Does “Knowledge” Equal Approval?
An Exploratory Analysis of Physical and Mental Chronic Illness, Health Literacy, and Stigma

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by
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INTRODUCTION

“Just because you don’t understand it doesn’t mean it isn’t so.”
– Lemony Snicket, *The Blank Book*

Chronic illness is often concealable to other individuals, with most chronic illness sufferers anguish in pain and grief in an environment completely unaware (Bury 1991; Edwards 2013; Hadler 1996). Including both physical and mental aspects, approximately half of the United States’ population suffers from some form of chronic illness (Edwards 2013). Chronic illness represents specific disorders, diseases, and ailments in which an individual’s life course is affected due to the longstanding and incurable nature of the illness. While many sufferers have found ways to help circumvent different chronic illness symptoms, there is ultimately no be-all and end-all cure, thus their symptoms often wax and wane in so-called wave-like patterns (Bury 1991). In today’s 21st century, chronic illness frequently deals with medically unexplained etiology – or root causes/origin of a disease or illness – which often produces hesitation in both acceptances of being truly classified as sick or ill by the public and medical professionals, and also a reluctance of medical professionals to provide a diagnosis to these individuals (Nettleton 2006). Without physical evidence, most often in the form of such medical diagnoses, our culture is not easily accepting of such chronic illnesses. Even with some diagnoses there is much doubtfulness and unwillingness to actually acknowledge that an individual is truly sick; for example, those suffering from Fibromyalgia or Chronic Fatigue Syndrome (Nettleton 2006).

This aversive hesitancy that chronic illness sufferers face, on a daily basis, ultimately leads to stigma from the general population, as being ill is not the collective norm within society (Metzl 2010). This disinclination towards chronic illness leads to stigmatizing attitudes due to the trivialization, miseducation, delegitimation, and misconceptions the general public has of those sufferers (Ware 1992; Pescosolido, Boyer, & Medina 2013). As one researcher notes (Jorm
2000), the majority of accessible medical information on mental illness specifically is misleading, and in terms of physical illness the information is often disputed or contested, due to lack of support from a medical professional (Bülow 2008).

With approximately 76 percent of all physician visits, and over 81 percent of all hospital admissions due to chronic illness (Edwards 2013), understanding why and how the public stigmatizes these sufferers is imperative. Using data collected from a national representative probability online survey, “Comparing Social Constructions, Perceptions, and Stigmas of Chronic Illnesses, 2015” (N = 976), I examine four major chronic illnesses (two mental – Obsessive Compulsive Disorder (OCD) and Depression, and two physical – Chronic Fatigue Syndrome (CFS) and Fibromyalgia). As each illness is rather distinctive and not necessarily comparative, I view them on a continuum, further explained below.

Focusing on mental health literacy and stigma, I use quantitative methodology to enhance research and knowledge on how the public view chronic illness – their opinions, perceptions, and behaviors towards chronic illness in terms of both physical and mental illness – as well as how to better prevent stigma of chronic illness from happening in the future. With literature on mental health literacy rather low (Jorm 2000) and to date, to my knowledge relatively little is known of physical illness health literacy regarding CFS and Fibromyalgia. This work hopes to fill a void in both medicine and sociology. Overall, improving upon current medical and sociological research involving chronic illness and stigma by 1) exploring how the general public views their health literacy in regards to chronic illness (both physical and mental), 2) by exploring if the general public’s health literacy affects stigmatization, and 3) by discovering if both types of chronic illness (physical and mental) are stigmatized, with respect to each other.
LITERATURE

Social Construction of Illness

Throughout history two main conflicting frameworks regarding what illness is broadly have emerged – 1) the biomedical (physical) model and 2) the social constructionist (conceptual) outlook. The first framework argues that to be ill is the complete antithesis of being healthy, where disease and sickness are viewed in biological and/or genetic factors (Brown 1995). As the oldest illness schematic, the biomedical model focuses almost exclusively on the individual and procedurally uses anatomy, physiology, biology, genetics, etc. to diagnose individuals (Smart 2001). The relatively newer theoretical version, social constructionism, not only combines these biological and genetic factors to diagnose individuals but also takes into account societal and cultural aspects when discussing illness (Conrad and Barker 2010). Rather than focusing solely on the individual, social constructionists view illness as experiences shaped by the individual and the culture, education, and society around them; ultimately claiming that illness is not a natural occurrence in humanity but one our society has created (Barker 2010; Conrad and Barker 2010; Smart 2001).

The World Health Organization (WHO Preamble 1846:100) defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity,” thus emphasizing that an individual is not healthy merely by having their cancer cured, but by fully thriving and flourishing in all aspects of their life. The fact of the matter is that our society does not view individuals in this manner; we view people as either healthy and normal or as sick, ill, and deviant (Metzl 2010). This current polar viewpoint, despite the WHO’s definition that has been in effect since 1948 (Preamble 1846), leads to a societal acceptance of the fit and lively but a rejection of the sickly and feeble (Varul 2010). This bi-polar viewpoint
helps the public stray away from the truth – that often having an illness and being healthy are not always in opposition (Radley and Green 1987).

In the early 1950s, Talcott Parsons (Pescosolido, Boyer, and Medina 2013; Varul 2010) introduced society to what he labeled the “sick role.” Attempting to make illness more socially acceptable, Parsons specified certain expectations and obligations for both society and sick individuals. Beginning with the arrival of an individual’s first symptoms, the “role” began as apposition in society that individuals who were or became ill could attempt to enact (Frank 2013). The three main expectations to achieving the “sick role” involved – 1) acceptance that the disease or illness is not the individual’s fault, 2) the ill individual is excused/should be excused from regular activities, and 3) the ill person must seek medical help if necessary (Parsons 1975). The creation and enactment of this “role” allowed more individuals to seek help and take time off from work; however, much of society and many sick individuals did not follow these three contentions with society only wanting to accept the sick as truly sick if diagnosed by a medical professional (Pescosolido, Boyer, and Medina 2013; Frank 2013; Levine and Kozloff 1978; Glenton 2003).

For individuals unable to get a diagnosis, such as those suffering from chronic illness or medically unexplained symptoms, the “sick role” did little to help them become accepted into society (Jutel 2011). These individuals were blamed for their illnesses (as most of these illnesses were/are contested); often these individuals may seem fine one day, thus tending to not seek help (Dickson, Knussen, and Flowers 2007; Asbring and Närvänen 2002). While the “sick role” helped little in achieving acceptance into society for some individuals, medicalization and an increase in diagnoses did. Medicalization is defined as the manner in which non-medical experiences are medically defined and/or treated by medical methodology (Wehling, Viehover,
and Gündel 2012; Conrad and Slodden 2013; Aneshensel, Phelan, and Bierman 2013; Dew, Scott, and Kirkman 2016), and it ultimately allowed for more illnesses and diseases to emerge, thus allowing for more diagnoses. While diagnoses are often debated (Brown 1995), they rarely delegitimize an illness, and thus are the assumed key to social acceptance (Jutel 2010). However, there are several illnesses that have diagnoses – some debated, some not – that are still not readily accepted by society and thus have a negative connotation and enduring stigma associated with them.

Chronic Illness

While many individuals can recover from falling ill or becoming sick, those suffering from chronic illness are unable (Bury 1991). Representing a “black hole” in medicine, chronic illness demonstrates that there are still boundaries to what society can overcome and prevent. As Edwards (2013:11) states: “We do not like being reminded that there are still limits to modern medicine, and that named conditions exist that might not kill us but will not go away.” Chronic illness is demarcated by its time-span, a long-term persistence, and the fact that it is often accompanied with “poor or limited recovery prospects” with regard to the suffering individual (Bury 1991:452). Affecting half of the nation’s population, with the most notable chronic illness types being diabetes, cancer, and heart disease (Edward 2013), it does not occur inadvertently. “They [chronic illnesses] are socially patterned along lines of social class, gender [often affecting women more than men], age, marital status, and ethnicity” with societal inequality ultimately generating them (Dew, Scott, and Kirkman 2016:131; Ware and Kleinman 1992; Edwards 2013). With approximately seven of ten deaths in the United States due to chronic illness, it is not only the U.S.’s primary source of death, but also the U.S.’s primary source of disability (Edwards 2013). To live a life of chronic illness is to live a life of vulnerability (Hadler 1996).
Often chronic illness sufferers do not have observable signs of pain, such as a cut or bruise (Asbring and Närvänen 2002), thus making the illnesses concealable in nature and leading to contestation and delegitimation (Hadler 1996; Jackson 1992; Nettleton 2006). Four specific chronic illnesses that are sometimes viewed this way are two mental illnesses – Obsessive Compulsive Disorder and Depression, and two physical illnesses – Fibromyalgia and Chronic Fatigue Syndrome.

