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Impact of Cognitive Distortions and Perceived Stigmatization on Acceptance among Adults With Neurofibromatosis Type 1

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Philadelphia College of Osteopathic Medicine
School of Professional and Applied Psychology

**IMPACT OF COGNITIVE DISTORTIONS AND PERCEIVED
STIGMATIZATION ON ACCEPTANCE AMONG ADULTS WITH
NEUROFIBROMATOSIS TYPE 1**

By Shanna C. Drinkwine

Submitted in Partial Fulfilment of the Requirements for the Degree of

Doctor of Psychology

June 2019

SCHOOL OF
PROFESSIONAL AND
APPLIED PSYCHOLOGY™

DISSERTATION APPROVAL

This is to certify that the thesis presented to us by Shenna Drinkwine
on the 6 day of May, 2019, in partial fulfillment of the
requirements for the degree of Doctor of Psychology, has been examined and is
acceptable in both scholarship and literary quality.

COMMITTEE MEMBERS' SIGNATURES

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Abstract

Neurofibromatosis type 1 (NF1) is a genetic condition that is characterized by many physical and cognitive signs and symptoms. Many of the physical manifestations are widespread and visible, which may cause an individual to be a target of stigmatization. An individual's perception of this stigmatization could lead to emotional distress and a decreased quality of life. To date, there is no research investigating the underlying cognitive factors that drive emotional responses to these negative events in individuals with NF1. More specifically, a literature review reveals no research indicating that cognitive distortions or acceptance have ever been studied in this population. Thus, the purpose of this study was to explore the relationship between cognitive distortions, perceived stigmatization, and levels of acceptance among adults with NF1 in order to inform assessment and treatment of individuals with this disorder. Adults ($n = 48$) with NF1 volunteered to complete four self-report measures: the Inventory of Cognitive Distortions, the Perceived Stigmatization Questionnaire, the Ablon Scale, and the Acceptance and Action Questionnaire. Results indicated that the frequency of cognitive distortions was a significant predictor of acceptance. Furthermore, the frequency of cognitive distortions and self-rating of disease visibility predicted level of perceived stigmatization. On the other hand, age at NF1 diagnosis was not a significant predictor of level of acceptance. These results have implications for assessment treatment and support the use of cognitive behavioral therapy and acceptance and commitment therapy in this population.

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Chapter 1: Introduction

Research Questions

What is the relationship between cognitive distortions, perceived stigmatization, and levels of acceptance in adults diagnosed with neurofibromatosis type 1 (NF1) (World Health Organization, 1992; Q85.01)? Specifically, do the frequency of cognitive distortions and level of perceived stigmatization among individuals diagnosed with NF1 predict their level of acceptance? Additionally, does the frequency of cognitive distortions and rating of disease visibility among those with NF1 predict their level of perceived stigmatization? Lastly, does the age at diagnosis of NF1 predict level of acceptance?

Statement of the Problem

Neurofibromatosis type 1 (NF1) is a genetic neurocutaneous disorder that affects approximately 1 in 3,000 people (Radtke, Sebold, Allison, Haidle, & Schneider, 2007). It is one of the most common genetic syndromes, and its incidence is comparable to that of cystic fibrosis (Hart, 2005). NF1 is a disorder that is characterized by a number of signs and symptoms, some of which are highly visible, including multiple brown skin macules or darkened spots (café-au-lait spots), skin-folding, freckling, iris Lisch nodules (dome-shaped elevations projecting from the surface of the iris that are clear to yellow or brown), bony dysplasia, neurofibromas, and a predisposition to other benign and malignant tumors (Ferner et al., 2007).

NF1 is transmitted in an autosomal dominant manner, with 50% risk to offspring with one affected parent (Wang et al., 2012). Approximately 50% of cases develop as a result of a spontaneous change in one of the NF genes in the egg cell or sperm during

conception (Dubov, Toledano-Alhadeff, Bokstein, Constantini, & Ben-Shachar, 2016). Research shows that individuals with NF1 have an increased risk of experiencing a variety of psychosocial issues. Specifically, NF1 has been linked to depression, anxiety, low self-esteem, social withdrawal, behavioral problems, and a lower quality of life (QOL) (Granstrom, Mautner, Langenbruch, & Augustin, 2012; Page et al., 2006; Wolkenstein, Zeller, Revuz, Ecosse, & Leplege, 2001). Learning disabilities also affect as many as one half of patients with NF1 (Friedman, 2004).

NF1 is a variable condition and manifests differently in affected individuals. Physical complications, such as café-au-lait spots and cutaneous neurofibromas, occur in at least 95% of patients (Tonsgard, 2006). Lisch nodules, described as reddish brown spots in the iris, are present in 90% of adults, and optic gliomas are found in 15% of patients (Tonsgard, 2006). Individuals with NF1 also have abnormalities of growth. They tend to have a large head size and short stature (Tonsgard, 2006). Studies show that both the severity and the visibility of NF1 could have negative consequences for mental health (Wolkenstein, Zeller, Revuz, Ecosse, & Leplège, 2003), and patients with the most visible signs of NF1 report more emotional effects than those with less visible signs (Wolkenstein et al., 2001). NF1 patients appraise their bodies more negatively than patients with other disfiguring diseases, and the effect of disease visibility on psychological stress is mediated by patient perception (Granstrom et al., 2012). The literature on body image suggests that people with visible disfigurements may experience difficulties forming relationships (Thompson & Kent, 2001) and are often a target of stigmatizing and dehumanizing behavior (Lawrence, Fauerbach, Heinberg, Doctor, &

Thombs, 2006). Therefore, it is important to consider the underlying cognitive factors that contribute to their perception of stigmatization and related distress.

To date, there is little research exploring the underlying cognitive factors, or specific thought patterns, that may influence or directly impact perceptions of the condition or level of acceptance. Specifically, cognitive distortions and acceptance have never been studied in the adult NF1 population. Because NF1 is highly comorbid with a variety of psychiatric and emotional concerns, and cognitive distortions correlate with such mental disorders, cognitive distortions are worth exploring among this population (Rosenfield, 2004).

Cognitive distortions have been studied among a wide range of psychiatric disorders. Individuals who meet criteria for almost any diagnosis on Axis I or Axis II report a higher frequency of cognitive distortions than individuals free of psychological disorders, and the more severe the disorder(s), the more frequent the reported cognitive distortions (Rosenfield, 2004). Furthermore, individuals meeting criteria for a greater number of diagnoses report a higher frequency of cognitive distortions than individuals with fewer diagnosable disorders (Rosenfield, 2004). This indicates that as individuals are diagnosed with more disorders, they engage in more cognitive distortions (Rosenfield, 2004). For those with NF1, who have a high comorbidity rate of psychological disorders, it is hypothesized that cognitive distortions may play a role in the clinical picture. Specifically, frequency of cognitive distortions may predict a patient's level of perceived stigmatization. Therefore, cognitive distortions may be an underlying factor that drives patient perception of NFI and perceived stigmatization.

It is hypothesized that frequency of cognitive distortions will predict level of perceived stigmatization, ultimately impacting an individual's functioning. It is important to consider how individuals cope with their personal level of functioning and to assess their level of acceptance, or psychological flexibility. Identifying levels of acceptance has important implications for assessment and treatment planning among those with medical conditions (Dahl, Wilson, & Nilson, 2004). Treatments based on acceptance, such as Acceptance and Commitment Therapy (ACT; Hayes, Strosahl, & Wilson, 1999), appear to be effective in improving functional status of patients with both psychopathology and medical problems (Dahl et al., 2004).

Acceptance is defined as the willingness to experience events, including those that are aversive or unwanted private events, while pursuing one's values and goals (Hayes et al., 1999). There is now accumulating supportive evidence for the effectiveness of ACT across a variety of health conditions (Yu & McCracken, 2016). Within the ACT approach, the overarching goal is to increase psychological flexibility, or adaptive responding (Beacham, Linfield, Kinman, & Payne-Murphy, 2015, p. 97). Those with higher levels of psychological flexibility can adapt to internal and external cues, allowing them to live a life guided by their own values, while reducing the impact of pain, illness, loss, and other associated difficulties of an experience (Beacham et al., 2015). Because NF1 tends to be related to physical, cognitive, and emotional distress as well as visible disfigurement, the construct of acceptance, or the ability to engage in psychological flexibility, may have substantial relevance in the NF1 population. However, a literature review revealed no research exploring cognitive distortions in the NF1 population and

scant research regarding acceptance and perceived stigmatization in this population.

Such elucidation could be useful in guiding assessment, treatment, and support.

Chapter 2: Literature Review

Neurofibromatosis Type 1

As previously stated, Neurofibromatosis type 1 (NF1) is a genetic neurocutaneous disorder (Radtke et al., 2007). *Neurocutaneous disorder* is a broad term used to describe all disorders involving the nervous system and the skin (Barbagallo, Kolodzieh, Silverberg, & Weinberg, 2002). NF1 is believed to date back to 1,000 AD. The oldest cases of the disorder appear in the literature, described by Madigan, Schaw, and Masello in *Neurofibromatosis in the 13th Century and Report of NF-Like Case - Monstrorum History* (Antonio, Goloni-Bertollo, & Tridico, 2013). In 1881, von Recklinghausen coined the term *neurofibroma* (Zanca, 1980, p. 56). He observed a benign tumor that arose from the peripheral nerve sheath, and medical colleagues, in honor of his discovery, named the condition von Recklinghausen's disease (Ferner et al., 2007). At one time, neurofibromatosis 1 and 2 were both known as von Recklinghausen's disease; however, in the latter part of the 20th century, different forms of neurofibromatosis were delineated (Ferner et al., 2007).

The diagnostic criteria for neurofibromatosis type 1 are two or more of the following, all of which will be further explained below: (a) six or more café-au-lait spots, (b) two or more neurofibromas of any type or one plexiform neurofibroma, (c) bone abnormalities, including sphenoid dysplasia (absence of bone surrounding the eye), (d) family history of NF1, (e) two or more Lisch nodules, (f) freckles in the axillary (armpit) or inguinal (groin) region, and (g) optic pathway glioma (National Institutes of Health [NIH], 2017).

People with NF1 are usually born with one mutated copy of the NF1 gene in each cell (NIH, 2017). For a tumor to form, two copies of the NF1 gene must be mutated; the mutation of the second occurs during a person's lifetime and is not inherited (NIH, 2017). The clinical manifestations of NF1 are widespread and affect many different areas of functioning.

Neurofibromatosis type 2 is less common than NF1, affecting about 1 in every 25,000 people (Johns Hopkins Medical Center). The diagnostic criteria for NF2 includes bilateral vestibular schwannomas, which are benign tumors grown from an overproduction of Schwann cells in both ears (NIH, 2017). It is now understood that these are two distinct genetic disorders affecting two separate chromosomes (Huson, 1999).

NF1 is typically diagnosed during childhood, whereas NF2 is more commonly diagnosed in late adolescence (Smith et al., 2013). The long arm of chromosome 17 is thought to be the site of the gene defect for NF1 (Legius, Descheemaeker, Spaepen, Casaer, & Fryns, 1994). Chromosomes 2, 14, and 22 have also been implicated in the disorder (Hulsebos, Bijleveld, Riegman, Smink, & Dunham, 1996). The affected gene is a tumor suppressor gene that produces a protein called neurofibromin (Hart, 2005). Neurofibromin is similar to the protein guanosine triphosphatase-activating protein (GAP), which serves as a regulator of signals for cell proliferation and differentiation, that may be a factor in some types of cancers and a regulator of chemical interactions and cell growth (Rubenstein, 2005; Hart, 2005). The similarities between these two proteins indicate that neurofibromin may play a similar role in cell growth regulation, and a lack

of this protein may be responsible for the abnormal cell growth and tumor development that occurs in NF1 (Hart, 2005).

Neurofibromatosis type 3, also known as schwannomatosis (SWN) is a recently recognized form of NF. This disorder affects approximately 1 in 40,000 individuals (Evans et al., 2010). Whereas NF1 is characterized by neurofibromas, SWN is characterized by schwannomas. Neurofibromas and schwannomas are both benign nerve sheath tumors, but have different effects on the nerve root in which the tumor is located. Diagnostic criteria outlined by the National Institutes of Health for SWN include: (a) two or more non intradermal schwannomas (b) no evidence of a vestibular tumor on magnetic resonance imaging (MRI) scan (c) no known constitutional NF2 mutation and (d) one pathologically confirmed nonvestibular schwannoma and (e) a first-degree relative who meets the above criteria. Although SWN involves symptoms that are similar to NF1, for the purpose of this study, only NF1 will be considered.

Clinical Manifestations and Medical Concerns of NF1

In order to understand the physical manifestations of NF1, it is important to review the basic anatomy of the human nervous system. The nervous system consists of two parts: the central nervous system (CNS), which includes the brain and spinal cord, and the peripheral nervous system, which contains nerves all over the body that send signals to the CNS. These signals are sent with the help of nerve fibers that are covered in myelin. Myelin is a substance also known as nerve sheath and protects the nerve fibers and helps them send fast signals (Kaiser, 2017). At times, the cells that create the myelin, Schwann cells, can grow uncontrollably, forming a nerve sheath tumor (Kaiser, 2017).

One of the most common symptoms of NF1 is neurofibromas, which occur in more than 99% of the NF1 population (Ferner, 2007). Neurofibromas are benign peripheral nerve sheath tumors that can be focal cutaneous (in or just under the skin) or subcutaneous. They can appear as purplish depressions in the skin or pedunculated lesions that stick out from the skin (Tonsgard, 2006). Neurofibromas will typically develop in the patient's late teens or early twenties (Ferner, 2007). Neurofibromas may be tender to the touch and cause tingling in the distribution of the affected nerve (Ferner, 2007). Plexiform neurofibromas, seen in at least 50% of patients, are similar to cutaneous neurofibromas, but have more extracellular matrix (Tonsgard, 2006). They cause significant morbidity because they are diffuse, grow along the length of the nerve, and may involve multiple nerve branches (Ferner, 2007). Plexiform neurofibromas often arise from the dorsal spinal roots (roots emerging from spinal cord), nerve plexi (networks of intersecting nerves), large nerve trunks, or sympathetic chains (paired bundle of nerve fibers) and infiltrate surrounding soft tissue (Ferner, 2007; Tonsgard, 2006). Although neurofibromas are benign, there is also the possibility for individuals to develop malignant peripheral nerve sheath tumors (MPNST); however, there is only an 8% to 13% lifetime risk (Ferner, 2007). MPNSTs usually arise from preexisting plexiform neurofibromas, are hard to detect, metastasize widely, and signify a poor prognosis (Ferner, 2007).

