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Bracing for Idiopathic Scoliosis: Improving Adherence through Psychological Intervention

by

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DISSERTATION

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Abstract

Poor treatment adherence is increasingly being recognized as a significant problem in pediatric medicine. For the condition Adolescent Idiopathic Scoliosis, poor adherence rates to the most non-surgical intervention, orthotic bracing, have become a well-established fact. This treatment modality has been correlated with multiple psychosocial areas of difficulty, including low self image, suicidal ideation, feelings of isolation, social discomfort, depression, an external locus of control, increasing risk taking behavior, high levels of stress, anger, fear, shame, and eating disorders. Since the orthotic bracing has been linked to both poor adherence and to psychosocial problems, an intervention is created to increase adherence through the use of psychosocial techniques. Cognitive behavioral therapy has been used successfully to increase treatment adherence in both adult and pediatric patients. Thus, a comprehensive program is put forth that aims to increase bracing adherence by means of a cognitive behavioral intervention.

Additionally, methods for studying the psychometric properties of this intervention are proposed.

Keywords: Adherence, Scoliosis, Adolescent, Compliance, Group Treatment

Bracing for Idiopathic Scoliosis: Improving Adherence through Psychological Intervention

Treating Adolescent Idiopathic Scoliosis (AIS) through orthotic bracing is often hindered by treatment nonadherence. Additionally, literature has identified treatment nonadherence as increasingly problematic in multiple juvenile-onset medical conditions. Research has shown success in increasing treatment adherence in other pediatric conditions through the use of cognitive behavioral therapy (CBT). A program is designed to address treatment nonadherence in the AIS population using a CBT-based psychological intervention. A complete compendium has been created in order to fully manualize this program. Finally both a pilot and comprehensive study are proposed as steps to empirically support the program design.

Chapter 1: Statement of the Problem

What is Adolescent Idiopathic Scoliosis?

AIS is a spinal deformity that affects 1-3% of the adolescent population (Schiller, Thakur, & Eberson, 2010; Van Goethem & Van Campenhout, 2007; Weinstein, Dolan, Cheng, Danielsson, & Morcuende, 2008). The medical definition of AIS is "a structural, lateral, rotated curvature of the spine" of greater than or equal to 10 degrees, that develops during the adolescent years (Schiller et al., 2010; Van Goethem & Van Campenhout, 2007; Weinstein et al., 2008, p. 1527). The etiopathogenesis of this condition remains unknown in approximately 70-80% of the cases (Negrini et al., 2010; Reamy & Stakey, 2001; Van Goethem & Van Campenhout, 2007; Weinstein et al., 2008). The condition tends to progress more frequently in females than in males, with a ratio of up to 8:1 (Reamy & Stakey, 2001; Van Goethem & Van Campenhout, 2007). There is some evidence to suggest a genetic component to the disease, as family members

of those afflicted have a greater chance of being effected, and a number of potential genetic contributors have been identified (Van Goethem & Van Campenhout, 2007).

The curve is defined by its most lateral vertebra, which is known as the apex, or center of the curve (Van Goethem & Van Campenhout, 2007). The spine may develop a single C or backwards C shaped curve (known as a primary curve), or an S or backward S shape with a secondary curve that develops to balance the "head and trunk over the pelvis, not only in the frontal but also the sagital plane." (Van Goethem & Van Campenhout, 2007, p. 99) Even triple curves are known to develop (Van Goethem & Van Campenhout, 2007).

The severity and progression of the curvature is gauged through the Cobb technique, a method developed to measure the angle of the curvature on radiographs of the spine (Van Goethem & Van Campenhout, 2007). The major risk factors for progression of a curve have been identified as a larger curve magnitude, skeletal immaturity, and female gender (Van Goethem & Van Campenhout, 2007). Larger curves of 30-40 degrees generally progress more quickly than smaller curves of 20-30 degrees (Schiller et al., 2010). S shaped curves generally progress more quickly than C shaped curves (Schiller et al., 2010). A significant change in a curve is defined as a change in the Cobb angle by at least 6 degrees, as measured during two consecutive visits - a definition developed by the Scoliosis Research Society (Edgers, 1998). A curve of 25-30 degrees or one that progresses at a rate of more than 5 degrees per year is considered sufficiently significant to necessitate intervention (Van Goethem & Van Campenhout, 2007). Without treatment, generally 65-70% of curves between 20-30% will progress more than 5 degrees (Schiller et al., 2010). Approximately 3-10% of those diagnosed (0.03-0.1% of the general population given an incidence of 1%) require some form of treatment (Bunge, de Bekker-Grob, van Biezen, Essink-Bot, & de Koning, 2010; Negrini et al., 2010; Van Goethem & Van Campenhout, 2007). 10% of those who require treatment will need surgical intervention (Bunge et al., 2010; Negrini et al., 2010; Van Goethem & Van Campenhout, 2007).

The deformity, often appearing in early adolescence, can worsen significantly during periods of physical growth, especially in individuals who are skeletally immature and have significant curves (Reamy & Stakey, 2001; Schiller et al., 2010). Skeletal maturity is measured in a number of different ways. Orthopedic surgeons who treat scoliosis most commonly measure skeletal growth is through *Risser Stages* (Schiller et al., 2010). The Risser Stage, or Risser sign, is determined by the level of calcification on the iliac crest as seen on a radiograph (Van Goethem & Van Campenhout, 2007). This calcification, measured in stages from 1 to 5, with 5 being furthest along and 1 being the earliest stage, can be seen on the same radiograph taken to measure the Cobb angle and is thus a convenient and accurate way of measuring skeletal maturity (Schiller et al., 2010). A second way of measuring skeletal maturity is by examining calcification of the wrist bone, a technique known as *Skeletal Maturity by Bone Age* (Schiller et al., 2010). A third, less common, way of measuring skeletal maturity is through *Tanner staging*, which measures primary and secondary sex characteristics (Schiller et al., 2010).

Once skeletal growth is completed, the pace of the curvature increase is likely slow, but can continue throughout life (Weinstein et al., 2008). A curvature of greater than 30 degrees at the end of growth, seen in 0.2% of the population, increases the risk of health problems in adulthood significantly (Negrini et al., 2010; Reamy & Stakey, 2001). This spinal deformity, when sufficiently severe, can be seen by the naked eye and thus leaves the appearance of a deformed frame (Negrini et al., 2010). If left untreated, scoliosis can cause back pain, degenerative disc disease, limitations to movement, increased cosmetic deformity, cardiopulmonary problems, psychosocial difficulties, and higher mortality rates (Negrini et al.,

2010; Schiller et al., 2010; Weinstein et al., 2008). Additionally, severe deformity can displace internal organs, leading to multisystem organ problems (Weinstein et al., 2008).

Types of Treatment

Though standard treatment protocols differ by country, the most common form of nonsurgical intervention, and the one most often followed by medical doctors in the United States, involves wearing an orthotic brace that applies pressure to the trunk of the body (Schiller et al., 2010; Vandal, Rivard, & Bradet, 1999). Bracing is typically used in patients who are at a Risser sign of 3 or less to ensure the effectiveness of the treatment while the malleability of the bone remains high (Van Goethem & Van Campenhout, 2007). Orthopedic specialists generally consider a spinal curvature of 25-30 degrees to be sufficiently sizeable to warrant treatment through bracing (Negrini et al., 2010; Reamy & Stakey, 2001; Schiller et al., 2010). The minimum goal of bracing is to stop the increase of the curvature. Most brace types are prescribed to be worn 20-23 hours a day for a period of two to four years, until the end of skeletal growth, as determined by Risser sign or skeletal maturity by bone age (Schiller et al., 2010). Key factors in assessing the likelihood of curve progression include the initial size of the curve, as measured through the Cobb Angle, and the amount of growth remaining (Negrini et al., 2010; Schiller et al., 2010; Vandal et al., 1999)). Treatment effectiveness is measured by looking at the reduction of risk of requiring surgery and medical standards consider a curvature progression of less than 5% as successfully treated (Bunge et al., 2010; Richards, Bernstein, D'Amato, & Thompson, 2005).

There have been many different types of braces that have been developed for scoliosis treatment; each type is designed slightly differently, made of different materials, targets different areas of the spinal column, and demands different treatment protocols and generally named after

the cities in which they were developed (Negrini, 2008; Schiller et al., 2010). The Milwaukee brace, developed in the 1940s, is a cervico-thoracic-lumbar-sacral orthosis designed as an auto-elongation brace and has shown significant success in stopping curvature increase (Negrini, 2008; Schiller et al., 2010). The Milwaukee brace is designed for full-time wear, with breaks for sports activities and hygiene (Schiller et al., 2010). The brace is designed to come up to the neck and down to the hip, making it impossible to hide with clothing and potentially having the greatest psychological impact (Negrini, 2008; Schiller et al., 2010). Due to this increased psychological risk, as other bracing options became available the Milwaukee brace has fallen out of favor, except in cases where it is the only effective treatment (Schiller et al., 2010).

There are multiple types of braces that have been designed to target the thoracic, lumbar and sacral regions of the spine. The Wilmington was designed to improve adherence by making the device less bulky than the Milwaukee brace (Schiller et al., 2010). It is made of plastic, opens in the front, and is held closed with Velcro straps (Schiller et al., 2010). Like the Milwaukee brace, the Wilmington brace is for full-time wear (Schiller et al., 2010). The Cheneau brace is another full-time wear brace designed to target these areas of the spine (Zaborowska-Sapeta, Kowalski, Kotwicki, Protasiewicz-Fałdowska, & Kiebzak, 2011). The Cheneau Light is a modified form of the Cheneau brace designed specifically to reduce the amount of material required for the brace and to make it more comfortable to the wearer (Weiss, Werkmann, & Stephan, 2006)

The Boston brace, developed in the 1970s, is made of a polypropylene exterior and a soft foam polyethylene lining (Negrini, 2008; Schiller et al., 2010). It is designed to push against the spine from the exterior to move the spinal column back into its correct location (Negrini, 2008). It can be used for curves in all parts of the spine but is modified with a Milwaukee fitting if the

curve is above the tenth thoracic vertebra (Schiller et al., 2010). The Boston brace is also designed for full-time brace-wear (Schiller et al., 2010).

The Dynamic Spine-Cor brace is comparatively new. It became available in 1992 (Negrini, 2008). It uses Spine-Cor assistant software to create what they term *Corrective Movement* against the postural deformities of the scoliosis (Negrini, 2008; Schiller et al., 2010). The Dynamic Spine-Cor is a full-time brace that works on the principle of neuromuscular integration through active biofeedback (Schiller et al., 2010).

The Providence brace was designed for the purpose of counteracting the forces of the spine and holding the patient up to or even past the midline of the body (Schiller et al., 2010). It is made of acrylic and is able to treat all single and double curves (Schiller et al., 2010). It is designed to fit the individual through the use of computer-based technology (Schiller et al., 2010).

Overnight braces were designed specifically to reduce the psychological impact on the patient (Negrini, 2008). They are less effective, though, due to the decreased exposure time (Negrini, 2008). The Charleston brace is an overnight only brace designed to hold the patient in an overcorrected position to counteract the forces of the spine (Schiller et al., 2010).

If this nonsurgical treatment is not successful, spinal surgery is performed in the late adolescent years (Weinstein et al., 2008). Surgery involves fusing vertebra and placing metal rods along the spine to decrease the curvature and stabilize the vertebral column (Weinstein et al., 2008). This is a major operation that involves a long recovery period (Weinstein et al., 2008). Furthermore, once the operation is performed mobility is limited, scarring can be severe, and lung function may be decreased (Weinstein et al., 2008).

Problems with Bracing Adherence

The difference between adherence and compliance. Both the terms compliance and adherence are used within the literature when discussing a patient's ability to follow a doctor's prescriptive intervention. Both terms are frequently defined as the agreement between the patient's actions and the doctor's recommendations (Kyngas, 2007; Reichel & Schanz, 2003; Simons & Blount, 2007; Sperry, 2009; Vandal, Rivard, & Bradet, 1999). Adherence has also been defined as upholding medical directions from 80% of the time to 100% of the time (Vandal et al., 1999). Since these two terms are used synonymously within the literature, writing that addresses both concepts are explored to more completely review the available information. Within this document, though, the term adherence will be used, as it has a more collaborative connotation and is thus more in the spirit of a psychological intervention.

Brace adherence problems. Adherence to bracing treatment protocol is essential to avoiding surgical intervention for many individuals. Studies have shown a direct link between bracing adherence and treatment success with treatment success defined as not requiring surgery (Edger, 1998; Wiley, Thomson, Mitchell, Smith, & Banta, 2000). Unfortunately, research indicates that the majority of patients do not adhere fully with the bracing regimen set out by orthopedists, with nonadherence rates reported between 20-85%, making poor adherence a significant problem for the AIS population (Helfenstein, Lankes, Ohlert, Veroga, & Hahne, 2006; Reichel & Schanz, 2003; Schiller et al., 2010). Edgers (1998) reports a pattern of nonadherence dependent on stage of treatment. He suggests that the first four months presents with adherence rates of about 50% as the patient becomes used to the brace (Edgers, 1998). The highest levels of adherence, he proposes, are found in the following four months, followed by increasing drops in adherence (Edgers, 1998). Decreases in brace-wearing behavior have also

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been linked to the summer months and at the two-year milestone of treatment (Edgers, 1998). The data suggests that factors such as developmental stage and gender also influence scoliosis treatment, with brace adherence being highest in females who have not yet reached menarche (Edgers, 1998; Payne et al., 1997; Reichel & Schanz, 2003). Bracing adherence has generally been measured through self-report, either identified or anonymous, or through devices attached to the brace.

Self-report. Self-report is the simplest way of collecting adherence information. A self-report study completed by Gurnham (1983), focusing specifically on AIS brace-wearing adherence, found that 36% of patients either reported lack of adherence in brace-wearing (as defined as not wearing the brace within one hour of the prescriptive time on self-reports at four out of five visits) or did not follow through with treatment at all within the first year of bracing. A second self-report study by DiRaimondo and Green (1988), excluding patients who did not follow through with treatment at all, found that only 15% of patients were 90% or more adherent and that adherence decreased on average by 10-15% after the first year of bracing. Overall, the patients in this study reported wearing braces 65% of the prescribed time (DiRaimondo & Green, 1988).

Over-reporting of brace-wearing and objective measures. The reliability of these self-report studies are limited as patients tend to over report treatment adherence by as much as 50% (Morton, Riddle, Buchanan, Katz, & Birch, 2008; Vandal et al., 1999). As early as 1986 researchers have begun to use technology to objectively measure adherence through temperature, pressure, or brace closure sensors attached to the brace (Edgers, 1998; Mak et al., 2008; Vandal et al., 1999). One study, using brace closure measures, found that self-report measures indicated an adherence rate of 88%, but that objective measurement found adherence rates to be at only

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33% (Vandal et al., 1999). When patients were asked to report adherence rates anonymously, they averaged a 66% adherence rate (Vandal et al., 1999). These results show that patients over-report adherence rates, adding credence to the thought that adherence is low. Self-report measures often elicit over-reporting of socially desired behavior, making the results of Vandal's study unsurprising and suggesting that adherence rates from other studies are actually lower (V. Pantesco, personal communication, September 12, 2010). There has been some success with patient self-report for general medical adherence (not specific to AIS) by using 24-hour recall interviews to gather data, but this technique has not been known to be used with the AIS population (Johnson & Carlson, 2009).

Temperature sensors, developed originally in London in 1989, have been found to the most reliable objective adherence measures, as the method for rating brace closure has not been perfected and pressure sensors misread when the patient makes certain movements (Edgers, 1998; Helfenstein et al., 2006; Morton et al., 2008; Rahman et al., 2010). A study out of Germany using temperature sensors embedded in the brace found that the average brace-wearing time was 67.5% of the prescribed time (Helfenstein et al., 2006). A second study comparing actual and reported brace-wearing, using temperature sensors, found that the actual average brace-wearing during the first year of treatment was 47% of prescribed treatment compared to self-reports of 74% adherence (Morton et al., 2008).

Chapter 2: Relevance and Background

Risk of Nonadherence

Finding a successful way to increase treatment adherence in the AIS population would be useful for multiple reasons. As explained above, increased treatment adherence would help this patient population to boost rates of successful medical brace-based treatment of AIS. Successful treatment is ultimately linked to decreases in the need to provide surgical intervention with the AIS population. There is a direct link between bracing adherence and treatment efficacy, and adherence is reported as the greatest area of concern and most likely reason for poor treatment outcome (Lou et al., 2006; Schiller et al., 2010). Because surgical interventions inherently carry greater risks than nonsurgical interventions in this condition, it would be of benefit to the AIS population to find ways to decrease the likelihood of surgical intervention. Additionally, as mentioned above, moderate to severe scoliosis can lead to medical complications later in life. Thus, lack of adherence greatly increases not only the risk of surgical intervention, but also the potential for back pain, breathing difficulty, and psychosocial problems later in life (Weinstein et al., 2008). Increases in treatment adherence will decrease the risk of such complications. Finally, the significantly poor adherence rate has become, for some doctors, a reason to avoid prescribing bracing altogether and greatly increasing a patient's likelihood of surgery and the aforementioned risk factors (Negrini, 2008).

Larger Problems with Medical Nonadherence

Thinking more broadly, AIS is not the only chronic pediatric condition that requires intensive nonsurgical intervention. Between 18-31% of children suffer from a chronic health condition (Drotar, 2006; Gerhardt, Walders, Rosenthal, & Drotar, 2004). Researchers in the field of pediatric psychology have found that rates of nonadherence in a variety of juvenile onset

illnesses (e.g., asthma, diabetes type I, juvenile rheumatoid arthritis) average 50% or more (Drotar, 2000; Drotar, 2006; Kahana, Drotar, & Frazier, 2008; Lemanek et al., 2001; Rapoff, 1999; Spirito & Kazak, 2006). Level of treatment adherence has been correlated with the complexity of the treatment regimen, the number of components to treatment, and level of interference with daily schedules (Vandal et al., 1999). Higher rates of nonadherence have also been correlated with increased negative side effects and the length of treatment (Vandal et al., 1999).

High rates of nonadherence increase the risk of greater health and symptom difficulties and, in some case, poorer long-term prognosis (Drotar, 2006). Medical costs and healthcare utilization increase dramatically when patients do not follow treatment protocols (Baer, 1986; Pai & Drotar, 2010). The national focus on healthcare cost and on treatment guidelines makes it critical to establish empirically supported treatments that increase adherence (Spirito & Kazak, 2006). Drotar (2006) points out that currently a major barrier to address the problem of poor adherence is the lack of managed care reimbursement for psychological interventions for chronic illnesses. Such psychological support, if available, could serve as a protective factor against medical complications.