**Mental Illness**

While “the bulk of the population is neither mentally ill nor mentally healthy,” (Keyes 2002:614), approximately 50 percent of the nation’s adult population will experience a mental disorder of some sort in their lifecycle, with nearly 1 in every 5 citizens facing a mental illness each year (Keyes 2002; Sickel, Seacat, and Nabors 2014; Satcher 2000; Henderson, Evans-Lacko, and Thornicroft 2013). However, the majority, over 70 percent of those sufferers, will not seek treatment; roughly only ten percent of those who are ill will seek professional help in a given year, and nearly half will not seek help at all (Satcher 2000; Keyes 2002; Sickel, Seacat, and Nabors 2014; Henderson, Evans-Lacko, and Thornicroft 2013). Defined as “health conditions that are characterized by alterations in thinking, mood, or behavior…associated with distress and/or impaired function” (Satcher 2000:89), mental illness not only impacts an individual’s mental performance (e.g. perception, thinking, reasoning, etc.) but also their physical health. Most often seen in the less educated, younger, female individuals and those who are unmarried (Keyes 2002); mental illness is known to decrease an individual’s life span (Satcher 2000). Mental illness ranks as the number two cause, in the United States, for untimely death and disability (Satcher 2000; Tsang, Tam, Chang, and Cheung 2003). Mental illness also has monetary consequences, with those who suffer from mental illness often earning less than the
non-mentally ill (Sickel, Seacat, and Nabors 2014). Public acknowledgement of mental illness was historically sparse, with no strong foothold in American society, until a 1999 Surgeon General report (Satcher 2000). As the premier report on psychological well-being and the first given by the U.S. government, its primary messages to the nation were 1) mental illness is real, 2) mental illness is imperative to affecting our mental health, 3) individuals who believe they have a mental illness should seek help, and 4) stigma of mental illness can no longer be tolerated (Satcher 2000).

Obsessive Compulsive Disorder

A specific mental illness, classified under Anxiety, and one of the leading mental illness categories according to the DSM (Diagnostic Statistical Manual)\(^1\), Obsessive Compulsive Disorder (OCD), a chronic mental illness, manifests itself through obsessions (e.g. fear of germs/contamination, death/injury, etc.) that cause anxiety which lead to compulsions (e.g. frequent hand-washing, showering, counting, ordering, etc.) in order to counterbalance the anxiety (Bruce and Raue 2013; Davey, Dash, and Meeten 2014; Coles, Heimberg, and Weiss 2013; Bruce 1999). Obsessions are unwanted, invasive, and often disturbing feelings, urges, or images in the mind of the OCD sufferer, while compulsions are defined as recurring and/or ritualistic actions or thoughts (Bruce and Raue 2013). According to the most recent copy of the DSM, these obsessions and compulsions must last for more than an hour a day, and cause concern and/or impairment. With sufferers often falling on a continuum from mild to severe deficiency in life functioning, the obsessions and compulsions are not simply troubles of everyday life (Davey, Dash, and Meeten 2014).

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\(^1\) The DSM, now in its fifth revision, is the leading diagnostic criteria for mental illnesses and was first created in 1952 (Davis 2010).
Approximately two to three percent of the American population will potentially suffer from OCD in their life, as it has risen to “one of the top four mental disorders in the world,” affecting both men and women equally (Davis 2010:121). While there are several types of treatment for OCD – such as psychological therapy, antidepressants, cognitive behavioral therapy, etc. – sufferers often may never fully overcome or “cure” their OCD for various reasons, such as non-recognition of the illness, failure to seek treatment, or even perhaps severity of the illness (Coles, Heimberg, and Weiss 2013).

Depression

Another mental illness, Depression represents a broad spectrum of mental illnesses, such as Major Depression, Postpartum Depression, or Bipolar Disorder (NIMH n.d.; Bruce 1999). While everyone experiences depressing moods or thoughts at some point in their lifetime, depression as a chronic mental illness is defined by the WHO (2016) as any and all depressive disorders involving “sadness, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, feelings of tiredness, and poor concentration” and often affects more women than men (Bruce and Raue 2013; NIMH n.d.; Regier et al. 1988). In order for depression to be chronic it must be ongoing and/or persistent and significantly impact a person’s life (WHO 2016). Depression as a word and diagnosis is often used both informally and clinically, forcing the chronic illness to often be viewed as rather less severe than other illnesses (Bruce and Raue 2013; Regier et al. 1988).

Despite depression (and all the disorders that fall under its name) being the number one predominant mental illness category in the world (Bruce 1999), it is estimated that only one third of depression and depressive disorder sufferers actually seek professional medical treatment (Regier et al. 1988). For example, Bipolar Disorder, previously known as Manic-Depressive
Disorder, affects roughly 2.6 percent of the nation’s adults and is manifested through frequent changes (episodes) in mood and behavior: at one moment a sufferer may experience a high (mania, manic episode) and the next moment the sufferer may experience a low (depression, depressive episode; NIMH, n.d.), with each episode having its qualifications for a specific diagnosis. In general, the majority of depression cases can be treated or managed effectively, but many sufferers choose not to seek treatment and thus their depression remains chronic and potentially becomes more severe with time (Regier et al. 1988).

Overall, these two mental chronic illnesses, OCD and Depression, encompass part of the top two mental illness categories plaguing the world. The next section offers a different perspective dealing specifically with physical chronic illness.

**Physical Illness**

Often categorized based on etiology (such as genetics/hereditary traits or bacterial versus viral), severity (mild, moderate, to severe), and/or duration (chronic or acute), physical illness is often more socially acceptable in today’s society than mental illness (Biro 2012; Ouimette-Kinney 2011). Expressed as “disorders or diseases that compromise physical well-being, either temporarily or chronically” (Ouimette-Kinney 2011:n.p.), physical illnesses differ from their mental counterparts in that they are often delineated by more visual aspects such as fever, coughing, bleeding, etc. (Satcher 2000). Approximately one-quarter of the U.S. population suffers from chronic physical pain, explaining roughly over one-fifth of all physician visits (Edwards 2013).

**Fibromyalgia**

Coined in the 1970s by Philip Hench, the physical illness Fibromyalgia was not fully acknowledged in American society as a real medical disorder and cause of ailment until 1987,
with the WHO slowly following suit in 1992 (Jones and Hoffman 2009; Lippell 2008). Rooted in precursory illnesses such as fibrositis\(^2\) and muscular rheumatism\(^3\), Fibromyalgia was actually described in the early 1800s (Bohr 1995; ProHealth n.d.). It remains a controversial and often contested illness, as its etiology remains unknown (Sabik 2010). It has also been disputed to be more psychiatric than physical (Aaron et al. 1996). Researchers have suggested that due to the high number of mental illness diagnoses among those suffering from Fibromyalgia, the illness itself may be related to a psychiatric disorder (Aaron et al. 1996).

Recognized for its persistent, chronic nature, difficulty to diagnosis, and extensive pain, the number of Fibromyalgia sufferers is often highly disputed (Sabik 2010; Torres et al. 2010; Bohr 1995). Affecting more women than men as approximately 80-90 percent more women are diagnosed than men (Sabik 2010; Jones and Hoffman 2009), one researcher suggests there are approximately three to six million Americans suffering from Fibromyalgia (Engdahl 2012), while another (Sabik 2010) suggests around six to ten million sufferers, with others such as the ACPA (n.d.) – American Chronic Pain Association – suggesting upwards of 12 million Americans, to a staggering 15 million Americans actually having a professional diagnosis (Jones and Hoffman 2009). Usually, symptoms of Fibromyalgia include, but are not limited to, sensitivity or pain amongst a minimum of 11 of 18 tender points on the body, general musculoskeletal aching, trouble sleeping, and fatigue, etc. (Torres et al. 2010; Bohr 1995; Jones and Hoffman 2009). These symptoms often vary from patient to patient moving in wave-like patterns of good days and bad days where sufferer’s symptoms come and go in “flares” (Bohr 1995; Jones and Hoffman 2009). While there are types of ways to manage pain and fatigue,

\(^2\) Fibrositis is the “inflammation of fibrous tissue” (Farlex Partner Medical Dictionary 2012).

