

Eastern Michigan University
DigitalCommons@EMU

Master's Theses and Doctoral Dissertations

Master's Theses, and Doctoral Dissertations, and
Graduate Capstone Projects

11-19-2012

The development of a dyadic assessment for families experiencing

Sarah Cline

Follow this and additional works at: <http://commons.emich.edu/theses>

 Part of the [Psychology Commons](#)

Recommended Citation

Cline, Sarah, "The development of a dyadic assessment for families experiencing" (2012). *Master's Theses and Doctoral Dissertations*. 600.

<http://commons.emich.edu/theses/600>

This Open Access Dissertation is brought to you for free and open access by the Master's Theses, and Doctoral Dissertations, and Graduate Capstone Projects at DigitalCommons@EMU. It has been accepted for inclusion in Master's Theses and Doctoral Dissertations by an authorized administrator of DigitalCommons@EMU. For more information, please contact lib-ir@emich.edu.

The Development of a Dyadic Assessment for Families Experiencing
Adolescent Idiopathic Scoliosis

by
Sarah Cline

Dissertation

Submitted to the Department of Psychology
Eastern Michigan University

in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY IN CLINICAL PSYCHOLOGY

Dissertation Committee:

Michelle R. Byrd, Ph.D., Chair

Flora Hoodin, Ph.D.

Alida Westman, Ph.D.

Susan McCarthy, Ph.D.

November 19, 2012

Ypsilanti, Michigan.

Acknowledgements

My dissertation would not have been possible without the support and encouragement of many people. First, I would like to thank the Chair of my Dissertation Committee, Dr. Michelle Byrd, for her mentorship, tireless commitment, and steadfast belief in my ideas and abilities. I would like to thank the other members of my Committee, Drs. Flora Hoodin, Alida Westman, and Susan McCarthy, for helping me shape my ideas into a project that was both practical and valuable to the scoliosis literature.

Thank you to Ron Lupo and all the staff at Wright & Filippis for helping me recruit families, for sharing their website and offices, and for their wealth of experience and wisdom.

Thank you to Lori Dolan, Ph.D., and the other researchers affiliated with the Bracing in Adolescent Idiopathic Scoliosis Trail (BrAIST). Their belief in a junior colleague's project, willingness to collaborate, and advocacy on my behalf demonstrate a true commitment to research mentorship.

I would like to thank Robin Stoltz, LCSW, and all the members of Curvy Girls. I am humbled by their tireless commitment to improving the lives of individuals with scoliosis and their willingness to invite an outsider into their community to learn from their experiences.

I would like to thank my fellow lab mates—Natalie Morris, Emily Kavanagh, and Scott McPhee—for sacrificing precious time in their busy schedules to drive all over Southeastern Michigan for data collection and recruitment.

Thank you to all the small business owners who allowed me to post flyers in your facilities (even when they had never heard of scoliosis before). Thank you to all my mentors, supervisors, colleagues, and friends, who brainstormed, networked, recruited, advocated, and encouraged. Research is truly a “team sport,” and I could not have done it without them!

I would like to thank the Psychology Department at Eastern Michigan University for providing funding and all manner of logistical/practical support for this project.

Last, but certainly not least, thank you to all of the mothers and daughters who took time out of their busy lives to share their experiences in the service of helping others and improving what we know about the impact of scoliosis on the family.

Abstract

Adolescent idiopathic scoliosis (AIS) is a chronic disease involving curvature of the spine that is typically diagnosed in late childhood and early adolescence. The timing of most AIS diagnoses and subsequent treatment occur at a critical point developmentally and may place strain on the parent-adolescent relationship. The present study developed a measure, The AIS Dyadic Assessment, of the parent-adolescent relationship affected by AIS. This measure assessed three aspects of the parent-adolescent relationship: Communication Skills, Emotion Regulation, and Mutual Agreement about AIS. Twenty-six female adolescents who were currently prescribed a brace as part of their AIS treatment, and their mothers, participated. Dyads in the present sample were relatively high functioning and appeared to be coping well with AIS treatment. They rated their overall communication and problem-solving skills highly and were in agreement regarding basic facts related to the daughters' AIS diagnosis and treatment. The AIS Dyadic Assessment had preliminary and tentative evidence of reliability, convergent validity, and utility. Secondary aims of the study included novel application of the most commonly used measure in AIS research, the Scoliosis Research Society Outcomes Instrument-22r, to dyadic research. Dyads were in complete agreement on this scale. Results from the study contributed to the AIS literature by providing information on the effects of family system variables on adolescents' treatment, by informing psychosocial assessment practices in research and clinical practice and by directly comparing two different modalities of data collection.

Table of Contents

Acknowledgments.....	ii
Abstract.....	iv
List of Tables	viii
List of Figures.....	ix
Introduction.....	1
Literature Review.....	4
Research Design and Methodology	31
Results.....	41
Discussion.....	61
References.....	82
Appendices.....	99

List of Tables

<u>Table</u>		<u>Page</u>
1	Measures Included in the Present Study	39
2	Descriptive Statistics for the AIS Dyadic Assessment	43
3	Descriptive Statistics on Measures of Interest	45
4	Adjusted Means for Dependent Variables on the AIS Dyadic Assessment	53
5	Adjusted Means for Dependent Variables on the SRS-22r	58
6	Adjusted Means for Dependent Variables	60
7	Correlation Matrix for the SRS-22r and the AIS Dyadic Assessment	61

List of Figures

<u>Figure</u>	<u>Page</u>
1 Model of Parent-Adolescent Relationship Affected by AIS.....	16
2 Steps in Scale Development.....	35
3 Dyads' Communication and Problem-Solving Skills	47

The Development of a Dyadic Assessment for Families Experiencing Adolescent Idiopathic Scoliosis

Adolescence is characterized by physical, psychosocial, and cognitive changes, as well as increasing autonomy and responsibility (Lerner et al., 1996). At its most basic level, adolescence is defined as the time when the physical body attains sexual maturity and is able to reproduce (Papalia, Olds, & Feldman, 2004). Such physical changes may contribute to feelings of insecurity and preoccupation with body size during adolescence (Papalia et al., 2004).

Physical development is accompanied by changes in the psychosocial lives of adolescents as well. Relationships outside of the family, particularly peer relationships, strengthen and take on a more influential role than in childhood (Lerner et al., 1996). Adolescents' ability for abstract thinking, including hypothetical-deductive and moral reasoning, develops and deepens (Ginsburg & Opper, 1979). Although adolescence is a time of tremendous change and growth, it can be a time of vulnerability, particularly for developing mental illness (e.g., depression), engaging in problematic behaviors (e.g., drinking, unprotected sex), and falling into the "wrong" peer group (Papalia et al., 2004).

