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Chelsey Carter April 18, 2012

Gender Consciousness: Understanding the Illness Experiences and Explanatory Models of Men and Women with ALS in Georgia

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a thesis submitted to the Faculty of Emory College of Arts and Sciences
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Abstract

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By Chelsey R. Carter

Narratives of illness, disability, mental disorders, genetic disorders, chronic conditions, dying and death play a key role in shaping our understanding of the human condition. In the past decades efforts have been made to better understand these anthropological illness narratives, with an increasing on chronic illness. This medical anthropological research project is a cross-sectional study of the illness experience of men and women with amyotrophic lateral sclerosis, ALS. ALS presents a particular set of challenges for the construction of an illness narrative, as it has no known etiology, no treatment, and no cure. A critical medical anthropological approach is used to examine the limits and challenges of biomedicine through the lived experience of men and women with a visible and life-limiting chronic illness. The research aims were: 1) determine how health behaviors (with regard to terminal illness) vary between genders 2) identify the impact of gender on the attitudes of men and women with ALS related to family, emotional support, identity, and explanatory models 3) understand how individuals cope with an illness with no known etiology, no treatment and no cure. The study used nine participants, five men and four women living in Georgia. Qualitative and quantitative methods were used to collect data, including: semi-structured interviews, structured questionnaire including psychosocial instruments to assess coping style, and participant observation of support group meetings. Results identified both gendered and universal themes among individuals with ALS, and reflect various coping measures and health behaviors that emerge for men and women with ALS.

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Preface

My journey with ALS began when at the age of fourteen I became a volunteer with an organization called Extra Hands for ALS. Extra Hands for ALS, founded by ALS patient and alumnus of my high school, Jack Orchard, was a non-profit organization that matched ALS patients with student volunteers. Student volunteers would visit the homes of the persons with ALS (pALS) and complete an array of non-medical tasks, including but not limited to: household chores, yard work, reading, babysitting, companionship, etc. While in high school, I volunteered with three pALS and their families regularly. During this time, I met Mr. Ron Harrison. Mr. Harrison was a loving father and amazing husband; he became a genuine friend. I had the privilege of assisting Mr. Harrison in converting his "old school" records into CD's. During this tedious project, Mr. Harrison would share stories with me from his US Army days or career as an electrical designer. His stories would keep us occupied for hours laughing and joking, while I sat in his presence and learned from all he had to share. I remember joking with him saying, "You should write a book some day." He would laugh and say, "Maybe Chelsey, just maybe." I loved Mr. Harrison dearly and my other pALS. I vowed to dedicate my life to helping individuals with ALS. When I left for college in the summer of 2008 I was sad to leave home but especially sad to leave my pALS; partly because, I was not sure if I would ever see them again. I vividly remember getting a call during Freshmen Orientation at Oxford College telling me that Mr. Harrison had succumbed to ALS. Though not surprised, I was heartbroken to know that I would never spend time converting "old school" records into CD's and listening to stories for hours in his office. But what hurt me most was knowing that Mr. Harrison's story would never be told. Surely his wife Darlene, his children and grandchildren, would share his story, but it would not be shared by Mr. Harrison himself.

After taking a Medical Anthropology course at Emory I was truly engrossed and inspired by illness narratives and explanatory models. While learning about anthropological narrative techniques in Arthur Kleinman's *The illness narratives: suffering, healing, and the human condition,* I immediately thought about how I could share this technique with persons with ALS. Would illness narratives and explanatory models provide persons with ALS a way to share their experiences? I thought so in 2010 and I still think so today. During the summer of 2011, I assumed the position of Patient Services Intern for the ALS Association. As an intern I visited and facilitated support group meetings, shadowed home visits with the organizations full-time nurse, and revamped the organizations home assistance program (which I re-entitled Helping Hands). Using Jack Orchard's Extra Hands for ALS as a model we matched volunteers with ALS patients in Georgia to assist with non-medical support. My work re-inspired me to share pALS stories in a substantive and meaningful way. Building on my fervent passion, this research project gives pALS a voice. I hope this project challenges the view that only famous leaders, politicians, world figures and entertainers deserve to have their stories told and shows that an average person with ALS deserves to share his or her heroic journey against unbeatable odds. Like life, all journeys must come to an end. However, my hope is that my personal and academic journey with ALS will let many individuals with ALS share their fragmented, hopeful, and zealous illness experiences and that we as readers will find meaning, hope and power in their stories.

Chapter 1:Introduction/Background

I am quite often asked: How do you feel about having ALS? The answer is, not a lot. I try to lead as normal a life as possible, and not think about my condition, or regret the things it prevents me from doing, which are not that many.

Stephen Hawking in *Prof. Hawking's Disability Advice*

In the past several decades efforts have been made to better understand narratives of illness, disability, mental disorders, genetic disorders, chronic conditions, dying, and death (Cobb & Hamera 1986; Chatman 1978; Charon 2006; Greenhalgh 2001; Hatfield-Timajchy 2007; Kleinman 1988; Spencer 2003; Weingarten 1997; Weingarten 1999). Anthropological illness narratives have proliferated in the areas of chronic illness (Brody 1987; Garro 2002; Kelley 1996; Murphy 1987). However, such research has not fully explored the variability and differences in chronic illness between males and females. Furthermore, scholarly illness narratives on the rare/life-limiting disease, amyotrophic lateral sclerosis (ALS), are uncommon, with the exception of two studies (Brown & Addington-Hall 2008; Cobb & Hamera 1986). Although popular books by persons with ALS (pALS) or caregivers of pALS have been written, these accounts typically describe one person's illness experience (Albom 2002; Knight 2011; Rice 2005; Sinton 2002; Stuban 2009; Wakefield 2005). Missing from the literature are three key perspectives:

(1) Information regarding differences in illness narratives of men and women that vary based on journey to diagnosis, doctor interactions, disclosure, support, spiritual beliefs, economic concerns, body image, fears, support systems, and explanatory models

(2) Gender differences that exist for individuals with a chronic, life-limiting disease such

as ALS

(3) How individuals cope with an illness with no known etiology, no treatment, and no cure.

This study will fill these gap by providing illness experience and explanatory models of nine individuals with ALS. Results will identify both gendered and universal themes among individuals with ALS, as well as describe various coping measures and health behaviors that exist for men and women with this life-limiting chronic illness. This exploration of these themes will demonstrate the importance of narratives related to pain and suffering and give patients a voice and the power to share the significance of illness meaning (Charon 2006). From an activist approach, factors that affect the gendered differences among chronically ill persons will be discussed examining the inequities in men and women's health status. Viewing ALS through an anthropological lens highlights the use of illness narratives making a rare disease more tangible, creating a greater awareness of the disease.

The Project

This research project grows out of a commitment that is both passionate and personal. As I explained in the preface, I remember leaving a high school assembly presented by Jack Orchard, an alumnus and person living with ALS (pALS), and immediately going to the library to research ALS. I was overwhelmed to find a multitude of acronyms and disease affiliations. Terms such as ALS (Amyotrophic Lateral Sclerosis), Lou Gehrig's disease, MND (Motor Neuron Disease), are all names associated with the fatal disease. I vividly recall visiting a website highlighting Professor Stephen Hawking, theoretical physicist, cosmologist and best selling author of *A Brief History Time* (on the British *Sunday Times* bestseller list for a record

237 weeks). Professor Hawking's web page headshot was awkward and at the same time extraordinarily revealing of his condition. His picture was similar, in terms of its body language, to what I'd seen of Jack Orchard's at the assembly earlier that day. I came to discover that Stephen Hawking is arguably one of the most brilliant theoretical physicists since Einstein and had been diagnosed with ALS. I was amazed by Hawking's many accomplishments, despite the fact that he had lived most of his life in a wheelchair as a person with ALS. Hawking has published numerous articles and books and has won countless awards for his contributions to his field. Currently, he has lived with ALS for more than twenty years and continues to teach, write, and present at conferences. Hawking's story inspired me not only to research ALS but, more importantly, to do more for persons directly impacted by ALS. I began to volunteer with ALS patients in the Saint Louis area and was impacted by persons with ALS who ultimately became my extended family. I learned firsthand that, just as Hawking and Orchard had explained, ALS significantly affects many lives. Just as importantly, I noticed that the disease touched each person's life differently.

My experiences seven years ago led to this thesis. My journey did not begin the day I "googled" ALS, but the day I began volunteering with one of the most remarkable individuals I have ever met. Through my experiences as an ALS volunteer I have been inspired and humbled. Individuals living with ALS are determined. They are vulnerable. They are patient. They are impatient. They want a cure. They have families. Their families have been touched by illness. They have been challenged. They have been forced to persevere through remarkable and not so remarkable situations. They are committed. Together with these families, I've witnessed these individuals *live* and continue to live life with dignity and grace. They drove me to better understand the affects of chronic illness. My thesis provides a brief glimpse into the

lives of nine people, five men and four women, who have shared with me and with the readers of this thesis their own unique stories.

Research Objectives

The principal goal of this project is to understand, compare, and contrast the experiences of males and females with ALS. After summer experiences as the patient service intern of Georgia working with individuals living with ALS, I wanted to better understand if and how the social constructions of gender and gendered identities affected illness experience. Is the physical deterioration and eventual paralysis of ALS (and accompanying challenges to a masculine social identity) more difficult to bear for men? For women with ALS, are their relationships with their children and grandchildren differently affected than male ALS patients' child and grandchild relationships? How does the progression of chronic illness alter women's femininities and nurturer identities? I hypothesized that illness experience for women with ALS will differ substantially from their male counterparts, whom I expected to have more difficulty coping with the disease. I expected to see that differences would exist in coping techniques, response to family (children, spouse, close relatives), understanding/explanation of disease, acceptance of illness and challenges living with the disease.

As a social scientist, one of my objectives is to contribute to the understanding and meaning of ALS. Because ALS is a disease with no cure or treatment and no known etiology, currently health care providers can only offer ALS patients palliative care. Palliative care focuses on the pain, symptoms and stress of disease, with the objective of relieving and preventing the suffering of patients. Some research (Bosario et al. 2001; Bosario 2001; Bosario & Voltz 1997; Fanos et al. 2008; Mitsumoto et. al 2007) has examined palliative care of ALS

patients, however these studies have been largely epidemiological and symptomatic. Rarely do these studies provide patients with a voice to discuss their symptoms outside of the outwardly physical strains or reports from their attending neurologist (Bosario 2001; Albert 2005; Robbins 2001). Furthermore, available studies have not endeavored to understand the ALS illness experience through the lens of gender and gendered identities. Arthur Kleinman proposes that we can learn from human pain and suffering which will help us better understand the chronically and terminally ill (Kleinman 1989). By eliciting Kleinman's explanatory model, this project aims to contribute to the research of illness narratives. Kleinman's model uses the following eight questions:

> What do you think has caused your problem?
> Why do you think it started when it did?
> What do you think your sickness does to you? How does it work?
> How severe is your sickness? Will it have a short or long course?
> What kind of treatment do you think you should receive?
> What are the most important results you hope to receive from this treatment?
> What are the chief problems your sickness has caused for you?
> What do you fear most about your sickness?

This research differs greatly from the lay autobiographies and scholarly illness ethnographies currently available. Illnesses such as HIV/AIDS, cancer, multiple sclerosis, Parkinson's disease, lupus, and fibromyalgia do not all have a definite cure but they all have a known cause and treatment plan. This reality is particularly significant for persons with ALS who do not know the cause, have a cure or treatment for their disease. How does one cope with a disease that seems hopeless and whose landscape is one of unanswered questions? This study will fill this gap by identifying significant themes and coping mechanisms that pALS employ to continue living with ALS.

Illness Narratives

Illness narratives have become an emerging and central aspect of medical anthropology. Illness narratives offer a vulnerable and open-ended method to understand the individuals experiencing illness. In recent years, analyses of patient narratives have been used to explore a broad range of chronic conditions like fibromyalgia (Greenhalgh 2001) and Lupus (Hatfield-Timajchy 2007) to neurological conditions like multiple sclerosis, Parkinson's disease and Motor Neuron Disease (ALS) (Riessman 2003; Solimeo 2007; Murphy 1987; Brown & Hall 2008). The use of ethnographic data through narratives allows anthropologist to interpret the practices and beliefs of people's cultures.

The importance of narratives in anthropology is described in 1986 publication, *The Anthropology of Experience* by Edward Bruner and Victor M. Turner. The book explores how people actually experience their culture and how those experiences are expressed in reality (Turner & Bruner 1986). Linda C. Garro and Cheryl Mattingly (2000,1) write that

> creating a narrative, as well attending to one is an active and constructive process- one that depends on both personal and cultural resources. Stories can provide a powerful medium for learning and gaining understanding about others by affording a context for insights that one has not personally experienced.

Within medical anthropology, ethnographers look at narratives to better understand the practices and cultural construction of health and illness. To understand illness experience, anthropologists seek illness narratives to acquire an understanding of the patients' meaning of illness and its cultural meanings; this makes the personal narrative unique (Kleinman & Benson 2006; Steffen 1997). Kleinman gives an example of the illness narratives in his book, *The Illness Narratives: Suffering, Healing and the Human Condition.* The illness experience categorizes and explains the forms of anguish caused by the physiological processes of disease (Kleinman 1988). Through thoughtful in-depth analysis Kleinman offers several narratives with patients with varying

illnesses through the use of his explanatory model theory. Kleinman shared narratives of individuals with chronic pain syndrome, neurotic obsession of pre chronic illness, neurasthenia, chronic asthma, psoriasis, metastatic carcinoma, cancer, heart disease, muscular dystrophy and many more chronic illnesses. To understand these various chronic illnesses, Kleinman sought to understand the meaning of illness by investigating the structure of illness meanings: how are things made meaningful? How does one create meaning? And what social situations and determine the meaning of illness? Understanding illness meanings is not only particular of one individual experience but also contributes to the social networks, social situations and social realities that sick persons encounter daily (Kleinman 1988). Other anthropologists studying chronic illnesses such as fibromyalgia, tumors of the spinal cord and ALS have sought to explore the meaning of illness, building off of Kleinman's model.

Two personal narratives on illness have been written by accomplished anthropologist Susan Greenhalgh and Robert F. Murphy. Susan Greenhalgh (2001) gives a thoughtful analysis of chronic pain related to fibromyalgia in her auto-ethnography *Under the Medical Gaze, Facts and Fictions of Chronic Pain.* Using her own experiences as a case study, Greenhalgh studies the doctor patient interactions, misdiagnoses, and biomedical failures of the medical system, as she searches for answers for her chronic pain. She shows the effects, both negative and positive, of her fibromyalgia diagnosis on her life, physical health, and over-all well-being. Similarly, Robert F. Murphy maps his diagnosis with a tumor of the spinal cord that led him into quadriplegia. Using his own experiences as examples Murphy shows his readers the meaning of his illness in society's complicated web of myths, fears and misunderstandings about disability. He explains how paralytics are quite literally "a prisoner of the flesh," searching for answers, understanding and meaning for their illness (Murphy 2001, 112). What illness narratives literature lacks is an

understanding of the illness experience of a life-limiting chronic disease like ALS.