\(^3\) Muscular rheumatism is “any of several muscular conditions marked by tenderness, soreness, pain, and local spasm” (Farlex Partner Medical Dictionary 2009).
there is no cure, and individuals are constantly subjected to ongoing attempts to manage their chronic physical illness with pain, sleep, and mood-altering medications, as well as diet and exercise; that is, if they seek treatment (Jones and Hoffman 2009). With little objective evidence that the illness exists and because symptoms vary greatly from sufferer to sufferer, a diagnosis of Fibromyalgia is one of omission or exclusion, where other illnesses must be ruled out first (Sabik 2010).

Chronic Fatigue Syndrome

Another physical illness Chronic Fatigue Syndrome (CFS), has an estimated $9.1 billion spent combatting it every year (Engdahl 2012). There are approximately 2.5 percent of American individuals suffering from CFS and a massive 80 percent of those individual’s women (Engdahl 2012). To be officially diagnosed with CFS, an individual must have frequent, extreme fatigue for a period of six months or longer (that is not due to any physical exertion of energy and that is cured by rest) (Looper and Kirkmayer 2004; Dickson, Knussen, and Flowers 2007; Engdahl 2012). This fatigue must create a disruption in the individual’s life, i.e. personal activities, job, etc., and the individual must also have at least four of the following symptoms: memory loss, trouble concentrating, muscle pain, joint pain, tender lymph nodes, trouble sleeping, and/or sore throats (Looper and Kirkmayer 2004; Dickson, Knussen, and Flowers 2007; Engdahl 2012).

Presented in the early 1980s with the first documented cases, CFS introduced itself with symptoms similar to Myalgic Encephalomyelitis\(^4\) (McKay, Duffy, and Martin 2009; Engdahl 2012). CFS, with its symptom variations among sufferers (much like Fibromyalgia), remains relatively contested and controversial as a physical illness (Engdahl 2012). Preventing its

\(^4\) “Myalgic Encephalomyelitis (ME) is a chronic degenerative neuro-immune disease” (NAME 2015).
sufferers from performing everyday routine tasks (Ware and Kleinman 1992), Chronic Fatigue Syndrome, like Fibromyalgia, is often diagnosed by excluding other disorders and illnesses first (Engdahl 2012) as there is no real etiology or objective test for CFS (Looper and Kirkmayer 2004). Residing in this state of contestation, even the name CFS has and is being challenged (Jason et al. 2015): beginning as Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS), arriving at Chronic Fatigue Syndrome (CFS), and currently the Institute of Medicine advising a name (along with symptom criteria) change to Systemic Exertion Intolerance Disease (SEID) (Jason et al. 2015). With no cure, only symptom management, CFS patients are prescribed medication, rest, and exercise to combat symptoms, while their chronic physical illness comes and goes in good days and bad days (Engdahl 2012).

While CFS presents as a physical illness, the WHO lists it as both a neurological condition and “as a mental health diagnosis” (McKay, Duffy, and Martin 2009:885). This presentation of CFS as well as some symptoms paralleling those of Depression, has led researchers to believe CFS is more psychiatric in nature than physical (DeLuca, Johnson, Ellis, and Natelson 1997). There has also been found to be a “high rate of psychiatric disorder” in those suffering from CFS (DeLuca, Johnson, Ellis, and Natelson 1997:151).

Fibromyalgia and CFS, while not extremely prevalent physical illnesses, represent a chronic illness underdog, slowly gaining relevance in today’s society. While these two physical and earlier discussed two mental chronic illnesses may not be comparable or contrastable, they are relatable and the next section focuses specifically on how these four chronic illnesses are associated.
The Continuum

While these four chronic illnesses – OCD, Depression, Fibromyalgia, and CFS – are not able to be compared directly – two are mental, two are physical, three affect women more, one affects men and women equally, three are specific illnesses, one is a broad umbrella illness – they are capable of being viewed on a chronic illness continuum. I have chosen these four chronic illnesses because they are all concealable – the nature of the illnesses allows the individual who suffers from them to hide their symptoms from others to some extent (Chaudoir, Earnshaw, and Andel 2013). These four illnesses, despite having medical diagnosis criteria, still have individuals within society (though they may be far and few) who dispute that these are serious illnesses, and even that they exist at all (Dickson, Knussen, and Flowers 2007).

Both OCD and Depression are specific terms that are used too colloquially in today’s society, with individuals sometimes claiming to have one, or the other, or even both illnesses despite no symptoms (SASNJ 2016). OCD often refers to “anal-retentive” or “perfectionist” while Depression often represents this vacuous term for dissatisfaction or sadness. On the other hand, both CFS and Fibromyalgia are terms not used enough in society, as their sufferers are often scared to mention or attempt to claim they may have the illnesses, as individuals often worry about delegitimation (Sabik 2010). Although Fibromyalgia, perhaps due to its precursor illnesses and several TV commercials, is beginning to make a breakthrough.

Also, both CFS and Fibromyalgia are sometimes viewed by society and medical professionals as more psychological/mental than physical illnesses, hence by definition closer to OCD and Depression than to other physical illnesses (DeLuca, Johnson, Ellis, and Natelson 1997; Aaron et al. 1996). By viewing these four chronic illnesses on a continuum, I propose that the different experiences, different exposure, and different knowledge individuals have of these
illnesses will create different reactions and viewpoints of mental and physical chronic illness. Therefore, I postulate that overall, the general public will have more contact with mental chronic illness than with physical chronic illness (H1 and H2). Thus:

**H1:** More respondents will know individuals suffering from mental chronic illness as opposed to physical chronic illness.

Also, as Depression is more prevalent and encompasses a wider array of mental illnesses, I hypothesize that:

**H1a:** More respondents will know individuals suffering from Depression, as opposed to Obsessive Compulsive Disorder.

Similarly, with regards to physical chronic illness, since Fibromyalgia is arguably more prevalent and more commercialized, I hypothesize that:

**H1b:** More respondents will know individuals suffering from Fibromyalgia, as opposed to Chronic Fatigue Syndrome.

With regards to personal diagnoses, I propose that due to the high prevalence of the two mental illnesses as opposed to the two chronic illnesses, the general public will have more personal diagnoses involving mental chronic illness. Thus:

**H2:** More respondents will be more likely to be personally diagnosed with a mental chronic illness, as opposed to a physical chronic illness.

As Depression is the most prominent mental illness category in the world, I hypothesize:

**H2a:** More respondents will be likely to be personally diagnosed with Depression as opposed to Obsessive Compulsive Disorder.

Whereas, in terms of physical chronic illness, as Fibromyalgia is believed to be more prevalent than Chronic Fatigue Syndrome; I hypothesize:
**H2b:** More respondents will be more likely to be personally diagnosed with Fibromyalgia, as opposed to Chronic Fatigue Syndrome.

These hypotheses and others will be discussed further in the results and discussion section.

*Health Literacy*

Health literacy represents “the cognitive and social skills as well as the abilities of an individual to gain access to, understand, and use health information in ways that promote and maintain good health” (Kickbusch and Maag 2008:205). Health literacy is a phrase often used to designate interests surrounding physical and mental illness, such as recognition of an illness, opinions and beliefs about how such illnesses will develop and progress, illness prevention, and help-seeking behavior (Jorm et al. 1997). Health literacy has even come to signify the knowledge that people with specific illnesses may experience stigma (Coles, Heimberg, and Weiss 2013). While not everyone may face contact directly with severe physical or chronic illness in their lifetime, it is extremely likely that they will know someone who does (Jorm 2000); thus having relatively sound knowledge in health literacy is beneficial for both the individual and society.

It is well known that knowledge and education greatly increase one’s health, as “only education correlates positively and consistently with health[y] behaviors” (Mirowsky and Ross 2010:35). However, most of our nation’s society is underwhelming in health literacy knowledge, as several members of our society cannot readily distinguish between specific mental illnesses or even comprehend basic medical psychiatric terms (Jorm 2000). Some researchers even argue that the current information available to the public at large is sometimes misleading and inaccurate (Jorm 2000). Therefore, I hypothesize that where individuals get their information will be important. Thus:
H3: Respondents who receive medical information from a medical professional will have higher health literacies, than respondents who do not receive medical information from a medical professional.

In a research survey involving the Health Activities Literacy Scale (HALS), it was found that roughly 19 percent of the nation’s adults, age 18 or older, are completely lacking in proper health literacy skills; while 27 percent lack the necessary health literacy skills to properly function in a “health environment” (Kickbusch and Maag 2008). Another survey from 1997 showed that just less than three-fourths of women in the nation believed they only had a one percent risk of heart disease, despite the fact that approximately one in every two females, in America, will die of heart disease or stroke; as they are the current leading causes of death in American women (Mosca et al. 2000). Using the Anxiety Knowledge Survey (AKS), intended to gauge mental health literacy (specifically focusing on anxiety disorders), researchers found that the majority of participants (two-thirds) were unable to recognize common symptoms of OCD (Coles, Heimberg, and Weiss 2013). Approximately 14.7 percent of respondents believed that sufferers should conceal their symptoms due to possible shame or humiliation, despite the vast majority (89.5 percent) believing the sufferer should seek professional help (Coles, Heimberg, and Weiss 2013). For those respondents who did recognize common symptoms, the respondents were more likely to be educated (Coles, Heimberg, and Weiss 2013). In general, these findings show that health literacy among Americans is low, and when individuals do know information, they still tend to denounce the actual victim’s pain and suffering.