One of the hallmark manifestations of NF1 is known as café-au-lait spots. More than 99% of individuals with NF1 will have café au lait spots on their skin, and some patients are distressed by their appearance (Ferner, 2007). These are hyperpigmented flat spots, or macules, that are generally round or oval (Tonsgard, 2006). They are present at

the time of birth and will increase in size and number throughout the first 5 to 7 years of life (Tonsgard, 2006). NF1 patients will develop more than five spots within the first year of life and spots may continue to develop until age 4 (Debella & Friedman, 2000). These macules do not correlate with the number of NF1 tumors; they are benign and do not cause any functional disability in the patient (Hart, 2005). Similarly, skin-fold freckling is another type of hyperpigmentation sign of NF1. This characteristic will appear by age 7 and will occur in 90% of individuals (Feldman, Jordan, & Fonseca, 2010).

NF1 may also have ocular manifestations, affecting the iris, retina, and optic nerve (Tonsgard, 2006). Patients may have Lisch nodules, which are proliferations of melanocytes (melanin producing cells) and fibroblasts (cells that produce collagen) that appear as reddish brown spots in the iris (Tonsgard, 2006). These typically have no effect on vision and will appear in the teenage years (Tonsgard, 2006). Optic pathway gliomas (OPG) are seen in about 15% of NF1 individuals and children under the age of 7 are at greatest risk (Ferner, 2007). OPGs are the primary central nervous system tumors (visual pathway tumors) associated with NF1 and produce thickening of the optic nerve (Hart, 2005). They are frequently bilateral, involve the chiasm, and may extend to the optic tracts or the hypothalamus (Tonsgard, 2006). Some gliomas produce impaired visual acuity, abnormal color vision, visual field loss, squint, and hypothalamic dysfunction (Ferner, 2007).

Orthopedic symptoms may be a concern in NF1. In addition to sphenoid dysplasia (NIH, 2017), other common problems are hypotonia (low muscle tone) and poor coordination (Tonsgard, 2006). Bony dysplasia (abnormal bone development),

bony erosion, demineralization, nonossifying fibromas (benign bone tumors) and scoliosis are all potential features of NF1 (Tonsgard, 2006). Erosion or demineralization is often caused by pressure from adjacent plexiform neurofibromas (Tonsgard, 2006). Approximately 5% of individuals with NF1 develop bowing of leg bones below the knee (Children's Tumor Foundation). This is caused by an intrinsic bone defect occurring during early bone development, with bowing often visible in the first few months of life (Ferner, 2007). Because of this concern, children with NF1 need a yearly spinal assessment. NF1 may cause disruption in bone maintenance and reduced bone mineral density (Lammert et al., 2005). Abnormalities of growth are also a common feature of NF1. There is evidence of large head size and short stature (Hart, 2005; Tonsgard, 2006). Failure to gain weight occurs in less than 1% of patients in the first 2 to 3 years of life (Tonsgard, 2006).

There is also evidence of neurologic impacts of NF1. Headaches, seizures, and brain tumors are common. Headaches will occur in 20% of NF1 patients, and most are consistent with migraines (Hart, 2005; Tonsgard, 2006). In addition to the 15% of patients that report visual pathway tumors (optic gliomas), another 3% to 5% of patients have other types of brain tumors, often on the brainstem or cerebellum (Tonsgard, 2006). The reduced neurofibromin in the body provides a growth advantage for astrocytes in the brain. Therefore, these tumors are astrocytic, meaning they originate from astrocytes in the cerebellum (Tonsgard, 2006). Tumors are often identified on MRI. Seizures, although not a common characteristic, occur in up to 10% of patients (Tonsgard, 2006). In a study of 536 individuals with NF1, researchers found that 9.5% had a history of at least one unprovoked seizure, and 6.5% had documented epilepsy (Ostendorf, Gutmann,

& Weisenberg, 2013). Those with seizures were more likely to have inherited NF1 from their mother (Ostendorf et al., 2013). Focal (partial) seizures were the most common type, occurring in 57% of individuals with seizures (Ostendorf et al., 2013). Not only does NF1 have a substantial impact on the physical body, but the disorder also impacts neurocognitive functioning.

Neurocognitive Impact of NF1

Neurocognitive studies of NF1 patients have focused mainly on children, and data in adults are reported less frequently (Descheemaeker, Plasschaert, Frijns, & Legius, 2013). However, a handful of studies have examined the impact of NF1 on adult cognitive functioning, and deficits have been noted (Pavol et al., 2006). For example, in a study involving 103 patients with NF1, researchers found a significant difference between NF1 patients and controls in full scale, verbal, and performance IQ (Ferner et al., 2006). However, it is important to note that the intellectual impairment was mild and the majority of NF1 patients had IQs in the low-average range (Ferner, Hughes, & Weinman, 1996). Results from a study of 20 NF1 adults confirmed this finding and found a mean estimated IQ score of 89.96 (Descheemaeker et al., 2013). Ferner et al. (1996) also found that NF1 patients had higher error rates and slower reaction times on automated performance tests, and they were slow to formulate and adapt strategies to cope with complex and unfamiliar tasks (Ferner et al., 1996). NF1 participants were also found to have poorer reading, short term memory, and attention skills (Ferner et al., 1996). Moreover, NF1 patients had deficits in executive function, visual-spatial abilities, and attention (Acosta et al., 2006; Descheemaeker et al., 2013).

Adults with NF1 performed significantly lower on tests of visual constructive skills in comparison to control groups (Descheemaeker et al., 2013). In a study conducted by Pavol et al. (2006) involving 20 NF1 patients, results indicated that measures of visual and attention-executive function skills discriminated between NF1 patients and controls. They also found that receptive vocabulary was a significant predictor in discriminating NF1 patients and controls (Pavol et al., 2006). Learning disabilities are common, affect as many as one half of patients with NF1, and can range from attention deficit hyperactivity disorder (ADHD) to intellectual impairment (Korf, 1992). Learning disabilities and ADHD occur in as many as 60% of patients (Tonsgard, 2006), and ADHD is thought to contribute to the learning disabilities and poor social skills in NF1 (Barton & North, 2004). Recently, there have been advances in the understanding of the molecular, cellular, and neural system underpinnings of NF1-associated learning deficits in animal models; however, much remains to be learned about the spectrum of cognitive, neurological, and psychiatric phenotypes associated with NF1 (Acosta et al., 2012). These findings indicate that screening for learning disabilities in the early school years is beneficial for early intervention.

Psychological Impact of NF1

Due to the nature of NF1 and its variable physical and cognitive impacts, it is important to consider the psychological burden of living with the disorder. Empirical evidence indicates a wide range of psychosocial issues that are common with NF1. There is a consistent pattern of reduced emotional well-being in NF1 patients compared to the general population (Wang et al., 2012). For instance, those with NF1 are at increased risk for experiencing social and emotional difficulties, including depression, anxiety, low

self-esteem, social withdrawal, behavioral problems, and difficulty forming interpersonal relationships (Granstrom et al., 2012; Page et al., 20016; Wolkenstein et al., 2001).

Levels of anxiety and depressive symptoms in an NF sample of 248 patients were found to be higher than those reported by patients with other chronic diseases, including coronary artery disease and cancer (Wang et al., 2012). The same study found that, in adults with NF1 and NF2, 37% of males and 46% of females scored at or above the cut-off of 16 on the Center for Epidemiologic Studies Depression (CESD) scale, indicating a high likelihood of clinical depression (Wang et al., 2012). In a more recent study of 498 adults with NFI examining depression and quality of life, researchers found that 55% of participants scored above a 16 on the CESD, supporting previous findings of increased risk for clinical depression (Cohen, Levy, Sloan, Dariotis, & Biesecker, 2015).

Furthermore, they found that the degree of depressive symptoms was highly correlated with quality of life; approximately one third of the variation in QOL was explained by the level of depression (Cohen et al., 2015). Results of a 12 year follow-up study examining 48 adults with NFI indicated increased frequency of psychiatric symptoms and mental disorders (Zöller & Rembeck, 1999). Of these disorders, dysthymia was the most common diagnosis, found in 21% of the NF1 cases (Zöller & Rembeck, 1999).

Depression, in particular, appears to be quite common among those with NF1 (Cohen et al., 2015).

Adults with NF1 also tend to have significantly less prosocial behavior (Pride, Crawford, Payne, & North, 2013). Interestingly, the higher rate of impairment in this area is reported by family members and friends of those with NF1, rather than self-reports. This indicates that NF1 patients have reduced awareness of deficits in social

skills, which should be considered when selecting strategies and interventions for future clinical trials aimed at improving social skills (Pride et al., 2013). In a study of 62 adults with NF1, social deficits were found to have a significant association with executive functions and social skills, and adults with more severe deficits in behavioral regulation exhibited more frequent antisocial behavior (Pride et al., 2013). The presence of ADHD has also been found to be an important risk factor for poor social skills (Barton & North, 2004). Approximately 30% to 50% of these individuals meet the diagnostic criteria for ADHD (Hyman et al., 2005). Studies show that impairments in attention and executive functions explain a significant proportion of variance in social skills in disorders characterized by social dysfunction (Addington & Addington, 1999).

In summary, it is clear that NF1 can have varying physical, neurocognitive, and psychological impacts. Because the hallmarks of NF1 are often visible, such as café au lait spots, neurofibromas, and skin pigmentation abnormalities, it is important to consider how visibility of the condition impacts each individual patient and his or her quality of life.

Visibility, Perceived Visibility, and Stigmatization of NF1

NF1 symptoms are typically more noticeable than those of NF2, yet both can be difficult to conceal (Smith et al., 2013). Visible plexiform neurofibromas are present in 30% of patients, and 20% have internal plexiform neurofibromas that are visible through imaging (Granstöröm et al., 2012). Visibility of NF1 symptoms may cause significant psychological distress and social burden. Appearance concerns are common among the general population: 35% of men and 61% of women (Harris & Carr, 2001). In considering NF1, which manifests in visible symptoms, these concerns may be

exacerbated. In a study of 127 women with NF, researchers found that 85% were concerned with their appearance. Kodra et al. (2009) found that 40% of patients with NF1 reported feeling embarrassed about their skin condition, and more than 20% worried about having scars. In a 2012 study, women with NF1 felt less attractive and self-confident and more insecure about their bodies compared to normative controls (Granstörn et al., 2012). Women with NF1 and NF2 experience a high level of social self-consciousness related to their appearance (Smith et al., 2013). Similarly, patients with NF1 who have more visible symptoms report that their skin condition has a greater impact on their emotions, mental health, and social functioning (Page et al., 2006). In a study of 60 Australian adults with NF1, researchers found that many of the participants reported the visible appearance as the worst aspect of the condition (Crawford et al., 2015).

In NF1 patients, disease visibility is associated with psychiatric morbidity that is linked to cosmetic impact, and reduces the quality of life (Wolkenstein et al., 2001, 2003). Psychiatric problems may arise as a reaction to disfigurement or perceived social stigma (Wolkenstein et al., 2003). Research shows that patients with a higher concern about the visibility of their disease are at higher risk of developing low self-esteem, self-rejecting cognitions, problems in interpersonal relationships, and negative body image (Rumsey & Harcourt, 2004). In a study of 129 Italian adults with NF1, researchers found that cosmetic features have a greater impact on all aspects of skin-disease-specific quality of life, especially with regard to limitations because of emotional problems, or the emotional aspect (Kodra et al., 2009). In this study, the most frequent items endorsed in emotional aspect were being worried that the disease would become worse and would

result in a more complex course of the disorder (Kodra et al., 2009). Similar findings were found by Wolkenstein et al. (2001) in a study of 128 adults with NF1, in which patients with the most visible symptoms reported emotional effects of their skin condition on their quality of life. They also reported significantly greater overall effects on their skin disease quality of life, which included emotions, physical symptoms, and functioning (Wolkenstein et al., 2001). These findings are further supported by Page et al. (2006), whose study of 169 adults with NF1 yielded the same results. Appearance seems to play an important part in the perception of severity and has a direct impact on quality of life and personal body image (Wolkenstein et al., 2003).

Schilder (1950) first proposed a psychological approach to body image, consisting of how a person perceives his or her own body and related attitudes and feelings. According to Cash (2011), the cognitive-behavioral model of body image identifies three coping strategies in which individuals who experience distressing body-related cognitions and emotions commonly engage. These are: (a) *experiential avoidance*, or attempts to avoid distressing body image cognitions, emotions, and situations; (b) *appearance fixing*, or efforts aimed at correcting or concealing ones' perceived physical flaws; and (c) *positive rational acceptance*, or behaviors such as self-care and positive self-talk that focus on the acceptance of ones' experiences. Data from Cash, Santos, and Williams (2005) revealed that those who engaged in more body image experiential avoidance also experienced greater body image dissatisfaction and dysphoria and lower body image quality of life.

Literature on body image suggests that people with visible disfigurements may experience difficulties forming relationships, particularly with sexual partners

(Thompson & Kent, 2001). Negative body image and perception also have an impact on depressive states and distress (Granstörn et al., 2012). Those with visible disfigurements or distinctions are often a target of stigmatizing and dehumanizing behavior (Lawrence et al., 2006). These behaviors can be overt, such as staring, double takes, whispering, and teasing, or subtler, such as avoiding eye contact, ignoring, pity, etc. (Beuf, 1990). In the aforementioned study of 60 Australian adults with NF1, certain participants experienced situations in which strangers approached them, made comments, or taunted them about their physical condition, which they reported as a distressing, humiliating experience (Crawford et al., 2015). According to Bull and Rumsey (1988), there are three specific effects of being a target of these behaviors: poor body esteem, a sense of social isolation, and a violation of privacy effect, which refers to a person's right to remain anonymous in crowds.

Most of the theory and research on the concept of stigmatization can be traced back to Goffman (1963). There have been a number of relevant theories about stigma. For instance, Goffman defined stigma as “an attribute that is deeply discrediting” (p. 6). More specifically, stigma is a worldwide devaluation of an individual who has an attribute or characteristic that is different from most (Goffman, 1963). Stigma then arises during a social interaction when actual social identity does not meet society's expectations or standards (Kurzban & Leary, 2001). Following Goffman's work, other perspectives of stigma have been noted in the literature. Jones et al. (1984) stated that a person is stigmatized when a deviation initiates an attributional process through which people interpret other aspects of the individual in terms of the deviation. Another perspective proposes that stigma is a form of deviance that leads others to judge

individuals as illegitimate for participation in interaction (Elliott, Ziegler, Altman, & Scott, 1982). Once the individual is deemed illegitimate for participation, he or she is beyond the protection of social norms and may be excluded or ignored (Elliott et al., 1982). Lastly, Crocker, Major, and Steele (1998) believe stigma arises from membership in a group that is negatively valued in a specific situation. All of the aforementioned theories involve an aspect of negative evaluation and attributions. Through the process of stigmatization, certain individuals are excluded from particular sorts of social interactions because they possess a particular characteristic or are a member of a particular group (Kurzban & Leary, 2001).

Positive social interaction is a crucial component for psychological and physical health. Those who experience stigmatization are susceptible to a variety of behavioral, emotional, and physical problems, suggesting that humans may have an innate need to belong (Baumeister & Leary, 1995). NF1 is not the only disorder that may result in negative psychological impacts and stigmatization. There are a variety of other conditions with visible symptoms that could result in similar experiences.

