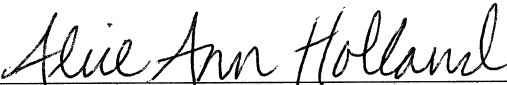ADHD AND MEDICAL CORRELATES OF BULLYING OF PEDIATRIC

NEUROFIBROMATOSIS PATIENTS

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DEDICATION

I would like to thank the members of my Graduate Committee for their time and participation in

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ADHD AND MEDICAL CORRELATES OF BULLYING OF PEDIATRIC

NEUROFIBROMATOSIS PATIENTS

by

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THESIS

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Abstract

Neurofibromatosis Type 1 (NF1) is an autosomal dominant disorder that involves nervous system tumor growth, and it is one of the most frequently occurring genetic disorders. NF1 is a multisystem disease with a complex phenotype. Given the range in severity of presentation in NF1, research has shown that disease severity could impact children's social-emotional functioning. Physical deformities such as tumor growth often are associated with NF1, and as a result, children and adolescents with NF1 may be at greater risk for being victims of bullying by peers. Children with NF1 also tend to have higher rates of Attention-Deficit/Hyperactivity Disorder (ADHD) as compared to children without NF1 (Barton & North, 2004; Martin et al., 2012). Common issues experienced by children with ADHD, such as social immaturity and behavioral dysregulation, may put them at higher risk for both bullying and peer victimization (Wiener & Mak, 2009; Unnever & Cornell, 2003). Overall, the current study found that parent-reported ADHD symptoms predicted parent-reported but not self-reported bullying. Furthermore, the current study found that parent-reported ADHD symptoms were more predictive of being bullied than provider-rated severity of physical deformity. Since the present study was the first to examine whether physical appearance and ADHD symptoms may be associated with bullying in children with NF1, the novel information gained from the study may be used to direct future research, educate parents and teachers, and inform the development of interventions specific to the NF1 population.

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CHAPTER ONE

Introduction

Children with Neurofibromatosis Type 1 (NF1) tend to experience more problems with social skills, anxiety, depression, aggressive behavior, and symptoms of Attention-Deficit/Hyperactivity Disorder (ADHD) as compared to children without NF1 (Barton & North, 2004; Martin et al., 2012). NF1 is an autosomal dominant disorder that involves nervous system tumor growth, and it is one of the most frequently occurring genetic disorders. NF1 is considered to be a multisystem disease with a complex phenotype. Due to the multifunctional properties of the affected gene (17q.11.2), NF1 can manifest in a variety of ways, and symptom presentation may vary among individuals affected. The protein product of the NF1 gene is neurofibromin, which is expressed in all cells; however, its expression level is highest in neurons, Schwann cells, glial cells, and leukocytes (Abramowicz & Gos, 2014). Neurofibromin is considered to be a multifunctional protein; it is involved in the regulation of many cellular signaling pathways related to cell growth and proliferation. Abnormal activation of these pathways not only contributes to neoplastic transformation (conversion of a tissue with a normal growth pattern into an abnormal growth pattern), but can also cause a wide spectrum of clinical symptoms, as seen in NF1. Clinical presentation of NF1 can range from a few benign physical symptoms to fatal tumors. Physical deformities such as visible tumor growth often are associated with NF1, and as a result, children and adolescents with NF1 may be at greater risk for being victims of bullying by peers.

Bullying can be defined as a form of aggressive behavior that is intentional, repetitive, and causing harm or distress to someone else (Olweus, 1994). Since most bullying occurs without apparent provocation on the part of the targeted child or youth, it is usually considered to

be a form of proactive aggression (Olweus, 2013). The three main components of bullying are

defined as intentionality, an imbalance of power, and repetition (Olweus, 2013). Use of these

three components for classification of what can be called traditional or conventional bullying

(e.g., kicking, teasing, hitting) has been well accepted among both researchers and practitioners

for a substantial number of years (Smith & Brain, 2000; Smith et al., 2012). Traditional bullying

includes spoken words, physical contact, gestures, or purposeful exclusion from a group

(Olweus, 1993). Bullying becomes a significant problem when it continues over a period of time.

Chronic bullying, also known as peer victimization, is a form of bullying in which a single child

is repeatedly the target of aggressive behavior. Because bullying involves a bully and a victim,

early research tended to separate children into one of these two mutually exclusive groups.

However, research now has identified a third group, known as bully-victims, who both bully and

are bullied by others (Hayne et al., 2001; Veenstra et al., 2005).

Non-traditional types of bullying, such as cyberbullying, which can be defined as a

particularly damaging form of psychological aggression (Cross et al., 2015), occurs when an

individual or group uses information and communication technology to intentionally and

repeatedly negatively impact a person who finds it hard to stop this bullying from continuing

(Smith et al., 2008). Cyberbullying has become a growing concern in recent years, with 95% of

12–17 year olds reporting utilization of the Internet (Lenhart et al., 2011). Cyberbullying appears

to be on the rise among both children and adolescents due in part to increased access to

electronic devices and less online supervision (Waasdorp & Bradshaw, 2015).

Numerous prior studies have shown that children and adolescents who display physical

deformities are more likely to be victims of bullying (Horowitz et al., 2004; Janssen et al., 2004;

Swearer & Carey, 2003; Smith et al., 2012; Sweeting & West, 2001). In addition, studies have

shown that children with NF1 are more likely to present with ADHD (Hyman et al., 2005), which could place them at greater risk for being victims of bullying (Carter & Spencer, 2006; Cummings et al., 2006; Maiano et al., 2016; Mishna, 2003; Rose et al., 2010; Shea & Wiener, 2003). Furthermore, children with NF1 tend to have fewer reciprocated friendships and tend to be less well liked than healthy peers, and more severe neurological symptoms in children with NF1 have been associated with reduced social popularity (Noll et al., 2007; Page et al., 2009; Reichel & Schanz, 2003; Wolkenstein et al., 2009). This raises the question as to whether children who have medical conditions that affect physical appearance are more at risk for being bullied than physically healthy children. However, no research has previously examined the relationships between physical appearance, ADHD, and bullying experiences in children diagnosed with NF1. The present study was designed to address that gap in the literature.

Firstly, the current study will compare self-reported rates of bullying to parent-reported rates of bullying in a sample of children and adolescents diagnosed with NF1. Based on existing literature indicating discrepancies between self-reported and parent-reported bullying (Achenback et al., 1987; Holt et al., 2008; Waters et al., 2003), it is hypothesized that self-reported rates of bullying will be higher than parent-reported rates of bullying in a sample of children diagnosed with NF1.

Secondly, the current study will also examine the contributions of physical deformity and parent-reported ADHD symptoms on self-reported and parent-reported rates of bullying in a sample of children and adolescents diagnosed with NF1. Based on existing literature indicating a positive correlation between bullying (Shakoor et al., 2011; Upton et al., 2008) and ADHD symptoms (Shea & Wiener, 2003; Wiener & Mak, 2009) or severity of physical deformity (Horowitz et al., 2004; Janssen et al., 2004; Sweeting & West, 2001), it is hypothesized that

parent-reported ADHD symptoms and provider-rated severity of physical deformity (i.e., café-au-lait spots, neurofibromas, spine/scoliosis deformity) will positively predict parent-reported bullying in a sample of children and adolescents diagnosed with NF1. Based on existing literature indicating a positive correlation between bullying (Taylor et al., 2010; Twyman et al., 2010) and ADHD symptoms (Shea & Wiener, 2003; Wiener & Mak, 2009) or severity of physical deformity (Horowitz et al., 2004; Janssen et al., 2004; Sweeting & West, 2001), it is also hypothesized that parent-reported ADHD symptoms and provider-rated severity of physical deformity (i.e., café-au-lait spots, neurofibromas, spine/scoliosis deformity) will positively predict self-reported bullying in a sample of children and adolescents diagnosed with NF1.

Lastly, the current study will determine whether parent-reported ADHD symptoms or provider-rated severity of physical deformity will be more predictive of self-reported and parent-reported bullying in a sample of children and adolescents diagnosed with NF1. Since physical deformity becomes more severe with age whereas ADHD symptoms typically manifest in early childhood, and based on existing literature indicating a positive correlation between ADHD symptoms and bullying (Taylor et al., 2010; Twyman et al., 2010; Wiener & Mak, 2009), it is hypothesized that parent-reported ADHD symptoms will be more predictive of parent-reported bullying than provider-rated severity of physical deformity in a sample of children and adolescents diagnosed with NF1. Similarly, it is also hypothesized that parent-reported ADHD symptoms will be more predictive of self-reported bullying than provider-rated severity of physical deformity in a sample of children and adolescents diagnosed with NF1.

CHAPTER TWO

Review of the Literature

Neurofibromatosis

NF1 is one of the most frequently occurring genetic disorders, affecting approximately 1 out of every 3,000 to 4,000 live births (Hart, 2005). NF1 presentation can range from a few benign physical symptoms to fatal tumors. Neurofibromatosis 1 and 2 were once collectively referred to as von Recklinghausen's disease; however, it is now understood that they are two distinct genetic disorders affecting separate chromosomes (Hart, 2005). Neurofibromatosis type 2 (NF2) is a similar disorder involving nervous system tumor growth; however, it is rarer than NF1 (1 out of every 37,000 live births) and is hallmarked by the occurrence of bilateral schwannomas, which are peripheral nerve-sheath tumors (Batista et al., 2015). NF2 is caused by a gene defect on chromosome 22, whereas the gene locus for NF1 is on chromosome 17.

NF1 is an autosomal dominant disorder caused by the presence of mutation in the NF1 gene located on chromosome 17 (17q.11.2), and similar to NF2, also involves tumor growth (Abramowicz & Gos, 2014). The NF1 gene was identified with positional cloning, formerly known as reverse genetics, in 1990 by Wallace and colleagues (Wallace et al., 1990). The NF1 gene has been identified as one of the largest genes in the human genome, encompassing approximately 280kbp (kilo-base pair) of genomic DNA (Abramowicz & Gos, 2014). However, the large size of the NF1 gene does not fully explain the high rate of new mutation formation. Since mutations identified to date are randomly distributed within the gene, and not localized in "hot spot" regions more prone to mutation occurrence, the size of the NF1 gene does not play a role in the high rate of mutation (Abramowicz & Gos, 2014).

Approximately 50% of mutations found in patients with a clinical diagnosis of NF1 are *de novo* ones, and therefore not inherited from a parent. Furthermore, identified mutations not only have complete penetrance, but also have a pleiotropic effect (Abramowicz & Gos, 2014). A pleiotropic effect occurs when one gene influences two or more seemingly unrelated, observable traits. As a result, patients within the same family (e.g., parents, siblings), with the same mutation may present with extremely distinct clinical signs of NF1. This finding suggests the significant role of modifier genes or epigenetic factors that are partly responsible for the variability of NF1 phenotypic expression (Ferner, 2007). Furthermore, rates of spontaneous mutation are higher in the NF1 gene than any other human gene (Hart, 2005).

Neurofibromin.

The protein product of the NF1 gene is neurofibromin, which is expressed in all cells; however, its expression level is highest in neurons, Schwann cells, glial cells, and leukocytes (Abramowicz & Gos, 2014). Neurofibromin is considered to be a multifunctional protein; it is involved in the regulation of many cellular signaling pathways related to cell growth and proliferation, particularly the RAS/MAPK pathway. The RAS/MAPK pathway is one of the major cellular signaling pathways that mediates cell growth and proliferation, both of which are stimulated by growth factor. Proper activity of this pathway is also essential for cell differentiation during organism development (Gos et al., 2012). Since neurofibromin acts by modulating the activity of the RAS-family proteins, NF1 is associated with improper functioning of the RAS/MAPK signal transduction pathway. Abnormal activation of the RAS/MAPK pathway not only contributes to neoplastic transformation, but can also cause a wide spectrum of clinical symptoms, such as pigmentation disturbances, cardiovascular defects, and changes in the skeletal and nervous system (Abramowicz & Gos, 2014).

Neurofibromin expression is regulated at the level of transcription and translation. This can result in rapid change of mRNA (messenger ribonucleic acid) and protein level, potentially modifying the clinical expression of NF1 (Abramowicz & Gos, 2014). Research has shown changes in DNA sequence are responsible for approximately 90% of NF1 cases. The remaining 10% of cases are associated with the presence of a NF1 single exon deletion or large deletions on chromosome 17q.11.2 encompassing the entire NF1 gene (Abramowicz & Gos, 2014). Furthermore, the analysis of mutation inheritance has revealed that point mutations often occur on the allele of the paternal origin (>80%), while microdeletions are more common on the maternal allele (Abramowicz & Gos, 2014; Upadhyaya et al., 1998). Mutations within the NF1 gene result in loss of function in the neurofibromin protein, which results in increased production and proliferation of tumors and the expression of clinical symptoms (Basu et al., 1992).

