not a

new technique. Dr. Richard Chalfen and Dr. Michael Rich (2004:17) used visual methods to “teach your clinicians about your illness.” They also believed it “rehumanize(d) medical care.” (Chalfen and Rich 2004:27) So too, the digital story piece has the potential to educate a broader audience about what it is like living with combat-related diseases. This is especially important when the effects of the disease are not necessarily obvious and more elusive in populations not likely to seek treatment (Chalfen and Rich 2004; Oliffe and Bottorff 2007; Rich and Chalfen 1999; and Wang 1999). This will not only shed light on the focused population but hopefully all combat veterans. It is through the digital story that the two sides of the coin, disease and illness, come together in order to advance veteran research.

Emily McKee (2010), working among Bedouins, found complexity and contradictions among participants; for example their love of both nomadic and city life. She witnessed previous scholars embrace an overly-simplified or highly complex portrayal (McKee 2010 and Speed 2006). I did my best to ensure that the veterans were portrayed fairly in the interview process. It was important for me to show that we are all not simply wallowing in self-pity but fighting to maintain a normal life. This struggle is multi-faceted and highly complex. The knowledge produced from this research will be used to offer insight into what it means to be a sick combat veteran. This is not just seeing the disease in the individual but through the individual to the broader context (Singer 1994). By positioning the veteran narratives at the forefront of this research, despite the limitations, it produced much needed visibility and understanding.

CHAPTER 5:

THE HEALTHY WARRIOR

My own illness narrative began in July, 2009 while on a humanitarian trip to Afghanistan. A previously unknown dizziness engulfed me and I sat down in order to avoid falling. I woke up in a pool of blood after catching my head on a sharp object as I fell forward. It was not until later that I realized I had my sixth and final anthrax vaccination 30 days prior, well within the window for a "bad reaction." Despite the timing and classic symptoms, the Vaccine Healthcare Clinic blamed a TBI I received while on a mission in Iraq in 2006. The TBI clinic in Tampa, Florida, one of the best in the nation, stated clearly that in no way was that experience related to my TBI. I stopped fighting the finger-pointing bureaucracy because I knew I simply could not win. My narrative includes diagnoses of fibromyalgia, chronic migraines, and irritable bowel syndrome as well as multiple shingles outbreaks and many abnormal and still undiagnosed symptoms.

I know that it took great courage for my participants to speak out, to share their story. In solidarity, and to fully understand what their participation means, I share my narrative. This is not to overshadow my participants but to face my own fears of stigma. It seemed unfair to ask them to tell their story, to allow us to peer inside their world, without first sharing my own. I am entrusted with the illness narratives of 10 combat veterans. For most of them, they are not just "participants" but fellow combat veterans

whose bond was forged in fire and blood. I took great care with their stories, and what follows (although not placed in the order of the conducted interviews), is in the chronological order of these veteran's experiences.

The Nostalgia of Health

The lived experience of the veterans' multidimensional bodies is not just about the disease or the illness but the evolution of the diagnosis (Scheper-Hughes and Lock 1987). In the not so distant past, these were healthy warriors. Each one deployed in support of OEF and/or OIF.[7] Despite being diagnosed with autoimmune diseases, they battle additional health issues like damaged spines or TBI. In the broadest of terms the participants are comprised:

- Ten retired service members and one honorably discharged veteran
- Two U.S. Air Force, five U.S. Marine Corps, two U.S. Navy, and one U.S. Army
- One special operator
- Four enlisted, two officers, and four who enlisted and then became officers
- Five who deployed more than once
- Four who deployed to locations in addition to Iraq and Afghanistan

These participants were all white males between thirty and sixty-years-old. This was not a diverse demographic, not by choice but by necessity. My participants, as approved by IRB, were referred to by pseudonyms and signed photo release forms (Appendix F) for any images in which they were shown.

During the photo elicitation interview, in which eight of the 10 veterans participated, we explored their lives prior to their diagnoses through pictures and memories of their military service. This exercise was intended to remind them of their

[7] Deployment lengths varied. Each Service had typical deployment lengths for units. For example, Marines deployed seven months, Air Force four months, and Army twelve months. However, deploying with a higher headquarters staff usually meant a twelve month rotation. Additionally, Army units did eighteen month deployments during the height of the wars. SOF typically do four month rotations.

healthy warrior past. I asked them to provide their favorite photographs from deployment, which are shown below unedited. I did not specify the number of pictures to share because I wanted to ensure they chose what mattered most. During the open-ended interviews, they each made additional points which added to the individuality. The veterans are introduced through this part of the interview process.

Jake

Jake enlisted in the United States Air Force and was discharged after eight years. He earned his bachelor's degree, and then returned as a second lieutenant. He retired after 22 years of service with five deployments including Iraq, Afghanistan, the United Arab Emirates (UAE), and Qatar. He did not take any photographs in Iraq or Afghanistan in order to lessen his family's stress. The few pictures taken in UAE and Qatar were not electronic and he was unable to locate them.

Figure 2

Bob

Bob retired as a Master Sergeant from the Marine Corps after 24 years. He deployed in support of Operation Desert Shield/Desert Storm as well as Enduring Freedom and Iraqi Freedom. Bob provided pictures that spanned his career. Most of his pictures from Desert Storm were destroyed in a house flood so "Figure 2" is one of the few remaining. For Bob this picture represented a different time in the Marine Corps; different, "uniforms, gear, equipment, regulations, you name it."

The pictures from Iraq and Afghanistan, were starkly different; a focus that carried over into his photo voice pictures. He chose these pictures because he looks "happy" both with a great dog named Diego (Figure 3) and with great friends (Figure 4). Bob and Jason remain close and speak often so this picture, "just represented good times." He also provided two pictures of the American flag from both Afghanistan

Figure 3

Figure 4

(Figure 5) and Iraq (Figure 6). "The flag represents freedom…a lot of people hate our flag, I love it." Finally, he provided an aerial picture from Afghanistan, "here you are, you're in a conflict, in a time of war, but I never really focused on that." (Figure 7)

Figure 5

Figure 6

Instead he focused on experiencing the place. He spoke of visiting a building built at the time of Alexander the Great or a forward base, desolate except for a single

Figure 7

rosebush. His photographs and the interview focused on freedom, pride, and finding beauty in the unexpected.

Jim

Jim retired as a Sergeant Major in the Marine Corps after 27 years. He deployed three times in support of OIF; once to Kuwait and twice to Iraq. He brought a single picture which sits on his endtable. Taken after he returned home from his final deployment, it features him hugging his son as his daughter cries in the background (Figure 8). This is the "most awesome picture I have in my whole collection…" showing that "welcome home where you are really missing the family." As he spoke about the photo, he focused on coming home, happy times, and family as the most important part of life.

Figure 8

Larry

Figure 9

Larry is a retired United States Navy officer with 20 years of service. He deployed to Qatar for 6 years in support of both OIF and OEF. For Larry, his wedding picture is his favorite military picture (Figure 9). He is in uniform kissing his wife under the arch of swords comprised of his closest friends from Reserve Officer's Training Corps (ROTC). He said it exhibits the two best decisions he made; marrying his wife and joining the Navy. "So that picture captures the most significant life decisions: commitment, a promise, a contract on some levels, both military and marriage." He believed it also "captures those importants in your life—family, friends, civil society, public servants, Navy, military, country…"

Matt

Figure 10

Matt enlisted in the Marine Corps before becoming a Chief Warrant Officer. He retired after 26 years and deployed to Iraq twice. His pictures showed accomplishments like cutting a ribbon with a local Iraqi Sheik at a rehabilitated school (Figure 10) or opening a humanitarian assistance tent for the distribution of food, water, blankets, and damage claims (Figure 11). His self-titled photograph, "why we're here" featured his team in

Figure 11

Figure 12

front of the “Contractor Bridge” in Fallujah (Figure 12). This bridge was named in honor of the four Americans killed in an ambush before their burned bodies hung there in March of 2004. His final picture was taken with his Army replacement as they poured over a map (Figure 13). For Matt, it meant, “the best tour of my career was coming to an end and I had a lot of accomplishment and confidence at that point for what we had done.” His pictures and interview showed a forward momentum, obstacles overcome, and a sense of purpose and pride.

Figure 13

Peter

Peter was the only soldier to participant. He retired after 30 years in the United States Army and deployed in support of Desert Shield/Desert Storm and OEF. He provided a picture taken outside his “hooch” with the

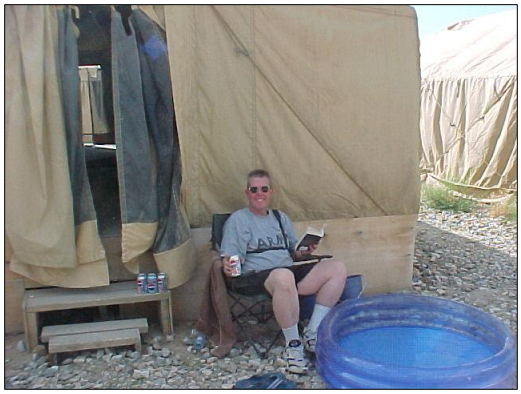

Figure 14

Figure 15

Figure 16

Figure 17

blowup swimming pool his mom sent (Figure 14). The rest of the pictures we discussed focused on building a case for exposures in Afghanistan. They highlighted the variety of toxins from the sandstorms overtaking a patrol (Figure 15) to the CH-47 helicopter

Figure 18

Figure 19

Figure 20

kicking up dust and dropping jet fuel during take-off (Figure 16). He included pictures of the sun hidden from a dust storm (Figures 17 and 18) and inside his tent where everything was covered in dust despite efforts to keep it clean (Figures 19 and 20).

Figure 21

Figure 22

Figure 23

Even the picture displaying carpets was shared, “because you wouldn’t believe how much dust comes out of those rugs.” (Figure 21) Another photograph displayed two socks – one washed in Afghanistan while the other was washed with Clorox while home

on leave (Figure 22). His final picture features black soot rising from a burn pit. After learning what was burning there, he verbalized his concerns to leadership and was told, “Just go do your job, colonel,” (Figure 23) just as he was told as a captain after he expressed the same concerns over the burning oil wells in Kuwait.

Tom

Figure 24

Tom enlisted in the Air Force before being accepted into the Officer Commissioning Program. He retired after 25 years on active duty. Tom deployed to Qatar in support of OEF, where he suffered a significant back injury. He provided a picture taken in Qatar in front of one of the tents (Figure 24). He said, “If you look at what kind of shape I am in…that’s how I was when I deployed. I was lean, mean, had a little body fat, because I was a very active person.” This picture represents for him, “his fitness days.”

Andy

Figure 25

Andy is a retired naval officer with 29 years of active service. He enlisted in the Marine Corps before moving to the Navy as a special operator; first as enlisted and then as an officer. He deployed in support of Operation Desert Shield/Desert Storm and then Africa, Bosnia, Afghanistan, and Iraq. He called “Figure 25” his “first in-country shock” picture; when he learned there was marijuana

Figure 26

everywhere in Afghanistan. Special operators used local weapons and so he shared a picture holding a short-barreled AK-47, his favorite to fire (Figure 26). During his tour in Iraq, he provided security for Prime Minister Allawi who lived outside the safety of the Green Zone in Baghdad (Figure 27). His final picture was of the famous crossed swords over Saddam's parade ground (Figure 28). Andy spent time in the University of South Florida's anthropology doctoral program which was evident in the pictures and stories he shared. He spoke of destroyed heritage and visiting sites like the Palmyra Crusader's Castle and the Bamiyan Buddha statues. His pictures showed a unique perspective and experiences.

Figure 27

Figure 28

Alex and Sam

There were two participants who did not complete the second interview but were still included in this research. Sam spent three years in the Marine Corps Reserves and deployed to Iraq once. Part-way through this research, he was diagnosed with liver cancer and was unable to complete the interview process. Alex is a retired Marine Corps Master Sergeant with 30 years. He was called out of retirement in order to deploy to Iraq a second time.

The Biographical Disruption

As I moved through this research, I learned that the veterans' biographical disruptions were not necessarily a well-defined, singular point in time, but an ongoing transition spanning multiple years (Bury 1982:264). The start of the illness narrative was a period marked by confusion, frustration, and the unknown (Kleinman and Kleinman 1996; and Kleinman 2013). It began by chasing an elusive diagnosis.

The Elusive Diagnosis

For most of these veterans, this ongoing search was characterized by long periods of time and multiple diagnoses along the way. Each of them struggled to understand what was happening to their health. It was certainly a time of a "subjective and fluid relationship between the various parts of the body…where health and sickness reside." (Scheper-Hughes and Lock 1987:7) The side-by-side health and sickness existed at the individual level but was undoubtedly shaped by the relationship between doctors and their patients at the micro-social level (Singer and Baer's 1995).