Psychological Effects of *Other* Visible/Disfiguring Conditions

NF1 is just one of various disorders and skin conditions that present with physical symptoms. Often, these visible differences lead to stigmatization by others that result in negative psychological impact. To provide context, a few of other of these conditions will be discussed, such as psoriasis, congenital and acquired facial differences, acne vulgaris, genetic skeletal dysplasias, and HIV/AIDS.

Psoriasis is a chronic skin condition characterized by red lesions on the skin (Schon & Boehncke, 2005). Systematic reviews examining the psychosocial impact of

psoriasis demonstrated social stigmatization, high stress levels, physical limitations, depression, and employment problems. They also found high rates of poor self-esteem, anxiety, depression, sexual dysfunction and suicidal ideation (Kimball et al., 2005; Russo, Ilchef, & Cooper, 2004). As with NF, patients with psoriasis commonly experience stigmatization, which they consider one of the more distressing characteristics of the condition (Schmid-Ott et al., 2005). This experience of stigmatization contributes to additional stressors, such as disability, depression, and reduced quality of life, in these patients (Richards et al., 2001). In a recent study examining the predictors of perceived stigmatization, researchers found that higher levels of perceived stigmatization were correlated with sociodemographic and disease-related variables, personality, illness cognitions such as helplessness, and social support (van Beugen et al., 2017). This study stressed the importance of finding interventions to address stigmatization in treatment.

Studies have also examined the individuals with congenital abnormalities and other facial differences and how these differences impact their perceived stigmatization and psychological well-being, specifically pediatric patients with a cleft-lip/palate or other craniofacial deformities that compromise speech functions (Carroll & Shute, 2005). In a study conducted by Masnari et al. (2012), of self- and parents perceived stigmatization in children and adolescents with congenital or acquired facial differences, these children are at high risk for experiencing stigmatizing behaviors. More specifically, they are at risk of behaviors such as staring, startled reactions, teasing, and expressions of pity (Masnari et al., 2012). In regards to psychological and behavioral adjustment, adolescents with acquired facial differences have been found to report poorer self-image than adolescents with congenital conditions (Patrick et al., 2007); however, this finding is

not consistent among adults (Versnel, Plomp, Passchier, Duivenvoorden, & Mathijssen, 2012).

Acne vulgaris (AV) is a genetic-hormonal illness effecting the skin that results in lesions in exposed areas such as the face and thorax (Vilar, Santos, & Sobral Filho, 2015). This common inflammatory condition affects both adolescents and adults (Joseph, 2010). The effect of acne on psychological well-being is significant because it is most prevalent during adolescence, which is a time of social, emotional and physical development (Joseph, 2010). Because acne affects the face and thorax, it is highly visible, which adds to the psychological burden of the disease; there is evidence in some patients of severe psychological impact, leading to clinical depression, anxiety, suicidal thoughts, and even suicide (Joseph, 2010). Studies of quality of life among adolescents with acne indicate that there is a correlation between the severity of acne vulgaris and lower quality of life; however, self-esteem was not significantly associated with the occurrence or severity of acne vulgaris (Vilar et al., 2015).

Genetic skeletal dysplasias result in similar experiences due to their physical burden and impact. *Skeletal dysplasia* is an umbrella term that includes a variety of disorders that impact bone and cartilage growth. In a study conducted by Apajasalo, Sintonen, Rautonen, and Kaitila (1998), the researchers focused on three specific genetic dysplasias: achondroplasia, cartilage-hair hypoplasia, and diastrophic dysplasia. All of these subtypes result in congenital severe short stature (Apajasalo et al., 1998). Other symptoms of these dysplasias include disproportionate short-limbed stature, characteristic facial features, sparse hair, and limitation of joint movements (Gorlin, Cohen, & Levin, 1990; Makitie & Kaitila, 1993). Findings from the aforementioned study indicate that the

perceived health-related quality of life of adult patients with skeletal dysplasias is significantly lower than that of health controls (Apajasalo et al., 1998). More specifically, they found that adult patients reported more problems for dimensions of usual activities and sexual activity, whereas adolescents had more problems with school, hobbies, and friends and were more concerned with their physical appearance. Short stature is common among most, if not all, skeletal dysplasias, and it commonly has a negative impact on functioning. Studies show that short stature impacts development and psychosocial functioning, increasing the risk for psychosocial problems (Abe et al., 2009; Magnusson et al., 2005). Psychosocial effects that have been documented include negative comparisons with peers, social stigmatization due to height-related perceptions, social exclusion, and bullying at school (Harter, 2001; Sandberg & Colman, 2005; Sandberg & Voss, 2002)

HIV/AIDS is another condition that is highly associated with stigma. HIV is a virus that attacks the body's immune system, which ultimately leads to the inability to fight off infections and disease (Centers for Disease Control and Prevention [CDC], 2010). The virus is spread only through certain body fluids, such as blood, semen, preseminal fluid, rectal fluids, vaginal fluids, and breast milk (CDC, 2010). HIV-related stigma occurs as a result of negative attitudes associated with behaviors linked to HIV transmission, such as homosexual sex or injectable drug use (Herek, 1999). Research on the impact of HIV-related stigma is extensive. The most commonly found associations are increased feelings of despair and depression, decreased self-esteem, and increased mental health problems (Berger, Ferrans, & Lashley, 2001; Buseh & Stevens, 2006; Mak, Poon, Pun, & Cheung, 2007). Researchers have found that the psychological well-

being of people with HIV is both a consequence and a predictor of perceived HIV stigma (Miller et al., 2017). The experience of stigma within a healthcare setting has been found to negatively impact health-related behaviors, such as accessing testing and treatment and adherence to medical regimens (Butt, 2008; Fortenberry et al., 2002). Furthermore, because psychological symptoms such as depression and other types of mental illness are risk factors for acquiring HIV, these individuals may be susceptible to stigmatization (Miller et al., 2017).

Although many signs of HIV can go unnoticed, there are some symptoms of early and latent HIV that can be visible. These include a maculopapular rash (red bumps on a flat, red patch of skin), skin lesions and thrush (yeast infection around the mouth), and enlarged lymph nodes. There are also physical side effects of treatment, such as visible redistribution of body fat and/or localized fat loss around the buttocks, legs, arms, or face (Carr et al., 2003; Tien & Grunfeld, 2004). These physical manifestations may intensify the level of experienced stigma. In a study of people living with HIV comparing a group who could conceal their HIV versus those who could not, people with visible signs of HIV experienced more psychological distress and had lower self-esteem and reported less social support than those who could conceal their HIV status (Stutterheim et al., 2011). These findings were supported by a similar study in 2013 of the role of visible symptoms in HIV-related stigma. Researchers found that individuals with visible symptoms experienced more HIV-related stigma and had poorer outcomes on a range of psychological and mental health measures than those who were able to conceal their disease (Brener, Callander, Slavin, & de Wit, 2013).

In summary, it is clear that conditions involving visible symptoms have a great impact on well-being and psychological adjustment. Specifically, these symptoms often result in experiences of social stigmatization. Because stigma leads to social marginalization and resultant stress, it is important to screen individuals with NF1 for level of perceived stigmatization. Due to the nature of NF1 (abnormal physical appearance and characteristics), stigmatization may be a common and serious concern.

Measures of Perceived Visibility and Stigmatization

Measures of perceived visibility specific to individuals with NF1 are scarce. Specific to NF, there are currently only two measures of disease severity and disease visibility, the Riccardi Scale and the Ablon Scale. The Riccardi scale was developed to evaluate the severity of the disease (Riccardi & Kleiner, 1977). This instrument yields a single score and can be completed by patients, clinicians, or researchers using medical files. Grades of severity range from 1 to 4, in which 1 is minimal NF or few features of NF and 4 is severe NF or the presence of serious compromise.

The Ablon scale was developed to evaluate the visibility of the disease (Ablon, 1996). The ratings are based on appearance of the individual fully dressed and how readily physical symptoms could be perceived in impersonal interactions. This instrument is measured on a 3-point scale, in which 1 is no visible tumors with normal gait and posture and 3 is numerous tumors on the face, optic glioma, and severe skeletal features. Granstrom et al. (2012) developed a scale of four items for patients to self-assess whether their disease was visible to others when fully dressed. The scale measures subjective, perceived visibility on a scale from 0 (*not visible*) to 4 (*highly visible*). This scale is considered reliable and has a Cronbach's alpha of 0.85 (Granstrom et al., 2012).

For the purpose of this current study, researchers wanted to measure participants' perceived visibility of the condition using the 3-point Ablon scale. Additionally, researchers wanted to get a measure of perceived stigmatization as it relates to their reported disease visibility.

The Perceived Stigmatization Questionnaire (PSQ) is a 21-item, 3-factor measure. It measures the frequency of various stigmatizing social behaviors experienced by people with physical distinctions (Lawrence et al., 2006). The PSQ was originally validated in a sample of long-term adult burn survivors (Lawrence et al., 2006). The three factors are: absence of friendly behavior, confused and staring behavior, and hostile behavior (Lawrence, Rosenberg, Mason, & Fauerbach, 2011).

Underlying Mechanisms of Perceived Visibility and Stigmatization

Individuals with NF1 experience the condition in different ways. Visibility of NF1 varies among cases, as does patient perception of these symptoms. Research has illustrated the detrimental impact that may result from living with NF1, indicating the need for effective interventions to help many patients cope with appearance-related difficulties and accompanying patterns of psychological distress and problematic social interactions (Smith, Wang, Plotkin, & Park, 2013). Similarly, level of perceived stigmatization also varies across cases. To date, there is little research exploring the underlying cognitive factors that may influence or directly impact perceptions of NF1 symptoms and related stigmatization, which may aid in guiding psychological interventions. Because NF1 is highly comorbid with a variety of psychiatric and emotional concerns and cognitive distortions correlate with such mental disorders (e.g., Rosenfield, 2004), cognitive distortions are very relevant in this population. Cognitive

distortions are a construct that stems from the cognitive model and the work of Aaron Beck. It is important to understand the history of cognitive therapy and the development of cognitive distortions in order to fully explore their relevance in regard to NF1.

Overview of Cognitive Therapy

Cognitive therapy was developed in the late 1960s as a response to objections to the psychoanalytic model, the inability of behavior therapy to account for the cognitive processes of human behavior, and the growing demands of both the public and managed care for brief, effective treatment (Beck, 1976; Dobson & Dozois, 2001). Many behaviorists of that era realized that their approach needed to expand beyond pure black-box operant and classical conditioning models to account for the growing evidence for human cognitive processes (Hayes et al., 2005). This set the stage for basic cognitive models as a logical alternative.

Albert Ellis and Aaron Beck played a large role in incorporating cognitive aspects into the field of psychology. Albert Ellis began to focus on the cognitive contribution to human dysfunction by distinguishing healthy from unhealthy feelings and rational from irrational thinking (Backx, 2011). Ellis (1962, 1977) founded rational emotive therapy that proposed that the way people think makes them feel and behave in a certain way. His formulation opposed psychoanalytic insights and influence (Backx, 2011). In contrast, Aaron Beck's cognitive therapy model (Beck, 1967; 1976) incorporated psychoanalytic influence, which made it less challenging for long-standing psychoanalysts to make the "revolutionary step" towards the cognitive model (Backx, 2011, p. 268). Despite this difference, both models were based on the concept that irrational beliefs were the source of emotional distress or the cause of dysfunctional

behavior. Summarized in short by Forman and Herbert (2009), cognitive behavior therapy is a collaborative, short-term treatment that uses both behavioral and cognitive strategies to alleviate distress.

Meta-analyses show cognitive behavioral therapy (CBT) to be effective in the treatment of a variety of disorders. Studies indicate that CBT is a highly effective treatment model for adult unipolar depression, adolescent unipolar depression, generalized anxiety disorder, panic disorder with or without agoraphobia, social phobia, posttraumatic stress disorder, and childhood depressive and anxiety disorders (e.g., Butler, Chapman, Forman, & Beck, 2006). Support for CBT as an effective intervention for health anxiety, or hypochondriasis, has also been documented in a recent meta-analysis (Cooper, Gregory, Walker, Lambe, & Salkovskis, 2017). These findings are supported by Olatunji et al. (2014), who found that CBT for health anxiety outperformed control conditions at posttreatment and follow up. CBT also has shown promising results as an adjunct to pharmacotherapy in the treatment of schizophrenia and large improvements in the symptoms of bulimia nervosa (Butler et al., 2006). Similarly, in a meta-analysis of CBT for adult depression, researchers found that combined treatment of CBT and pharmacotherapy is significantly more effective than pharmacotherapy alone (Cuijpers et al., 2013).

The efficacy of CBT in adults with substance abuse disorder has also been well documented. Hofmann et al. (2012) conducted a review of 106 meta-analytic studies examining the efficacy of CBT across a variety of psychiatric conditions, including substance use disorder. Their review found support for the efficacy of CBT among adults with cannabis dependence, and this efficacy increased with more sessions. These

findings are supported by Magill and Ray (2009), who conducted a meta-analytic review of 52 studies that used CBT to treat adult alcohol and drug users. They found that 29% of patients who received CBT had better outcomes than the typical person who did not receive any treatment. These effects were strongest for women and for cannabis users. In regard to adolescents and substance use, Macgowan and Engle (2010) found that CBT effectively reduced alcohol and other drug use over time. It may be such an effective mechanism of change partly because of the skills that are taught in CBT (Waldron & Kaminer, 2004).

From a behavioral health and integrated care perspective, cognitive behavioral therapy shows great promise. Due to the brief nature of CBT interventions and the impetus to improve evidence-based treatments for mental health conditions, there is benefit to utilizing this treatment within primary care. In a study investigating the effectiveness of a CBT and mindfulness group for patients with mood and anxiety disorders within primary care, participation in a brief, evidence-based treatment group was associated with a statistically significant decrease, with large effect sizes for both depression and anxiety symptoms (Craner, Sawchuk, & Smyth, 2016). Furthermore, 65% of the participants enrolled in the group completed at least four sessions, which supports the feasibility of group treatment in primary care.

Meta-analyses have also explored the long term effect of CBT interventions. Findings strongly suggest that across many disorders the effects of cognitive therapy are maintained for substantial periods beyond treatment. Significant evidence for long-term effectiveness was found for depression, generalized anxiety, panic, social phobia, obsessive-compulsive disorder, sexual offending, schizophrenia, and childhood

internalizing disorders (Butler et al., 2006). In a recent study, researchers found that CBT is effective in decreasing relapse rate and improving depressive symptoms, mania severity, and psychosocial functioning, with a mild-to-moderate effect size (Chiang et al., 2017).

Beck's Model of Cognitive Therapy

Beck's cognitive therapy is the most prominent model of CBT. Beck began his psychiatric training as a classic Freudian psychoanalyst and studied depression and anger (Beck & Weishaar, 1989). His original belief was that "melancholia" was explained as anger directed inward (Roberts, 2015). However, his own research found no support for this psychodynamic approach, but rather that individuals experienced a sense of loss and had a need for acceptance (Beck & Weishaar, 1989).