General Benefits of Increasing Adherence

Pediatric medical specialists struggle to find ways of increasing adherence rates in juvenile populations. Thus far, most research on improving pediatric regimen adherence has been confined to a small number of diagnoses (e.g., diabetes, juvenile rheumatoid arthritis, and cancer) and no single approach to increase adherence has been established within the literature as empirically supported (Spirito & Kazak, 2006). If ways of increasing treatment adherence with

AIS patients can be found, then such methods could be examined for use with a broader variety of diagnoses.

Increasing Medical Adherence

Research has shown that interdisciplinary care, including medical, nursing, and mental health components, is highly effective at addressing problems in medical treatments, including to help reach maximum adherence (Gerhardt et al., 2004). Goodheart and Lansing point out that "living with an uncertain physical reality requires a stable internal psychological structure of self." (1997, p. 117) This suggests that the use of psychological interventions to increase treatment adherence in the general medical population is a natural component of treatment. Psychological methods of increasing treatment adherence specifically for AIS patients can be modeled after recent attempts to increase adherence in a number of other pediatric medical settings. Success has been found with educational, cognitive, behavioral, and socially-based interventions (Chen, Cole, & Kato, 2004; Drotar, 2006; Graves, Roberts, Rapoff, & Boyer, 2010; Johnson & Carlson, 2009; Kahana et al., 2008; Last & Grootenhuis, 2007; Lemanek et al., 2001; Lindeman & Behm, 1999; Rapoff & Bernard, 1991; Roter et al., 1998; Thompson & Gustafson, 1996).

Educational. Medical education has been one of the most frequently explored methods of increasing adherence. Multiple studies and meta-analyses have found that patients who are educated about their condition are more likely to adhere to treatment than those who do not have such targeted education (Christophersen, & Mortweet, 2001; Graves et al., 2010; Lemanek et al., 2001; Rapoff et al., 2002; Rotor et al., 1998; Thompson & Gustafson, 1996). More specifically, interventions that made use of both oral and written components were shown to be more effective than either format alone (Johnson & Carlson, 2009; Thompson & Gustafson, 1996).

Interestingly, researchers found that educational interventions when given in isolation of other forms of intervention were not successful in increasing adherence, nor were other forms of intervention without the educational component (Johnson & Carlson, 2009; Kahana et al., 2008; Rapoff & Bernard, 1991). Thus, patient education appears to be necessary but not sufficient to increasing adherence.

Behavioral. Behavioral treatments always consist of multiple components to most effectively increase specific medically relevant behavior. Behavioral methods used with success include: token economy systems (Christophersen, & Mortweet, 2001; Lemanek et al., 2001; Rapoff & Bernard, 1991); behavioral contracting (Chen et al., 2004; Christophersen, & Mortweet, 2001; Lemanek et al., 2001; Rapoff & Bernard, 1991); self-monitoring of treatment (Johnson & Carlson, 2009; Lemanek et al., 2001; Thompson & Gustafson, 1996) or other individuals monitoring treatment (Drotar, 2006; Rapoff & Bernard, 1991; Rapoff et al., 2002); positive verbal feedback (Lemanek et al., 2001; Rapoff & Bernard, 1991) or other conditioning strategies (Christophersen, & Mortweet, 2001; Drotar, 2006; Lemanek et al., 2001; Rapoff et al., 2002; Thompson & Gustafson, 1996); modeling (Last & Grootenhuis, 2007; Lemanek et al., 2001; Rapoff & Bernard, 1991); rehearsal (Lemanek et al., 2001; Rapoff & Bernard, 1991); goal setting (Johnson & Carlson, 2009; Lemanek et al., 2001); negotiation (Lemanek et al., 2001); exposure (Last & Grootenhuis, 2007); the use of cues or prompts (Johnson & Carlson, 2009; Rapoff & Bernard, 1991; Rapoff et al., 2002); using reminders (Johnson & Carlson, 2009); and incentives, sometimes financial (Johnson & Carlson, 2009; Rotor et al., 1998).

Cognitive. A number of cognitive interventions have shown success in increasing treatment adherence, specifically when used in combination or in conjunction with behavioral and or educational components. Such interventions have included: increasing attention regulation

(Ritvo, Irvine, Katz, & Shaw, 2000); relaxation techniques (Chen et al., 2004; Ritvo et al., 2000); mindfulness (Ritvo et al., 2000); problem-solving (Lemanek et al., 2001); contingency management (Christophersen, & Mortweet, 2001; Drotar, 2006; Last & Grootenhuis, 2007; Rapoff et al., 2002); altering negative perceptions (Last & Grootenhuis, 2007); setting positive and realistic goals (Lindeman & Behm, 1999; Ritvo et al., 2000); and decision making (Lemanek et al., 2001).

Other models. A number of other treatment methods have shown success when used in conjunction with the above-mentioned methods. Social support and social learning skills have shown success with a number of different groups (Chen et al., 2004; Christophersen, & Mortweet, 2001; Lindeman & Behm, 1999). Interventions that help improve affect have proven useful (Rotor et al., 1998). Kahana and colleagues (2008) found that ongoing interventions were more effective than short-term interventions. Lindeman and Behm (1999) found that improving sleep helped increase adherence behaviors. Chirstophersen & Mortweet (2001) have linked level of family support and involvement with adherence rates. Additionally, the use of mindfulness based practices has been shown to help increase adherence (Ritvo et al., 2000).

Many of the interventions that have proven most successful within the literature have been multi-component designs. These designs most often include both educational and cognitive-behavioral pieces (Christophersen, & Mortweet, 2001; Kahana et al., 2008; Johnson & Carlson, 2009; Rotor et al., 1998). Based on the results of these studies, it appears that multi-component psychological interventions based on cognitive-behavioral techniques may prove to be an effective method of increasing treatment adherence in AIS.

The Link between Psychosocial Functioning and Medical Adherence

Though it may not seem immediately clear that psychological interventions could have an effect on adherence to AIS treatment, the research reported above shows that such interventions have been effective with other medical conditions. This success may be rooted in the fact that intensive medical treatment has been found to have notable effects on a person's psychological functioning. Drotar states that, "a chronic illness can affect the individual child's psychological adjustment as well as his or her activities and level of functioning in a wide range of important settings," (2006, p. 10) Adherence requires both the physical activity of complying with a treatment regimen and also the psychological functions that produce the commitment to comply. Lacking the psychological functions that produce the commitment to comply is a necessary but not sufficient component to illicit nonadherence. Lacking the physical activity of complying with treatment is necessary and sufficient to produce the condition of nonadherence. Simons and Blount (2007) point out, "individual beliefs and perceptions are important predictors of treatment adherence." (p. 832) Thus, lacking these psychological functions is related to the physical act of not adhere with treatment, which in turn produces the condition of nonadherence. Additionally, since there are multiple psychological components that produce the commitment to comply, deficiency in any one of these components could jeopardize final commitment. Tones, Moss, and Polly state, "comorbid psychological distress can negatively affect the patient's adjustment to treatment *via* noncompliance with bracing schedules." (2006, p. 3034)

The Link between Brace-wearing and Psychosocial Functioning

As the following studies show, research has examined the psychological functioning of AIS patients as well as its potential link to treatment adherence.

Early research. As early as 1970, the medical community recognized the link between brace-wearing and psychosocial functioning (Myers, Friedman, & Weiner, 1970). One of the seminal pieces of work in this area of research, published in 1974 in Denmark, was by Bengtsson, Kallstrom, Jansson, and Nachemsom. This article has become one of the foundation pieces of literature linking brace-wearing to concerns in psychosocial functioning despite numerous experimental shortcomings (Bengtsson et al., 1974).

This mostly qualitative study was completed using a sample group of 26 people selected from a population of research subjects during a 1970 experiment examining respiratory impairment in scoliosis treatment (Bengtsson et al., 1974). The criteria for selecting the original 1970 sample group is not explained in the Bengtsson study and because the original publication is not in English, it could not be reviewed by this author. The Bengtsson study indicates that the sample group had scoliosis onset as infants, juveniles, and adolescents and that their average Cobb angle was 105 degrees (Bengtsson et al., 1974). Sample participants were given a comprehensive psychological examination (using Hutts psychopathological scales), which included structured interview, unstructured interview, and review of family history (Bengtsson et al., 1974). This data was used to categorize subjects on a 4-point Likart scale of psychological disturbance (Bengtsson et al., 1974). Additionally, psychological assessments were administered, including the Rorschach (no specific scoring system mentioned), a gestalt-psychology test, the Bender (also evaluated based on Hutt's psychopathological scales), and intelligence testing (specific protocol not mentioned; Bengtsson et al., 1974). The same 4-point Likart scale was used again to categorize each participant, based on the results of the projective testing (Bengtsson et al., 1974). Two individual case histories are presented in the article, as examples of the qualitative data collection method (Bengtsson et al., 1974).

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The methodological soundness of this study is called into question at this time by this author due to the procedures for sample selection, data collection, and result reporting (Bengtsson et al., 1974). Because the original population and sample are not known to this author, with the original study not printed in English, it is not possible to evaluate how representative the sample is of the population of scoliosis patients. Additionally, the sample uses patients whose scoliosis onset occurred during vastly different times in childhood development, which can significantly affect self-image and other psychological factors (Bengtsson et al., 1974). To compound the difficulty in analyzing the data, the qualitative information was grouped into uninterpretable categories (Bengtsson et al., 1974). The first categorization set consisted of the following four categories: *Mental Insufficiency*; *Sick* (which prompted the investigators to prescribe an antidepressant); Other Need for Psychotropic Medications (which the investigators prescribed); and Some Mental Disturbance (Bengtsson et al., 1974). None of these categories are defined or described in any way and there is no known standard definition to these terms that could be applied. (Bengtsson et al., 1974). A second categorization set, examining level of adjustment and quantified as Well Adjusted, Acceptably Adjusted, Poorly Adjusted, or Very Poorly Adjusted, was also not defined or explained (Bengtsson et al., 1974). Furthermore, both the original psychiatric evaluation and Bender scoring make use of Hutt's evaluation criteria (Hutt, 1969a; Hutt 1969b). The use of the Bender with Hutt's scoring system for evaluating psychopathology has been found to be psychometrically unsound and is no longer in use, suggesting that this criterion organization is not valid (Belter, McIntosh, Finch, Williams, & Edwards, 1989; Field, Bolton, & Dana, 1982; Wasserman, 1995). Lastly, there is no mention of how many investigators were involved in the data collection process and thus the potential for poor inter-rater reliability is unknown (Bengtsson et al., 1974).

Despite these shortcomings, this article has become a foundational piece of research that is cited 54 times in articles directly relating to scoliosis and psychosocial functioning, according to Google Scholar (retrieved on July 3, 2011 at 12:07 PM). The results of the article, at the very least, show that individuals with scoliosis may have a higher level of mental health concerns than the average population (though the statistical validity of that statement is not conclusive within the context of this specific study; Bengtsson et al., 1974). As a result, the past forty years have produced a body of research that examines this difference.

Recent research. Research worldwide indicates that brace-wearing is linked to psychosocial problems. Data collected over the past forty years shows that adolescents who are treated nonsurgically for AIS have low self-image (Lindeman & Behm, 1999; Olafsson, Saraste, & Ahlgren, 1999; Payne et al., 1997; Reichel & Schanz, 2003; Sapountzi-Krepia et al., 2001). Body image disturbances, comprised of both affective and cognitive components, among braced AIS females were found in nearly all studies that examined this factor (Taleporeos & McCabe, 2002; Tones et al., 2006). Projective testing found that those braced experienced a lower self-perception of body integrity (Eliason & Richman, 1984). Increasing physical activity was found to help restore body satisfaction, though individuals who were highly active before bracing were found to have an especially difficult time adjusting to the bracing experience (Eliason & Richman, 1984; Tones et al., 2006).

Research has also examined levels of social support, mood, anxiety, and stress in the AIS population (Bengtsson et al., 1974; Lindeman & Behm, 1999; MacLean, Green, Pierre, & Ray, 1989; Olafsson et al., 1999; Payne et al., 1997). AIS has been directly linked to increased suicidal ideation, feelings of isolation, social discomfort, distress, and depression (Tones et al., 2006). More specifically, self-consciousness, fear of injury, and physical difficulties were linked

with social discomfort and isolation in about 35% of patients (Tones et al., 2006). Additionally, scoliosis treatment has been linked to a more external locus of control and higher levels of externalizing behaviors such as alcohol consumption, violence, and truancy (Eliason & Richman, 1984; Matsunaga, Hayashi, Naruo, Nozoe, & Komiya, 2005; Payne et al., 1997; Tones et al., 2006; Wickers, Bunch, & Barnett, 1977).

A whole body of research has recently been produced outside the United States, further examining the psychological effects of bracing. It is important to consider that such studies are not fully applicable to a United States population due to cultural differences; nevertheless such results should still be reviewed and taken into consideration. A qualitative study published out of Greece in 2006 found that braced adolescents reported experiencing stress, fear, anger, and shame related to their brace-wearing (Sapountzi-Krepia et al., 2006). The adolescents in this study felt they had positive experiences receiving information about their bracing, but did not receive enough support from health care professionals (Sapountzi-Krepia et al., 2006). A study out of Italy in 2008 found that adolescent females with scoliosis had a significantly higher rate of eating disorders (anorexia nervosa, bulimia nervosa, and eating disorder-not otherwise specified) than the general population (Alborghetti, Scimeca, Costanozo, & Boca, 2008). The study found a positive relationship between the severity of the scoliosis and the severity of the disease when anorexia nervosa was diagnosed (Alborghetti et al., 2008).

As mentioned above, researchers have acknowledged that the type of brace affects the psychosocial functioning of the wearer (Negrini, 2008). Females who were braced with a Milwaukee brace reported feeling higher levels of discrimination and more overall body dissatisfaction than their same-aged peers (Noonan, Dolan, Jacobson & Weinstein, 1997). Milwaukee braced adolescent girls also report significant differences in social acceptance,

athletic competence, physical appearance, romantic appeal, and global self-worth as compared to peers (Liskey-Fitzwater, Moore, & Gurel, 1993). Because of such studies, researchers have begun to focus on which types of braces produce fewer psychosocial effects. A recent study out of Germany, examined the experiences of patients who were first braced with the Cheneau type then moved to the Cheneau Light (Weiss, Werkmann, & Stephan, 2007). The study found patients reporting significantly less stress when wearing the Cheneau Light as compared to the Cheneau brace (Weiss et al., 2007). Ultimately, the research suggests that the braces that are more flexible and less noticeable may correlate with higher psychosocial functioning.

The Link between Psychosocial Functioning and Brace Adherence

Research within the United States. Given our knowledge that bracing has an impact on psychosocial functioning, some scientists have begun to examine the connection between psychosocial functioning and bracing adherence. One study looked for psychological factors correlated with failure to wear the Milwaukee style back brace (Wickers et al., 1977). The results of the study found adolescents who were nonadherent had higher levels of maladaptive behavior as compared to those who adhered with treatment (Wickers et al., 1977). A second study examined correlates of treatment nonadherence, and found that it was linked to the expectation of failure, low self-esteem, and lack of seeking social support (Lindeman & Behm, 1999). A meta-analysis completed in 1984 developed a theoretical formulation postulating why bracing leads to low adherence rates (Eliason & Richman, 1984). Eliason and Richman (1984) argued that scoliosis interferes with a number of developmental tasks that occur in adolescence including, but not limited to, "gaining independence from adults, adopting peer codes and lifestyles, identity formation... and seeking acceptance from significant others." (p. 170) As a result of the brace, patients became increasingly dependent upon adults and had increased

difficulty following clothing trends and other culturally defined norms. Self-identity can be disturbed by poor body image and there may be real or imagined limitations on peer and family acceptance (Eliason & Richman, 1984). All these contributing factors, argue Eliason and Richman, create a situation that is ripe for future nonadherence.

Research outside the United States. One Greek study proposed that self-image and emotional reactions may affect adherence (Beka et al., 2006). This study examined whether brace-wearing would effect an individual's emotional reaction towards their physical state (Beka et al., 2006). This study found no differences between brace-wearers and non-brace wearers in how they react towards their physical states (Beka et al., 2006). Rivett, Rothberg, Stewart, and Berkowitz (2009) point out that the Beka et al. (2006) study did not use a condition-specific measure for studying the patients' emotional states, and thus calls into question the full validity of the research.

In 2009, a study was published out of South Africa examining the relationship between quality of life and adherence with brace-wearing (Rivett et. al.). This study found that individuals who had lower adherence also scored lower on the condition-specific Quality of Life Bracing Questionnaire in the areas of self-image and self-esteem (Rivett et al., 2009). These people also functioned poorly in the physical, emotional and social domains (Rivett et al., 2009). The results differ from the Greek study, suggesting that the international literature has yet to form a consensus on the topic.

A number of presentations given at the 7th International Conference on Conservative Management of Spinal Deformities focused on psychosocial factors and adherence to bracing. One presenter reported that when assessing influence on adherence, adolescents appear to care more about the opinion of their schoolmates than society in general (Papadopoulos, 2010). A

second study had examined the effect of bracing time requirements (Selle, Seifert, Carus, 2010). This study found that 86% of patients found that their quality of life was most affected during daytime use, versus only 7.2% during nighttime use (Selle et al., 2010).

This small body of research suggests that there appear to be some psychological correlates to AIS bracing treatment though the exact details are still unknown. Based on success in other pediatric populations, attempting to increase bracing adherence through psychological intervention could provide a new way to increase adherence rates. Such increases in treatment adherence may lead to increases in treatment success and lower rates of surgery.

Chapter 3: Conceptual Framework

Using CBT to Increase Adherence

Research into other pediatric conditions (i.e., Juvenile Rheumatoid Arthritis, Diabetes, Cystic Fibrosis, Asthma), as mentioned before, has found that Cognitive and Behavioral Therapy (CBT)-based interventions have been effective in increasing treatment adherence (Drotar, 2006; Kahana et al., 2008; Lemanek et al., 2001). Vandal et al. (1999) point out that, "according to Becker et. al. (1977), the notion of compliance underlies a process comprising both cognitive and behavioral elements." (p. 61) CBT is a commonly used form of psychotherapy that is predicated on how cognitions mediate behavior and using behavioral change to alter emotions and cognitions (Okun, 1990). The origins of CBT are based in Beck's theories of maladaptive cognitive schemas, Bandura's social learning theories, Watson's classical behaviorism, and in Skinnerian learning theory (Okun, 1990). Though there are many forms of CBT, they all operate under the same basic principles: a focus on the maladaptive cognitive and behavioral processes, such maladaptive behaviors and cognitions can be altered, and an emphasis on empirically supported techniques (Okun, 1990). CBT interventions are usually structured (often manualized), time limited, and goal oriented (Okun, 1990). Additionally, a standard measure for change is examining behavioral change which is also the ultimate goal in any intervention targeting adherence.