Diagnostic criteria.

NF1 is progressive in nature; therefore, affected individuals may or may not show symptoms of the disorder at birth. Some signs and symptoms can be present at birth and others begin to gradually appear in the first few years of life, with most NF1 patients showing manifestations by 8 years of age. Later discovery of NF1 is a greater possibility in cases of spontaneous mutation, where family history is not accountable.

Because of the multifunctional properties of neurofibromin, NF1 can manifest in a number of ways and symptom presentation may vary among affected individuals. To receive a diagnosis of NF1, an individual must meet two or more of the following criteria: café au lait macules, axillary or inguinal area freckling, lisch nodules, optic gliomas, neurofibromas, enlarged or deformed bone, severe scoliosis, and/or have a first degree relative with NF1 (Hart, 2005).

Café au lait macules are benign, lightly colored birthmarks that typically appear at birth and can continue growing in size with age. Café au lait spots are frequently the first manifestation of NF1. The size and prevalence of café-au-lait macules can vary greatly between affected persons. However, the number of café au lait spots do not correlate with the number or locations of future NF1 tumors (Hart, 2005; Korf, 2002). To meet the criteria for the specific symptom of café au lait macules, an individual must have 6 or more café au lait macules that are more than 5 mm in greatest diameter before puberty, or 15 mm after puberty.

Axillary and inguinal area freckling refers to clusters of melanin in the armpit and groin regions and is considered another hyperpigmentation sign of NF1. Characteristic freckling usually develops by 7 years of age and is often the second sign of NF1 to be discovered after café au lait macules because it is visibly obvious. Individuals presenting with café au lait macules or freckling warrant the need for a thorough screening for other diagnostic manifestations, in addition to an ophthalmology referral to examine for Lisch nodules or optic gliomas.

Lisch nodules are a clinical manifestation of NF1 and although they are useful in the diagnosis of the disorder, they may not always be present in individuals with NF1. Lisch nodules consist of areas of hyperpigmentation on the iris that can typically be identified by 6 years of age through a slit lamp examination (Hart, 2005; Korf, 2002). Lisch nodules do not affect vision (Hart 2005).

Conversely, optic gliomas are primary tumors of the central nervous system that can lead to vision loss. Optic gliomas are slow growing, benign tumors that affect the optic nerve. They are the second most common form of tumor, second to neurofibromas, in individuals with NF1 and are seen in approximately 15% of children with NF1 (Gutmann & Gutmann, 2010).

Individuals who present with symptoms such as proptosis (protrusion of the eyeball), developmental delays, signs of increased intracranial pressure, and/or endocrine disturbances should be evaluated for optic gliomas. Because of the severe morbidity associated with optic gliomas, early identification is imperative (Hart, 2005; Korf, 2002).

Neurofibromas are benign nerve sheath tumors that consist primarily of Schwann cells, fibroblasts, and axons. Individuals with NF1 develop peripheral and plexiform neurofibromas. Peripheral neurofibromas are well-defined cutaneous and subcutaneous tumors that have the ability to develop along any nerve sheath in the body. These tumors usually begin to appear in late childhood and proliferate during periods of accelerated growth and during pregnancy (Hart, 2005; Korf, 2002). Peripheral neurofibromas can continue to increase in size and number throughout an individual's lifespan. Although neurofibromas can be removed if they are disfiguring or bothersome, the underlying problem, a lack of neurofibromin, still exists; therefore new tumors may replace the ones removed.

Plexiform tumors are invasive subcutaneous tumors that can be self-limiting or grow to be very large, disfiguring tumors. Tumors that grow very large can lead to organ dysfunction, interfere with soft tissue and bone growth, or promote malignant transformation (Hart, 2005). Plexiform tumors can be congenital; therefore, they may not be easily identified at birth or during early childhood because they look like raised areas of hyperpigmentation. Plexiform tumors can also be nodular with satellite lesions, which are lesions surrounding the tumor (Hart, 2005; Korf, 2002). Because of their potential to cause disfigurement and disability, plexiform tumors are considered to be one of the most difficult physiological and psychological manifestations of NF1 (Hart, 2005). These tumors often are difficult to remove because they

extend through multiple layers of tissue and removal may result in damage to healthy tissues and organs (Hart, 2005).

When benign tumors become malignant, they are referred to as malignant peripheral nerve sheath tumors (MPNST), also known as neurofibrosarcomas. Plexiform and nodular plexiform tumors are more likely to become malignant than other NF1 tumors. Although individuals without NF1 can develop MPNST, they are more prominent in individuals with NF1. A study conducted by Evan et al. (2002) discovered that the lifetime risk for developing MPNST may be as high as 8% to 13% in patients with NF1. Due to the metastatic nature of MPNST, they are often associated with plexiform neurofibromas, but can also occur in areas where there is no plexiform tumor.

Skeletal growth abnormalities associated with NF1 include short statute, kyphoscoliosis (deformity of the spine characterized by outward curvature of the vertebral column in two planes), macrocephaly (larger head circumference), macrodactyly (larger toes and fingers), pectus excavatum (chest wall deformity characterized by a caved in appearance of the anterior chest wall), and osseous lesions (lesions in the bones), such as thinning of the long bones (Hart, 2005; Korf, 2002). Additionally, enlargement or disfigurement of bone experienced by individuals with NF1 may include bowing of the long bones, malformation of facial bones or eye sockets, and overgrowth of limbs.

Scoliosis is one of the most common skeletal malformations associated with NF1 (Hart, 2005). Scoliosis is characterized by the curvature of the spine and may be associated with spinal tumors or dysplastic thoracic vertebrae, both of which can result in spinal cord damage (Korf, 2002). Therefore, scoliosis should be monitored during annual exams, especially during periods of rapid growth in children and adolescents.

NF1 is a complicated disorder with many life-threatening complications occurring in childhood and progressing through adulthood. In adulthood, individuals with NF1 continue to struggle with increased risk for morbidities such as cancer, while simultaneously battling disfigurement from tumors and bone malformations. Individuals with more severe expression of the disorder have decreased life expectancy of approximately 15 years (Hart, 2005). Additionally, there are a number of symptoms that are often associated with NF1 that do not necessarily need to be present for a diagnosis of NF1 to be made. These symptoms include neurocognitive deficits, specific learning disabilities, Attention Deficit Hyperactivity Disorder (ADHD), epilepsy, and various social and emotional difficulties.

Associated symptoms.

Cognitive dysfunction.

Hyman, Shores, and North (2005) performed extensive cognitive assessments in areas of general intellectual functioning, academic achievement, attention, executive functioning, memory, receptive and expressive language, and fine motor coordination. The study included 81 children with NF1, aged 8 to 16 years, and compared their performance with 49 unaffected sibling controls. Results indicated that 81% of children with NF1 had moderate to severe impairment in one or more areas of cognitive functioning. Although 51% of children with NF1 performed poorly on tasks of reading, spelling, and mathematics, specific learning disabilities (as defined by IQ–achievement discrepancies) were present in only 20% of children. Difficulties with sustained attention were present in 63% of children with NF1, with 38% of children with NF1 fulfilling the diagnostic criteria for Attention-Deficit/Hyperactivity Disorder, also known as ADHD (Hyman et al., 2005).

The NF1 neuropsychological profile commonly is characterized by deficits in

visuospatial and visuoperceptual skills, planning and executive functioning, and sustained

attention and attentional shifting (Hyman et al., 2005; Orraca-Castillo et al., 2014). A study by

Hyman and colleagues showed that both verbal and visual memory were unaffected in NF1

children. However, memory skills in NF1 children were in general stronger than their level of

general intellectual function (Hyman et al., 2005). Therefore, although both expressive and

receptive language skills are significantly impaired in children with NF1, they appear to be

relatively better preserved than visuospatial abilities once IQ is taken into account (Hyman et al.,

2005; Orraca-Castillo et al., 2014). Overall, there is an extremely high frequency of cognitive

problems in children with NF1, making cognitive dysfunction one of the most common

complications to affect quality of life and academic achievement in children with NF1.

Specific Learning Disorder (SLD).

There is a lack of consensus in the literature regarding the frequency of general and

specific learning disabilities in children with NF1, which seems to be related to the lack of a

consensus regarding methods for diagnosing Specific Learning Disorder (SLD; Hyman et al.,

2006; Johnson et al., 2010). SLD often is diagnosed through a multimodal approach combining

clinical review of an individual's developmental, medical, educational, and family history, in

addition to performance on standardized measures of academic skill development, teacher

observations, and response to academic interventions.

According to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition

(DSM-5), current academic skills must be "substantially and quantifiably below those expected

for the individual's chronological age" (DSM-5, p. 67) on culturally and linguistically

appropriate tests of reading, writing, or mathematics (American Psychiatric Association, 2013).

According to the DSM-5, the diagnosis requires persistent difficulties in reading, writing,

arithmetic, or mathematical reasoning skills during formal years of schooling. Symptoms may

include inaccurate or slow and effortful reading, poor written expression that lacks clarity,

difficulties remembering number facts, or inaccurate mathematical reasoning. The individual's

difficulties must not be better explained by developmental, neurological, sensory (vision or

hearing), or motor disorders and must significantly interfere with academic achievement,

occupational performance, and/or activities of daily living (American Psychiatric Association,

2013). Hyman, Shores, and North (2006) examined the frequency of SLDs in NF1, using an

intellect–achievement discrepancy model for diagnosis, in addition to examining the frequency

of general learning difficulties associated with a low general intellectual ability in a sample of

children with NF1. In a cohort of 81 children with NF1, problems with academic achievement

were present in 52% of children. However, only 20% of the children with NF1 were diagnosed

with an SLD; 32% had more general learning problems associated with a low IQ (Hyman et al.,

2006). Furthermore, studies have shown that children with NF1 may show a slightly different

distribution of specific SLD presentation as compared to a healthy sample of children with

SLDs, as children with NF1 show a greater tendency to have difficulties with nonverbal abilities

rather than language abilities (Hyman et al., 2006; Johnson et al., 2010).

Attention-Deficit/Hyperactivity Disorder (ADHD).

ADHD is characterized by a pattern of behavior present in multiple settings (e.g., school

and home) that can result in performance issues in social, educational, and/or work settings. The

DSM-5 divides ADHD symptoms into two categories: (1) inattention and (2)

hyperactivity/impulsivity. The DSM-5 divides diagnosis into three presentation types: (1)

Combined presentation, (2) Predominantly inattentive presentation, and (3) Predominantly

hyperactive-impulsive presentation (American Psychiatric Association, 2013). Combined

presentation is diagnosed when at least six symptoms of inattention and six symptoms of

hyperactivity/impulsivity are met over the past six months. Predominantly inattentive

presentation is diagnosed when criteria for inattention are met but criteria for

hyperactivity/impulsivity are not met over the past six months. Predominantly

hyperactive/impulsive presentation is diagnosed when criteria for hyperactivity/impulsivity are

met but criteria for inattention are not met in over the past six months. According to the DSM-5,

several symptoms must be present prior to age 12 years in order to meet criteria for ADHD.

Symptoms can include behaviors such as failure to pay close attention to details, difficulty

organizing tasks and activities, excessive talking, fidgeting, or an inability to remain seated in

appropriate situations. Older adolescents and adults (over the age of 17 years) must present with

five symptoms (American Psychiatric Association, 2013).

Hyman, Shores, and North (2006) found that of their sample of patients with NF1, 38%

(31 out of 81) satisfied the Diagnostic and Statistical Manual of Mental Disorders, Fourth

Edition (DSM-IV) diagnostic criteria for ADHD, compared to 12.2% (6 out of 49) healthy,

sibling comparison children. Out of the 31 patients with NF1 and ADHD, 1.7% of the sample

had a hyperactive presentation, 12.3% met criteria for the predominately inattentive presentation,

and 24.7% demonstrated a combined presentation for both hyperactivity and inattention.