Beck focused on the negative thoughts and distortions that were common among his depressed patients (Beck, 1976). In looking at these patterns, Beck discovered the cognitive triad: negative view of the self, the world, and the future (Beck, 1976). Beck's model suggests that dysfunctional thinking regarding the cognitive triad is common to all emotional disorders or states of distress (Beck & Beck, 2011). The conceptual framework of Beck's cognitive therapy relies on the belief that early life experiences shape fundamental views of the self, world, and future (Beck, 1967). These constellations of beliefs are known as schemas, which help individuals organize and perceive new information (Young, 1994). Once these schemas are established, secondary beliefs develop and act as assumptions that are consistent with the cognitive triad (Beck et al., 1979). Beck believed that negative schemas affected the encoding,

storage, and retrieval of information (Beck, 1967), and therefore cognitive distortions develop through the chain of schema and secondary assumptions (Roberts, 2015).

Defining Cognitive Distortions

The concept of cognitive distortions was first proposed by Aaron T. Beck (Beck, 1976). Cognitive distortions are defined as processing information in a predictable, problematic manner, resulting in identifiable errors of thinking (Beck, 1995). The term *cognitive distortions* further refer to self-statements that are inaccurate or maladaptive and/or reflect a misinterpretation of events (Beck, 1995). When faced with a cognitive distortion, individuals may act in accordance with the thought as they learn to treat the distortion as a rule to govern behavior. Behaving in this way may lead to limited behavioral repertoire, increased emotional distress, and persistent maladaptive behavior (Torneke, Luciano, & Valdivia, 2008).

For those with a physical disease, cognitive distortions may play a role in personal perception of their condition. For instance, this appears to be the case in disorders involving pain; cognitive responses, such as thoughts and beliefs, play a key role in the perception of pain and how people adjust to pain (Keefe et al., 2005). According to Beck (1976), there is a systematic negative bias in the cognitive processing of patients who suffer from psychiatric disorders such as depression. Norman, Miller, and Klee (1983) found that depressed subjects selected significantly more depressed distortions on the Cognitive Bias Questionnaire (Krantz & Hammen, 1979) than did non depressed subjects.

Cognitive distortions take place in the domain of cognitive processes, which are the mechanisms by which an information processing system processes information over

time (Kendall, 1992). If individuals process information based on a maladaptive schema or belief system, rather than accurate perceptions and interpretations of the environment, this may affect their overall level of adjustment, which may lead to emotional distress or disorder (Kendall, 1992). When individuals process a distortion, they are actively processing information, but the thinking is misguided (Kendall, 1992). Because emotional disorders stem from the presence of these dysfunctional distortions (Burns, 1999), the goal of Beck's cognitive therapy is to correct cognitive distortions and, ultimately, to alter maladaptive schemas and alleviate symptoms of emotional distress (Beck, 1979; J. Beck, 2011; Roberts, 2015).

Types of Cognitive Distortions

From observed patterns of inaccurate reasoning among depressed individuals, Beck originally proposed six types of cognitive distortions (Beck & Weishaar, 1989): dichotomous thinking, arbitrary inference, magnification and minimization, overgeneralization, personalization, and selective abstraction (Beck & Weishaar, 1989). In 1999, Burns expanded Beck's original list to ten cognitive distortions. Burns' Checklist of Cognitive Distortions consists of all-or-nothing thinking, discounting the positive, emotional reasoning, jumping to conclusions, labeling, magnification, mental filter, overgeneralization, blaming and personalization, and should-statements (Burns, 1999). Following Burns, Freeman and DeWolf (1992) and Freeman and Oster (1992) proposed three additional distortions: comparison, externalization of self-worth, and perfectionism.

Cognitive Distortions in the Medical Setting

Cognitive distortions have been associated with both psychological and medical disorders. In regards to the latter, research now shows that physical illnesses impact a state of mental health (Uhl, 2007). Psychologists believe that patients should have the opportunity to address psychosocial problems related to their physical illness (Belar & Deardroff, 1995). Specifically, clinical health psychologists are interested in the meaning that patients attach to their illness and aim to be aware of a patient's worldview and cognitive style (Belar & Deardroff, 1995). Research has identified a number of medical conditions in which cognitive distortions play a role in psychological functioning, including chronic pain, cardiac disease, chronic illness and obesity (Marlatt & Gordon, 1985; Shnek, Irvine, Stewart, & Abbey, 2001; Smith, Christensen, Peck, & Ward, 1994;).

Chronic pain has been studied extensively in relation to cognition. Physical limitations as a result of chronic pain have an adverse impact on a self-image (Eimer, 1989). Individuals often suffer from negative self-perception, patterns of self-defeating beliefs, and depression (Uhl, 2007). In a longitudinal study of cognitive distortion and depression among individuals with chronic pain due to rheumatoid arthritis, researchers found that higher levels of cognitive distortion and perceived helplessness predicted higher levels of depressive symptoms over a 4-year span (Smith et al., 1994). Among these same patients, those exhibiting tendencies to overgeneralization, selective abstraction, personalization, and catastrophizing were more vulnerable to depression than patients with an adaptive coping style (Smith et al., 1994).

Cognitive distortions have also been studied among individuals with diabetes. Using the Irrational Health Belief Scale (IHBS; Christensen, Moran, & Wiebe, 1999),

researchers found that higher scores on the IHBS had a significant correlation with objective measures of poor diabetes management (Christensen et al., 1999). This study indicates that cognitive distortions may play a role in health-related behavior, which in turn, may impact prognosis and health outcomes. Individuals who are more likely to engage in negative health habits (as measured by the Millon Behavior Medicine Diagnostic) are more likely to engage in cognitive distortions (Uhl, 2007).

Because clinically significant depressive symptoms among cardiac patients have been estimated to occur in 14% to 27% of heart patients (Shnek et al., 2001), cognitive distortions have been studied among these individuals. Researchers who studied adults with a myocardial infarction or unstable angina found that higher levels of learned helplessness and cognitive distortions and lower levels of self-efficacy and optimism were significantly related to depressive symptoms at 1 month after hospital discharge and at 1 year follow-up (Shnek et al., 2001). Despite these levels of cognitive distortions, the influence of cognitive distortions on depressive symptoms dissipated over time in comparison to the lower levels of optimism (Shnek et al., 2001).

Individuals who are obese are considered to be at high risk for an array of psychological complications (Shook, 2010). Researchers have found that binge eating is related to increased rates of depression among individuals who are obese (Stunkard, 2002). Additionally, individuals who are obese are at a significantly greater lifetime prevalence of Axis 1 disorders (Eldredge & Agras, 1996). Given their rates of psychological distress, cognitive distortions were explored among those who are obese. In a study of 385 adults, Shook (2010) found that participants who engaged in more cognitive distortions were more likely to have a drug problem or eating problem.

Research shows that overeating may be related to cognitive distortions such as all-or-nothing thinking, which are the distortions implicated in the high relapse rates by alcoholics and smokers (Marlatt & Gordon, 1985).

In summary, research demonstrates that cognitive distortions play a major role in the lives of individuals affected by medical conditions. However, to date, there is no research on cognitive distortions among the NF1 population. As previous research indicates, depressed persons and those with various medical conditions have more cognitive distortions than those not meeting diagnostic criteria for such disorders (Hammen, 1978). Because individuals with NF1 are at increased risk for depression (Cohen, 2015), a high frequency of cognitive distortions is likely among this population. Measuring and identifying such maladaptive thought processes associated with NF1 can help to guide treatment.

Measuring Cognitive Distortions

Several self-report instruments have been developed for measuring cognitive distortions. These measures include the Automatic Thoughts Questionnaire (ATQ; Hollon & Kendall, 1980), the Cognitive Errors Questionnaire (CEQ; Lefebvre, 1981), the Cognitive Distortions Scale (CDS; Briere, 2001), the Dysfunctional Attitude Scale (DAS-A, DAS-B; Weisman, 1979) and the Inventory of Cognitive Distortions (Yurica, 2002).

The Automatic Thoughts Questionnaire is a 30-item instrument designed to measure the frequency of automatic negative self-statements associated with depression, and differentiates between depressed and non-depressed individuals (Hollon & Kendall, 1980). It uses a Likert scale ranging from 1 (*not at all*) to 5 (*all the time*) and the total score is the sum of all 30 items (Hollon & Kendall, 1980). It proves to have strong

internal reliability and concurrent validity and is useful as a measure of cognitive distortions related to depression (Hollon & Kendall, 1980). The ATQ was revised in 1989 and continued to differentiate depressed from non-depressed participants; however, it included positive and neutral self-statements in addition to the established negative self-statements (Kendall, Howard, & Hays, 1989).

The Cognitive Errors Questionnaire was developed to investigate the application of the cognitive theory of depression in depressed psychiatric patients, depressed low back pain patients, non-depressed low back pain patients, and non-depressed individuals without low back pain (Lefebvre, 1981). It measures an overall level of cognitive distortions as well as four specific types of cognitive distortion: catastrophizing, overgeneralization, personalization, and selective abstraction (Lefebvre, 1981). The CEQ is comprised of 24 vignettes. Each vignette is followed by a negative thought about the vignette reflecting one of the four cognitive distortions. Using a Likert scale ranging from 1 (*almost exactly as I would think*) to 5 (*not at all as I would think*), respondents are then asked to rate how likely they would be to react in a similar situation. The CEQ has high test-retest reliability (.80 to .85), high alternate forms reliability (.76-.82), and high internal consistency reliability (.89 to .92).

The Cognitive Distortions Scale is a 40-item self-assessment of cognitive distortions for adults (Briere, 2000). Specifically, the CDS is used to evaluate cognitive distortions in returning veterans with posttraumatic stress disorder (Owens, Chard, & Cox, 2008). It has also been used to distinguish between female patients with dual diagnoses of PTSD and substance abuse disorder (Najavits, Gotthardt, Weiss, & Epstein, 2004). Respondents rate how often they have had different thoughts or feelings in the

last month, using a Likert scale ranging from 1 (*never*) to 5 (*very often*). Internal consistency for the CDS was found to be strong, ranging from .89 to .97, and an overall mean alpha of .93.

The Dysfunctional Attitude Scale is also a 40-item scale that measures dysfunctional attitudes as they relate to depression (Weissman, 1979). It includes single-sentence items and measures seven value systems: approval, love, achievement, perfectionism, entitlement, omnipotence, and autonomy. Respondents answer using a Likert scale ranging from 1 (*totally agree*) to 5 (*totally disagree*). The instrument has high internal consistency (.84 to .92) and strong test-retest correlations (.80 to .84).

Inventory of Cognitive Distortions

In order to quantify specific cognitive distortions, Yurica and DiTomaso developed the Inventory of Cognitive Distortions (ICD; Yurica, 2002). Using cognitive distortions found in the literature, Yurica (2002) performed a factor analysis that revealed 11 fundamental cognitive distortions, 10 of which closely resembled previously identified distortions. One additional distortion, emotional reasoning and decision-making, was therefore included. Among cognitive therapy experts, there was 100% independent agreement (Yurica, 2002). These 11 distortions are: externalization of self-worth, fortune-telling, magnification, labeling, perfectionism, comparison to others, emotional reasoning, arbitrary inference/jumping to conclusions, minimization, mind-reading, and emotional reasoning and decision-making (Yurica, 2002).

The ICD is a valuable measure that has many advantages over other measures of cognitive distortions. Previous instruments lack specificity in the terms used to describe cognitive distortions (Roberts, 2015). The terms *belief*, *schema*, *cognitive distortions*,

thinking errors, and *dysfunctional attitudes* are used interchangeably (Weissman, 1979).

Additionally, some of the previous measures of cognitive distortions, specifically the ATQ and the DAS, are limited in that they measure cognitive distortions specific to depression (Yurica, 2002).

The ICD has been used in many studies, demonstrating good validity across different populations. In a study investigating the relationship between cognitive distortions and Axis I and Axis II psychopathology, Rosenfield (2004) found that individuals who meet the criteria for almost any Axis I or Axis II disorder report a greater frequency of cognitive distortions, as measured by the ICD, than individuals who are subclinical. Moreover, both the severity of pathology and the number of comorbidities on both clinical syndromes and personality disorders correlated with an increased frequency of cognitive distortions.

Results of validity testing suggested the higher the endorsement of cognitive distortions, the higher the frequency of dysfunctional thinking and the greater the endorsement of depressive symptoms (Yurica, 2002). Also, the ICD was able to distinguish between depressed and non-depressed individuals, as well as differentiate between individuals suffering from an anxiety disorder and individuals in a control group (Rupertus, 2004; Yurica, 2002). Uhl (2007) used ICD to assess distortions in medical sample. He found that the more frequently a patient engaged in cognitive distortions, the more likely they were to engage in negative psychological and health risk behaviors, such as the use of drugs, overeating, increased use of caffeine, being less active, and smoking. Also within a medical setting, the ICD was found to be useful in identifying the

relationship between patterns of unhealthy behavior and cognitive distortions in those individuals who are obese (Shook, 2010).

Overall, the ICD has proved useful across a variety of populations and contexts. The instrument was able to differentiate individuals suffering from anxiety or depression and could predict unhealthy lifestyles in a sample of medical patients, by their level of cognitive distortion (Rosenfield, 2004; Rupertus, 2004; Shook, 2010; Uhl, 2007; Yurica, 2002). By using the ICD to measure cognitive distortions among the NF1 population, clinicians can determine if there is a need to address maladaptive thinking patterns in treatment. In turn, such an increase in more rational thinking could aid in improving adaptive functioning, mood, and acceptance of the disorder.

History of Acceptance

In recent years, acceptance-based and mindfulness-based therapies have attracted a great deal of attention. These therapies are part of an overarching family of cognitive and behavioral therapies (Forman & Herbert, 2009). Mindfulness-based cognitive therapy originally derived from the Buddhist practice of mindfulness (Gordon, Griffiths, & Shonin, 2014). Buddhism originated approximately 2,500 years ago and is based on the teachings of Siddharth Gautama (more recently known as Shakyamuni Buddha) (Gordon et al., 2014). The three main principles of Buddhism, wisdom, meditation, and ethical awareness, are collectively known as the three trainings, which influenced Western psychology and interventions.

In the 1980s, Jon Kabat-Zinn adopted the word *mindfulness* from its use in Western Buddhism (Kabat-Zinn, 1990). He defined mindfulness as “paying attention in a particular way: on purpose, in the present moment, and nonjudgmentally” (Kabat-Zinn,

1994, p. 4). In 1979, Zinn developed mindfulness-based stress reduction (MBSR), traditionally used for chronic pain (Kabat-Zinn, 1990). At the same time, other writers were converging on practices similar to mindfulness (Dryden & Still, 2006). Steven Hayes developed techniques for developing awareness and acceptance, in which he also acknowledged Buddhism (Hayes, 1984). Hayes, well known for his development of acceptance and commitment therapy (ACT), proposes that these approaches are a new generation of cognitive behavior therapy. The history of behavior therapy is generally regarded in three distinct waves: traditional behavior therapy, CBT, and a third generation of contextualistic approaches (Hayes, 2004).