The AKS was the first study to measure mental health literacy of OCD (Coles, Heimberg, and Weiss 2013).
Thus, based on the health literacy of our nation and the hypothesized personal contact, I hypothesize:

**H4:** Respondents will be more likely to know about mental chronic illness, as opposed to physical chronic illness.

**H4a:** Respondents will be more likely to know about Depression, as opposed to Obsessive Compulsive Disorder.

**H4b:** Respondents will be more likely to know about Fibromyalgia, as opposed to Chronic Fatigue Syndrome.

*Stigma*

Erving Goffman defines stigma⁶ as “an attribute that is deeply discrediting” or demeaning among an individual or group (Goffman 1963:3). Goffman (1963) argues that individuals are stigmatized based on discredited (external or non-concealable) traits or discredditable (internal or concealable) traits (Chaudoir, Earnshaw, and Andel 2013). The discredited, due to the non-concealable nature of their “trait” are much more likely to be stigmatized, whereas the discredditable can often “pass” or conceal their “trait” in most situations, making stigmatization less likely (Chaudoir, Earnshaw, and Andel 2013). In terms of mental and physical illness, mental illness is often referenced in regards to discredditable traits while physical illness is referenced in regards to discredited traits.

Stigma, a universal occurrence, also involves several processes such as labeling, stereotypes, and a separation of “us” versus “them” (Becker and Arnold 1986; Yang, Cho, and

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⁶ While there are different types of stigma – public, perceived, etc. – this thesis focuses on public stigma. “Public stigma attempts to map the levels and nature of stigma in the general population” while “perceived stigma represents agreement with a statement that prejudice and discrimination exist toward a labeled group” (Pescosolido and Martin 2015:93, 94).
Kleinman 2008; Link and Phelan 2001; Pescosolido and Martin 2015). Labeling is when a
description is attached to an individual or group of individuals based on how others see them
(Link and Phelan 1999; 2001). Labeling Theory, a cause of stigmatization, suggests that
individuals/groups are labeled with a specific description that attaches to them specific
stereotypes – essentially pigeon-holing who they are and should be (Link and Phelan 2001;
Rüscher, Angermeyer, and Corrigan 2005). Often inferring a division between the non-labeled and
the labeled, a stigma is created that treats those labeled as “less than fully human” (Rüscher,

Sometimes referred to as the societal reaction perspective, Labeling Theory (Gove 1970)
is a framework developed by Howard Becker (1963) and was ultimately created with the intent
to understand how individuals understand and view the actions of others. The framework
postulates that deviance – ultimately created by the world we live in – forces individuals to
“label” and designate, in order to treat differently those individuals who are different (Becker
1963). Once an individual is officially labeled with a diagnosis of either mentally or physically
ill, it is hard to have that label removed and those stereotypes overlooked, because through
socialization, individuals have already established thoughts and beliefs about what it means to be
ill (Link, Mirotznik, and Cullen 1991).

Another key aspect of stigma is that the stigmatizing group holds power over those that
are stigmatized – such as those who hold both formal and personal power—otherwise, these
labels and stereotypes would hold no merit (Yang, Cho, and Kleinman 2008). Ultimately, stigma
is a societal force to be reckoned with, that while the majority of differences amongst humanity
are disregarded, some seem to be ever too compelling, such as health (Rüscher, Angermeyer, and
Corrigan 2005). Regardless of how stigma is created, enforced, or reinforced, it can be viewed in
terms of degrees, such that one can be more or less stigmatized on a sort of continuum that ultimately impedes the lives of those affected (Phelan, Lucas, Ridgeway, and Taylor 2014; Link and Phelan 2001; Scheffer 2003; Pescosolido and Martin 2015).

Stigma may also cause a loss of status due to an individual’s place in the social hierarchy that is now being questioned, as their status has been marked as either discrediting or demeaning, and social rejection may come from the idea that for as long as the group in power believes the stigmatized is different, they will be viewed that way by the rest of society (Link and Phelan 2001). Often this impacts the stigmatized individual’s rates of employment (further causing downward mobility, not just from status loss) thus affecting not only individuals who are directly stigmatized, but also their friends and families (Coleman 1986; Scheffer 2003).

In regards to physical illness, a scarcity of both knowledge and awareness about certain illnesses has led to an increase in stigma due to the fact that people often believe the illnesses are not real – specifically with regards to Fibromyalgia and CFS (Armentor 2015). Studies involving sufferers of Fibromyalgia and Chronic Fatigue Syndrome continually experience their friends and family asking accusatory questions about the contestability and concealability of their illness (Dickson, Knussen, and Flowers 2007; Asbring and Närvänänen 2002). These sufferers were often questioned on possible exaggeration of their symptoms or if they were simply lying to be excused from work (Dickson, Knussen, and Flowers 2007). In a study by Herek and Capitanio (1992) involving AIDS/HIV (Auto Immune Deficiency Syndrome/Human Immunodeficiency Virus) a physical illness often stigmatized with regards to contamination and risk, it was found that approximately 40 percent of the nation holds some stigma towards those

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7 To my knowledge, the majority of research involving CFS and Fibromyalgia stigma is done using qualitative methodology from the point of view of the sufferer, not the general public (Dickson, Knussen, and Flowers 2007; Asbring and Närvänänen 2002).
suffering from AIDS, with one-sixth of those Americans possessing high levels of stigma. The study also indicates that approximately 50 percent of the respondents would not shop at their local grocery store if they knew the owner suffered from AIDS, despite their overall willingness to show sympathy and compassion for those who suffer from the disease (Herek and Capitanio 1992; Rochkind, Dupont, and Ott 2009).

With regards to mental illness, the majority of studies often show that the public stereotypes those suffering from mental illness as inept, subordinate, stupid, feeble, unwelcome, and dangerous (Sabin and Mancuso 1970); with a general attitude of NIMBY (Not In My Backyard) expressing the idea that individuals suffering from mental illness should be helped but not from a location nearby those who are not suffering (Barney, Corser, and White 2010; Trute and Loewen 1978; Phelan, Lucas, Ridgeway, and Taylor 2014; Corrigan, Kerry, and Knudsen 2005; Smith and Cashwell 2011). Despite these stereotypes, the majority (roughly 80 to 90 percent of those suffering from a mental illness) never actually commit a brutal or violent action (Scheffler 2003). The general public has also been found to view the mentally ill as needing supervision, necessitating less engagement in societal roles, such as limiting their right to marry, adopt and have children, and their right to vote (Corrigan, Kerry, and Knudson 2005). According to some researchers (Corrigan, Kerry, and Knudson 2005), over 40 percent of the fifty United States restrict the marriage rights of those suffering from mental illness. It has also been noted that some U.S. insurance companies often refuse to provide equal insurance for the mentally ill as done for the physically ill, “because they judge that it would be too expensive” and consequently too risky (Yang, Cho, and Kleinman 2008:224).

While the majority of the nation does recognize and relatively accept most mental illnesses, a study of the General Social Survey (GSS) regarding mental illness, in both 1950 and
1996, shows that the nation’s overall perceptions of these sufferers as violent and/or scary
significantly increased by almost two and a half times (Phelan, Link, Stueve, and Pescosolido
2000). Often, individuals still have trouble even recognizing or being health literate about mental
illness disorders (Link et al. 1999). In one of the very first mental illness national surveys, the
GSS – a periodic national probability sample of households that included Shirley Star’s mental
illness vignette experiment in 1996 – discovered that “very few Americans identified the
described conditions [vignettes] as mental illness” (Pescosolido et al. 2010; Link et al.
1999:1328). Roughly 30 percent of the respondents believed the vignette/condition involving
major depressive disorder “was somewhat or very unlikely” to indicate mental illness (Link, et
al. 1999:1331).