The diagnosis of a chronic illness that coincides with this developmental stage potentially adds a layer of additional stress and difficulty for the parent-adolescent dyad. Adolescent Idiopathic Scoliosis (AIS), in particular, may place undue stress on the parent-adolescent relationship, because treatment for the condition consists of self-care behaviors (e.g., wearing a brace, restricting activities) that require the adolescent to be more responsible than she may be developmentally ready to be or than her parents are willing to acknowledge she is ready to be. Developmental changes in adolescence are likely to have a significant impact on the adolescent's perceptions of AIS, and, conversely, the diagnosis and treatment of AIS may change the

developmental path of a given adolescent. However, researchers have not often conceptualized AIS within a developmental context or theoretical framework.

Treatment for a condition like AIS, one that is rooted primarily in self-care behaviors, could easily become a source of contention between parents and adolescents. In many ways, a diagnosis of AIS in late childhood coupled with the expected developmental changes in adolescence is a “perfect storm” for the parent-adolescent dyad. For example, at a time when dyads are negotiating autonomy and independence, the adolescent may be expected to take responsibility for self-care behaviors that are at the core of most AIS treatment, including wearing a brace for the prescribed amount of time, keeping the brace clean, complying with restrictions on physical activity, attending medical appointments, and so on. Surgical patients have a number of self-care behaviors to attend to also including keeping the incision clean, “log-rolling” (i.e., rolling from side to side to prevent stiffness), and re-learning how to perform basic personal hygiene tasks while recovering. This increase in responsibility may be overwhelming for adolescents who are just beginning to acquire the developmental skills necessary to manage routine self-care successfully, no less a relatively complex medical regimen. Moreover, adolescents spend significantly more of their time outside of the direct observation of their parents than they did in their childhood. By virtue of the typical schedule of an American adolescent, parents will have to rely on the adolescent to take responsibility for following treatment recommendations, something many parents may not be prepared to do, and likely a strong contributing factor to high rates of medical non-compliance among chronically ill adolescents (Harris et al., 2008).

The literature on AIS has focused predominantly on factors predicting adolescent compliance with brace wearing or the psychosocial consequences of wearing a brace on

adolescents. By comparison, a small portion of the literature focuses on the psychosocial effects of a diagnosis of AIS on parents' emotional well-being and family functioning; however, there is some call for further investigation of the effects of AIS on family system variables.

Therefore, the purpose of the proposed study was to develop a measure of the parent-adolescent relationship affected by AIS. Drawing on the AIS, juvenile diabetes, and other adolescent chronic illness literatures, the measure developed in the present study assessed three components of the parent-adolescent relationship believed to be critical for successfully navigating chronic illness treatment: Communication Skills, Emotion Regulation, and Mutual Agreement about AIS. In medical settings, this measure could provide staff with information about the dyad's readiness to engage in the next phase of treatment, as well as highlight areas of the relationship that may benefit from outside referral to a psychologist or other helping professional. In research settings, this measure could be used to predict future health and psychological outcomes for families, predict healthcare utilization rates, and predict parent-adolescent conflict related to issues of treatment engagement.

In addition, this study examined the utility of using an established AIS measure, the Scoliosis Research Society-22 Health Related Questionnaire (SRS-22r), to examine interactional variables important to the mother-adolescent dyad. Comparing responses from both mothers and daughters was a novel approach that had not been previously undertaken in the AIS literature.

Literature Review

Overview of Adolescent Idiopathic Scoliosis

Adolescent idiopathic scoliosis (AIS) is a curvature of the spine of unknown origin, affecting 1-3% of otherwise healthy children ages 10-16 years old (Weinstein, Dolan, Cheng, Danielsson, & Morcuende, 2008). An AIS diagnosis is typically made in late childhood (Sapountzi-Krepia et al., 2006) and is more common in females than males (National Scoliosis Foundation, 2010). Curve progression tends to be significantly faster and more severe in females; therefore, they are eight times more likely to receive an active treatment such as bracing, as opposed to “watchful waiting” (Lyons, Boachie-Adjei, Podzius, & Podzius, 1999; Neuwirth & Osborn, 2001; Reamy & Slakey, 2001). Currently, there is little information on the prevalence of AIS among different ethnicities in the U.S. However, Lonner and colleagues found more adolescents of European American descent than adolescents of African American descent met diagnostic inclusion criteria for AIS in their database of 1,658 AIS patients (2010).

Although the definitive etiology of AIS is currently unknown, high heritability rates in families suggest a strong genetic component in the development of the illness. For example, one meta-analysis of AIS twin studies found a concordance rate of 73% among monozygotic twins and 36% among dizygotic twins (Kesling & Reinker, 1997). Abnormalities in melatonin metabolism (Burwell, 2003; Lowe et al., 2000), platelet development (Burwell, 2003; Lowe et al., 2002), neuroanatomy structure (Benli et al., 2006; Emery, Redondo, & Rey, 1997; Inoue et al., 2005; Maiocco, Deeney, Coulon, & Parks, 1997), and paravertebral muscles (Chu et al., 2006; Guo, Chau, Chan, & Cheng, 2003; Huynh, Aubin, Rajwani, Bagnall, & Villemure, 2007; Rajwani et al., 2004; Villemure, Aubin, Dansereau, & Labelle, 2004) have been implicated in the etiology of AIS. It is quite possible that the heritability of this disorder may have psychosocial

consequences as well, in that mothers who themselves have AIS may react differently to daughter's diagnosis from families without a medically significant family history. The present study took a preliminary step toward exploring that question.

The diagnosis of AIS is one of exclusion and is made after a Cobb angle of at least 10° is found. Most curves require no intervention other than “watchful waiting” or close monitoring for signs of curve progression, particularly if the adolescent is still growing (Kesling & Reinker, 1997; Parent, Newton, & Wenger, 2005). However, severe curvature, defined as a Cobb angle of more than 45°, is associated with back pain, cardiopulmonary problems, and cosmetic concerns and warrants immediate intervention (Weinstein et al., 2008).

Treatment efforts focus on preventing progression of the curve and corresponding complications of severe curvature (e.g., impaired respiratory and cardiovascular functioning). The standard of care in North America focuses on bracing for patients with a curve of more than 25°, while European doctors generally recommend physical therapy (Kesling & Reinker, 1997; Parent et al., 2005). Importantly, treatment recommendations (e.g., bracing or physical therapy) are controversial, with divergent outcomes reported (Weinstein et al., 2008). However, the lack of strong evidence may be due to poor adherence with bracing recommendations.

For example, DiRaimondo and Green found that only 15% of AIS patients in their sample were highly compliant with brace wearing while the average patient only wore the brace an estimated 67% of the time they were prescribed (1988). Commonly cited reasons for not wearing the brace as prescribed included concerns about the brace limiting physical activity, the visibility of the brace, reactions from peers (R. R. Gratz & Papalia-Finlay, 1984), skin irritation, discomfort, and difficulty eating or breathing (MacLean, Green, Pierre, & Ray, 1989). While these data are somewhat historical and some technical advances in brace construction have been

made, more recent data have not been published. One aim of the present study was to re-examine these historic findings to shed light on whether patients still report the same reasons for not wearing their brace. Furthermore, in addition to this replication, the literature was extended by examining whether mothers were aware of these perceived barriers to brace-wearing.