CBT is an effective intervention for problems of nonadherence because it targets both behavioral and thought barriers to treatment. Beka and colleagues (2006) state that, "Lazarus and Folkman (1984) conceptualized coping as the use of cognitive and behavioral strategies to help mediate a stressful situation." (p. 487) Any medical treatment, whether it be bracing for AIS or chemotherapy for cancer, is by its nature stressful. In order to successfully adhere to treatment, a

patient must find an effective way to cope with this stressful situation and come to a place where they feel as though the ultimate goal of treatment will be worth the difficult treatment. Because CBT is analogous to Lazarus and Folkman's conceptualization of coping it becomes the ideal way to address such stressful situations and adherence to them.

Health-Based Theory of Change

Health psychology theorists have developed a number of cognitive-behavioral models to explain why patients with chronic medical conditions struggle with treatment adherence. The *Health Belief Model* hypothesizes that people are more likely to engage in preventative health practices if they (a) are at increased risk; (b) there is something that they can actively do; and (c) the perceived costs of the preventative activity are outweighed by the benefits (Drotar, 2006; Johnson & Carlson, 2009). This theory is based upon the patient's perceived threat of the illness (Drotar, 2006; Johnson & Carlson, 2009). Research, which has included pediatric populations, has shown that the perceived severity of the illness is related to treatment adherence (Drotar, 2006). Additionally, the patient's perceptions of benefits versus barriers to treatment are also correlated to adherence (Drotar, 2006; Thompson & Gustafson, 1996). The majority of pediatric adherence research that has a theoretical base has used the Health Belief Model as its orientation (Thompson, & Gustafson, 1996).

Though other CBT models of change have less empirical support, each provides important ways of considering change for health-compromised individuals. The *Self-Efficacy Theory*, with a small body of research backing it, found a correlation in adolescents between increased adherence and a higher level of self-efficacy for engaging in treatment and expect better outcomes (Drotar, 2006; Johnson & Carlson, 2009; Ritvo et al., 2000). The *Theory of Reasoned Action/Planned Behavior* posits that behavior is a product of intentions and perceived

control (Johnson & Carlson, 2009). A fourth model, the *Illness Uncertainty Theory*, recognizes the difficulties individuals have in assimilating the concept of being ill into their self-schemas (Drotar, 2006). A final theory, the *Personal Meaning Model*, considers the individual meaning different aspects of treatment may have for each person (Drotar, 2006). One personal meaning may consist of associating adherence to treatment with a lack of independence, while another personal meaning may associate adherence with stigmatization of some kind (Drotar, 2006). Ultimately, all these models are similar in their theme of maladaptive cognitive schemas hindering treatment adherence.

Developmental Considerations

The above theories addressing adherence are all applicable to many different stages of life. To have an adherence intervention provide the greatest likelihood of change, though, one must consider the developmental stage of the target population. In the case of AIS, the target population is in adolescence, a time where increased independence and identity formation are of central developmental focus. This is also a time where the responsibility for medical adherence transfers slowly from parent to child (Drotor, 2006). Erikson referred to this period as characterized by Identity versus Role Confusion (Berk, 2007). From Erikson's perspective, adolescence is a time where the child attempts to separate their own thoughts, feelings, and opinions from their caretakers (Berk, 20007). When applied to treatment adherence, the adolescent must differentiate his will to adhere from that of his parents. The social demands of adolescence make it a time period particularly vulnerable to the impact of perception on adherence (Thompson, & Gustafson, 1996). At this time during development an adolescent's perception of how others view them is of utmost importance. Thus, any intervention must take into consideration these unique developmental characteristics to be optimally successful.

Chapter 4: Program Design, Scoliosis Adherence Manual

The International Scientific Society on Scoliosis Orthopedic and Rehabilitation

Treatment (ISSORT) published a series of guidelines in 2009, outlining best practice standards

for managing idiopathic scoliosis (Negrini, Grivas, Kotwicki, Rigo, & the International Scientific

Society of Scoliosis Orthopedic and Rehabilitation Treatment, 2009). Among these standards is a

suggestion that every patient receive the appropriate time, commitment, and counseling to ensure

success of treatment (Negrini et al., 2009). More specifically, a commenter at the symposium in

which these guidelines were created suggests that the use of a psychologist to help increase

treatment adherence may be useful (Negrini et al., 2009). The Scoliosis Adherence Manuel

(SAM) makes use of psychological professionals to help improve adherence just as the ISSORT

suggests.

In creating this intervention, it is important to consider the stage of illness, the stage of treatment, and the stage of development (Drotor, 2006). The SAM addresses secondary prevention for AIS patients. Such patients have already begun treatment and thus the bracing is no longer a brand new experience but patients have not necessarily entered into a pattern of nonadherence. The intervention is created to address the long-term adaptation phase of treatment, rather than onset or maintenance phases. Once the brace has been worn consistently for approximately four months, an individual's willingness to fully adhere may no longer be as high as at the start of treatment (Edgers, 1998). At some point in treatment, the negative aspects of treatment may begin to outweigh the original perceived benefits. Alternatively a patient may be entering into a life transition (such as entering high school) that has the possibility of increasing stress and the risk of nonadherence. AIS is a disorder specific to adolescence and the SAM intervention was formulated to target adolescents. Additionally, adolescence is a time of

increased developmental transition that can be stressful. Youth want increased independence and finding the right balance of supervision versus autonomy with parents can be difficult (Drotor, 2006). This balance for autonomy is further complicated when treatment adherence becomes a factor (Drotor, 2006). There may be a struggle between parent and youth to find a balance of treatment responsibility.

The format of this intervention is a CBT-based group, lead by a trained mental health professional. A discussion within medicine in the United States to move towards an integrated model where mental health professionals are working side by side with other allied health care professions. As this integration increasingly occurs, mental health workers will become more available to provide intervention services alongside physicians and services to help increase medical adherence. Group interventions specifically have shown improvement in illness management by enhancing problem-solving skills, self-monitoring, and social skills (Drotor, 2006; Dishion & Stormshak, 2007). Goodheart and Lansing explained, "adolescents often respond to group support because they are especially peer-oriented at this stage of their lives." (1997, p.126) Thus, a group format, which provides the additional component of social support, can positively affect treatment with the proper professional guidance (Hinrichsen, Revenson, & Shinn, 1985).

This intervention will make use of educational, cognitive, and behavioral components to encourage change. Patient education is shown to be necessary, but not sufficient to increasing adherence rates (Rapoff & Bernard, 1991). Cognitive interventions give AIS patients the opportunity to "reconsider interpretations of situations and to develop or learn new coping thoughts." (Drotar, 2006, p. 41) In conjunction, operant conditioning behavioral interventions are

implemented to increase brace-wearing behavior. The combination of such strategies works to target multiple areas that block maximum adherence.

This intervention is twelve sessions long. Most sessions are designed to be one hour long. The family session, session ten, is designed to be two hours long. Each session has an ordered set of components with each component containing identified goals and interventions (see Appendix A). Some components are repeated weekly, while other components are the focus of a single session. All sessions should follow the general guidelines and make use of the leader's clinical judgment.

Pretreatment Meeting

Before the actual treatment begins, it will be important to have a pretreatment meeting with participants and their legal guardians. This pretreatment meeting can either be in a group format or with individual families, depending upon the preference of the provider. There will be multiple goals to this pretreatment meeting. The first goal is to obtain informed consent with the guardian and informed assent with the participant. Without both the consent and assent, treatment will not be legal or effective. The next goal of this pretreatment meeting is to give an overview of the treatment program and goals of the intervention. A conversation should occur with the guardian about how involved they would like or expect to be in the treatment process. This conversation can help to inform the provider as to the best way to keep the parent informed and integrated in the treatment process.

It is important for the group leader to consider how they will keep parents aware of and involved the course of treatment throughout the intervention. Though the family session in week ten is a standard part of the treatment, leaders may want to assess if more regular contact with parents will increase treatment benefits. The pretreatment meeting is the optimal time to assess

the needs and abilities of each family with regard to level of involvement. Such contact could be accomplished through regular telephone calls to parents or handouts for parents that review the contents of each week. Group leaders may also choose to hold a parent group that runs concurrently with the youth group. Such a parent group could be structured as a Psychoeducation group or in a peer-support format. The nature and frequency of parent contact should be based upon clinician judgment of need and ability.

General Guidelines

Room setup. Participants should sit in a circle. Additionally, having a dry erase board or easel with paper where the group leader can write should be available. Though, interventionists should work to avoid creating a classroom type environment, there will be times when it will be useful to write down information that all group members can see (e.g., listing barriers to adherence, troubleshooting alternatives for contingency management).

Environment. The leader should work to build and maintain a positive rapport with each group member and the group as a whole. This can be done through using developmentally appropriate language; interacting in a warm and friendly manner; and creating a open, friendly, and respectful environment. Also, leaders should consider keeping track of and following up on important individual or family milestones, events, or interactions of relevance that may have an effect on adherence (Christophersen & Mortsweet, 2001). Remember that adherence can be much more difficult to some people than to others, so it will be important to create an environment that both recognizes and is accepting of this fact (Christophersen & Mortsweet, 2001). Though the ultimate goal is complete adherence, no one should feel embarrassed when disclosing that their adherence has been poor. It is more important for participants to feel able to tell the truth than to feel pressure about adherence. Individual progress should be rewarded with

praise. Never compare one participant to another as everyone has different barriers and challenges to adherence.

Presenting new material. When beginning any new topic, start by inviting participants to share their current knowledge, any worries, experiences, or expectations (Christophersen & Mortsweet, 2001). Each time the leader presents new information to participants it is important to avoid the use of medical jargon or be sure to explain such jargon in a way that is easily understandable (Christophersen & Mortsweet, 2001). Participants will benefit from being alerted to particularly important instructions (e.g., stating 'this part is especially important') or have participants repeat back specific components of instructions that are particularly important (Christophersen & Mortsweet, 2001). Though advice giving on the part of the leader should be minimal, when any is given, it should be specific and concrete (Christophersen & Mortsweet, 2001).

Other considerations. There are a number of other general considerations group leaders must be aware of when engaging in this intervention. The first consideration is the risk of iatrogenic effects when working in groups. A review of literature has shown that peer pressure, when exerted within group therapy, can cause participants to learn maladaptive patterns of thinking and behaving from one another (Dishion & Stormshak, 2007). It will be important for group leaders to be familiar with how to recognize this concern and be vigilant in helping to avoid the potential treatment pitfalls.

When forming the group, it will be important for the mental health professional to consider the make-up of the group members for optimal group success. Though the typical age range for bracing treatment for scoliosis is between twelve and seventeen, having this full age range within a single group may not be ideal due to differences in development. Conversely,

having a group with this whole age range may allow for older youth to serve as role models for the younger participants. Ultimately this decision is left to the interventionist to consider.

Week One

On the first week of the intervention, participants are introduced to the group leader, the group format and content, each other, the weekly log sheet, and provide patient education. Introductions to the group leader and group format are given through didactic presentation and explanation of goals of the group. Introductions to fellow participants occur though interactive games, often called ice breakers, that are designed to allow participants to learn about one another and increase comfort in the group setting. The SAM suggests completing one or two icebreakers, though group leaders are encouraged to use their own clinical judgment about the exact number necessary to make the room comfortable. Throughout these first activities, it is the goal of the group leader to create a therapeutic holding environment for the members.

Patient education has regularly proven to be an important component in any intervention for treatment adherence (Christophersen, & Mortweet, 2001; Graves et al., 2010; Lemanek et al., 2001; Rapoff, 2002; Rotor et al., 1998; Thompson & Gustafson, 1996). Thus, participants are given a comprehensive educational session on their spine, Scoliosis, bracing, and the risk of surgery. Form E contains a comprehensive handout on these topics that will be given to participants. It is important for group leaders to develop an understanding of the medical treatment that is sufficient to successfully provide such education. Information should be presented both in written and oral format to ensure a more comprehensive understanding (Johnson & Carlson, 2009; Thompson & Gustafson, 1996). When providing patient education, it is important to discuss both the advantages and disadvantages of treatment and to present the information about treatment and treatment goals in a realistic manner (Christophersen &

Mortsweet, 2001). Patients need to understand what realistic expectations for improved functioning can and cannot be as a result of the medical treatment (Christophersen & Mortsweet, 2001). The leader should strive to make this education session as interactive as possible to ensure the participants are fully engaged. Having participants take turns reading, discussing, and asking and answering questions are all good ways to help engagement and comprehension.

Next, the brace monitoring system and log sheet will be introduced (see Appendix B, Form B). The leader should be sure that all participants fully understand how the log sheet is utilized before leaving the session. It may be beneficial to fill out a practice log together as a group to help with comprehension. When introducing and practicing, make sure to stress the importance of accurately logging time, and that accuracy is more important that level of adherence. Spend a little time exploring the importance of being open and honest in both logging and group interactions.

Reviewing log sheets and calculating points will occur each subsequent week. Leaders may want to consider creating a larger version of Form D, which is used to collect weekly goals and points. In this way, participants can track their progress visually. One of the goals of the weekly log sheet is to provide participants an opportunity to increase self-monitoring skills. The logging of brace-wear time allows patients to self monitor their adherence (Johnson & Carlson, 2009; Lemanek et al., 2001; Thompson & Gustafson, 1996). To improve the accuracy and honesty of self-monitoring, Rapoff and Barnard (1991) have suggested a number of tools. First, they suggest that the target behavior that is being monitored, in this case hours of brace wearing, is clearly specified (Rapoff & Bernard, 1991). Next, the group leader should be sure to emphasize the importance of accuracy and honesty in self-reporting and to explain the concept of self-monitoring clearly (Rapoff & Bernard, 1991). Finally, Rapoff and Bernard suggest that there

should be supervised practice in self-monitoring. For this intervention, supervision occurs through the log sheets, which are turned in weekly to the group leader.

Participants will be working to collect information on multiple variables related to adherence. *Goal Adherence*, defined as the mean adherence rate that a participant is aiming to reach for that week, will be determined each week for each participant by the group. *Prescribed Adherence* is the number of hours per day that the participant's orthopedist has stated that the participant should wear her brace. The Goal Adherence will be based upon the previous week's Goal Adherence and the actual mean adherence rate that the participant tracked for the previous week with consideration of the prescribed adherence.

Example 1: The group decides that Cindy's Goal Adherence for the upcoming week should be 14 hours per day. They have come to this decision after considering that Cindy had a Goal Adherence of 12 hours per day, and was successful at wearing her brace an average of 12.5 hours a day the previous week. They also have taken into account the fact that Cindy's doctor wants her to be wearing her brace a total of 20 hours per day and that before the group began she was only wearing the brace 8-10 hours per day.

Participants *Adherence Success* when they are successful in meeting their Goal Adherence rate for that day of the week. Thus some days a participant may reach or exceed goal, while other days she may not.

Example 2: Delia was given a Goal Adherence of 16 hours per day for Week 6. On that week, she managed to wear her brace 17 hours on two of the days, 16 hours on four of the days, and only 12 hours on the final day. This means that she met Adherence Success six out of seven days that week.

Ultimately, participants are aiming for *Complete Adherence*, which is having the Goal Adherence and her Adherence Success be both equal to or above her prescribed adherence.

Finally, the last portion of the session will be spent introducing the Robo-calls. Robo-calls are automated voice or text messages that each participant will receive daily in the evening to serve as a reminder for wearing and tracking the brace (see Appendix B, Form C). Reminders can be a useful behavioral intervention to help participants increase a learned behavior such as brace wearing (Johnson & Carlson, 2009). At the start of each subsequent session, participants will sign in and be given the opportunity to change the method of contact for reminders. This is a practical component to the session that allows the group leader to track attendance. It also allows for participants to explore the best mode of contact for reminders. It will be the responsibility of the leader to send out such reminders - a function that can be set up though an automated system.

Week 10 will include family members of participants. Thus, at the end of this first session, it important to pass out the "Save the Date" flier (see Appendix B, Form J), so families can prepare their schedules ahead of time. This session will include any members of the participants' immediate families that would like to attend.

Week Two

The aim of Week Two is to introduce the concepts of contracting and rewards. First contracting is introduced. From this week forward, participants will engage in a weekly contract with the group for a brace wearing commitment. The contracting is found on the Weekly Contract and Tracking Form (see Appendix B, Form B). On the top of this form contains a contract that the participant will fill out. The participant will write in his name and the daily brace wearing goal for that week and then sign the contract.

The aim of the contracting exercise is to set optimistic but realistic goals for increased brace wear for each week. The contract is a written agreement between the participant and group stating that she will aim to adhere to an agreed upon brace wearing time for the upcoming week. This is not a prescription, as the participant will have say in the time span chosen. The contract is a way to help the participant hold herself accountable for the agreed upon time frame (Chen et al., 2004; Christophersen, & Mortweet, 2001; Flannery-Schroeder & Lamb, 2009; Lemanek et al., 2001; Rapoff & Bernard, 1991). This contract also allows participants to set and achieve goals that they have set for themselves (Johnson & Carlson, 2009; Lemanek et al., 2001).

The Goal Adherence will be decided upon by the group based on the previous week's adherence rate and with consideration for the ultimate goal of complete adherence. This ultimate goal is individualized, based upon the prescription of each patient's doctor. Each day of each week, participants will be aiming to reach their Goal Adherence for that week. Thus some days a participant may reach or exceed goal, while other days she may not.

Participants will continue to contract weekly for their Goal Adherence for the following week. Based on the adherence rate from the previous week and the prescribed adherence, participants will decide upon a Goal Adherence for the following week. The aim is to meet or exceed the goal daily.

Example 1: Participant A, who was prescribed an adherence rate of 18 hours per day, wore her brace the following hours over the days of the past week: 17, 12, 14, 18, 18, 16, 15. This averages out to 15.7 hours per day. Thus, an appropriate goal for Participant A may be 16.5 hours per week.

Example 2: Participant B, who was also prescribed an adherence rate of 18 hours per day, wore her brace the following hours over the days of the past week: 12, 10, 6, 11, 12,

9, 2. This averages out to 8.9 hours per day. Thus, an appropriate goal for Participant B may be 11.5 hours per day.

It is important to remember when contracting that the participant should be aiming for Complete Adherence by Week Ten, so the increases in weekly goals must reflect the distance to this final goal. Participants will have a slightly higher goal each week, building towards a goal of Complete Adherence by the tenth week of the group, if not earlier. In this way, participants will have at least two weeks of Complete Adherence during the treatment.

If a patient does not meet Goal Adherence contracted for on the previous week, it is likely that they will work towards that same Goal Adherence for the next week.