Other research involving stigma of the mentally ill has shown mixed results, indicating
that both members of the lower social class are more willing to accept and therefore stigmatize
the mentally ill less (Trute and Loewen 1978), while some (Johannsen 1969; Stuber, Rocha,
Christian, and Link 2014) argue that more upper class, younger, and more educated individuals
are less likely to stigmatize sufferers of mental illness. This in opposition to Pescosolido (2013)
who found that the stigmatization towards the mentally ill was in regards to the age of the
sufferer and not the stigmatizers. In a study by Pescosolido and colleagues (1996) it was
determined that 38.2 percent of participants refused to befriend a person with mental illness,
while 75 percent of participants refused to have a person with mental illness as a family member,
and 67.4 percent of participants refused to have a person with a mental illness as a coworker.
Another study of community attitudes by Link and colleagues (1989) indicates that roughly
three-fourths of the respondents would not want to hire a former mental patient, with around 80
percent not wanting to date a former mental patient, and approximately 71 percent believing a former mental patient is dishonest and unreliable.

With regards to the literature on stigma and health literacy, I hypothesize that:

**H5:** Respondents who are more health literate with regards to chronic illness will be less likely to stigmatize those suffering from chronic illness.

I also believe, based on the health literacy information, that where respondents receive their medical information, whether it is from a medical professional or not (such as a non-medical web page, friend, book, etc.) may impact how respondents stigmatize those suffering from chronic illness. Thus, I hypothesize that:

**H6:** Respondents who receive medical information from a medical professional will be less likely to stigmatize those suffering from chronic illness.

Also, due to the fact that the majority of these illnesses affect women more, and the fact that women are generally more tolerant (i.e. less stigmatizing) of the mentally ill specifically (Sartorious 1999; Smith and Cashwell 2011), I hypothesize that sex may play a role in stigmatization and knowledge about these chronic illnesses. Thus, following from the literature from gender effects, I hypothesize that:

**H7:** Men will be more likely to stigmatize individuals suffering from chronic illness as opposed to women (regardless of whether it is physical or mental).
METHODOLOGY

Data

Primary data is used in this thesis, in order to explore the general public’s view of chronic illness, as well as their health literacy. I created an online survey titled “Comparing Social Constructions, Perceptions, and Stigmas of Chronic Illnesses, 2015” with the intent to capture a nationally representative sample of the public’s overall perceptions, viewpoints, and opinions, and believed health literacy of four different chronic illnesses (OCD, Depression, Fibromyalgia, and CFS). Administered between February and March of 2016, there were approximately 1001 partial surveys and 976 full or complete surveys. All respondents were age 18 and above, with the average respondent age 59. All of the study variables are distributed normally, with the exclusion of three variables (does the respondent have CFS/Fibromyalgia/OCD, respectively). These three variables are all slightly positively skewed, with more respondents having been diagnosed with these illnesses than is nationally represented.

Exogenous Variables

Several observed exogenous variables are used for this thesis, mainly as control variables. The first represents sex, and is coded “0 for female” and “1 for male.” Just over 60 percent of my respondents were female, with 0.11% of the data missing on this specific variable. Race was split into three dummy categories, with approximately 11 percent of respondents Black/African.

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8 In order to ensure respondents were not focused on only these four illnesses, and had no idea the survey was only intended to measure these four illnesses, the exact questions were included within the survey regarding two other physical chronic illness (Heart Disease and Diabetes) and two other mental chronic illnesses (Anxiety and Schizophrenia).
9 A partial survey represents a survey that was not fully completed, or a survey in which respondents answered at least one of my two random “attention” questions (in order to make sure the respondent was paying attention) as wrong.
10 Unless specified, no other variables have missing data.
American, 12 percent Latino/a, and 70 percent White\textsuperscript{11}, with 1 representing “Yes” the respondent is a member of that racial category, and 0 representing “No” the respondent is not a member of that racial category. The final observed exogenous variable represents whether or not respondents receive any medical information from a medical professional, with “1 for Yes” and “0 for No,” and with 70.49 percent of respondents receiving some medical information from a medical professional.

**Endogenous Variables**

The majority of the variables within my data are observed endogenous, all predicted by other variables (See Tables 1 and 2 for descriptive statistics of all study variables and correlations.) The first four deal with some of my main hypotheses and represent health literacy: that is believed health literacy of CFS/Fibromyalgia/OCD/Depression. This is not true health literacy as I cannot gauge the actual respondents’ knowledge in one question, but it is the respondents’ believed health literacy of each chronic illness, ranging on a scale from “0 – I know nothing about this illness, not even the name,” “1 – I only know the name of this illness,” to “7 – I know almost everything about this illness.”\textsuperscript{12}

Respondents were asked if they had ever been personally diagnosed with each illness, these four dichotomous variables were then summed and indexed into one variable representing if the respondent had been personally diagnosed with anywhere from “0 – No diagnoses” to “4 – All 4 diagnoses”.\textsuperscript{13} As for knowing someone with a chronic illness, respondents were asked if they knew someone diagnosed with each illness (a family member, neighbor, friend, coworker), and this was turned into a dummy variable for each illness with “1 – Yes, I know someone with

\textsuperscript{11} White is used in all SEM Models below as a reference category.

\textsuperscript{12} See Figure 1 for more info.

\textsuperscript{13} See Figure 2 for more info.
CFS/Fibromyalgia/OCD/Depression diagnosis” or “0 – No, I do not”. Then these four dummy variables were summed and indexed into one variable representing if the respondent knew anyone with “0 – None of the illnesses” to “4 – All 4 of the illnesses”14.

Finally, my main observed endogenous variables were a set of five scales representing stigma – Physical Stigma, Mental Stigma, Social Distance, Social Control, and Social Responsibility. All scales were created using questions and adaptations of questions from other scales and surveys – the Opinions About Mental Illness Scale (Cohen and Struening 1962), the Mental Health Population Survey 2008 (Aromaa 2011), Attitudes to Mental Illness 2012 Research Report (Mind 2013), Community Attitudes Toward Mentally Ill (CAMI) Scale (Taylor and Dear 1981), and the Community Attitudes to Mental Illness (Barney, Corser, and White 2010). The Physical Stigma scale ($\alpha = 0.8173$) consists of eight unique variables all relating to physical chronic illness and individual perception/opinion dealing with stigmatization that load on a single factor (eigenvalue 3.007). Mean replacement was used to account for missing data (those respondents who answered “Don’t Know” or “Prefer Not to Answer”). The Mental Stigma scale ($\alpha = 0.8681$) consists of seven unique variables all relating to mental chronic illness and individual perception/opinion dealing with stigmatization that load on a single factor (eigenvalue 3.42). Mean replacement was also used with this scale to have zero percent missing data. As for the Social Distance scale ($\alpha = 0.7974$), it consists of six unique variables all relating to social isolation and separation of the individuals from the chronically ill. This scaled variable loads on a single factor (eigenvalue 2.492), and contains a total of 10.87 percent missing data15. Social distance represents respondents’ eagerness or inclination to engage in activities with the mentally

14 See Figure 3 for more info.
15 Mean replacement was not used to account for missing data on this scale or the next two, in order to maintain high alpha reliabilities.
and physically ill, such as living with or working with the mentally and physically ill (Corrigan et al. 2001; Bogardus 1925). The Social Control scale ($\alpha = 0.7025$) consists of five different variables, all representing the chronically ill, supervision, and liability. All five variables load on a single factor (eigenvalue 1.69), with 13.02 percent missing data. Social control refers to the respondents’ opinion that the mentally and physically ill are a burden on society, need similar supervision/discipline as children, and are able to be distinguished simply because of how they look. The final scale, Social Responsibility ($\alpha = 0.8170$), consists of six distinctive variables representing chronic illness and individual’s obligations and accountability. All six variables load on a single factor (eigenvalue 2.7) with 14.35 percent missing data. Social responsibility represents respondents’ opinions on whether or not the mentally and physically ill should be allowed to hold public office, vote, or have and adopt children.
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<th>Variable</th>
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<th>Mean</th>
<th>Std. Dev.</th>
<th>Min.</th>
<th>Max.</th>
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Analytic Strategy

To measure my hypotheses, I use Structural Equation Modeling (SEM) and Maximum Likelihood Estimation to create five different recursive models to test the general public’s opinions, health literacy, and stigma of chronic illness. SEM was chosen because it is adaptable and allows for the examination of relationships between multiple dependent variables and multiple independent variables (Nachtigall, Kroehne, Funke, and Steyer 2003). It also fits well with my specific variables and my large sample size, and also allows me to test overall model fit versus individual coefficient statistics.