Although studies have shown that males are more likely than females to be diagnosed with

ADHD in the general population, Hyman and colleagues (2006) found that when comparing a

pediatric NF1 sample to non-affected siblings, females were equally as likely to have ADHD as

males. Furthermore, when the comorbidity of ADHD and SLD was assessed, 7 out of 10 children

with NF1 and poor performance on academic achievement tests (reading, spelling, and

mathematics) also met criteria for ADHD (Hyman et al., 2006). Children with NF1 may be more

likely to be diagnosed with ADHD than healthy children; however, to date, no research has

investigated the correlation between bullying and ADHD in children with NF1.

Seizures.

As with ADHD and SLD, seizures are more common in individuals with NF1 as

compared to rates of seizures in the general population. Studies have shown that among

individuals with NF1, 9.5% have a history of at least one unprovoked seizure, occurring in the

absence of precipitating factors, and 6.5% have documented epilepsy (Ostendorf et al., 2013).

Research has also shown that NF1 individuals with a history of seizures are more likely to have

inherited NF1 from their mother (Ostendorf et al., 2013). Focal seizures are the most common

type of seizures in the NF1 population, occurring in up to 57% of those individuals, although

generalized seizures (affecting both cerebral hemispheres), specific electroclinical syndromes (a

group of clinical entities showing a cluster of electroclinical characteristics), and the presence of

multiple seizure types have also been noted in patients with NF1 (Ostendorf et al., 2013;

Vivarelli et al., 2003).

Bullying

Definition.

Due to the physical deformities that can be caused by Neurofibromatosis, children and

adolescents with NF1 may be more at-risk for being bullied by peers. Bullying can be defined as

a form of aggressive behavior that is intentional, repetitive, and causing harm, or distress to

someone else (Olweus, 1994). Bullying implies a relational power imbalance where a bully acts

negatively toward a victim who can hardly defend himself or herself (Olweus, 1994; Solberg et

al., 2007). Bullying differs from aggression, conflict, and violence in its repetitive nature, or the

high likelihood that it will be repeated, and the asymmetric power relationship involved between

at least two persons (Gladden et al., 2014; Juvonen & Graham, 2014; Maiano et al., 2016). The three main components of bullying are defined as intentionality, an imbalance of power, and repetition (Olweus, 2013). Use of these three components for classification of what can be called traditional or conventional bullying (e.g., kicking, teasing, hitting) seems to have been well accepted among both researchers and practitioners for a substantial number of years (Smith & Brain 2000, Smith et al. 2012).

Typically, bullying is classified as physical, verbal, or relational. Physical forms of bullying include hitting, pushing, kicking, and hair pulling. Verbal forms include name calling, teasing, laughing at, and ridiculing the victim. Relational bullying consists of exclusion or social isolation (e.g., barring from a group, leaving out, or shunning), lying, spreading rumors, or manipulating relationships (Juvonen & Graham, 2014; Olweus, 2013). Because bullying involves a bully and a victim, early research tended to separate children into one of these two mutually exclusive groups. However, research now has identified a third group, known as bully-victims, who are at the highest risk of both bullying and being bullied by others (Hayne et al., 2001; Veenstra et al., 2005). Bullying becomes a significant problem when it occurs more than once and continues over a period of time. Chronic bullying, also known as peer victimization, is a form of bullying in which a single child is repeatedly the target of aggressive behavior (Gladden et al., 2014; Maiano et al., 2016).

Risk factors.

Children who are chronically victimized by peers or who chronically bully others are at risk for serious adjustment problems, more so than children who are bullied or bully others once or twice (Cook et al., 2009; Ladd et al., 1997; Sourander et al., 2006). Studies have shown that risk factors for children to be bullied include a range of demographics, psychosocial factors, and

physical appearance. A study by Jansen and colleagues (2012) aimed to examine socioeconomic disparities in bullying and victimization among young elementary school children in the Netherlands. The study found that children from socioeconomically disadvantaged families have a higher risk for being bullied than children from higher socioeconomic backgrounds. Furthermore, Jansen and colleagues (2012) found that single parenthood, low educational level of parents, and young parental age were independently associated with the risk of children being bullies or bully-victims; however, only low maternal and paternal education was associated with an increased risk of victimization.

Although bullying is more common among elementary school students than middle school and high school students (Dake, Price & Telljohann, 2003; Glew et al., 2005), studies have also shown that students transferring to middle school and high school are at a higher risk of peer victimization in their first year of transitioning compared to other age brackets (Orpinas et al., 2003; Raskauskas & Stoltz, 2007; Scheithauer et al., 2006). Scheithauer and colleagues (2006) investigated age trends and self-reported rates of peer victimization in a sample of 2,086 fifth through tenth grade students from schools in two German federal states. Results showed that self-reported rates of peer victimization were highest among sixth through ninth grade students, with a steady decline as students aged.

Peer affiliations may also be important buffers of subsequent peer victimization. Studies have shown that peer rejection can be a social risk factor that contributes to victimization (Hodges & Perry, 1996; Pellegrini & Long, 2002). A study by Pellegrini and Long (2002) followed approximately 150 students in a rural school system in North America as they transitioned from the fifth grade to the seventh grade. Data collected over the three years examined the role of peer affiliations and the subsequent effects on self-reported rates of peer

victimization. Pellegrini and Long (2002) found that stronger peer affiliations and reciprocal friendships inhibited peer victimization. They posited that bullies feared damage to their social reputations and fear of retribution. Several other studies have also found that both the number and quality of friends serve to protect individuals from peer victimization; in fact, having at least reciprocated best friend serves as protective factor (Hodges & Perry, 1999; Pellegrini et al., 1999; Slee & Rigby, 1993).

Certain physical attributes (e.g., tumors in NF1, extracranial malignancies in cancer) also place children at risk (Lähteenmäki et al., 2002; Llewellyn, 2000; Van Cleave & Davis, 2006). A study by Lähteenmäki and colleagues (2002) assessed school-related problems of 43 childhood cancer patients (i.e., acute leukemia, Hodgkin's disease, non-Hodgkin's lymphoma, Wilms' tumor, neuroblastoma, osteosarcoma, soft tissue sarcoma, germ cell tumor) in the eighth grade in the area of Turku University Hospital and compared the responses to healthy children. Lähteenmäki and colleagues (2002) found that the largest problem faced by the cancer patients was bullying compared to healthy children. Patients reported being bullied approximately three times as much as healthy children due to their physical appearance. Previous studies have also shown that children with a physical disability are more likely to be victimized than healthy children (Dawkins, 1996; Voss & Mulligan, 2000; Yude et al., 1998).

Prevalence.

There are disparities in reported prevalence rates of children who report a history of being bullied, in part to due to definitional differences and in part due to methodological differences. A recent meta analysis analyzing prevalence rates in children who reported a history of bullying and reported a history of victimization across 22 countries found that in the United States, 22.1% of the population were male bully perpetrators; 15.1% were female bully perpetrators; 23.7%

were male victims; 18.8% were female victims; 10.6% were male bully-victims; and 4.9% were

female bully-victims (Cook et al., 2009). Children in this study ranged in age from 3 to 18 years

old. The approach to measuring bullying was predominantly through self-report (74%), with

16% relying on peers, and the remaining 10% using teachers to report bullying. In this study,

bullying was measured using behavioral descriptors of aggressive acts (e.g., "Do you tease

others?"; "How often do you hit others?") and included five time periods (past week, past 30

days, past 60 months, past year, or no period specified). The rates reported above refer to a

reported history of bullying and victimization over the past year. Over half of the data were

collected in Europe (55%), with 26% conducted in the United States.

Prevalence of bullying in schools is difficult to ascertain; however, Orpinas, Horne, and

Staniszewski (2003) found that 40% of third grade students in the United States reported being

victims of chronic bullying. Nansel and colleagues (2001) analyzed data from a sample of 15,686

students in sixth grade through tenth grade who attended public or private schools in the United

States and completed the World Health Organization's Health Behavior in School-aged Children

survey during the spring of 1998. A total of 29.9% of the sample reported moderate or frequent

involvement in chronic bullying, with males more likely than females to be both perpetrators and

targets of bullying (Nansel et al., 2001). Nansel and colleagues (2001) also found that the

frequency of chronic bullying was higher among sixth through eighth grade students than among

ninth and tenth grade students. Raskauskas and Stoltz (2007) found that over the past academic

year close to 49% of middle and high school students in the United States report having been

cyber-bullied—that is, bullied through electronic formats such as blog postings, social

networking sites, text messages, and e-mails.

Research suggests that bullying peaks during school transition (i.e., between elementary

and middle school and between middle and high school) as youth negotiate new peer groups and use bullying as a means to achieve social dominance (Pellegrini et al., 2011). Overall prevalence decreases over time. Youth who continue to be chronically bullied into high school are at higher risk of negative outcomes (Golmaryami et al., 2015; Pellegrini et al., 2011). Generally, studies find that 10-20% of youth are chronically victimized at any given time; whereas, childhood incidence is around 40-75%.

Chronic bullying is experienced by approximately 10-20% of children in the United States. Victims of chronic bullying by peers (peer victimization) are at increased risk for loneliness, diminished self-esteem, social withdrawal, psychosomatic complaints, suicidal tendencies, anxiety, depression, dislike and avoidance of school, and poor academic performance (Boivin et al., 1995; Cook et al., 2009; Hawker & Boulton, 2000; Kaltiala-Heino et al., 2000; Olweus, 1991; Perry et al., 2001; Smokowski et al, 2014). Chronic victimization of children also can contribute to social adjustment problems such as friendlessness and peer rejection as they transition into adolescence and early adulthood (Ladd et al., 1997).

Outcomes.

Children's adjustment and long-term outcomes are a concern due to the high prevalence of children who are bullied. Adverse behavioral and psychological outcomes have been found across groups of youth who are bullied (Cook et al., 2009; Golmaryami et al., 2015; Hawker & Boulton, 2000; Kaltiala-Heino et al., 2000). The immediate effects of bullying can be extremely debilitating to victims. For example, the academic performance, specifically test scores and grades, of victims can significantly decrease (Hazlerr, et al., 1997; Ross, 2002). In addition, studies have shown that low morale and acute despair that may be experienced by victims of bullying could put them at a higher risk for truancy (Gastic, 2008; Reid, 1990). Additional

studies concluded that victims of bullying may experience anxiety, depression, poor self-esteem, impaired concentration, and avoidant behavior into early adulthood (Austin & Joseph, 1996; Kochenderfer & Ladd, 1996; Olweus, 1993).

Kaltiala-Heino and colleagues (2000) surveyed a number of 14 to 16 year old Finnish adolescents taking part in the School Health Promotion Study (n=8787 in 1995, n=17643 in 1997) about bullying and victimization in relation to psychosomatic symptoms, depression, anxiety, eating disorders and substance use. A total of 9% of girls and 17% of boys reported being involved in bullying on a weekly basis (Kaltiala-Heino et al., 2000). Anxiety, depression and psychosomatic symptoms were most frequent among bully-victims and equally common among bullies and victims. Additionally, frequent excessive drinking and use of any other substance were most common among bullies and thereafter among bully-victims (Kaltiala-Heino et al., 2000). A study by Seals and Young (2003) investigated the prevalence of bullying victimization among 454 public school students in the seventh and eighth grade, and found that 24% reported bullying involvement. Furthermore, both bullies and victims manifested higher levels of depression than students who were neither bullies nor victims (Seals & Young, 2003).

Klomek and colleagues (2006) investigated the association between bullying behavior and depression, suicidal ideation, and suicide attempts through self-report surveys completed by ninth through twelfth grade students (n=2342) in six New York state high schools from 2002 to 2004. Approximately 9% of the sample reported peer victimization and 13% reported bullying others in school frequently (i.e., more than once a week). Klomek and colleagues (2006) found that students who were involved in bullying behavior, either as a victim or a bully, were are at significantly higher risk for depression, serious suicidal ideation, and suicide attempts compared with students who were never victims or bullies. For instance, students who were frequently

victims were seven times more likely to be depressed compared to students who were never victims (Klomek et al., 2006). Furthermore, students who frequently bullied others were three times more likely to be depressed compared to students who never bullied others (Klomek et al., 2006). Hinduja and Patchin (2010) analyzed data collected from 1963 middle school students (6th through 8th grades) in one of largest school districts in the United States and found that children who were bullied were 1.7 times more likely and children who bullied others were 2.1 times more likely to have attempted suicide than children who did not engage in any bullying behavior.