For eight of the participants, there were never-ending medical appointments which ended with "there's nothing wrong" or an incorrect diagnoses. Or the veteran "sucked it up" until they could not ignore their failing health. Only two of the 10 veterans, once examined, waited less than a year to receive a diagnosis. Conversely, all three of the Desert Shield/Desert Storm veterans mentioned having health issues following that deployment, which was one-to-two decades earlier. For some, the multiple diagnoses were comorbid with their autoimmune disease. Two of the 10 participants were diagnosed with extremely rare diseases. Two of the participants

spoke more about other combat-related diagnoses, specifically TBI or vertebrae damage.

Prior to his final deployment, Jake spent four years moving through the medical system, seeing “doctor after doctor after doctor with the same litany of ailments.” Despite this, no one could identify what was causing his symptoms. He was not sure if they took his concerns seriously or, “were just pushing me through the system. Trying to get through-put for the day.” After changing duty stations, his doctors were in a specialty clinic so he once again described his symptoms. This time, they recognized what they saw in his movements and diagnosed him with fibromyalgia and eventually comorbid chronic migraines and irritable bowel syndrome. He said he “doesn’t have an official diagnosis but just several little diagnoses.”

Larry started to have, “serious abdominal pain and skin rashes and mouth sores…that was unexplained.” The doctors at Bethesda Naval Hospital blamed his pain on something different each time before sending him home. One suggested he add more fiber to his diet. After three years of tests, treatments, and procedures, Larry thought, “good Lord, I’m in trouble if they can’t figure it out.” After years, the doctors said, “I don’t know what else to look for because I don’t know what’s wrong with you.” Finally one asked Larry if he was ever tested for Celiac Disease.[8] Two days later the results were positive for celiac antibodies and he was scheduled for a biopsy. The

[8] The AARDA (2017) defines celiac disease as, **“**an autoimmune disease in which people can’t eat gluten because it will damage their small intestine. If you have celiac disease and eat foods with gluten, your immune system responds by damaging the small intestine. Gluten is a protein found in wheat, rye, and barley. It is found mainly in foods but may also be in other products like medicines, vitamins and supplements, lip balm, and even the glue on stamps and envelopes.”

biopsy came back positive as well for Celiac Disease, which explained why adding more fiber to his diet made his symptoms worse.

Nine years after his final deployment, Alex noticed blood in his urine. The doctor explained that, "this is not unusual…a lot of people that…are active will have blood in their urine from time-to-time." Four to five months after this initial incident he found significant blood in his urine, so the doctors ran additional tests and discovered bladder cancer. Immediately following surgery and chemotherapy, he noticed a swollen lymph node in his groin. Medical tests revealed Castleman Disease.[9] The specialist who diagnosed him, though studying it throughout his career, never saw it in a patient. "Castlemans is rare…it's so rare I was fortunate that the pathologist found it, in fact, he had to wind up sending it to UVA to a specialist to get the confirmation that that's what it was. And, even then, when going to the VA, I went to the oncologist at the VA and he didn't know a whole lot about it."

Sam was on recruiting duty when he started having "extreme, excruciating, sharp, stabbing pain" in his peritoneal cavity. He was in and out of the VA hospital 20 times having, "colonoscopy after colonoscopy and CAT scans" but was unable to get an MRI due to embedded shrapnel from an improvised explosive devices (IED). None of these visits produced a diagnosis so he was given pain medication and told, "you're fine, there's nothing wrong with you." Eventually they removed his appendix and gall

[9] The AARDA (2017) defines Castleman disease as **"**a rare disease of lymph nodes and related tissues. Castleman disease can occur in a localized (unicentric) or widespread (multicentric) form. This means there is an abnormal overgrowth of cells of the lymph system that is similar in many ways to lymphomas (cancers of lymph nodes). Treatment and outlook vary, depending on the type of Castleman disease you have. The localized type can usually be successfully treated with surgery...multicentric Castleman disease can be life-threatening."

bladder. He had biopsies done on his ileum intestine, stomach, and liver, and finally was diagnosed with Crohn's Disease[10] and treated. Within the last year he was diagnosed with liver cancer and is currently undergoing treatment.

Tom retired from the military and was living in Hawaii when he was diagnosed with psoriasis on his elbow and knees. After each new and ineffective medication he awoke to find double the spots. Two-and-a-half years after being seen for "psoriasis" Tom was diagnosed with Lichen Planus[11] on his ears. Trying to find relief through treatment, he was sent to the Mayo Clinic where he was diagnosed with Indeterminate Cell Histiocytosis. This extremely rare disease causes papules on the skin and one's platelets to crash. In fact this disease is so rare, over 1,500 doctors looked at his case. It has now progressed to Chronic Lymphocytic Leukemia.

Jim's former mother-in-law first noticed a popped vein on his leg while on a trip to Walt Disney World to celebrate his homecoming. A few years later, after heart palpitations and difficulty recovering after physical training, he was given an inhaler and diagnosed with seasonal asthma. It took roughly five years for Jim to figure out his multiple diagnoses. He was eventually taken to the emergency room when the inhaler for his "seasonal asthma" ceased to work. After five days in the hospital undergoing multiple tests, all with negative results, they decided to release him. Before discharging him they ran one last test. He was rushed into surgery after they found numerous blood

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[10] The AARDA (2017) defines Crohn's disease as "an inflammatory autoimmune bowel disease characterized by severe and persistent inflammation of the lining or wall of the gastrointestinal tract. The part of the gastrointestinal tract most commonly affected is the segment between the ileum and the rectum.

[11] The AARDA (2017) defines lichen planus as, "a condition that forms an itchy rash on the skin or in the mouth."

clots settled in his lungs. In addition to the pulmonary embolisms, he was diagnosed with Factor V Latent Mutation[12] and placed on blood thinners. Despite addressing these issues he said, "My health was still deteriorating; they couldn't figure out what was going on and that's when they started sending me out to all these different specialists…rheumatologists, hematologists, pulmonologists, cardiologists…" These specialists diagnosed him with undifferentiated connective tissue disease.[13] Finally, after a friend helped him get an appointment at the Mayo Clinic, he was diagnosed with fibromyalgia and severe chronic fatigue.

In 2008, Matt's neighbor who works in the medical field told him, "You sure are coughing a lot. Maybe you got cancer." He replied to her prescient statement, "Hey thanks, Meg." After this, he noticed the veins running down the left side of his chest from his neck. Although Matt knew something was wrong, it was not until he had trouble swallowing, lost significant weight, and developed night sweats that he went to the doctor. He was diagnosed with non-Hodgkin's Lymphoma.

Andy watched as friends from the first Gulf War got sick, but did not acknowledge problems himself until getting migraines in Iraq. He said after Desert Shield/Desert Storm he "figured something was going on" but it was not until years later that he knew that "something is definitely not right." Andy toughed it out for five years and then had a

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[12] "A clotting factor produced primarily in the liver that circulates in an inactive form in blood plasma and in its activated form combines with factor X on the surface of platelets to accelerate the conversion of prothrombin to thrombin." (https://www.merriam-webster.com/dictionary/factor%20V)

[13] The AARDA (2017) defines undifferentiated connective tissue disease (UCTD) as "a systemic autoimmune disease. This means the body's natural immune system does not behave normally. Instead of serving to fight infections such as bacteria and viruses, the body's own immune system attacks itself. In UCTD, autoimmunity may cause the immune system to attack specific parts of the body resulting in a variety of problems."

parachute accident which seriously injured his back. After his accident they looked more carefully at his medical record and sent him before a medical review board. It was during this process he was diagnosed with fibromyalgia.

Peter was diagnosed after Desert Shield/Desert Storm with dangerously low bone density, so low that if he fell he would shatter a bone. His osteoporosis diagnosis was in his medical record but he was not alerted to it until after returning from Afghanistan. Medical personnel informed him he should have never deployed. Although this osteoporosis was treated, other spinal issues arose. During his interview, Peter said his autoimmune disease, ankylosing spondylitis, so quickly I almost missed it.[14] He did not realize this was an autoimmune disease and related to multiple spinal problems like a compression fracture in his back (Magrey and Khan 2019; and Ralston et al. 1990). He was placed before a medical review board and forced to retire from the Army.

Bob developed chronic sinus infections after Desert Shield/Desert Storm but did not have any other major medical issues. It was after his tours in Iraq and Afghanistan that his health significantly declined. After being hit by an IED during his tour in Iraq, he suffered a serious TBI. After that deployment he was diagnosed with multiple complications from the TBI, to include vertigo, severe memory loss, and nystagmus. He was also diagnosed with neck and spinal nerve damage and, "a tumor on T6 (and) I've had most of my disc removed at S1, and L5." He also deals with asthma, unexplained skin rashes, and fatigue.

[14] The American Autoimmune Related Diseases Association (2018) defines ankylosing spondylitis as "a type of arthritis of the spine. It causes swelling between your vertebrae…and in the joints between your spine and pelvis.

Regardless of the path to diagnosis, all but one of these veterans expressed frustration; whether or not they explicitly used that word. These narratives, in a very matter of fact way, articulated the pain and how their lives changed through ongoing medical appointments as they moved toward getting answers (Hyden 1997). These experiences highlighted Kleinman's (2013) idea that while doctors diagnose the disease, patients live the illness. The patients spent years, sometimes in extreme pain, trying to go to work, raise their families and live normal lives. At the same time they were going to doctor appointments in order to chase that elusive diagnosis. This of course also proved that there were real things at risk for these men; jobs, family, and even their lives (Kleinman and Benson 2006; Kleinman 2013; and Scheper-Hughes and Lock 1987)

Research

Illness. Throughout this process, all of the participants conducted considerable research on symptoms, diagnoses, and possible causes. Peter said he researched, "more than you can imagine." For each of them, the struggle to get a diagnosis forced them to explore what was happening. Jake claimed that you "almost have to be an MD yourself to help the docs out to tell them what's going on with you." Bob too did significant research because, "I always wanted more answers. I'm not a, 'ok, yes whatever you say' (guy)." For those with rare diseases, conducting research was vital. Larry studies because not everyone understands celiac disease, even his doctors. Despite being a paramedic, Alex knew nothing about bladder cancer so he "had to figure out all the different kinds and what the different stages were and what they meant and how they developed."

Andy's wife is also a Desert Shield/Desert Storm veteran diagnosed with fibromyalgia, so he was familiar with it after helping her research. He did not think that it was possible for him to have it since it is a "white healthcare, female worker's disease. My wife has that." However, after he was diagnosed, "I'm a geek googling through the boards trying to figure out, ok, how do we fix this?" He wanted to know, "What do we do? How do we make this work? Or make it better?" Tom, Jake, and Sam also had support from their wives in conducting research. Jake's wife continues to look up symptoms he mentions and discusses treatment possibilities.

After the diagnosis, the decision to continually investigate their diagnosis varied by participant. Four said they do persist in their research. Jake stated, "Absolutely, have to (for both diagnoses and treatments). I do it to find out as my symptoms, if they change, what caused them to change? I'm always doing that." Both he and Larry share their research with their doctors. Larry believes everyone should do their "own homework." Alex and Andy only look at new and emerging information about their diagnoses. Andy "still subscribe(s) to all the boards and stuff so when new stuff comes up, I try and see where the science is going and what they are trying to do about it." Jim, though collecting boxes full of research binders has not done any lately. Sam stated "Now my liver is my main focus, but the colon, the diarrhea, the fatigue…loss of weight, loss of appetite…it's all a vicious cycle. I don't know what to look up anymore." Matt too has simply given up.

Cause. From the combination of experience and research, each participant believed something physical caused their diseases; equally divided between vaccinations and the environment. Jake was unsure of what caused his issues but

initially blamed deploying to a different part of the world. He also thought perhaps he was emotionally drained, but a required exam by a mental health professional upon returning from deployment, ruled that out. He now "assumes that everything diagnosed (has a) physical" cause. The three Desert Shield/Desert Storm veterans questioned whether or not exposures and vaccines from that operation affected their health.

Shots. While in Saudi Arabia during Desert Shield/Desert Storm, Andy's unit was sent for their vaccinations. They brought their medical records, but the Army medic was not annotating their shots. His lieutenant informed the medic that if the vaccinations were not being put in their medical records then his platoon would leave without them. The medic remained firm, so they backed out of line and returned to their boat. Andy said, "I see all of my friends that were in other platoons were jacked up, and my platoon, everybody is still healthy. So, I'm wondering…" Looking back, he is grateful his lieutenant did not back down.

With all of his diseases, Jim spent seven years researching possible causes. He firmly believes his diagnoses are directly linked to the anthrax vaccine. Several years ago the *Tampa Bay Tribune* (Levesque 2014) featured an article on Jim and the anthrax vaccine. More than 40,000 sick veterans reached out to the author and hundreds of those contacted Jim to talk about their health struggles. Tom and his wife are also convinced that the anthrax vaccine caused his diseases. This is plausible, since he never set foot in Iraq or Afghanistan. After other autoimmunity-linked diagnoses like degenerative disc disease and fatty liver (although not acknowledged by the AARDA), Larry too researched possible causes. He believes the smallpox and anthrax vaccines triggered his autoimmune response.