All SEM models are the same with the only change being the stigma variable – Physical Stigma, Mental Stigma, Social Control, Social Distance, Social Responsibility (See Figure 1 below), and each SEM model only includes a structural model component as no latent variables/constructs are introduced. Due to the exploratory nature of my hypotheses, I have all

Table 2. Correlation Matrix for All Study Variables

|                  | 1.  | 2.  | 3.  | 4.  | 5.  | 6.  | 7.  | 8.  | 9.  | 10. | 11. | 12. | 13. | 14. | 15. | 16. | 17. | 18. | 19. | 20. | 21. | 22. | 23. | 24. |
|------------------|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|-----|
| 1. Male          |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     | 
| 2. Black/African American | 0.28 |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     | 
| 3. Latino/a      | -0.19 | 0.34 |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     | 
| 4. White         | -0.45 | -0.56 | -0.59 |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     | 
| 5. Have CFS      | -0.07 | -0.07 | -0.07 |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     | 
| 6. Have Fibro    | -0.12 | -0.08 | -0.06 | -0.11 | -0.18 |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     | 
| 7. Have OCD      | -0.03 | -0.06 | -0.01 | -0.01 | -0.15 | -0.09 |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     | 
| 8. Have Dep      | -0.18 | -0.08 | -0.09 | -0.12 | -0.19 | -0.24 | -0.19 |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     | 
| 9. Personally Diagnosed | -0.18 | -0.12 | -0.08 | -0.12 | -0.56 | -0.62 | -0.48 | -0.81 |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     | 
| 10. Know Someone CFS | -0.09 | -0.02 | -0.09 | -0.09 | -0.33 | -0.18 | -0.16 | -0.14 | -0.28 |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     |     | 
| 11. Know Someone Fibro | -0.22 | -0.11 | -0.10 | -0.21 | -0.21 | -0.28 | -0.15 | -0.19 | -0.31 | -0.38 |     |     |     |     |     |     |     |     |     |     |     |     |     |     | 
| 12. Know Someone OCD | -0.07 | -0.07 | -0.05 | -0.10 | -0.12 | -0.09 | -0.29 | -0.20 | -0.27 | -0.38 | -0.32 |     |     |     |     |     |     |     |     |     |     |     |     |     | 
| 13. Know Someone Dep | -0.17 | -0.07 | -0.01 | -0.09 | -0.08 | -0.12 | -0.12 | -0.36 | -0.32 | -0.25 | -0.29 | -0.27 |     |     |     |     |     |     |     |     |     |     |     |     | 
| 14. Know Someone Diagnosed | -0.19 | -0.10 | -0.09 | -0.18 | -0.25 | -0.24 | -0.25 | -0.32 | -0.42 | -0.68 | -0.72 | -0.73 | -0.69 |     |     |     |     |     |     |     |     |     |     |     | 
| 15. Health Lit CFS | -0.09 | -0.01 | -0.02 | -0.04 | -0.11 | -0.22 | -0.13 | -0.17 | -0.29 | -0.39 | -0.24 | -0.20 | -0.13 | -0.33 |     |     |     |     |     |     |     |     |     |     | 
| 16. Health Lit Fibro | -0.24 | -0.12 | -0.08 | -0.18 | -0.24 | -0.39 | -0.12 | -0.23 | -0.38 | -0.32 | -0.44 | -0.21 | -0.19 | -0.41 | -0.62 |     |     |     |     |     |     |     |     |     | 
| 17. Health Lit OCD | -0.02 | -0.05 | -0.01 | -0.02 | -0.07 | -0.01 | -0.24 | -0.12 | -0.17 | -0.19 | -0.12 | -0.31 | -0.11 | -0.25 | -0.44 | -0.38 |     |     |     |     |     |     |     | 
| 18. Health Lit Dep | -0.05 | -0.05 | -0.01 | -0.05 | -0.66 | -0.66 | -0.12 | -0.39 | -0.31 | -0.13 | -0.11 | -0.21 | -0.10 | -0.27 | -0.38 | -0.33 | -0.54 |     |     |     |     |     |     |     | 
| 19. Info Med Professional | -0.16 | -0.08 | -0.04 | -0.15 | -0.09 | -0.08 | -0.01 | -0.10 | -0.11 | -0.07 | -0.12 | -0.02 | -0.15 | -0.13 | -0.02 | -0.06 | -0.05 | -0.00 |     |     |     |     |     |     | 
| 20. Mental Stigma Scale | -0.14 | -0.01 | -0.09 | -0.11 | -0.00 | -0.06 | -0.01 | -0.16 | -0.12 | -0.05 | -0.10 | -0.07 | -0.16 | -0.14 | -0.04 | -0.04 | -0.04 | -0.09 | -0.09 |     |     |     |     |     | 
| 21. Physical Stigma Scale | 0.21 | 0.02 | -0.19 | -0.24 | -0.01 | -0.03 | 0.04 | -0.07 | 0.04 | -0.04 | -0.10 | -0.02 | -0.13 | -0.12 | -0.13 | -0.06 | -0.02 | -0.06 | -0.22 | -0.59 |     |     |     |     | 
| 22. Social Distance Scale | 0.17 | -0.00 | 0.08 | -0.12 | -0.01 | -0.06 | 0.04 | -0.17 | -0.14 | -0.08 | -0.14 | -0.10 | -0.19 | -0.18 | -0.04 | -0.01 | -0.04 | -0.15 | -0.18 | -0.79 | -0.69 |     |     | 
| 23. Social Control Scale | -0.21 | -0.02 | -0.15 | -0.18 | -0.01 | -0.06 | 0.02 | -0.12 | -0.09 | -0.02 | -0.10 | -0.02 | -0.14 | -0.12 | 0.09 | 0.03 | 0.04 | 0.00 | -0.18 | -0.69 | -0.59 | 0.57 |     |     | 
| 24. Social Responsibility Scale | 0.15 | 0.03 | -0.18 | -0.20 | -0.02 | -0.04 | 0.02 | -0.11 | -0.07 | -0.05 | -0.09 | -0.04 | -0.15 | -0.12 | 0.06 | 0.05 | 0.06 | -0.07 | -0.12 | -0.85 | -0.74 | 0.63 | 0.63 |     |
exogenous variables, with the exception of whether respondent’s receive medical information from a medical professional, influencing whether or not the respondent will be personally diagnosed as well as influencing if the respondent will know someone diagnosed with a chronic illness. I also have all endogenous and exogenous variables influencing stigma. As for correlations, the error terms for being personally diagnosed and knowing someone diagnosed with a chronic illness are correlated, while all four health literacy error terms are correlated. All exogenous variables are also correlated.

**Figure 1. Heuristic Model**
RESULTS

Overall, I found that more respondents had a higher believed health literacy of Depression ($\mu = 5.00$), as compared to OCD ($\mu = 4.22$) providing support for Hypothesis 4a; while similarly more respondents were diagnosed and know someone diagnosed with Depression (27.25%, 65.78% respectively) as compared to OCD (4.61%, 29.30% respectively), thus providing support for Hypotheses 2a and 1a. With regards to physical illness, respondents had roughly similar believed health literacies of Fibromyalgia ($\mu = 3.07$) and CFS ($\mu = 3.05$) providing little to no support for Hypothesis 4b, yet more respondents are diagnosed and know someone diagnosed with Fibromyalgia (5.49%, 40.57%) as compared to CFS (3.69%, 16.60%) providing support for Hypotheses 2b and 1b. Thus, overall more respondents know about mental chronic illness as opposed to physical chronic illness, ultimately supporting Hypothesis 4. Support is also provided for Hypotheses 2 and 1 as more respondents are likely to be personally diagnosed and/or know someone diagnosed with mental chronic illness rather than physical chronic illness (0.32, 0.09; 0.95, 0.57 respectively). Respondents are also much more likely to know someone diagnosed than to be personally diagnosed with a chronic illness overall ($\mu = 1.52, 0.41$ respectively). See Figures 2, 3, and 4 for more information.
Figure 2. Respondents' Believed Health Literacy (by Percent)

Figure 3. Respondents with a Diagnosis (by Percent)
All five stigma scale models (Physical Stigma $\mu = 1.78$, RMSEA 0.064, CFI 0.996, SRMR 0.016, CD 0.190; Mental Stigma $\mu = 2.70$, RMSEA 0.064, CFI 0.996, SRMR 0.016, CD 0.135; Social Distance $\mu = 2.36$, RMSEA 0.065, CFI 0.996, SRMR 0.016, CD 0.168; Social Control $\mu = 2.80$, RMSEA 0.064, CFI 0.996, SRMR 0.016, CD 0.191; and Social Responsibility $\mu = 2.27$, RMSEA 0.074, CFI 0.994, SRMR 0.017, CD 0.157) have relatively good fit statistics despite the chi-square statistic being significant, which may be due to the large sample size. See Tables 3 and 4 for main standardized coefficients of SEM models and model fit statistics.