Additionally, bullies appear to be at heightened risk for experiencing psychiatric problems, difficulties in romantic relationships, and substance abuse problems (Cook et al., 2009; Craig & Pepler, 2003; Houbre et al., 2006; Pepler et al., 2006). Studies have also shown that bullies are significantly more likely to be convicted of a criminal offense when they are adults than their noninvolved peers (Cook et al., 2009; Sourander et al., 2006; van der Wal et al., 2003). A study by van der Wal and colleagues (2003) assessed the association between bullying and indicators of psychosocial health among 4811 children aged 9 to 13 attending primary schools throughout Amsterdam. Results indicated that delinquent behavior (e.g. "taking something from a shop without paying") was more common in children who bullied others. For example, 37.7% of the boys and 30.6% of the girls who frequently bullied other children reported delinquent behavior as opposed to 4.6% of the boys and 3.1% of the girls who never bullied other children (van der Wal et al., 2003). Furthermore, depression and suicidal ideation were also more common in children who bullied others (van der Wal et al., 2003; Hinduja & Patchin, 2010).

Bully-victims are also at high risk for the long-term psychological problems associated with peer victimization. Kaltiala-Heino and colleagues (2000) found that bully-victims were at

greater risk than both bullies and victims for depression, anxiety, and psychosomatic symptoms. Among girls, 39.6% of bully-victims reported two or more mental health problems, compared to 29.8% of bullies and 15.6% of victims (Kaltiala-Heino et al., 2000). Among boys, 18.6% of bully-victims reported two or more mental health problems, compared to 13.9% of bullies and 9.1% of victims (Kaltiala-Heino et al., 2000). Fekkes and colleagues (2004) assessed the association between bullying behavior and a wide variety of psychosomatic health complaints (headaches, sleeping problems, abdominal complaints, bed wetting, and feeling tired) and depression. In a cross sectional study of 2766 elementary school children, aged 9 to 12 years, bully-victims (n=56) had significantly higher chances for depression and psychosomatic complaints compared to children not involved in bullying behavior (Fekkes et al., 2004). Klomek and colleagues (2006) found that boys who were frequently bully-victims were six times more likely to be depressed and nine times more likely to have serious suicidal ideation than boys who were not involved in bullying behavior. Girls who were frequently bully-victims were 32 times more likely to be depressed and 10 to 12 times more likely to have serious suicidal ideation or to attempt suicide compared to girls who were not involved in bullying behavior (Klomek et al., 2006). Perhaps reflecting their dual involvement in bullying and victimization, bully-victims are at risk for worse psychosocial outcomes than either bullies or victims alone (Fekkes et al., 2004; Klomek et al., 2006; Swearer et al., 2001).

Cyberbullying.

Cyberbullying can be a particularly damaging form of psychological aggression (Cross et al., 2015) that occurs when an individual or group uses information and communication technology to intentionally and repeatedly negatively affect a person who finds it hard to stop this bullying from continuing (Smith et al., 2008). Such behaviors may include but are not

limited to offensive or threatening messages sent via the Internet or mobile phones, sharing others' images or messages without permission, deliberate exclusion online, and pretending to be others in order to take actions that might hurt or embarrass the target.

Cyberbullying has become a growing concern in recent years, with 95% of 12–17 year olds reporting utilization of the Internet (Lenhart et al., 2011). Cyberbullying appears to be on the rise among both children and adolescents due in part to increased access to electronic devices and less online supervision (Waasdorp & Bradshaw, 2015). In a study conducted by Aricak and colleagues in 2008, 269 Turkish high school students were asked about different types of electronic bullying to which they were exposed, with 19% reporting threats and 81% reporting some form of embarrassment (e.g., teasing, insults, rumors, pictures displayed by others without consent).

Despite these distinct characteristics of cyberbullying, policy makers and educators have assumed traditional bullying and cyberbullying to be functionally similar (Law et al., 2012). For example, the recent federal definition of cyberbullying included the use of electronic media to harm another individual as an example of a relational form of bullying (Gladden et al., 2014). Just like more traditional forms of bullying, cyberbullying can significantly affect children and adolescents' social, emotional and academic well-being. Adolescents victimized by their peers, in both online and offline settings, are more likely to report emotional distress, symptoms of anxiety and depression, social isolation, loneliness, and to demonstrate increased school absenteeism and poor academic achievement (Kowalski & Limber, 2013; Landstedt & Persson 2014; Ortega et al., 2012; Sinclair et al., 2012). Although the two different forms of aggression have similar psychological consequences, there is evidence that both forms of victimization have some distinct correlates and characteristics.

Although cyberbullying may be repeated over time, a single incident can be repeatedly experienced if electronic media are forwarded to multiple people or posted online and viewed by multiple people. Thus, the unwanted aggressive behavior may be perceived by the victim as repetitive in nature not due to repeated acts of the bully but rather due to the enduring nature of electronic content with repeated viewings and potential for being shared widely (Horner, et al., 2015). Furthermore, the ability to be anonymous online and the possibility that those who are not socially influential can be technologically savvy shift the notion of power (Dempsey et al., 2011; Law et al., 2012). This shift in power, in addition to the anonymity of electronic media, allows bullies a larger platform to bully their victims. The implications for a shift in power provide students who do not typically exhibit aggressive behavior with tools to victimize peers online. Although electronic bullying involves a power differential between the bully and the victim, across online and off-line contexts, the source of a bully's strength and the reasons why a victim feels defenseless may vary considerably depending on the type of electronic media used and the frequency in which it is distributed (Mason, 2008). As opposed to traditional bullying, in which bullies often rely on a combination of attractiveness, local popularity, and physical strength as a source of power, studies have hypothesized that in electronic bullying the power is based more exclusively on a bully's online popularity and prestige (Patchin & Hinduja, 2006).

Few longitudinal studies have investigated how cyberbullying interacts with traditional bullying among young people, who are increasingly using online environments to seek information, for entertainment, and to socialize (Cross et al., 2015). Adolescents who experience cyberbullying victimization are more likely than non-victimized students to later report symptoms of depression (Gámez-Guadix et al., 2013; Schultze-Krumbholz et al., 2012), and cyber victimization predicts more symptoms of depression compared to traditional bullying

victimization (Patchin & Hinduja 2006; Perren et al., 2010). This suggests that those who experience cyberbullying are at heightened risk of negative emotional consequences, perhaps due to features of the online environment that enable anonymity for bullies, in addition to wide audiences and unlimited access. In addition, those who are cyberbullied are frequently also victims of traditional bullying behaviors (Cross et al., 2015; Riebel et al., 2009). Furthermore, studies suggest that both cyber and traditional victimization, independent of each other, may contribute to negative psychological and psychosocial outcomes (Waasdorp & Bradshaw, 2015).

Bullying and Disabilities.

Overall, recent reviews examining the prevalence rates of being bullied among youth with disabilities show that youth with various types of disabilities (e.g., psychiatric diagnoses, SLD, physical disabilities, ADHD) experience greater levels of bullying than their peers without disabilities (Carter & Spencer, 2006; Cummings et al., 2006; Maiano et al., 2016; Mishna, 2003; Rose et al., 2010). This heightened risk has been attributed to possible negative effects of youth with disabilities, including physical appearance, academic difficulties, inappropriate behaviors, and/or a limited social network or unstable friendships (Carter & Spencer, 2006; Cummings et al., 2006; Maiano et al., 2016; Mishna, 2003; Rose et al., 2010). Deficits in social and problem-solving skills, attributing to a lack of social awareness or social rejection, may also cause students with disabilities to be more susceptible to being bullied. Mishna (2003) indicated that children diagnosed with learning disabilities may be less socially competent than their peers due to problems with language, attention, and information processing.

Studies have shown that visible physical disabilities (e.g., scoliosis, cerebral palsy) put children at increased risk for being bullied relative to children with no visible physical disabilities (Carter & Spencer, 2006; Dawkins, 1996; Llewellyn, 2000; Van Cleave & Davis,

2006; Yude et al., 1998). For example, studies have shown that children with cerebral palsy (Dickenson et al., 2007; Lindsay & McPherson, 2012) and children with cancer (e.g., extracranial tumors, hair loss) were at higher risk for being bullied than healthy children within a school setting (Lähteenmäki et al., 2002). Additionally, studies have shown that children with visible physical deformities are perceived as "different" from their peers, which places them an increased risk for bullying (Hearst, 2007; Sweeting & West, 2001).

NF and Bullying

Physical abnormalities, neurocognitive symptoms, and other associated symptoms of NF1 are likely to put these children at increased risk for a myriad of social and emotional problems. For instance, plexiform neurofibromas, which are present in 30% to 50% of patients with NF1, are benign tumors that can be disfiguring and limit physical functioning (Friedrich et al., 2005; Martin et al., 2012). Research has shown that plexiform neurofibromas in children can negatively impact quality of life and social and emotional functioning (Kim et al., 2009; Page et al., 2009; Wolters et al., 2015), which may make them an easier target for being bullied. Additionally, other NF1-related physical symptoms that can impact psychological well-being and/or quality of life include scoliosis, optic pathway gliomas, and visible or disfiguring manifestations of the disease, such as café au lait macules, axillary or inguinal freckling, and lisch nodules (Page et al., 2009; Reichel & Schanz, 2003; Wolkenstein et al., 2009). These symptoms can affect the way children with NF1 are treated compared to visibly healthy children, putting them at a higher risk of being bullied or targeted in school. In addition to these physical risk factors, research has shown that children with NF1 experience more problems with social skills, anxiety, depression, and aggressive behavior compared to normative and unaffected children (Barton & North, 2004; Martin et al., 2012), which represent further risk factors for

bullying, peer victimization, and being a bully-victim. However, no studies to date have examined the frequency and impact of being bullied specifically in children with NF1.

ADHD and Bullying

Research has shown that the behavioral, psychological, and social characteristics children diagnosed with ADHD often display make them more susceptible to being bullied and being viewed by peers as bully-victims (Shea & Wiener, 2003). Common presentations of ADHD such as social incompetence, emotional dysregulation, lack of insight, and immaturity may predict both bullying and peer victimization in students diagnosed with ADHD (Wiener & Mak, 2009; Unnever & Cornell, 2003). Other attributes that can increase the likelihood of victimization for children diagnosed with ADHD include poor social skills, anxiety, depression, and low self-esteem (Wiener & Mak, 2009). Indeed, studies have shown that children with ADHD report higher overall rates of verbal, physical, and relational victimization by peers than do children without ADHD (Taylor et al., 2010; Twyman et al., 2010; Wiener & Mak, 2009). Wiener and Mak (2009) also found that parent ratings of ADHD symptoms predicted self-reported victimization by peers.

Self-Report vs. Parent-Report

In a study by Graf and colleagues (2006), children with NF1 and their parents both reported impairments in various domains of health-related quality of life (HR-QOL), including social, emotional, and cognitive functioning. However, research has shown that there can be discrepancies between self-report and parent-report measures in the assessment of a healthy child's behavior (Achenbach et al., 1987; Cremeens et al., 2006; Davis et al., 2007). A meta-analysis of 119 studies by Achenbach, McConaughy, and Howell (1987) found that different informants' (e.g., children, parents, teachers) ratings of social, emotional, or behavior problems

in children often are discrepant. These differences can be influenced by a number of factors, including parent bias in their perception of their child's behavior (Richters, 1992), parents' personality traits (De Los Reyes & Kazdin, 2005; Kolko & Kazdin, 1993), and parental stress (Joyner, Silver, & Stavinoha, 2009). In addition, parents tend to report more externalizing problems, such as conduct disorder and oppositional disorder, whereas children report more symptoms of internalizing difficulties, such as anxiety or depression (Hodges et al., 1990; Løhre et al., 2011; Shakoor et al., 2011; Upton et al., 2008). Adolescent reports are more likely than parent reports to reflect pain, mental health problems, health in general, and the impact of their health on family activities (Waters et al., 2003).

Holt, Kaufman Kantor, and Finkelhor (2008) examined parent and child perspectives on bullying. The sample consisted of 205 fifth grade students attending school in the Northeast, and their parents. Students completed self-report measures about bullying involvement, attitudes toward and responses to bullying, and bullying in the home. Parents responded to self-report survey questions about attitudes toward and responses to bullying, perceptions of their child's involvement in bullying, and family characteristics. Rates of being bullied were higher when reported by students than parents, and parents were particularly unaware of their children bullying others (Holt et al., 2008; Løhre et al., 2011). Additionally, higher levels of criticism, fewer rules, and more child maltreatment characterized the homes of victims who were bullied; bullies' homes were characterized by lack of supervision, child maltreatment, and exposure to domestic violence (Holt et al., 2008). Since self-reports and parent-reports of bullying do not always correlate (Holt et al., 2008; Løhre et al., 2011; Matsunaga, 2009), obtaining both perspectives allows for a more comprehensive reporting of symptomology and functioning. Overall, a majority of the bullying literature shows that moving away from the peer context (i.e.,

self-report, to peer-report, to teacher-report, to parent-report) creates more disparate ratings.