Brown and Addington-Hall (2008) studied how pALS told their ALS stories. They determined if narratives were: sustaining, enduring, preserving or fracturing (Brown and Addington-Hall 2008). Though engaging, the study lacked further analysis of illness experience as meaning rather than just providing methods of storytelling. In a 1986 study, two nurses ,Ann K. Cobb and Edna Hamera, studied the illness experiences of two women with ALS. Participant A and B were interviewed in their home every two months to examine the effects of illness on familial relationships, social networks, and the medical system. Using Kleinman's explanatory model the nurses argued that a greater emphasis of evaluation therapies was necessary. In addition to being a small study, research methods only allowed for participants to be diagnosed with ALS within the last six months and had to be between the ages of fifty and sixty. Researchers wanted to enlist at least one male participant but were unable to find a participant that fit their criteria. Major findings of their research showed that study participants did not change their explanatory models over time, even though social relationships went under radical change throughout the illness experience; and they emphasized the "importance of a link between profession and popular health care sectors, since so much of the care of ALS persons is given at home" (Cobb and Hamera 1986: 649). Though the findings were important contributions to their field, the study is limited due to an exceptionally small sample size and limiting selection criteria for participants.

Gender and Illness

Gender, or rather the social construction of gender, plays an important role in understanding health and even access to healthcare. Gendered health concerns date back to the

mid-1980s, which marked a watershed era in research and policy reform on gender and health (Read & Gorman 2010). The decade of the 80s saw the beginnings of significant research on women's experiences of medical encounters or comparisons between men and women's health practices on an individual basis and on a greater scale. It is indisputable that men and women differ in their "physical health profiles, regardless of how health is defined" (Read and Gorman 2010, 373). In much of the health disparities literature it has been well documented that women have longer life expectancies than men but undergo complications from chronic diseases (Bird & Rieker 2008, Branch et.al 1991, Verbugge et.al 1987, Read & Gorman 2010).

Gender differences in health are evident when it comes to mortality and morbidity. In nearly every developed country in the world women live longer than men. The contradiction, however, is that female morbidity rates generally exceed male morbidity rates. Recent data shows that in the United States the life expectancy at birth for women is 80.4 years, where as for men it is 75.2 years (National Center Health Statistics 2009). On average this means that women are living 5.2 years longer than men. Since the peak era of gendered health research this average has decreased, being that in the mid 1970s women lived on average 7.8 years longer than men (Read & Gorman 2010). The mortality gap is significant, as is the morbidity gap between men and women. Read and Gorman note that when men are younger, they tend to engage in more health damaging behaviors than women which adversely affect their "well-being and increase their risk of death via accidental injuries and homicide" (Read & Gorman 2010, 373). Yet, women are more likely to suffer more from chronic conditions that are not fatal but greatly affect their quality of life. Why are women living longer than men but have a higher incidence of morbidity? Some social scientists explain that females' higher incidence of illness and use of health care is because women are more sensitive to bodily discomforts and consequently, are

more willing to "report symptoms of distress and illness than are men" (Macintyre 1996). Research suggests several explanations, which typically reference many biological, social, cultural, and psychosocial and behavioral consequences. Men and women are exposed to conditions that foster good health differently and also seek healthcare support differently.

Some researchers suggest that men and women are socialized and that their gender roles to which they adhere impact their views on health care and if they choose to seek health care. (Galdas, et al. 2005; Noone and Stephens 2008). The literature suggests that men are far less likely than women to access healthcare services - also the pattern in prehistorical times (Classen and Joyce 1997). Suggestions have been made that gender differences in health may be protecting ideas of masculinity and femininity.

Gender research has proven that differences between physical illness and gender indeed exist (Clarke 1983; Bierd & Rieker 1999; Courtneay 2000; Read & Gorman 2010). In a review of gender and illness in previous decades social scientist have found that "illness is multifaceted and to some extent experienced differently by different people and differently by the same people at different times." (Clarke 1983). Undeniably sex and gender differences exist in the way illness symptoms are perceived and managed. Furthermore, some social scientists explain that females' high use of health care services results because women are more sensitive to bodily discomforts and consequently are more willing to "report symptoms of distress and illness than are men" (Macintyre 1996). Sex and gender differences exist in the way illness symptoms are perceived and managed. Various studies examine cancer, comma cold, and mental health disease and have found strong evidence of gender differences (Clarke 1985; Allen 1994; Lorber & Moore 2004; Matud 2004). These findings support my research at this stage and in fact suggest a difference in illness experience according to gender differences. Gender is particularly

interesting in the context of ALS. ALS does not discriminate across race, age, or ethnicity; however, research has shown that ALS is more common in men than women (The ALS Association 2011; Logroscino 2008; Kihira 2005)

Chronicity

Chronic disease has been the focus of medical anthropology and biomedicine for decades. Biomedicine fits into the medical framework by examining the limits and boundaries of people living with a chronic disease. Scholars have found that the epidemiological shift marked an emergence of chronic disease as the major cause of death (Charmaz and Rosenfeld 2010). Many early studies of illness addressed specific physical conditions. For example, Anselm Strauss and Barney Glaser's (1975) *Chronic Illness and the Quality of Life* analyzed the problematic circumstances across diverse chronic illnesses. Strauss offered an *emic* perspective on the illness experience in explicit contrast the to sick's role, *etic* perspective (Strauss and Glaser, 1975). Rosenfeld and Charmaz (2010) explain that Strauss and his colleagues emphasized that people with chronic illness and their families have extraordinary lives that are influenced by the havoc of maintaining their new lives and influenced by "regimens, mobility, self-care, and routine interactions" (Rosenfeld and Charmaz 2010, 315). Later in *Chronic Illness and the Quality of Life's* second edition (1984), Strauss and his colleagues stressed the idea that ill persons engaged in biographical work (discussing accounts of their lives) were helped by the process and some came to terms with deteriorating health (Strauss et al 1984). Later, in 1982, the focus on the experience of chronic illness was made more formal in *Social Factors in the Etiology of Chronic Disease* which argued that chronic disease challenged how people understood the world and their place in the world which the author writes, "disrupts the structures of everyday life and the forms

of knowledge which underpin them" (Bury 1982, 169). Bury's frameworks set the stage for work focused on chronic illness and illness meaning/experience (Kleinman 1988; Saillant 1990; Balsham 1991; Kagawa-Singer 1993; Matthews et al. 1994). In Western society's view of biomedicine, it's imperative to begin looking at the problems that people with chronic disease face: living under duress, experiencing biographical disruptions, being viewed as acceptable and constructing self-identities.

When seeking to understand an ill person's construction of his or her identity, anthropological research on chronic illness can unveil the importance and additive impact of gender. Gender is a social construction across all of societies, both Western and Eastern; furthermore, differences exist in all areas of a male or female's life. One study found that men and women likely experience major life transitions and their accompanying life changes differently (Bird and Rieker 1999). Consequently, health-related behaviors likely change at these moments of transition, and we may expect to see differences in these changes by gender (Cullen 1999). Similarly, socioeconomic status inequities in health are different in men and women (Matthews 1999). The World Health Organization (WHO) has found that gender norms and values have given rise to gender inequalities in healthcare:

> A country's lung cancer mortality rate for men far outstrips the corresponding rate for women because smoking is considered an attractive marker of masculinity, while it is frowned upon in women which shows how gender norms and values negatively affect health.

As before mentioned, gender inequalities exist in health and are evident in the mortality and morbidity research. Studies have shown that women experience more illnesses than men, despite the fact that they live on average several years longer than men. Sometimes gender can affect the achievement of well-being and one's experience with chronicity. However, negative gender health behaviors are not fixed; they evolve. Differences in behaviors may also play a role in

differences in prevalence of disease (Parson 1999). Since the inequalities do exist scholars suggest that through biographical work and illness narratives the inequalities can be addressed to better support the ill person (Parson 1999; Langley 2003).

Disease and Illness

It is important to distinguish the differences between disease and illness to understand this project. Leon Eisenberg (1977) provides an exemplary explanation of disease and illness. He writes that diseases are "are abnormalities in the function and/or structure of body organs and systems" (Eisenberg 1977, 13). Doctors *diagnose* "disease". Illness, on the other hand, "are experiences of discontinuities in states of being and perceived role performances" (Eisenberg 1977, 13). Illness may be a feeling; how one person feels is different than another. Patients *suffer* illness. The distinction is extremely important to my research. As I study persons with ALS, I do not want to look not at disease, but rather illness. How do ALS patients perceive their illnesses? How do people live with chronic diseases?

Research has shown that anthropological interest in chronic disease has grown over the past two decades. Broad research has been done in the United States and abroad on several public health concerns like hypertension, obesity, and cancer. Kleinman's methods of looking at chronic disease help emphasize and find the meaning and power of illness. Through explanatory models or "EMs", a patient's perspective of illness is elicited (Kleinman 1978). EMs can provide a better understanding of a patient's illness experience. Illness explanatory frameworks differ profoundly both within and across cultural sub groups (Lynch & Medin 2006). However, in a study done on ALS and illness experience Ann K. Cobb and Edna Hamera (1986, 642) write that,

> ALS as an incurable disease of unknown etiology, challenges the explanatory models of biomedical science…there is a gross discrepancy between the expectation of cure …and the actuality that no cure exist."

Patients and health care professionals share a cultural expectation of cure for diseases. When this is not possible, there is no culturally acceptable explanation within the health care system for this medical breakdown. Many ALS patients can only be offered palliative and symptomatic care for the disease, but no cure (Bosario 2001; Robbins 2001). Therefore, it is expected that the EM's of health care providers and ALS patients may vary. However, patients can still provide insight on ideas of causation, recognition of symptoms, course of illness experiences, evaluation of therapies, and therapies (professional or personal). These explanations will further the discussion on not only how we study illness experiences but also how health care systems are analyzed at an individual level. One would conjecture that persons living with the disease know their body best. Therefore, why not allow the patient to explain their illness so that through their narratives researchers like myself can then mitigate the impact that gender constructions play on their illnesses. My project expands beyond the current literature on chronic illness and examines a chronic illness with no cure, no treatment and unknown cause. This context creates a uniquely specific illness experience and meaning; which, chronic illness literature has yet to fully explore. Constructing an explanatory model and narrative for a disease with no explanation is unique because each individual's model is bound to be exclusive, fragmented and capricious. Furthermore this study broadens the parameters of Cobb and Hamera's (1986) study to investigate nine female *and* male individuals with ALS.

Chapter 2: Understanding Amyotrophic Lateral Sclerosis

Why ALS?

Amyotrophic Lateral Sclerosis (ALS) is one medicine's most perplexing and fatal chronic illnesses. ALS is a progressive neurodegenerative disease of the nerve cells in the brain and spinal cord. The disease is not common, the incidence is two in every 100,000 individuals worldwide and it is estimated that 30,000 Americans may have the disease at one time. Little is known about the disease including its etiology or cure; thus, ALS treatments are non-existent. ALS specialist and neurologist typically focus on providing symptomatic relief for their patients. Diagnosis for most patients occurs years after the first symptom; on average ALS patients live three to five years after official diagnosis. Thus, an ALS diagnosis is devastating and most literally a death sentence.

ALS attacks the motor neurons that control the body's voluntary muscle groups. Increasing muscle weakness and deterioration of motor neurons affects the total body including speech, swallowing and breathing. The constant loss of muscle strength and foreboding decline makes the disease extraordinarily unsettling. For example, once one accepts the loss of mobility in the right arm, the left foot begins becomes paralyzed and so on until one reaches total body paralysis. Diagnosis with a chronic illness like ALS prompts feelings of extreme familial/social isolation and weakness, which may complicate coping and cause severe depression. Arguably, these feelings are amplified by the fact that mental functioning remains unaffected in ALS patients.

ALS offers a distinctive window for peering into the life-limiting chronic illness

experience and for examining biomedicine. As a chronic illness, ALS defies the curative disease model that the biomedical system offers. As a visible illness, it influences societal stigma towards those with disability. As a terminal illness, it challenges views on coping, dying and death. From a medical anthropological perspective, ALS is interesting because it is a lived bodily experience with the before mentioned challenges. This chapter presents an overview of the history and current understanding of ALS. I hope to create a sound awareness of ALS in a way that allows the reader to understand the symptoms, treatment, and review current ALS research.

Brief History of ALS

In 1865, "The Father of Neurology", Jean-Martin Charcot noted the first characteristics of ALS. Through careful clinical observation and laboratory work detailing the pathophysiology that lead to ALS, Charcot discovered ALS as a separate and distinct disease of the motor neurons (Kumar 2011). Charcot and his team meticulously conducted studies between 1865 and 1869, eventually noting key aspects of ALS: lesions in the motor component of the spinal cord that resulted in chronic progressive paralysis and contractures (Kumar 2011). At the time of his first descriptions Charcot dubbed the disease "Charcot's disease". Nine years later, once his lectures were compiled, the term amyotrophic lateral sclerosis was offered (Goetz 2000; Tan & Shigaki 2007). In 1939, baseball legend Lou Gehrig was diagnosed with ALS and died two years later. Due to the popularity surrounding Gehrig, the disease became known in the United States as Lou Gehrig's disease. While in some parts of the world ALS is still referred to as Charcot's disease, it is more commonly known as Lou Gehrig's disease, motor neuron disease (which includes five classifications of diseases affecting the upper and lower motor neurons; more commonly used in

Australia, New Zealand and Europe)[1] and amyotrophic lateral sclerosis, ALS (Eisen 2009).

Description of ALS

Amyotrophic refers to a loss of muscle mass, lateral refers to the nerve tracks that run down both sides of the spinal cord, where many neurons affected by ALS are found; sclerosis refers to the scar tissue that remains following deterioration of nerves (Eisen 2009; Brujin 2004). According to the Mayo Clinic, "Worldwide, ALS occurs in one to three people per 100,000", however approximately 30,000 in the United States are currently living with the disease (Brujin 2004; Mayo Clinic 2008; Eisen 2009; Miller 2005). ALS affects the upper and lower motor neurons, which over time degenerate and stop sending nerve signals to the muscles. As the motor neurons die, the ability of the brain to initiate and control muscle movement is totally lost. As a consequence the disease initially causes muscle weakness, muscle atrophy and muscle fasciculation's (twitches in the muscle). Eventually all voluntary muscles are affected and patients lose ability to move their arms, legs, and body. Often most ALS patients die from respiratory failure (without ventilator support)[2] due to the deterioration of the muscles in the diaphragm. Statistically, persons with ALS live two to five years after onset of their first symptom.

Initial signs that an individual may have ALS are muscle weakness, cramps, muscle twitches, and muscle atrophy (Miller 2005). ALS manifests itself in different ways, depending on which muscles weaken first. Symptoms may include tripping and falling, loss of motor

[1] Motor neuron disease is a general name classifying four types: ALS (amyotrophic lateral sclerosis), PBP (progressive bulbar palsy), PMA (progressive muscular atrophy), and PLS (primary lateral sclerosis). FONT??