Exposure. Alex alleged that his diseases were linked to environmental hazards, which was confirmed by his civilian doctors who told him his cancer "is not hereditary we don't believe. We think it was probably some exposure you had." He spoke about experiences that he now questions.

> "There was one building out there, one old house that was supposedly vacant that nobody was in but when we walked out there to search the grounds and patrol out in that area there were, I mean, just all kinds of used needles, syringes and things, medical waste…not to mention the fact that when we went in downtown Fallujah, and we found those couple of places where they had been torturing people…blood all over the walls and walking waist deep in crap and things." Additionally he talked about the burning tanks from his first tour, destroyed with rounds containing depleted uranium rods."

Matt thought his cancer was also linked to environmental hazards in Iraq. His civilian doctor wrote a letter to the VA regarding his cancer and a link to depleted uranium in an attempt to get his disability approved. "I belonged to the Marine Corps for 25, 26 years and I took good care of myself and they took good care of me. And every year they checked me out…to make sure I was in good medical condition. All of a sudden, we go to Iraq two times and I come back and I develop this cancer." He too spoke of the ordnance dropped in Fallujah then "driving around turning up all that dust. And never mind that we were standing in inches of water…"

Peter too strongly believed in an environmental link stating, "Oh, I know it is from the environment over there." He then continued, "It has to be, there's no other…because I did a paper with another Major at the time on environmental health effects or hazards with soldiers deploying to Albania and Kosovo. And I knew the environmental hazards there." He arrived in Afghanistan while working for the Army Environmental Policy Institute. He shared how the Russians, while in Afghanistan, were

continually shot at by snipers. In order to take away this vantage point, they cut down all of the trees in Kabul. This deforestation "changed the whole topography there and enabled the dust storms to come through. Blew the top fertile soil just like it did in the Dust Bowl back in the thirties." There was no getting away from the contaminated sand. He also addressed the burn pits where nonflammable waste burned because of the jet fuel poured over it. The fumes from smoldering garbage exposed the military in both Iraq and Afghanistan to toxic smoke.

Conclusion

In this chapter we met 10 veterans whose very identities shifted through the process of diagnosis (Barnard 2000). Despite variations in their rank, Service, time in the military, number of deployments, and careers, they shared a path which began with a deployment in support of OIF and/or OEF and continued through a diagnosis of autoimmune diseases and/or cancer. From an insider perspective, this crooked path to diagnosis was not in any way surprising. I could type pages about many fellow service members with similar struggles; like the sergeant diagnosed with hemorrhoids who in reality had stage 4 colon cancer. He was 45 years old when he died. Or the lieutenant colonel diagnosed with acid reflux who was actually having a massive heart attack and so on and so forth.

These veteran narratives were shaped by the daily experiences of seeking out a diagnosis while trying to maintain a certain level of normalcy (Kleinman and Kleinman 1991). Although the diagnoses were life changing, for many they provided a sense of relief. As Sam said, "And then now this, so hopefully, I'm not saying 'hopefully this is cancer,' at least it's something." The diagnosis provided them a point from which to

start over as these were not veterans who sat by and waited for medical personnel to bring them answers. Each and every one of them actively researched their symptoms, diagnoses, treatments, and outcomes. They look outside the box for ways in which to heal their bodies. The only thing they all shared was a desire for this dissertation to shed a light on the diseases plaguing veterans.

The experiences of moving through the system, be it military, civilian, or VA gave these veterans a perception of their value – “anchored in and through the body” – based on their treatment throughout (Csordas 2005: and Strathern and Stewart 1998:237). Yet these interviews were told matter-of-factly but with strong feelings about finding a solution. I shared quotes as often as possible so their voices would be heard over my own. I cannot state strongly enough that there was no self-pity in these interviews. Just veterans who spent years struggling to understand their own declining health and who now want to understand the “why” so others may be spared similar futures.

CHAPTER 6:

THE SICK VETERAN

Although my research is focused on the experiences in, through, and around the biological self, (Strathern and Stewart 1998) in this chapter all three of Scheper-Hughes and Lock's (1987) bodies are explored. The remaining interview questions were specifically associated with the social and political bodies; "regulation, surveillance, and control." (Scheper-Hughes and Lock 1987) They were concentrated on the physical, mental, and emotional self and meant to tease out power and resistance existing at multiple levels (Scheper-Hughes and Lock 1987; and Singer and Baer 1995).

Photo Voice

I used the photo voice interview questions to learn how the veterans created new meaning after their diagnoses (Kleinman and Kleinman 1996; and Scheper-Hughes and Lock 1987). I asked each of the participants to spend a few weeks taking photographs of things that define their life now that they are sick. I did not give them additional guidance or place restrictions on what they provided. Some of the participants used photographs they already had, which they believed were better than anything they would take. After analyzing their pictures, I grouped the participants into two categories: the first was "glass half full" and the second was "a different kind of fight."

Glass Half Full

Figure 29

Jake. Jake shared 10 pictures which focused on happiness, escape, and peace. He sent these "intentionally because I am always the eternal optimist … never mind anything I am undergoing or enduring. I am always looking for the happier side of things rather than dwelling on the past." Jake's family provided him unwavering support so it was not surprising that family time dominated his pictures. Figures 29 and 30 were taken on family trips to Tennessee which is "one of our go-to locations that we really enjoy, just to get away … you can forget about things." This allowed them to "not focus on things that bring you down… (but focus) on the here and now… (it) lets you be at peace with yourself." Figure 30 showed the view from the lodge where they stayed, "it was peaceful, serene, calm; so anytime you are thrust into thinking about how bad things truly are you can look up there and see everything is peaceful."

Figure 30

Figure 31

Figure 32

On trips to Michigan to visit family (Figures 31 and 32) were the moments where "instead of worrying about and dreading … who you are, what you are, how you are, you can go there and enjoy family and the moments

and yourself..." The picture of the University of Michigan stadium represented how much he loves sports. "U of M is kind of a mecca of sorts for sport, for football, and also it symbolizes the whole Michigan family" connection. For Jake, it is a happy place.

Figure 33

Figure 34

Also tied to his love of sports was "The Swamp" (Figure 33). He attended the University of Florida and "…even in the hectic-ness of 90,000 people (it) is still a great place to go, there is lots of camaraderie there, there is lots of brotherhood there, win or lose it's great to be a Gator, so that always takes me to my happy place." For Jake's whole family, Cinderella's Castle at The Magic Kingdom (Figure 34) is "the happiest place on earth. There's really nothing more you can say about that." They go as often as they can because "any time day or night and always find something that will…completely take you away from your current state. No matter what mood you are in, good, bad, or otherwise, you can go there – it's the happiest place on earth for a reason."

Figure 35

The next three pictures were of home. Alligators are not only the official mascot of his school but the unofficial mascot of the neighborhood. They live in the lake he drives by each day (Figure 35). "We are always…looking for the alligators because

Figure 36

they are not always there, but when you see it, it's like, oh my goodness, awesome." This is "another way of diverting my attention from anything that could be oppressive to something joyous in my mind." Jake's dog Percy knows when he is in pain or when he is having a bad day (Figure 36). He "always has that simple joy and unconditional love." Figure 37 is his pool where he can "just go out there and let life happen, kind of the no worries Jimmy Buffett-style."

Figure 37

The only "negative" picture was of several cases of beer (Figure 38). Jake said "I'm not marketing or anything" but he chose this picture because it represents what he is no longer able to do. In the past he could drink beer and watch a football game or have a glass of wine with dinner. "Now I can't have a drop without some sort of ill circumstance taking over and just feeling atrociously sick. Those are days gone by." Jake said he could have focused all of his pictures on the negative. "I could have sent pictures of the VA hospital and all of the appointments I have to go to, or I could have sent you a picture of my medicine box which is literally a box because I have a substantial box of them. I could have sent you pictures of my track marks – when I go to (the hospital) for enduring migraines, and … it doesn't resolve, then I have

Figure 38

to go tomorrow and get poked again." He chose "to look at the lighter or happier side of things rather than dwelling on the negative."

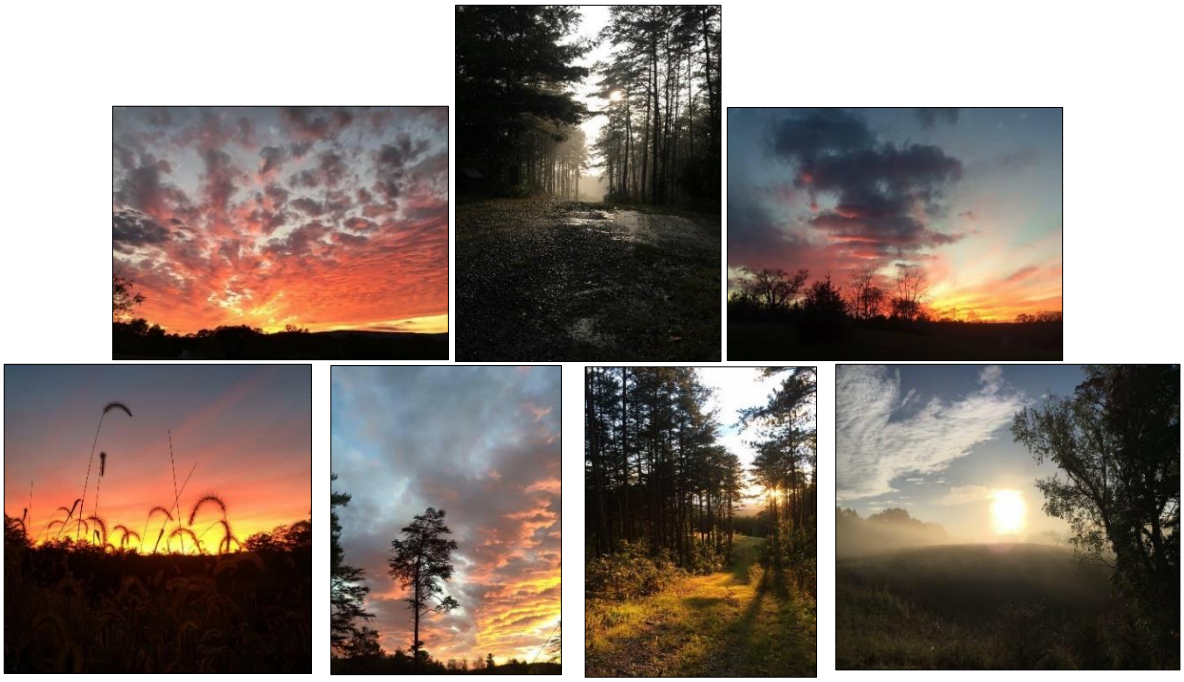

Figure 39

Bob. Bob's focus on beauty carried over to his photo voice pictures (Figure 39). These were images captured on his property and he picked them "for the peace and the serenity. You know…life is easy, life is peaceful and beautiful. … we can make it complicated or we can make it easy. … People take things for granted. … When's the last time you watched the sunset or the sunrise? I just enjoy those things. It's just peaceful."

Figure 40

His love of the flag carried over as well. He shared a picture from his home gym. It is an American flag made by a blacksmith (Figure 40). He had the Marine Corps emblem and the words from Lee Greenwood's

Figure 41

song, “God Bless the USA” added. It contains two things Bob is proudest of, the flag and his Marine Corps service. In the gym he continues to work out, and competes, despite being told he would never lift weights again (Figure 41). For Bob, working out “is what keeps him alive.” It is his pain management – a way to return to where he was physically or even better. He said that he is stronger now than when he was in his twenties.

Figure 42

Figure 43

Bob also has motorcycles which he loves to ride (Figure 42). His motorcycle represents freedom “just hop on your bike and go. You can just go and ride and have a good time.” When he rode out west to visit friends, he stopped at the *Middle East Conflict Memorial* where the names of his friends from the first Gulf War, Iraq, and Afghanistan are engraved (Figure 43).