The Current Study

Numerous prior studies have shown that children and adolescents who have severe

physical deformities are more likely to be victims of bullying (Horowitz et al., 2004; Janssen et

al., 2004; Smith et al., 2012; Swearer & Carey, 2003; Sweeting & West, 2001). These findings

raise the question as to whether children who have medical conditions that often affect physical

appearance, such as NF1, are at increased risk for bullying victimization. Furthermore, children

and adolescents with ADHD are also more likely to be victims of bullying (Taylor et al., 2010;

Twyman et al., 2010; Wiener & Mak, 2009). Unfortunately, no research has previously

examined the relationships between physical appearance, ADHD, and bullying experiences in

children and adolescents diagnosed with NF1. The present study was designed to address that

gap in the literature.

Aim 1: To compare self-reported rates of bullying to parent-reported rates of bullying in a

sample of children and adolescents diagnosed with NF1.

Hypothesis 1: Based on existing literature indicating discrepancies between self-reported and

parent-reported bullying (Achenbach et al., 1987; Holt et al., 2008; Waters et al., 2003), it is

hypothesized that self-reported rates of bullying will be higher than parent-reported rates of

bullying in a sample of children and adolescents diagnosed with NF1.

Aim 2: To determine the contributions of physical deformity and parent-reported ADHD

symptoms on self-reported and parent-reported rates of bullying in a sample of children and

adolescents diagnosed with NF1.

Hypothesis 2A: Based on existing literature indicating a positive correlation between bullying

and peer victimization (Shakoor et al., 2011; Upton et al., 2008) and ADHD symptoms (Shea &

Wiener, 2003; Wiener & Mak, 2009) or severity of physical deformity (Horowitz et al., 2004; Janssen et al., 2004; Sweeting & West, 2001), it is hypothesized that parent-reported ADHD symptoms and provider-rated severity of physical deformity (i.e., café-au-lait spots, neurofibromas, spine/scoliosis deformity) will positively predict parent-reported bullying in a sample of children and adolescents diagnosed with NF1.

Hypothesis 2B: Based on existing literature indicating a positive correlation between bullying (Taylor et al., 2010; Twyman et al., 2010) and ADHD symptoms (Shea & Wiener, 2003; Wiener & Mak, 2009) or severity of physical deformity (Horowitz et al., 2004; Janssen et al., 2004; Sweeting & West, 2001), it is hypothesized that parent-reported ADHD symptoms and provider-rated severity of physical deformity (i.e., café-au-lait spots, neurofibromas, spine/scoliosis deformity) will positively predict self-reported bullying in a sample of children and adolescents diagnosed with NF1.

Aim 3: To determine whether parent-reported ADHD symptoms or provider-rated severity of physical deformity is more predictive of self-reported and parent-reported rates of bullying in a sample of children and adolescents diagnosed with NF1.

Hypothesis 3A: Since physical deformity becomes more severe with age whereas ADHD symptoms typically manifest in early childhood, and based on existing literature indicating a positive correlation between ADHD symptoms and bullying (Taylor et al., 2010; Twyman et al., 2010; Wiener & Mak, 2009), it is hypothesized that parent-reported ADHD symptoms will be more predictive of parent-reported bullying than provider-rated severity of physical deformity in a sample of children and adolescents diagnosed with NF1.

Hypothesis 3B: Since physical deformity becomes more severe with age whereas ADHD symptoms typically manifest in early childhood, and based on existing literature (Taylor et al.,

2010; Twyman et al., 2010; Wiener & Mak, 2009), it is hypothesized that parent-reported ADHD symptoms will be more predictive of self-reported bullying than provider-rated severity of physical deformity in a sample of children and adolescents diagnosed with NF1.

CHAPTER THREE

Method

This study involved the administration of paper self-report questionnaires regarding bullying experiences and attitudes. This project at Children's Medical Center Dallas (CMCD) was a branch of a multi-site study involving bullying; however, this branch was the only site specifically evaluating Neurofibromatosis Type 1 (NF1). De-identified data will be shared with the parent site at the University of Nebraska at Lincoln (Dr. Sue Swearer, Primary Investigator). The study was approved by the University of Texas Southwestern (UTSW) Institutional Review Board (IRB).

Participants

The questionnaires were administered to patients aged 8-18 years diagnosed with NF1 and their consenting parent/guardian during a routine follow-up visit to the Neurofibromatosis Clinic at Children's Medical Center Dallas (CMCD). A total of 57 participants have been consented on this protocol, including projected screen failures and early withdrawals from completion of measures. Conditions that would result in a participant exiting the study prior to the expected completion date include non-compliance, participant withdrawal of consent, or severe emotional distress.

Inclusion criteria included diagnosis of NF1, current age 8-18 years, enrollment in the third grade or above, proficiency in English, completion of a signed informed consent by a legal guardian, and patient's assent to participate. Exclusion criteria included active chemotherapy treatment, deficits that would prohibit measure completion, and physical disfigurement unrelated to NF1. The total sample size for the entire project across all sites will be 160.

Researchers used the Hollingshead Four Factor index method (1975) to calculate socioeconomic status. The four factors refer to occupation type and education level for the head of household, and occupation type and education level for another working spouse. The Four Factor Index took an average of the occupation type and education level of both spouses to determine SES. This method also included a detailed list of occupations based on U.S. Census classifications. The occupations were classified into nine groups, ranging from "Higher Executives, Proprietors of Large Businesses, and Major Professionals" at the top to "Farm Laborers/Menial Service Workers, unemployed, homemakers" at the bottom. Each family's composite score was computed by multiplying the occupation scale value by a weight of 5 and the education scale value by 3, summing the products, and then averaging the scores to obtain one score per family (Hollingshead, 1975). Using this score, the SES of participants were rated on a 5-point Likert scale (1 = *Lower* to 5 = *Upper*).

Parent Measures

The Bully Survey, Parent version.

The BYS-P (Swearer et al., 2001) is a questionnaire that rates experiences with the rater's child being a victim or perpetrator of bullying (verbal, relational, physical, cyberbullying), as well as parental attitudes about bullying. This survey was developed in the United States with principal components factor analysis that yielded a two-factor solution with items loading onto physical or verbal bullying with no cross-loadings. The BYS-P demonstrated adequate internal consistency reliability (Cronbach's alpha = .71-.87) and satisfactory test-retest reliability (Swearer et al., 2001; Tavakol & Dennick, 2011). The BYS-P is used both nationally and internationally (Germany, Guatemala, and Peru) with parents of school-age children. The BYS-P consists of three sections: A) rater's experiences with their child being bullied, B) rater's

experiences with their child bullying, and C) rater's thoughts about bullying. Part A asks the

raters about their observations or knowledge of their child being bullied in school, and includes 9

questions, some of which consist of multiple parts, for a maximum of 29 questions. Part B asks

the raters about their observations or knowledge of their child bullying others in school, and

includes 8 questions, some of which consist of multiple parts, for a maximum of 35 questions.

Part C includes 16 questions, one of which consists of multiple parts, for a maximum of 30.

Several of the questions use a 5-point Likert scale. The current study used parent-report data

from item 1 of section A of the BYS-P ("*Has your son or daughter been bullied this school*

year?"*)*, recorded as a dichotomous variable: yes or no.

SNAP-IV checklist.

The Swanson, Nolan, and Pelham–IV Questionnaire (SNAP-IV) 18-item version

(Swanson et al., 2001) is a questionnaire that allows parents or teachers to rate children on a

comprehensive selection of symptoms of Attention-Deficit/Hyperactivity Disorder (ADHD).

Parent ratings on the SNAP-IV 18-item version have been shown to have useful accuracy in

differentiating children who meet diagnostic criteria for AD/HD from those who do not (Bussing

et al., 2008). The SNAP-IV demonstrated optimal internal consistency reliability (Cronbach's

alpha = .89-.94) and satisfactory predictive reliability (Bussing et al., 2008; Tavakol & Dennick,

2011). For the current study, a parent/legal guardian was asked to select a response that best

described their child for each item on a 4-point Likert scale (0 = *not at all* to 3 = *very much*).

Patient history form.

This is a 34-item questionnaire developed at Children's Medical Center to obtain

information regarding the patient's developmental and school history, as well as parental

education history and current employment information. The purpose of this questionnaire was to

better characterize the sample's psychological, educational, and demographic characteristics.

Patient Measures

The Bully Survey, Student version.

The BYS-S (Swearer et al., 2001) is a questionnaire that allows a child to rate his/her experiences being a victim or perpetrator of bullying (verbal, relational, physical, cyberbullying), as well as his/her attitudes about bullying. The BYS-P demonstrated adequate internal consistency reliability (Cronbach's alpha = .71-.87) and satisfactory test-retest reliability (Swearer et al., 2001; Tavakol & Dennick, 2011). The BYS-S consists of 4 sections: A) a child's experience of being bullied by others, B) a child's experiences of seeing other students get bullied, C) a child's experiences of bullying others, and D) a child's thoughts about bullying. Part A asks the child about their experiences when they were bullied, and includes 14 questions, some of which consist of multiple parts, for a maximum of 36 questions. Part B asks the child about other students that have been bullied, and includes 9 questions, some of which consist of multiple parts, for a maximum of 31 questions. Part C asks the child about their experiences bullying another student, and includes 11 questions, some of which consist of multiple parts, for a maximum of 39 questions. Part D asks the child his/her thoughts about bullying, and includes 11 questions, some of which consist of multiple parts, for a maximum of 25 questions. Several of the questions use a 5-point Likert scale. The current study used self-report data from item 1 of section A of the BYS-S ("*Have you been bullied this school year?*"), recorded as a dichotomous variable: yes or no.

Provider Measures

Medical Chart Review Form

This screening form was developed at Children's Medical Center Dallas (CMCD). The

medical chart review includes a review of the inclusion criteria, current medication, and any medical or psychiatric diagnoses. A Pediatric Hematologist-Oncologist and an Advanced Nurse Practitioner completed the medical chart review form.

Disease Severity Rating Form

All patients were also screened by a physician to receive a rating of disease severity according to physical markers of NF1 (i.e., plexiform neurofibroma, cutaneous neurofibroma, café au lait macules, spine/scoliosis deformity). This form allowed physicians to identify the location of different physical symptoms associated with NF1 and categorize the severity of physical symptoms on a 4-point Likert scale (0 = *No visible findings or < 2 café au lait macules* to 3 = *Visible plexiform neurofibromas and/or > 3 cutaneous neurofibromas visible and/or visible spine deformity and/or > 50% of face affected*).

Procedure

Patients were identified from the investigators' patient population or from physician referrals. Data for this study were collected as part of a larger study examining the role of health correlates of bullying in a broad pediatric medical sample. Parent consent and patient assent were obtained in accordance with UTSW IRB standards. Research personnel approached parents to participate in the study during pediatric patients' outpatient clinic visits to the Neurofibromatosis Clinic at CMCD. To minimize undue influence or coercion, specific wording regarding the voluntary nature of the study was included in the consent and assent documentation provided to the family. During the informed consent process, researchers emphasized that participation was optional and that the participants may withdraw from the study at any time, for any reason. After consent and assent from all participants were obtained, participating parents and patients were asked to complete study materials via paper-and-pen. Participants were not financially

compensated for participation in this study, nor were they responsible for any research-related

costs.

CHAPTER FOUR

Statistical Analyses

Preliminary Analyses

SPSS Version 23 was used for all analyses. Data were screened for multivariate normal distribution, linearity, and outliers. The data did not include variables with non-normal distribution; therefore, no variables needed to be transformed to allow parametric tests, or recode outliers to the next most extreme participant score on the scale. A *priori* power analysis: G*Power 3.1 (Faul et al., 2009) was used to determine adequate sample size for the planned regression analysis. Using an error probability of .05, the required sample size to obtain a power of .75 was determined to be 56 participants.

Data Analytic Plan

Hypothesis 1: Self-reported rates of bullying will be higher than parent-reported rates of bullying in a sample of children and adolescents diagnosed with NF1.