[2] Medical ventilators are used as auxiliary support for breathing once lung muscles become to weak to work on their own. Ventilators are optional for persons with ALS

control in hands and arms, difficulty speaking, swallowing and/or breathing, persistent fatigue, and twitching and cramping, sometimes quite severely. Nevertheless, typically pain is not associated with ALS symptoms. Frequently most patients first have difficulty moving, walking, speaking/forming words, and swallowing; however, the progression of ALS varies from person to person, but ultimately it spreads to the rest of the body, causing paralysis. According to the Mayo Clinic (2008),

> Symptoms of upper motor neuron involvement include tight and stiff muscles (*spasticity*) and exaggerated reflexes (*hyperreflexia*) including an overactive gag reflex… [whereas] Symptoms of lower motor neuron degeneration include muscle weakness and atrophy, muscle cramps, and fleeting twitches of muscles that can be seen under the skin (*fasciculations*) .

As the weakening and paralysis continue, eventually the patient's breathing will be affected, causing permanent ventilator support in order for the patient to survive (ALS Association 2008, Kurtzke 1982).

Diagnosis and (possible) Etiology

The etiology of ALS is currently unknown in *most* patients. Much of this may be attributed to the variability of the disease and other conditions that mimic ALS. Commonly the pinching of nerves or spinal cord caused by arthritis are commonly diagnosed as ALS (Miller, 2005). Other conditions like cervical spine disease, Kennedy's disease, radiation damage, Lymphoma, and HIV-AIDS mimic the disease (Miller 2005; The Packard Center 2009). Thus doctors must do extensive testing to accurately diagnose ALS. Physicians obtain the patients full medical history and typically conduct a neurological examination at regular intervals to assess whether symptoms such as muscle weakness, hyperreflexia, and muscle atrophy and spasticity is

becoming progressively worse. Because ALS symptoms can seem similar to other diseases, appropriate test must be conducted to exclude other possible conditions. No single test is definitive for diagnosing ALS, thus most patients must undergo MRIs, electro-diagnostic studies, electromyography, nerve conduction, and blood and urine tests (Miller 2005). A reason diagnosis testing varies is because the pattern deterioration varies between individuals with ALS. One may lose their ability to walk first where another may lose their ability to speak first. In my informant sample, pALS stages range from walking to completely paralyzed. Some individuals in this study have been diagnosed for six months and others for twenty-four years. Though, two to five years is the typical life span of an ALS patient, rare cases exist, like that of Stephen Hawking, where individuals survive with the illness for more than twenty cares. I conjecture that individuals with ALS for more than twenty years may have been misdiagnosed with other non-fatal motor neuron disease like PLS (Primary Lateral Sclerosis, described later in Chapter 4) or utilize ventilator support.

There are two types of ALS: familial and sporadic. In five to ten percent of all ALS cases a clear genetic history exists. According the Packard Center at John Hopkins, "the disease is classed as autosomal dominant in these patients; that is, that almost half of all family members show an undeniable history of ALS" (Packard Center 2010). Familial ALS cases are caused mutations in the gene for the enzymes superoxide dismutase 1 (SOD1) or copper zinc superoxide dismutase (Miller 2005; Donkervoort 2009; ALS Association 2008). However, sporadic ALS does not have such a definitive cause. Researchers are currently investigating oxidative damage, aggregated proteins, abnormal mitochondria, cell death pathways, axon transport defects, free radicals, autoimmune deficiencies, environment, military service and high glutamate levels (Mayo Clinic 2008; Packard Center 2010; Miller 2005; Kasarkins 2009). Scientists are looking

into other causes of ALS by other gene abnormalities, neurotransmitters (glutamate), environmental causes, occupation, nerve cell inflammation, and lifestyle choices (specifically smoking) (Miller et. al 2005; Donkervoort 2001; Bellingham 2010; Weisskopf et.al 2005; Cronin 2007). Despite the difference in sex distribution of ALS, scientists have not yet considered race as a possible of ALS factor.

Globally, many clinical trials are being conducted to find a cause, explore prevention or create symptomatic relief for ALS patients; there are currently no cures or ways to prevent for ALS. The only FDA-approved drug for the treatment of ALS is riluzole or its brand name, Rilutek. The drug was approved in 1995. Rilutek is aimed at symptomatic relief, prevention of complications and maintenance of maximum optimal function and optimal quality of life (Bellingham 2010). The drug is only estimated to increase life expectancy by possibly one to three months, toward the end of the ALS life span. The drug does not provide symptomatic relief.

One of the most groundbreaking trials thus far has been Jonathan Glass and his team of researchers at Emory University, most recent attempt at stem cell injection into the spinal cord, which began in August of 2010 (MDA/ALS 2010). Like Emory, other research institutions are currently trying to find other clues of this devastating disease. Other trials include using skin biopsies to generate cell lines for the study of ALS, ALS biomarkers studies, a study of electrical impedance myography (measure of muscular phenomena) in search of explanations for muscle weakness and neuron activity, and a myriad of other trials.

The age of disease onset is highly variable, affecting persons as young as 20. It is unknown why certain people develop the disease; however, as previously noted, the disease is more common in men than women by a ratio 3:2 (Miller et. al 2005). The reasons for this are

still unclear. Military veterans are also more likely to contract ALS. In the 1950s, scientists noted an epidemic of the condition among the Chamorro people, a native tribe of Guam (Garruto 1985). A 2010 report released by the ALS Association found that men and women with military history in the last 100 years are at a 60% greater risk of developing the disease than non-veterans (The ALS Association 2008). Doctors and researchers at the Kentucky VA Medical Center (Kasarskis et. al, 2009) suggest that although veterans deployed during the Persian Gulf War exhibited typical clinical ALS features before the war, they actually experienced shorter ventilator-free survival lengths than non-deployed veterans. Other studies are currently being done by the Department of Defense to find the precise connection between ALS and war veterans; however, no significant findings have been discovered.

Chapter 3: Methods and Limitations

The objective of my project is to determine if the illness narratives of men and women with ALS vary based on journey to diagnosis, doctor interactions, disclosure, support, spiritual beliefs, economic concerns, body image, fears, support systems, and explanatory models. The project intends to:

1. Determine how health behaviors (towards terminal illness) vary between genders.
2. Identify the impact of gender on the attitudes of men and women with ALS related to family, emotional support, identity and explanatory models.
3. Understand how individuals cope with an illness with no know etiology, no treatment and no cure

Study Design

This medical anthropological thesis research project is a cross-sectional study of the illness experience of men and women with amyotrophic lateral sclerosis (ALS) and one ALS-like motor neuron disease. The study was conducted in Georgia from 2011 to 2012. There were two aims for this study. One aim was to determine if the illness experiences and explanatory models of men and women with ALS differ. The second was to understand the lives of individuals with ALS, gauge the most salient challenges of living with ALS, and create an ethnographic "snap shot" of ALS illness experience in various diagnosis stages (six months to twenty-four years; walking to completely paralyzed). Qualitative and quantitative methods were used to collect data. Methods included: open-ended interview, coping questionnaire (to assess the ways patients have been coping with their illness) and participant observation at support group

meetings. Nine persons with ALS participated in the study, five men and four women. Interviews were conducted from January to March of 2012. Participant observation was conducted on support group meetings from various support group meetings from January 2012 to March 2012.

Study Population and Enrollment Procedures

The study sample was drawn from the metropolitan Atlanta area and parts of north Georgia outside of the metro-Atlanta area. Originally, the sample size was to include ten participants, five men and five women. However, one of the female participants succumbed to ALS just days before our scheduled interview. The nine participants in this study are of various races, ages, socioeconomic status, marital status, and diagnosis lengths (see table 1; found in chapter 4). The only sampling criterion was gender. Gender was chosen due to the visual demographic characteristics of ALS. Although, there is little research on ALS demographic studies shows that there are men diagnosed with ALS than women. Furthermore, from personal visual demographic observances as a seven-year ALS volunteer and intern with three ALS-specific organizations, I had noticed a greater occurrence of men with ALS and personally never volunteered with a female ALS patient. Lastly, gender was observed due to observances in support group meetings and patient home visits from May 2011 to August of 2011. During the venture of this research/volunteering I noticed significant differences in language, copying styles, and challenges between men and women with ALS.

As an intern with The ALS Association, Georgia Chapter (ALSAGA), I met with the organization's full-time nurse to select a group of study participants. Individuals recruited were called and asked whether they would like to participate in the research study. A reminder call or

email was made the night before the schedule appointment. Signed informed consent was secured at the time of the interview or electronic confirmation through email if individuals chose to email their responses. Three individuals sent part of their interviews electronically.

Participant observation was conducted at support group meetings sponsored by The ALS Association, Georgia Chapter. As the patient service intern with the organization in summer 2011, I attended support group meetings intending to advertise the organizations new program, The Helping Hands Program, and observed patient interactions in preparation for my research project. Group consent was obtained at my first meetings at the Watkinsville, Marietta, and Fayetteville meetings in May/June.

Research Methods

Qualitative and quantitative research methods were used. The research methods were used in this project included: open-ended interviews, participant observation, and the Brief Cope (Carver 1997) questionnaire. The following section describes each data collection method.

Semi-structured interview

Each participant in the study was interviewed one time. Semi-structured interviews lasted approximately 1 hour to 3 hours and were conducted in the participant's home. Every interview began by asking the patient to recall their first ALS symptom: “I'd like to understand your journey to the ALS diagnosis. Can you tell me about your first symptoms?” As the interview progressed, the questions I attempted to use were based on a standard script; however depending on responses each interview some questions varied. As each interview progressed, I made a decision to allow myself to stray from the prepared script of question, based on the

responses in each interview. I explored the following eleven topics throughout each interview. (See Appendix A)

Though I relied on Kleinman's EM, I did not use Kleinman's model verbatim but instead used variations of his questions, such as: What do you think caused ALS in your body? Why do you think ALS started? Kleinman explains that these informal questions regarding one's sickness can have salient clinical significance and moreover, elicit strong emotions that are difficult to express, but at the same time shape an individuals understanding of their illness (Kleinman 1988). All of the interviews were conducted in one sitting unless follow-up questions were required either by email or phone. (See Appendix A)

Participant Observation

Participant observation was conducted at support group meetings sponsored by The ALS Association, Georgia Chapter from January 2012 to March 2012. Seven meetings in Watkinsville, Marietta, and Fayetteville were attended. Attendance at the meetings varied from 10 to 20. Meetings are held monthly at each of the locations and four other locations provided by ALSAGA. The meetings were mixed by gender with more women in attendance in all counties. Meetings were attended by persons with ALS, caregivers (often spouses), widowers, and professionals from various technological services (i.e. wheel chair companies, home healthcare, etc). The Watkinsville meeting has been held since 2007 and the Marietta/Fayetteville meetings since 2005.

All support groups were facilitated by the part-time and full-time nurses of the ALSAGA for two-hour periods. The support groups in Watkinsville and Marietta typically started with a welcome, then introductions/updates from attendees, presentation (i.e. ALS Clinic nurses,

hospice provider, home remodeling company, etc), and finally lunch provided by one of the professional organizations in attendance. At the Fayetteville support group meetings, meeting format typically consisted of introductions/updates, question and answer session (typically among the attendees), and lunch. The meetings were typically very casual, allowing for those in attendance to communicate frustrations, share advice, and support one another in any capacity. There were no ground rules for the meetings. In theory, attendees were able to say whatever was on their mind. I did not audio record support group meetings, at the request of the individuals in attendance. I wrote brief field notes during the meeting and extensive field notes immediately after.

Brief COPE Questionnaire

As a quantitative measure each respondent was given the Brief COPE Survey by C.S Carver at the end of the survey (1997). The Brief COPE is a questionnaire used to assess a number of different coping behaviors and thoughts a person may to a specific situation. The questionnaire is typically "self reported", however, due to the range of abilities I knew I would encounter, the questionnaire was done verbally. The Brief COPE is an abbreviated version of the larger COPE Inventory by C.S Carver. Carver writes, "we created the shorter ten set partly because samples become impatient at responding to the full instrument" (Carver 1997, 93). In the interest of combating participant fatigue, I chose the Brief COPE because it was meaningful, thorough and short. The questionnaire took no more than fifteen minutes. The scale contains scales that measure psychosocial fifteen variables including: self-distraction, active coping, substance use, denial, use of emotional support, use of instrumental support, venting, behavioral disengagement, positive reframing, planning, humor, acceptance, religion and self blame

whereas the COPE Inventory has 28 scales). I would describe the situation to the persons with ALS and then asking them to rate the frequency of use 1 ("I haven't done this at all) to 4 (I've been doing this a lot) for each behavior described.

The questionnaire has been cited as useful among breast cancer patients, patients with dementia, severely mentally ill and young adults sustaining spinal cord injury (Carver 1997, Cooper 2008, Meyer 2001; Augutis 2011). Carver cited the reliability of these questionnaire to be ∞=0.57 -0.90 and in a study with a populations of parents with children with autism spectrum disorders the reliability was ∞=0.54 to 0.93 (Carver 1997, Benson 2009). (See Appendix B)

Data Analysis

Both qualitative and quantitative data were collected to obtain a complementary understanding for each gender's ALS illness experience. Manual coding and data analysis were performed for both qualitative and quantitative data.

Immediately following interviews and support group meetings, detailed field notes were prepared. I outlined key themes of each discussion in yellow or orange highlighter. Later, I returned and highlighted themes that I found for each gender in blue (men) and pink (women). Later, I re-listened to interviews, and reviewed and highlighted select quotes. These quotes were transcribed into a Microsoft Word document and coded to indicate the theme(s) present. This qualitative data was used to identify differences and commonalities in explanatory models, behaviors and illness experiences among men and women with ALS. This analysis also generated commonalities that were universal to persons with ALS. Questionnaire data was analyzed by the 14 major scales, using Microsoft Excel. Following, Carver survey results were inputted into a Microsoft Excel spreadsheet using the person with ALS' pseudonym. The results

were stratified by gender.

Limitations of this Study

Despite careful study design and data collection, this study is subject to certain limitations. The majority of limitations are related to methodology used during interviews. First, I am not a professional interviewer. This did not affect my interviews overall; however, I acknowledge that supportive statements and responses I offered to individuals who expressed anguish or anger when answering a question may have placed certain limitations on this study. Because I wanted the person to feel better and stop crying or yelling, I may have limited their responses by not probing for further information in these moments. Second, when I first began interviewing I was very nervous and unsure about how to talk with a person about his or her terminal illness. My own fear and nervousness dissipated as I continued the interview process; however, I believe that the first three interviews I completed were minimally limited in comparison to later interviews.