Andy. Andy also focused on happy times while participating in events through SOF charities, which provided him more unique experiences. For example, he went to Costa Rica for a week to go marlin fishing (Figures 44 and 45). “The guide says, ‘oh Andy, you were in the Navy? Did you ever drive a boat? Get up here and drive!’” So Andy drove the boat at 165 miles per hour. “It was awesome!” He was also able to do

Figure 44

Figure 45

a gator hunt at an event sponsored by the American Legion (Figure 46). "Everybody was just so nice. The boy scouts came out and cooked breakfast for us." He also

Figure 46

Figure 47

Figure 48

shared a picture from the 4th of July when visiting a fellow sailor in Michigan at their lake house. He said, "…they were just so gracious, because they know (his wife) is a vet, a Gulf War vet...they were just so grateful for people that served in the military." (Figure 47)

His last two pictures focused on friends and family. Several years ago he joined an association which participates in a local celebration (Figure 48). At first he did not want to get involved but then heard how much fun it was to participate. They build a float each year and won the contest a few years ago. The association is made up of "a

lot of old vets…and a lot of professional people so it's a good networking opportunity … we've had a pretty good time doing that." His final picture was he and his wife out on an island "that's where we used to go on the weekends." (Figure 49)

Figure 49

A Different Kind of Fight

Larry. Larry took a picture of the wall in his office, which he described as "my room…my little zone, I shut the door and have some peace and quiet." The picture is of what we call in the military, a "me wall." (Figure 50) It is the space where we showcase awards, plaques, and other items gathered during our military career. Larry's "me wall" is a circular display of his time in the Navy. The most important picture to him on the wall is of the USS Theodore Roosevelt on which he deployed in support of OEF, 10 days after 9/11. He said "There was no question of our purpose, our mission, for that deployment for sure." It was "just a great tour – meaningful, a good way to wrap up sea duty, because I didn't really go back to sea after that tour." There were also framed gifts, like the John Paul Jones' quote which defines the ideal naval officer. His President's Certificate of Commissioning rounded out the wall. Larry defined this picture as "a full picture of there and back again in hobbit terms." These prized mementoes hung in his space and remain a reminder of a successful career.

Figure 50

Jim. Jim's pictures were his current reality; still determined, just in a new way. He learned techniques for maintaining an active life from the Mayo Clinic. If he takes his blood thinners faithfully, the fibromyalgia will not kill him but does alter the way he lives. "They were adamant that I need to get back to doing physical activity, my normal routine, and learn how to manage my time and incorporate the proper recovery with my rest and naps." His German Shepherds, or "the girls, have been an essential part of my recovery." (Figure 51) He started with walking a quarter mile after which he struggled to breathe. He worked up to running and walking together. Now he and "the girls" run three miles every day. They "don't want to hear that I am too tired and don't want to go. … I have to say they are a huge part of where I have quality of life today." He said he "can't thank them enough for their dedication to getting the old man out on the road and hitting the pavement."

Figure 51

Figure 52

The second picture is his chair (Figure 52). He calls this picture, "re-plugging in." He uses a cell phone as an analogy to explain this new reality. Unlike his life before, his battery now drains very quickly so he has to rest and recharge in order to continue to the next physical task. Regardless of where he is or what he is doing, when his battery drains he must "take that time and be a little stubborn" and rest. If he does not it will take multiple days to recover. "That was very difficult because as a Marine, (it's) mission first, and the

mission around my house now is chores." So the picture of his chair "is my happy place where I can get my quality of life for the rest of the day to get me through so I can have a great time with the family, with the kids."

Figure 53

Matt. Matt shared two pictures. The first was taken in Iowa of him in the kitchen just before starting chemotherapy. He said "You can see I look pretty gaunt in that picture." His mother-in-law asked him "'how ya feeling?' And I was like, 'I'm doing good!'" (Figure 53) The last picture was with his daughter while visiting her at college. After it was posted on Facebook his daughter messaged him to say that he "looked so good in that picture, so happy and healthy." (Figure 54) Matt feels that he is "back to where I think I am as healthy as a guy can be that's my age and been through everything I've been through."

Figure 54

Tom. Tom's photographs centered around three aspects of his life: loss of memory, who he was before, and his new reality. His loss of memories weighed heavily on him. He said "I really don't remember anything about my childhood. I just really don't have the memory anymore to remember my childhood." He also does not

Figure 55

Figure 56

remember high school (Figure 55). He spoke of going through a box of pictures with his daughters and he was unable to answer any questions about the stories behind them. He remembered his mom telling him a story of what took place but he did not remember the events themselves. Next to his computer screen, he keeps a collage in an attempt to spark his memory (Figure 56). Tom once had a photographic memory and said he was promoted as an enlisted airman because he could quote the page and number of regulations. He is currently in graduate school for the third time in an effort to strengthen his memory. He said he has to re-research what he was taught years ago because he just does not remember anything.

Figure 57

Figure 58

His frustration was evident as he spoke of the things he was no longer able to do. Before getting sick he would “always go camping and do stuff like the outdoor adventure stuff.” (Figure 57) But now “it’s changed, something I had a passion for…we haven’t been...” Something he does not have today is pictures with his younger daughters travelling like he does with his oldest daughter. For example, his family was able to visit Hawaii (Figure 58). His two younger daughters “were born after the war, so that’s a special moment with her

Figure 59

that I didn't get to have with my other kids." He is also unable to go away for the weekend with his wife like they did before despite having a daughter old enough to babysit (Figure 59).

Tom said "I wanted to show what the machine looked like that my life revolved around. Without that machine I would not be here right now. It gives me the UV-B radiation that's needed to keep my immune system okay. It doesn't cure it, it just keeps it at a high enough level that I don't get sick and die." (Figures 60 and 61) This light treatment was previously untested but has proven successful by creating vitamin D in Tom's system. When he first used it he was only able to stand in front of the lights for one and a half minutes leaving his skin blistered. His treatments are currently 10 minutes per session as the required dose of radiation continues to rise. The intensity of the light caused skin cancer so he has had several spots removed.

Figure 60

Figure 61

He is able to spend time outdoors in his "pride and joy," his garden (Figure 62). Friends came over and built a fence around it and his brother rototills it for him each year. "Then I go out there and I do some gardening and I can listen to the birds chirping and it just brings peace to mind." It was obvious that his

Figure 62

Figure 63

Figure 64

family is also his pride and joy. Like the other veterans, Tom's family is the center of his world. He said that Figures 63 and 64 "sums up my life. That's why I live." He shared that dancing with his daughter at her graduation in his uniform shows that "even though everything I've been through you can see I still have pride in what I did."

Peter. Peter's pictures also showed the tension between the old life and new. Figure 65 are the "the pills I take every day. I used to have more because I was taking vitamins." This container of pills adds stress, not just because of the sheer magnitude,

Figure 65

but also because there are medications that need to be taken at different times of day. Some are provided by civilian pharmacies and some through the VA. Additionally, some require refrigeration, some are injected, and some require prior authorization. He said "I hate to say it, the medications rule my life."

Figure 66 shows a closet of filing boxes containing medical documents. Peter keeps meticulous records because his fight with the VA is ongoing; 12 years and counting. Part of that struggle is over getting necessary medical devices. He wears a

Figure 66

back brace and uses a walker and cane at home to get around (Figures 67 and 68). He tried to get a wheelchair approved, but according to VA regulations he is too young despite the need to safely navigate his house as his multiple back issues caused one of his legs to atrophy (Figure 69).

Figure 67

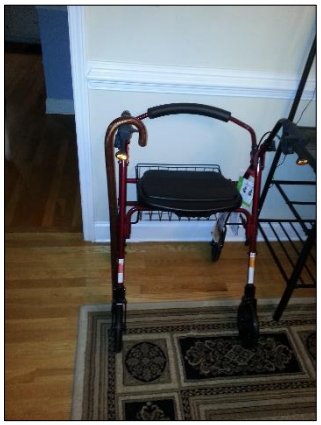

Figure 68

Like Jake and Jim, Peter's dog is an important part of his staying active (Figure 70). He said "she comes over and sits with me and she makes me get up and walk around and do stuff and go outside with her." Like Jake, he appreciates that she always welcomes him when he gets home. "She's the only female that is always, always, always glad to see me when I get home…the tail is wagging back and forth." He lives on a small lake and is able to go fishing every day (Figure 71). "I don't have any music or anything I just listen to nature because we got all kinds of stuff…It's very relaxing. … I sit out there and it

Figure 69

gives you a lot of time to think. It relaxes me because I'm thinking about catching a fish."

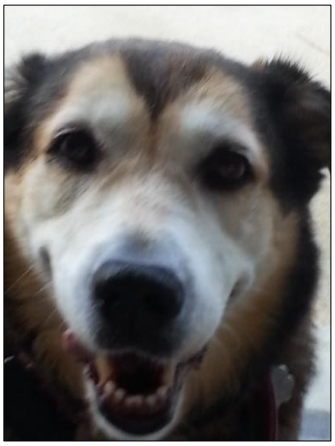

Figure 70

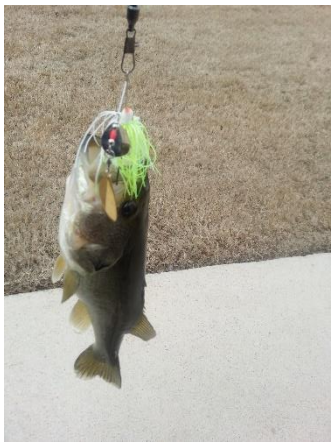

Figure 71

The New Normal

The lives of these participants were significantly altered yet they continued to move forward in their new normal. Throughout these interviews a number of themes emerged some of which were in response to a specific question and some were addressed without prompting. It was clear that these veterans were well researched and very knowledgeable not only about their health challenges but also about working through the system. They were all passionate about the struggle veterans currently face with autoimmune diseases and cancer.

The Bureaucracy and …

It is hard to understand traversing a bureaucracy until you have moved within such a monolith. Larry's description was succinct in that "… its main priority in life is its existence, the propagation of the bureaucracy is its main endeavor" he also stated that it is "up in arms when it's threatened with reductions, loss of budget." In the military we call this "fighting over rice bowls." Larry's assessment highlights these competing resources and political tensions of the critical medical anthropology critique (Singer and Baer 1995:5-6).

The veterans were well aware of their struggle against, within, and through the system; no doubt because they existed within the DOD for most of their careers. The

participants engaged in a discussion of these bureaucracies often without prodding. They mentioned several within the U.S. government but spoke most often about the VA. Perhaps this is because the VA exerts tangible control over the veterans while bureaucracies like the DOD exerts intangible control; for example the specter of military culture. Regardless, when it comes to the transition from health to sickness, these institutions bring to bear enormous power over the veteran's transition due to medical care, benefits, hospitals, and doctors.

...**Medical Care.** As their health declined, eight of the participants were still on active duty and two were retired, which created a military-VA-civilian medical relationship. The veterans were unique in that all but one had medical options during all or part of their health transition. The retirees were able to see civilian doctors through Tricare insurance and through federal employee healthcare benefits.

Military. My previous chapter established that there were failures within the military medical system. The veterans overall did not have good experiences while on active duty. After Peter's realization that they did not treat his severe osteoporosis, he found follow-on civilian doctors far more forthcoming. Jake dealt with the nonstop appointments in the regular Air Force medical system and was only diagnosed when he moved to a specialty clinic. However, Larry was not as fortunate. He was at Bethesda Naval Hospital "where I was doing my specialty care" for severe stomach and intestine pain. It took years of testing before he was diagnosed. Jim was misdiagnosed in military medical and almost died. Bob felt fortunate to be stationed in Georgia because having a small medical facility, he was "hooked up with some good specialists" in town.

Civilian. Overall, despite some failures, the civilian medical system received the best remarks. Peter said he could walk into a civilian doctor's office and after one exam receive a diagnosis. In fact, an orthopedic surgeon told him about his spinal stenosis after one x-ray, compared to the years it took to get information from the Army regarding his back. Matt was living in Iowa with his wife while she worked for the federal government. He saw civilian doctors and believed he got "good medical care. Best place I've been to for medical care. … They're all young guys, young women…graduates of the most recent (medical classes). And they've got good mentors." Alex too found civilian care outstanding. "I can honestly say that my local urologist that did all the surgery …for the bladder cancer and all was…has been a tremendous help."

VA. The medical care provided by the VA received mixed reviews by the veterans. Alex's oncologist as well as the other care he received "has been extraordinary. It has been really, really good. They have been very accommodating and as far as I can tell, as far as I know, just really provided excellent treatment." Bob is also in the VA system and had no complaints with the doctors he dealt with locally. In fact, he had a great deal of praise for them and had not experienced the issues that many other veterans have.

Larry continues to use the VA, along with his civilian care, to force them to look at the linkage between his autoimmune disease and his other issues he believes are "linked to immune system problems" and the vaccinations he received. He expressed frustration that VA doctors did not always have access to the right medical records, or have in the past not even bothered to look at them. Larry did acknowledge that the VA

is fixing what is broken. Although primarily going to civilian doctors, Jake had good experiences at the VA. He, in fact, asked the VA doctors if it was better to be seen at their clinics or by his civilian doctors. They told him to "use the civilian folks downtown." This advice was puzzling and as he said it "doesn't give you a vote of confidence in the VA system at all."

Peter believed that the "VA is totally incompetent." Jim felt "fortunate" that he has Tricare and his civilian primary care doctor who "has been the go to person for me, to get me to the specialists and things that I needed." In fact he is, "scared to think that if I even had to use the VA system; just the short periods and appointments I had to go through the VA to get my claim was frustrating enough."