In the 1950s, the first generation of behavior therapy took an empirical, objective, scientific approach in response to the perceived shortcomings of psychoanalytic theory and as a result of the findings of the early behaviorists (Forman & Herbert, 2009). Existing clinical theories were vague and lacked scientific evidence (Hayes, 2004). Behaviorists aimed to modify problematic behavior and emotion through the application of classical and operant learning principles (Forman & Herbert, 2009). Psychoanalytic clinicians, such as Freud, argued against this new approach, which became grounds for debate (Hayes, 2004). Despite this new focus and shift away from analytic and humanistic concepts, proponents of behaviorism and clinicians recognized that behavioral principles needed to expand to include cognitive processes (Bandura, 1969). This new insight led to the second generation of behavior therapy.

The second wave of behavior therapy occurred in the late 1960s (Forman & Herbert, 2009). Cognitive factors were now presumed to play an important role in an individual's interpretation of, and emotional and behavioral response to environmental

stimuli (Bandura, 1969). Several psychotherapies were developed, including rational emotive behavior therapy (Ellis, 1962), stress inoculation training (Meichenbaum & Deffenbacher, 1988), and cognitive therapy (Beck, 1979). Proponents of these therapies believed that maladaptive thoughts, schemas, or information-processing styles were responsible for distress and negative behavior (Forman & Herbert, 2009).

The third wave of behavior therapy began to arise in the 1990s (Forman & Herbert, 2009). Examples of third wave interventions include dialectical behavior therapy (Linehan, 1993), mindfulness-based cognitive therapy (Segal, Williams & Teasdale, 2002), meta-cognitive approaches (Wells, 2007), and ACT (Hayes et al., 1999). For many, ACT is strikingly similar to CBT and is debated as being an entirely new treatment approach; however, there are subtle differences that should be noted. There is a critical difference between ACT and CBT in the way each therapy addresses cognitions. Whereas CBT distinguishes actions, emotions, and cognitions as separate entities, ACT includes cognitions under the term *behavior*. Therefore, the word *cognition* has a different meaning in ACT than in CBT (Hofmann & Asmundson, 2008). These two modalities also differ in regards to the role of emotions. Although they share many of the same techniques to reduce emotional distress, they differ in specific emotional regulation strategies. ACT targets experiential avoidance and the attempts to manage unpleasant emotions through suppression and other dysfunctional emotion regulation strategies (Hofmann & Asmundson, 2008). In contrast, CBT focuses on the situation that generates the emotional experience. In sum, ACT counteracts response-focused emotional regulation strategies, whereas CBT promotes adaptive antecedent-focused emotion regulation strategies (Hofmann & Asmundson, 2008). Although these differences

between ACT and CBT do exist, there is great overlap in these two modalities of treatment. A thorough literary review resulted in no research specifically investigating the direct relationship between cognitive distortions and acceptance. For the purpose of this study, a more exhaustive history of ACT will be provided.

Acceptance and Commitment Therapy

ACT is based on the theory of functional contextualism (Biglan & Hayes, 1996). Contextualism views psychological events as ongoing actions of the whole organism interacting with historically and situationally defined contexts (Hayes et al., 2006). The core components of functional contextualism are: “(a) focus on the whole event (b) sensitivity to the role of context in understanding the nature and function of an event (c) emphasis on a pragmatic truth criterion, and (d) specific scientific goals against which to apply that truth criterion” (Hayes, 2004, p. 646). Within ACT, there is a conscious openness and acceptance to all psychological events, even if they are previously negative, irrational, or psychotic (Hayes, 2004, p. 647). From this perspective, behavioral events are interpreted as ongoing acts within their current and historical context (Yu & McCracken, 2016). ACT does not focus on creating change in the content of thoughts and feelings, but instead to alter their function, or change the individual’s “relationship with” thoughts or feelings (Yu & McCracken, 2016, p. 12). This gives the individual more behavioral choices in which to engage (Yu & McCracken, 2016).

ACT therapeutic approaches emerged from a behavioral theory known as relational frame theory. Relational frame theory states that the core of human language and cognition is the ability to relate events under arbitrary contextual control (Hayes, 2004); in short, it is necessary to analyze cognition in order to understand human

behavior. From this standpoint, a primary source of psychopathology is the way that language and cognition interact with contingencies to produce an inability to persist in or change behavior (Hayes et al., 2006). This inability to change behavior or persist, termed *psychological inflexibility*, develops from weak contextual control over language processes (Hayes et al., 2006). The goal of ACT is psychological flexibility: being able to contact the moment as a conscious human being more fully, based on what the situation offers, and persisting based on chosen values (Hayes et al., 2013). The terms psychological flexibility and psychological inflexibility are similar to those of acceptance and experimental avoidance (Wolgast, 2014). *Experimental avoidance*, in ACT, refers to the unwillingness to remain in contact with aversive private experiences and taking action to avoid and/or alter them (Hayes et al., 1996). In contrast to experimental avoidance is the construct of *acceptance*, the willingness to experience unwanted private events (Hayes et al., 2006). There are six processes within the ACT model in order to establish psychological flexibility: acceptance, cognitive diffusion, the now, self, values, and committed action (Hayes et al., 2013).

Acceptance Defined

Acceptance involves the active and aware embrace of private events without unnecessary attempts to change their frequency or form (Hayes et al., 2006). Research shows that acceptance interventions alone, and in combination with other ACT components, increase persistence and willingness to engage in distressing tasks (Hayes, Bissett, et al., 1999). However, acceptance is not merely tolerance, it is the active nonjudgmental embracing of experience in the here and now (Hayes, 2004). In ACT, acceptance is not possible without cognitive diffusion, which can be defined as changing

the way one interacts with or relates to thoughts (Hayes et al., 2006). Acceptance inherently involves exposure, in which an individual experiences an event actively and fully in the present, moment by moment, for the sole purpose of experiencing actively and fully (Hayes, 2004). For individuals experiencing either a physical or psychological disorder, it may be a challenge to practice the act of acceptance. Cognitive resources may be limited among these individuals, making it more challenging to relate to their thoughts in a new way. Furthermore, coping with physical limitations may make it difficult to focus on the present moment if considering the course of their disorder and future complications. Therefore, the construct of acceptance is worth measuring in NF1 individuals, who present with both physical and psychological complications, in order to help guide therapeutic treatment and increase psychological flexibility.

Measuring Acceptance

Measures of acceptance are often called measures of psychological flexibility or experiential avoidance. Hayes et al. (2004) first proposed the importance of establishing a measure of experiential avoidance for population-based studies, as the construct was implicated in a wide range of clinical problems and disorders from substance abuse to suicide (Hayes et al., 2004). Hayes acknowledged the success of other researchers who had established measures of avoidance of specific thoughts and feelings involved in a particular clinical problem. For example, he credits McCracken (1998) for developing a measure of avoidance of pain and Gifford (2002) for developing a measure of avoidance of thoughts associated with smoking cessation. It was during that time, Hayes and coworkers (2004) developed the first version of the Acceptance and Action Questionnaire (AAQ), a 32-item measure designed to assess a high need for emotional and cognitive

control, avoidance of negative private events, and the inability to take needed action in the face of these events. Over time, measures of acceptance have been adapted and modified to address specific disorders or concerns. However, because a specific acceptance measure has not yet been created for experiences related to NF1, for the purpose of this study, a more generalized measure of psychological flexibility will be utilized.

The Acceptance and Action Questionnaire (AAQ) is the most widely used measure of experiential avoidance and psychological inflexibility (Bond et al., 2011). The original scale included 9 to 16 items and was a Likert-type scale. The scale contained items on negative evaluations of feelings, avoidance of thoughts and feelings, distinguishing a thought from its referent, and behavioral adjustment in the presence of difficult thoughts or feelings (Bond et al., 2011).

The AAQ has proven to be useful and has led to a number of versions. A meta-analysis of the AAQ found that it predicted a variety of quality of life outcomes, such as psychopathology, stress, pain, job performance, and negative affectivity (Hayes et al., 2006). As use of the measure began to grow, a number of versions were tailored to particular areas or populations, such as pain (McCracken, Vowles, & Eccleston, 2004), smoking (Gifford et al., 2004), diabetes management (Gregg, Callaghan, Hayes, & Glenn-Lawson, 2007), tinnitus (Westin, Anderson, & Hayes, 2008), weight-related difficulties (Lillis & Hayes, 2008), and coping with epilepsy (Lundgren, Dahl, & Hayes, 2008). Although the AAQ is widely used, there are documented concerns regarding the internal consistency. In a validation study by Hayes et al. (2004), the alpha coefficient was only .70, and its test-retest reliability was .64 over 4 months. These low alpha levels

are consistent and may be due to the complexities of individual items (Bond et al., 2011). The AAQII was developed in response to the shortcomings of the AAQI, as a measurement of psychological inflexibility.

Acceptance in Health Care

The construct of acceptance and the efficacy of ACT have been studied among a variety of disorders in health care. ACT has been explored in treating various mental health conditions, anxiety, and body image.

Mental health disorders.

There is now accumulating evidence for the effectiveness of ACT across a variety of mental health conditions (Yu & McCracken, 2016). In a meta-analysis of 18 randomized controlled trials in which ACT was compared to inactive control conditions and established treatments, an overall advantage was found for ACT; the average ACT-treated participant had greater improvement than 66% of the participants in the control group (Yu & McCracken, 2016). In exploring the effectiveness of ACT within the field of mental health, we will consider its effect on conditions such as depression, anxiety, and body image. Although this list is not exhaustive, it provides insight into the usefulness and promise of ACT as an intervention.

A meta-analysis found that ACT demonstrated moderate group and pretreatment/posttreatment effects for symptom reductions for anxiety and depression (Hacker, Stone, & MacBeth, 2016). Despite these results, the researchers acknowledged that ACT may not be more effective than traditional treatment approaches, and further inquiry was warranted. In a separate meta-analytic review of studies examining the relationships between the core ACT process of change (psychological flexibility) and

anxiety symptomatology, results showed a positive and significant relationship between the AAQ scores and general measures of anxiety and specific measures of disorder severity (Bluett, Homan, Morrison, Levin, & Twohig, 2014). This indicates that a higher level of inflexibility correlates with anxiety. Further exploration found that mindfulness meditation (an ACT technique) was associated with statistically significant improvement in depression, physical health-related quality of life, and mental health-related quality of life (Hilton et al., 2017)

Acceptance has also been investigated in regards to body image. Body image is an important aspect in which individuals evaluate themselves and estimate their social rank and is very relevant to the current study (Gilbert, 2002). In the general and clinical populations, body dissatisfaction (BD) is highly prevalent, for example, affecting more than 80% of women (Mond et al., 2013). BD has been found to be an important risk factor for disordered eating behaviors, such as rigid dietary restraint and bulimic behaviors (Anton, Perri, & Riley, 2000). Research also shows that body dissatisfaction can negatively affect quality of life in various domains, specifically psychosocial functioning and mental health (Liimakka, 2014; Mond et al., 2013). When considering ACT for body image, rather than attempting to change the content of distressing body image-related cognitions and emotions themselves, an alternative ACT approach is to focus on the relationship with these experiences (Lee, Smith, Twohig, Lensegrav-Benson, & Quakenbush-Roberts, 2017) by using *body image flexibility*, which is the ability to openly experience body image dissatisfaction and related experiences in a way that promotes adaptive life functioning and values-consistent behavior (Sandoz, Wilson, Merwin, & Kellum, 2013).

Body image flexibility shares conceptual foundations with ACT's psychological flexibility construct as applied to the context of body image (Sandoz et al., 2013). It shares elements of a positive rational acceptance style in coping with body image-related stressors (Cash et al., 2005). Specifically, body image flexibility involves openly engaging painful or unwanted thoughts and emotions regarding body size, shape, or weight with mindful acceptance (Sandoz et al., 2013).

Body image flexibility has been assessed using the Body Image Acceptance and Action Questionnaire (BI-AAQ; Sandoz et al., 2013). The BI-AAQ is a domain-specific measure of psychological flexibility, based on the more general measure of psychological inflexibility, the Acceptance and Action Questionnaire-II. Although acceptance in relationship to the construct of body image is often studied among those with eating disorders, it can be generalized to all individuals experiencing body-image distress.

Physical Disorders.

ACT has been applied both to mental health concerns and physical disorders and complications, as well. The most commonly explored physical condition in which ACT has been applied is chronic pain.

The construct of acceptance has been extensively studied among individuals experiencing chronic pain. In this context, acceptance is conceptualized as an underlying psychological state of willingness to experience pain and its cognitive and emotional facets while continuing to live life as normally as possible (Reneman, Dijkstra, Geertzen, & Dijkstra, 2010). ACT for chronic pain involves identifying helpful ways to respond to thoughts and feelings, exploring values, and developing mindfulness skills (Baranoff, 2016). The goal of ACT is not to eliminate pain, but to change the relationship with pain

so that pain is not the defining feature of life. This shift in perspective resulting from the aforementioned ACT processes ultimately helps the person to accept the experience of pain, refocus to values and goals and, ultimately, to achieve and maintain a higher QOL (McCracken & Eccleston, 2003).

In studies of chronic pain, acceptance has been defined as being comprised of two factors: activity engagement (a commitment to engaging in valued activities even in the face of illness related symptoms) and willingness (a willingness to experience sometimes painful or aversive symptoms if it means being able to participate in valued life activities) (McCracken, 2010). Activity engagement and willingness factors of chronic pain acceptance are strongly associated with key predictors of medical, behavioral, psychosocial, and functional outcomes (McCracken and Velleman, 2010). Research also shows that acceptance is associated with higher quality of life in patients with low back pain, a decrease in the impact of pain flares in patients with rheumatoid arthritis, and adaptive functioning in patients with mixed pain conditions (Dahl, 2009; McCracken, 2007; Vowles et al., 2008)

Recently, mindfulness has also been determined to be a key mediator between pain experiences and outcome (Hofmann et al., 2010). The effectiveness of mindfulness-based processes for medical conditions with chronic pain has been shown in symptom reduction and improvement of emotional well-being (Baer, 2003). A meta-analysis of 30 randomized controlled trials found that mindfulness meditation was associated with a small effect of improved pain symptoms, compared with treatment as usual and educational support groups (Hilton et al., 2017.)

Many clinical manifestations of NF1 are associated with pain, making the disorder a potential candidate for ACT research and treatment. For instance, cutaneous neurofibromas are sometimes painful as they first develop, and plexiform neurofibromas sometimes produce nerve root pain (Tonsgard, 2006; Tucker et al., 2009). Malignant peripheral nerve sheath tumors (MPNSTs) are often associated with significant pain (Crawford et al., 2015; Tonsgard, 2006). Among the 60 Australian adults with NF1, one quarter of participants reported pain (Crawford et al., 2015). With the exception of pain associated with MPNSTs, the source of pain is often benign, varies in its origin, and is difficult to treat (Crawford et al., 2015). Headaches, back pain, orthopedic problems, and gastrointestinal complications are also common symptoms of NF1 that result in chronic pain (Oates et al., 2013; Tonsgard, 2006). Despite the pain that is often associated with the disorder, research on acceptance among those with NF1 is limited.