Study participants are not representative of all ALS patients in the world. As such, I cannot generalize about gender disparities among all ALS illness experiences based on my interviews with five men and four women with ALS. Future research should include a larger sample of participants and utilize both qualitative and quantitative methods. Completing life illness narratives with persons with ALS and employing a greater range of surveys focused on coping, doctor-patient trust, social support, and a quality of life assessment could improve qualitative methods.

Chapter 4: ALS Stories

"The body can no longer can be taken for granted, implicit and axiomatic for it has become a problem" Robert Murphy, The Body Silent (Murphy 1987, 13)

This chapter introduces nine persons with ALS who describe their experiences with ALS: prior to diagnosis, the journey to diagnosis and living with ALS. These nine individuals have varying experiences although they share a common finding: living with ALS is unequivocally and often an insurmountable challenge. Specifically, data collection methods yielded quantitative and qualitative data from five men and four women living in Georgia. Quantitative data will be presented in this chapter to provide both group, gendered, and individual attitudes and behaviors of persons with ALS. Demographic data are presented on each person, using pseudonyms. The author has chosen to use pseudonyms to emphasize the humanity of individuals with ALS; they are not just subjects, but people. Observations from support group meetings will follow each pALS short narrative. Results from the Brief COPE questionnaire will be presented at the end of the chapter.

Demographics of the Study Population

Below are the demographic data of the men and women interviewed in this study (Table 1 and 2). Each table includes gender, age, race, perceived socioeconomic status, marital status, number of children/grandchildren, level of education, veteran status and length of diagnosis.

Table 1: Demographics of male respondents

Male Respondent:	Tyrone	George	Darrell	Doug	Steven
Age	42	37	62	62	54
Race	Black	Latino	White	White	White
Estimated socioeconomic status	Lower Middle Class	Middle Class	Upper Middle Class	Lower class/Upper class*	Middle Class
Relationship status	Never married; dating	Married	Divorced; not dating	Divorced	Married
Children	3; 2 son & daughter	2; son and daughter	2; adult sons	3 adult kids; son and 2 daughters	No children
Grandchildren	1 Grandchild	None	None	None	None
Highest level of education	High school	College	College	College	High school
Veteran	Yes	No	No	No	Yes
Length of Diagnosis	3 years	7months	2.5 years	6 months	24 years

Table 2: Demographics of female respondents

Female Respondents:	Sarah	Krystal	Florence	Kendra
Age	41	35	62	61
Race	Black	White	White	Black
Estimated socioeconomic status	Lower Middle Class	Upper Class	Upper Class	Upper Middle Class
Relationship Status	Never married; dating	Married	Married	Married
Children	One adult daughter and 1 adult son	One young son	3 adult daughters	1 adult daughter and 1 adult son
Grandchildren	Grandson	N/A	8 Grand-children	3 Grandsons
Education level	High school	College	College	Graduate Degree
Veteran	No	No	No	No
Length of Diagnosis	1.5 years	5 years	6 years	4 years

Table 1 and 2 indicate the comprehensive distribution in all categories. Study participants ages range from 35 to 62 and have been diagnosed with ALS between six months and twenty-four years. Asterisks present in the demographic table will be explained in each individual narrative (i.e. Darrell).

Narratives

This section will provide brief narratives of each person with ALS. The narratives of the women will precede the narratives of the men from youngest to oldest participant.

Women

Krystal

Krystal is an author, wife, and mother of one five year-old son, Will. Our interview was mostly conducted via email and through a short home visit. Krystal is no longer able to speak and is nearly paralyzed, other than movement in her toes and head. She spends most of her time in bed; that way she is able to communicate through SmartNav software on her computer. Nevertheless, Krystal has a power chair that she is able to get in a couple of times a week to go to Will's karate practice. In Krystal's answers she wrote, "I'm at the point now where I need help with everything", which was definitely confirmed during my home visit. On the day of my visit Krystal's husband James (who is a proprietor of a law firm, real estate company, non-profit CEO of an ALS foundation, and book company) was preparing his wife for our meeting and instructing the new nurse on Krystal's care.

It was emotional to watch thirty-five year-old Krystal ferociously cough up mucus for nearly ten minutes. Due to her weak lungs she is unable to cough up mucus that falls into her trachea and requires that someone immediately suction out the mucus. Through simple observation anyone can see that Krystal's life has changed drastically since being diagnosed with ALS when she was twenty-nine years old. I asked how her life has changed since being diagnosed with ALS,

> It would be easier to answer what hasn't changed, since no part of my life remotely resembles what was. I am still able to do everything I could a year ago, which is actually pretty amazing. I'm still using SmartNav to navigate my computer and have complete use of all the programs. I'm still breathing on my own during the day only using the vent at night in place of the bipap [colloquial term for a BPAP, a bilevel positive airway pressure, for a breathing machine that delivers air into the lungs], and I am so grateful to be rid of that mask! I can still get out and about with the help of my power chair, van, and the travel suction kit.

Krystal attended Georgia Institute of Technology and majored in Computer Science. After

graduation, she married her high school sweetheart, James, and worked as a software engineer for seven years. She played competitive soccer during this time, continuing until she discovered she was pregnant. At the time of her ALS diagnosis, five years ago, Krystal had just entered a brand new phase of her life, motherhood. When her son was 6 months old, "I came to the heartbreaking realization that I could no longer safely care for him on my own. ALS affected my hands and arms first and I was terrified of causing him injury." Krystal's narrative is interwoven with thoughts of motherhood and the affect her disease has played on that role. Alli, who began as her son's nanny, is now both Krystal and Will's primary caregiver.

During my visit, Krystal explained that she is a type A personality and she said, "I hate being a spectator". Later she wrote, "I am so thankful for my son, but it's hard to be content with such a diminished role. There are so many things I am missing out on. I do have a voice in how [Will] is raised, but it's not nearly enough." Her son's name was written throughout her narrative twenty-eight times, while husband/James was on mentioned eleven times. Her connection to Will is very strong, referring to him as "the most beloved person in life". Her biggest fear is that Will might not have clear memories of her. Before her voice was affected she recorded a number of lullabies and narrated a few books so that Will could always hear her voice. She also writes in a journal so that he can get to know her when he's older and writes letters for her son to read at different ages and milestones that she will not be able to share with him. She noticed her first ALS symptoms while pregnant with Will but her doctor attributed her symptoms to her pregnancy.

After her son was born her entire left arm was weak. She made an appointment with a specialist who immediately diagnosed her with ALS, which Krystal attributes to the fact that the neurologists' father had ALS. Immediately angry she went to the Emory specialist for second

opinion and insisted on every test in hopes of another explanation. When none was found she even went to John Hopkins for a third opinion to no avail. Krystal explained that she did not accept her ALS diagnosis until she began taking the drug Rilutek. “Taking the drug meant that I would no longer be able to nurse my son. It was an acknowledgement of both the diagnosis and the fact that an important part of being a mother had been taken from me.”

Krystal’s explanatory model of her illness is unique to her current experience. Since she can no longer verbally explain her illness to other people she now has an informational sheet on ALS that she attaches to her power chair. The sheet has ALS written in a large font with Amyotrophic Lateral Sclerosis and "Lou Gehrig's Disease" written underneath. She also invites readers to read visit her website to earn about her foundation and children’s book. Her theory of the cause of her illness was that during her first trimester of pregnancy she interfered with the changes that a woman’s body goes through and somehow they “got flipped”.

She wrote, “It just feels like too much of a coincidence that I started showing symptoms four months later.” However, she has no explanation for how ALS works in her body other than what medical professionals have suggested regarding connections to the brain and muscles. As far as treatment, Krystal takes an ALS experimental (not FDA approved) drug, Rilutek, ALS symptom specific medication and several supplements. However, she noted that physician should provide treatments that improve quality of life. To an extent Krystal’s faith has not wavered because of her illness. She was a Christian before diagnosed and had a strong faith base. She wrote, “When I say my prayers, I honestly don’t pray for a cure. I pray for patience and strength. I pray that my husband and son remain healthy. I pray that Will will always know how much I love him even though I haven’t been able to give him a hug or kiss for years. I pray future families will not have to endure this loss.”

Sarah

Sarah is a 41 year-old black mother and grandmother living in Atlanta, Georgia. She recalled having her first ALS symptom about twelve years ago when she felt her legs becoming restless while working. As the owner/founder of a successful cleaning business she was constantly on her feet. After several years Sarah went to the doctor and the doctor diagnosed her with an autoimmune disease called polymyositis. She described it as an autoimmune disease that was her doctor's explanation for the weakness in her legs. The doctor she saw prescribed steroids and chemo medicine, yet Sarah said she continued to get weaker. After a year her rheumatologist suggested she see a neurologist. The neurologist conducted a nerve biopsy and EMG and shortly after diagnosed her with ALS on November 30th, 2010. She remarked that the doctor was very good but he still sent her to the Emory ALS specialist for a second and definitive opinion.

Currently, Sarah is still able to move but with a walker. The biggest challenges for her have been constant fatigue. She has a hard time breathing and swallowing. Her close friend whom she calls a sister (who was in and out during our interview) noted, "Her voice had gotten heavier". Three weeks before our interview Sarah had recently visited the Emory ALS Clinic and found that her breathing had gotten worse and was prescribed a Bypap machine to use during the night. Furthermore, the Emory specialist highly recommended that it was time for Sarah to get a feeding tube-a development she vehemently opposes. Though eating is difficult, she explained that if she takes her time she is able to eat what pretty much anything. She expressed that getting a feeding tube "Will be the last thing I do." I asked why, and she quickly shot back, "I still have a little diva in me!" I asked Sarah what she meant by "diva" and she mentioned that

she used to love shopping for really nice clothes, make-up, shoes, and getting her nails and hair done. Along those same lines, she ardently misses going to the nightclub, which she does not attribute to her disability but to her weight gain. The Emory specialist suggested that she eat all she wanted as treatment for her ALS. Because of significant muscle atrophy, which causes extreme weight loss, often ALS doctors suggest patients eat a lot to keep their weight up. However, Sarah lamented that she used to be very skinny and hates that she has gained so much weight. Therefore, despite doctor's suggestions, she confessed, "I've cut back on sweets to lose some weight." She wishes she could work out more, but due to muscle weakness she is not able to walk without significant support from a walker or, at times, her motorized scooter (which she only uses in the apartment complex). Sarah admitted to me that she recently has been having cramping feelings in her arms but she is afraid of telling her Emory neurologist.

One of Sarah's principal fears that mentioned was completely losing her independence. But more than that she fears missing watching her children and grandchildren grow up. Sarah is in love with her grandchild, Brandon, who lives with her along with her daughter, Mary. While I was there Brandon accidently got a cleaning product in his eye and Sarah was adamant that her daughter immediately attend to his red eye. She even asked me at one point if I thought his eyes were going to be okay. Eighteen month-old Brandon would crawl into the room and Sarah could not help but give him love and attention. She explained that she was afraid that Brandon would not remember who she was, which breaks her heart. She says that now she tries to make as many memories with her grandson that she can. She says she reads to him, sings to him and takes him out around Atlanta.

> I want to see my grandkids grow up. And spend a little time with them. I fear that I may pass and like Brandon may not have enough of a memory of me. So I try to make a lot of memories with him as much as I can…I sing to him, I read to him, when [boyfriend] comes in town we take him out. We

> take him out to see the Christmas lights, take him to the zoo, and take him to the aquarium. We will probably take him to the circus this week.

She is afraid also of what is going to happen. Her voice dropped and she said, "It says that you could be laying there completely paralyzed and can only move your eyeballs. My fear is what's going to happen, not the dying. Sometimes I think and you may think its crazy that when I start progressing like that that my family will give me something to take me out so that I won't have to lay there suffering." Sarah admitted to having thoughts about assisted suicide when she becomes totally dependent on someone else for care.

Even though she has ALS, Sarah says she stills tries to go out, but not nearly as much because of mobility. Although she has a scooter she remarked that it is not safe because she's flipped over in the scooter on multiple occasions. The Emory doctor keeps emphasizing that Sarah use her power wheelchair. Her insurance provided her a $33,000 power wheel chair but that she is adamantly against using the chair until the day she is completely dependent and absolutely needs it. I asked her if her reason behind not using the power wheel chair was the diva coming out and she laughed, "Exactly. You got it. You are learning. You are learning. I am not getting in anything like that. Uh uh. And if I did and I think I would do, I have been thinking about it I would only use it in the house, I'm don't think I would go out in it. And I may start doing it just to keep that thing charged." Our conversation got interrupted several times by her "play sister" (a close friend she refers to as her sister) who was assisting her with laundry. She was very concerned about her lingerie being washed appropriately because her boyfriend was coming to visit her for Valentine's Day. She met her boyfriend, who lives in Bermuda, online several months ago. Sarah admitted that she was very nervous to meet him at first because, "I don't know really know too many men that want to be with a sick woman. I just felt that if he

knew I was sick and my mobility was low that he wouldn't want to out with me. But it was totally opposite." Nevertheless, she eventually told him. She explained to him that she had muscle surgery (preferring to the muscle biopsy performed during to determine ALS diagnosis), was diagnosed with ALS a few and that it only affected her legs. She suggested he should do his own research. Sarah doesn't mention that her disease is life limiting. To others she describes her sickness as "I would just say that it's a disease, a terminal disease that you know our brain signals, to work our muscles that with ALS the nerves don't signal the muscles and they die slowly. And mine at this point only affect my muscles. Or I just tell people to look online". She has been dating her boyfriend for eleven months and gushes when she talks about their romantic vacations around the United States. She explains that he handles her very well. "I get depressed and I cry sometimes and I get it out and then I get back to my business." She says that she keeps her spirits up because her ALS is moving slowly. Sarah expressed that she does not feel sick, just tired. "My fear is what is going to happen. I don't want to lose my independence."

Sarah is a Jehovah's Witness and regularly attends a Kingdom Hall near her home. She found out about her diagnosis after she was baptized as a Jehovah's Witness. She mentioned that she has a group of spiritual sisters at the Hall that support her and keep her spirits up. She also has Bible study in her home or with her spiritual sister on a regular basis. One of her spiritual sisters went with her when she got ALS diagnosis. She says that her faith has helped her a lot and attends service regularly at the Kingdom Hall. "I get depressed and I cry sometimes and I get it out and then I get back to my business".

Kendra

Sixty-one year old Kendra is a wife, mother, grandmother, and award-winning

elementary school teacher in Georgia. Her symptoms lasted from 2004 to 2006 before she saw anyone. She thought that she was out of shape so she began to exercise with a physical trainer to help her lose weight but the problems still persisted. After a while she started stumbling and falling. Her biggest concern occurred when she realized she couldn't turn the wheel of her car. She had a huge accident in 2006 when she got stuck in the middle of traffic because she could not turn the wheel because of weakness in her right arm. She was afraid because there was huge tractor-trailer that was coming in her direction. She managed to turn the wheel and get out of traffic. After the incident she went to see the first neurologist with whom she had a bad experience.