Surgery to permanently correct the curve and prevent future curve progression is generally recommended when the primary curve exceeds a Cobb angle of 45° (Weinstein et al., 2008). An estimated 23% of patients who wore braces and 22% of patients under observation subsequently have surgery. These conversion rates should be read with caution, however, because they were based on a review of individual studies with widely varying individual rates of surgery (Dolan & Weinstein, 2007). Advances in surgical procedures have significantly reduced the complications and recovery time of surgery; however, it is not without risks, particularly for adults (Bridwell, Anderson, Boden, Vaccaro, & Wang, 2007). Orthopedic surgery to correct curve progression appears to be quite successful, particularly in improving “quality of life, self-image, pain, and disability” (Weinstein et al., 2008, p. 1534).

Psychological factors associated with AIS. The diagnosis of scoliosis and subsequent treatment comes at a critical time in development when adolescents are attempting to establish a sense of identity while simultaneously coping with significant cognitive and physical changes (Erikson, 1968; Ginsburg & Opper, 1979). Therefore, adolescents coping with an AIS diagnosis and treatment may experience more challenges in successfully meeting all the demands of treatment than would be expected if an adult were asked to meet the same requirements. Adolescents’ relationships with parents or caregivers may be significantly affected, as well.

Pessimism about AIS prognosis is associated with increased depression in adolescents (Kahanovitz & Weiser, 1989). Payne and colleagues found AIS to be an independent risk factor

for suicidal thoughts and alcohol consumption among females with AIS and preoccupation with weight among males with AIS (1997). Similarly, Freidel and colleagues found that adolescents with AIS were unhappier with their lives and had lower self-esteem and higher depression scores than healthy peers (2002). Recently, Alborghetti and colleagues (2010) found a higher prevalence of eating disorders among a sample of AIS patients than population base rates. The authors suggest bracing often comes at a time that is crucial to development of a healthy body image and consequently may exacerbate any predisposing factors to developing an eating disorder (Alborghetti et al., 2010). Importantly, the negative perceptions of body and health associated with AIS may be lessened by engagement in moderate physical activity, particularly for males (Dekel, Tenenbaum, & Kudar, 1996).

Some studies have suggested that adolescents have differing responses to AIS, depending on which treatment was prescribed. The introduction of a very visible brace that often must be worn for more than 16 hours a day (Lyons et al., 1999), or the necessity of a temporarily debilitating surgery resulting in a lasting scar, is anticipated to be a stressful event for adolescents (Drench, 1994; Eliason & Richman, 1984; Fallstrom, Cochran, & Nachemson, 1986). Indeed, several studies have found AIS patients who are braced report psychological distress including poorer psychosocial functioning and impaired body image than healthy peers (Ascani, Bartolozzi, Logroscino, et al., 1986; Bjure & Nachemson, 1973; Clayson, Luz-Alterman, Cataletto, & Levine, 1987; Fallstrom et al., 1986; Kahanovitz & Weiser, 1989; Olafsson, Saraste, & Ahlgren, 1999; Schatzinger, Brower, & Nash, 1979). Moreover, the majority of adolescents with AIS report moderate to severe anxiety about the possibility of needing surgery including concern about side effects, recovery time, and the development of

physical scars (Bridwell et al., 2000; Kotzer & Foster, 2000; LaMontagne, Hepworth, Johnson, & Cohen, 1996; Nathan, 1977).

In contrast, other studies suggest that adolescents with AIS are no different, psychologically speaking, from their peers once the initial stress of diagnosis dissipates (Anderson, Asher, Clark, Orrick, & Quiason, 1979; Apter et al., 1978; Danielsson, Wiklund, Pehrsson, & Nachemson, 2001; Kahanovitz & Weiser, 1989; Olafsson et al., 1999; Ugwonali et al., 2004). Salient concerns at the onset of treatment are indicative of psychological and emotional distress (Liskey-Fitzwater, Moore, & Gurel, 1993); however, as treatment progresses, some studies have found that the emotional reactions felt initially appeared to return to levels comparable with healthy controls, although there were still some concerns with feeling self-conscious and restrictions on physical activity (Mayo, Goldberg, Poitras, Scott, & Hanley, 1994; Weinstein et al., 2003). Thus, although the initial diagnosis and treatment are stressful in at least one older study, most adolescent girls found the emotional distress associated with AIS to dissipate over time (Gratz & Papalia-Finlay, 1984).

Although psychological functioning appears to improve into adulthood, concerns about body image and disability continue to be prominent for some adults previously diagnosed with AIS (Goldberg, Mayo, Politas, Scott, & Hanley, 1994; Noonan, Dolan, Jacobson, & Weinstein, 1997; Tones, Moss, & Polly, 2006). Retrospective studies comparing the long-term psychological effects of bracing or surgery for AIS are inconclusive (Weinstein et al., 2008). Some studies show little difference in quality of life for adults who wore braces or had surgery in adolescence (Danielsson & Nachemson, 2003a, 2003b). Indeed, many adult patients appear indistinguishable from healthy controls later in life (Danielsson et al., 2001; Grimard et al., 2002). Yet other studies indicate that adults who underwent surgery for AIS believe that the

surgery negatively impacted their functioning, quality of life, and ability to socialize (Mayo et al., 1994), without ameliorating all symptoms (Dickson, Mirkovic, Noble, Nalty, & Erwin, 1995). Because these retrospective studies included participants who had experienced different surgical procedures that have evolved over time, it is possible that some of the differences may be attributable to advances in medical technology.

Taking into consideration all of the information to date on the psychological and emotional effects of AIS diagnosis/treatment, as well as the advances in medical technology that make treatment considerably less debilitating today, it does not seem that a diagnosis of AIS in and of itself accounts for long-term psychological distress or impairment in emotional or social functioning. Indeed, the body of research focusing on the psychological functioning of adults several years post-AIS diagnosis suggests adults, on average, are indistinguishable from their non-AIS peers in terms of psychological, emotional, and social functioning, with some exceptions. While this is the case, there also remains sufficient evidence of acute distress related to AIS to warrant additional research consideration. In particular, the extant research suggests that AIS patients are at higher risk for depression, substance use, decreased self-esteem, and concerns regarding body image, including eating disorders.