Sam was the one forced to rely solely on the VA. He said, "I don't know what to expect with the VA anymore." He was particularly frustrated with them during his path to a Crohn's diagnosis. At one point, they asked him if he had abdominal issues in Iraq. "I'm like I don't know. Hey look, a mortar just landed 150 yards away. Do I have a stomachache? I don't know!" He saw a nurse practitioner through the VA for eight years. He stopped going because for five years she focused on his liver and said, "You have fatty liver tissue disease, you have an extremely enlarged liver, and then nothing else was done." Despite this, he did say that his VA was getting better. However, once his liver cancer was diagnosed, he sought out civilian cancer specialists.

...**Medication.** Going back decades, there is an across-the-Services joke about receiving 800 milligrams of Motrin for everything from a scratch to an amputation. This trend continues, but with narcotic pain relievers. In today's opioid-addicted society it was alarming to hear from the veterans how easily they were prescribed large quantities

of medicine. Peter's pill box is a great example of what these veterans all shared. Larry felt the "frustration factor (in) nobody understanding what it's like to live with Celiac… (and) doctors not understanding the impact on a person with chronic pain." He continued to say there is a "complete unpreparedness of your normal VA doctor to deal with the consequences of chronic pain. They don't understand it so they prescribe opioids, when that is absolutely not what should be prescribed." He acknowledged that it is done less often today, but the non-specialist primary care doctors "are the first ones…to whip out the computer and prescribe a narcotic pain reliever."

Sam too was, "pumped…with a lot of pain medication" and began to get addicted, while Bob was "on every medication under the sun. It was disgusting." After his undifferentiated connective tissue disease, Jim said, "…they started medicating me…I can't even remember the medications." Jake said "sooner or later your life becomes inundated with pills or doctors or both." Because they agreed this was unacceptable; Bob, Sam, and Jim all weaned themselves off their prescription medication. Bob said, "I don't take anything now. In 2011 is when I…needed to stop sitting on the sidelines." In addition to working out, he eats clean and will not stay with a doctor who pushes prescriptions.

The ease of getting alternative treatment was locally-specific. Bob helped bring new treatments to his VA like acupuncture and is now working to get yoga therapy approved. Conversely, Jake found his VA to be "incredibly hesitant" to provide new treatments. For example, to get fibromyalgia and migraine treatments "was a six month fight with them (the VA) to get something issued or allow me to use (a device until)

finally they relented." Tom got his UV-B radiation machine approved through Tricare; he believes this was possible because "there's no precedent" for treating his illness.

...**VA Administrative Side.** The administrative side of the VA received the harshest criticism. Larry called it "that horrible side of the VA medical system." He criticized the online *myhealthevet.va.gov.* It is through this system that veterans can refill prescriptions, message their doctor, and see upcoming appointments. He spoke of pull down menus that do not list the doctor you need to see or speak with, and when you do message them they take a week to get back to you. Unfortunately, the pull down menu is the only way to message a specific doctor. Larry said "The care is good that I'm getting, when I need it, but it's only because I'm so persistent with the administrative side of that." He also said the *myhealthevet.va.gov* "is a perplexing system at so many levels and so many passwords that they are really slow to respond and it's frustrating." If you go to someone at the VA and ask them to help you with the website, all they do is suggest the next class. He feels for the older veterans who are not technologically savvy.

He also used the Veterans Choice Program, when available. A veteran is eligible for this program if the VA is unable to provide care within 30 days, their clinics are more than 40 miles away from the veteran's home, or there is some difficulty in the veteran going to the closest VA facility (Department of Veterans Affairs 2018). However, he appreciates the program as long as the clerical staff members remember to click on the box, so he does not get charged for the doctor's visit and bring about another administrative fight. I also had this issue and received a bill for $450. Fortunately, the doctor's office rebilled the VA so that I did not have to fight them.

Tom struggles with the administrative side as well. His back problems constitute a rated disability, which means the VA acknowledged they are linked to his service. Yet, if his VA doctor says he needs physical therapy for a set period of time, the administrative offices are able to override the doctor and approve therapy for a much shorter period of time. Tom can either spend the time fighting the VA to get it approved, which requires another doctor's request, or pay the $12 copay and do therapy through Tricare. He said that if you call the VA with a question, "you talk to whoever was willing to take the job for the cheapest price and they are not smart enough to refer you to the right person, so it's the same old dilemma with the VA hospital issue."

As discussed, Tom must use his UV-B machine every other day in order to stay alive. He tried to figure out a way to use a similar machine in other VA hospitals around the country or even in Italy, where his in-laws live, so he could travel. After a lengthy process trying to get an answer, he learned there is a program for him to be seen in hospitals outside the U.S. but not inside the U.S. He said "You shouldn't have to hire attorneys to represent us to find ways to be taken care of."

Andy, after his fibromyalgia diagnosis, was told to see a rheumatologist. When the VA learned he was not 55, they told him he was not eligible for this specialist. Fortunately, he was able to see a civilian doctor through Tricare. He said that this "is kind of concerning in the long run because you've got all these people with autoimmune diseases, now they can't get access to a rheumatologist who is the only one to really treat those." If they do not have other insurance options, they cannot get treatment. These age restrictions are not just a barrier with the VA. Jake, like me, had shingles multiple times. The vaccination is only approved through the CDC for Americans over

55. There is no way possible to get this vaccination if you are under 55 years old. With so many combat veterans getting shingles multiple times, this is problematic.

...**VA Benefits.** The VA benefits process was a conundrum for all of these veterans. Tom responded to a letter asking if he had skin issues and was awarded 100 percent disability without filing a claim. Yet, although Tricare provided him a UV-B machine so he did not have to drive three hours for treatment, they only covered 80 percent. He paid 20 percent out-of-pocket as well as for maintenance and the extra electricity it takes to run the machine. Despite the link to his service overseas, the VA denied his request for reimbursement.

Jim requested a reevaluation after receiving additional diagnoses, which took two years to be approved. Part of the back-and-forth included resubmissions in order to ensure that he "finally got the paperwork with the right verbiage and that was the frustrating part." For Larry, his frustration came from a lack of understanding. He was given a disability rating for sinus infections and degenerative disc disease. He said they acknowledged his celiac disease is connected to his service, but because it is a "disability you can mitigate by not eating wheat" he was given zero percent. He said that it "is seriously frustrating. The doctors do not understand what it is to be told that a part of your life is gone forever. 'Sorry about that, see you later.'"

Matt submitted a package for his non-Hodgkin's lymphoma, which included a letter of acknowledgement from his civilian cancer doctors that it was tied to exposure from depleted uranium. They denied his cancer as a disability related to service in Iraq but did approve him for 10 percent because he was stationed at Camp Lejeune during

the water contamination scandal. Thus far, Peter's 12-year fight with the VA has included being sent to a gynecologist for a disability-related medical examination.

Barriers

Each of the veterans were asked to talk about the biggest barrier in getting care. For Tom is was travelling distance. His primary care doctor at the VA, which he could see at no charge was 30 miles away, but in Washington, D.C. traffic that could take hours. He chooses to see a civilian doctor through Tricare, even with the copay. The civilian doctor is less than five miles from his home "So what do you do? You suck it up and you do what you have to do."

Jake said it "is what appears to be a lack of awareness or a lack of education on vet's issues/syndromes so they can efficiently diagnose you. You know they won't come out and say 'I haven't seen this before' or 'I've seen it and I just don't know what it is, so let's find someone who can do it.'" Andy also saw the lack of being "receptive to a lot of this. They are still 10 years behind, as we all know, so most of my care I got outside the military."

Jim believes "It's admittance. The biggest barrier is DOD would have to admit that based on the research that we did …that they added an adjuvant to the vaccination that was not FDA approved and that made it… experimental. And that would mean they violated the law." Larry also pointed to the lack of acknowledgement by the VA of a link between the vaccines and autoimmune diseases; "when I ask what studies are being done nobody has a clue."

Support

For Themselves. The greatest support these veterans received was without a doubt from their families. Jake said, “if we’re not talking professionally, I’d say definitely my family. I mean, I can chat with them and usually they won’t judge me. Sometimes they’ll wonder is this really going on, but they still listen with a caring shoulder.” Additionally Alex, Matt, Tom, and Sam credited the support they got from their families. Sam and Jim also mentioned how important friends were in supporting them. Jim said, “So my good friend that I was working with, he set up meetings with all these specialists and he went to my appointments with me. He went to every single one of them…and said, look we’ve got to get to the bottom of this…he’s got no quality of life.”

For Others. All of the participants knew other sick veterans and despite their own health struggles, they found ways to help them. Jim worked with an organization to try and find answers. Bob helped prepare recruits for boot camp. The other participants spoke of guiding other veterans through the VA process. Jake, Larry, and Peter all spoke of helping new veterans navigate the benefits systems. In fact, Andy chose to become a lawyer in order to help other veterans fight the system. He said he was better prepared by helping his wife, a Gulf War veteran, which “set me up for success when I medically retired and had to deal with all of mine.”

Veteran Organizations. Hundreds of organizations exist to support veterans. Despite this, Jake, Alex, Jim, and Larry did not belong to any of them. Matt received help from the Organization of the Purple Heart when he was fighting the VA, and Sam spent time with veterans at the American Legion. Andy took advantage of trips sponsored by SOF non-profits. He also talked about participating in these organizations

as a new rite of passage. As a veteran you once spent time with active guys and "you never think of going to the Legion…now you've crossed that bridge so you're on the other side of the fence now where it's kind of nice talking with the guys because it's the camaraderie of being in the military."

Stigma

Despite helping other veterans navigate the bureaucracy, they were hesitant to discuss their own illness; this was telling. This careful navigation showed the concern over how veteran illness is received and a fear of stigmatization. They all approached this subject with other combat veterans in similar ways.

Do you talk to other veterans? Jake does speak to other veterans about his health issues.

> "Yes. (It's) part of my therapy, because once you start talking about it you realize that you are not alone because you often think that going through this you are walking this path alone, but come to find out that the folks on your left and right are probably undergoing some similar issues or illnesses as you. A lot of commonalities out there. So, yes, it absolutely helps for therapy."

In contrast to Kilshaw's statement about veterans going to meetings to create their illness narrative, Jake's statement verifies that these veterans find solidarity with others when they know they are not alone. Despite talking to others, he was still careful in how he approached the subject. "At work we have super type-A folks and … you have to walk that fine line between, am I complaining…will they receive it? Fortunately, it's been good. Everyone I talk to, they receive it well…you also have to feel out who you can and can't discuss things with because there are folks out there that 'suck it up,' you know, 'suck it up and move on' sort of thing."

Jim said, “I know plenty of sick veterans. Yes I do. And unfortunately more than I care to even think that we should know out there.” He speaks to others but tempers what he says because, “it is a difficult subject to approach (with) certain veterans. I’ll talk to anybody because I could care less. The hard part is when you tell them your story and based on the research that you’ve done why you believe you are sick from the vaccine… it’s almost like a conspiracy.” He broached the subject carefully: “Very much so. I temper what I say, little bits and pieces and ask questions like, “what are your health issues? Can you give me an example?” He also said he would speak more openly with a veteran he knew. If he does not know someone well, he steers them toward research. “I don’t just come out and say, hey this is my thoughts; what I do is, I find out what’s wrong with them, find out what their diagnosis is and talk to the duty experts that have done the research on sick veterans and ask them about doing this test or that test.”

Larry said “I try not to complain… because some vets came back in body bags. I don’t mind talking about it. Every vet that I know of that got the smallpox/anthrax series I ask them because I am curious if they’ve suffered any ill effects, and I find it relatively a third of the ones I talk to are willing to admit that they’ve suffered some kind of a lingering condition from it.” Andy spoke to veterans who have the same issues but “Usually, you have to feel them out first. Some people don’t believe that fibromyalgia is a real thing so I usually bring it up casually in conversation first to see where they go with it.” Peter spent time reading and responding in online forums and said, “I go in there as often as I can and try and help people that are going through the same things I’m going through and the same problems that I’m having.”

Not all of the participants discussed their health issues with other veterans. Alex for example said, “Not a lot. I’ve had a few…just a couple of conversations…maybe with someone I know.” Bob said, “You know, for the most part when I was on active duty, I’ve always been a person that keeps to himself. It’s like, my life is my life, it’s nobody’s business…so people like that or you know, like people that I’m close with I’m more apt to share, you know, information and stuff.” Matt simply said, “Nope. No.”

Suck it up. Members of the military generally fight against stigma by “sucking it up,” so one does not appear “broken.” Although only two of the veterans actually used the phrase “suck it up,” the sentiment was certainly present throughout the interviews. Jake talked about the “suck it up” mentality at work regarding illness, and Sam said, “I don’t know what else to do -- I’m just gonna basically suck up the pain” when he spoke of his current diagnoses. He also talked about being broken when he was forced out of the Marine Corps.