> He had a real bad attitude…because I had difficulty getting up from a seated position. He wanted to test if I was HIV positive and all this other stuff. I felt that his motivation was more racially motivated than medically motivated. I'm usually spot on with situations like this…Even my trying to get up from a seated position he wouldn't assist me. Most people would say let me help you with that. So I didn't want to go to him anymore.

She was disgruntled about this situation and stopped seeing the first neurologist. He felt like she had ALS; however Kendra does not consider his observations a diagnosis. She visited the Emory ALS clinic where they completed several test like a muscle biopsy, EMG test and MRI. She found that the Emory doctors were much more receptive and received her first official diagnosis in January of 2008. She lamented that she had to stop school (she was working on a doctorate, but she was unable to drive and it became too difficult to continue her studies). I asked her about her initial feelings and emotions regarding her ALS diagnosis and she disclosed,

> I didn't think about it that much. I really didn't. I didn't think about it that much because in terms of my mobility I couldn't drive but that didn't make a really big *big* dent in anything because I still went wherever I wanted to go, if we wanted to run out and go to dinner or wherever we wanted to go we still did that and all…so i didn't feel like I was trapped or anything. But as the illness continued to progress then I started to…one starts to come to grips with there own reality and that was the part that made me, you start

> planning things a little differently. And you see your family a little differently.

She says that her relationship with her husband has stayed the same because they both understand the ups and downs of marriage.

> There's a great deal of strength in the relationships that we have….we understand each other and understand what a marriage is and don't fantasize about any part of it. We just deal with the nuts and bolts of everything. We enjoy traveling and we both enjoying the same kinds of music. We like the same politics...we are still friends. So friends can fall in and out of love with one another but we are still friends, which is what kind of seals everything.

Nevertheless she admits,

> I think it's been harder on him than it has on me. Because he has had to come to grips with things. You know he has to make special accommodations if we do travel….how we travel, if we travel, if we travel with someone or not with someone, its made a difference because we didn't have to factor those things in before.

She explains that she worries most about him once she passes because of their strong friendship. She tries to prepare him for her passing because she wants him to live his life after she is gone. Kendra does not really have a fear of death because she truly understands that "death is a part of life and that we didn't come here to stay". Her strength with her illness is obvious though she says that her diagnosis has been hard on her two adult children, her son that now lives with her and her daughter that lives in Italy. Her grandchildren on the other hand are not very aware of her sickness and just think that she is sick. Tears came to Kendra's eyes when she discussed her grandchildren. One of her grandsons, whom she describes as "extremely intelligent," wants to write a children's book with her. While she can still talk she wants to record each of her grandchildren a special message for special occasions in their life.

Her strength with her illness comes from the fact that both of her parents are deceased and that her father was a Methodist pastor. Kendra explained that living in a Christian home definitely shaped her understanding of life and death and has furthermore helped her quickly come to grips with her illness. "My worldview is very different than the average person" she explained to me. She believes that she is helping everyone around her cope and prepares her family "taking it one day at a time". She expressed that she did not respond negatively to her diagnosis because she understands that life is terminal. "ALS is terminal, so is life. That's my outlook."

Kendra takes medication for hypertension and diabetes but no ALS medication. She explains that Rilutek is insanely expensive, costing $1,800 a month for a pill a day. She expressed that she feels underinsured because she has to pay for her caretaker who comes for five hours everyday and a hospice service that sends a caregiver six days a week to give her a bath. She thinks that ALS physicians should improve quality of life for ALS patients. Kendra believes she may have gotten ALS because of an overproduction of gluten or simply "the luck of the draw". She quickly avoided the questions and explained that it is not how she got the illness, but rather how she is living with the illness. She still vacations with her husband (recently attended to the MLK Memorial ceremony in DC), throws parties in their home, shops, and gets dressed up.

She admits, "I don't have the same level of control of my life. I can't just go see a girlfriend if I want to". However, her love for shopping --"I love to dress up and get cute" -- has not changed. She even found a young lady who works as a stylist who comes by and styles her. She shares the following story:

> I took her with me one time shopping. *gasp* I like shopping with her…But when Kim comes by here I go anywhere. Kim doesn't care how

> much of my money I'm spending. We went accessory shopping one day and she has such excellent taste and one night my husband I were going out. We were going to dinner we were invited by our state senator and of course I was in the wheel chair, but by the time Kim got done hooking me up, I was just too cute…I was just too cute in my little make up and everything.

Though she does not do the things she loves as often she still does them. She expressed that her femininity has been challenged in ways. For example, when the hospice caregiver was moving her to the bed she was disgruntled that her "pocketbook was exposed." She admits that events such as the before mentioned are challenges but nevertheless "The girly things about me have not changed. The disease has not changed my spirit. Only the outside has changed."

Florence

Florence is sixty-two years old with a unique motor neuron disease, PLS. According to the Mayo Clinic Primary Lateral Sclerosis causes muscle nerve cells to slowly die causing muscle weakness in the voluntary muscles (Mayo Clinic: Primary Lateral Sclerosis 2010). Similar to Krystal, Florence and I conducted the majority of our interview via email and had a short home visit. Florence and I first spoke on the phone a month before our interview. It was obvious that her illness had impacted her voice because it was very difficult to understand her. I was able to explain to her my project and with much effort on my part to understand her, she asked me for my email address and explained that she could email me. As soon as I hung up the phone she quickly emailed me saying, "As you can see, it is hard to understand me. I would do the questionnaire through email." Within weeks she quickly sent back her responses and we scheduled a home visit.

An ALS diagnosis for Florence was rather slow, taking more than a year (mid 2006 to August of 2007). She first noticed symptoms in her left foot which caused a slight limp which

she did not think too much of. While at a routine visit with her primary care physician, Florence shared the slight limp and the fasciculations (muscle twitching) in her arms. Her doctor suggested she see a neurologist. In October, she saw a first neurologist who had no diagnosis and after many tests suggested she come back in a month. This "come back next month" routine became tiresome for Florence so in March she stopped going to the first neurologist and attended the Emory ALS specialist in April. She mentioned that he was "a little more aggressive and started running test." After a spinal tap and a nerve conduction test she was diagnosed with PLS in August of 2007. Florence wrote,

> I had never really heard of ALS or PLS and after the second neurologist suggested that I might have it, I started reading about it and of course the prognosis was not good so I was very worried. When Dr. Glass confirmed it was PLS, naturally I was upset, but somewhat relieved at the diagnosis of PLS as opposed to ALS. Neither are good, but mine has definitely been a slow progression.

Nevertheless, Florence refers to her diagnosis of PLS as ALS. I asked her how she understood her illness and she explained that PLS affects the upper motor neurons and not the lower neurons, whereas ALS affects both. She also mentioned that PLS patients do not have muscle wasting or atrophy. However, many of the symptoms are the same such as, speech, walking, and spasticity. Another difference she mentions is that ALS patients have fasciculations and she does not (although when diagnosed she noted fasciculations). She explained,

> I have read that life expectancy can be normal. But I am not an authority by any means. I'm not 100% sure it is PLS but everything I have read, it sounds like it. Mine is slow progressing, which is another factor.

Unlike persons with ALS, Florence's illness is not life limiting but it will ultimately still leave her paralyzed. She has no idea what caused her PLS, but does consider there might be a

genetic weakness of the neurological system component because her father died of Parkinson's disease. She remarked, "Who knows? When you ask the doctor, they can't give you an answer. And I have no idea why it started when it did. They can't answer that either." She is also not sure what kind of treatment she should receive but believes a cure would be nice. Florence goes to the Emory ALS Clinic every six months and takes baclofen (for tight muscles), a high blood pressure medication, a high cholesterol prescription, and a drug for her osteoporosis. She also takes a mix of multivitamins, vitamin D, E, calcium and fish oil, which she says she took before the PLS. She also sees her primary care physician regularly for checkups.

The first to know of her PLS symptoms were her three daughters. Her three adult daughters are all mothers of two or more children. She wrote,

> One thing that is very frustrating to me is not being able to interact with my grandchildren. They can barely understand me and it breaks my heart. That is one of the most frustrating things about this disease for me is not being able to help my daughters with their children.

During my visit I asked Florence how she coped with not being able to help her daughters with her children and she began to cry uncontrollably for five minutes. Unfortunately we were unable to return to the question because it deeply bothered her. The pain of not being able to communicate with her grandchildren and be the grandmother she wants is obviously overwhelming. When I visited Florence her assistant Betty, whom she called "wonderful", was there to assist her. She says that ALS has affected her life in every aspect. She is no longer able to get around as much, talk, walk without a walker, cook for herself, and drive herself or complete household tasks. She is thankful that Betty is able to assist her with these tasks now. However, since she still has use of her hands (albeit slower) she is still able to dress herself in the

morning, sew (one of her favorite hobbies), and puzzles: crossword and jigsaw. She emphasized that her mind is still sharp and she tries to keep it stimulated as much as she can. During my visits she mentioned that she really misses getting dressed, going out and wearing heels. She can still do her own hair and makeup but she does not go out anymore. She expressed, "I am very dependent. ALS takes away your independence". Despite, Florence has a very warm disposition regarding her illness, which is evident in person and throughout her narrative. I asked if her Christian background she describes in her narrative influences her positive attitude and she "Definitely yes". She wrote, "I do have spiritual beliefs. I have gone to the Methodist church all my life. Having faith in God helps one cope better I think".

Men

George

Thirty-seven year old George was my first and my most receptive interviewee. We had built a past relationship working at the ALS Association of Georgia, which allowed for us to build a relationship, which I'm sure made it easier for him to participate in the study. George is Ecuadorian, a father of two children, a husband, a former manager of Publix, and a proprietor of a business renting recreational equipment. When I arrived at George's house he was sitting in his office and his wife answered the door. Since I last seen him his ALS had progressed. He was now using a walker instead of a cane that I had seen him use four months prior. George experienced his first symptom in his right leg three and a half years ago. Furthermore, he demonstrated a significant lack of coordination and overall weakness. Over the next sixteen months he saw five doctors. The first diagnosis he received was radiation necrosis (a tumor lesion requiring radiation

and/or radio-surgery), which doctors attributed to a previous AVM he had at 19. An AVM (arteriovenous malformation) he explained was an abnormal connection between the arteries and veins in the brain, which usually appears before birth. Doctors in Ecuador found the AVM and required him to leave his homeland, Ecuador, and travel to Mexico for surgery. He explained that they inserted balloons in his brain to prevent a fatal cerebral rupture. In search for answers in 2010, he saw three neurologists at first. He explained:

> We felt that we almost had to pull teeth to get these doctors to believe me that something was wrong. They rely so much on equipment and testing that are great but sometimes you have to rely on us, in my opinion what the patient is saying…they wouldn't pay much attention to the symptoms…A couple of them would say your MRI looks good you don't have anything. Maybe its stress. But I knew something was wrong.

Finally, he visited the fourth neurologist, a woman. He explained that he was very happy with her because she listened to him and was the first to really do something and give him real answers. The female neurologist referred him to the Emory ALS specialist where he was formally diagnosed on July 13, 2011; diagnosis, an eighteen-month process.

Currently George has overall weakness in his right arm, leg, and hand. H3 laments that his left leg and foot are starting to become weak as well. He has muscle spasms at night and fasciculations daily but they are not always painful and he has gotten used to it. He emphasized that they were not painful and that when he does have pain, he quickly overcomes the feeling. Currently George needs support to get up in the morning. He uses his walker to go to the bathroom but he needs help showering and taking care of "all of my hygiene regimen". It's hard for him to go up and down the stairs in house as well. Typically once he comes down in the

morning he stays down the entire day. George explains that it is very frustrating because he can't do things on his own anymore. When he goes out to the store he has to stay in the shopping scooter and he can't reach things for himself. He also becomes uncomfortable when others stare at him. He knows he is very young, and he looks young, so it is hard to be stared at. It's extremely hard for George not to be able to do things for himself and for his family. He explains that he was very dependent on his family. I asked if George felt that ALS had challenged his masculinity in anyway and he affirmed again that he was insecure with his personal looks. He wasn't fat before but he said he has gained weight in his stomach. He also says that it hurts him to get a disability check. He says that the "benefit check", as he calls it, is something he'd rather earn on his own. His pride is threatened when he gets the check every month; however, he knows that it helps his family pay the bills tremendously.

He does not feel like he is getting any benefits from going to clinic, although he's only been twice. He expresses that he is more of a help to researchers.

> What am I really gaining on these visits? Did I gain anything last time? and the answer is always no. We know there is no cure. If anything they are getting data from me so they want to see my progress…I'm not sure if I'm going to help for research or I guess its a two way street so I'm not sure.

Clinics, he expresses, are very long and a waste of time, but he remarks that the staff is really nice. On one of his visits he explained that he was given a sheet of paper by an occupational therapist and was told to "try these at home." Clinic doctors offer him medications for symptomatic relief, but he refuses all of them. Though he does not know an exact treatment for his condition, he expresses that they should the patients something that will help them feel better. I asked George how he got ALS and he replied, "If I knew the answer we'd have the cure. I have no idea". He does not explain his disease to other people and leaves it at, "I just say I have Lou Gehrig's."

Throughout his narrative he often refers to everything as "we": "When I say we I refer to me and my wife who has been walking me through this journey". His wife, Joy, has truly been his strongest supporter through his journey with ALS. Joy walked out a few times to check on her kids but for the most part she participated with the interview either joking every now and then or filled in the blanks when George could not remember a detail. Joy joked

> We have had a lot of speed bumps in our marriage…but now its just like you just think all that stuff is just water under the bridge compared to now. Those same irritations could still come up but you just grit your teeth and just say 'whatever'.

Before ALS he had a very stressful job working at Publix as a Store Manager. He said the pay was really good but that it was high-demand, long hours, and kept him away from his family. He said the job took away from his sleep and he didn't sleep much or if he did he didn't eat well. He said while working at Publix he also developed hypertension and high cholesterol. Now that he has ALS I asked George if he had made any lifestyle changes and he said that it's physically challenging to go to the gym so he doesn't which he thinks is the reason he's put on weight. He is really upset about his weight gain. He also said that his life is really boring now and "now there's a stop sign in his face".

Throughout the conversation George kept mentioning his faith but never directly said he was a Christian or believed in God or any higher being/deity. I asked him about his religion and how or if that has been a support for him since being diagnosed. He said he and his family attend a Baptist church. However, George then began to sob. His wife stepped in and began to explain that the AVM George had at 19, was something he was born with and he survived it. While George composes himself his wife explains:

> I don't know if he told you The AVM is congenital, so you were born with it. so to be born with something that is life threatening and survive it is a

> miracle….so typically it's discovered at death…then to have this, now for him it's like Why God? Why me?…he worked very hard a Publix and dealt with our kids health…I was the rebel. He was the good boy.