A chi square test was conducted to determine whether self-reported rates of bullying in children diagnosed with NF1 differed compared to parent-reported rates of bullying in a sample of children with NF1. Data from item 1 of section A of the BYS-P were compared to data from item 1 of section A of the BYS-S. A significance level of $p = .05$ was used to determine statistical significance.

Hypothesis 2A: Parent-reported ADHD symptoms and provider-rated severity of physical deformity (i.e., café-au-lait spots, neurofibromas, spine/scoliosis deformity) will positively predict parent-reported bullying in a sample of children and adolescents diagnosed with NF1.

A hierarchical multiple regression was conducted for the predictor variable (item 1 of section A of the BYS-P), controlling for grade and SES. Order of entry was: (Step 1) grade and

SES, (Step 2) parent-reported ADHD symptoms, and (Step 3) provider-rated severity of physical deformity. Since physical deformity becomes more severe with age whereas ADHD symptoms typically manifest in early childhood, parent-reported ADHD symptoms and provider-rated severity of physical deformity were entered at step two and step three, respectively. A significance level of $p = .05$ was used to determine statistical significance.

Hypothesis 2B: Parent-reported ADHD symptoms and provider-rated severity of physical deformity (i.e., café-au-lait spots, neurofibromas, spine/scoliosis deformity) will positively predict self-reported bullying in a sample of children and adolescents diagnosed with NF1.

A hierarchical multiple regression was conducted for the predictor variable (item 1 of section A of the BYS-S), controlling for grade and SES. Order of entry was: (Step 1) grade and SES, (Step 2) parent-reported ADHD symptoms, and (Step 3) provider-rated severity of physical deformity. Since physical deformity becomes more severe with age whereas ADHD symptoms typically manifest in early childhood, parent-reported ADHD symptoms and provider-rated severity of physical deformity were entered at step two and step three, respectively. A significance level of $p = .05$ was used to determine statistical significance.

Hypothesis 3A: Parent-reported ADHD symptoms will be more predictive of parent-reported bullying than provider-rated severity of physical deformity in a sample of children and adolescents diagnosed with NF1.

Based on the previous analyses for Hypothesis 2A, the beta weights of the two predictor variables were visually examined at step three of the regression to evaluate the relative contributions of the two predictor variables to the overall model.

Hypothesis 3B: Parent-reported ADHD symptoms will be more predictive of self-reported bullying than provider-rated severity of physical deformity in a sample of children and adolescents diagnosed with NF1.

Based on the previous analyses for Hypothesis 2B, the beta weights of the two predictor variables were visually examined at step three of the regression to evaluate the relative contributions of the two predictor variables to the overall model.

CHAPTER FIVE

Results

Demographics

Table 1 lists demographic information for the study sample. The 57 participants included 30 female and 27 male children. Of the participants, 54.4% were White, 22.8% were Hispanic/Latino, 14% were African American, 7% were Asian, and 1.8% classified themselves as "Other." Ages of participants ranged from 8 to 18 years ($M = 11.98$; $SD = 2.86$). Grade levels of participants ranged from grade 2 to grade 12 ($M = 6.72$; $SD = 2.85$). The socioeconomic status (SES) variable ranged from 1 (Lower) to 5 (Upper), with a mean SES of 3.05 (Middle; $SD = 1.30$).

Table 2 lists descriptive statistics for the variables of interest. Of the 57 participants included, 35 participants (61.4%) reported having been bullied in the last academic school year, compared to 33 parents (57.9%) who reported that their child had been bullied in the last school year. The overall mean SNAP-IV score reported by parents was 1.16 ($SD = 0.69$), which falls below the 5% cut-off score (1.67) established by the authors of the SNAP-IV checklist to indicate statistically significant presence of ADHD symptoms. Overall, three parents (5.3%) did not report any ADHD symptoms in their child, and 14 parents (24.9%) reported an overall SNAP-IV score greater than 1.67, indicating the presence of ADHD symptoms to a degree that further testing is warranted for diagnostic purposes. Regarding provider-rated severity of physical deformity, scores ranged from 0 to 3, with a mean score rating of 1.46 ($SD = 0.93$). Eleven participants (19.3%) received a severity score of 0; 15 participants (26.3%) received a score rating of 1; 25 participants (43.9%) received a score rating of 2; and six participants (10.5%) received a score rating of 3. Of the 46 participants with a severity score rating from 1 to

3, twelve participants were identified as having visible physical deformities on the face and neck, all of which were only café-au-lait macules.

Results of Hypothesis-Testing

Hypothesis 1: Self-reported rates of bullying will be higher than parent-reported rates of bullying in a sample of children and adolescents diagnosed with NF1.

A chi square test was performed to examine the relationship between parent-reported (item 1 of section A of the BYS-P) and self-reported (item 1 of section A of the BYS-S) rates of bullying. The difference between these informants was not significant; self-reported rates of bullying were not found to be significantly higher than parent-reported rates of bullying, X^2 (1, N = 57) = 0.04, p = 0.85. Thus, Hypothesis 1 was not supported.

Hypothesis 2A: Parent-reported ADHD symptoms and provider-rated severity of physical deformity (i.e., café-au-lait spots, neurofibromas, spine/scoliosis deformity) will positively predict parent-reported bullying in a sample of children and adolescents diagnosed with NF1.

A hierarchical multiple regression was conducted with parent-reported bullying as the dependent variable (item 1 of section A of the BYS-P). Grade and SES were entered at step one, parent-reported ADHD symptoms were entered at step two, and provider-rated severity of physical deformity was entered at step three. Since physical deformity becomes more severe with age whereas ADHD symptoms typically manifest in early childhood, parent-reported ADHD symptoms and provider-rated severity of physical deformity were entered at step two and step three, respectively. Regression variables and statistics for this hierarchical multiple regression are reported in Table 3. A *post-hoc* power analysis: G*Power 3.1 (Faul, Erdfelder, Buchner & Lang, 2009) was used to obtain observed power after data were collected. Effect sizes of

significant main effects were evaluated using Cohen's (1988) recommendations ($d \geq 0.2$ = small effect size, $d \geq 0.5$ = medium effect size, $d \geq 0.8$ = large effect size; Cohen, 1988). Using an error probability of .05 and sample size of 57, an effect size of .10 and power of .65 was achieved.

The hierarchical multiple regression revealed that at step one, grade and SES did not contribute significantly to the regression model, (F [2,54] = 0.30, p = .745). Once parent-reported ADHD symptoms were added to the regression model, the overall model was significant, (F [1,53] = 4.41, p = .040). The addition of provider-rated severity of physical deformity did not contribute significantly to the overall regression model, (F [1,52] = 0.11, p = .746). Thus, Hypothesis 2A was partially supported.

Hypothesis 2B: Parent-reported ADHD symptoms and provider-rated severity of physical deformity (i.e., café-au-lait spots, neurofibromas, spine/scoliosis deformity) will positively predict self-reported bullying in a sample of children and adolescents diagnosed with NF1.

A hierarchical multiple regression was conducted with self-reported bullying as the dependent variable (Item 1 of Section A on the BYS-S). Grade and SES were entered at step one, parent-reported ADHD symptoms were entered at step two, and provider-rated severity of physical deformity was entered at step three. Regression variables and statistics for this hierarchical multiple regression are reported in Table 4. A *post-hoc* power analysis: G*Power 3.1 (Faul, Erdfelder, Buchner & Lang, 2009) was used to obtain observed power after data were collected. Effect sizes of significant main effects were evaluated Cohen's (1988) recommendations ($d \geq 0.2$ = small effect size, $d \geq 0.5$ = medium effect size, $d \geq 0.8$ = large effect size; Cohen, 1988). Using an error probability of .05 and sample size of 57, an effect size of .06

and power of .47 was achieved.

The hierarchical multiple regression revealed that at step one, grade and SES did not contribute significantly to the regression model, (F [2,54] = 0.05, p = .952). When parent-reported ADHD symptoms were added to the regression model, the overall model still was not significant, (F [1,53] = 1.66, p = .203). The addition of provider-rated severity of physical deformity did not contribute significantly to the overall regression model, (F [1,52] = 1.78, p = .230). Thus, Hypothesis 2B was not supported.

Hypothesis 3A: Parent-reported ADHD symptoms will be more predictive of parent-reported bullying than provider-rated severity of physical deformity in a sample of children and adolescents diagnosed with NF1.

Based on the previous hierarchical multiple regression conducted to investigate Hypothesis 2A, the beta weights were visually examined to evaluate the relative contributions of the two predictor variables to the overall model. Parent-reported ADHD symptoms accounted for a beta weight of .28 (t[53] = 2.10), whereas provider-rated severity of physical deformity only accounted for a beta weight of -.46 (t[52] = -.33). The discrepancy between the beta weights of these two predictor variables suggests that parent-reported ADHD symptoms were more predictive of parent-reported bullying than provider-rated severity of physical deformity. Thus, Hypothesis 3A was supported.

Consistent with this finding, as discovered in the analyses related to Hypothesis 2A, grade and SES accounted for 1.1% of the variation in parent-reported bullying. The addition of parent-reported ADHD symptoms increased the R^2 value to 8.7%, therefore accounting for an extra 7.6% of the variance in parent-reported bullying. Lastly, the addition of provider-rated severity of physical deformity only slightly increased the R^2 value to 8.9%, therefore accounting

for only an extra 0.2% of the variance in parent-reported rates of bullying.

Hypothesis 3B: Parent-reported ADHD symptoms will be more predictive of self-reported bullying than provider-rated severity of physical deformity of a sample of children and adolescents diagnosed with NF1.

From the previous hierarchical multiple regression conducted to investigate Hypothesis 2B, the beta weights were visually examined to evaluate the relative contributions of the two predictor variables to the overall model. Parent-reported ADHD symptoms accounted for a beta weight of .18 ($t[53] = 1.29$), whereas provider-rated severity of physical deformity accounted for a beta weight of -.17 ($t[52] = -1.22$). The relative contributions of the beta weights of these two predictor variables suggests that parent-reported ADHD symptoms were not more predictive of self-reported bullying than provider-rated severity of physical deformity. Thus, Hypothesis 3B was not supported.

Consistent with this finding, as discovered in the analyses related to Hypothesis 2B, grade and SES accounted for 0.2% of the variation in self-reported bullying. The addition of parent-reported ADHD symptoms increased the R^2 value to 3.2%, therefore accounting for an extra 3% of the variance in self-reported rates of bullying. Lastly, the addition of provider-rated severity of physical deformity increased the R^2 value to 5.9%, therefore accounting for an extra 2.7% of the variance in self-reported rates of bullying (roughly equivalent to the additional 3% of the variance accounted for by parent-reported ADHD symptoms).

CHAPTER SIX

Discussion

Although previous studies have found that children with various types of disabilities (e.g., psychiatric diagnoses, ADHD, scoliosis, cancer) experience greater levels of bullying, no studies to date have examined the frequency and impact of peer being bullied specifically in children with Neurofibromatosis Type 1 (NF1). The current study was the first to examine not only rates of being bullied in pediatric NF1 but also how physical appearance and ADHD symptoms may be associated with bullying experiences in the pediatric NF1 population. Additionally, this study was the first to examine whether self-reported rates of bullying differ from parent-reported rates of bullying of a sample of children with NF1.

The current study found that there was no significant difference between self-reported and parent-reported rates of bullying. Previous research has shown that there often are discrepancies between self-report and parent-report measures in the assessment of a child's behavior and experiences; however, such previous findings were not consistent with results from the current study. Overall, the present study detected high rates of bullying in comparison to national averages in pediatric medical populations (Cook et al., 2009; Nansel et al., 2001; Raskaukas & Stolz, 2007). The present study also found highly consistent rates of parent-reported and self-reported bullying. One possibility regarding the consistency of reporting between parent-reported and self-reported rates of bullying could be attributed to a family history of NF1. Twenty-eight participants from the current study sample reported a family history of NF1. It is possible that parents diagnosed with NF1 may have greater awareness of the potential for symptoms of NF1 (e.g., café au lait macules, neurofibromas) and its associated features (e.g., learning difficulties, ADHD) to lead to bullying. Another possible explanation for the consistent

rates of reporting between parent-reported and self-reported rates of bullying could be parental

overprotection and perceived child vulnerability associated with parenting a child with chronic

illness. Previous studies have shown that parents of children with chronic illness report higher

parental overprotection and perceived child vulnerability than parents of healthy children

(Hullmann et al., 2010; Lopez et al., 2008; Mullins et al., 2007). It is also possible that the mean

age of the study sample ($M = 11.98$) could have led to consistent reporting between parents and

children. Middle school and high school aged children may be more likely to report their

bullying experiences compared to younger age groups who may not be aware or truthfully report

their bullying experiences (Orpinas et al., 2003; Raskaukas & Stolz, 2007; Scheithauer et al.,

2006). Of course, other possible explanations for the highly consistent rates of parent-reported

and self-reported bullying could be attributed to methodological limitations, which are discussed

in further detail below.