Parent-Adolescent Relationship

The common perception of the parent-child dyad in adolescence is that of a relationship marked by conflict, disagreement, and intense affect. While cross-sectional research tends to find stability in the parent-teen dyad (Laursen, Coy, & Collins, 1998; Paikoff & Brooks-Gunn, 1991), results from longitudinal studies support the common perception of disrupted relationships (McGue, Elkins, Walden, & Iacono, 2005). For example, Kim, Conger, and Lorenz (2001) found that adolescents' negative affect towards their parents increased substantially between ages 12-

15. The same time period was marked by a significant decrease in parents' opinions about the positive aspects of parenting in a study by Loeber and colleagues (2000). Changes to the parent-teen dyad between the ages of 11 and 14 are notable for their "marked deterioration," including greater conflict, less involvement from parents, and substantial decrease in mutual positive regard (McGue et al., 2005, p. 981). However, conflict between parents and adolescents does not appear to have the same frequency or intensity throughout all of adolescence; rather, conflict seems to follow a developmental trajectory marked by frequent and intense conflict at the onset of adolescence that reduces by late adolescence. The decrease in conflict by late adolescence is attributed to the resolutions achieved by parents and adolescents regarding issues of autonomy and responsibility (Fulgini & Eccles, 1993; Laursen et al., 1998; Molina & Chassin, 1996; Steinberg, 1988).

Parent-adolescent relationship in the AIS literature. Research efforts examining family variables related to AIS have primarily focused on factors that affect treatment success rather than better understanding how having a child with AIS may impact the family. Some studies have examined dyadic reactions to coping with AIS, focusing on the mother-daughter relationship.

There appears to be a strong association between mothers' views and expectations of AIS treatment and some AIS outcomes. More specifically, when this maternal perception is positive, it is associated with better treatment outcomes (Kahanovitz & Weiser, 1989; Olafsson et al., 1999). Gratz and Papalia-Finlay found that mothers were initially "upset," "shocked," and "depressed" upon learning their daughters would need to wear a brace, but these reactions dissipated within the first three to six weeks of treatment (1984). Parents assumed visible signs of body deformity would be more emotionally stressful than adolescents did at the beginning of

treatment (Misterska, Glowacki, & Latuszewska, 2012). Similarly, 84% of parents found the initial treatment stressful (MacLean et al., 1989), and 68.8% of parents labeled their daughter's AIS diagnosis a "crisis" (Gratz & Papalia-Finlay, 1984). Creating a sense of "mastery" over managing their child's condition helped parents to feel better (MacLean et al., 1989). Gratz and Papalia-Finlay (1984) found mothers were more worried about their daughter needing surgery in the future than about the barriers to effective bracing (e.g., clothing, extracurricular activities, discomfort in the summer months). Bridwell and colleagues found parents and teens were equally concerned about the risks associated with surgery, but teens were more worried about managing the demands of daily living post-surgery than parents were (2000).

Regarding the impact of AIS on daily living and overall functioning of the family, 53% of parents indicated needing to find additional money to cover medical expenses (MacLean et al., 1989). Of those parents, 26% indicated that finding the extra money was "problematic" (MacLean et al., 1989). Forty-seven percent of parents expressed concern about missing work in order to attend their child's AIS appointments (MacLean et al., 1989). One of the aims of the present study is to learn more about the impact of an AIS diagnosis on the family system, particularly on the mother-daughter dyad.

Findings from parent-adolescent focus groups in a recent unpublished dissertation (Lynch, 2006) indicated that aspects of the parent-adolescent relationship influenced how often the adolescent adhered to treatment recommendations (e.g., wearing a brace for the prescribed amount of time). For example, parents admitted they knew when adolescents were not wearing their brace and sometimes encouraged their child to remove the brace against medical advice (Lynch, 2006). Moreover, parents recognized that their adolescents' feelings of embarrassment or feeling different were common reasons for not wearing their brace (Lynch, 2006). This

suggests that parents' opinions about brace wearing are influential, as are their reactions (whether emotional, verbal, or behavioral) to their adolescents' experiences.

It is important to note that adolescents described not knowing how to predict whether a new situation would be embarrassing, physically uncomfortable, or restricted by wearing a brace. Indeed, they anticipated high embarrassment, discomfort, and physical limitations in most new situations, leading to high levels of anxiety (Lynch, 2006). However, adolescents reported feeling more comfortable and more willing to wear their brace around "supportive persons" including immediate family. Interestingly, this feeling of support increased their willingness to wear a brace, even when unfamiliar people were around (Lynch, 2006). It is possible adolescents with AIS may be turning to parents for guidance about how to handle emotions related to the management of their condition whether by consciously seeking advice, modeling parental behaviors, or by feeling more emotionally regulated in the presence of a loved one. One of the aims of the present study is to begin assessing this possibility via survey methods.

Parent-adolescent relationship in the adolescent diabetes literature. Conflict between parents and adolescents with chronic illnesses does not follow the same trajectory as conflict between parents and healthy adolescents. Research from the diabetes literature indicates that conflict surrounding diabetes management increases over the course of adolescence rather than decreasing in later adolescence as would be anticipated (Anderson et al., 2009). Not coincidentally, responsibility for diabetes management follows the same pattern; the older the adolescent, the more responsibility he or she assumes for managing the disease and the more conflict the dyad is likely to experience (Anderson et al., 2009). Moreover, at every age level, higher family conflict, particularly between parent and adolescent, is associated with poorer glycemic control (Anderson et al., 2009; Anderson, Miller, Auslander, & Santiago, 1981;

Anderson et al., 2002; Bobrow, Avruskin, & Siller, 1985; Hauser et al., 1990; Jacobson et al., 1994; Miller-Johnson et al., 1994; Wycsocki, 1993). As yet, no study has attempted to examine whether conflict is correlated with adherence among adolescents with AIS. The present study will take a preliminary step toward exploring that question.

Moreover, parents who are unable to accept adolescents' needs for autonomy, privacy, and control may inadvertently hinder their adolescents' adherence to treatment recommendations (Anderson & Coyne, 1993). Children with diabetes who perceive their mothers as intrusive have poorer compliance with their prescribed diabetes regimen (Harris et al., 2008; Wiebe et al., 2005). Parents' use of "nagging, criticism, and coercion" to increase their child's adherence is associated with poorer metabolic control (Schafer, Glasgow, McCaul, & Drecher, 1983; Schafer, McCaul, & Glasgow, 1986). Although it is difficult to tell what started the cyclical pattern – adolescents' lack of responsibility or parents' nagging – it is clear this style of interaction is not healthy for either parent or adolescent. Moreover, it seems likely interventions that target only one member of the dyad will be less effective than efforts aimed at the relationship itself. Again, like conflict, no study has yet endeavored to examine intrusiveness as a correlate of treatment adherence in the AIS population. The present study took a preliminary step toward exploring that question.

Parent-adolescent relationship in other adolescent chronic medical illness

literatures. Similar patterns of conflict have been found in other adolescent chronic illness literatures to that of diabetes literature. Adolescents identify more barriers to following through with treatment recommendations than parents do, and higher numbers of reported barriers by adolescents are associated with poorer adherence (Modi & Quittner, 2006). In focus groups, parents of adolescents with cystic fibrosis and asthma express uncertainty about when to

encourage their adolescents to take primary responsibility for managing their own illness, as well as when to lessen parental involvement and monitoring of treatment adherence appropriately (Hafetz & Miller, 2010).