Also, his children have had numerous health issues and Jennifer expressed that their marriage has had its "speed bumps" as well. However, they overcome all those things. But to be faced with an absolute death sentence is hard for George to reconcile she explained. He feels like "Why me, God?" He sees people close to him doing the wrong thing and not being a good Christian but yet they are living the life and now he has an incurable disease. Throughout her explanation George cried more and more and even Jennifer became teary-eyed. Everyone including myself took a moment to collect themselves and George wiped his eyes and began to explain that he knows people that are dishonest, that he put 110% into his career, tried to provide for his family but then God punishes him with this disease. Sometimes he is really strong in his faith but other times George explains that he can't but help to be upset with God.

Tyrone

Tyrone is a father, former semi-pro football player, and veteran. Tyrone is a man of very few words. The TV stayed on ESPN so to I asked Mr. Terry if he was happy about the Patriots and the Giants and remarked that he was highly "pissed off" about the outcome. He explained that his first symptoms were in his left arm in September of 2008. "I was losing strength in my arm, they were getting little." When he realized something was wrong he immediately went to the doctor and was misdiagnosed. They said he had spinal infection and forced Tyrone to undergo surgery in February of 2009. He knew something was still wrong because "I used to go to sleep my hands would get numb. So numb that it would wake me up." A year after the surgery he continued to have symptoms and his right arm started to get week. He mentioned that he

noticed these symptoms because he was playing semi-pro football with the Atlanta Prime. He emphasized that he used to weigh 215 pounds but now he weighed no more than 155. As his symptoms progressed after the surgery he went to Grady to for his first official diagnosis from "some Emory interns...I could tell they weren't no old doctors." After Grady diagnosed him in September 2009, the doctors sent him to the Emory ALS specialist for further consultation. After his surgery and diagnosis he did not try to and play football any longer be cause because he didn't have his strength any more.

He has never taken Rilutek and does not take any medications. I asked if his lifestyle changed in anyway and he mentioned, "Honestly, I used to smoke marijuana but I don't anymore…I don't think it would help. It would hinder me more than it would help…never smoked cigarettes." He mentioned on several occasions that he was "buckwild." When reminiscing on the partying days he definitely smiled.

> I mean I partied a lot…I just partied a lot. We drunk when we went out. I was never the guy that can drink before dawn. You know the guys that drink in the morning, I couldn't do that [but] we went out regularly, Thursday to Sunday.

He explained that he stopped going out because, "I can barely carry myself anymore."

Getting Tyrone to talk was exceptionally difficult. He kept his answers brief and simple. Within the first twenty minutes of our conversation Tyrone mentioned his former 215-pound muscular build body ten times. Out of curiosity I asked him to show me pictures of what he looked like before and our interview took an incredible turn. Tyrone began showing me picture of his mom and paternal grandmother, pictures while stationed in the Germany, pictures of he and his friends partying and many more. While describing the pictures he expressed "I'm not tryna brag or anything but I use to be able to do anything", Tyrone asserted. He needs help

cooking, bathing and getting dressed, especially for church. If he needs to bathe he has his girlfriend, Beth, assist him and he always needs one of his kids to be home on Sunday morning to help him dress for church. He feels bad expecting so much from them.

> Ah man, that's the worst, that's the worst. That's terrible…Cause the family used to depend on me. You know what I mean? Any time the family needed something they'd call Tyrone…my kids are kids they shouldn't have to take care of anyone.

If anyone needed anything they would just say "Call Tyrone" and now he people can't depend on him because of his sickness. "I always been the guy, man come on man, give him a dollar", Tyrone like to give people and says that even still he likes to help those that are "weak".

Tyrone portrayed an invincible attitude and feels that ALS is something that he would soon overcome. He admits that the hardest thing for him is no being able to do the things that he used to do. "I hate not doing the stuff I use to." However, he says that he is coping with it by "rolling with it." He doesn't let it bother him too much. I asked what he calls his disease when he talks to people and Tyrone only tells people he is sick. We returned to the topic of him being "buck wild" and I asked him why he thinks he got ALS? He remarks "The Lord was trying to slow me down." He was getting into trouble, having bar fights and selling drugs with his father who is now incarcerated. I asked what his treatment plan was and Tyrone quickly asserted, "I think I'm gonna beat it. I think I'm finna come out of it. I have faith in the Lord that he gonna heal me." He says his mother gets mad at him because when she calls she ask how his ALS is progressing and he responds, "What ALS?" He does not think he has a life-limiting disease but rather he is sick. He goes to church on the Southside at Springfield Baptist Church and explains that he hadn't always been religious but was again "buck wild". He mentioned that he rejoined the church two years before he got ALS but he didn't start going regularly. He even said,

"What's crazy is I joined the church two years before the ALS". Now he's an active church member, participating in many fundraisers for his church. Despite almost complete loss of arm strength he still drives his Cadillac to church every Sunday and multiple times during the week. When he sees guys that he sees church members and guys he played football with before his ALS diagnosis they always mention that he used to be a big guy, "dudes look like they are about to cry and they ask me what happened and I just say 'Wait till I get back.'"

Steven

Steven is a retired firefighter, veteran and husband. He is fifty-four years old and has had ALS for twenty-four years. He is completely paralyzed except for his head/eyelids. Our interview techniques were particularly unique. Before our home visit, Steven emailed me answers to a few questions, my home visit was mainly with his wife, Saundra, and other questions were completed via email after the home visit. Steven uses computer technology to type out his responses, however it takes patience and a lot of time. When I walked in to their home, Steven was essentially lying in a room (seemingly a den) to the right of the front door. He is the first person you see when you walk into the house, which Saundra later explained that Steven likes so that he can be involved in daily comings and goings. Most of the interview took place with Saundra; however, Steven used his computer to answer a few questions to me through over the past few weeks. They provided me a video that their church made called "Real Life Stories of Mercy and Grace" which helped to answer many of my questions. To communicate with one another, Saundra uses an optical board with various letters and symbols that Steven can see on the other side. Steven then gazes towards letters he is trying to say. Nonetheless, after so many years of using the board, Steven and Saundra no longer have to use the board cause they have memorized the placement or Saundra intuitively guess what Steven is saying.

Steven had his first symptoms when he was thirty years old. He first noticed symptoms in his left shoulder, fasciculations in his arms, and difficulty speaking and singing. First the couple went to an EMT who immediately knew something was wrong. They went to the doctor to get an MRI, then a nerve conduction test and finally an EMG. Eventually, Steven was diagnosed with ALS at Emory in 1990. After Steven's first symptoms he continued to work for about 11months as a firefighter. Saundra emphasized that "he [Steven] removed himself" and he worked light duty for about five months. He finally resigned at the end of April in 1990. His job left it up to him when he was going to leave. The couple no longer attends the Emory ALS Clinic and actually stopped way before Steven got a ventilator, which was 16 years ago.

Saundra has to suction him often because the ALS causes him to create six times more saliva than the average person. Though he took a medication that helped control the saliva, he stopped taking the medicine because it caused constipation and dry eyes. Currently he takes a breathing inhalation treatment, a nerve medication, a host of vitamins, and methadone. Saundra explained says he has never complained about having ALS or asks why me? She explains, "He's always started out with an attitude that all kinds of people have to deal with hard issues so why should I be exempt from a challenge." She admits that she has not always had the same attitude. He has never dealt with depression except for ten years ago when they went to the neurologist. But the neurologist changed up all the medications – which Steven calls a "witches brew"- causing a chemical depression.

Via email Steven explained:

> I've found that, in general, having to be dependent on **anyone** for **anything** attack's our pride viciously. And specifically, for a man surrounded and pressured by society's mores' and folkways, no longer able to contribute physically to their family or society, that pressure is elevated exponentially. You know, that "masculinity myth" you referred to in one of your first questions. The whole philosophy that says, once your ability to

> contribute physically ceases, so does your value, flies in the face of thousands of years cultural wisdom and proven effectiveness where life is revered.

I asked what Saundra believed the biggest challenges were for Steven, she explained that (1) Steven was very communicative so not being able to communicate is difficult. She describes him as a very Type A personality so his loss of speech has been devastating. (2) "Not being able to serve other people", Saundra said. (3) She explains they both miss communicating between each other. She misses being able to lie in bed and talk for hours. Saundra mentioned,

> A man's innately programmed to want to protect and provide for the family…The protection thing has been hard for him because he wants to take care of me. We have to rely on God for this because you can't do everything for yourself.

She explains that though, "He can't work it is because of [Steven] we still have the things we need directly from God". Steven agreed and wrote in an email,

> You asked about my masculinity and just the fact of my being sedentary affects that aspect of life. The lack of circulation hinders erection in males and the corresponding blood flow problems in the female organs. But on my Saundra's we have exhaustion and long term sleep depravation, which pushes sex farther down the priority list. As much as sexuality is important in any intimate relationship. You soon learn that lovemaking is so much more than getting each other off but letting my baby sleep or if I need suction during the night just letting my chest rattle and let my Saundra sleep…the little things that my Saundra does to make me comfortable that no nurse would ever do. That is love.

In the video Steven writes, Saundra echoes Steven explaining that love is a whole lot more than a physical relationship.

Christ is at the center of Steven and Saundra's life. In their video Saundra explained, "We have found of course God's word to be true that the joy of the Lord is our strength." Steven explained, "We provoke each other to have a an "other" centered outward focus instead of a me centered navel centered which only brings on depression." Their Christian outlook helps them

cope with the disease and believe that God placed this challenge in their life and it is their responsibility to live as long and as best as possible. “Are there challenges that break my heart that only God can remedy? Certainly. I long to hold my Saundra but my arms don’t work. …I find strength through God’s grace because when I’m weak God’s strong. I never feel forgotten or forsaken”.

Darrell

Darrell is a sixty- one year-old bachelor who lives with his male roommate/ caretaker Ben, who is a nursing student at a local university. His first symptoms occurred in January of 2009 when his entire upper body from wrist to wrist began to twitch uncontrollably. In May of 2009 when swim season began for Darrell, his new doctor said that if the twitching did not stop in a month he should see a neurologist. He began his swimming workout of “head out of the water breaststroke but about 300 laps a week. A month or so later, “She put her hand on my shoulder and said these are not the shoulders of a swimmer. You’ve been swimming for a month and you have not gained a pound”. She gave him a referral and he began to see a new doctor who did testing on his reflexes and nerves and said, “Darrell, I think you have ALS”. The second doctor suggested he see the Emory ALS specialist. After leaving the meeting, Darrell called his best friend who is a Physicians Assistant for advice, and he suggested he go to the Emory ALS Specialist. In November of 2009 he went to see the Emory ALS Clinic and “[the doctor] gave the fatal news. You don’t recover, you don’t get better. It’s a death sentence”. He quickly remarked, “no comments in terms of personality” regarding the head Emory ALS Clinic doctor.

Darrell wishes that the ALS Clinic provided a more helpful and productive treatment plan for pals.

> They check our vitals and you know they have nothing to give us…they're taking blood pressure, they're testing reactions, testing cognitive…but never are we giving. Here Darrell your weak in the hands let's try a calcium supplement or why don't we try to certain things to help build up coordination or what have you.

He explained that the clinic specialist complete reactive and cognitive test where he still scores highly but the strength tests are difficult for Darrell. He is very paranoid about having sick people around him and contracting a respiratory infection. I asked for a tissue and he ask me "Don't tell me you have a cold? [which I deny and explain I have allergies]…We are so susceptible to respiratory issues. In fact I'm having a little bit of hard time getting rid of cold from Christmas…it's that crazy horrible congestion."

His weight and body image are of great concern to him. He mentions his weight ten times during the narrative. Throughout our entire interview Darrell is eating constantly because he explains, "at 144 I have to keep my weight up". He tries to consume nearly 5,000 calories a day yet he is disgruntled by the fact that he is still losing weight. He only drinks spring water because he believes that maybe it's better for his overall health. When I walked into the house Darrell has nearly twenty-five different vitamins/medicine containers on his dining room table. He is dedicated to improving his life and continuing a slow progression of symptoms. He is very critical of the lack of research that ALS researchers have made in the past few decades. He mentions that Rilutek was approved in1996 but no other major drugs or significant findings have been made. He is extremely frustrated that the doctors do not acknowledge any common elements of ALS. He took Rilutek before but stopped when saw that his symptoms were rapidly getting worse. Darrell currently takes body building supplements, serotonin, vitamin D, and

multivitamins/minerals. Darrell tries to do anything. He talks about his friends with multiple sclerosis who was once in a wheel chair and now she's disappointed because "she can't break 100 on the golf course". Therefore Darrell's attitude is, "What do I have to lose?" thus, he tries anything. "In the research they concentrate on the whole automobile…instead of getting specialist focused on the legs or the vocal chords". He believes the need to break down ALS understanding by each symptomatic challenge. Darrell believes he got ALS in the following way:

> What it appears if you're carrying the gene you need a trigger to kick it off. And I'm convinced that my trigger was in 2008 when I by hand defoliated the back yard by pulling up all the ivy all by myself and I got a severe case of poison ivy that I've never been allergic. And since it was 2008 and then 2009 I was twitching. And poison ivy has been known to be a trigger…another individuals might have arthroscopic surgery and that may be a trigger…another person and I don't know how well he is doing, but he had a massive heart attack in the airport in Dallas and they revived him and then within in six months the heart attack symptoms were resolved and he ended up with ALS…the common theme and they call it the nice persons disease. We tend to be active and outgoing and friendly and all that good stuff and… the common theme is the trigger, always the trigger.

He continued giving examples of other individuals who had other "triggers" of ALS.

Despite his disabilities he does nearly everything on his own. He is not ashamed to be on his knees to load the dishwasher or use his teeth to make his bed in the morning. In every water bottle he has straws to help him drink easier. On the door of the house, he has a belt attached to help him open the door easier. Darrell also uses cabinet liners to help open jars, doors, and other objects that challenge his hand strength. He has many challenges with daily tasks but still does what he can and uses various aids to assist him. He admits,

> I gave up my car...for now. I mean cause I'm hoping I get my dexterity back…but my coordination is such that I wouldn't want to risk the lives of other people. In the event of the emergency I could…at normal speed I can drive just like anyone else. It's just when it's slowly, it's like driving in cement."

Darrell has two adult sons that live in New York and Charlotte, NC. He mentions that his youngest son has cerebral palsy. His two children are from his first and only wife whom he divorced years before. I asked if he had any fears regarding ALS because he says that his boys are wonderful and he has many friends. He mentions he has over 1000 friends. He bragged about his friends raising $10,000 for his charity, which is what pays Ben, the nursing student and pays for his cleaning service. He recalls,

> I still play in my dreams, when I'm having trouble getting to sleep. I'll have myself at the first tee and I'll put my swing on it like I use to be able to swing and I'll get down there and say ok I better hit this and you know you always better in your dreams than they do in real life".

He also has three or four friends that make food for him and chop the food up.