Example 3: On Week 3, Patient A, who had a Goal Adherence of 16.5 hours the previous week, only reaches an average adherence of 14.9. This week she will repeat the same Goal Adherence of 16.5 hours as she had the previous week.

If a patient is unable to meet her goal two weeks in a row, then it may be necessary, based upon the clinical judgment of the interventionist, that the weekly average goal be decreased for the following week.

At the start of the second week, after sign in, participants will have the opportunity to discuss the weekly monitoring homework. This feedback and processing opportunity will occur each week henceforth. Though every week will have additional content areas in which to cover, it is important for the leader to spend ample time on this portion of the session, as this weekly monitoring is one of the central components of the intervention. Participants need the opportunity to explore their experiences with the bracing requirements, to share with their peers, identify strengths, and to troubleshoot areas of difficulty.

Also, starting on this second week of the intervention, patients will begin to receive points weekly for reaching their Goal Adherence. Participants will receive one point for each day they reach Goal Adherence and two points for every day they reach Complete Adherence.

Adherence points will be placed into Form D held by the group leader for score keeping. The highest total possible score is 140, indicating Complete Adherence on every single day of the intervention. Members who have a score of 105 or higher, indicating Complete Adherence half the time and Adherence Success the other half of the time, will receive a \$25 gift certificate.

Members who have a score of 70 or higher, indicating Adherence Success for the entire intervention, will receive a \$10 gift certificate. This points system is a token economy system whereby participants receive points for Adherence Success (Johnson & Carlson, 2009; Thompson & Gustafson, 1996). The final prizes service as financial incentives for the participants to achieve their stated goals (Johnson & Carlson, 2009; Rotor et al., 1998). The points system also places emphasis on the importance of accuracy in logging time.

Week Three

On Week Three, the practice of mindfulness is introduced. This practice has become increasingly popular within the field of cognitive behavioral treatment for its ability to target multiple problem types, including: self-regulation values clarification; cognitive, emotional, and behavioral flexibility; and exposure (Shapiro & Carlson, 2009). Mindfulness is an attention regulation practice that can help to move cognitions away from distressing medical experiences and towards more positive outcomes (Ritvo et al., 2000). The act of mindfulness creates "states of optimal regulation attained through deliberately mobilizing attentional capacities toward intended targets." (Ritvo et al., 2000, p. 266) During mindfulness practice, participants are

working towards states of identification and detachment and away from states of judgment (Ritvo et al., 2000).

For this week, it is the job of the group leader to model nonjudgmental self-monitoring (Ritvo et al., 2000). The aim of the mindfulness exercise is to allow participants to objectively recognize aspects of the bracing experience. These may include physical aspects, such as pain associated with brace wearing, or psychological aspects, such as feelings of low self worth when wearing the brace. Participants are lead through the process of recognizing these thoughts and feelings, then encouraged to them to objectively recognize the reality of those experiences and then move past them. Participants will learn to separate themselves from these bracing experiences and examine such experiences at a distance. They will begin to recognize these experiences as less overwhelming or frightening (Ritvo et al., 2000). By doing so, participants become able to see themselves as more than just the treatment and its negative corollaries and learn to identify what aspects of the experience are worth addressing and what aspects are worth just letting go.

Week Four

This week is spent discussing realistic goals for increased adherence. Goal setting and the theory behind it is covered in Week Two. Participants will spend this week discussing their own goals and any barriers they see to achieving such goals. Participants will have the opportunity to learn from each other and get support surrounding their respective goals. The focus of this week is to learn to set positive, realistic goals for their brace wearing.

It is possible that during the course of this discussion other topics related to bracing will come up that are relevant to goal setting. Discussion of these topics are acceptable as long as the group leader frames the discussion within the context of goal setting and can draw the discussion

periodically back to this theme. The group leader has some freedom to allow participants time for discussion within this context.

Week Five

Various relaxation-training exercises have been shown to be effective for pain management among a number of different painful disorders (Block et al., 2003; Christophersen & Mortsweet, 2001; Drotor, 2006; Ritvo et al., 2000). For scoliosis, significant pain is often associated with the bracing process, as specialized padding on the inside of the brace is designed to press against the body (Negrini, 2008). Christophersen and Mortsweet (2001) explain that relaxation training can "help children identify their own bodily sensations... and learn how to relax." (2001, p. 186) Two relaxation-training exercises are presented to participants in this week of treatment. The first exercise is deep breathing, an exercise designed to slow the heart rate, center the body, and decrease stress (Block, Gatchel, Deardorff, & Guyer, 2003). The second exercise is progressive muscle relaxation, designed to help participants become more aware of unknown tensed muscle states (Christophersen & Mortsweet, 2001). Coping of these exercises (see Appendix B, Form G) will be provided to participants to take home.

Week Six

Everyone has an internal dialogue running most of the time. This dialogue, called *self-talk*, is commenting on and interpreting events experienced by the person (Block et al., 2003). Self-talk can be positive, neutral, or negative. Some forms of self talk present automatically, such as when a person stubs their toe and thinks 'ouch.' When self-talk includes automatic statements that are counterproductive to one's goals, it is referred to as *Negative Automatic Thoughts* (Block et al., 2003). Negative automatic thoughts most often fall into one of several categories of thinking, including: catastrophizing, filtering, black-and-white thinking,

overgeneralization, mind reading, should statements, and blaming (Block et al., 2003). Specifically, for adolescents being treated for scoliosis with bracing, much of these negative automatic thoughts may be focused on their bodies and low self image (Lindeman & Behm, 1999; Olafsson et al., 1999; Payne et al., 1997; Rapoff & Bernard, 1991; Reichel & Schanz, 2003; Sapountzi-Krepia et al., 2001). Negative automatic thoughts for these girls may also consist of statements regarding their abilities to succeed with treatment.

Addressing negative self-talk can increase participant's' expectations of success in treatment and increase self-image (Block et al., 2003; Lindeman, 1999). Thus, the focus of treatment this week is identifying and addressing negative self-talk in which participants may be engaging. The handout for this week, Form H, gives examples of the different types of negative self-talk that can occur. The clinician running the group should help participants identify such negative self-statements that they may be experiencing, how such statements may be getting in the way of other things they want from their lives, and lead the group in discussion as to how to replace these statements when they arise. The goal is to substitute these negative self-statements with positive, more adaptive ones and ultimately being able to feel more successful and positive about themselves.

Example 1: Sally explains that she hates looking in the mirror because whenever she does, the first thing she sees are the edges of her brace poking out from her clothes and thinks how everyone must think she is a freak for having to wear the brace. Sally is coached in session to come up with an alternative statement to say to herself each time she looks in the mirror. After a few moments, Sally decides to replace her negative automatic thought with a statement about how good her posture is when she is in her brace. For the next week, each time she looked at herself in the mirror and this negative

automatic thought popped into her mind, she would immediately recite the new selfstatement in her head. As group the following week, Sally reports that she is no longer avoiding the mirror as often as she used to.

The leader should stress the importance of regularly addressing negative self-talk in order to change perceptions. Participants should be encouraged to each identify one or more negative automatic thoughts related to themselves and their bracing. There are no expected or prescriptive statements that are required or expected. Rather the clinician must work with the statements participants provide and help them to alter these perceptions.

Week Seven

The aim of Week Seven is to help participants learn how to address problems that come up during the course of bracing. Strengthening problem-solving skills has proved to help medical patients increase adherence (Drotor, 2006). Participants will learn the steps of problem solving, outlined in Form I, and have practice applying them within the group session. Problem solving is a multi-step process that provides a systematic way for figuring out the best way to respond to a situation (Flannery-Schroeder & Lamb, 2009). The first step in problem solving is identifying the given problem. If the problem has not been explicitly identified, coming up with the best solution becomes much more difficult. Once the problem has been identified, the person is challenged to come up with multiple potential solutions (Flannery-Schroeder & Lamb, 2009). There is never only one course of action, or solution, in response to a given problem or situation. Often though, people can only see one course of action and feel bound by this course that may not produce the results they would like. Thus, the challenge in problem solving is coming up with as many different solutions as possible to provide the individual with choices. Once a list of potential solutions has been identified, the next step is to identify the consequences of each

solution (Flannery-Schroeder & Lamb, 2009). Some solutions may produce very negative consequences, while other solutions will likely produce more acceptable consequences. A solution to proceed with can then be chosen based upon the most desired consequence. If this solution does not result in the expected consequence, depending upon the situation, there may be another solution that can be tried or even more solutions can be thought of (Flannery-Schroeder & Lamb, 2009). By being able to use problem-solving skills, participants are better able to handle both expected and unexpected situations that may challenge their abilities to maintain complete adherence. Using problem solving, participants can figure out the optimal time off from the brace for themselves given their individual situations.

Week Eight

Regardless of what providers, parents, peers, or clinicians' want, ultimately the choice to wear the brace as prescribed rests upon the patient. There is no reasonable or realistic way to force a patient to wear her brace. Thus, the focus of this week's discussion is on this choice. A patient's initial intent to comply can be a good indicator of adherence (Rapoff & Bernard, 1991). Starting off this conversation by assessing each participant's original intent can help the group leader to gain a better understanding of where the conversation will go and the level of investment each participant has in the process (Rapoff & Bernard, 1991). Though motivation is not always the same as intent, assessing intent is a good way to begin to think about motivation as well. Level of motivation, like initial intent, has been linked to long-term medical adherence (Kyngas, 2007). It is also good to understand how much control a participant feels over the brace wearing process. Patients may easily feel out of control of this decision (Christophersen & Mortweet, 2001; Matsunaga et al., 2005; Payne et al., 1997; Wickers, Bunch, & Barnett, 1977).

more control over their situations and thus more easily able to make the decision to wear the brace as prescribed.

Motivational interviewing, a therapeutic technique designed to increase a person's motivation to change, has shown some success when used in a group format to increase medical adherence and healthy behaviors in adult and adolescent populations (Holstad, DiIorio, Kelley, Resnicow, & Sharma, 2011; MacDonell, Brogan, Naar-King, Ellis, & Marshall, 2012). For adolescents this technique is particularly relevant due to relational and technical components that can be easily adapted for this developmental period (Naar-King, 2011). Though motivational interviewing is not specifically prescribed for use in this session, knowledge of these techniques may be very helpful for the interventionist to use in increasing motivation for change.

Week Nine

Telling family and friends that you have a medical problem, especially one that will change the way you function during treatment, and that may lead to major surgery, is not a simple or easy decision for many people. How family and friends respond to this news is as much about their own cultural background and personal experiences as it the patient's. Research clearly shows, though, that level of social support is directly linked to treatment adherence both in bracing and for other medical treatments (Lindeman & Behm, 1999; MacLean et al., 1989; Olafsson et al., 1999; Payne et al., 1997). Therefore, telling close family and friends can greatly increase the chances of successful treatment occurring.

One pressure that could easily keep patients from disclosing this kind of information is a concern about social perception (Christophersen & Mortweet, 2001). Social perception is of key importance for adolescent girls, as this is a time in development when the need for positive perception and social acceptance is at its peak. The aim of this week's discussion is to discuss

some of these concerns about social perception that participants may have and help them come to understand the benefits of family and peers knowing about their treatment. Some of the participants may have already disclosed this information to trusted friends. Making use of the provided questions in the SAM (see Week 9, Activity 4) can help those who have not disclosed understand how such admissions can be beneficial. For those who have not yet disclosed, these questions and topic areas help participants explore their resistance to disclosure and hopefully help them to move past this resistance.

Week Ten

Young adolescents, despite wanting to be treated like adults and have the associated freedoms and responsibilities, are still children in many important ways. Their decision making, time management, and delay of gratification capacity all remain underdeveloped (Barkley, 1997). It is the role of any parent to teach their youth and help them learn how to successfully negotiate the world as such functions develop. It is the parent who is with the child every day of the week and is available to help the child when she approaches difficult decisions. Thus, any intervention targeting children of any age would be incomplete without some type of parent component. Previous research has shown the success of multifamily treatment on patient health for people with severe mental illness and veterans with traumatic brain injury (Perlick et al., 2011). Additionally, research has shown a robust connection between family support and level of medical adherence (Christophersen & Mortweet, 2001; Drotor, 2006; Rapoff & Bernard, 1991).

With these considerations in mind, the tenth week is focused on including the family in this treatment process. This session will be 120 minutes long in order to allow necessary time to address all topics. Families are encouraged to bring any and all members that have questions or concerns about the treatment how it affects the youth and the family. Siblings who have the

capacity and willingness to join in such a dialogue are encouraged to attend. Family members will be introduced to the techniques and discussion topics that have been covered in the past weeks to gain a better understanding of the skills the participants have developed. Family members will have the opportunity to experience some of the relaxation techniques that have been used by participants and understand how their children have progressed both with regard to cognitions and adherence. The topic from the previous week, social support, will be further discussed in order to give parents the opportunity to become more comfortable disclosing the bracing treatment to extended family. Participants will be tasked with introducing all of these topic areas in order to give them a sense of mastery of these skills.

Week Eleven

Week eleven is purposefully left as an unscheduled week. It is possible, if not likely, that topics have come up during previous weeks that would benefit from further discussion. This open week was left primarily for such discussions to continue. Additionally, it will likely be helpful to spend some time processing the parent session from the previous week. On the chance that there are not areas of discussion that would benefit from further time included below are a number of topic areas that have been linked to adherence and may be of benefit. It is left up to the discretion of the group leader as to how to use the time. Additional areas of focus can be used as well.

Anger. Goodheart and Lansing (1997) state, "Anger is frequently a by-product of frustration, pain, loss, and trauma. It is also a response to anxiety in some people." (p. 124) Some or all of these emotional experiences may be familiar to participants when thinking about their bracing. It is likely that members of the group have reacted with anger on at least one occasion when faced with this treatment. Giving participants an opportunity to process this anger and

better understand where it comes from may be beneficial. Learning to tolerate the legitimacy of these angry feelings may be important to some group members who view their anger as an unacceptable reaction (Ritvo, 2000). Such anger should be normalized and participants should understand that it is okay to express their anger in appropriate ways (Ritvo, 2000). The leader should leave space in the room for the expression of these intense negative emotions that the patient may be experiencing, then take a step back to try and use this sentiment to mobilize patients to shift from any emotionally dominated thinking to critical thinking regarding their current situations. Appropriate versus inappropriate ways of anger expression can be discussed (e.g., punching a heavy bag or screaming in to a pillow versus hitting or yelling at family members). Participants will benefit from discussing how anger can be expressed or how to channel this energy into productive venues (Ritvo, 2000). Reframing this negativity can be an opportunity for participants to learn and empower themselves (Ritvo, 2000).

Anxiety and stress. As mentioned in the section above, anxiety and stress are often reactions to medical interventions (Lindeman & Behm, 1999; MacLean et al., 1989; Olafsson et al., 1999; Payne et al., 1997). Participants may benefit from discussing how previously learned techniques can be used to help in anxiety or stress producing situations. Additional techniques known to the group leader can be introduced, as well.

Body image. The combination of typical early adolescent concerns and bracing may lead to poor body image. One study has shown that individuals who are braced have more overall body dissatisfaction than their same aged peers (Noonan et al., 1997). Thus, if participants have expressed body dissatisfaction, it may be appropriate to spend some available time during this week discussing body image and explore the source of the youth's dissatisfaction. The group

leader can make use of cognitive restructuring to help participants begin to gain a better self-image (Flannery-Schroeder & Lamb, 2009).

Week Twelve

This is the final week of treatment. After a last sign in and mindfulness practice, participants will be lead through the progressive muscle relaxation protocol a second time in order to get a second supervised experience with the exercise. Once this exercise is complete, much of the rest of the session will be spent following up on some of the cognitive skills learned over the past weeks. The group leader should check in with participants about negative thoughts, problem solving, decision-making, and social support. For each topic area, leaders should inquire about any progress that has been made in their cognitions that may have lead to increased adherence. Reinforce the use of new skills and advances that has been made. For participants who continue to struggle with specific skills, it may be appropriate to discuss what barriers to change they notice.

The final part of this last session is the culmination of the reinforcement portion of the program. Participants will turn in their adherence sheets for the past week and final adherence levels will be tallied. Participants who have surpassed the predetermined goals will receive prizes. Everyone will receive a certificate of completion.

Chapter 5: Research Methodology

To most effectively examine the psychometric properties of this new manualized intervention, completing both a pilot study and a comprehensive study is proposed. The pilot study, consisting of a single intervention group, would require fewer resources to complete than a comprehensive study and would reveal any glaring manual or procedural errors. Such errors then will be rectified for the comprehensive study, whose sample size aims to allow for statistical relevance of the analyzed data and will require significantly more resources. There will likely need to be changes to the intervention after the pilot study, but until such time that such alterations are identified, the comprehensive study will replicate the parameters of the pilot study (with the exception of the sample size).

The null hypothesis for the pilot study states that an intervention group using the SAM will show no increase in adherence as compared to the AIS population as reported in the literature. The null hypothesis for the comprehensive study states that the intervention with the SAM will show no increase in adherence as compared to the control group. For both studies, the alternative hypothesis expects an increase in adherence rates as compared to the comparison groups.

Participants

Participants will be included for the study based upon the following criteria. Participants will be females between the ages of 12-17 (the average age range of treatment) who are prescribed full-time brace wearing (18+ hours a day of wearing). Participants are diagnosed with AIS and no other spinal problem. Participants are in the long-term adaptation phase of treatment, as they have already begun wearing their braces, but have had them for less than one year. Participants are not prescribed Milwaukee or SpineCore style braces (as those brace styles have

characteristics that impact their psychosocial sequelae). Participants do not have any diagnosed mood or anxiety conditions, eating disorders, or a low IQ.

Participants will be recruited through scoliosis specialist clinics at participating pediatric orthopedic centers. Participants for the pilot study will be recruited from a single center and participants for the comprehensive study will be recruited from multiple centers. For both the pilot and comprehensive studies, recruitment will be based upon direct referrals from doctors, nurses, and orthotists.

The population and sample are based on a categorical model with a specific chronic condition (Drotor, 2006). The scope of this intervention is generalized; targeting all adolescent females who have just began their bracing treatment (Drotor, 2006). This is a secondary prevention type of intervention; as it is directed to a population who is already being treated for scoliosis with a brace, but does not necessarily yet show signs of nonadherence (Drotor, 2006). Of the recruited sample for the comprehensive study, a group will be chosen randomly to participate in the intervention while the rest of the sample will be used as a wait list control comparison. To ensure maximum reliability all attempts should be made to ensure that the experimental and control groups are well matched across a variety of demographic variables.