Overall, research indicates that ACT is effective for individuals with various types of pain. However, despite reports of pain, NF1 is distinct from these other conditions because many individuals with NF1 have comorbid learning and attention problems. Within the context of therapy, these cognitive deficits could make therapeutic interventions more challenging, if the individual has difficulty focusing in session or following through on therapeutic homework.

To date, there is little research exploring acceptance among adults with NF1. In a pilot study examining the effectiveness of ACT among youth with NF1, researchers found that ACT interventions resulted in less pain interference and lower patient-reported pain in follow-up data (Martin et al., 2016). Pain interference in this study was defined as “how much the pain has interfered with sleep, mood, social activities, etc. in the past

two weeks” (Martin et al., 2016, p. 1465). These preliminary results suggest that ACT may be an effective tool for decreasing pain among those with NF1. There is currently an ongoing clinical trial that is examining the efficacy of ACT among individuals with NF1 (National Cancer Institute, 2017). More investigations on the feasibility and efficacy of ACT within this population are needed (Martin et al., 2016).

Purpose of the Study

The purpose of this study was to explore the relationship between cognitive distortions, perceived stigmatization, and acceptance among adults with NF1. Understanding how cognitive distortions and perceived stigmatization impact levels of acceptance may permit clinicians to tailor treatment to address these specific maladaptive thinking patterns. If cognitive distortions predict levels of perceived stigmatization (and the accompanying dysphoria and dysfunction) clinicians may be able to make therapeutic interventions more efficient by focusing on ameliorating those cognitive mechanisms. Treatment can then focus on increasing acceptance and improving functioning for individuals with this disorder.

Chapter 3: Research Hypotheses

H₁: The frequency of cognitive distortions and level of perceived stigmatization will predict the level of acceptance among adults with NF1. Frequency of cognitive distortions will be operationalized as total scores on the Inventory of Cognitive Distortions; level of perceived stigmatization will be operationalized as scores on the Perceived Stigmatization Questionnaire; level of acceptance will be operationalized as scores on the Acceptance and Action Questionnaire II.

H₂: The frequency of cognitive distortions and rating of disease visibility will predict the level of perceived stigmatization among adults with NF1. Frequency of cognitive distortions will be operationalized as total scores on the Inventory of Cognitive Distortions; disease visibility will be operationalized as the score on the Ablon scale; level of perceived stigmatization will be operationalized as scores on the Perceived Stigmatization Questionnaire.

H₃: The age at NF1 diagnosis will predict the level of acceptance among adults with NF1. Age at diagnosis will be collected via the demographic questionnaire; level of acceptance will be operationalized as scores on the Acceptance and Action Questionnaire II.

Chapter 4: Method

Research Design

This study employed a cross-sectional, correlational design. Data was collected via online survey.

Participants and Recruitment

Participants were recruited online through five national NF organizations. This was done by providing a recruitment message to each organization to advertise this study via their listservs or websites. These organizations were:

- Neurofibromatosis Network, a national organization that advocates for NF research and federal funding. They offer access to clinical studies and support groups for those with NF.
- Children's Tumor Foundation (CTF), a funder of scientific research. Over 70% of all data on NF has been research funded or co-funded by the CTF.
- National Organization for Rare Disorders, a coalition formed to help advocate for individuals with rare diseases including NF and to advance medical research.
- Johns Hopkins Comprehensive Neurofibromatosis Center, part of a national collaboration of medical centers providing and managing care for those with NF. They are affiliated with the Children's Tumor Foundation providing access for families and individuals coping with the disorder.
- Neurofibromatosis Therapeutic Acceleration Program, a program focused exclusively on improving treatment options for people with NF1. In addition to the aforementioned formal organizations, participants were recruited via

Facebook, other social media networks via snowball sampling, and word of mouth.

Inclusion and Exclusion Criteria

Eligible participants were between the ages of 18 and 65. Participants reported having been diagnosed with NF1 by a physician at some time in their life. They must have reported having access to the internet, being fluent in English, and at least an eighth-grade education.

Participants were excluded if they reported that they were not between the ages of 18 and 65, did not have access to the internet, or were not fluent in English. They were also excluded from the study if they did not have at least an eighth-grade education or if they had a previous diagnosis of intellectual disability or endorsed current psychotic symptoms.

Measures

For the purpose of this study, a screening questionnaire (Appendix A) was administered to determine eligibility. A demographic questionnaire (Appendix B) was administered to all qualifying participants. Following completion of these questionnaires, four brief measures were utilized: Inventory of Cognitive Distortions (ICD), Ablon scale, the Perceived Stigmatization Questionnaire (PSQ), and Acceptance and Action Questionnaire. Reported completion times for each measure are: Inventory of Cognitive Distortions approximately 20 to 25 minutes, Ablon scale approximately 5 minutes, Perceived Stigmatization scale approximately 10 to 15 minutes, and Acceptance and Action Questionnaire approximately 5 minutes.

Inventory of Cognitive Distortions (Yurica, 2002). The Inventory of Cognitive Distortions is a 69-item self-report measure comprised of various statements reflecting 11 different cognitive distortions. The ICD items are scored on a Likert scale ranging from 1 (*never*) to 5 (*always*) which reflects a respondent's level of agreement to each statement. The total score is calculated and ranges from 69 to 345, in which higher scores indicate greater endorsement of cognitive distortions (Yurica, 2002).

Psychometric evaluation of the ICD reflects strong internal consistency and test-retest reliability. In regards to internal consistency, Cronbach's alphas have ranged from .97 to .98 (Roberts, 2015; Rosenfield, 2008; Yurica 2002). In regards to test-retest reliability, following a 5-week interval, reliability was also found to have a high reliability coefficient (.998); (Yurica, 2002). This measure has also been positively correlated with accepted measure of depression demonstrating good validity. The ICD correlates strongly with similar measures of dysfunctional thinking, anxiety, and depression, suggesting strong concurrent validity; positive correlations have been documented with the Dysfunctional Attitudes Scale ($r = .70$), the Beck Depression Inventory II ($r = .70$), and the Beck Anxiety Inventory ($r = .59$) (Roberts, 2015; Yurica, 2002).

Ablon scale (Ablon, 1996). The Ablon scale is a measure used to evaluate the visibility of the disease. Ratings can be completed by the patient or an observer; however, for the purpose of this study, the patients completed this scale in regards to their own appearance. Ratings are based on appearance of the NF1 individual when fully dressed and how readily symptoms could be perceived in impersonal interaction. This instrument is scored on a 3-point scale. The individual with NF1 is assigned a single

qualitative score of either 1 (*mild*), no visible tumors with normal gait and posture; 2 (*moderate*), Some tumors on neck, face, hands, and mild scoliosis or other skeletal feature without noticeable limp; or 3 (*severe*), numerous tumors on the face, optic glioma that affect sight and eye socket, and severe skeletal features with noticeable limp. There are currently no documented psychometric properties for the Ablon scale; however, it has been adopted and used by many researchers, specifically in studies of quality of life. The widespread use of this measure indicates good clinical utility.

Perceived Stigmatization Questionnaire (Lawrence et al., 2010). The PSQ is a 21-item, 3-factor measure of perceived stigmatization. It measures the frequency of various stigmatizing social behaviors that have been experienced by people with physical distinctions. The items are scored on a Likert scale ranging from 1 (*never*) to 5 (*always*). Total scores range from 21 to 105. Higher scores indicate higher levels of perceived stigmatizing behaviors. Psychometric analyses show that the Cronbach's alpha on the PSQ total score was .86 among children and .89 among adults. Cronbach's alpha on the PSQ subscales ranged from .79 to .81 in the child sample and .82 to .86 in the adult sample. The three subscales of the PSQ, used only for validation of the measure, are confused behavior and staring, absence of friendly behavior, and hostile behavior.

Acceptance and Action Questionnaire II (AAQII) (Bond et al., 2011). The AAQII is a 7-item instrument used to measure the construct of acceptance. More specifically, it is a measure of experiential avoidance and psychological inflexibility. Each item is rated on a 7-point Likert scale ranging from 1 (*never true*) to 7 (*always true*). Total scores on the AAQII range from 7 to 49. Higher scores indicate greater psychological inflexibility (Bond et al., 2011). There is no established cutoff for the

AAQII; however, scores above a range of 24 to 28 are associated with higher levels of psychological distress. Lower scores indicate greater psychological flexibility, or greater levels of acceptance (Bond et al., 2011). Psychometric analysis of this measure indicates satisfactory reliability and validity. The mean alpha coefficient was 0.84, and the 3- and 12-month test-retest reliability was .81 and .79, respectively. These results show that the AAQII appears to measure the same concept as the AAQ, but with better psychometric consistency (Bond et al., 2011). In addition to its sound reliability, validation studies indicate that the AAQII demonstrated good construct validity (Bond et al., 2011). For example, higher levels of psychological inflexibility, as measured by the AAQII are concurrently associated with greater depressive symptoms ($r = .71$ with the BDI-II), anxiety-related symptoms ($r = .61$ with the BAI), and overall psychological distress ($r = .30$ with the General Health Questionnaire).

Procedure

Selected organizations were contacted via Email, providing them with a recruitment message to post through listservs and website postings. The introductory/organizational recruitment Email explained the purpose of the study and offered subjects access to the results of the study upon completion. They were provided with a participant recruitment posting to utilize at their discretion. This same participant recruitment message was also posted and advertised on social media networks, such as NF groups on Facebook. Participants were also recruited via snowball sampling, Facebook pages and other general social media networks, and by word of mouth.

The study was available only to those with access to the Internet. Each participant was provided with a document of study summary, including the study's

purpose and procedures. Participation in this project was voluntary for all subjects, and they retained the right not to participate or to withdraw at any time without explanation or penalty. All participants remained completely anonymous. No names were collected. Only demographic information was gathered from participants. A separate, optional sweepstakes incentive (two \$50 gift cards) was offered to all respondents willing to provide contact information, but there was no link between participant identities and their responses.

Upon agreeing to participate in the study, respondents completed an eligibility screening questionnaire (Appendix A). If they did not meet inclusion criteria, they were thanked for their time and redirected from the survey link. If deemed to meet eligibility criteria, participants completed a brief demographic questionnaire (Appendix B) that supplied descriptive data, including age, age at NF1 diagnosis, gender, and ethnicity. They were then provided access to the four measures (the ICD, Ablon scale, PSQ, and AAQII) via Survey Monkey, a widely accepted website used to collect survey data. Anticipated duration of participation in the study was approximately 45 minutes. After participants completed the measures, data was confidentially stored and uploaded into SPSS 24.0 for statistical analysis, where it was encrypted and stored on a password-protected computer.

Chapter 5: Results

To examine the first hypothesis, a multiple regression was conducted to investigate whether the frequency of cognitive distortions and level of perceived stigmatization predict the level of acceptance. A multiple regression was also conducted to investigate the second hypothesis that the frequency of cognitive distortions and rating of disease visibility would predict the level of perceived stigmatization. A simple regression was conducted to determine if the age at NF1 diagnosis predicted level of acceptance (H₃).

Statistical Analyses

The variables were analyzed using SPSS 24.0. A G*Power analysis was conducted to determine the necessary sample size for the present study. In this analysis, the effect size was set to medium, the significance level was set at 0.05, and the power level was set at 0.80, according to conventional standards (Cohen, 1988, 1992). This analysis determined that a minimum of 67 participants was needed to perform the multiple regression analyses. Allowing for attrition/incomplete protocols, especially given potential cognitive limitations of this population, the maximum number of participants was set at 200.

Demographic Analysis

The sample consisted of 48 participants: 37 females and 11 males. Initially, 202 participants began the study; however, there was a high attrition rate during completion of the survey. The participant age range was 19 to 64, with a mean age of 41. Participants identified as 89.6% White, 6.3% Asian, 2.1% mixed race, and 2.1% ethnicity unspecified. Of the participants who completed the study, 10% endorsed a diagnosis of

ADHD, 42% endorsed a diagnosis of depression, 40% endorsed a diagnosis of anxiety, and 23% endorsed a diagnosis of a learning disability.

To examine whether the frequency of cognitive distortions and level of perceived stigmatization predicted the level of acceptance among adults diagnosed with NF1, a multiple linear regression was conducted using frequency of cognitive distortions (as measured by the ICD) and level of perceived stigmatization (as measured by the PSQ) as the predictor variables and level of acceptance (as measured by the AAQII) as the criterion variable.

Tests of assumptions of a multiple linear regression were met. According to Field (2009), the Durbin-Watson statistic tests for “serial correlations between errors in regression models” (p. 874) and can vary between 0 and 4. The Durbin-Watson statistic in this multiple regression was 2.38, indicating that the residuals are uncorrelated. Collinearity diagnostics revealed that for each of the predictor variables, there was no evidence of significant multicollinearity. In this analysis, tolerance statistics had a value of .87 suggesting that multicollinearity was not a concern. Tolerance statistics should not be below 0.1 and even values below .2 can be a concern (Field, 2009). The variance inflation factor value was found to be 1.15 for both variables, indicating no concern. A plot of standardized residuals against standardized predicted values revealed that assumptions of linearity and homoscedasticity were met. A histogram and normal probability plot of residuals were examined and revealed that the assumption of normality was also met. The normal probability plot examining observed cumulative percentages to expected cumulative percentages also supported the assumption of normality; the

probability-probability (P-P) scatter plot showed some mild deviation around the line, but was generally consistent with what would be expected in terms of normality.

The overall regression analysis, as shown in Table 1, revealed a significant regression, $F(2, 47) = 53.304, p = .001$, indicating that the combination of these predictors made a significant contribution to the prediction of acceptance. The results of the multiple linear regression analysis, as shown in Table 2, revealed a multiple correlation of $R = .839$, with a coefficient of determination of $.703 (R^2 = .703)$, indicating that approximately 70% of the variance observed can be attributed to the combination of frequency of cognitive distortions and perceived stigmatization. The adjusted coefficient of determination ($R^2_{adj} = .690$) suggests that there would be some shrinkage from sample to general population. An examination of each of the predictor variables, as shown in Table 3, revealed that only one of the predictors, frequency of cognitive distortions, made a significant contribution to the level of acceptance.