> Well what I've tried to do is distract myself by trying to give back. I'm very active in my church. I'm a greeter at the 10 o'clock mass, and I have so many people so that are so wonderful over there, Chelsey. Just say oh Darrell we didn't see you for the last two weeks and I say oh I slept in and came to the 1130. I've very much found my Catholic upbringing again. And um what it's helped me do, Chelsey, is refrain from holding grudges, help me refrain from any temptation in terms of out right lying to oh there's a five dollar bill over there I think I'll just take it. I'm trying desperately to live in the spirit of our Lord and Mary and Saint Joseph and things like that. In fact my praying at night helps but me to sleep.

He has found his religion and it's really helped him sleep better at night. He believes his faith also has helped him not develop any fears with ALS.

Doug

Doug is a sixty-two year old father and self-admittedly "broke" bachelor with ALS. Within the first two minutes of our four-hour interview (the longest interview),

Doug expressed,

> I'm usually am not so careful but I just lost my file folder on um hud section eight housing which is the next place I'm trying to get to. This is a pretty house and I got on a nice shirt, I think, I love it but this is all when I had money. And I am like, I lost my business which is not the reason I got ALS and but I lost my business and I am B R O K E, broke".

This quote encapsulates the direction of our conversation: scattered, open, opinionated and idiosyncratic. Doug currently lives with his pregnant daughter and her fiancé. Doug constantly deflected my questions and getting direct, honest answers from him was exceptionally difficult. His first symptoms occurred in December of 2010. He dropped an ice bucket that slipped out of his hands while working. He was a certified nursing assistant doing Alzheimer's casework, and he was unable to stand his patient up. In January of 2011 he noticed that his arm was shaking when he shaved and brushed his teeth. His internist sent him to a neurologist who immediately ordered a MRI. After the neurologist did extensive blood work, which he mentioned cost $600 because he doesn't have insurance. During the testing his first neurologist sent him to get an ECG (an electomyogram), which tested, for muscle electrical activity. The next test, a CT Scan, revealed a cervical radiculopathy (bone spurs on the third and fourth lumbar). Within a few days the second neurologist realized that his right arm was showing weakness but the CT scan showed that the symptoms should show up in his left arm for it to be cervical radiculopathy. When the second neurologist realized that it was not cervical radiculopathy he went to another doctor in Augusta who was a friend and an ALS specialist from the Medical College of Georgia. After his Augusta and third neurologist tracked his progress for four months the doctor confirmed that he had ALS in August of 2011. Doug explained:

> I still went back to Augusta for clinic to get tested again, actually not for clinics but I went back to Augusta cause he wanted to test me, follow me, however at this point my Emory doctor and my children agreed that there

> was no reason to be tested any further because who knows better than me what the problems are. Right now I drink one beer every two weeks and I'm not supposed to smoke pot either but I do and this all recent.

He told four of his various friends about his diagnosis friends but he made his friends swear that they would not tell anyone until he told his three children. He told his children about his diagnosis at Five Guys in September of 2011. His children were furious that he told them at Five Guys instead of at home where they could talk about the disease. He admitted that his judgment about where he disclosed his diagnosis was inappropriate and that he should have done it at home.

When explaining his disease to others he simply says he has "Lou Gehrig's Disease". To his friends he gives a very detailed explanation helping them understand the difference between voluntary and involuntary muscles. Also, he explains that his brain and five senses will never be affected buy the disease. He then explains,

> And then I explain my lungs, that is what will bite me in the ass. Then I explain to them what is happening with my arms with the bicep in the right down to my hands and fingers. And even though my leg and tongue and trapezes has been diagnosed…that I have absolutely no disability in my legs, tongue, or my lungs.

He makes sure to highlight all his strengths when he describes his disability and abilities to his friends. He believes he received ALS because there is a protein that everyone requires for motor neuron use doesn't get to the brain and neurons. However, the motor neurons don't send signals to your muscles causing muscles to die.

Before his career as a CNA, Doug was and the CEO of his family business (a wholesale clothing company) from 1973 to 1995. He said that he was exceptionally wealthy before 1995, specifically a millionaire. After the family business dissolved he began working in sales, selling expensive suits and cars to his colleagues that he formally

worked with when the family business was successful. Since his diagnosis he can no longer work, and as he proclaimed, is “B. R. O. K. E.” Though he admits to being substantially poor throughout the entirety of his narrative he is content with his financial state and is simply trying to get out on his own so he doesn’t have to live with his daughter once his grandchild comes. Doug admits that it bothers him that his arms look like “a seventy-five year old guy they are all shriveled and wrinkled but I still wear short sleeve shirts”.

Doug is very proud that he can still do “25 dances out of 60 on a Saturday night, maybe even 30.” He is an avid shag dancer and goes out to ShagAtlanta or the American Legion Hall every weekend. When he moved to Atlanta from Augusta he joined a Facebook group and described his ALS story on a wall post and immediately gained many friends who now picking him up to Shag dance. Doug revels in the fact that he still has a very active sex life with his girlfriend. He explains even though he cannot grab his girlfriend or hold her when they sleep, “She still has a great ride…I always brag to my guy friends that I am still able to make love to my girlfriend.” Doug explains that he has become very dependent on others, including hiring an assistant to help him bathe, organize his papers, and go shopping. “I’m healthy as a damn horse! I mean I might die of a heart attack tonight, ya know? Or go blind from glaucoma...but no I don’t feel at all that I’m suffering from lack of independence.” He has confidence in the system that will help him. He has no fear in accepting resources the ALS Association, MDA, hospice services, etc. He knows he only has a short time to live.

Since he knows he is dying from ALS, he has been trying to contact all his friends from the past and rebuild relationships. He strongly believes that he has ten years left to live. I asked "why ten years?" and he explained that he believes God is going to allow him to live for ten year

after he spoke with his Rabbi. He also logically reasoned that since 50% of people live for one to five years, 30% of people live three to five years, 20% of people live five to fourteen years, and the elite group pushing twenty five plus years; therefore, he will live for ten years. He jokes, "I signed up for the ten year plan…I bought seven years with God and my brother bought another three years." For Doug ALS is a journey, a "long winding road and I'm read for the ride."

Support Group Observations

The ALS Association's monthly support group meetings in Watkinsville, Marietta, and Fayetteville were all very different. Of the nine individuals that I interviewed only one person, Darrell, regularly attended support group meetings. Doug found the meeting helpful to learn new information and support fellow friends with the disease however the other eight respondents found the support group meetings "lousy" and inconvenient (Florence), "unhelpful"(Emma and Marco), something they were not ready for (Sarah) or they simply had no interest in attending (Tryone). Female caregivers, patients, and/or widows overwhelmingly dominated attendance at support group meetings. During the meeting that I attended, male participants (caregivers, patients and on one occasion a widower) were typically quiet and if they did share the subject of conversation always dealt with technology and assistive devices. Religion and spiritual beliefs were often a focal point of the meetings as pALS shared challenges or successes of the month. My attendance at the six support group meetings provided an abundance of information requires further analysis. Thus, a more detailed examination of support group meetings will be provided in a later paper.

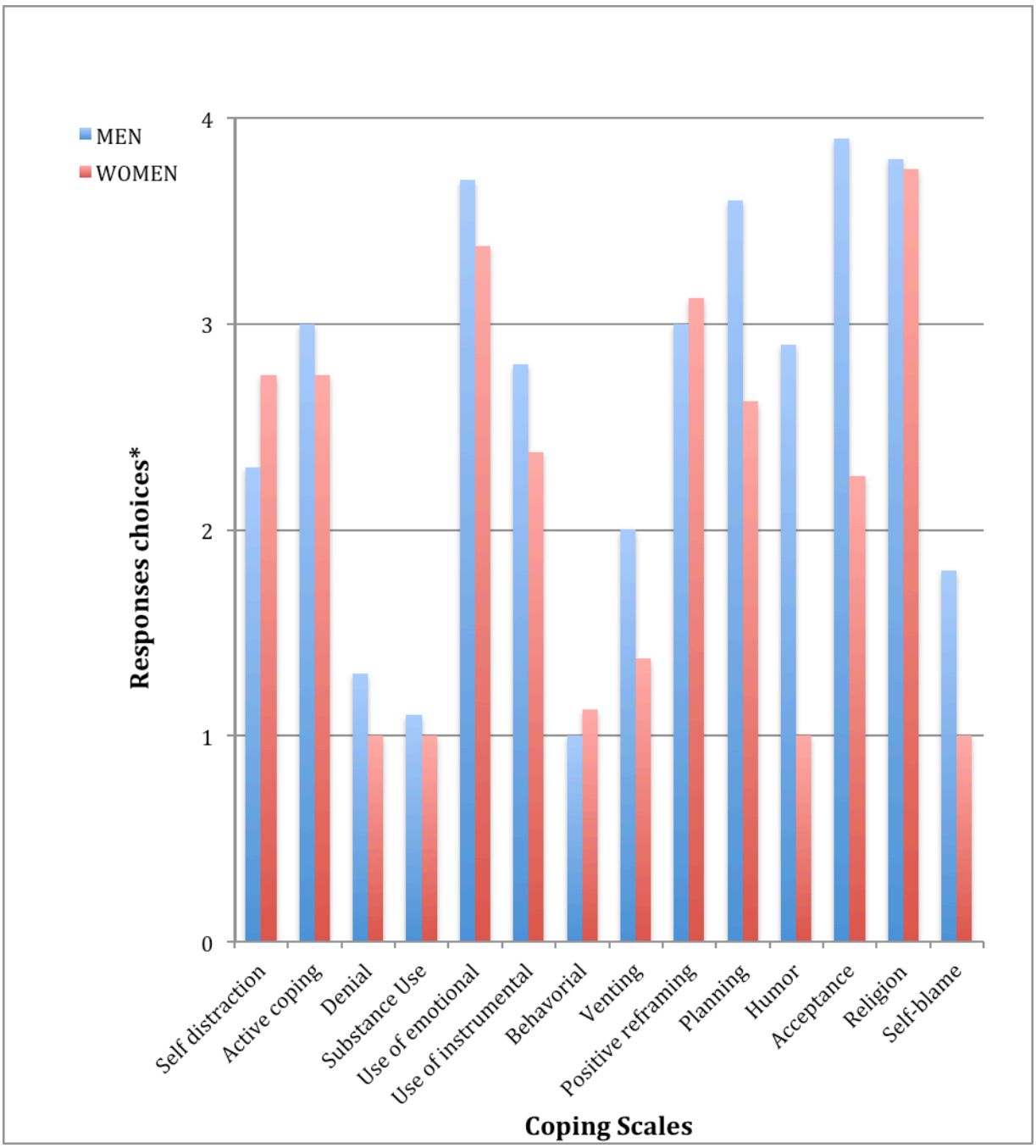
Brief COPE Questionnaire Results

The Brief COPE questionnaire measuring coping techniques based on the following scales: self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, and self-blame. Responses choices were from 1 to 4. One meaning: I haven't been doing this at all. Two meaning: I've been doing this a little bit. Three meaning: I've been doing this a medium amount and four meaning: I've been doing this a lot. Each gender's coping responses choices were averaged according to each coping scale to determine general themes between women and men (see Chart 1).

Overall, women used self-distraction techniques more than men. Florence mentioned knitting or playing crossword puzzles and similarly, Krystal mentioned being an avid reader to keep her mind off of her illness. On the contrary men did not self distract very much. For example, George explained that he found himself very bored now that he didn't work. Other significant questionnaires differences showed that women planned "a little bit of the time." Most of the male respondents answered that they had at least been planning a little but to a lot. Steven explained that when he was first diagnosed he and his wife diligently thought through the choices they were make towards his life living with ALS. Lastly, across the board women never used humor to cope with their illness. Conversations with Doug, George and Tyrone showed subtle and overt jokes regarding their illness and thoughts about their disease. A discrepancy in the survey may exist because results showed that overall men and women respondents were not in denial about their illness. However, results of the questionnaire showed that men accept their disease nearly all the time and women accept their illness a little bit. The data also disagrees with this data being that two (Tyrone and Doug) of the five men interviewed used language that demonstrated a denial towards their illness. The questionnaire also suggests that of the nine

participants most did no one coped with their illness using harmful substances like drugs and alcohol or employed behavioral support. On the whole, men and women used religion and emotional support from others "a medium amount to a lot"

Chart 1: Respondent Results of the Brief COPE Survey



Chapter 5: Discussion

Chapter 4 provided a small "snap shot" into the illness experiences of nine individuals courageously living with ALS. Regrettably, every minute detail of their personal narratives could not be included due to space and time constraints. However, the purpose of each narrative was intended to provide a brief glimpse into the key themes and language used throughout each interview. Analyzing data for this project proved to be exceptionally difficult. There were unquestionable differences in the way men and women's ALS experience. Nevertheless, evidence strongly suggests similarities in the coping strategies, explanatory models, and illness memoirs of both genders. This chapter highlights significant gendered themes found in the narratives and the results of the Brief COPE questionnaire. Furthermore, I intend to emphasize themes unbiased by gender. Lastly, this chapter seeks to explain and support these findings through literature addressing masculinity and femininity.

Unique female experiences

The narratives of female pALS showed the following themes: a longing for aesthetic beauty/feminine qualities, maternal concern/compassion, spousal anxiety, and acceptance. Florence, Sarah, and Kendra all expressed missing "being a diva", "get dressed up", "wearing high heels and going out" and "looking good". Each missed able being to regularly shop, getting their hair and nails done, and dress up. ALS has caused Florence, Sarah, and Kendra tremendous muscle pain hindering their mobility from these "girly characteristics", as Kendra describes. Though men did discuss their bodily appearance they never discussed it regarding clothing, makeup and self care regimens to maintain a standard of appearance.

Unlike the men, every single woman expressed significant sadness regarding their children or grandchildren. Krystal and Kendra each plan to write or record their voices for their children/grandchildren on special occasions and monumental milestones that they may not be at. Sarah says that she tries to spend as much time as she can with her grandson so that he will have memories of her and remember her voice. Her greatest fear is that her grandson may not remember her. Florence says that the hardest thing for her to deal with is not being able to help her three daughters raise her eight grandchildren. When Florence, Kendra and Sarah spoke about their grandchildren they became obviously emotional about their diminished or non-existent role in their lives. The maternal instinct was apparent and deeply affected each woman personally. Though many of the male participants had children and grandchildren, speaking about their children never evoked significant emotion nor was a central topic of the interview.

Every female interviewee was either married or in a serious committed relationship, which did not hold true for all the male participants. Older women like Florence and Kendra worried about what would happen to their husbands after the passed away. The younger women, Sarah and Krystal, were elated to have such supportive significant others in their lives. The relationships these women had with the men in their lives was significant in their coping styles and substantial parts of there narratives. I would predict that the support these women felt from their spouses affected their overall acceptance of their illness. Female respondents may not have been forthcoming with all the information about their disease (Sarah), however their spouses were the first person with whom they shared their symptoms and diagnosis.