   The current study found that parent-reported ADHD symptoms predicted parent-reported

but not self-reported bullying. This finding suggests that ADHD and bullying of children with

NF1 are associated, specifically in parent-reported measures. It is possible that social skills

deficits associated with ADHD could result in these children not realizing they are being bullied.

It is also reasonable to expect that questionnaires completed by the same rater (i.e., the parent)

may be more closely related, as compared to the relationship between questionnaires completed

by two different raters (i.e., parent and child). That said, there is considerable evidence that

ADHD is associated with bullying experiences in children and adolescents (Taylor et al., 2010;

Twyman et al., 2010; Unnever & Cornell, 2003; Wiener & Mak, 2009), and findings of the

present study seem consistent with this prior evidence. The current study also expands upon this

previous research, as it is the first to examine this potential association in the pediatric NF1

population. Findings of the present study suggest that parents and teachers need to recognize that

ADHD symptoms may represent a significant risk factor for bullying of children with NF1.

The clinical implications of highly consistent rates between parent- and self-reported

rates of bullying suggest that parent-report measures of ADHD symptoms alone potentially could

be used in screening to identify NF1 children at relatively higher risk for being bullied. That

point is further supported by findings that parent-reported ADHD symptoms were more

predictive of bullying than provider-rated severity of physical deformity in this pediatric NF1

sample. Previous research has shown that visible physical disabilities/deformities—which are

common symptoms of NF1 (e.g., café-au-lait macules; plexiform neurofibromas)—put children

at an increased risk for being bullied relative to children with no visible physical deformities

(Carter & Spencer, 2006; Dawkins, 1996; Hearst, 2007; Llewellyn, 2000; Sweeting & West,

2001; Van Cleave & Davis, 2006; Yude et al., 1998). In the present sample, provider ratings of

physical deformity identified only 12 participants with visible face and neck deformities, which

could explain why provider-rated severity of physical deformity—even though a total of 46

participants were rated as having some sort of physical deformity—did not contribute as

significantly as parent-reported ADHD symptoms to parent-reported and self-reported bullying.

Children with ADHD symptoms may primarily be perceived as "different" by peers due to their

behavior in academic settings (e.g., acting out, interrupting peers, and having difficulty with

social interactions), which could place them at an increased risk for bullying. Since only 14

participants (24.6%) met the SNAP-IV cutoff score (1.67) for parent-reported ADHD symptoms,

it is possible that even subclinical symptoms may predict bullying of children with NF1.

The current study's findings imply that in pediatric NF1, symptoms of ADHD such as

behavioral dysregulation and social immaturity may be more significant risk factors for being

bullied than physical deformities. This information could inform anti-bullying programs and school legislation and policies, with a specific focus on ADHD symptoms, in an effort to minimize the prevalence of bullying of children with NF1. Specifically, the current study indicates that with regard to risk factors for bullying in children with NF1, parents and teachers need to recognize that ADHD symptoms may be the most important consideration, despite the common-sense assumption that physical deformities represent the biggest risk for bullying in this population.

Limitations

A number of limitations to the current study merit discussion. First, a relatively small sample size was used in this study. Although stronger power would have been preferable, a lower power is generally considered sufficient for a pilot study (Kraemer et al., 2006; Lancaster, Dodd & Williamson, 2004; Leon, Davis & Kraemer, 2011) such as the present study, as this was the first study to date to examine whether ADHD and physical appearance may be associated with bullying experiences in children and adolescents diagnosed with NF1. Additionally, the results of the study may have limited generalizability, as the majority of the sample was White (50.8%) and middle class, and the entire sample consisted of only English-speaking participants; however, previous studies suggest that Caucasians with NF1 actually tend to be more severely affected by NF1 than other ethnicities (Abadin et al., 2015).

Another limitation of the study is related to the age range of participants. Although signs and symptoms of NF1 can be present at birth and begin to gradually appear in the first few years of life, visible physical manifestations of NF1 begin to appear and become more severe with age (Hart, 2005). Although the present study had 12 participants with visible physical deformities, those deformities consisted of only café au lait macules in the face and neck and not more severe

visible deformities, such as neurofibromas. It is possible that provider-rated severity of physical deformity would have had a more significant contribution to parent-reported and self-reported bullying if a larger age range had been studied; however, the current study is a pilot study that aimed to specifically focus on patients 8 to 18 years of age.

It should also be noted that having parents and children filling out the measures in the same room at the same time could have biased responses, although study personnel gave clear instructions that the parent and child were to answer their respective questionnaires independently. Since the current study consented participants in a hospital setting, it was not feasible to consent parents and children in separate rooms in a timely manner. Furthermore, the current study at CMCD is a branch of a multi-site study designed by researchers at the University of Nebraska at Lincoln to consent and enroll participants in a hospital setting using self-report and parent-report measures. Additionally, since the BYS-S measure only asked about bullying experiences within the past academic year, the present study did not capture more the distant experiences of children and adolescents who may have been bullied in previous academic years.

Another potential limitation of the study is related to the validity of the provider-rated severity of physical deformity. No confirmatory analyses have been conducted to determine whether this measure is psychometrically valid. That said, in qualitative review of the scale, this only appeared to be a potential issue for higher ratings on the scale. Since the current study had a low rate of high ratings on the provider-rated severity of physical deformity scale (only 6 participants, 10.5% of the sample, received a score of 3), the lack of validity testing for this scale may not have significantly impacted the results of hypothesis testing for the present study.

A final limitation of the present study is the lack of functional impairment ratings, as such impairment could potentially contribute to bullying—for example, if a child is not able to

participate in athletics and is bullied for this. For this pilot study, adding a functional impairment rating was beyond the scope of the study design and was not added to the protocol developed by the University of Nebraska at Lincoln in order to maintain a manageable amount of time required for study participation.

Future Research

Although adding a functional impairment rating was beyond the scope of the current study design, it may be of interest to include a rating of functional impairment in future studies of bullying of the pediatric NF1 population, especially as this may capture physical aspects of NF1 that could contribute to such experiences more so than physical deformities. Future research studies should also incorporate into analyses the specific locations of physical deformities, especially in the face and neck area, as previous research suggests that severe visible physical deformities may more significantly influence bullying in children and adolescents than non-visible deformities. Future studies should also attempt to collect data on more NF1 children and adolescents with visible deformities, as the present study only captured 12 patients with such deformities, all of which were only café-au-lait macules and not more disfiguring deformities such as plexiform neurofibromas.

Future studies on the topic of bullying of pediatric NF1 patients should attempt to collect measures from children and their parent/legal guardian in separate rooms in order to minimize biased responding, and if possible, aim to include teacher reports and peer reports for additional depth of data. Future research also may wish to examine sibling report of bullying experiences in children with NF1 and whether having siblings close in age serves as a protective factor against bullying for children with NF1. Furthermore, studies could examine the effect of protective factors, such as having a best friend, reciprocal friendships or a stable support system, in an

effort to better understand and prevent bullying, and improve interventions for bullying in children with NF1.

Future research on bullying of children with NF1 also should aim to recruit a larger sample of participants with a greater age range and more demographic diversity (e.g., ethnicity, SES) to increase generalizability. Developing, validating, and utilizing Spanish versions of all the measures would allow for a larger and more culturally varied sample of participants. Furthermore, future research should also include longitudinal studies to capture any changing physical manifestations of NF1 with age. By collecting data at different time points, studies may be able to track how changes in physical presentation of NF1 symptoms may affect experiences of bullying. Additionally, future research should include teacher reports and peer reports to provide an additional perspective in bullying experiences in children with NF1.

Instead of examining solely the association between parent-reported ADHD symptoms and self-reported bullying, future studies may also consider including a self-reported ADHD measure for children and comparing this to self-reported bullying. Inclusion of self-reported ADHD symptoms may be used to examine how children perceive their behavior in an academic setting and how this may impact their bullying experiences. Including teacher reports in the current study might also provide an additional valuable perspective and could be used to compare to rates of self-reported and parent-reported bullying. Additionally, future research should incorporate neuropsychological testing in order to measure ADHD symptoms more accurately in children with NF1, instead of solely relying on parent report. In doing so, researchers should also investigate potential differences in bullying experiences among children with different ADHD presentation types (Combined Presentation, Predominately Inattentive Presentation, and Predominately Hyperactive-Impulsive Presentation).

If future studies confirm the findings from the current study and/or identify other risk factors through the analysis of larger and more diverse samples, the next step could involve designing interventions specific to those risk factors for the pediatric NF1 population. Currently, no bullying interventions have been designed specifically for the pediatric NF1 population; however, there exist interventions designed to target bullying in children with ADHD (Espelage et al., 2015; Houchins et al., 2016; Raskauskas & Modell, 2011; Rose & Monda-Amaya, 2011). The Second Step: Student Success Through Prevention (SS-SSTP) Middle School Program (Espelage et al., 2015) focuses on reducing bullying, physical aggression, and peer victimization among students with disabilities such as ADHD by implementing social-emotional learning skills into the curriculum. These skills include empathy, bully prevention behaviors, communication skills, and emotion regulation strategies. Results of a 3-year randomized clinical trial of the SS-SSTP Middle School Program showed that incorporating these skills into the curriculum significantly decreased bullying in children with disabilities (Espelage et al., 2015).

Future interventions could incorporate social-emotional learning skills in a classroom and school-wide setting specifically for children with NF1 who display symptoms of ADHD. Utilizing learning groups in a classroom where students with NF1 and ADHD symptoms are placed into small peer groups with quiet, industrious, on-task children and close monitoring by a teacher or aide, with interventions as needed to promote positive social interactions, could help increase social skills for those children with NF1 and ADHD. On a larger scale, forming a school-wide bullying prevention committee could facilitate the organization of school-wide anti-bullying days, one of which could be focused on teaching students and staff about symptom presentation of NF1, with a specific focus on ADHD symptoms. Providing this education could help teachers and peers learn more about the clinical presentation of NF1 and allow them to

better understand and monitor their own behaviors—such as practicing more patience—when interacting with children with NF1 who exhibit symptoms of ADHD such as interrupting in class and having difficulties staying on task.

Future studies could also look at existing interventions for healthy children and adolescents in an effort to tailor those interventions for children and adolescents with NF1. For example, the Lunch Buddy Mentoring program (Cavell & Henrie, 2010; Craig et al., 2016; Elledge et al., 2010; Gregus et al., 2015) could be implemented specifically for children with NF1 and symptoms of ADHD. Another existing intervention is the Olweus Bullying Prevention Program (OBPP; Olweus & Limber, 2010), a comprehensive school-wide program designed to reduce bullying and improve peer relations among students in elementary, middle, and junior high school grades. The OBPP has teachers and school administrators incorporate anti-bullying messages into the curriculum to facilitate discussions about bullying. Research has shown that implementation of the OBPP can substantially reduce bullying in schools (Kallestad & Olweus, 2003; Olweus, 1994; Olweus, 2005). This makes the OBPP a strong candidate program to be tailored for children with NF1. To better support children with NF1, the OBPP could incorporate anti-bullying messages specific to children with disabilities, such as NF1 and/or ADHD, into their classroom curriculum. Using more specific, concrete, and less abstract concepts when integrating such anti-bullying themes into a classroom setting could be particularly beneficial for children with symptoms of ADHD.

Finally, clinicians and researchers could consider incorporating web-based interventions for NF1 during a patient's hospital visit, possibly tailoring the interventions to ADHD symptom severity. No web-based interventions have been designed specifically for the pediatric NF1 population; however, the FearNot! intervention program (Enz et al., 2008) is an anti-bullying

virtual learning program designed to help children learn and experience effective strategies for dealing with bullying. The FearNot! intervention involves a virtual school environment complete with characters representing various roles (i.e., bullies, victims, bystanders, defenders) and different scenarios in which children are capable of making autonomous decisions. Research has shown that implementation of the FearNot! intervention program can substantially reduce bullying and peer victimization in children (Sapouna et al., 2010; Vannini et al., 2011; Watson et al., 2007). Researchers might tailor modules and narratives included in the FearNot! intervention so that it can be delivered easily in a hospital setting. Tailoring vignettes to NF1- and/or ADHD-related bullying and shortening the duration of the vignettes could allow children to complete modules during a hospital visit, ideally facilitated by a psychologist or social worker.