In the same focus group study, so-called positive emotional experiences influence treatment outcomes. For example, greater family cohesiveness, defined as supportive emotional connectedness among family members, is associated with better treatment adherence in children with cystic fibrosis (White, Miller, Smith, & McMahon, 2009; Wolman, Resnick, Harris, & Blum, 1994). However, some children/adolescents admitted to hiding important illness-related information from parents, in part because they did not want to worry their parent or their parent was in a “bad mood” (Hafetz & Miller, 2010). It appears some children/adolescents with chronic illnesses are aware of their parents’ emotional reactions at least and may be changing their verbal behavior to avoid perceived negative emotional outcomes.

Summary of Literature Review

The above review of the literature highlights areas that change significantly in the course of normal adolescent development, including maturity of the physical body, cognitive processes, and depth of social relationships. Adolescent development is a stage often characterized by intense emotions, a need for increasing independence, and reliance on peer relationships. Subsequently, this developmental stage is characterized by an increased conflict with parents and other caregivers. Research on the diagnosis of a chronic illness in adolescence demonstrates that the impact of an illness is often more than the defining physical symptoms. Such a diagnosis, like AIS, may be associated with numerous psychosocial stressors for the adolescent (i.e., depression, anxiety, concern with body image, worry over peers’ reactions), for the parent (i.e., stress, worry about the future, financial/work concerns), and for the parent-adolescent relationship (i.e.,

negotiating autonomy and responsibility, conflict). Moreover, similar psychosocial outcomes have been found in other adolescent chronic illness literatures (e.g., juvenile diabetes, asthma, cystic fibrosis).

Developing a Model of AIS within a Developmental Framework

Based on the extant literature on psychosocial correlates of AIS and that of other adolescent chronic illness literatures, the parent-adolescent relationship affected by AIS was the construct of interest in the present study. More specifically, the present study took a first step toward building a model to better understand parent-adolescent dyads affected by AIS. This model attempts to account for coping with AIS broadly speaking, as well as illness-specific variables such as conflict, negotiation of disease management processes, and perceived barriers to successful disease management and medical outcomes. Although the present study aimed to develop a measure to assess key components of the model only (Communication Skills, Emotional Regulation, Mutual Agreement about AIS), a graphical representation of the entire model is presented in Figure 1, followed by a more thorough explanation and justification of each component of the model.

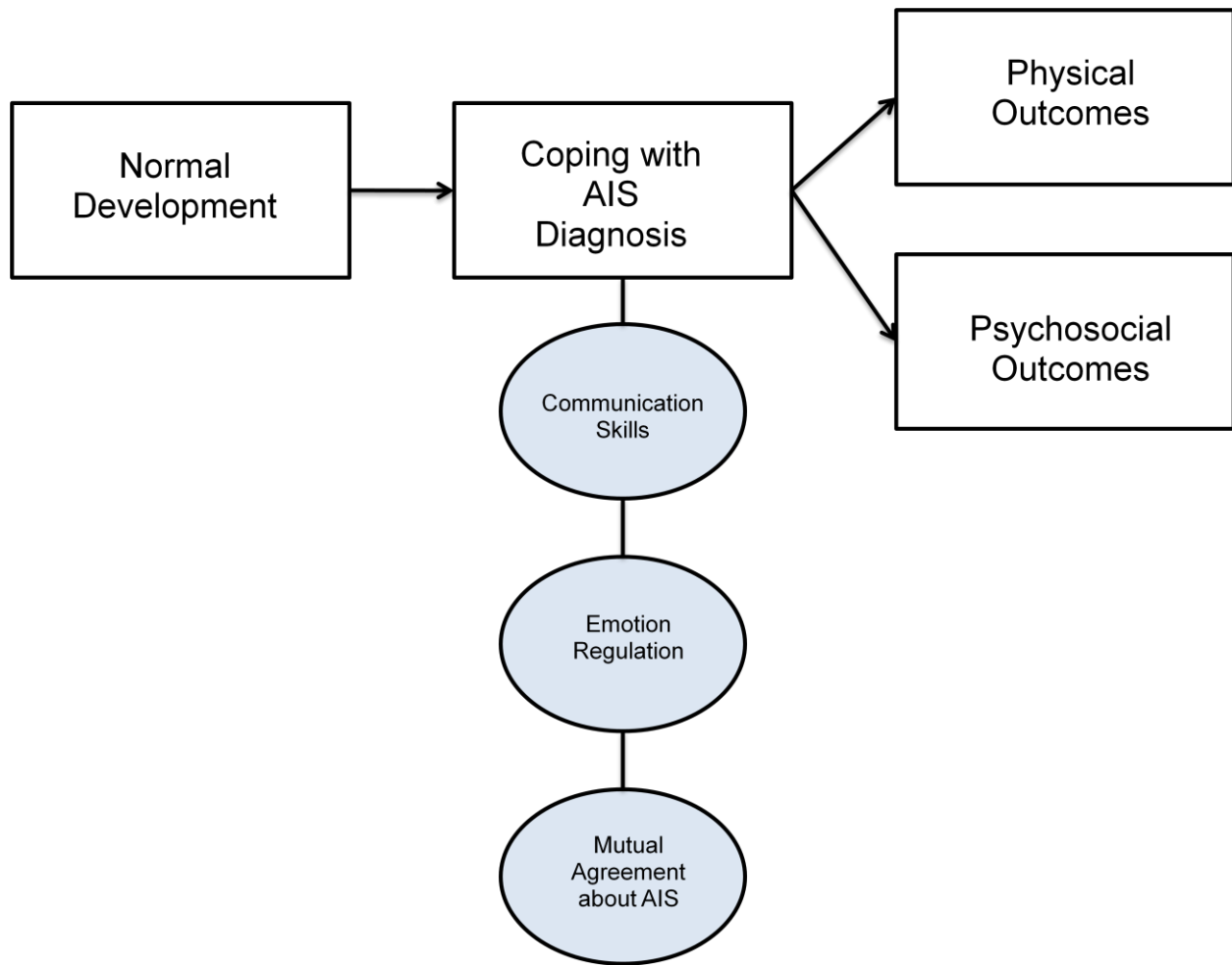


Figure 1. Model of Parent-Adolescent Relationship Affected by AIS

This model focused on three core aspects of the parent-adolescent relationship affected by AIS: Communication Skills, Emotional Regulation, and Mutual Agreement about AIS. Because the purpose of the present study was to develop a measure that assesses the relationship between parents and adolescents affected by AIS, the three components were best conceptualized as properties of the relationship itself, rather than as variables inherent to either member of the dyad. In an effort to replicate and extend the existing literature, the present study tried to determine if the dyads communicated effectively, were emotionally regulated, and had an adequate and shared understanding of medical information related to AIS.