Unique male experiences

Male ALS narratives uniquely dealt with an acute awareness of diagnosis date, lack of

familial provision/protection, dependability, weight and body image, sexual performance and physical activity. Other than veteran ALS champion Steven, every male participant had a precise memory to the date of his ALS diagnosis. The date of diagnosis nearly symbolized a monumental change in their life and in a way marked the beginning of a new life. Saundra, Steven's wife, mentioned that it is an innate quality for a man to want to provide and protect for his family. This assertion is validated by the necessity of every male respondent to in some way provide and protect for his family. Though he could no longer work, Darrell was grateful for his friends that created several charitable events in his honor that helped him pay for his caregiver, monthly bills, and incidentals. Though his children are successfully on their own, Darrell mentioned the importance of helping his elderly sick parents, whom he described as "critical" in terms of their health and finances. Through various Catholic charities he hopes to provide stability for his parents. Similarly, though George does not like receiving government benefits for his illness he recognizes that it is because of his illness that he is able to still contribute to his family's finances. He does not have political views against government assistance but wishes he could provide for his family by working directly. Furthermore, due to scrupulous financial planning while working as Publix manager, George has financially prepared his family for the future. In a way all ALS patients interviewed miss their complete independence. Though many illnesses take away one's independence ALS causes a rapid and constant loss of independence. Nevertheless, the men I interviewed found it difficult to not be dependable for their family.

Men with ALS also measured their masculinity by their sexual function and body image. All men did not disclose their sexual encounters however, Steven, Doug and Darrell mentioned varying views about sex. Steven acknowledged the total paralysis inhibited him from having sex with his wife however he has found other ways to express his love for her. Doug who is not

totally paralyzed gloated about his continued sexual function and love making to his girlfriend. Though Darrell does not have a girlfriend, he imagined that sex would be difficult due to motor neuron loss that he believes would affects a man with ALS masculinity more than a woman. In various ways George, Tyrone, Darrell and Doug mentioned a concern with their weakened physical appearance. George was concerned that he had gained weight since his diagnosis, which upsets him immensely. Losing weight is typical symptom of ALS because of muscle atrophy. Darrell and Tyrone constantly mentioned how much weight they had lost since their ALS symptoms began and that they try to continue to eat a lot or workout to help rebuild muscle. Doug mentioned that his masculinity has been challenged since his arms now look like an elderly old man. Collectively these men are having challenges coping with their "weakened" physical appearance that relates directly to muscle atrophy as their motor neurons die. For all male respondents when they first noticed physical changes in their activities. Doug noticed his arm strength weakening while dancing, Darrell noticed his upper body weakness and fasiculations during swim season/golfing, Tyrone noticed his arms weakening/nightly numbness towards the end of football season and Steven noticed that he could no longer be the outdoorsmen he once was. Loss of physical strength signified that males diagnosed with ALS could no longer fully engage in physical activities they had been passionate about. Other than Krystal's love for competitive soccer, the other females with ALS did not mention physical activities/sports that have ceased due to ALS.

Common experiences

A significant finding for my study showed that certain experiences are universal for men and women with ALS. All respondents had distinctive explanatory models for their illness and

connected to a set of spiritual beliefs. Cobb and Hamera (1986) demonstrated that the illness experiences and explanatory models of two women with ALS varied substantially in illness experiences and explanatory models. Though Participant A and B of the study both had ALS their experiences differed substantially regarding ideas regarding causation, efficacy of therapies, explanation of sickness, and desired treatment (Cobb and Hamera 1986). The same concepts held true in my study. Study participants had a range of possible etiologies including protein loss, genetic triggers, a divine plan, or simply no idea. Furthermore, each pALS explained their illness differently depending on who they were speaking to and their ability to communicate their illness on their own. For example, Doug gave an overly thorough explanation of his of his disease to his close friends, Sarah's disease explanation omitted significant details depending on whom she spoke with (family vs. boyfriend), and Krystal provided people with handouts describing her sickness. Each explanatory model was unique to each person with ALS.

Each pALS in this study expressed spiritual or religious beliefs. Lois White (2005, 211) writes:

> Often, spiritual beliefs assume a greater significance at the time of illness than at other times in a person's life. These beliefs assist some people in accepting their illnesses and help explain illness for others. Religion can both help people live fuller lives and in console or strengthen people during suffering and in preparation for death.

For Kendra, Krystal, Florence and others their spiritual beliefs helped them accept their illness and live fuller lives. Tyrone's spiritual beliefs helped him explain his illness. Others like George were conflicted by their spiritual convictions. At times George's spirituality helped him cope with his illness and at other times his spirituality hindered him and made him angry with God for forsaking him.

Explanations and factors affecting illness experiences

Kleinman explains that the disease/illness distinction is the main difference in the explanatory models between the patient and the doctor (Kleinman 1988) Diseases are the malfunctions of the biological process whereas illness is interpreted as the experience of the disease, meaning the way the individual, their family and friends explain, label, evaluate, and respond to disease. A major concern that Cobb and Hamera (1986) argued over twenty-five years ago is that ALS research as been primarily disease oriented thus physicians are not equipped to understand the various illness narratives of their patients with ALS. For many chronic illnesses, but especially for an incurable, untreatable disease like ALS, a paradigm shift must occur in order for physicians to understand peculiarities and complexities of ALS that can only be understood through the people living with the disease. Furthermore, understanding ALS narratives through a gendered lens offers a useful approach in bridging communication between physicians and patients in order to understanding biomedicines shortcomings for ALS patients. ALS Narratives were nonetheless influenced by gender. West and Zimmerman (1987, 146) explain,

> "For human beings there is no essential femaleness or maleness, femininity or masculinity, womanhood or manhood, but once gender is ascribed, the social order constructs and holds individuals to strongly gendered norms and expectations, Individuals may vary on many of the components of gender and may shift genders temporarily or permanently, but they must fit into the limited number of gender statuses their society recognizes. In the process, they re-create their society's version of women and men.

This idea of "doing gender" demonstrates the idea that everyone in society is acting out the essential nature of a specific gender in order to fit in. What this project shows that even within the context of a chronic life-limiting illness gender constructions are challenged and gendered characteristics are evident. Scholars go on to suggest that society has contributed to the portrayal of men as healthier and women as a sicker gender. Furthermore, these nine narratives

reveal a longing for typical masculine and feminine behaviors and values limited by ALS. My study did not find significant gender disparities or inequities in quest for diagnosis. In one narrative, Kendra described prejudice by a doctor based on her race however; overall informants did not discuss major gender inequities experienced by doctors or clinicians.

Further Research

This research raises numerous questions that need to be addressed in future research on illness narratives of individuals with ALS. Additional research should identify different factors that affecting coping with ALS such as age, gender, race, and level of education. Examining these factors will provide greater insight into the field of medical anthropology helping to facilitate cross cultural competence, communication, and patient understanding for clinicians. Moreover, this project highlighted the significance of spiritual beliefs in coping with a life-limiting illness as well. Questions that arose in this area include: Do spiritual beliefs affect the illness narratives over time? Does a faith-centered perspective affect an individual acceptance with ALS?

In the future support group findings should be evaluated to explore connections in gendered chronic illness differences. Since many support groups were attended my caregivers a project focused on ALS caregivers could be useful to this literature. The explanatory model and illness experiences that the patient has for himself or herself is shaped by their family and network around them.

I strongly recommend that physicians re-evaluate the strong encouragement that patients be involved in certain treatments (no " ") and clinical visits. The study demonstrates that patients find ALS clinics useless because they do not receive any benefits from attending. Patient-

centered clinics could offer more palliative care options, muscle strengthening/prevention, and suggestions to improve patient quality of life. Since the disease has no known cause or cure, doctors ought to think "outside of the box" to offer patients tangible care even though it may not be life saving. Study participants desired preventative therapies for muscle strength, dexterity, or balance. Understanding that these specific treatments are not guaranteed to prevent strength, dexterity, balance concerns, pALS would feel like they did everything they could to prevent the worsening or progression of symptoms. Similarly, like many other illnesses ALS affects quality of life. Stepping outside of the biomedical paradigm of "curing, physicians could offer pALS with treatments that improve quality of life. Research has shown that quality of life research is become an important measurement of medicine and health care; determining the impact of treatment and measuring morbidity (Rees et al. 2001). Doctors could provide patients with effective support group meetings, life planning sessions, healthcare management assistance and psychological support. Since ALS patients cannot come to their neurologist for a cure, treatment, or an explanation, they seek something in return for their doctor's visits. Quality of life improvements and preventative/experimental symptomatic treatments could offer pALS an answer.

Six out of nine study participants had high levels of education, either college or graduate level degrees. Many of these participants had fairly scientific explanatory models. Teacher Kendra who holds an educational specialist degree, explained that she believed that her ALS might have been caused by an overproduction of gluten. College graduate, Darrel also explained that there must be a genetic trigger caused by excessive activity that caused his and many of his friend's ALS. Each of the college-educated informants had varying explanations for how their illness was caused. Moreover, many of their explanations are rooted in the research about ALS

causality. However, the explanations were not verbatim and some were a mix of possible etiologies. Veteran, Steven explained that ALS research has shown a connection to Gulf War veterans but also believes that his ALS may have been caused by a protein malfunction. On the contrary, high school graduates, Sarah and Tyrone, did not know how their disease started. In a way college educated individuals with ALS in this study have created folk scientific theories. It would be a significant contribution to literature to assess how levels of education influence explanatory models of illness.

Conclusion

It is troublesome that in 2012, with so many medical breakthroughs and technological advances towards improving human health, 5,600 individuals a year in the United States are diagnosed with an incurable, untreatable, unknown disease. This is alarming not because one expects medical advances to have solved every medical mystery to date, but rather because anyone is susceptible to this deplorable disease that begins with a series of seemingly benign symptoms and progresses with bewildering inexorability to its conclusion. I join ALS families and supporters plagued by this disease in urging medical researchers to work harder to find a cure. There is a substantial gap between the lay and biomedical perceptions of disease. I urge medical researchers and physicians to employ a holistic approach to medicine's mysteries like ALS. Additionally, since gender differences continue to persist in health care (especially with regard to chronic illness), it is critical that scholars identify the social constructions of gender that elicit different health attitudes and shape our understanding of disease and illness. Technology and medical advances are important to understanding a life-limiting/unknown/incurable chronic illness like ALS, but the voice of the patient living with the

disease is essential towards a path to a cure.

World famous storyteller Karen Blixen/Isak Dineson once wrote, "To be a person is to have a story to tell." Narratives of illness are meaningful and ought to be seen as journeys. ALS patient memoirs are uncommon because the disease has low incidence and the narratives' ending is always the same: the patient dies. The familiar trajectory of many illness narratives from diagnosis through struggle to victory over disease does not apply to ALS. However, it is essential to see ALS illness narratives as a journey. As Michael Bury explains, chronic illnesses cause disruptions in the illness narrative and in life. With ALS in particular these narratives are often fragmented. However, that does not take away from the powerful emotional responses that these narratives can provide. Narratives shape our life experiences, and when life experiences are disrupted our narratives must be reshaped to fit the new context. Through a gendered lens these abbreviated narratives of this thesis demonstrate the experiences of nine average individuals with ALS. If changes are to happen in the way ALS patients are cared for, are treated, and live their lives, it is important for researchers in the biomedical world to hear the stories of pALS in order to effect real change.

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Appendix I

Interview Questions:

1. I'd like to understand your journey to the ALS diagnosis. When did you have first symptoms? Where on your body? Who did you tell first? Did you go to the doctor? How many doctors did you visits? First opinion? Second opinion?
2. How soon did you tell someone when you had your first symptoms? Who did you tell? Why did you tell that person?
3. What were your initial thoughts after diagnosis?
4. Life before ALS: Briefly tell me about your career. Any health problems? Surgeries? Proudest moments? I just want to get to know you better.
5. How do you cope with your diagnosis? Support system? Family? Friends? Church? Hobbies?
6. Do you have a set of spiritual beliefs? If yes how have the shaped your journey with ALS? If not, why not?
7. What do you call your disease to other people?
8. What do you think caused ALS for you? Possible causes?
9. Why do you think it started when it did?
10. What does YOU think ALS does to the body? How does it work?
11. What kind of treatment do you think patients should receive? Do you go to clinic? Do you see a regular doctor? Do you take medications?
12. How has your disease affected your relationship with your wife? Children?
13. What are you passionate about? Hobbies? Are you still able to do them?
14. What are your daily challenges living with ALS?
15. Do you have any fears?
16. How has your life changed since your diagnosis?
17. Since your diagnosis has your masculinity/femininity been challenged by ALS? Do you find some things more difficult for you to deal with as a man/woman

Themes of interview questions:

- Journey to diagnosis
- Doctor interactions
- Symptom/diagnosis disclosure
- Support networks
- Life before diagnosis,

- Finances since diagnosis
- Spirituality/religion
- Coping styles
- Challenges
- Passions/hobbies
- Arthur Kleinman's explanatory model.

Appendix II

Brief COPE Questionnaire and Scale by C.S Carver

These items deal with ways you've been coping with the stress in your life since you found out you had ALS. There are many ways to try to deal with problems. These items ask what you've been doing to cope with this one. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with it. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others.

1 = I haven't been doing this at all 2 = I've been doing this a little bit 3 = I've been doing this a medium amount 4 = I've been doing this a lot

1. I've been turning to work or other activities to take my mind off things.
2. I've been concentrating my efforts on doing something about the situation I'm in.
3. I've been saying to myself "this isn't real."
4. I've been using alcohol or other drugs to make myself feel better.
5. I've been getting emotional support from others.
6. I've been giving up trying to deal with it.
7. I've been taking action to try to make the situation better.
8. I've been refusing to believe that it has happened.
9. I've been saying things to let my unpleasant feelings escape.
10. I've been getting help and advice from other people.

11. I've been using alcohol or other drugs to help me get through it.
12. I've been trying to see it in a different light, to make it seem more positive.
13. I've been criticizing myself.
14. I've been trying to come up with a strategy about what to do.
15. I've been getting comfort and understanding from someone.
16. I've been giving up the attempt to cope.
17. I've been looking for something good in what is happening.
18. I've been making jokes about it.
19. I've been doing something to think about it less, such as going to movies, watching, TV, reading, daydreaming, sleeping, or shopping.
20. I've been accepting the reality of the fact that it has happened.
21. I've been expressing my negative feelings.
22. I've been trying to find comfort in my religion or spiritual beliefs.
23. I've been trying to get advice or help from other people about what to do.
24. I've been learning to live with it.
25. I've been thinking hard about what steps to take.
26. I've been blaming myself for things that happened.
27. I've been praying or meditating.
28. I've been making fun of the situation.

Scale of measurement:

Self-distraction, items 1 and 19

Active coping, items 2 and 7

Denial, items 3 and 8

Substance use, items 4 and 11

Use of emotional support, items 5 and 15

Use of instrumental support, items 10 and 23

Behavioral disengagement, items 6 and 16

Venting, items 9 and 21

Positive reframing, items 12 and 17

Planning, items 14 and 25

Humor, items 18 and 28

Acceptance, items 20 and 24

Religion, items 22 and 27

Self-blame, items 13 and 26