Andy said that, “I just toughed it out” instead of seeing a doctor when his health failed. Jim also expressed this when he said, “look at how my health was before that deployment and then during the second deployment how there were a lot more struggles than I care to recognize, being a Marine.” Bob believed showing others how he overcame his health challenges is setting a good example so he “dedicates hours upon hours upon hours every day in the gym to stay physically fit.” When the doctors told him his body pain came from working out he said, “No, working out is what keeps me alive every day, because my body is in so much pain that’s what…that’s my pain management.”

Within the System

Trust is a 4-Letter Word. Overwhelmingly, the participants did not trust the government to do right by veterans and tell the truth about combat-related diseases. Two of the veterans hedged their answers, neither agreeing nor disagreeing. Jake said, "I don't know if trust is the word. I rely on them to do so. … I think they do the best they can do given the skillsets that they have." Larry also said he did not know. He believed that based "on the nature of the bureaucracy (it) is very impersonal and it isn't always traceable to a single person or a single person's judgments or ethics."

Tom took umbrage with the VA approving him for 100 percent disability after he responded to a letter about skin issues, but not admitting what he was exposed to or why he was dealing with all of his very serious health issues. Larry tried to bring up a link between the vaccines and his health but he believed the doctors "are coached to say, it's not our job to assess linkage to any condition. We're here to treat you so we really can't get into that." He pointed out that they cannot commit the government for anything that could cost money.

When Jim was on active duty he emailed the Commandant of the Marine Corps to ask questions about the anthrax vaccine. He received a response promising that he would "personally assign someone to reach out to me." However, "the Sergeant Majors' mafia reached out and began to interrogate" instead. From that point, Jim's once stellar career was called into question. "I was almost blackballed … they knew I was going to be medically retired, there was no more career, it was done and over with, so how can we put more pressure on him to stop asking questions?" His career spanned 27 years and "Instead of asking, 'hey this is a man who made it to sergeant major, that evidently

had to do something right to get promoted, to get to that position,' and say 'hey, there might be something behind what he is asking.'"

There was consensus regarding getting answers about the cause of these diseases in a way that mirrored Agent Orange and GWS. Larry said that when it comes to Agent Orange "what's most concerning about that is by the time they have some actual answers …they're all dying, there's been no effort to change their quality of life or address their disability income for all those years that it could have been done. I understand that research takes time, but when they're dead it really doesn't help."

Matt, agreed in saying: "I don't think enough people have died…enough people are sick. Just like … the guys with Agent Orange. Nobody's made the connection between environmental exposures and Iraq and listed them, 'ok, here's what we know. Here's the toxins you were exposed to. And here are the diseases.'" Tom also pointed to the long wait for Agent Orange to be acknowledged: "That's probably what's going to happen; when most of us are dead and they don't have to pay for that many people any more, then they will come out and admit to what happened. And it's a shame."

These sentiments are given credibility when VA personnel tell veterans, as they did Jim, the VA

> "won't even entertain (admitting to Iraq and Afghanistan exposures) until they are done taking care of the Vietnam veterans and the Agent Orange issue. That's somebody who knows the system well, for them to say…and of course they will never say it on record. But they will tell it to you to your face behind closed doors, but will deny it was ever said when you walk out that door."

Larry: "Again I think it's the psychology of the bureaucracy – if it came out that there was hard research to support that kind of linkage, the VA will have to spend an awful lot of money for many, many veterans to give disability payments, and somebody

somewhere is thinking about how much that's gonna cost overall compared to the larger VA budget. Alex agreed: "(the VA) motivation to acknowledge any type of impairment in a service member… is tied to cost. And for them to acknowledge that there are…direct links to being in the combat zones and direct links to these injuries and illnesses that have come out of there is in my mind is directly tied to cost."

Resistance. Resistance against the powerful bureaucracies was evident throughout this research; both overt and covert. From the moment they were diagnosed, these veterans began to research, to ask questions, and to push back when what they were told did not make sense. They weaned themselves off medications and found alternative ways to deal with their pain. They did not give up on getting exercise, getting outdoors, having a life. For Tom, fighting back took the form of a third Master's degree and finding ways to retrain his memory. Bob continues to lift weights without apology and enter competitions. Both he and Jake refuse to become pessimists because of failing health. Peter, Andy, and Larry fight by helping other veterans navigate the VA system so they have someone supporting them along the way.

For Jim, resistance took the shape of forming a group to get answers and provide support, but he learned that momentum was hard to maintain because "you keep fighting and fighting and fighting and when you try every avenue that you can possibly think of to gain answers you find out that … you're just spinning your wheels and you're not going anywhere. It can consume … your life and your time, every waking minute that you have … is spent trying to find answers and it becomes overwhelming and you just fizzle out."

The Final Question

Before I ended the interviews with these veterans I asked each of them if their illness struggle changed their minds about their service to this country. Did they regret going into the military now that they are sick? Not one of the participants said they would change their decision to join. Jake said, “I don’t think any person that you talk with will say that they regret it. They just regret what’s going on now.” Alex would join again even if he knew then about his cancer and Castleman diagnoses. Jim believed, “I’m sure that is probably shocking for most people to hear me say no, because I don’t’ think I would ever change.” Even though he, believing the vaccine made him sick, recognized he “would (be playing) Russian roulette.” Bob would deploy tomorrow if the Marine Corps asked him.

Larry said “yes, in a way.” He might question why the United States would give service members vaccinations that are not safe but “you have to balance that against the idea of being a public servant, which isn’t all about you.” Matt admitted it changed his mind about how he feels about the government, but not about the Marine Corps. The only change Peter would make is which Service to join. Andy said his “perceptions have definitely changed” but “I don’t regret my service at all.” Tom summed it up, “I would do it all again. I wrote a check to the military that they could cash for up to my life, and this is cashing the check for my life.”

Conclusion

Can doctors who do not understand their patient’s illness experience really provide meaningful help? I am confident now that this is not the case. I hope this research begins a dialogue about understanding the lived experience of veteran illness

(Thompson et al. 2008). I trust that the tone I set showed the matter-of-fact way these men spoke of their struggles. Despite all they deal with, I know that not one of them would place their diagnoses in a higher ranked order than those who were grievously wounded in combat or those who made the ultimate sacrifice.

They each stated that by sharing they wanted to bring about change for the collective, and bring those struggling together in mutual support (Mizock, Russinova, and Shani 2014; and Oliffe and Bottorff 2007). These men do have real things at risk, like Tom who was forced to quit his job because he had too many doctors' appointments. Because of these risks, these men reached out to others, albeit carefully, to ensure the sick are being helped.

Their lived experience of illness was shaped by doctors' appointments, diagnoses, limitations, treatment, medication and questions. However, despite this the photo methods showed men who refused to give in and quit; who created new meaning focused on peace, serenity, happiness, family, fun, and a new definition of health. They dealt with their new identities while remaining fiercely proud of their past. Their dedication to service and other sick veterans showed their character and made me very proud to be counted among their ranks.

CHAPTER 7

LESSONS LEARNED

Within the military, there are organizations dedicated to collecting data regarding all aspects, from hardware and software to people and tactics. The Joint Chiefs of Staff website defines their purpose as to “enhance joint force readiness and effectiveness by contributing to improvements in doctrine, organization, training, materiel, leadership and education, personnel, facilities, and policy.” (Joint Chiefs of Staff 2018) We call this gathering “lessons learned.” However, a lesson can only be learned if the data collected is used in a thoughtful way to make important changes to how business is conducted. I do not expect this document, focused on the experiences of 10 veterans, to completely revamp the way the United States Government deals with the issue of exposure-related disease. I do hope it begins a dialogue and brings awareness.

Recommendations

Although not an interview question, the participants provided a number of recommendations to go along with my own findings. These were thoughtful lessons learned through non-stop battles which began the first day symptoms appeared. Each of them originated in the political body (Scheper-Hughes and Lock 1987) while moving within the macro-social level (Singer and Baer 1995; and Baer, Singer, and Johnsen 1986). Foremost in the minds of these veterans was the VA, whether discussing medical care or disability compensation. Despite improvements made, the VA remains

broken, so it was not surprising that the majority of recommendations were directed toward this institution.

Transition Assistance Programs

It is common knowledge that the transition program, required of all active duty when they retire, is woefully inadequate. In fact, one retired admiral created a program to address this gap and supplement the DOD's offerings (Ruehlin Associates 2018). My participants stated they needed to be better prepared while transitioning from their service to deal with the VA. They were unaware of many of the available benefits or how to traverse the VA system to receive care. This is why three of the participants actively seek out other veterans in order to educate them about maneuvering around the VA.

Medical Education

Another recommendation was the requirement for the VA and military medical staff to be educated regarding combat-specific diseases. I was shocked by the number of years in which these veterans suffered chronic pain as they continued to return to the doctor only to be told nothing was wrong or be misdiagnosed. Additionally, they were easily prescribed large amounts of medication, including narcotics. There was overall consensus that lack of familiarity with combat exposures was partly to blame for the length of time to get diagnosed.

Seven of the 10 veterans were still associated with the military when they became sick, yet it took a significant amount of time for half of them to get a diagnosis. This meant that health and sickness lived side-by-side for these veterans, and their lives were characterized by ongoing doctor's appointments, misdiagnoses, and frustration

(Singer and Baer 1995). One of my initial assumptions was that sick veterans spent time proving they were sick, which in turn meant they had less time to get better. Although a correct assumption, I was surprised to learn how long it took to convince their doctors something was wrong.

Streamline and Simplify

My participants also stated that VA programs and systems need to be streamlined and made user-friendly. It engenders frustration to remain on hold for long periods of time only to be transferred to a voicemail box where no one calls back. Or to attempt to locate information on websites like *myhealthevet.gov* and *ebenefits.gov*, which are electronic labyrinths. The veterans believed that DOD and the VA must also have a means to communicate across their closed systems. As these men can attest, despite billions of tax dollars spent, DOD systems cannot speak across the Services, let alone across government departments. The participants pointed out that once retired they had to go to a new set of doctors and start over convincing them they were sick. This could be mitigated by military medical records automatically transferring to the VA.

Seeking Answers

More than anything else, these participants wanted more research, without agenda. They especially wanted the connection between exposures and/or vaccinations and the autoimmune diseases and cancers examined. Understanding the prohibitive cost of all sick veterans requesting disability, it seemed these men were more interested in getting answers in order to keep the next generation of veterans from the same fate.

A Role for Anthropology

I too want more research to find the cause of these diseases, be they cancer or autoimmune. If I am truly honest, I remain bitter that I was not able to stay in for 20 years in order to retire. The reality is that the military is hemorrhaging willing and previously able-bodied men and women with combat experience. There are others like me who did not want to be discharged and were willing to deploy again. The military cannot afford to have this as retention remains a focus. If the cause of these diseases is something we can control, like vaccines and/or burn pits, then changes must be made.

I believe my research is just the beginning of truly understanding the lived experience of veteran illness. There is so much more to learn, so many more questions to ask. Additional studies are needed to examine the differences for reservists who deployed but do not have the same opportunities for healthcare that retirees have through Tricare. Because most of my participants had Tricare, the reality for non-retired veterans may be much worse. The experience of female veterans may also provide a varied perspective. As we become a bigger population within the combat veteran ranks, our participation in research broadens the overall understanding, while bearing in mind that our experiences may not be different than our male counterparts.

Anthropologists must play a role in addressing the qualitative research gaps. Gusterson's (2003 and 2007) suggestion that military anthropology should focus on the study of Service cultures and policies is not only a place where the two entities could exist amicably, but it is an important piece of addressing veteran illnesses. As a combat veteran, I have pride in my service to this country. Having said that, I chose not to

return to work for the military in any anthropologist/researcher role. I have very strong thoughts on the military "doing culture." As an outspoken critic of faulty culture-related doctrine and Female Engagement Teams, I tried in a variety of ways to bring awareness to the harm they were causing in my time there. Having done so, I was patronized, criticized, accused of disrespecting those killed in combat, and excoriated by my leadership. When other anthropologist discuss this possibility, I am always honest about the struggle.

It is for this reason, I stake my position with that of Gusterson (2003 and 2007) in continuing to study military culture and policy in the fight to support veterans with combat-related disease. I believe my unique position as a combat veteran and an anthropologist gives me a perspective unlike those of my non-veteran colleagues. I embrace this positionality and do not hide the practical ways in which it informs my research. As stated, I would not even be aware of the diseases plaguing my fellow combat veterans if I was not diagnosed a decade ago.

Medical anthropologists are especially needed to move their research beyond PTSD and TBI to examine broader veteran diagnoses. Unlike in Kilshaw's research, I did not find the same condescending, even disdainful, tone in more recent works. Kilshaw's substantial participation in the post-Gulf War debate had consequences not only for British veterans but also those in the United States. Her treatment of veterans followed in the same vein as those who believe the military ranks to be filled with uneducated men and women.