Communication skills. Learning how to communicate effectively is a core component of many psychological interventions including most dyadic and many individual therapies (Nichols & Schwartz, 2001). The inability to articulate ideas and demonstrate reflective listening can lead to conflict, poor decision-making, and the inability to solve problems effectively (Gottman & Silver, 2000). As noted earlier, conflict increases during early adolescence (McGue et al., 2005), often coinciding with the initial diagnosis and treatment of AIS (Sapountzi-Krepia et al., 2006). As demonstrated in the adolescent diabetes literature, conflict between parents and adolescents, a symptom of ineffective communication, is related to poorer metabolic control in adolescents (Anderson et al., 2009; Schafer et al., 1983; Schafer et al., 1986). Parental behavior that is perceived as being overly intrusive (e.g., nagging, controlling, overly critical) by adolescents is associated with poor adherence to diabetes regimens (Schafer et al., 1983; Schafer et al., 1986). Parents of adolescents with other chronic illnesses admit they are uncertain how and when to transfer responsibility for illness management to adolescents (Hafetz & Miller, 2010).

Additionally, parents and adolescents often disagree about the severity of the illness and the number of barriers to successful adherence (Modi & Quittner, 2006). Thus, there are a number of illness management variables that parents and adolescents must be able to communicate effectively about, including who is primarily responsible for illness management, what adherence looks like, how to navigate barriers to adherence, and how serious the consequences of non-adherence are. Moreover, ineffective communications such as those viewed as overly intrusive may negatively predict medical and psychological outcomes. Based on the extant research findings outside of AIS, it was hypothesized that similar patterns between AIS parent-adolescent dyads exist. Thus, this study endeavored to measure perceptions of

communication patterns in dyads from the perspective of both parents of adolescents with AIS as well as the adolescents themselves.

Emotion regulation. The ability to regulate emotions is defined commonly in the literature as “the extrinsic and intrinsic processes responsible for monitoring, evaluating, and modifying emotional reactions, especially their intensive and temporal features, to accomplish one’s goals” (Thompson, 1994, pp. 27-28). This commonly cited definition was used to define emotion regulation in the present study.

Adolescents gain increasing emotion regulation mastery over time (Kopp, 1992; Southam-Gerow & Kendall, 2002). Although struggling with developing higher level emotion regulation skills is common, most adolescents have increased emotional flexibility, a broadened range of emotional experiences, and the ability to hold two or more contradicting emotions simultaneously (Ginsburg & Opper, 1979). However, such development does not occur in isolation but rather is highly dependent on relationships with parents and other attachment figures (MacDermott, Gullone, Allen, King, & Tonge, 2010). For example, when parents respond to children’s negative emotions with control and overprotection, children develop less adaptive emotion regulation strategies (Bell & Calkins, 2000; Fox & Calkins, 2003) and feel increased guilt and shame (Campos, 1995). However, when parents respond to children’s negative emotions with encouragement and support, children learn to develop a variety of effective emotion regulation strategies without feeling self-conscious (Calkins & Johnson, 1998).

Although less frequently studied than other aspects of the parent-adolescent relationship, dyadic emotional reactions in the course of treating an adolescent’s chronic illness have affected treatment outcomes. For example, as noted earlier, greater family cohesiveness is associated with better treatment adherence in children with cystic fibrosis (White et al., 2009; Wolman et al.,

1994). Children/adolescents with chronic illnesses admitted to hiding important illness-related information from parents, in part because they did not want to worry their parent or their parent was in a “bad mood,” a reflection of both impaired communication and emotion regulation (Hafetz & Miller, 2010). Moreover, in focus groups of parents of adolescents with AIS, parents reported being aware that their adolescents felt embarrassed about wearing a brace and admitted to giving their child permission to remove the brace, against medical advice (Lynch, 2006), presumably as a consequence of their inability/unwillingness to tolerate their child’s emotional discomfort. Although the exact mechanisms of emotional transmission between parents and adolescents with a chronic illness are unknown, emotional processes influence treatment adherence and warrant assessment in measuring the parent-adolescent relationship.

Mutual agreement about AIS. The presence of AIS in the parent-adolescent dyads in the present study was assumed to be a critical variable that distinguishes these particular dyads from dyads not affected by AIS. It is reasonable to predict that parents’ and adolescents’ shared understanding, or lack of agreement, about AIS may undermine other aspects of their relationship, including their ability to communicate effectively and navigate challenges associated with treatment. In the juvenile diabetes literature, for example, parent-child agreement about responsibility for diabetic care tasks was associated with greater glycemic control among preteens (Anderson et al., 2009).

Therefore, the present study assessed agreement between parents and adolescents on objective and subjective information about AIS including relevant medical facts (e.g., degree of curve, prescribed treatment regiment), adolescent’s physical functioning and level of pain, adolescent’s self-image, barriers to successful adherence, severity of illness, and mutual satisfaction with treatment progression. The goal of this part of the model was to assess whether

parents and adolescents were in agreement about what adherence looks like, what barriers interfered with successful treatment, and how the adolescent's life was impacted by AIS. Although not tested in the present study, it was anticipated that higher rates of disagreement on these aspects of AIS likely contributed to higher rates of conflict and, subsequently, lower adherence rates.

Review of Selected Dyadic Measures

Although there are existing measures that assess the parent-adolescent relationship, psychosocial outcomes of AIS, and the impact of the parent-adolescent relationship on the course of an adolescent's chronic illness (e.g., diabetes), there are no instruments that account for both parent-adolescent relationship variables and disease specific outcomes for AIS. Moreover, many extant measures of the parent-adolescent relationship, whether affected by chronic illness or not, focus on *individual* variables and perspectives rather than assessing the *interaction* between parents and adolescents. For example, common parenting measures like the Parenting Relationship Questionnaire [PRQ; (Kamphaus & Reynolds, 2006)] and the Parenting Stress Index [PSI; (Abidin, 1995)] measure the parent's perspective of the relationship only. Although the PRQ and the PSI have adequate psychometric properties, they do not measure the construct of interest in the present study. The following section will review measures designed to assess the parent-adolescent relationship from a dyadic perspective, AIS psychosocial outcomes/processes, and dyadic variables in other chronic illness literatures.

Measuring the parent-adolescent relationship. A recent review of measures designed to assess the parent-adolescent relationship yielded 20 measures focusing on assessing parent, adolescent, and/or mutual satisfaction with the parent-adolescent relationship (DeCato, Donohue, Azrin, Teichner, & Crum, 2002). Of the 20 instruments, only one had adequate reliability and

validity [(i.e., the Parent-Child Areas of Change Questionnaire (Jacob & Seilhamer, 1985))] and assessed “specific behavioral domains of the parent-adolescent relationship” such as “chores, peers, curfew, and communication” (DeCato et al., 2002, p. 858). However, there were a few problems with the scale including “double-barreled” items that yield unclear responses and lack of information about the racial/ethnic make-up of the development sample (DeCato et al., 2002).