Specifically looking at being personally diagnosed and knowing someone diagnosed, results indicate that respondents who are personally diagnosed and who know someone diagnosed are more likely to have higher believed health literacies of all four chronic illnesses across all five models. For CFS, respondents who are personally diagnosed or know someone diagnosed are likely to have a higher believed health literacy by 0.171 and 0.263 for Physical and Mental Stigma, 0.15 and 0.261 for Social Responsibility, 0.206 and 0.251 for Social Distance, and 0.187 and 0.265 for Social Control. As for Fibromyalgia, respondents who are personally

![Figure 4. Respondents Who Know Someone with a Diagnosis (by Percent)](image-url)
diagnosed or know someone diagnosed are likely to have a higher believed health literacy by 0.189 and 0.321 for Physical and Mental Stigma, 0.187 and 0.313 for Social Responsibility, 0.219 and 0.299 for Social Distance, and 0.214 and 0.308 for Social Control. For OCD, respondents who are personally diagnosed or know someone diagnosed are likely to have a higher believed health literacy by 0.100 and 0.249 for Physical and Mental Stigma, 0.086 and 0.241 for Social Responsibility, 0.086 and 0.254 for Social Distance, and 0.093 and 0.229 for Social Control. For Depression, respondents who are personally diagnosed or know someone diagnosed are likely to have a higher believed health literacy by 0.274 and 0.203 for Physical and Mental Stigma, 0.261 and 0.186 for Social Responsibility, 0.264 and 0.198 for Social Distance, and 0.275 and 0.184 for Social Control. I also found that respondents who are personally diagnosed are less likely to stigmatize those suffering from chronic illness among all models, with the exception of the Physical Stigma scale; however, the only significant decrease in stigmatization is among the Mental Stigma scale. Thus, being personally diagnosed significantly decreases an individual’s likelihood of stigmatizing the chronic mentally ill by 0.092. Knowing someone diagnosed with a chronic illness decreases stigmatization, as well, but significantly across all five models (Physical Stigma -0.085, Mental Stigma -0.114, Social Responsibility -0.114, Social Distance -0.132, and Social Control -0.094).

As for health literacy as a predictor of stigmatization, mixed support is provided for Hypothesis 5. For every one-unit increase in a respondents’ health literacy of CFS, their stigmatization increases among all five models (Physical Stigma 0.178, Mental Stigma 0.109, Social Responsibility 0.129, Social Distance 0.117, and Social Control 0.119). Respondents who have a higher believed health literacy of Fibromyalgia are also more likely to stigmatize those suffering from chronic illness, but only among one scale, i.e. Social Responsibility. A one-unit
increase in respondents’ believed health literacy of Fibromyalgia increases stigmatization among the Social Responsibility scale by 0.107. For OCD, however, respondents’ believed health literacy decreases stigmatization among all models, with the exception of the Social Control scale, but the only significant result is among the Social Responsibility scale. A one-unit increase in respondents’ believed health literacy of OCD decreases respondents’ stigmatization on the Social Responsibility scale by 0.091. For Depression respondents’ believed health literacy also decreases stigmatization, but it is only significant for two scales – Physical Stigma and Social Distance. A one-unit increase in respondents’ believed health literacy of Depression decreases stigmatization of Physical Stigma by 0.091 and Social Distance by 0.159. Thus, these results indicate that respondents’ believed mental health literacy ultimately decreases stigmatization more than does respondents’ believed physical health literacy.

Using race as a predictor, the models indicate black/African American respondents are less likely than white respondents to stigmatize those suffering from chronic illness. However, this decrease in stigmatization is only significant among the Mental Stigma scale (-0.069).

Black/African American respondents are also less likely as opposed to white respondents to be personally diagnosed or know someone diagnosed with a physical or mental chronic illness among all five scales (Mental and Physical Stigma -0.077, -0.081; Social Responsibility -0.077, -0.071; Social Distance -0.082, not significant; Social Control -0.082, -0.079 respectively).

Respondents who are black/African American, as compared to white respondents, are also significantly more likely to have a higher believed health literacy of Depression on all five scales (Mental and Physical Stigma 0.084, Social Responsibility 0.091, Social Distance 0.101, and Social Control 0.120). As for those respondents who are Latino/a, they are more likely than white respondents to stigmatize individuals suffering from chronic illness, but results are only
As for sex, there is support for Hypothesis 7, as results indicate that male respondents are significantly more likely to stigmatize physical and mental chronic illness among all five models (Physical Stigma 0.166, Mental Stigma 0.132, Social Responsibility 0.097, Social Distance 0.151, and Social Control 0.178). Also with regards to Fibromyalgia, male respondents are likely to have a lower believed health literacy than women (Physical and Mental Stigma -0.133, Social Responsibility -0.143, Social Distance -0.132, and Social Control -0.119). The findings also show that being male significantly reduces an individual’s chances of being personally diagnosed and knowing someone diagnosed with either a mental or physical chronic illness among all five models (Physical and Mental Stigma -0.157, -0.164; Social Responsibility -0.142, -0.165; Social Distance -0.148, -0.157; and Social Control -0.156, -0.169 respectively).

Focusing on receiving medical information from a medical professional, I found that the data indicate the majority of respondents do receive at least some medical information form a medical professional (approximately 70 percent). The data provide support for Hypothesis 6, showing that individuals who receive medical information in this way are less likely to stigmatize those suffering from chronic illness among all five models; however, it is not significant for all scales with the exception of the Mental Stigma scale. Thus, a one-unit increase in receiving medical information from a medical professional decreases stigmatization among the Physical Stigma scale by 0.168, Social Responsibility scale by 0.073, the Social Distance scale by 0.126, and the Social Control scale by 0.128. However, there is no support for
Hypothesis 3, as the data indicate that receiving medical information from a medical professional significantly lowers respondents’ believed health literacy of OCD among all five models. For every one-unit increase in receiving medical information from a medical professional, respondents’ believed health literacy of OCD decreases significantly by 0.084 for Physical and Mental Stigma, 0.077 for Social Responsibility, 0.078 for Social Distance, and 0.073 for Social Control.

Table 3. Standardized Coefficients of SEM Models

<table>
<thead>
<tr>
<th>Independent Variable</th>
<th>Physical Stigma</th>
<th>Mental Stigma</th>
<th>Social Distance</th>
<th>Social Control</th>
<th>Social Responsibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>.166*</td>
<td>.132*</td>
<td>.151*</td>
<td>.178*</td>
<td>.097*</td>
</tr>
<tr>
<td>Black/African American</td>
<td>-.025</td>
<td>-.069*</td>
<td>-.060</td>
<td>-.028</td>
<td>-.008</td>
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<tr>
<td>Latino/a</td>
<td>.123*</td>
<td>.034</td>
<td>.041</td>
<td>.102*</td>
<td>.139*</td>
</tr>
<tr>
<td>Health Literacy CFS</td>
<td>.178*</td>
<td>.105*</td>
<td>.117*</td>
<td>.119*</td>
<td>.129*</td>
</tr>
<tr>
<td>Health Literacy Fibromyalgia</td>
<td>.066</td>
<td>.069</td>
<td>.085</td>
<td>.054</td>
<td>.107*</td>
</tr>
<tr>
<td>Health Literacy OCD</td>
<td>-.050</td>
<td>-.019</td>
<td>-.006</td>
<td>.046</td>
<td>-.091*</td>
</tr>
<tr>
<td>Health Literacy Depression</td>
<td>-.091*</td>
<td>-.068</td>
<td>-.159*</td>
<td>-.042</td>
<td>-.048</td>
</tr>
<tr>
<td>Personally Diagnosed</td>
<td>.007</td>
<td>-.092*</td>
<td>-.072</td>
<td>-.052</td>
<td>-.045</td>
</tr>
<tr>
<td>Know Someone Diagnosed</td>
<td>-.085*</td>
<td>-.114*</td>
<td>-.132*</td>
<td>-.094*</td>
<td>-.114*</td>
</tr>
<tr>
<td>Info Medical Professional</td>
<td>-.168*</td>
<td>-.037</td>
<td>-.126*</td>
<td>-.128*</td>
<td>-.073*</td>
</tr>
</tbody>
</table>