Table 1

Overall Regression Analysis With Predictor Variables (Cognitive Distortions and Perceived Stigmatization) to the Dependent Variable (Acceptance)

Model	SS	df	MS	F	p
1 Regression	3398.82	2	1699.41	53.30*	.000 ^b
Residual	1434.66	45	31.88		
Total	4833.48	47			

^a = Criterion variable: level of acceptance

Table 2

Model 1 Summary of the Predictor Variables (Cognitive Distortions and Perceived Stigmatization) to the Dependent Variable (Acceptance)

Model	<i>R</i>	<i>R</i> ²	<i>R</i> ² Adj	<i>SEE</i>	<i>R</i> ² Change	<i>F</i> Change	<i>df</i> 1	<i>df</i> 2	Sig. <i>F</i> Change	Durbin- Watson
1	.884 ^{a*}	.70	.690	5.65	.70	53.30	2	45	.001	2.38

Table 3

Coefficients of Predictor Variables (Cognitive Distortions and Perceived Stigmatization) to the Dependent Variable (Acceptance)

Model	Unstandardized Coefficients		Standardized Coefficients			Collinearity Statistics	
	<i>B</i>	<i>SE</i>	β	<i>t</i>	<i>p</i>	Tolerance	VIF
1 (Constant)	-14.55	4.48		-3.25	.002		
Inventory of cognitive distortions	.16	.02	.76	8.73	.000*	.87	1.15
Stigma	3.78	1.90	.17	1.99	.053	.87	1.15

To examine whether the frequency of cognitive distortions and rating of disease visibility predicted the level of perceived stigmatization, a multiple linear regression analysis was conducted, using frequency of cognitive distortions (as measured by the ICD) and rating of disease visibility (as measured by the Ablon Scale) as predictor variables and the level of perceived stigmatization (as measured by the PSQ) as the

criterion variable. The tests of assumptions of the analysis were met with the Durbin-Watson (2.03) and tolerance statistics (.95) and variable inflation factors (1.05). These values suggest no significant multicollinearity. A plot of standardized residuals against standardized predicted values revealed that assumptions of linearity and homoscedasticity were met. A histogram and normal probability plot of residuals were examined and revealed that the assumption of normality was also met. The normal probability plot examining observed cumulative percentages to expected cumulative percentages also supported the assumption of normality; the probability-probability (P-P) scatter plot showed some mild deviation around the line, but was generally consistent with what would be expected in terms of normality.

The overall regression analysis, as shown in Table 4, revealed a significant regression, $F(2, 47) = 8.024, p = .001$, indicating that the combination of these predictors, frequency of cognitive distortions and rating of disease visibility, made a significant contribution to the predication of perceived stigmatization. The results of the multiple linear regression analysis, as shown in Table 5, revealed a multiple correlation of $R = .513$, with a coefficient of determination of $.263 (R^2 = .263)$, indicating that approximately 26% of the variance observed can be attributed to this combination of cognitive distortions and rating of disease visibility. The adjusted coefficient of determination ($R^2_{Adj} = .230$), suggests that there would be some shrinkage from sample to population if the population had been evaluated. An examination of frequency of cognitive distortions and rating of disease visibility individually, as shown in Table 6, revealed that both make a significant contribution to the level of stigmatization.

Table 4

Overall Regression Analysis With Predictor Variables (Cognitive Distortions, and Disease Visibility) to the Dependent Variable (Perceived Stigmatization)

Model	SS	df	MS	F	p
1 Regression	2.67	2	1.34	8.02*	.001 ^b
Residual	7.49	45	.17		
Total	10.16	47			

^a = Criterion variable: perceived stigmatization.

Table 5

Model 1 Summary of the Predictor Variables (Cognitive Distortions, and Disease Visibility) to the Dependent Variable (Perceived Stigmatization)

Model	R	R ²	R ² Adj	SEE	R ² Change	F Change	df1	df2	Sig. F Change	Durbin- Watson
1	.51 ^{a*}	.26	.23	.41	.26	8.02	2	45	.001	2.03

Table 6

Coefficients of Predictor Variables (Cognitive Distortions, and Disease Visibility) to the Dependent Variable (Perceived Stigmatization)

Model	Unstandardized Coefficients		Standardized Coefficients			Collinearity Statistics	
	B	SE	β	<i>t</i>	<i>p</i>	Tolerance	VIF
1 (Constant)	1.24	.27		4.61	.000		
Inventory of cognitive distortions	.00	.00	.28	2.15	.037*	.95	1.05
Visibility	.25	.09	.37	2.84	.007*	.95	1.05

To examine whether the age at diagnosis of NF1 was a significant predictor of level of acceptance, a simple linear regression was conducted using the age at diagnosis as a predictor variable and the level of acceptance (as measured by the AAQII) as the criterion variable. Assumptions of a simple regression were met. A plot of standardized residuals against standardized predicted values revealed that assumptions of linearity and homoscedasticity were met. A histogram and normal probability plot of residuals were examined and revealed that the assumption of normality was also met. The normal probability plot examining observed cumulative percentages to expected cumulative percentages also supported the assumption of normality; the probability-probability (P-P) scatter plot showed some mild deviation around the line, but was generally consistent with what would be expected in terms of normality.

Results indicated that there was no significant relationship between age at diagnosis and level of acceptance ($r = .020, p = .894$). Correlations and coefficients are presented in Table 7 and Table 8, respectively.

Table 7

Model 1 Summary of Predictor Variables (Age at Diagnosis) to the Dependent Variables (Level of Acceptance AAQ)

Model	r	R^2	R^2 Adj	SEE
1	.02 ^a	.00	-.021	10.25

^a = Predictors: (constant): At what age were you diagnosed with NF1

Table 8

Coefficients of Predictor Variables (Age at Diagnosis) to the Dependent Variables (Level of Acceptance AAQ)

Model	Unstandardized Coefficients		Standardized Coefficients		t	p
	B	SE	β			
(Constant)	24.61	2.18			11.31	.00
At what age were you diagnosed with NF1	-.02	.12	-.02		-.13	.89

Chapter 6: Discussion

This study examined the relationship between cognitive distortions, perceived stigmatization, and acceptance among adults with NF1, a disorder that is characterized by a number of signs and symptoms, some of which are highly visible and disfiguring. Although NF1 has gained a great deal of attention and research in the medical field, this study aimed to provide information from a psychological and cognitive perspective. There is currently little research exploring the underlying cognitive and psychological mechanisms associated with NF1. Previous research demonstrated the role of cognitive distortions among a variety of psychiatric concerns, including both clinical syndromes and personality disorders (e.g., Rosenfield, 2004), many of which are comorbid with NF1. However, to date, there has been no research exploring the role of cognitive distortions among the NF1 population and how these cognitions impact different perceptions and reactions. Furthermore, because NF1 has signs that are often visible in impersonal interactions, those with the disorder may be subject to stigmatizing behavior by others, which can foster emotional distress. The construct of acceptance, or the ability to engage in psychological flexibility, may have considerable relevance in the NF1 population as an adaptive means of coping with physical disfigurements and the reactions of others. A literature review revealed scant research exploring acceptance in the NF1 population. The goal of this study was therefore to begin to address these gaps in the literature.

Findings and Clinical Implications

Cognitive distortions, stigmatization, and acceptance. The current study initially found that together, cognitive distortions and perceived stigmatization

significantly predicted level of acceptance; however, when examined independently, it was determined that only cognitive distortions were significantly associated with level of acceptance. Nonetheless, the fact that perceived stigmatization was not found to be a significant predictor in this study seems to demonstrate the central role cognitive distortions in acceptance for this population. These findings have substantial implications for treatment planning and interventions.

As research has shown, higher levels of acceptance, or psychological flexibility, are associated with lower levels of depression and anxiety (Hacker et al., 2016), both of which are common among those with NF1. Among individuals with chronic pain, research has shown that higher levels of acceptance result in a greater quality of life (Dahl, 2009). Individuals with NF1 often report chronic painful physical symptoms. Extrapolating from these findings to the NF1 population, increased level of acceptance would benefit this population.

There are different approaches clinicians can take to address level of acceptance. The most common treatment modality is acceptance and commitment therapy and acceptance has been addressed implicitly and explicitly in cognitive therapy nearly from its inception (Beck, 1976, 1979). However, ACT elevates acceptance to primary importance and the focus of treatment, in contrast to standard CBT, in which acceptance has always been an integral element (e.g., Beck, 1979). There are various processes within the ACT model in order to establish psychological flexibility: experiential acceptance, cognitive diffusion, contact with the now, self-as-context, values, and committed action (Hayes et al., 2013). Many have posited that ACT has utility in the context of long-term conditions (Angiola & Bowen, 2013; Graham, Simmons, Stuart, &

Rose, 2015; Hadlandsmyth, White, Nesin, & Greco, 2013; Whittingham, 2014). For example, negative illness-related beliefs and distress may be realistic in certain conditions at certain times. Therefore, ACTs focus on investigating valued behaviors while accepting such thoughts and feelings may be more effective than attempts to alter these distressing but accurate cognitions (Graham et al., 2015; Low et al., 2012).

Some researchers have suggested that nonadherence to HIV medication or poor diabetes self-management is related to avoidance of disease-related thoughts and feelings, such as fear or shame (Hadlandsmyth et al., 2013; Moitra, Herbert, & Forman, 2011). ACTs focus on encouraging acceptance in the service of meaningful and, in this case, salubrious behavior may be particularly useful for disease self-management or adherence to medical recommendations (Graham et al., 2016). There is increasing evidence that ACT techniques are widely implemented by health professionals treating long-term conditions (Thewes et al., 2014). Some of these conditions include cancer, epilepsy, pediatric illness, cardiac disease, multiple sclerosis, and diabetes, and the range of conditions and applications demonstrates the flexibility of the ACT model (Graham et al., 2016).

Mindfulness-based stress reduction (MBSR) is another treatment for psychological distress, depressive symptoms, and anxiety for people with chronic disease that is rapidly growing in popularity in the United States. MBSR was developed by Kabat-Zinn in 1979 and was traditionally used for chronic pain (Kabat-Zinn, 1990). It is considered an ACT intervention that involves mindfulness meditation. Mindfulness is most typically defined as “paying attention in a particular way: on purpose, in the present moment, and non-judgmentally” (Kabat-Zinn, 1994, p.4). Mindfulness includes at least

three components: attentional control, the intention of attentional control (e.g., to decenter from negative thinking), and attitudes that are being trained (e.g., approach orientation and nonjudgment); (Alsubaie et al., 2017). MBSR has now been applied in people with chronic diseases such as cancer, fibromyalgia, and heart failure; it has positive effects on pain, anxiety and stress in people with chronic disorders such as fibromyalgia, coronary artery disease, back pain, and arthritis (Bohlmeijer, Prenger, Taal, & Cuijpers, 2010; Grossman, Niemann, Schmidt, & Walach, 2004; Rosenzweig et al., 2010). In recent systematic reviews examining MBSR interventions among people with physical and/or psychological conditions, researchers reported MBSR as a promising approach to cope with symptoms related to chronic illness; however, future research is warranted (Ahola Kohut, Stinson, Davies-Chalmers, Ruskin, & van Wyk, 2017; Alsubaie et al., 2017). To date, there are no studies examining MBSR with the NF population. However, the literature suggests that the intervention may play a role in reducing physical pain and comorbid anxiety related to the disorder.

Results of this study demonstrated an association between frequency of cognitive distortions and acceptance, supporting the notion that targeting cognitive distortions within the NF1 population may increase level of acceptance. Cognitive therapy is an effective treatment in modifying maladaptive beliefs and ameliorating cognitive distortions. If the frequency of cognitive distortions predicts level of acceptance, clinicians can aim to reduce distortions and ultimately improve their level of acceptance. Characteristics of CBT suit this population, as it is a short-term treatment that has demonstrated efficacy for a wide range of psychiatric and medical problems and health-related behaviors (Beck, 1995; Marcinko, 2003; Senecal, Nouwen, & White, 2000). CBT

aims to identify, evaluate, and respond to dysfunctional thoughts and beliefs (i.e. cognitive distortions) and modify maladaptive behavior and emotion (Beck, 1995).

CBT can address the underlying cognitive distortions in NF1 patients and has been adapted specifically for individuals with ADHD. Approximately 10% of study participants had a diagnosis of ADHD, and previous research shows that up to 60% of NF1 patients report a diagnosis of Learning Disability (LD) or ADHD (Tonsgard, 2006). Adults with ADHD may have greater difficulty using cognitive modification strategies and are likely to have had numerous disappointments in their life, contributing to their maladaptive belief systems (Ramsay, 2017).

Based on an understanding that adults with ADHD struggle with performance of desired actions (and not with a lack of knowledge), current manualized treatments of CBT for ADHD emphasize the consistent implementation of the coping strategies necessary to manage the effects of ADHD (Ramsay, 2017). Cognitive interventions help target the escape-avoidance coping style seen in ADHD and help promote engagement in tasks and follow-through on therapeutic coping strategies that would be helpful for the NF1 population (Ramsay, 2017). Because CBT has been and can be adapted for individuals with various cognitive limitations and directly targets cognitive distortions, CBT is a prime candidate for successful treatment of the NF1 population.

It is hoped that if clinicians can successfully target cognitive distortions, there will be an increase in acceptance among the NF1 population. Additionally, clinicians can use ACT interventions such as mindfulness to increase psychological flexibility, or acceptance. In turn, individuals with NF1 would experience fewer symptoms of pain, depression, and anxiety and would report a better quality of life.

Cognitive distortions, disease visibility, and perceived stigmatization. The current study found that together, cognitive distortions and self-rating of disease visibility were associated with perceived stigmatization. When examined independently, both the frequency of cognitive distortions and rating of disease visibility were associated with or predicted perceived stigmatization. This means that those who viewed their NF1 as more visible perceived more social stigmatization and engaged in more cognitive distortions. Consequently, if it is hoped that if the frequency of cognitive distortions predicts perceived stigmatization, clinicians directly treat cognitive distortions with CBT and thereby reduce perception of stigmatization and the attendant dysphoria. Although results found that perceived stigmatization did not significantly predict acceptance, cognitive distortions were associated with both acceptance and perceived stigmatization, making the cognitive distortions a prime target to increase acceptance and perceived stigmatization.

Although addressing cognitive distortions will help to reduce levels of perceived stigmatization among those with NF1, it is also important to consider interventions to help patients with NF1 cope with stigmatizing behaviors. A meta-analysis of stigma studies conducted in 2009 reported that active and problem-focused coping approaches may be more effective than passive or emotion-focused coping approaches addressing perceived health stigmatization (Pascoe & Richman, 2009). This review also reported that social support, engagement with an identity group (in this case, peers with NF1), and development of an active coping style can reduce the impact of stigma on stress, which ultimately reduces negative mental and physical well-being. Various studies have been conducted to determine if interventions reduce self-stigma. These studies have found that

psychosocial education (to replace stigmatized views about mental illness and recovery) in combination with CBT (teaching skills to challenge negative beliefs about the self) are effective in reducing self-stigmatization by persons with mental illnesses, HIV, and internalized weight stigma (Heijnders & Van der Meij, 2006; Mittal, Sullivan, Chekuri, Allee, & Corrigan, 2012; Pearl et al., 2016). It is hoped that NF1 patients can reduce negative social interactions and increase positive interactions through social skills training, cognitive and behavior therapies, support groups, and improving relationships with family, friends, and providers (Mouradian, 2001). Rumsey and Harcourt (2007) recommended that physicians use screening tools to routinely assess whether patients have experienced discrimination in order to make necessary therapeutic referrals.