Parent-adolescent measures specifically designed to assess aspects other than satisfaction with the parent-adolescent relationship are fraught with methodological shortcomings and inadequate psychometric data. The Parent-Adolescent Communication Scale (Barnes & Olson, 1982) and Parent-Adolescent Communication Inventory (Bienvenu, 1969), for example, both lack normative data about development samples, adequately developed norms for both parents and adolescents, and adequate reliability and validity (Edwards & Pfeiffer, 2004; Roberts & Sines, 2004). Measures designed to assess conflict, a symptom of ineffective communication, within the parent-adolescent relationship are better developed, including the Conflict Behavior Questionnaire (Foster, Prinz, & O’Leary, 1983; Prinz, Foster, Kent, & O’Leary, 1979) and the Issues Checklist (Robin & Foster, 1989). However, these measures focus on areas of general conflict (e.g., chores, curfew) only and do not include other aspects of communication in the parent-adolescent relationship (e.g., problem solving).

Arguably, the best measure of the parent-adolescent relationship, in terms of clinical utility, psychometric properties, and comprehensiveness is the Parent-Adolescent Relationship Questionnaire [PARQ; (Robin, Koepke, & Moye, 1990)]. This dyadic self-report, true/false measure yields 12 clinical scales assessing behavioral aspects across three broad domains (Problem-Solving/Communication Skills, Belief Systems, Family Structure) and two validity scales, and is rooted in Behavioral-Family Systems Therapy (Robin et al., 1990).

The Problem-Solving/Communication Skills domain refers to how well parents and adolescents negotiate matters of daily life including household responsibilities, school, and sibling relations. It also assesses whether the dyad communicates in a style that is effective, warm, and mutually satisfactory. The Belief Systems domain refers to parents' and adolescents' expectations regarding appropriate behavior, responsibility, developmental expectations, discipline, and autonomy. The Family Structure domain includes both the power structure within a family and the level of cohesiveness among family members (Robin et al., 1990). The PARQ has been used to assess progress of families with adolescent diabetes following three months of Behavioral-Family Systems Therapy and showed pre-/post-test differences on families' extreme beliefs and general conflict (Wysocki, Greco, Harris, Bubb, & White, 2001). Separate forms are available for parents and adolescents with respective normative data and *T* scores. In general, higher scores on subscales of the PARQ reflect worse functioning in that particular area.

The PARQ has adequate reliability (Cronbach's $\alpha \geq 0.70$ for parents and adolescents) and discriminant validity between distressed and non-distressed families (Robin et al., 1990). Additionally, the focus on effective communication in the PARQ is congruent with the model proposed in the present study. Therefore, the Problem-Solving/Communication Skills subscales were used in the present study to examine the validity of the Communication Skills subscale of the measure developed in the present study (i.e., AIS Dyadic Assessment).

Emotion regulation, expression, and other varieties of so-called "emotional closeness" are incorporated in some form in many existing parent-adolescent relationship measures. However, the focus on emotions in the dyad relationship is often limited in these measures. For example, in the PARQ, arguably the best measure of the parent-adolescent relationship, questions about emotions are limited to the general emotional "climate" of the family and the level of autonomy

each family member possesses (Robin et al., 1990). While important to understanding family dynamics, these two aspects do not account for the entirety of the broader construct of emotion regulation (e.g., self-monitoring and awareness of emotions, willingness to change reactions to emotions in the service of a broader goal) that was investigated in the present study.

Two psychometrically adequate measures of emotion regulation in the adult literature have been validated with adolescent samples: the Emotion Regulation Questionnaire (ERQ) and the Difficulties in Emotion Regulation Scale (DERS). The ERQ is a brief 10-item measure that focuses on two aspects of the emotion regulation literature: expressive suppression and cognitive reappraisal (Gross & John, 2003). Although psychometrically sound, the focus of the ERQ is too narrow for the purposes of the present study. In contrast, the DERS is both psychometrically sound and comprehensive. It is a 41-item, self-report, Likert scale that assesses problems related to identifying, accepting, or effectively dealing with so-called “difficult” or unwanted emotions (Gratz & Roemer, 2004).

Factor analysis of the DERS yielded six subscales: Nonacceptance of Negative Emotional Responses (Nonacceptance), Difficulties Engaging in Goal-Directed Behavior When Distressed (Goals), Difficulties Controlling Impulsive Behavior When Distressed (Impulse), Lack of Emotional Awareness (Awareness), Limited Access to Emotion Regulation Strategies (Strategies), and Lack of Emotional Clarity (Clarity), each of which have been replicated in adult samples (Gratz & Roemer, 2004) and in an adolescent sample (Neumann, van Lier, Gratz, & Koot, 2010). In general, higher scores on the subscales of the DERS represent poorer emotion regulation abilities in that area. The DERS has adequate reliability (Cronbach’s $\alpha = 0.93$; test-retest reliability $\rho_{I=}$ 0.69-0.89, all p s < 0.01) and validity (Gratz & Roemer, 2004). In the literature, the DERS was significantly correlated with the Negative Mood Regulation Scale (i.e.,

construct validity), and accounted for additional variance (i.e., predictive validity) in intimate partner violence among heterosexual couples (Gratz & Roemer, 2004). In the present study, the DERS was included to examine the validity of the Emotion Regulation subscale of the measure developed in the present study (i.e., AIS Dyadic Assessment).

Measuring AIS psychosocial outcomes/processes. The most commonly used measure of psychosocial outcomes/processes in AIS research, the Scoliosis Research Society Outcomes Instrument-22r (SRS-22r), is a 22-item, adolescent self-report, Likert scale that assesses quality of life in the scoliosis patient across five domains: functioning/activity, pain, self-image/appearance, mental health, and satisfaction with management of symptoms (Asher et al., 2006). In general, higher scores on the subscales of the SRS-22r reflect better outcomes in that domain. The SRS-22r is widely used within the scoliosis literature and has adequate reliability (Cronbach's $\alpha = 0.78-0.89$) and concurrent (Asher et al., 2006) and discriminant validity between scoliosis patients with no/moderate curves and large curves (Asher, Lai, Burton, & Manna, 2003). In the literature, the SRS-22r was used to discriminate among pre- and post-surgical scoliosis patients (Hashimoto et al., 2007). The SRS-22r was included in the present study to examine the validity of the Mutual Agreement about AIS subscale of the measure developed in the present study (i.e., the AIS Dyadic Assessment).

Other commonly used instruments in the AIS literature are the Oswestry Low Back Pain Disability Questionnaire (Fairbank, Couper, Davies, & O'Brien, 1980), the Scoliosis Quality of Life Index (Feise, Donaldson, Crowther, Menke, & Wright, 2005), the Pediatric Outcomes Data Collection Instrument (Lerman, Sullivan, & Haynes, 2002), and the Spinal Appearance Questionnaire (Sanders et al., 2007). All of these measures have adequate reliability and validity and have demonstrated utility in the literature. However, collectively they focus on outcomes

specific to the patient with AIS including indicators of pain, disability/physical functioning, psychological functioning, body image, and quality of life. The only one that is designed specifically to assess both adolescents' and parents' perspectives is the Spinal Appearance Questionnaire, which focuses on an individual variable (i.e., physical appearance), rather than a measure of the relationship (Sanders et al., 2007). Due to these contextual shortcomings, none of these instruments were used in the present study.