*p ≤ 0.05

Table 4. SEM Model Fit Statistics

<table>
<thead>
<tr>
<th>Model Fit Statistics</th>
<th>Chi2(2)</th>
<th>RMSEA</th>
<th>CFI</th>
<th>SRMR</th>
<th>CD</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Stigma *</td>
<td>10.072</td>
<td>.064</td>
<td>.996</td>
<td>.016</td>
<td>.190</td>
<td>975</td>
</tr>
<tr>
<td>Mental Stigma*</td>
<td>10.072</td>
<td>.064</td>
<td>.996</td>
<td>.016</td>
<td>.135</td>
<td>975</td>
</tr>
<tr>
<td>Social Distance*</td>
<td>9.239</td>
<td>.065</td>
<td>.996</td>
<td>.016</td>
<td>.168</td>
<td>869</td>
</tr>
<tr>
<td>Social Control*</td>
<td>8.994</td>
<td>.064</td>
<td>.996</td>
<td>.016</td>
<td>.191</td>
<td>848</td>
</tr>
<tr>
<td>Social Responsibility*</td>
<td>11.040</td>
<td>.074</td>
<td>.994</td>
<td>.017</td>
<td>.157</td>
<td>835</td>
</tr>
</tbody>
</table>

*p ≤ 0.05
DISCUSSION

This study and its results exemplify that the American public generally has more contact with individuals suffering from mental chronic illness as opposed to those suffering from physical chronic illness. With regards to mental chronic illness specifically, more individuals in America know someone diagnosed with/suffering from Depression, as opposed to OCD. Similarly, with regards to physical chronic illness, more American individuals know someone diagnosed with/suffering from Fibromyalgia, as opposed to Chronic Fatigue Syndrome. Overall, the general public is more likely to know someone diagnosed with/suffering from a mental chronic illness, rather than a physical chronic illness. As for personal diagnoses, the data shows that the general American public is in fact more likely to be personally diagnosed with a mental chronic illness rather than a physical chronic illness. A higher number of individuals are personally diagnosed with Depression as compared to OCD, and similarly, a higher number of individuals are diagnosed with Fibromyalgia, as compared to CFS.

However, with regards to receiving medical information from a medical professional, I find individuals who do this do not then have their health literacy significantly impacted. Receiving information this way only significantly impacts an individual’s believed health literacy of OCD, and in a negative direction. The more an individual receives their medical information from a medical professional, the less likely they are to rate their health literacy of OCD as high.

With respect to health literacy, individuals know more in general about mental chronic illness as opposed to physical chronic illness. Individuals are also more likely to know about Depression as opposed to OCD, and more likely to know about Fibromyalgia as opposed to CFS. This may be for a couple reasons: 1) that individuals believe they do and/or actually do know
more about the chronic illnesses they are diagnosed with or that someone they know is diagnosed with (i.e., more individuals are apt to be diagnosed with/know someone diagnosed with a mental illness vs. physical illness, Depression vs. OCD, and Fibromyalgia vs. CFS), or 2) mental chronic illness is more prevalent in the news, media, TV, etc., as compared to physical illness. Future research will have to determine which reason is more predominant; regardless, believed knowledge of chronic illness is severely lacking, even for Depression, in which the general public claims to know the most about.

In terms of stigma and health literacy’s impact, there is mixed support. Individuals who have higher health literacies of CFS and Fibromyalgia are more likely to stigmatize those suffering from chronic illness, while individuals with higher health literacies of OCD and Depression are less likely to stigmatize those suffering from chronic illness specifically among social responsibility stigma for OCD, and physical illness stigma and social distance stigma for Depression. I argue that because I measure believed health literacy, and not actual health literacy, it may be that some if not many of these individuals with high health literacies of these chronic illnesses in fact do not have accurate and relevant information, therefore making their viewpoints and opinions on stigmatization more negative. Or these individuals with high believed health literacies of physical illness do in fact have accurate and relevant information, and they are aware of the current stigma that CFS and Fibromyalgia undergo on a daily basis and simply wish to remain on the so-called band-wagon of stigmatization.

As for individuals who receive medical information from a medical professional they are in fact less likely to stigmatize those suffering from chronic illness. With regards to gender effects, men are more likely to stigmatize individuals suffering from chronic illness as opposed to women (regardless of whether the individual is suffering from mental or physical chronic
illness). Amongst all five stigma scales, being male increases an individual’s chances of stigmatizing the chronically ill with the highest impact on social control stigma. Thus indicating that men stigmatize chronic illness sufferers highly in terms of individuals wanting to control, prohibit, and hold power over what the ill are able to do. Also, being male increases one’s chances of having a lower believed health literacy with regards to Fibromyalgia among all five stigma scales. I suggest this is due to the high prevalence of Fibromyalgia among the female population, and my previous statement about individuals knowing their own diagnosis. Males, as opposed to females, are also less likely to be personally diagnosed and/or know someone diagnosed with a chronic illness. With women outliving men (Kirkwood 2010), this may mean that men are a) lying about being ill, or b) simply receiving diagnoses of more fatal and acute diseases/illnesses.

While race was merely used as a control variable and not focused on in any hypotheses, it did turn out to be an influential predictor in stigma, health literacy, and contact. Compared to whites, African Americans are less likely to stigmatize mental chronic illness overall, while Latino/as, as compared to whites, are less likely to stigmatize physical chronic illness overall, and chronic illness with regards to social responsibility and social control. African Americans, compared to whites, are also less likely to be diagnosed and less likely to know someone diagnosed with a chronic illness. In terms of stigma, African American individuals, as opposed to white individuals, are more likely to have higher believed health literacies of Depression among all five stigma scales, while Latino/as only have high health literacy of Depression among social distance stigma. Arguably these results make sense as “stigma overlaps with racism” and creates similar effects (Hatzenbuehler, Phelan, and Link 2013:813).
As for limitations, the biggest restriction is my survey sample and that it may not be quite as nationally representative as I had hoped. The fact that I titled my survey with chronic illness in the title, I may inadvertently have received more responses from individuals with a diagnosis or who know someone with a diagnosis than I would have otherwise. Specifically, while sex, age, and race were normally distributed, the amount of individuals actually diagnosed with each illness (with the exception of Depression) was slightly positively skewed.

Also, as Corrigan (2004) points out, numerous individuals are conscious and alert to stigmatization and the current discrimination that these sufferers of chronic illness face; however, being aware is not the same as endorsement and vice versa. And due to social acceptability/desirability bias, individuals may not truly answer stigmatization questions honestly, and therefore likely underreport the truth (Schnittker 2013). Another limitation is the previously mentioned chi-squared statistics, which may be overlooked due to the large sample size. While the sample is quite large and measures were taken to reduce survey respondent mistakes/errors, the data and results can still only be generalized to the population at hand, which is crudely the adult, American general public.
CONCLUSION

With chronic illness affecting approximately half of the United States adult population at any given time (Edwards 2013), it is intriguing to note that the general public does not view these four different, yet oddly similar chronic mental and physical illnesses the same when it comes to knowledge (believed health literacy) and that knowledge’s influence on stigmatization. Individuals who have higher believed health literacies of physical chronic illness are more likely to stigmatize chronic illness sufferers, as opposed to individuals who have higher believed health literacies of mental chronic illness who are less likely to stigmatize chronic illness sufferers. Future research should look into actual health literacy and the impact on stigmatization, as well as why health literacy (believed and/or actual) is different for mental and physical illness. With mental illness often deemed more dangerous and full of uncertainty, as compared to physical illness, it is a wonder that physical illness is stigmatized considerably more. Perhaps it has more to do with self-stigma and perceived stigma rather than public stigma, as my sample was composed of several more people diagnosed with CFS and Fibromyalgia than the national averages.

Despite the mixed results involving the impact of believed health literacies on stigmatization, receiving medical information from a medical professional significantly decreases the general public’s chances of stigmatizing the chronically ill. While so too does personal contact with the chronically ill, thus providing a possible look into stigma reduction implications and policy.

With researchers identifying three prominent approaches to decreasing stigmatization of the chronically ill – 1) protesting, 2) education, and 3) personal contact (Rüsch, Angermeyer, and Corrigan 2005), it is imperative that stigma reduction policies begin to be introduced and put in
place. While protesting may be a viable means to bring awareness, and education may be a start, the results above show that the real strategy for positive effects is to focus on personal contact. Personal contact with medical professionals (to receive accurate and relevant information) and personal contact with individuals who are diagnosed with chronic illnesses (both physical and mental). If we can increase the general public’s overall contact with individuals who know other individuals diagnosed or suffering from these illnesses, we can significantly decrease stigmatization of the chronically ill. This is not a new concept with regards to chronic illness (Wilder 2014; Angermeyer, Matshinger, and Corrigan 2004; Parcespe and Cabassa 2013). This data merely reinforces and emphasizes that personal contact is a necessity for decreasing stigmatization, and that just because we think we know or are educated about a topic, does not mean we really are and does not mean we will act accordingly.
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