Results of the present study showed that the majority of participants, 52%, rated their disease visibility as moderate (some tumors on neck, face hands; mild scoliosis or other skeletal features without noticeable limp). The remaining participants rated their disease visibility as mild (31%; no visible tumors with normal gait and posture) or severe (16%; numerous tumors on the face, optic glioma that has affected sight and eye socket, and severe skeletal features with noticeable limp). Research shows that patients with greater concern about the visibility of their disease are at higher risk of developing low self-esteem, self-rejecting cognitions, problems in interpersonal relationships, and negative body image (Rumsey & Harcourt, 2004). Considering the proportion of participants that rated their visibility as moderate, we can infer the presence of subsequent concerns such as low self-esteem and negative body image. Clinicians can utilize ACT to increase acceptance of body image, which focuses on body image flexibility. Body image flexibility is the ability to openly experience body image

dissatisfaction and related experiences in a way that promotes adaptive life functioning and values-consistent behavior (Sandoz et al., 2013). Specifically, body image flexibility involves openly engaging painful or unwanted thoughts and emotions regarding one's body size, shape, or weight with mindful acceptance (Sandoz et al., 2013). The treatment goal is to focus on the relationship with the body image-related cognitions and emotions rather than change them, thereby reducing the emotional toll (Lee et al., 2017).

Age at diagnosis and acceptance. Results of this study indicated that there is no significant relationship between the age at first NF1 diagnosis and level of acceptance. This implies that living with the condition for a longer period, alone, does not inherently foster increased acceptance. With this in mind, clinicians can likely implement the aforementioned interventions with NF1 patients regardless of either their age at onset or current age. Emerging research on ACT in the treatment of children is encouraging for the utility of this therapeutic approach (Swain, Hancock, Dixon, & Bowman, 2015). A pilot study examining the use of ACT with youth with NF1 and chronic pain demonstrated that small group ACT workshops seem to be a feasible and effective intervention (Martin et al., 2016). In regards to CBT, results from a meta-analysis suggest that CBT is an efficacious treatment for anxiety and depression among children (Crowe & McKay, 2017), although a literature review revealed no such studies specific to NF1.

Taken together, findings from this study highlight the relationship between cognitive distortions and acceptance among this population, with approximately 70 percent of the variance in acceptance attributable to cognitive distortions. This is evidence for the overlap in treatment models, or more accurately, a false dichotomy

between ACT and Beckian CBT. These findings support the importance of being able to utilize a variety of interventions to best suit individual patients. Both ACT and so-called second wave CBT stress the importance of cognitions in the role of psychopathology, although they differ in the degree of emphasis on, and their approach to cognitions (Herbert & Forman, 2013). Not only can clinicians choose interventions that specifically target cognitive distortions, but they can choose brief cognitive interventions that suit the cognitive limitations of this population. Results also stress the importance of acceptance among individuals with NF1 and how to best implement interventions to serve this population.

It is also important to recognize how patients perceive their own physical symptoms and how this can result in the perception of stigmatization. Screening and assessing perceived stigmatization can help clinicians tailor therapeutic treatment to help patients cope with those perceptions and the painful emotional sequelae. It is hoped that findings from this study provide context and direction for how clinicians may conceptualize and work with individuals with NF1 and other related medical disorders. More specifically, it is hoped that this study provides guidance in working with disorders with visible signs that result in stigmatization and subsequent psychological impacts.

Limitations

As with any research, this study has limitations. As research has shown, those with NF1 are at increased risk of depression and anxiety. The current study did not control for the confounding variables of comorbid psychiatric concerns, which could explain the presence of cognitive distortions. Individuals with diagnosed (and undiagnosed) anxiety, depression, ADHD, LD, etc. were able to participate in this study.

Of the 48 participants, 10% reported being previously diagnosed with ADHD, 42% had been diagnosed with depression, 40% had been diagnosed with anxiety, and 23% had been diagnosed with a learning disability. Previous researchers found that up to 55% of NF1 patients scored above a 16 on the CESD scale, indicating a high likelihood of clinical depression (Cohen, 2015). Although research shows that there is no relationship between ADHD and cognitive distortions, both anxiety and depression have been previously correlated with cognitive distortions (Rosenfield, 2004; Serine, 2016).

The sample size of the current study is a major limitation and negatively impacts the external validity of the results. Although the study had over 200 participants who started the survey ($n = 202$), there was a high dropout rate during the self-reports, resulting in a smaller sample ($n = 48$). It can be hypothesized that this high rate of attrition was due to the cognitive limitations of this population. Furthermore, there was feedback from participants that questions in the survey were very personal in nature, perhaps too personal to pursue, leading to avoidance and premature termination.

Demographically, there was an unequal number of male (11) and female (37) participants in the study. Research has shown that females with NF1 report major concern with the visibility of clinical manifestations, whereas males report less concern (Hummelvoll & Antonsen, 2013). This could greatly impact levels of perceived stigma or rating of disease visibility.

The self-report nature of the measures is also a potential limitation. Self-report in psychological research is a popular method for collecting data. Advantages of self-report include easy interpretability, richness of information, motivation to report, causal force, and sheer practicality (Lucas & Baird, 2006). Self-reports are often communicated in a

language common to the investigator and the respondent (Paulhus & Vazire, 2007). A wealth of information can be gained via self-report, including feelings and thoughts, and there is a quantity and breadth of information that can be reported (Paulhus & Vazire, 2007). Causal force refers to the idea that self-report engages a respondent's identity (Hogan & Smither, 2001) and that self-perceptions have a strong influence on how people interact with their environment and others (Paulhus & Vazire, 2007). Lastly, self-reports are extremely practical in that they are inexpensive and efficient. They can be administered to a large group of people, and multiple variables can be assessed in one session (Paulhus & Vazire, 2007). Despite these advantages, there are clear limitations to using the self-report method to collect data. The most salient concern is the reactive nature of the method and questions about subsequent validity. There are response sets and styles that may interfere with the validity of self-reported data. Some common examples are socially desirable responding, acquiescent responding, and extreme responding (Paulhus & Vazire, 2007). Socially desirable responding may involve impression management (exaggeration, faking, lying) or self-deception (self-favoring bias, self-enhancement, defensiveness, and denial) (Paulhus & Vazire, 2007). Acquiescent responding refers to agreeing with statements without regard to their content, and some researchers believe that acquiescent responding may be related to a personality trait linked to conformity and impulsiveness (Couch & Kenniston, 1960). Lastly, extreme responding (ER) refers to the tendency to use the extreme choices on a rating scale, for example, rating all 1s or 7s on a Likert scale); (Paulhus & Vazire, 2007). A major concern with ER bias is that it may induce false correlations among variables. Specific to this study, ER bias may indicate a relationship between cognitive distortions,

stigmatization, and acceptance that is not necessarily significant. This would undermine the results and implications for treatment.

In addition to the aforementioned concerns regarding self-reports, participants in this study were required to provide accurate and, presumably, honest reports regarding their NF diagnosis along with all of the other data. Individuals may also misreport information, which could have an impact on results and findings.

Future Directions

Although it is useful to have information and knowledge that will help in guiding psychological care, this information will be useless if NF patients do not seek treatment. Researchers may want to conduct exploratory studies examining the likelihood of seeking psychological treatment in this population. It would be beneficial to determine whether psychological treatment is being utilized among this population and if these patients are open to seeking psychological treatment.

Based on the findings of this study, researchers may want to explore other treatments and interventions regarding body image and visibility of NF1. Future studies investigating specific therapeutic techniques aimed at reducing negative body image and potentially related emotional distress could be beneficial. Furthermore, the current study examined visibility as rated by the NF1 patients. Because findings show that cognitive distortions play a large role among perceptions of stigmatization in this group, it is likely that cognitive distortions play a role in their perception of visible symptoms. Future studies can compare self and other visibility ratings to determine accuracy.

In future research, because depression is previously associated with cognitive distortions, depression should be screened and statistically accounted for in order to

measure cognitive distortions specific to NF1, regardless of level of depression.

Similarly, anxiety, ADHD, and LD should also be screened and statistically accounted for when conducting analyses.

Because CBT has been and can be adapted for individuals with various cognitive limitations and directly targets cognitive distortions, CBT is a prime candidate for successful treatment within the NF1 population. To date, there are no studies that have specifically examined CBT as an intervention with his population. It is hoped that the results of this study spark interest for CBT interventions to address cognitive distortions.

In regards to stigmatization, results of this study showed that perceived stigmatization is associated with levels of acceptance. This population does experience negative social interactions due to the physical manifestations of this disorder. It is hoped that NF1 patients can increase positive interactions through social skills training, cognitive and behavior therapies, support groups, and improving relationships with family, friends, and providers (Mouradian, 2001). By improving social relationships and social interactions, patients with NF1 may experience higher levels of acceptance.

Future researchers may wish to investigate acceptance and commitment and mindfulness-based interventions with this population, as the literature suggests that these interventions may play a role in reducing physical pain and comorbid anxiety related to the disorder. Although there have been pilot studies examining the effectiveness of ACT among youth with NF1, a gap in the research remains.

Because NF1 is typically diagnosed during childhood, it would be interesting to consider how the disorder manifests in regards to various attachment styles and development. This can be studied with cross-sectional and longitudinal designs.

Attachment theory was developed by psychiatrist John Bowlby to explain the tendency of humans to form close affectionate bonds (Bowlby, 1969). Bowlby hypothesized that security of attachment derives from caregivers' reliable and sensitive provision of love and comfort, as well as food and warmth (Levy, Johnson, Clouthier, Scala, & Temes, 2015). Infants with caregivers who meet their biological and psychological needs turn to their caregivers when experiencing distress or fear (Bowlby, 1969). Ainsworth, Blehar, Waters, and Wall (1978) adapted Bowlby's conceptualization of attachment differences in a seminal study. This study identified three major attachment styles: secure, anxious-ambivalent, and avoidant. Securely attached children seek closeness to their caregiver, indicate distress at separation, and demonstrate moderate interest in a stranger. Anxious-ambivalent children exhibit heightened distress at separation, are difficult to comfort when their caregiver returns, and require constant attention from their caregiver. Avoidant children do not appear distressed by separation from caregiver, may ignore the caregiver upon return, and treat a stranger and caregiver similarly. A fourth style, disorganization, was later added by Main and Solomon (1986). This style is characterized by confused and disoriented behaviors. Attachment theory has led to extensive research in developmental, personality, and clinical psychology; however, it is rarely explored within the medical field (Schmidt, Nachtigall, Wuethrich-Martone, & Strauss, 2002). There are two reasons why attachment theory would be suitable to apply as a theory of coping within a medical context. First, attachment theory is able to predict the vulnerability or resilience to stressful life events (Bowlby, 1988). More specifically, attachment theory may predict why some individuals can shift from one strategy to another, whereas others hold on to rigid methods of coping (Grossmann et al., 1989).

Secondly, Bowlby believed that the attachment behavioral system is activated in times of stress and disease (Bowlby, 1988). Despite these points, the relationship among attachment, affect regulation, and coping has rarely been investigated within the context of coping with chronic disease. In a study of individuals with breast cancer, chronic leg ulcers, and diffuse and androgenetic alopecia, researchers found a significant relationship between attachment styles and coping strategies. Specifically, ambivalently attached individuals showed high elevations on all of the three coping dimensions of diverting, negative emotional, and seeking attention and care, whereas avoidant attached individuals showed low scores on all coping dimensions (Schmidt et al., 2002).

Consequently, it may be warranted to explore attachment theory in NF1.

Researchers may also wish to examine attachment styles longitudinally, comparing young children with NF1 to subsequent adult attachment style as they enter romantic and committed relationships, e.g., attachment style as it relates to physical symptoms and intimacy.

Lastly, as this study had an unequal number of male and female participants, future researchers may wish to consider gender differences in cognitive distortions, perceived stigmatization, and acceptance in this population.

Summary and Conclusions

This study examined the relationship between cognitive distortions, perceived stigmatization, and acceptance in NF1. Results demonstrated that together, the frequency of cognitive distortions and level of perceived stigmatization are predictive of acceptance. Additionally, the frequency of cognitive distortions and rating of disease visibility was predictive of perceived stigmatization. These findings suggest that cognitive distortions

play a significant role in this population regarding their perceptions and internal experiences of the disorder. It is hoped that if clinicians successfully target cognitive distortions, there will be an increase in acceptance among the NF1 population.

Additionally, clinicians can use ACT interventions such as mindfulness to increase psychological flexibility or acceptance. Individuals with NF1 will then experience fewer symptoms of pain, depression, and anxiety and report a higher quality of life.

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Appendix A

Screening Questionnaire

Please respond Yes or No to the following questions:

1. Are you between the ages of 18-65?
2. Do you have an 8th grade education or higher?
3. Have you ever been diagnosed with an intellectual disability?
4. Have you ever been diagnosed with NF1?
5. Are you currently experiencing 2 or more of the following symptoms:
 - a. Dark flat spots on your skin that doctors call café au lait spots.
 - b. Nerve tumors that appear as purplish depressions in the skin or sores that stick out from the skin that doctors call neurofibromas, or any type of plexiform neurofibroma.
 - c. Bone abnormalities that could include absence of bone around the eye, bone development that is not normal, bone tumors that are not cancer, or scoliosis.
 - d. Someone else in your family was diagnosed with NF1, such as parent, grandparents, brother, sisters, etc.
 - e. Reddish brown spots in the colored part of your eye that doctors call Lisch Nodules.
 - f. Freckling in armpit or groin region.
 - g. Tumors on the visual pathway causing thickening of optic nerve that doctors call Optic Pathway Glioma.

6. In the past month, have you seen or heard things that other people have not seen or heard?

Appendix B

Brief Demographic Questionnaire

Please read and answer the following questions:

1. How old are you?
2. At what age were you diagnosed with NF1?
3. What is your gender?
 - a. Male
 - b. Female
 - c. Other
4. Which of the following best represents your ethnicity?
 - a. American Indian or Alaska Native
 - b. Asian
 - c. Black or African American
 - d. Hispanic or Latino
 - e. Native Hawaiian or Other Pacific Islander
 - f. White
 - g. Mixed race
 - h. Other
5. What country do you live in?
6. Do you have any of the following:
 - a. Psoriasis
 - b. Congenital abnormalities
 - c. Acne Vulgaris
 - d. Skeletal Dysplasia
 - e. HIV/AIDS
 - f. NF1
7. If you have any of these physical conditions, above which do you find to be the most distressing?
 - a. Psoriasis
 - b. Congenital abnormalities
 - c. Acne Vulgaris
 - d. Skeletal Dysplasia
 - e. HIV/AIDS
 - f. NF1
8. Please check conditions for which you have ever been diagnosed
 - a. ADHD

- b. Depression
 - c. Anxiety
 - d. Learning Disability
 - e. None of the Above
9. Please check problems which you are currently getting mental health treatment for
- a. ADHD
 - b. Depression
 - c. Anxiety
 - d. Learning Disability
 - e. None of the Above