Sample Size

As mentioned above, the sample size for the pilot study will differ from that of the comprehensive study. For the pilot study, a single intervention group of six to ten participants will be used. To account for attrition, twelve to fourteen candidates will initially be identified. For the comprehensive study, the sample size is based upon the need for statistical power. Based on Cohen's (1992) power primer, the sample size needed for a medium effect size at a power of .80 for an alpha of .05 to answer the first question would be less than 156 (which is the required

amount for a between-groups design), while the required sample size to answer the second question is 87. To ensure enough power for a medium effect size and to allow for the possibility of seeing a small effect size, the intervention sample size proposed will be 156. This large sample size will also allow sufficient power given the expectation of attrition during the course of the experiment. Being that the sample size needed to answer the second question is only 87, the required sample size for the control group can be significantly smaller. The control group will have a sample size of 40, half of the total required sample size to get a medium effect size of the between groups chi square design.

Since there is currently no standard intervention for treatment nonadherence, it would be well within acceptable ethical boundaries to have a 'no treatment' control group. Controls would track their adherence in the same way as the intervention group, turning in weekly sheets. This form of a control group would help to account for the effect of tracking adherence. This would also allow for long-term follow up on the effect of the intervention on adherence.

Due to the low base rate of AIS in the general population, it may be difficult to obtain this sample size required to observe medium effect size (La Greca & Varni, 1993). Additionally, no single group can be effective with 87 participants. Thus, there would need to be multiple intervention groups that were run either concurrently or consecutively across multiple sites in order to gather the appropriate sample size for meaningful results. Finally, it is important to recognize the reality of attrition in any study. Participants who initially commit may drop out. Active participants may miss sessions or neglect to record brace wearing. In order to account for such attrition, it would be prudent to increase the recruited sample size so that accurate results can still be gathered.

There cannot be random selection for a sample group such as this. Researchers cannot control who has scoliosis, who will need treatment, or even who will volunteer to participate in the study. The one thing that can be controlled by the researchers is assignment between groups. Thus, to help ensure the highest possible level of accuracy for our results, participants will be randomly assigned between the control and intervention groups.

Feasibility

The implementation of a pilot study precursor to the comprehensive study will help to identify some of the feasibility concerns. The pilot study will be conducted using a single interventionist and a single recruiter and data analyst. Participants will be recruited from a single site over a single period of time. All of these modifiers will decrease psychometric concerns. When then comprehensive study is completed there will be many more opportunities for problems to arise. Multiple groups will be conducted at multiple sites by multiple interventionists over a much longer period of time. The addition of a control group will increase the complexity of the statistical analysis. In order to complete this comprehensive study, a whole research team will be necessary for effective implementation.

The research team will consist of a principle investigator, co-investigators recruited from the various research sites, a project coordinator to facilitate recruitment, organize data collection and analysis, and interventionists to run the groups. Since subjects for the full intervention study would be recruited from and groups run out of multiple study sites, multiple interventionists will be required. To help ensure consistency across groups, interventionists will participate in training before the study begins to ensure the closest possible protocol among sites. Additionally, regular phone consultation by the principle investigator will continue to help ensure fidelity of treatment across sites.

Background Data

Background data will be collected on all research subjects before the intervention proceeds. Participant's age, household make-up, curve type and location, brace type, number of months in the brace, and bracing prescription will all be collected as demographic information. Additionally, the level of supervision participants receive from their parents will be assessed through a Likert scale. This eight point scale will be as follows: (a) I am solely responsible for every aspect of my brace wearing; (b) I am mostly responsible for my brace wearing, but will get assistance if I ask; (c) I am responsible for my brace wearing, but will get intermittent reminders; (d) I am partially responsible for my brace wearing but get regular reminders and intermittent assistance; (e) I share the responsibility of my brace wearing, getting reminders and regular assistance; (f) I take a minor role in the responsibility of my brace wearing. It happens mostly due because my parents intervene; (g) I take no responsibility for my brace wearing; (h) I do not wear my brace. This information, though not directly related to treatment outcome, will help further elucidate the pre-intervention condition of each participant and is directly related to part of the intervention itself.

Measures

Two types of outcomes will be measured. The primary, short-term outcome is to increase the target construct, which, in this case, is treatment adherence. The secondary outcome that will be measured is the avoidance of surgery, which is the long-term outcome we are aiming for when attempting to increase adherence.

Adherence behaviors will be measured in two ways, a subjective self-report and an objective temperature measure. Both measures will be taken at three points in time: pre-intervention, post-intervention, and six month post intervention. The goal of these measures is to

track bracing adherence over the course of intervention and after intervention has finished. For the self-report data, participants will report the hours of day that they wore their brace for a full week. That information will be averaged to find the subjective average wear number. The second measure will be a temperature gauge placed on the inside of the brace (Edgers, 1998; Helfenstein et al., 2006; Morton et al., 2008; Rahman et al., 2010). Measurements with this temperature gage will be taken for a full week at each of the three points in time. The week's worth of measurements will be averaged to find the objective average weekly wear. Each data point for both the subjective and objective average wear will be divided by the prescribed time to find the adherence rate for that week.

Table 1

Adherence in Brace-wearing by Treatment Time

Time	Mean	sd		
Time 1: pre-treatment				
Time 2: post-treatment				
Time 3: 6-month follow-up				

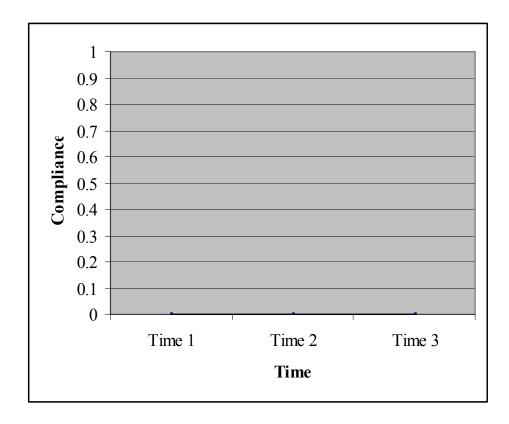


Figure 1. Mean adherence rates over time

The secondary outcome of surgery avoidance will be examined at the end of bracing treatment. As mentioned above, brace wearing decreases the chance of surgery. Because the primary aim of the adherence intervention is to increase brace wearing time, the hope is that there would be a secondary gain of decreasing the likelihood of surgery. Participants or their doctors will report as to whether or not participants require surgery. Examining results will elucidate if the intervention was effective.

Intervention. The intervention model is a CBT based group intervention to increase brace wearing adherence, with the primary outcome measure in brace wearing hours (Drotor, 2006). The intervention group will participate in a manualized CBT-based treatment developed by this writer that targets feelings, thoughts, and behaviors known to be associated with AIS nonadherence (Lindeman & Behm, 1999; MacLean, Green, Pierre, & Ray, 1989; Olafsson et al., 1999; Payne et al., 1997). The intervention will be composed of eleven 50-minute sessions and one 120-minute session. Therapeutic techniques used within this treatment include: psychoeducation; token economy systems; contracting; self-monitoring; positive verbal feedback; decision making; mindfulness; problem-solving; reinforcement; goal setting; relaxation techniques; altering negative perceptions; social support; and family support.

Ethics and informed consent. Research protocol will adhere to the highest level of ethical standards. Parents or guardians of all the research subjects will sign an informed consent document. This document outlines the research protocol, subject participation expectations, and possible side effects or unexpected outcomes. Parents will receive a copy of the consent they sign. Participants will sign a document of informed assent to ensure their understanding of the research protocol and agreement to participation. All research subjects are numerically coded to ensure anonymity in the data. All data is kept locked and only researchers have access.

Chapter 6: Proposed Data Analytic Strategy

Fidelity

As mentioned above, monitoring of fidelity is important within this study due to the multiple intervention sites and multiple interventionists. The investigators will need to examine if the study was completed as planned or if there were problems with its implementation.

Investigators will need to closely assess if any differences between sites or interventionists are of enough significance to affect the results. Such problems will need to be identified and analyzed to assess for their effects on the data set. If possible, some of these problems may be controlled for statistically during the analysis process. All problems or unexpected occurrences that happened will be reported in any study presentation.

Pilot Study

The analysis of the pilot study will examine if the intervention group shows an adherence rate that is statistically greater than the rate as reported in the literature. A one-tailed T-Test will be used to analyze data to compare the pilot numbers to the general population.

Comprehensive Study Question One

This analysis examines the effects of a CBT-based intervention on bracing adherence. Adherence rate data will be collected at three points in time and examined through the use of a repeated measures one-way analysis of variance (ANOVA) test. The medium effect size for the ANOVA is .25. The three-level discrete independent variable is time period measured at pretreatment, post-treatment, and follow-up. The continuous dependant variable is adherence rate, also measured at pre-treatment, post-treatment, and follow-up. Table two displays the means and standard deviations for adherence rates at the three time points. Figure one displays a graph of

the means of adherence rates over time. Table three displays the output of the within subjects one-way ANOVA completed on the adherence data.

Table 2

Methods of Hypothesis Testing

Hypothesis	Variable	Analysis
1. Providing a psychosocial intervention	Measure of brace-	Repeated measures one
based on psychoeducation and CBT will	wearing adherence	way ANOVA
increase brace-wearing adherence.		
2. Providing a psychosocial intervention	Presence of	Chi-Square
based on psychoeducation and CBT will	surgery	
decrease the need for surgery.		

Table 3

Analysis of Variance for the Effects of Intervention

Source	df	SS	MS	F
Between				
Within				
Total				

Comprehensive Study Question Two

A Chi Squared test will be used to compare the sample and intervention groups on the question of surgery. The current sample size has been chosen to be sufficiently large to assume enough Power for a medium effect size. The medium effect size for the Chi Square is .30. It is possible that the data sample will be sufficiently large to find a small effect, particularly for the Chi Square analysis. If there is not a sufficiently large sample size to see a small effect size with either statistical test and no medium sized effect is seen, then the null hypothesis will be accepted.

Table 4
Success of Treatment: Chi Square Analysis

Treatment	Successful	Unsuccessful	Total
Intervention			
Control			
Total			

Chapter 7: Discussion

There are two major dimensions to the above research that have been discussed. The first major aspect is the program development while the second major aspect is a proposed way to examine this new program for empirical support. The development of a manualized intervention to increase treatment adherence for AIS is a new entity that has not before been presented in the literature. Its creation allows for the possibility of increasing AIS adherence rates to a level where the orthopedic community will be able to generally accept the treatment as effective, a status it does not currently hold due to such poor adherence rates. Such a manualized approach to intervention allows multiple people, with various levels of psychological training, to be able to implement the protocol. Therefore an intervention will not rely on experts in both psychological interventions and AIS nonadherence for implementation. This drastically increases the scope of providers.

The results of the proposed study will be able to explore how effective the use of the manual was in increasing bracing adherence based on the self-report measure. It will also explore the effects of the manualized treatment on the treatment outcome, based on the presence of surgery. Since there are no other studies that have used psychologically based interventions to increase treatment adherence with the AIS population, there will be no opportunity to make any direct comparisons with the literature at this time. It will be possible, though, to make comparisons with CBT-based interventions that have been utilized with other chronic pediatric conditions.

More globally, such an intervention may have applications to other chronic pediatric illnesses. With small changes, this manualized intervention could be generalized and used with other populations that struggle with adherence. Changes could be made with relative ease to

make an intervention applicable to specific populations or more general changes could make it applicable to all chronic pediatric illness. Such flexibility would allow for providers to create intervention groups for at risk populations in their areas.

It is important to note, though, that generalizing the intervention to other populations has some limitations. One limitation to this study is the generalizability of the population. Since only adolescent females were used within this study it is not known whether the same manualized protocol will be as effective with a population that includes males. Additionally, since the subject of adherence is of significant interest with behavioral medicine today, it is important to consider if this protocol is generalizable to a larger medical population. This protocol was designed for a specific developmental age group and with a specific known set of psychosocial areas of need. Working with other age groups may not show the same level of effectiveness due to differences in cognition and developmental stage. Additionally, each chronic illness carries its own set of psychosocial areas of difficulty. Though some may overlap with the AIS population, it will not be identical. Since the intervention was designed specifically to target the AIS areas of need, it may not be effective in targeting areas of need seen in other chronic pediatric illnesses.

In addition to limitations of the protocol, there are limitations provided by the study. One known limitation of this study is that that self-report measures have a tendency to produce over reporting and there was not statistical control used for this bias. Since a substantial of the literature uses self-report measures, using this type of measure will allow an easier comparison to the published literature. Nevertheless, it must be assumed that all these studies suffer from some level of over-reporting bias. Lastly, other limitations to the research may appear as the protocol is developed and the study is carried out that cannot be foreseen at this time.

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BRACING FOR IDIOPATHIC SCOLIOSIS

Appendix A

Scoliosis Adherence Manual

Week	Activity	Goal	Intervention	Instructions
Week 1:	Activity 1:	Goal:	Group leader	The leader will address the
Introduction	What is this	Introduction	will introduce	following questions:
	about?	to the group	him or herself	- Why are we here? We are all
	(10 min)		to the group	here today because each one of
			and give an	you has been prescribed a back
			outline of	brace to help treat your
			what the	scoliosis. You have had some
			group is	time to adjust to your bracing
			about.	and have some sense of what
				parts of this treatment are
				easier and more difficult for
				you. Some of you may be
				struggling with wearing your
				brace as often as your doctor
				would like. Others of you may
				be entering a new phase of life
				where you might come across
				more challenges in wearing
				your brace.
				- What are we going to be
				doing? Throughout these twelve
				weeks we will discuss many
				things related your braces, how
				they affect your lives, and some
				of the challenges some of you
				might face as you deal with this
				treatment. We can help each
				other figure out how to handle
				situations and learn from one
				another. We will also learn
				about why the doctor has
				prescribed your brace and
				what the doctor hopes wearing
				it will accomplish.
				- Who am I? The group leader
				gives a little background
				information on his/herself.
				- How long this will go on?
				This will be a twelve-week long
				group. You will have
				homework, though it is not the
				kind of homework you are used

Activity 2: Introduction to each other (10-15 min)	Goal: To get to know one another	Participants will play one or two introduction game(s) to get to know one another	to. Some of it will involve keeping track of things while other homework will require you to practice new skills we have learned in session. Each session is 50 minutes long, and I ask that you are here a little early each week so we can get started right on time. Introduction games can be chosen based on the discretion of the group leader. All games should have the individual's name being used. Some suggestions: Saying a food that starts with same letter as name Saying a favorite activity Saying what school attends Introduce partner: everyone turns to the person next to them and gets to know something about them. The group then gets back together and everyone has to introduce their partner. You can assign specific things people have to learn about their partner (e.g., favorite color, pets, family constellation, etc.) Saying how long you have been in a brace Explaining why you joined the group
Activity 3: Psychoeducation (15-20)	Goal: To ensure that participants have a clear	Learn about scoliosis via both written and oral	- Participants will be given Form E - The leader will go through the information in Form E with the
	understanding of scoliosis, how a brace works, and why they are being braced	methods	participants. The leader can present this information in any way he or she sees fit Participants will have the opportunity to have questions about scoliosis and treatment answered.

Activity 4: Goal: Participants will receive a formula brace monitoring (8 min) Activity 4: Goal: Participants will receive that will be used to hold monitoring sheets and all handouts.	
(0 min) about vyooldy bondouts	
(8 min) about weekly handouts.	
monitoring monitoring Participants will receive their	r
their own sheet (Form first monitoring sheet. The	
brace-wearing A) and will leader will explain how to fi	1
and keeping learn how to out monitoring sheet.	
track of On fill the sheet Participants will record	the
and Off time out time that they put their	
brace on and then the ti	me
they take their brace of	
The difference between	
those two times then	
becomes the "Bracewea	ır
Time". There is room o	n
the forms for participan	ts
to take on and off their	
braces up to five times j	
day. The bracewear tim	
will be added up for the	
"Total Wear Time" for	the
day.	
□ Each day starts at midn	_
and ends at midnight, th	
the first "Time On" slot	
begins at midnight and	
last "Time Off" slot end	
midnight. That does not	
mean that participants h	
to take their braces off a	ıt
midnight and put them	
back on, rather it keeps	
things uniform for each	
day.	
Thus the first time in the	e
morning that the	
participant takes off her	
brace, it will be recorde	
the first open "Time Of	l
slot and when the	
participant puts her brace	
on for the night, it will be recorded in final "Time	Je
recorded in final "Time	
On" slot.	* 7
□ Not all lines for each da	ıy

				have to be used.
	Activity 5: Introducing Robo-calls (2 min)	Goal: Participants will learn about daily reminders to track adherence	The leader will explain that participants will get daily reminders via an automated system to track their	Participants will fill out a form (Form C) that allows them to choose their preferred method of reminder (this form also serves as the weekly attendance)
	Activity 6: Save the Date (1 min)	Goal: To give families enough time to schedule for the family week	Pass out "Save the Date" fliers (Form J) for participants to bring home to their families, with an explanation that families are invited to session ten	
Week 2: Contracting - Rewarding	Activity 1: Sign in (1 min)	Goal: To collect attendance	Participants will fill in Form C	If a participant wants to change a phone number or method of reminder, they may do so at this time
	Activity 2: Review Monitoring (5 min)	Goal: To assess how monitoring of adherence went for the previous week and to ascertain level of adherence for each participant	over the past	After adherence is reviewed, participants will turn in adherence sheets
	Activity 3: Introducing Contracting (25 min)	Goal: To explain what a behavioral contract is and how it will be used within the context of the group.	Participants will contract with each other and the leader, agreeing to a goal adherence for	- Goal Adherence is considered having an adherence rate of the contracted adherence. This is assessed daily. Thus some days a participant may reach or exceed goal, while other days she may not If participants are able to meet