Conclusion

The present study was the first to examine whether physical appearance and ADHD symptoms may be associated with bullying of children with NF1. Findings suggest that ADHD symptoms may significantly contribute to experiences of bullying of the pediatric NF1 population. Although more research is warranted, the current study represents a significant step toward understanding risk factors for bullying of children and adolescents diagnosed with NF1. Since present findings suggest that ADHD symptoms may be a greater risk factor than physical deformity for bullying of children with NF1, this novel information may be used to direct future research, educate parents and teachers, and inform the development of interventions specific to the NF1 population.

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Table 1

Demographic Statistics for Participants

Variable	N (%)	*M* (*SD*)	Range
Sex			
Female	30 (52.6)		
Male	27 (47.4)		
Ethnicity			
Caucasian	31 (54.4)		
Hispanic/Latino	13 (22.8)		
African American	8 (14.0)		
Asian	4 7.0)		
Other	1 (1.8)		
SES		3.05 (1.30)	1-5
1	6 (10.2)		
2	17 (29.8)		
3	13 (22.8)		
4	10 (17.5)		
5	11 (19.3)		
Age		11.98 (2.86)	8-18
Grade		6.72 (2.85)	3-12

Note. SES = Socioeconomic Status; 1 = Lower, 2 = Lower-middle, 3 = Middle, 4 = Upper-middle, 5 = Upper.

Table 2

Descriptive Statistics

Variable	N (%)	*M* (*SD*)	Range
Parent-Report Bullying			
No	24 (42.1)		
Yes	33 (57.9)		
Self-Report Bullying			
No	22 (38.6)		
Yes	35 (61.4)		
ADHD[a]	14 (24.9)	1.16 (0.69)	0.00-2.89
NF Severity		1.46 (0.93)	0-3
0	11 (19.3)		
1	15 (26.3)		
2	25 (43.9)		
3	6 (10.5)		

Note. NF Severity = Severity of physical deformity; 0 = No visible findings OR <2 café au lait macules, 1 = >2 café au lait macules visible AND/OR <25% of face affected; 1 visible neurofibroma, 2 = 2-3 neurofibromas visible, AND/OR > 5 café au lait macules visible OR >25-50% of face affected, 3 = Visible plexiform neurofibroma AND/OR > 3 cutaneous neurofibromas visible AND/OR visible spine deformity AND/OR >50% of face affected.
[a]ADHD 5% parent cutoff = 1.67.

Table 3

Hierarchical Multiple Regression for Parent-Reported Bullying and Peer Victimization

Predictor	F	p	R	R^2	ΔR^2	β	t
Step 1	0.30	.75	.10	.01	.01		
Grade, SES							
Step 2	4.41	.04*	.30	.09	.08	.28	2.10
Grade, SES							
ADHD Combined							
Step 3	0.11	.75	.30	.09	.00	-.46	-.33
Grade, SES							
ADHD Combined							
NF Severity							

*p < .05.

Table 4

Hierarchical Multiple Regression for Self-Reported Bullying and Peer Victimization

Predictor	F	p	R	R²	ΔR²	β	t
Model 1	0.05	.95	.04	.00	.00		
Grade, SES							
Model 2	1.66	.20	.18	.03	.03	.18	1.29
Grade, SES							
ADHD Combined							
Model 3	1.48	.23	.24	.06	.03	-.17	-1.22
Grade, SES							
ADHD Combined							
NF Severity							

Appendix A

SNAP-IV Checklist

Name:_____ Gender:_____ Age:_____ Grade:_____ Date:_____

Ethnicity (check one) ___African-American ___Asian ___Caucasian ___Hispanic ___Other _____

For teacher: Completed by: _____ Type of Class: _____ Class Size: _____

Telephone # at school: _____ Recommended times for follow-up call: _____

For parents: Completed by: _____ # Parents Living in Home: _____ Family Size. _____.

Period of Time Covered by Rating: ___Past Week ___Past Month ___Past
Year ___Lifetime ___Other_____

For each item, select the box that best describes this child. Put only one check per item.	Not at all (0)	Just a Little (1)	Quite A Bit (2)	Very Much (3)
1. Often fails to give close attention to details or makes careless mistakes in schoolwork, work, or other activities				
2. Often has difficulty sustaining attention in tasks or play activities				
3. Often does not seem to listen when spoken to directly				
4. Often does not follow through on instructions and fails to finish schoolwork, chores, or duties				
5. Often has difficulty organizing tasks and activities				
6. Often avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort (e.g., schoolwork or homework)				
7. Often loses things necessary for tasks or activities (e.g., toys, school assignments, pencils, books, or tools)				
8. Often is distracted by extraneous stimuli				
9. Often is forgetful in daily activities				
10. Often fidgets with hands or feet or squirms in seat				
11. Often leaves seat in classroom or in other situations in which remaining seated is expected				
12. Often runs about or climbs excessively in situations in which it is inappropriate				
13. Often has difficulty playing or engaging in leisure activities quietly				
14. Often is "on the go" or often acts as if "driven by a motor"				
15. Often talks exessively				
16. Often blurts out answers before questions have been completed				
17. Often has difficulty awaiting turn				
18. Often interrupts or intrudes on others (e.g., butts into conversations/games)				
	Sum of Items for Each Scale	Average Rating Per Item for Each Scale	Teacher 5% Cutoff	Parent 5% Cutoff

Appendix B

Patient History Form

For Office Use Only   Patient ID: _____   Date of Evaluation: _____

HISTORY FORM

Please complete the following information as completely as you can. This information will be helpful in gaining a better understanding of your child.

Child's Name: _____

Age: _____ Date of Birth: _____ Race/Ethnicity: _____

Sex: _____ Male   _____ Female   Handedness: _____ Right   _____ Left

Languages spoken: _____ Preferred language: _____

DIAGNOSTIC HISTORY

Has your child ever been evaluated for ADHD? ____ Yes, Date(s): _____
                                              ____ No

If yes, who conducted the evaluation? Name: _____
Role: ___ Psychologist   ___ Physician   ___ Counselor
               ___ Psychiatrist   ___ School   ___ Other: _____

If yes, what diagnosis (if any) was given? _____

Is your child currently prescribed ADHD medications?
               ____ Yes, _____
               ____ No

PARENT HISTORY

Mother's Occupation (specific job title): _____

Mother's Age: _____ Highest grade completed: _____ Degree obtained: _____

Father's Occupation (specific job title): _____

Father's Age: _____ Highest grade completed: _____ Degree obtained: _____

Appendix C

Medical Chart Review Form

For Office Use Only   Patient ID: _____   Date of Evaluation: _____

Patient's Name: _____ MRN: _____

Date of Birth: _____ Gender: Male _____ Female _____

Date of Evaluation: _____   Age at Evaluation: _____

INCLUSION CRITERIA MET
_____ Diagnosis of neurofibromatosis
_____ Current age: 8 to 18 years
_____ Current grade: third or higher
_____ Proficiency in English
_____ No physical disfigurement unrelated to neurofibromatosis
_____ Not currently undergoing chemotherapy
_____ Completion of signed informed consent by parent/guardian or 18-yo subject
_____ Subject's assent to participate in the protocol if minor

Height: _____   BMI: _____

Weight: _____   BMI Percentile: _____

Medication (Current)	Dose

Diagnosis (Medical or Psychiatric)	Current?	Former?

Appendix D

Disease Severity Rating Form

Patient: _____

Reviewer: _____

Front	Back
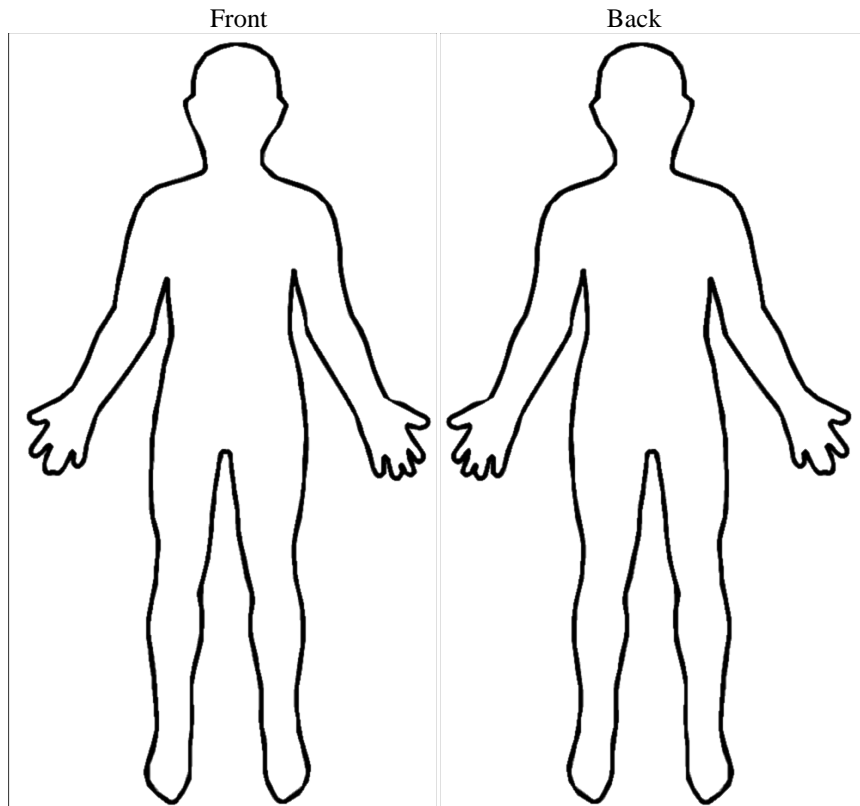
PN = Plexiform Neurofibroma
O = Cutaneous Neurofibroma
XX = CALMs
S = Spine/Scoliosis deformity
To examine: Face, arms to short sleeve length, legs to shorts.

0   No visible findings OR <2 café au lait macules

1   >2 café au lait macules visible AND/OR <25% of face affected; 1 visible neurofibroma

2   2-3 neurofibromas visible, AND/OR > 5 café au lait macules visible OR >25-50% of face affected.

3   Visible plexiform neurofibroma AND/OR > 3 cutaneous neurofibromas visible AND/OR visible spine deformity AND/OR >50% of face affected.

Family history of NF-1: _____

BIOGRAPHICAL SKETCH
Sarita Patel
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EDUCATION/TRAINING

INSTITUTION AND LOCATION	DEGREE	YEAR(s)	FIELD OF STUDY
Southern Methodist University The University of Texas Southwestern Graduate School of Biomedical Sciences	B.A. M.R.C.	2007 2016	Biological Science Rehabilitation Counseling Psychology

Positions and Employment
2013-2015   Clinical Research Assistant (Baylor Research Institute)
2012-2013   Research Assistant (Southern Methodist University)
2007-2008   Milieu Therapist (Children's Medical Center - Psychiatry)

Clinical Experience
2015-Current Clinical Research Assistant (Children's Medical Center – Pediatric Neuro-Oncology)
2014-2015   Research Assistant (Children's Medical Center – Intensive Outpatient Program)
2012-2014   Support Group Coordinator (Baylor Regional Medical Center)

Presentations and Publications
2015   Abstract: Treatment Expectancy and Its Impact on Treatment Outcomes in Depressed Youth. American Academy of Child & Adolescent Psychiatry.
2015   Abstract (First Author): Interrupted Attempt, Actual Attempt and Acquired Capability for Suicide in a Clinical Adolescent Sample.
2015   Abstract: Predicting Drop-out among COPD Patients Randomized to a Lifestyle Physical Activity Effectiveness Trial.
2014   Manuscript: Developing a Targeted Intervention for Suicide Prevention: A Qualitative Report. (Submitted for publication, *Journal of Technology in Human Services*).
2013   Abstract: Posttraumatic stress disorder (PTSD) following traumatic injury at six months: Associations with alcohol use and depression. (Accepted for publication, article in press, *Journal of Trauma and Acute Care Surgery*).

Professional Memberships
2013-Current American Psychological Association
2015-2016   International Association of Rehabilitation Professionals