The Illness Narrative

Through Photo Methods

The illness narrative provided a medium with which to understand how these veterans negotiated the lived experience of illness. This narrative is a living, breathing thing – expanding, contracting, and morphing as the veterans make sense of their experience and as new diagnoses emerge. When shared, they can also be highly redacted – depending on the audience. Additionally, those shared within this research were bounded both by space and time. In truth, only the veterans themselves know how much fact or fiction their illness narratives contained (Bury 2001, Hyden 1997, Kilshaw 2004, Kirmayer 1992, and Mattingly 2008). I suggest this while acknowledging that, in the past, I told many varied versions of my own narrative.

The use of photo methods provided rich data but was not without complications. Visual methods allowed a fascinating glimpse into these veterans' experiences. Because the participants controlled more of the interview process, I believed them to be empowered. However, I could not help but wonder if the photographic piece created some anxiety. I never considered the concern Jake raised, about whether his children would be able to "Google" this research in the future and read about his struggles. He did not want them to remember him for his health issues. As stated, I had strong relationships with all but three participants. I do not share this to cause future researchers to shy away from using visual methods. I do suggest that every effort is made to protect your participants, while understanding the military veteran's fear of stigmatization for being weak.

The strength in using photo methods was creating an illness narrative both orally and visually. As discussed, each veteran's photographs had a theme that ran from before through after their biographical disruption (Bury 1982) showing what mattered most. All of the veterans, through the pictures they shared, were easily placed in one of two categories: one, a glass half full and two, a different kind of fight. There was one commonality among the participant's photographs, a thing or place that made them happy or provided peace. Through their photographs we were able to see their world, through their eyes, from their perspective. Although just a glimpse, I believe this to be very powerful.

Through the Digital Story

As a means to move from data collected to lessons learned, I created a digital story. I utilized photographs and quotes from the participants in order to highlight their illness experiences. Often it is difficult to understand an issue when it has no face, no story. My goal for this short video is to provide a glimpse into the daily struggle of millions of veterans (if we include Desert Shield/Desert Storm). I intend it to be an educational tool pulling back the curtain on this issue for a wide-ranging audience (Charmaz and Rosenfeld 2006; Goffman 1959; and Oliffe and Bottorff 2007). The digital story can be found at: https://youtu.be/ZPA8XNfIqPQ.

Conclusion

Veteran Transition

The transition from healthy to sick for these veterans was shaped predominately by the structural, which exerted incredible control over the biological self (Csordas 2005). They were all outspoken critics of the multiple institutions they worked in and

through; the VA, DOD, and civilian medical organizations. They did point out positives, but usually with a caveat; for example, receiving good care through the VA as long as they were their own aggressive advocate. It was interesting to note that the veterans, armed with an overview of my research, continually answered interview questions without my having to ask. This did not mean they all had the same answer, but that the experiences were shaped from many of the same systemic issues.

After I conducted the interviews I learned that one of my initial assumptions was wrong. I believed there were varying degrees of understanding when it came to veteran illness issues. However I found that, at least within this population, they were a well-researched and extremely knowledgeable group, not only about their diagnoses but also about probable causes and treatments. They looked for alternative ways to deal with their illnesses and avoid medications. They looked at non-medical forms of treatment like supplements, diet, exercise, massage and yoga.

These veterans also understood about the effects of Agent Orange and GWS. Half of the participants referred to Vietnam veterans in terms of getting help, answers, and acknowledgment. Despite this, there was overall limited involvement in veteran organizations. Even if they belonged to veterans' groups, they did not seem to be as active as generations past. Like Vietnam and Desert Shield/Desert Storm veterans, they shared an unwavering view about what caused their diseases. Whether vaccinations or environmental exposures, they all believed the cause was physical.

Military Culture

Bootcamp is a rite of passage where one is born into a Service's culture. Participants spoke of the need to suck it up, or at the very least, mask what they were

dealing with, and of cautiously discussing their illness experience with other veterans. If the discussion was not well received, they backed away from the conversation. This showed the concern for being stigmatized as broken, despite being a veteran.

Backing away from this discussion topic did not mean these men were defeated. They resisted through a variety of ways and refused to allow their diseases to define them. This was despite the daily fight against their own broken bodies and the various institutions which compounded the struggle. In thinking about this research, I in some ways reproduced the “broken” identity for these veterans by focusing on their autoimmune diseases and/or cancer, and I wonder if that is one reason I struggled to get participants.

Final Thoughts

So how do veterans of OEF and OIF negotiate the transition from healthy warriors to sick veterans struggling with multiple illnesses? In the simplest of terms, with incredible tenacity and strength. The broader answer however, was much more nuanced and complex. These participants lived at the intersection of disease and illness; which also contained elusive diagnoses and a fight for answers.

Without a doubt, quantitative and clinical research provides important data from which to learn about diseases and their effects on the body. Yet we cannot forget the importance of learning, through qualitative methods, what it means to live with this disease. We can say that a veteran has an autoimmune disease and cancer, but how much more important is it to enhance this knowledge with the realization that he cannot be separated from his UV-B machine because he would die. Although veterans overall are uncomfortable speaking about living with disease, we must continue to push for

qualitative research. Listening is not only educational for researchers, but may also be healing for veterans.

I have incredible pride to be counted among these men. Tom spoke for all of the participants when he stated that “he wrote a check to the military that they could cash for up to his life and (his diseases are) cashing the check for his life.” I was not surprised that each of them would serve again despite what they know now. I stand with them to carve out a space within the ranks of all veterans. A space defined by disease but not failure. As I complete this research, certain words come to mind: warriors, strength, heroes.

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APPENDIX A

LETTER OF SUPPORT

UNITED STATES SPECIAL OPERATIONS COMMAND
OFFICE OF THE CHIEF OF STAFF
7701 TAMPA POINT BLVD.
MACDILL AIR FORCE BASE, FLORIDA 33621-5323

MEMORANDUM FOR UNIVERSITY OF SOUTH FLORIDA, DEPARTMENT OF ANTHROPOLOGY, 4202 E FOWLER AVE, TAMPA, FL, 33620-8100

SUBJECT: Letter of Support for Dissertation Research

1. This memorandum confirms that Ms. Jodie Sweezey, FMD J1-LD, has my full support to conduct research on Special Operations Forces (SOF) service members living with autoimmune diseases. The Care Coalition will provide Ms. Sweezey access to SOF service members who, once contacted, may or may not choose to participate in this research. The service member has the right of refusal throughout the process. Ms. Sweezey's approximate research population is thirty.

2. This research examines how veterans of OEF and OIF negotiate the transition from healthy warriors to sick veterans, struggling with multiple illnesses and the many forces that interact with that transition. It is focused on the lived experience of illness as it is non-verbally expressed through embodiment, verbally expressed through illness narratives, and negotiated to avoid stigma.

3. Ms. Sweezey is the sole owner of the data and has sole rights to the final visual methods product. However, we are entitled to use the final product in support of the Care Coalition's mission. Ms. Sweezey is fully cognizant of the sensitivity of the data as it could pertain to national security. She will not collect sensitive or classified information but will focus on the individual's story of living with disease.

4. The POC for this research is Ms. Jodie Sweezey; jodiesweezey@mail.usf.edu.

CARY HARBAUGH
Colonel, U.S. Army
Director, Care Coalition

APPENDIX B

MEMORANDUM OF UNDERSTANDING

MEMORANDUM OF UNDERSTANDING

BETWEEN

U.S. SPECIAL OPERATIONS COMMAND

AND

UNIVERSITY OF SOUTH FLORIDA BOARD OF TRUSTEES

SUBJECT: Collaborative relationship between U.S. Special Operations Command and University of South Florida.

1. **PURPOSE.** To establish a collaborative relationship between U.S. Special Operations Command (USSOCOM) and University of South Florida (USF), hereinafter the Parties, with the goal of empowering each institution to seek meaningful interagency, military, and academic collaboration.

2. **BACKGROUND.** USSOCOM and USF are service-oriented institutions that strive to maintain and improve the lives of Service members and civilians. USF furthers knowledge through discovery, invention, transmission, and application; USF does so using its constituent institutions for instruction, research, scholarship, creative activities, and through public service. USSOCOM supports U.S. national defense and foreign policy and defends U.S. interests globally, by manning, equipping, training, and educating special operations forces personnel within its subordinate commands to execute special operations missions. Both organizations seek to establish a partnership that allows collaboration to benefit their missions by leveraging the distinctive capabilities of the partner institution.

3. **RESPONSIBILITIES.** This Memorandum of Understanding (MOU) is intended to provide an overarching understanding of how the Parties will interact. There is no intent to limit the type or topic of interaction, except when interaction interferes with the mission of either institution. Potential collaboration initiatives will be considered in areas such as, but not limited to: conferences, workshops, forums, guest speakers, and professional exchanges; resilience and rehabilitative care programs; degree completion and credit accumulation; subject-matter experts and internship opportunities; research projects; training and education; and other areas or opportunities that may arise. USSOCOM and USF may fund these activities with prior approval and legal review. Potential areas of collaboration may include, but are not limited to, private sector and donor initiatives in support of the Preservation of the Force and Families Task Force, Care Coalition, Veterans Reintegration Steering Committee, Citizenship Initiative (Tribal Dynamics workshops and Transformations of War project), Center for Strategic and Diplomatic Studies, and Water and Security conferences. Neither organization is obligated to undertake any action under this MOU. This MOU in no way limits the interactions of either Party pursuing other initiatives with other parties or agents.

4. **EFFECTIVE DATE, PERIODIC REVIEW, AND TERMINATION.** This MOU may be amended by mutual consent and should be reviewed annually to ensure it remains valid. Either party, upon giving a 60-day written notice to the other Party, may cancel this agreement. Any such notice will be communicated to the following address, if to USSOCOM: 7701 Tampa Point Boulevard, MacDill AFB, FL 33621-5323 and if to USF: Office of the General Counsel, 4202 E. Fowler Ave, CGS 301, Tampa, FL 33620-4301

5. **ANNEXES.** Annexes to this MOU may be subsequently negotiated by the Parties or their designated representatives for each collaborative initiative to ensure visibility and coordination.

6. **GOVERNING LAW.** This MOU shall be governed by the laws of the State of Florida. Venue of any dispute will be in Hillsborough County, Florida. This MOU becomes effective on the date of the last signature.

University of South Florida	Headquarters, U.S. Special Operations Command
Martin R. Steele	
Martin R. Steele Executive Director, Military Partnerships Office of Research, Innovation and Global Affairs	James B. Laster Major General, U.S. Marine Corps Chief of Staff
16 November 2012 (Date)	16 NOV 2012. (Date)

APPENDIX C

SCRIPTS

Email:
Good (morning or afternoon),
Jodie Sweezey, a doctoral student at the University of South Florida, is conducting research with OIF/OEF veterans to examine the lived experience of illness the transition from healthy warrior to sick veteran. This research is approved by the University (IRB #265841). If you are interested in participating in these research interviews, please contact her directly for information (jodiesweezey@mail.usf.edu; 571-213-8775). Thank you, (Name of Care Coalition Advocate)

Phone:
Hello, (name of operator), this is (name of Care Coalition representative). We are currently supporting a research study for Ms. Jodie Sweezey, a doctoral candidate at the University of South Florida, IRB number Pro00026851. She is examining the lived experience of illness for combat veterans of OIF and OEF. She is exploring how they transition from healthy warrior to sick veteran. If you are interested in participating in these interviews, we will pass on your contact information so she can reach out and discuss the details further. Would you be interested? Would you like her contact information? If so, it is jodiesweezey@mail.usf.edu; 571-213-8775.

We appreciate your time.

APPENDIX D

INFORMED CONSENT

Study ID:Ame1_Pro00026851 Date Approved: 9/14/2016 Expiration Date: 8/9/2017

UNIVERSITY OF SOUTH FLORIDA

Informed Consent to Participate in Research Involving Minimal Risk

Pro #___26851_____

You are being asked to take part in a research study. Research studies include only people who choose to take part. This document is called an informed consent form. Please read this information carefully and take your time making your decision. Ask the researcher to discuss this consent form with you, please ask her to explain any information you do not clearly understand. The nature of the study, risks, inconveniences, discomforts, and other important information about the study are listed below.

We are asking you to take part in a research study called:

"Livin' the Dream?" How Veterans of Operations ENDURING AND IRAQI FREEDOM Negotiate the Experience of Illness as They Transition from Healthy Warrior to Sick Veteran

The person in charge of this research is Jodie Sweezey, the Principal Investigator. She is being guided in this research by Dr. Elizabeth Bird. The research will be conducted at your place of residence or anywhere else you feel more comfortable. This research is being supported by HQ Special Operations Command Care Coalition.

Purpose of the study

The purpose of this study is to examine how veterans of OEF and OIF negotiate the transition from healthy warriors to sick veterans, struggling with multiple illnesses and the many forces that interact with that transition. This research is focused on the lived experience of illness as it is non-verbally embodied, verbally expressed through illness narratives, and negotiated to avoid stigma. The goal is to shed light on the growing epidemic of combat veteran illnesses by focusing on how these diagnosed diseases effect daily lives. In no way is this research meant to demean those struggling with disease, but to show the part of their narrative that is not always evident in a clinical setting.