Tracking Form (Form B) given to the participants and on the Data Tracking Form (Form D) kept by the leader. Activity 4: Schedules of Reinforcement (15 min) Activity 4: Schedules of Reinforcement schedule and reviewing the pre			the week. The contracted adherence rate will be written on the Weekly	
D) kept by the leader. D) kept by the leader. D) kept by the leader. Goal Adherence, participants will decide upon a Goal Adherence for the following week. The aim is to meet or exceed this goal daily. If a participant struggles significantly with a goal one week, they will repeat the same contracted adherence rate the next week. Henceforth, each week, after reviewing the previous week's results, participants will contract to meet a new weekly goal. The contract is between a given participant and her peers and leader. Activity 4: Schedules of Reinforcement (15 min) Goal: To learn about will learn that reaching goal adherence has tangible rewards stangible rewards Farticipants will learn about the point system for adhering to contract. Participants will receive one point for each day they reach goal Adherence. Participants will receive one points for every day they reach prescribed adherence. Adherence points will be placed into Form D and Form F for score keeping. Members who have a final score of 105 or higher on Week			Form (Form B) given to the participants and on the Data Tracking	the prescribed adherence rate. - The aim of the contracting exercise is to set optimistic but realistic goals for increased brace-wear for each week. - Based on the adherence for the
Activity 4: Schedules of Reinforcement (15 min) Activity 4: Schedules of Reinforcement for adhering to prescribed brace-wearing Activity 4: Schedule and reward system for adhering to prescribed brace-wearing Activity 4: Schedules of Reinforcement schedule and reward system for adhering to prescribed brace-wearing Activity 4: Schedules of Reinforcement schedule and rewards system for adhering to prescribed brace-wearing Activity 4: Schedules of Reinforcement schedule and rewards system for adhering to prescribed brace-wearing Activity 4: Schedules of Reinforcement schedule and rewards system for adhering to point system for adhering to contract. Participants will learn about the point system for adhering to contract. Participants will receive one point for each day they reach Goal Adherence. Participants will receive one points for every day they reach prescribed adherence. Adherence points will be placed into Form D and Form F for score keeping. Members who have a final score of 105 or higher on Week			D) kept by the	prescribed adherence, participants will decide upon a Goal Adherence for the following week. The aim is to meet or exceed this goal daily If a participant struggles significantly with a goal one week, they will repeat the same
Schedules of Reinforcement (15 min) about reinforcement schedule and reward system for adhering to prescribed brace-wearing brace-wearing about reinforcement schedule and reward system for adhering to prescribed brace-wearing adherence has tangible rewards adherence has tangible rewards Participants will receive one point for each day they reach Goal Adherence. Participants will receive two points for every day they reach prescribed adherence. Adherence points will be placed into Form D and Form F for score keeping. Members who have a final score of 105 or higher on Week				next week Henceforth, each week, after reviewing the previous week's results, participants will contract to meet a new weekly goal. The contract is between a given participant and her peers and leader.
1 I welve will receive a \$25 gift	Schedules of Reinforcement	about reinforcement schedule and reward system for adhering to prescribed	will learn that reaching goal adherence has tangible	the point system for adhering to contract. Participants will receive one point for each day they reach Goal Adherence. Participants will receive two points for every day they reach prescribed adherence. Adherence points will be placed into Form D and Form F for score keeping. Members who have a final score of 105 or higher on Week

	Activity 5	Goal: To	If there is	- Members who have a final score of 70 or higher on Week Twelve will receive a \$10 gift certificate
	(Optional): Ice breaker	increase participants' comfort with each other	available time at the end of the session, the leader can run another activity to help participants get to know one another better.	
Week 3: Mindfulness	Activity 1: Sign in (1 min)	Goal: To collect attendance	Participants will fill in Form C	If a participant wants to change a phone number or method of reminder, they may do so at this time
	Activity 2: Review Monitoring and Contracting (15 min)	Goal: To assess how monitoring of adherence went for the previous week and to ascertain level of adherence for each participant	Participants will show adherence sheets and relay the level of adherence over the past week	- Participants will then tally up the number of points they have earned over the past week. - Participants will receive one point for each day they reach goal adherence. - Participants will receive two points for every day they reach prescribed adherence. -After adherence is reviewed, participants will turn in adherence sheets.
		Goal: To contract with participant for adherence for new week.	Based upon the previous week's adherence, the participant, peers, and leader will decide on a new goal	Participants will be given new copy of Form B, fill in, and sign the contract
	Activity 3: Introduction to Mindfulness (35 min)	Goal: To teach a coping technique to help	Quiet Mindfulness and Subsequent	- Participants will be introduced to the concept of mindfulness as a way to "become relaxed and detached so you can become in

	participants become more in touch with their bodies, feelings, and bracing experiences	Reflection	better touch with your own thoughts and feelings." - Participants will be instructed that for a short period for each of the subsequent weeks, the group will work on their mindfulness skills This first week we will practice both in and out of the brace. First with participants wearing their braces and next with participants out of their braces How do we practice mindfulness? Participants will sit quietly in a comfortable position. They will close their eyes then listen to the leader's voice as s/he reads the following instructions slowly and evenly, in a quiet and soothing voice: In Brace Instructions: "I want everyone to find a place they find comfortable for them. You may cross your legs if you would like. You may sit on the floor if you like. I want you to find a place where you can be completely relaxed. Close your eyes and rest your arms comfortably by your sides. Now I want you to pay attention to your hands. Think about where they are resting. Are they on your lap? Are they by your sides? Are they cold or warm? Do they tingle? Now move up to your arms. Are they tight or loose? And now up to your shoulders. Are they relaxed? Do you feel your brace digging into your armpits? Is your brace
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		digging into anywhere else
		in your body? Does it
		pinch? And now focus on
		your torso. Are you hot
		and sticky? Or are you
		comfortable? Are you
		having any pain? What
		kind of pain? Is it sharp?
		Or throbbing? Do you
		have cramping anywhere?
		I want you to focus on
		what hurts but also focus
		on what doesn't. What
		parts of your body did you
		not notice until now. Stay
		with your thoughts. If any
		feelings come up,
		recognize those feelings
		and them let them pass. Do
		not get overwhelmed by
		your feelings. Realize you
		have them and then think
		about where the feeling
		came from – why you just
		had this feeling. When you
		are done, put the feeling
		aside. Remain sitting
		quietly until I tell you that
		you may open your eyes.
		Give Participants 2-3
		minutes of silent time,
		based upon what they seem
		able to tolerate.
		- Next have participants open
		their eyes and come back into a
		group. Spend some time
		processing the exercise. First
		focus on what it was like to sit
		for a few minutes quietly like
		this. Make sure all participants
		talk. Second, move to the
		experience. Find out where
		people's thoughts went. Did
		they notice anything they had
		not noticed before? Try to not
		only dwell on what hurts but
		experience. Find out where people's thoughts went. Did they notice anything they had not noticed before? Try to not

what did not hurt, as well. Make sure everyone speaks and try to illicit at least one positive response from each person.

Now have all participants take off their braces (if they need assistance encourage them to assist each other) and go back to that comfortable place in the room. Ensure them that they will only be out of brace for a few minutes, though they should all remember to log this as out of brace time.

Out of Brace Instructions: "I want everyone to find a place where they can sit comfortably. You may cross your legs if you would like. You may sit on the floor if you like. I want *you to find a place where* you can be completely relaxed. Now close your eyes and rest your arms comfortably by your sides. Now I want you to pay attention to your hands. Think about where they are resting. Are they on your lap? Are they by your sides? Are they cold or warm? Do they tingle? Now move up to your arms. Are they tight or loose? And now up to your shoulders. Are they relaxed or tight? What about your neck? And now move down your body slowly. Pay attention to your torso. Are you cold or warm? Does anything hurt? What parts of your body did you not notice until now. Stay with your thoughts. If any

minutes of silent time, based upon what they seem able to tolerate. -Ask how it was different than the first time. Try to get participants to identify at least one difference and once similarity. - Finally, after participants have an opportunity to get their braces back on, talk about the exercise. What was it like to sit, focusing on their bodies? Was it hard or easy? Did anyone struggle? Remind them that it is okay for their thoughts to wander from the moment and the room. - Participants should encouraged to try and take a few minutes every day to practice this mindfulness skill. At this point go around the group and ask each participant to suggest a good time they might practice this skill during the day. If participants are having trouble coming up with a time, suggest that their time be right as they wake up or right as they wake up or right as they wake up or right as they or to bed. Week 4: Activity 1: Goal: To Participants If a participant wants to change	based upon what they seem able to tolerate.
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Goal Setting	Sign in (1 min)	collect attendance	will fill in Form B	a phone number or method of reminder, they may do so at this time
	Activity 2: Review Monitoring and Contracting (10-15 min)	Goal: To assess how monitoring of adherence went for the previous week and to ascertain level of adherence for each participant	Participants will show adherence sheets and relay the level of adherence over the past week	 Participants will then tally up the number of points they have earned over the past week. Participants will receive one point for each day they reach goal adherence. Participants will receive two points for every day they reach prescribed adherence. After adherence is reviewed, participants will turn in adherence sheets.
	Activity 3: Mindfulness Practice (5-10 min)	Goal: To continue to gain a better understanding of experiences	Participants will practice mindfulness in the group and reflect on the experience	- First check in to see who has practiced over the past week and how it has gone Read through the appropriate prompt. Continue to increase the length of time participants sit quietly, working towards a goal of five minutes. Once this goal is reached, continue with five minutes of mindfulness each week After the session is over, always make sure to spend at least some time reflecting upon the experience. See who has noticed something new or if something has changed from a previous week.
	Activity 4: Goal Setting (35 min)	Goal: To learn how to set positive, realistic goals for adherence and the bracing process	Participants will have the opportunity to discuss both bracing goals and current barriers to such goals	- The clinician will facilitate a discussion around bracing goals. All participants will have the opportunity to present current and future goals about bracing adherence - Each participant will identify potential barriers to their goals. " With each barrier presented, the group will discuss how that individual could overcome this

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	Activity 5: Contracting	Goal: To contract with participant for adherence for new week.	Based upon the previous week's adherence, the participant, peers, and leader will come to a consensus about a new goal	barrier. Participants will identify what type of barrier this is (e.g., scheduling, pain, psychological, etc.). On the following week, participants will report back to see if the barrier could be overcome as a result of the discussion in the group. The focus of the discussion should be on setting positive, realistic goals for success. Participants are all in a different place with regard to their adherence. Goals need to be individualized for each participant, each week moving slightly closer towards full adherence. Participants will be given new copy of Form B, fill in, and sign the contract
Week 5:	Activity 1:	Goal: To	Participants	If a participant wants to change
Relaxation	Sign in	collect	will fill in	a phone number or method of
Techniques	(1 min)	attendance	Form C	reminder, they may do so at this
				time
	Activity 2:	Goal: To	Participants	- Participants will then tally up
	Review	assess how	will show	the number of points they have
	Monitoring and	monitoring of	adherence	earned over the past week.
	Contracting	adherence	sheets and	 Participants will receive
	(10 min)	went for the	relay the level	one point for each day they
		previous week		reach goal adherence.
		and to	over the past	 Participants will receive
		ascertain level	week	two points for every day
		of adherence		they reach prescribed
		for each		adherence.

	participant		-Participants can check in about barriers to goals that come up and how they may have been overcomeAfter adherence is reviewed, participants will turn in adherence sheets.
	Goal: To contract with participant for adherence for new week.	Based upon the previous week's adherence, the participant, peers, and leader will come to a consensus about a new goal	Participants will be given new copy of Form B, fill in, and sign the contract
Activity 3: Mindfulness Practice (5-10 min)	Goal: To continue to gain a better understanding of experiences (can skip this week if time constrain or wait until the end of the week to assess for time)	Participants will practice mindfulness in the group	- First check in to see who has practiced over the past week and how it has gone Read through the appropriate prompt. Continue to increase the length of time participants sit quietly, working towards a goal of five minutes. Once this goal is reached, continue with five minutes of mindfulness each week After the session is over, always make sure to spend at least some time reflecting upon the experience. See who has noticed something new or if something has changed from a previous week.
Activity 4: Relaxation Techniques (20-25 min)	Goal: Participants will learn two techniques for relaxation and pain management	Participants will learn Deep Breathing	 The clinician will introduce the concept of deep breathing as a way to relax and help pain subside. The clinician will lead the participants in the following exercise, making sure to read slowly and evenly: I want everyone to close their eyes. Get comfortable

four. Out, two, three, four. Now, we will start with your toes and feet. Flex your feet and curl your toes as hard as you can. Keep tightening. Feel how bent your feet are and tight your toes are. Keep them tight for just a little longer. Now relax. Let go of the tension. Let your feet flop and your toes uncurl to a comfortable place. Do your feet and toes feel relaxed? Good. Now, we will move to our legs. Tighten all the muscles of your legs. Start with your calves, then move up to your thighs. Tense the muscles further. Hold onto this tension. Feel how tight and tensed the muscles in your legs are right now. Squeeze the muscles harder, tighter... Continue to hold this tension. Hold it a few seconds more... and now relax. Let all the tension go. Feel the muscles in your legs going limp, loose, and relaxed. Notice how relaxed the muscles feel now. Feel the difference between tension and relaxation. We will move to your upper body now. Ball up your fists, squeezing as tightly as possible. Squeeze so hard that your nails dig into your hands. Continue to squeeze. Harder.... harder... and relax. Notice how calm and relaxed your hands feel now. Enjoy this

feeling. We will now move to our arms. Tighten your biceps and triceps, move to your lower arm and tighten those muscles as well. Move up to your shoulders and tighten the muscles by your neck. Let your arms raise as you tighten your shoulders so much they are practically up by your ears. Tense the muscles in your arms as tightly as you can. Squeeze harder.... harder.... hold the tension in vour arms and shoulders. Hold it for a few more moments.... and now release. Let the muscles of your arms and shoulders relax and go limp. Feel the relaxation as your shoulders lower into a comfortable position and your arms relax at your sides. Focus again on your breathing. Slow, even, regular breaths. Breathe in relaxation.... and breathe out tension.... in relaxation...and out tension.... Continue to breathe slowly and rhythmically. Now focus on the muscles of your rear. Tighten these muscles as much as you can. Hold this tension.... and then release. Relax your muscles. We will now move to our core. Tighten the muscles of your stomach... the muscles of your chest... Keep squeezing... Feel your front contract as these muscles squeeze and

your body pushes against your brace. Squeeze as tightly as you can. Now relax. Finally we will move to the muscles of our backs. Feel your back tighten, the back of your shoulders and your spine as it tightens and tries to arch against your brace. Continue to squeeze. Pay attention to which parts of your back feel the most pressure as you do this. Now you can relax. Let all the muscles in your body go as you remain still breathing. Pay attention to your back. Does it hurt more or less? Feel how relaxed your body is compared to before. Enjoy it. We will now move back to our breathing, remaining calm and relaxed as we do so. In. two, three, four. Out, two, three, four. Continue breathing as you enjoy the calm.... Good job everyone. When you are ready to rejoin the group, you may reawaken your body. You might want to take a deep stretch, reaching your arms towards the sky, You can wiggle your toes and legs... your fingers and arms. Welcome back everyone. - Allow participants to discuss how the experience made them feel. - Allow participants to come up with times this activity could be

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Week 6: Altering Negative Perceptions	Activity 1: Sign in (1 min) Activity 2: Review	Goal: To collect attendance Goal: To assess how	Participants will fill in Form C Participants will show	used (e.g., before going to bed at night, when taking some space to cool down) - Allow participants to discuss the merits of each relaxation technique. - Participants will be given Form G (Relaxation Techniques) in case they would like to review the scripts at home when using the techniques. If a participant wants to change a phone number or method of reminder, they may do so at this time - Participants will then tally up the number of points they have
	Monitoring and Contracting (15 min)	monitoring of adherence went for the previous week and to ascertain level of adherence for each participant	adherence sheets and relay the level of adherence over the past week	earned over the past week. Participants will receive one point for each day they reach goal adherence. Participants will receive two points for every day they reach prescribed adherence. After adherence is reviewed, participants will turn in
		Goal: To contract with participant for adherence for new week.	Based upon the previous week's adherence, the participant, peers, and leader will come to a consensus about a new goal	adherence sheets. Participants will be given new copy of Form B, fill in, and sign the contract
	Activity 3: Mindfulness Practice (5 min)	Goal: To continue to gain a better understanding of experiences (can skip this	Participants will practice mindfulness in the group and reflect on the experience	 First check in to see who has practiced over the past week and how it has gone. Read through the appropriate prompt. Continue to increase the length of time participants sit

	week if time constrain or wait until the end of the week to assess for time)		quietly, working towards a goal of five minutes. Once this goal is reached, continue with five minutes of mindfulness each week. - After the session is over, always make sure to spend at least some time reflecting upon the experience. See who has noticed something new or if something has changed from a previous week.
Activity 4: Altering Negative Perceptions (25 min)	Goal: To gain insight into individual negative perceptions	Participants will learn about automatic thoughts and how to alter them	- Clinician will start by asking participants what they think about first when they think of their braces. (If there is a dry erase board or large poster, writing these thoughts out may be helpful.) - Clinician will use some these examples given by participants to introduce the concept of automatic thoughts Example Explanation: An automatic thought is a thought that comes to your mind automatically in response to something. Everyone has automatic thoughts about almost everything. Sometimes, though, our automatic thoughts about a specific person, thing, or situation, are not productive. When I asked you to tell us the first thing that comes to mind when you think of your brace, each of you responded with an automatic thought. For some of you those automatic thoughts may have been negative and conflict with your ability to succeed in this treatment process. We are going to talk today about how we can change these automatic thoughts so that they are move adaptive to our

Week 7: Contingency	Activity 1: Sign in	Goal: To collect	Participants will fill in	functioning. - Provide participants with a copy of Form H. Explain that these are the different ways we might approach or react to a situation to cause a negative automatic thought. The questions in the second column can help us analyze our automatic thoughts to figure out if they are useful. - Clinician will walk through each automatic thought the group members gave and help the group to categorize and analyze the thought. Ideally alternative, more positive ideas can be provided for each automatic thought. - Encourage participants to try to reflect on their automatic thoughts at home over the coming week. If a participant wants to change a phone number or method of
Management	Activity 2: Review Monitoring and Contracting (10 min)	attendance Goal: To assess how monitoring of adherence went for the previous week and to ascertain level of adherence for each participant Goal: To	Form C Participants will show adherence sheets and relay the level of adherence over the past week Based upon	reminder, they may do so at this time - Participants will then tally up the number of points they have earned over the past week. Description Participants will receive one point for each day they reach goal adherence. Participants will receive two points for every day they reach prescribed adherence. -After adherence is reviewed, participants will turn in adherence sheets. Participants will be given new
		contract with participant for adherence for new week.	the previous week's adherence, the participant, peers, and	copy of Form D, fill in, and sign the contract

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		leader will	
		come to a	
		consensus	
		about a new	
		goal	
Activity 3:	Goal: To	Participants	- Give each participant time to
=	reinforce skill	-	_ = =
Negative		will report in	report on any success in altering
Thoughts Follow	learned last	on success in	any negative automatic thoughts
Up	week	altering	from the past week.
(10 min)		negative	- Give positive praise for use of
		automatic	new skill
		thoughts	
Activity 4:	Goal: To learn		- Ask participants to share any
Problem Solving	how to handle	will learn how	experiences that they may have
(25 min)	unusual or	to develop	had that made adherence
(20 11111)	unexpected	multiple	especially hard. They can be
	situations	contingencies	one-time experiences or an
	Situations	_	l =
		for a situation	ongoing situation.
		and problem	- Ask participants to explain
		solve to find	how they handled the situation.
		the most	- Ask participants to explain
		useful	how they came to the decision
		contingency	of how to handle the situation.
			- Explain that this process of
			coming to a decision is called
			problem solving.
			Deptional Script: With
			problem solving, you come
			up with a bunch of
			different options and then
			choose the best one. How
			do you know which is the
			best one? Most likely, even
			if you didn't realize it, you
			thought of a bunch of
			alternative choices, and
			then examined the outcome
			of each choice. Ultimately,
			_
			you probably picked the
			choice with the outcome
			that most fit with your
			desired goal. The process
			of problem solving allows
			us to analyze our choices
			and come up with the
			optimal one based on the
			optimat one basea on the

				potential outcomes. - Hand out Form I. Explain that Form I is a template for problem solving. Participants are not expected to fill out a similar form for every situation they must problem solve. More likely, they are going through the steps of problem solving in their heads to come up with an answer. Go over the steps in problem solving. Go over example. The group will take some time, perhaps choosing some problems participants have yet to solve, and complete Form I for each problem. Encourage participants to try this new technique out in the coming week.
	Activity 5 (Optional):	Goal: To continue to	Participants will practice	- First check in to see who has practiced over the past week and
	Mindfulness	gain a better	mindfulness	how it has gone.
	Practice	understanding	in the group	- Read through the appropriate
		of experiences	and reflect on	prompt. Continue to increase the
		(if time permits).	the experience	length of time participants sit quietly, working towards a goal
		permits).		of five minutes. Once this goal
				is reached, continue with five minutes of mindfulness each week.
				- After the session is over, always make sure to spend at
				least some time reflecting upon
				the experience. See who has
				noticed something new or if something has changed from a
				previous week.
Week 8:	Activity 1:	Goal: To	Participants	If a participant wants to change
Decision	Sign in	collect	will fill in	a phone number or method of

Making	(1 min)	attendance	Form B	reminder, they may do so at this time
	Activity 2: Review Monitoring and Contracting (10-15 min)	Goal: To assess how monitoring of adherence went for the previous week and to ascertain level of adherence for each participant	Participants will show adherence sheets and relay the level of adherence over the past week	 Participants will then tally up the number of points they have earned over the past week. Participants will receive one point for each day they reach goal adherence. Participants will receive two points for every day they reach prescribed adherence. After adherence is reviewed, participants will turn in adherence sheets.
		Goal: To contract with participant for adherence for new week.	Based upon the previous week's adherence, the participant, peers, and leader will come to a consensus about a new goal	Participants will be given new copy of Form B, fill in, and sign the contract
	Activity 3: Mindfulness Practice (10 min)	Goal: To continue to gain a better understanding of experiences.	Participants will practice mindfulness in the group and reflect on the experience	- First check in to see who has practiced over the past week and how it has gone Read through the appropriate prompt. Continue to increase the length of time participants sit quietly, working towards a goal of five minutes. Once this goal is reached, continue with five minutes of mindfulness each week After the session is over, always make sure to spend at least some time reflecting upon the experience. See who has noticed something new or if something has changed from a previous week.
	Activity 4: Problem Solving	Goal: Reinforce	Participants will report on	- Allow participants time to report in on any use of this new

	Check-In	skills learned	success in	skill this week.
	(5 min)	last week	using problem	
	(6)		solving to	skill through verbal praise.
			address	
			unexpected	
			situations	
	Activity 5:	Goal: To	Participants	- Start by having participants
	Decision Making	place locus of	will learn to	report their level of the
	(25 min)	control with	own their	agreement with the following
		participants	control over	statements "I WANT TO
			treatment	WEAR MY BRACE AS
				PRESCRIBED" and "IT IS
				ULTIMATELY MY
				DECISION WHETHER OR
				NOT I WEAR MY BRACE"
				- Remind participants that
				regardless of who else may be
				part of the treatment team
				(doctors, nurses, family, group,
				counselors/clinicians), it is ultimately up to each patient to
				decide if they will adhere to
				treatment. No one else can make
				them adhere.
				- Discuss positive and negative
				consequences of adhering
				versus not adhering. (Could use
				dry erase board to create lists of
				each)
				- Discuss level of control
				participants feel for brace-
				wearing.
				- Address specifically any
				participants who are reporting
				little to no control over brace-
				wearing. Take the time to
				explore why participants feel
				that way, and if necessary work
				to alter some automatic
				thoughts.
Week 9:	Activity 1:	Goal: To	Participants	If a participant wants to change
Social	Sign in	collect	will fill in	a phone number or method of
Support	(1 min)	attendance	Form C	reminder, they may do so at this
	A .: :. 2	C 1 T	D	time
	Activity 2:	Goal: To	Participants	- Participants will then tally up
	Review	assess how	will show	the number of points they have

Monitoring and Contracting (15 min)	monitoring of adherence went for the previous week and to ascertain level of adherence for each participant	over the past	earned over the past week. Participants will receive one point for each day they reach goal adherence. Participants will receive two points for every day they reach prescribed adherence. After adherence is reviewed, participants will turn in adherence sheets.
	Goal: To contract with participant for adherence for new week.	Based upon the previous week's adherence, the participant, peers, and leader will come to a consensus about a new goal	Participants will be given new copy of Form B, fill in, and sign the contract
Activity 3: Mindfulness Practice (10 min)	Goal: To continue to gain a better understanding of experiences	Participants will practice mindfulness in the group and reflect on the experience	- First check in to see who has practiced over the past week and how it has gone Read through the appropriate prompt. Continue to increase the length of time participants sit quietly, working towards a goal of five minutes. Once this goal is reached, continue with five minutes of mindfulness each week After the session is over, always make sure to spend at least some time reflecting upon the experience. See who has noticed something new or if something has changed from a previous week.
Activity 4: Discussion on Social Support (25 min)	Goal: To gain an understanding of the importance of social support.		 Start by acknowledging the importance of friends and a social life. Ask how many participants have told friends about the bracing.

communities	For those who have
Communicies	disclosed:
	$\sqrt{\text{How did these}}$
	disclosures happen?
	√ How many people
	know?
	√ What were their
	reactions?
	√ Are you glad you told
	them?
	For those who haven't
	disclosed
	$\sqrt{\text{Why haven't they}}$
	disclosed?
	√ What fears might there be about disclosing?
	- Address the importance of
	having social support in order to
	get the through the treatment
	successfully
	- Come up with a list of Pro's
	and Con's (on dry erase board if
	available) for disclosing to
	friends.
	 Have participants identify
	why adherence may be
	easier if friends know of
	and are supportive about
	their bracing (e.g.,
	someone to help them get
	in and out of the brace at
	school, choosing social
	activities that are easier in
	the brace).
	 Have participants identify
	what barriers to adherence
	may occur if friends know.
	 If any negative or
	destructive perceptions
	present in either column,
	take some time to use the
	'altering automatic
	thoughts' skills to address
	these perceptions.
	- Develop a script for how
	participants may disclose the

	1	1	
			treatment to friends.
			 Use the experiences of
			those who have already
			made disclosures to guide
			the script.
			 Ensure that the script
			includes:
			It is not contagious
			$\sqrt{1}$ I am still the same
			person
			$\sqrt{\text{How things will stay}}$
			the same (almost
			everything)
			√ What things might
			change
			√ It will not kill me
			- For those who have not yet
			disclosed, have them identify at
			least one person that they would
			like to disclose to – encourage
			them to do so in the next week.
Activity 5:	Goal: To	Participants	- People who can come:
Introduction to	explain	will be	 People who can come. All family members over
Family Week	Family Week	reminded that	the age of five are
(2 min)	Tallilly WCCK	next week is	welcome to attend.
(2 min)		family week	If a participant has a family
		lailing week	member under the age of
			five and they would like
			them to be there AND
			think the child can handle
			the session, inform them
			this is okay. Encourage participants to
			Encourage participants to
			try and get multiple family
			members to attend, but
			remind them that
			attendance of at least one
			family member is
			mandatory (though there
			will be no consequences if
			there is no available family
			member).
			If immediate family is
			unable to attend, but a
			close member of the
			extended family is

	1		1	
Week 10: Family Week	Activity 1: Introduce Families	Goal: To include families in	Introduce treatment techniques to	available OR if there are close members of the extended family (e.g., grandparents, aunts, uncles) that participants would like in attendance, this is fine as well. Review how the session will run Family members will be in the room the entire time to see how All the regular things will happen with families present. We will review techniques learned in previous weeks. If possible have different participants volunteer to take the lead on explaining different techniques. Use Form L to assign different topic areas. Start this week by having each participant introduce the family members who have come.
Week	(5 min)	treatment	families	- Explain that the session will be spent showing the families what we do each week and the treatment techniques that have been learned so far.
			Address concerns families may have	Families will also have the opportunity to ask any questions or address any concerns they have towards the end of the session
	Activity 2: Sign in (5 min)	Goal: To collect attendance	Participants will fill in Form C	- If a participant wants to change a phone number or method of reminder, they may do so at this time - Have designated participant explain the sign in process and the robo-call process.
	Activity 3: Review Monitoring and	Goal: To assess how monitoring of	Participants will show adherence	- Have designated participant(s) explain how monitoring, contracting, rewards, and goal

Contr. (20 n	racting nin)	adherence went for the previous week and to ascertain level of adherence for each participant	sheets and relay the level of adherence over the past week	setting work - Participants will then tally up the number of points they have earned over the past week. □ Participants will receive one point for each day they reach goal adherence. □ Participants will receive two points for every day they reach prescribed adherence. -After adherence is reviewed, participants will turn in adherence sheets.
		Goal: To contract with participant for adherence for new week.	Based upon the previous week's adherence, the participant, peers, and leader will come to a consensus about a new goal	Participants will be given new copy of Form B, fill in, and sign the contract
		Goal: To give a brief overview of the information participants learned	Present material to families	Have the designated participant(s) give a quick overview of what they have learned about the bracing process
		Goal: To continue to gain a better understanding of experiences	Participants will practice mindfulness in the group and reflect on the experience	- Have designated person explain what mindfulness is and why it is used Then check in to see who has practiced over the past week and how it has gone Begin with deep breathing. Read through the "in brace" prompt. Allow for a three- minute mindfulness exercise After the session is over, spend a little time reflecting upon the experience. See who has noticed something new or if something

			has changed from a previous week. Have family members share their experiences with the exercise.
Activity 6: Relaxation Review (10 min)	Goal: To expose family members to relaxation	Designated participant will explain the goal and process of the two relaxation techniques used	 Allow time to complete a deep breathing exercise using the prompt from the original activity Encourage participants to lead their families in a progressive muscle relaxation exercise at home (due to time constraints).
Activity 7: Cognitive Techniques Review (25 min)	Goal: To explain the cognitive techniques that have been presented and learned in session	Have assigned participants explain the concepts and interventions involved	`
Activity 8: Disclosures (20 min)	Goal: To teach families about the benefit of telling others.	Discuss with participants and their families who has been informed of the treatment.	- Ask participants if any new disclosures have been made in the past week and how they went Have designated participant explain the social support discussion from the previous week Ask families what kinds of disclosures they have made to other family members and friends Lead a processing group about the importance of disclosure, barriers to disclosure, and fears associated with disclosure. Encourage participants to explain the importance of disclosure to their families.
Activity 9: Questions,	Goal: To address any	Allow a time for questions	Address families questions and, whenever possible, refer back to

Week 11: Open – If there are	Comments, Concerns (10 min) Activity 10: Goodbye (1 min) Activity 1: Sign in (1 min)	questions, comments, or concerns family members may have Goal: Thank Family for Participation Goal: To collect attendance	Participants will fill in Form C	previously explained interventions Remind participants that they have two weeks left. If a participant wants to change a phone number or method of reminder, they may do so at this
specific topics that the clinician feels are important to address or to bring back up for more discussion, this is the time to do so. It is up to the group leader to	Activity 2: Review Monitoring and Contracting (15 min)	Goal: To assess how monitoring of adherence went for the previous week and to ascertain level of adherence for each participant	over the past	- Participants will then tally up the number of points they have earned over the past week. - Participants will receive one point for each day they reach goal adherence. - Participants will receive two points for every day they reach prescribed adherence. - After adherence is reviewed, participants will turn in adherence sheets.
decide what will be the specific content of the session (new or otherwise).	A ativity 2:	Goal: To contract with participant for adherence for new week.	Based upon the previous week's adherence, the participant, peers, and leader will come to a consensus about a new goal	Participants will be given new copy of Form B, fill in, and sign the contract
	Activity 3: Mindfulness Practice (10 min)	Goal: To continue to gain a better understanding of experiences (can skip this week if time constrain or wait until the	Participants will practice mindfulness in the group and reflect on the experience	 First check in to see who has practiced over the past week and how it has gone. Read through the appropriate prompt. Continue to increase the length of time participants sit quietly, working towards a goal of five minutes. Once this goal is

		end of the week to assess for time)		reached, continue with five minutes of mindfulness each week. - After the session is over, always make sure to spend at least some time reflecting upon the experience. See who has noticed something new or if something has changed from a previous week.
	Activity 4: Reflect on Previous Week (5 min)	Goal: To process the family experience	Lead a discussion on the experience of including the family.	Have participants share any feedback the family members may have given and if any concerns arose.
	Activity 5: Activity or Subject of Leaders Choosing (25 min)	Goal: To allow flexibility in treatment plan to provide for unexpected or previously unaddressed content areas	Clinician's choosing	
Week 12: Wrap Up	Activity 1: Sign In (1 min)	Goal: Attendance	Participants will sign in on Form C.	
	Activity 2: Mindfulness Practice (10 min)	Goal: To continue to gain a better understanding of experiences	Participants will practice mindfulness in the group and reflect on the experience	exercise After the session is over, always make sure to spend at least some time reflecting upon the experience. See who has noticed something new or if something has changed from a previous week.
	Activity 3: Review of Progressive Muscle Relaxation	Goal: To have another experience with guided Progressive	Participants will be led through the Progressive Muscle	Clinician can refer back to session five for the script.

(10 min)	Muscle Relaxation	Relaxation technique used in session five.	
Activity 4: Negative Thoughts Follow up (5 min)	Goal: To reinforce changing automatic thoughts	Participants will report in on success in altering negative automatic thoughts.	 Give each participant time to report on any success in altering any negative automatic thoughts from the past few weeks. Identify any areas participants may still be struggling with and spend some time addressed the thoughts.
Activity 5: Problem Solving Follow Up (5 min)	problem solving skills	Participants will report on uses and successes in problem solving	 Give each participant time to report on any successes in problem solving over the past few weeks. Allow participants some time to problem solve as a group any new or particularly difficult problems that have arose.
Activity 6: Decision Makin Follow Up (5 min)	Goal: To reinforce positive decision making	Remind participants that it is ultimately their choice to adhere.	Remind them why and how they have the skills to be successful.
Activity 7: Social Support Follow Up (5 min)	Goal: To reinforce the importance of social support	Inquire about any new disclosures that have been made since the discussion. Find out if participants have new plans to make disclosures. Find out if family members have made disclosures since the family session	What has changed for people with their relationships with friends or family who now know?
Activity 8: Review	Goal: To assess how	Participants will pull out	- Participants will then tally up the number of points they have

-Tally up total adherence and those who meet the preset goals will receive the appropriate prizes. - Praise everyone for the hard	Report Tools (10 min)	monitoring of adherence went for the previous week and to ascertain level of adherence for each participant	over the past	earned over the past week - Participants will receive one point for each day they reach goal adherence Participants will receive two points for every day they reach prescribed adherence After adherence is reviewed, participants will turn in
participant participants will turn in adherence sheetsTally up total adherence and those who meet the preset goals will receive the appropriate prizes Praise everyone for the hard				±
adherence sheets. -Tally up total adherence and those who meet the preset goals will receive the appropriate prizes. - Praise everyone for the hard				, ,
those who meet the preset goals will receive the appropriate prizes. - Praise everyone for the hard		participant		<u> </u>
will receive the appropriate prizes Praise everyone for the hard				v 1
prizes Praise everyone for the hard				1 0
				11 1
I I I I I I I I I I I I I I I I I I I				- Praise everyone for the hard work they did.