Why are you being asked to take part?

You are asked to take part in this research because you are a member of SOF, a combat veteran of OIF/OEF, and diagnosed with an auto-immune disease in accordance with the American Autoimmune Related Diseases Association (AARDA) or cancer.

Study Procedures:

If you take part in this research, you will be asked to:

- Participate in two sit-down interviews which you partially control. Each interview should not last more than one hour, unless you ask for a longer period of time or that additional time is

needed to complete the task. Longer interviews will only be conducted with your request and/or approval.

- Each interview will be recorded. The recordings and transcripts will remain in the possession of the Principal Investigator. Your name will not be stored with the recordings or transcripts which will have numbers for identification. The key containing the names and corresponding numbers will be kept in a locked filing cabinet while the recordings and transcripts will be kept in a locked safe. The transcripts and recordings will be maintained by the researcher for no more than five years from the submission of the dissertation. Both the transcripts and the key will be destroyed with a shredder. The recordings will be deleted from their stored hard drive.

- For the first interview, you will bring favorite pictures from your deployment(s) as well as during the period of time when you began to notice you were getting sick. We will talk about those photographs with (but not limited to) the following questions:
    - Questions asked while looking at deployment photographs
        - Why did you choose this photo?
        - Who is in the picture with you? (if anyone else is)
        - What is happening in this picture?
        - When was this picture taken? (if they can reveal this information)
        - Where was this picture taken?
        - How does this photographs make you feel?

    - Additional questions
        - At what point did you first start to notice you were sick? What did you think was happening?
        - How did you learn you were sick? How long did it take to get answers and/or a diagnosis?
        - Did you think your changing condition was physical, mental, or emotional?
    - Questions asked while looking at transition photographs
        - What is this picture of?
        - Did you know you were starting to get sick here?
        - How did you know?

- Prior to the second interview, you will take twenty or so pictures that define your life now that you are sick. If you do not have a camera, one will be provided. These can be pictures of anything you want. If they include other people a separate release form will be need to be signed by each individual. The second interview will focused on your pictures and will include (but is not limited to) the following questions:
    - Questions for each of your pictures
        - What is this picture of? Tell me about it.
        - What does this picture mean to you?
        - Why does this picture define your life now?
    - Additional questions
        - Did you do research about your illness? How do you continue to learn about your illness?
        - Do talk about your illness with other operators? If so, how do they receive it?

    - Were there barriers in getting answers about your illness? As you sought treatment for your illness? Where have you found help and support?
    - Was your experience different for benefits and healthcare?
    - Do you trust the government to do right by you and tell the truth?
    - Do you know other sick veterans?
    - Do you belong to any veteran organizations?
    - Has your illnesses changed your perceptions of your service to this country?
- Participation is voluntary and you can opt out at any time. Additionally, throughout the research, you are encouraged to ask questions regarding anything you do not understand or was not clearly explained.
- Both interviews, along with the pictures, will be used for a digital story. This is accomplished by using your own words to create a script, then adding the pictures to construct a video in order to build understanding for the struggle of sick veterans.

Total Number of Participants

About thirty individuals will take part in this study.

Alternatives / Voluntary Participation / Withdrawal

You do not have to participate in this research study. You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study. You are free to participate in this research or withdraw at any time. You also have the right to choose which pictures you share from deployments as well as which pictures you take in between interviews. This is about your voice, your experience. You will be provided a separate release form itemizing which photographs may be used in the digital story, dissertation, and any follow-on products. You have the right to contact the Principal Investigator at any time with any questions regarding the research and/or the process; contact information provided below.

Benefits

The potential benefits of participating in this research study include raising awareness about OIF and OEF combat veteran illness issues.

Risks or Discomfort

This research is considered to be minimal risk. That means that the risks associated with this study are the same as what you face every day. There are no known additional risks to those who take part in this study.

Compensation

You will receive no payment or other compensation for taking part in this study.

Costs

It will not cost you anything to take part in the study. If you do not have access to a camera for the second part of the project, one will be provided to you.

Conflict of Interest Statement

No conflict of interest exists.

Privacy and Confidentiality

We will keep your study records private and confidential. Certain people may need to see your study records. Anyone who looks at your records must keep them confidential. These individuals include:

- The Principal Investigator and Research Advisor.
- Certain government and university people who need to know more about the study, and individuals who provide oversight to ensure that we are doing the study in the right way.
- Any agency of the federal, state, or local government that regulates this research.
- The USF Institutional Review Board (IRB) and related staff who have oversight responsibilities for this study, including staff in USF Research Integrity and Compliance.

We may publish what we learn from this study.

You can get the answers to your questions, concerns, or complaints

If you have any questions, concerns or complaints about this study, or experience an unanticipated problem, call Ms. Jodie Sweezey at (571) 213-8775.

If you have questions about your rights as a participant in this study, or have complaints, concerns or issues you want to discuss with someone outside the research, call the USF IRB at (813) 974-5638 or contact by email at RSCH-IRB@usf.edu.

While we are conducting the research study, we cannot let you see or copy the research information we have about you. After the research is completed, you have a right to see the information about you, as allowed by USF policies. You will receive a signed copy of this form.

Consent to Take Part in this Research Study

I freely give my consent to take part in this study. I understand that by signing this form I am agreeing to take part in research. I have received a copy of this form to take with me.

_____ _____

Signature of Person Taking Part in Study Date

_____

Printed Name of Person Taking Part in Study

Statement of Person Obtaining Informed Consent

I have carefully explained to the person taking part in the study what he or she can expect from their participation. I confirm that this research subject speaks the language that was used to explain this research and is receiving an informed consent form in their primary language. This research subject has provided legally effective informed consent.

_____ _____
Signature of Person obtaining Informed Consent Date

_____
Printed Name of Person Obtaining Informed Consent

APPENDIX E

REVISED SCRIPT

Email:
Hello, my name is Jodie Sweezey, a member of Team Archangel – you participated in one of our surveys a few years ago regarding OIF/OEF veterans getting sick. Now, I am conducting my doctoral research for the University of South Florida (jodiesweezey@mail.usf.edu; 571-213-8775), IRB number Pro00026851. I am examining the lived experience of illness for combat veterans of OIF and OEF; how they transition from healthy warrior to sick veteran. If you are interested in participating in these interviews, I would like to discuss further the details. Please respond to this email for further discussions. I appreciate your time and consideration. V/R, Jodie

APPENDIX F

PHOTO RELEASE FORM

UNIVERSITY OF SOUTH FLORIDA

Photo Release Form

Pro # 26851

I hereby consent to the use of the below identified photographs taken or used in support of the dissertation research by Jodie L. Sweezey, "Livin' the Dream? **How Veterans of Operations ENDURING AND IRAQI FREEDOM Negotiate the Experience of Illness as They Transition from Healthy Warrior to Sick Veteran" for the following purposes:**

In the completion and production of the dissertation narrative.

In the completion and production of the digital story product.

For any other purpose in support of the goals as stated in the research proposal statement. (I propose to examine how veterans of OEF and OIF negotiate the transition from healthy warriors to sick veterans, struggling with multiple illnesses and the many forces that interact with that transition. This research is focused on the lived experience of illness as it is non-verbally expressed through embodiment, verbally expressed through illness narratives, and negotiated to avoid stigma.)

Picture Thumbnail

Picture description:

Picture Thumbnail

Picture description:

_____ *Printed Name*

_____ *Date*

_____ *Signature*

APPENDIX G

INTERVIEW QUESTIONS

Interview 1

The operators will be asked to bring their favorite pictures from their deployments as well as their transformation period or when they began to notice they were getting sick. They will be told that the interviews are a combination of structured and unstructured interviews.

- Questions asked while looking at each deployment photograph
  - Why did you choose this photo?
  - Who is in the picture with you? (if anyone else is)
  - What is happening in this picture?
  - When was this picture taken? (if they can reveal this information)
  - Where was this picture taken?
  - How does this photographs make you feel?

- Transition questions
  - At what point did you first start to notice you were sick? What did you think was happening?
  - How did you learn you were sick? How long did it take to get answers and/or a diagnosis?
  - Did you think your changing condition was physical, mental, or emotional?

- Questions asked while looking at each photograph taken during their transformation from healthy to sick
  - What is this picture of?
  - Did you know you were starting to get sick here?
  - How did you know?

The operators may also choose to talk about other topics that are evoked by the pictures. I may also ask additional questions that are guided by the discussion while looking at the photographs.

Interview 2

This interview will be focused on the 20 or so pictures taken by the operator that defines their life since getting sick. The initial questions below are included just to get the dialogue started, if necessary.

- Questions for each of their pictures
  - What is this picture of? Tell me about it.
  - What does this picture mean to you?
  - Why does this picture define your life now?

- Additional questions
  - Did you do research about your illness? How do you continue to learn about your illness?
  - Do talk about your illness with other operators? If so, how do they receive it?
  - Were there barriers in getting answers about your illness? As you sought treatment for your illness? Where have you found help and support?
  - Was your experience different for benefits and healthcare?
  - Do you trust the government to do right by you and tell the truth?
  - Do you know other sick veterans?
  - Do you belong to any veteran organizations?
  - Has your illnesses changed your perceptions of your service to this country?

APPENDIX H

INSTITUTIONAL REVIEW BOARD APPROVAL

UNIVERSITY OF SOUTH FLORIDA

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(813) 974-5638 • FAX (813) 974-7091

8/10/2016

Jodie Sweezey
Anthropology
4202 East Fowler Ave
Tampa, FL 33620

RE: **Expedited Approval for Initial Review**
IRB#: Pro00026851
Title: "Livin' the Dream?" How Veterans of Operations ENDURING AND IRAQI FREEDOM Negotiate the Experience of Illness as They Transition from Healthy Warrior to Sick Veteran

Study Approval Period: 8/9/2016 to 8/9/2017

Dear Ms. Sweezey:

On 8/9/2016, the Institutional Review Board (IRB) reviewed and **APPROVED** the above application and all documents contained within, including those outlined below.

Approved Item(s):
Protocol Document(s):
Study Protocol.pdf

Consent/Assent Document(s)*:
Photo Release Form.pdf.pdf
Sweezey_SB Adult Minimal Risk.pdf.pdf

*Please use only the official IRB stamped informed consent/assent document(s) found under the "Attachments" tab. Please note, these consent/assent document(s) are only valid during the approval period indicated at the top of the form(s).

It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR46.110. The research proposed in this study is categorized under the following expedited review category:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval via an amendment. Additionally, all unanticipated problems must be reported to the USF IRB within five (5) calendar days.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

Kristen Salomon, Ph.D., Vice Chairperson
USF Institutional Review Board

APPENDIX I

INSTITUTIONAL REVIEW BOARD CONTINUING APPROVAL

UNIVERSITY OF SOUTH FLORIDA

RESEARCH INTEGRITY AND COMPLIANCE
Institutional Review Boards, FWA No. 00001669
12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799
(813) 974-5638 • FAX (813) 974-7091

7/18/2017

Jodie Sweezey
USF Anthropology
4202 E. Fowler Avenue
Tampa, FL 33620

RE: **Expedited Approval for Continuing Review**
IRB#: CR1_Pro00026851
Title: "Livin' the Dream?" How Veterans of Operations ENDURING AND IRAQI FREEDOM Negotiate the Experience of Illness as They Transition from Healthy Warrior to Sick Veteran

Study Approval Period: 8/9/2017 to 8/9/2018

Dear Ms. Sweezey:

On 7/17/2017, the Institutional Review Board (IRB) reviewed and **APPROVED** the above application and all documents contained within including those outlined below.

Approved Item(s):
Protocol Document(s):
Study Protocol_V2_5Dec16.pdf

Consent/Assent Document(s)*:
Photo Release Form.pdf.pdf
SB Adult Minimal Risk_V3 5Dec16.pdf.pdf

*Please use only the official IRB stamped informed consent/assent document(s) found under the "Attachments" tab on the main study's workspace. Please note, these consent/assent document(s) are valid until they are amended and approved.

Following Chair Review: The application for continuation has been reviewed in detail. Deviation log has been reviewed. Noncompliance was not serious and not continuing. There was no increased risk to participants and no further action is required.

The IRB determined that your study qualified for expedited review based on federal expedited category number(s):

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with USF HRPP policies and procedures and as approved by the USF IRB. Any changes to the approved research must be submitted to the IRB for review and approval by an amendment. Additionally, all unanticipated problems must be reported to the USF IRB within five (5) calendar days.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

John A Schinka, Ph.D.

John Schinka, Ph.D., Chairperson
USF Institutional Review Board

APPENDIX J

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Policies

Contents

- Philosophy of *The Qualitative Report*
- Who Can Submit?
- General Submission Rules
- Manuscript Review and Production Process
- Formatting Requirements
- Rights for Authors and NSUWorks

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For more information, please see *The Qualitative Report* Aims and Scope page.

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