Appendix B

Form A: Week One Tracking Sheet

	Day 1			Day 2			Day 3	
Time On	Time Off	① In Brace	Time On	Time Off	① In Brace	Time On	Time Off	① In Brace
12:00 _{AM}	•AM/PM		12:00 _{AM}	•AM/PM		12:00 _{AM}	•AM/PM	
•AM/PM	• AM/PM		•AM/PM	• AM/PM		• AM/PM	•AM/PM	
•AM/PM	• AM/PM		•AM/PM	• AM/PM		• AM/PM	•AM/PM	
•AM/PM	• AM/PM		•AM/PM	• AM/PM		• AM/PM	•AM/PM	
•AM/PM	12:00 _{AM}		•AM/PM	12:00 _{AM}		AM/PM	12:00 _{AM}	
Total Time I	In Brace:		Total Time In Brace: Total Time In Brace:			In Brace:		

	Day 4		Day 5 Day 6					
Time On	Time Off	① In Brace	Time On	Time Off	① In Brace	Time On	Time Off	① In Brace
12:00 _{AM}	•AM/PM		12:00 _{AM}	AM/PM		12:00 _{AM}	•AM/PM	
AM/PM	•AM/PM		•AM/PM	AM/PM		•AM/PM	•AM/PM	
•AM/PM	AM/PM		•AM/PM	•AM/PM		•AM/PM	•AM/PM	
•AM/PM	•AM/PM		•AM/PM	•AM/PM		•AM/PM	•AM/PM	
•AM/PM	12:00 _{AM}		AM/PM	12:00 _{AM}		AM/PM	12:00 _{AM}	
Total Time	In Brace:		Total Time In Brace: Total Time In Brace:					

Day 7					
Time On	Time Off	① In Brace			
12:00 _{AM}	•AM/PM				
•AM/PM	•AM/PM				
•AM/PM	•AM/PM				
•AM/PM	•AM/PM				
•AM/PM	12:00 _{AM}				
Total Time In Brace:					

Averag Total Weekly Time	ge Weekly Time
	7
Average Weekly Time	

Form B: Weekly Contract and Tracking Sheet

I, , will try my hardest to wear my brace
hours each day of the next week. I realize I may not be able to meet my goal
every day, but I will strive to do so. I acknowledge that by signing this contract I am entering
into an agreement between the other members of my group, my group leader, and myself.
Signature:

	Day 1			Day 2		Day 3		
Time On	Time Off	① In Brace	Time On	Time Off	① In Brace	Time On	Time Off	① In Brace
12:00 _{AM}	•AM/PM		12:00 _{AM}	•AM/PM		12:00 _{AM}	• AM/PM	
•AM/PM	•AM/PM		•AM/PM	•AM/PM		•AM/PM	••AM/PM	
•AM/PM	•AM/PM		•AM/PM	•AM/PM		•AM/PM	••AM/PM	
•AM/PM	•AM/PM		AM/PM	•AM/PM		•AM/PM	• AM/PM	
•AM/PM	12:00 _{AM}		•AM/PM	12:00 _{AM}		•AM/PM	12:00 _{AM}	
Total Time I	In Brace:		Total Time In Brace: Total Time In Brace:					

Day 4			Day 5			Day 6		
Time On	Time Off	① In Brace	Time On	Time Off	① In Brace	Time On	Time Off	① In Brace
12:00 _{AM}	•AM/PM		12:00 _{AM}	•AM/PM		12:00 _{AM}	• AM/PM	
•AM/PM	•AM/PM		•AM/PM	•AM/PM		AM/PM	•AM/PM	
AM/PM	•AM/PM		AM/PM	•AM/PM		•AM/PM	AM/PM	
AM/PM	•AM/PM		• AM/PM	•AM/PM		•AM/PM	•AM/PM	
•AM/PM	12:00 _{AM}		•AM/PM	12:00 _{AM}		•AM/PM	12:00 _{AM}	
Total Time In Brace: Total T		Total Time I	In Brace:		Total Time I	In Brace:		

Day 7					
Time On	Time Off	① In Brace			
12:00 _{AM}	AM/PM				
•AM/PM	•AM/PM				
•AM/PM	•AM/PM				
•AM/PM	•AM/PM				
•AM/PM	12:00 _{AM}				
Total Time In Brace:					

Average Total Weekly Time	ge Weekly Time
	7
Average Weekly Time	

Form C SIGN IN SHEET

1.	Name	7. Name
	Phone Number: ()	Phone Number: ()
	Call Text	Call Text
2.	Name	8. Name
	Phone Number: ()	Phone Number: ()
	Call Text	Call Text
3.	Name	9. Name
	Phone Number: ()	Phone Number: ()
	Call Text	Call Text
4.	Name	10. Name
	Phone Number: ()	Phone Number: ()
	Call Text	Call Text
5.	Name	
	Phone Number: ()	
	Call Text	
6.	Name	
	Phone Number: ()	
	Call Text T	

BRACING FOR IDIOPATHIC SCOLIOSIS

Form D DATA TRACKING FORM

Name:	Doc Rec	Goal	Actual	Points
Week 2				
Week 3				
Week 4				
Week 5				
Week 6				
Week 7				
Week 8				
Week 9				
Week 10				
Week 11				

Name:	Doc Rec	Goal	Actual	Points
Week 2				
Week 3				
Week 4				
Week 5				
Week 6				
Week 7				
Week 8				
Week 9				
Week 10				
Week 11				

Name:	Doc Rec	Goal	Actual	Points
Week 2				
Week 3				
Week 4				
Week 5				
Week 6				
Week 7				
Week 8				
Week 9				
Week 10				
Week 11				

Name:	Doc Rec	Goal	Actual	Points
Week 2				
Week 3				
Week 4				
Week 5				
Week 6				
Week 7				
Week 8				
Week 9				
Week 10				
Week 11				

^{*} Doc Rec indicates the amount of time the individual's orthopedist has recommended that the individual wear the brace. This time should remain the same for all weeks.

Form E POINTS CHART

Name					
Wk 2					
Wk 3					
Wk 4					
Wk 5					
Wk 6					
Wk 7					
Wk 8					
Wk 9					
Wk 10					
Wk 11					

^{*} Row 1 for each week contains the points for that week

** Row 2 for each week contains the points total

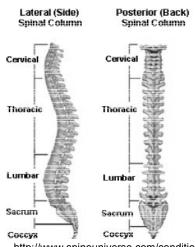
Form F SCOLIOSIS FACT SHEET

ANATOMY OF THE SPINE

The spine is one of the most important parts of the body. It allows people to stand upright, walk, move about freely, and bend. Inside the spine is the spinal cord. The spinal cord is made up of millions of nerves that connect the brain to the rest of the body. Messages from the spinal cord control everything in the body.

The spine is made up of 24 bones, called vertebrae. Ligaments and muscles connect these bones together to form the spinal column. The spinal column wraps around and protects the spinal cord. The many muscles that connect to the spine help support the upright posture of the spine and move the spine.

The spine is divided into five sections based upon location:



http://www.spineuniverse.com/condition s/spondylosis/arthritis-your-spineintroduction

Cervical Spine: Consists of the top seven vertebrae starting at the base of the skull

Thoracic Spine (midback): Consists of the twelve vertebrae of the upper back

Lumbar Spine (lower back): Made up of the five vertebrae of the lowerback

Sacrum: A set of five fused vertebrae that connects the base of spine to the pelvis

Coccyx (tailbone): A set of four vertebrae at the end of the spine that attaches to muscles and acts as a shock absorber when a person sits down

rme normal spine has a mild "S"-like curve going from front to back when you look at it from the side. The "S" curve helps a healthy spine withstand all kinds of stress. The cervical spine curves slightly inward, the thoracic slightly outward, and the lumbar slightly inward. Even though the lower portion of the spine holds most of the body's weight, each segment relies upon the strength of the others to function properly. Without its gentle curving down the back, we wouldn't be able to balance, walk, or move properly. But the spine curves from side to side in people with scoliosis, and sometimes this can cause problems.

WHAT IS SCOLIOSIS?

The word scoliosis (pronounced: sko-lee-oh-sis) comes from a Greek word meaning crooked. If you have scoliosis, you're not alone. About 3 out of every 100 people have some form of scoliosis, though for many of them it's not much of a problem.

Scoliosis is a disorder in which there is a sideways curve of the spine. This is different from the regular curve in your spine. This curve you would see if you looked at your spine from the front or back. Curves are often S-shaped or C-shaped. Although small curves generally do not cause problems, if the curve gets severe it can be visible and cause discomfort.

People with milder curves may only need to visit their doctor for periodic exams. Some people whose curves are bigger need treatment.

HOW DO YOU GET SCOLIOSIS?

Scoliosis is sort of a medical mystery — since no one knows for sure what causes the most common form of scoliosis, idiopathic (id-ee-o-PATH-ik) scoliosis. ("Idiopathic" is a medical term that means it's not known what caused the condition or disease.) Doctors do know that scoliosis can run in families, though. So a person who has scoliosis may have family members who have it. So a child who has a parent, brother, or sister with idiopathic scoliosis should have regular checkups by the family doctor.

WHO HAS SCOLIOSIS?

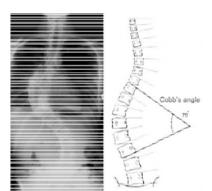
People of all ages can have scoliosis. One you have scoliosis it will never go away, though it may get better with treatment. Idiopathic scoliosis usually starts in children age 10 to 12 and in their early teens. This is the time when children are growing fast. Girls are more likely than boys to have this type of scoliosis, and girls with scoliosis are more likely than boys with scoliosis to need treatment.

HOW IS SCOLIOSIS DIAGNOSED?

Sometimes scoliosis will be easily noticeable. A curved spine can cause someone's body to tilt slightly to the left or right. Many teens with scoliosis have one shoulder blade that's higher than the other or an uneven waist with a tendency to lean to one side. If a curve gets really severe, it can even affect a person's breathing and heart function and can lead to damage in the joints of the spine and pain in adulthood.

Doctors routinely assess preteens and teens for scoliosis during regular physical exams. Some schools in the United States also check for scoliosis, but the most accurate way to diagnose it is to see a specialist called an orthopedist. An orthopedist is a doctor who specializes in bones.

Orthopedists use a medical and family history, physical exam, and tests when checking a person for scoliosis. An x-ray of the spine is the most definitive way of helping the orthopedist decide if a person has scoliosis. The x-ray lets the orthopedist measure the curve and see its location, shape, and pattern.



The orthopedist will examine you and study X-rays of your spine. You may hear the orthopedist mention something called a Cobb angle. The Cobb angle is a measure of the curvature of the spine in degrees, and the number of

degrees helps the doctor decide what type of treatment is necessary. A scoliosis curve of ten to fifteen degrees usually means that nothing needs to be done except for regular checkups until the person has gone through puberty and finished growing (the curvature of the spine usually doesn't get worse after that point). If the curve is twenty to forty degrees, the orthopedist will generally suggest a back brace. A Cobb angle of forty to fifty degrees or more may mean that surgery is necessary.

HOW IS SCOLIOSIS TREATED?

Treatment for scoliosis is based on:

http://medipicz.blogspot.com/2011/09/c obbs-angle.html

- The person's age
- How much more he or she is likely to grow
- The degree and pattern of the curve
- The type of scoliosis.

The doctor may recommend observation, bracing, or surgery.

Observation:

The doctor will check every 4 to 6 months to see if the curve is getting better or worse. Observation is used for those who have a curve of less than 25 degrees and are still growing.

Bracing:

Doctors might advise wearing a brace to stop a curve from getting worse. Bracing may be used when:

- The person is still growing and has a curve of about than twenty five to thirty degrees (depends on the doctor).
- The person is still growing and has a curve between about twenty to twenty-nine degrees that is getting worse (depends on the doctor).
- The person has at least two years of growth remaining and has a curve that is between twenty to twenty-nine degrees (depends on the doctor). If a girl, she should not have started having her monthly periods yet.

About 1 in 5 teenagers with scoliosis need to wear a back brace. There are several different types of braces. Some braces are worn for eighteen to twenty hours a day while others only at night. Which one the orthopedist chooses depends on the person, where the curve is on his or her back, and the severity of the curve.

The brace acts as a holding device that keeps the spine from developing more of a curve. A brace won't ever make the spine straight. But if it does its job well, the curve won't increase more than five or ten degrees and may prevent the need for surgery.

Surgery:

Sometimes, even with a brace, someone with severe scoliosis will need surgery to correct the curve. Doctors use surgery to correct a curve or stop it from getting worse when the person is still growing, the curve is more than fourty-five degrees, and the curve is getting worse. Surgery often involves fusing together two or more bones in the spine so that the spine can no longer continue to curve. The doctor may also put in a metal rod or other device. These devices are called implants. The metal parts are placed deep under the spine muscles, and in most cases can't be felt and do not hurt. They stay in the body and help keep the spine straight after surgery.

Teens who have had surgery to correct scoliosis usually go back to school about a month after surgery, then return to some activities in 3 or 4 months. Most people should be able to go back to all normal activities after 6 to 12 months. Of course each patient's surgery and recovery might be different, depending on the type of surgery and the person's age. After about a year, the bones will have fully fused. Although the metal rods are no longer needed, they are left in the patient's back because they aren't doing any harm and taking them out would involve another operation.

CAN EXERCISE HELP?

People with scoliosis can have active, normal lives. Doctors don't know of any activities that make scoliosis worse. So teens who have scoliosis should still be able to play their favorite sports and carry on as normal (except if they are recovering from surgery, of course).

Exercise programs have not been shown to keep scoliosis from getting worse. But it is important for all people, including those with scoliosis, to exercise and remain physically fit. Weight-bearing exercise, such as walking, running, soccer, and gymnastics, helps keep bones strong.

Information retrieved from:

- 1. National Scoliosis Foundation. *Scoliosis Media Guide*. http://www.nlm.nih.gov/medlineplus/ency/imagepages/1114.htm
- 2. National Institute of Arthritis and Musculoskeletal and Skin Diseases. National Institutes of Health: Bethesda, Maryland. http://www.niams.nih.gov/Health-Info/Scoliosis/default.asp

Form G RELAXATION TECHNIQUES

Deep Breathing:

I want you to close you eyes. Get comfortable in your chair. You will now practice deep breathing. Take a long, slow breath in through your nose. Now let it out through your mouth. Breathe in for four counts and out for four counts. In, two, three, four. Out, two, three, four. In, two, three, four. Out, two, three, four. Continue breathing like this until I tell you to open your eyes.

Progressive Muscle Relaxation:

Begin by finding a comfortable position sitting or lying down. Start with your toes and feet. Flex your feet and curl your toes as hard as you can. Keep tightening. Feel how bent your feet are and tight your toes are. Keep them tight for just a little longer. Now relax. Let go of the tension. Let your feet flop and your toes uncurl to a comfortable place. Do your feet and toes feel relaxed? Good.

Now, move to your legs. Tighten all the muscles of your legs. Start with your calves, then move up to your thighs. Tense the muscles further. Hold onto this tension. Feel how tight and tensed the muscles in your legs are right now. Squeeze the muscles harder, tighter... Continue to hold this tension. Hold it a few seconds more.... and now relax. Let all the tension go. Feel the muscles in your legs going limp, loose, and relaxed. Notice how relaxed the muscles feel now. Feel the difference between tension and relaxation.

Move to your upper body now. Ball up your fists, squeezing as tightly as possible. Squeeze so hard that your nails dig into your hands. Continue to squeeze. Harder... harder... and relax. Notice how calm and relaxed your hands feel now. Enjoy this feeling.

Now move to your arms. Tighten your biceps and triceps, move to your lower arm and tighten those muscles as well. Move up to your shoulders and tighten the muscles by your neck. Let your arms raise as you tighten your shoulders so much they are practically up by your ears. Tense the muscles in your arms as tightly as you can. Squeeze harder.... harder.... hold the tension in your arms and shoulders. Hold it for a few more moments.... and now release. Let the muscles of your arms and shoulders relax and go limp. Feel the relaxation as your shoulders lower into a comfortable position and your arms relax at your sides. Focus again on your breathing. Slow, even, regular breaths. Breathe in relaxation.... and breathe out tension.... in relaxation....and out tension.... Continue to breathe slowly and rhythmically.

Now focus on the muscles of your rear. Tighten these muscles as much as you can. Hold this tension.... and then release. Relax your muscles. We will now move to our core. Tighten the muscles of your stomach... the muscles of your chest...Keep squeezing... Feel your front contract as these muscles squeeze and your body pushes against your brace. Squeeze until it hurts. Now relax.

Finally move to the muscles of your backs. Feel your back tighten, the back of your shoulders and your spine as it tightens and tries to arch against your brace. Continue to squeeze. Pay attention to which parts of your back feel the most pressure as you do this. Now you can relax.

Let all the muscles in your body go as you remain still breathing. Pay attention to your back. Does it hurt more or less? Feel how relaxed your body is compared to before. Enjoy it. We will now move back to our breathing, remaining calm and relaxed as we do so. In, two, three, four. Out, two, three, four. Continue breathing as you enjoy the calm.... Good job everyone. When you are ready to rejoin the group, you may reawaken your body. You might want to take a deep stretch, reaching your arms towards the sky, You can wiggle your toes and legs... your fingers and arms. Welcome back.

Form H MALADAPTIVE PATTERNS OF THOUGHT

Maladaptive Thought Pattern	Examples of This Type of Thought	Questions to Challenge These Thought Patterns		
Filtering	Everything in my life is going bad; Why do I always get the short end of the stick?	Am I only noticing the bad things? Am I ignoring any of the good things that have happened recently?		
Mind Reading	That girl must think I look really ugly with my brace on; Everyone is going to know that I wear a brace	Am I assuming that I know what other people are thinking? These are my thoughts, not the thoughts of those around me.		
Shoulds	I have to wear my brace exactly the prescribed time.	Am I putting to much pressure on myself? Are my expectations realistic?		
Blaming	The reason that my scoliosis is getting worse is because I don't make my full prescribed time once in a while	Are there alternative explanations for this outcome? Could there be more than one reason this outcome is occurring?		
Overgeneralization	I am not going to be able to do anything anymore. I won't be able to participate in any of my favorite activities.	Am I overexagerating the risk? Is the result going to be as bad as I am expecting?		
Catastrophizing	I am going to have to have major surgery, even after I go through this whole bracing thing.	Is it helpful to be thinking about the worse possible outcome? What is the real likelihood that this worst outcome will happen?		
Black and White Thinking	If I don't wear my brace exactly as prescribed, then I will have to have surgery.	Life and treatment are not black and white. With lots of factors, there is no clear outcome.		

Form I PROBLEM SOLVING

Step 1: Identify the problem

Step 2: Come up with potential solutions

Step 3: Recognize what the consequences of each solution will be

Step 4: Choose the solution that provide the consequence you want

Step 5: Act upon the chosen solution

Step 6: Did the chosen solution cause the effect you expected? If not, go back to

step 3 (or even step 2)

Example:

Problem: Though Molly usually uses her off brace time for her dance lessons on Saturday, this week she has been invited to a pool party later in the day.

Potential Solution	Only go to dance and skip the pool party	Skip dance to go to the pool party	Wear brace to pool party.	Wear brace to dance class.
Effects of Solution	Will miss the pool party - Don't want to do that, since all her friends will be there and she has been looking forward to it.	Will miss dance - Will miss learning a part of her performance piece and will have to catch up.	Won't get to wear a bathing suit or go in the water - (Is it worth not getting to do those things in order to go to dance?)	Can Molly move well enough in her brace to participate in class? Is there any use in going to class with the brace on? Can Molly go to class and just watch?

^{*}As you may see, there is no correct answer here. It is up to Molly to decide which effect is optimal for her.

oblem:			
Potential Solution	Effects of This Solution		

Form J

Save The Date!!!

Our Family Session will be Fromuntil
This is an opportunity for any and all members of your immediate family to come and learn about what we have been doing. This is also a time to ask any questions that family members might have about treatment.
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Form K

You Are Invited....

To Family Week!!!

It will be next week,	
It will last from until	
This is an opportunity for any and all members of your immediate family come and learn about what we have been doing. We will tell you all about different things we have learned about our scoliosis treatment and ourselves. We will show you some of the techniques we have learned to help make this experience easier for us.	ut
This is also a time to ask any questions that family members might have about treatment. You can ask questions about scoliosis, about bracing, about what we have been doing in the past 9 weeks. Additionally, this is great time to bring up any bracing related problems your family might be struggling with.	and a
We encourage most family members to come, but request that you find childcare for children under the age of 5 as this will be a long time for the to sit and listen. Siblings over the age of 5 are encouraged to attend as experience effects the whole family. (If there are any questions or conceabout the appropriateness of a family member's attendance please continue the group leader at the number below.)	this erns
Please RSVP with the suspected number of attendees by, three days before the meeting.	
Call at	

BRACING FOR IDIOPATHIC SCOLIOSIS

Form L FAMILY WEEK ASSIGNMENTS

Robo-calls	
Brace Monitoring	
Contracting	
Rewards	
Goal Setting -	
Review Of Psychoeducation -	
Mindfulness	
Deep Breathing	
Progressive Muscle Relaxation -	-
Altering Negative Perceptions	
Contingency Management and Problem-solving	
Decision Making	
Social Support -	