Measuring dyadic variables in other adolescent chronic illness literatures. Similar to the broader category of parent-adolescent relationship measures, assessments in the diabetes literature focus on parents' perceptions or adolescents' perceptions. Only two measures include both adolescent and parent report in measuring diabetes care behaviors. The Diabetes Family Conflict Scale (DFCS) is a 17-item, self-report, Likert scale given to adolescents and their parents to assess family conflict around specific diabetes self-care behaviors; the higher the ratings, the greater the family's level of conflict around a particular behavior (Hood, Butler, Anderson, & Laffel, 2007). The Diabetes Family Responsibility Questionnaire (DFRQ) is a 17-item, self-report, Likert scale given to adolescents and their parents to assess perceptions of responsibility for diabetes care behaviors. Discordance scores between parents and adolescents reports are summed to indicate the overall level of agreement about responsibility (Anderson, Auslander, Jung, Miller, & Santiago, 1990). Although both the DFCS and the DFRQ have adequate reliability and validity and have demonstrated utility in diabetes research (Anderson et al., 1990; Anderson et al., 2009; Hood et al., 2007), both measures focus on only one aspect of the parent-adolescent relationship affected by a medical illness: how to improve adherence to prescribed regimens. Nevertheless, their utility in the diabetes literature implies any measure developed in the AIS literature that seeks to assess the parent-adolescent relationship ought to

include ways to measure communication about the illness. Both the DFCS and DFRQ inspired the items included in the AIS Dyadic Assessment developed in the present study.

To help examine the validity of the AIS Dyadic Assessment (the measure created in the present study), the Helping for Health Inventory (Anderson & Coyne, 1993) and The Brief Illness Perception Questionnaire (Broadbent, Petrie, Main, & Weinman, 2006) were given in the present study. The HHI is a 15-item Likert scale based on the theoretical construct of “miscarried helping,” that is, how the efforts of well-intentioned parents of children with chronic diseases may be communicated ineffectively and become barriers to successful treatment (Anderson & Coyne, 1991). Aspects of “miscarried helping” include parental investment, the success of parental efforts, the amount of parent-child conflict about parental helping behaviors, and attributions of blame for poor treatment outcomes (Harris et al., 2008). In general, higher scores on the HHI reflect greater endorsement of “miscarried helping,” arguably a less productive communication style. The HHI has adequate psychometric properties and is a reliable (Cronbach’s $\alpha = 0.81$; Test-retest reliability = 0.74) and valid (e.g., demonstrates concurrent and predictive validity) measure of the construct of “miscarried helping” (Harris et al., 2008). Parents’ responses from the HHI were compared to responses on the Communication Skills subscale of the AIS Dyadic Assessment.

The Brief IPQ is a 9-item, patient self-report “designed to rapidly assess the cognitive and emotional representations of illness” (Broadbent et al., 2006). The first eight items are Likert scaled and the last item asks patients to list, in rank-order, the three most important causes of their illness from their perspective. Although higher scores on the items 1-8 reflect greater endorsement of the content, the interpretation varies by item. For example, higher scores on the Timeline item reflect the belief that their back condition will last longer, while higher scores on

the Understanding item reflect the respondents' belief they are very knowledgeable about their back condition. The Brief IPQ has good test-retest reliability, concurrent validity with measures of similar constructs, and predictive validity (Broadbent et al., 2006). It predicted attendance at cardiac rehabilitation classes and timely return to work in a sample of myocardial infarction patients (Broadbent et al., 2006). Adolescents' responses from the Brief IPQ were compared to their responses on the Mutual Agreement about AIS subscale of the AIS Dyadic Assessment.

Purpose of the Present Study

Currently the AIS literature offers information on the psychological effects of bracing and surgery on adolescents themselves, as well as limited data about the psychological impact of an AIS diagnosis on parents. However, it is much less clear how adolescents and parents process information about AIS and subsequently communicate about responses to the condition including discussions about responsibility for and adherence to AIS treatment recommendations.

The purpose of the present study was to create an assessment tool, the AIS Dyadic Assessment, which measured three aspects of the current parent-adolescent relationship affected by AIS: Communication Skills, Emotion Regulation, and Mutual Agreement about AIS. Based on the outlined model, two parallel measures (one for mothers, one for daughters) were developed and subsequently analyzed dyadically. As no measure of the parent-adolescent relationship affected by AIS currently exists, it was important to empirically investigate whether an instrument developed specifically in the context of AIS had greater utility than either (1) established measures of the parent-adolescent relationship unaffected by chronic illness or (2) established measures in other adolescent chronic illness literatures (e.g., diabetes).

Ideally, in future empirical investigations, the instrument developed in the present study may be able to identify barriers to successful treatment outcomes and identify parent-adolescent

dyads that may be at risk for developing psychosocial distress in the course of treatment and/or problems related to medical adherence. At a minimum, use of such a measure in routine clinical practice creates an opportunity for families to talk about concerns they may have otherwise kept to themselves. Moreover, families experiencing these problems may benefit from a referral to adjunctive psychological services.

A secondary aim of the present study included novel application of the SRS-22r to dyadic research. In the present study, both parents and adolescents completed the SRS-22r, and their responses were compared to determine level of agreement about how AIS has impacted adolescents' quality of life. Comparing parents' and adolescents' responses on the same standardized instrument made it possible to answer questions about how well parents and adolescents were communicating about AIS and how much information about the adolescent's quality of life was known to the parent. Such information underlies parents' ability to help adolescents navigate treatment and may ultimately affect adherence.

Proposed Hypotheses

Based on the review of the existing literature it was hypothesized that:

1. Factor analysis of responses on the AIS Dyadic Assessment would yield three subscales related to communication, emotion regulation, and mutual agreement about AIS.
2. Parents' responses on the HHI would be significantly correlated with parents' responses on the AIS Dyadic Assessment (Communication Skills subscale).
 - a. There would be higher rates of endorsement on the AIS Dyadic Assessment than on the HHI.

3. Parents' and adolescents' responses on the DERS would be significantly correlated with parents' and adolescents' responses, respectively, on the AIS Dyadic Assessment (Emotion Regulation subscale).
 - a. There would be higher rates of endorsement on the AIS Dyadic Assessment than on the DERS.
4. Adolescents' responses on the Brief IPQ would be significantly correlated with adolescents' responses on the AIS Dyadic Assessment (Mutual Agreement about AIS subscale).
 - a. There would be higher rates of endorsement on the AIS Dyadic Assessment than on the Brief IPQ.
5. There would be discrepancies between parents' and adolescents' reports on the SRS-22r.
6. Method of data collection (i.e., in person or online) would not be associated with significant differences in participants' responses on outcome measures.

Anomalies in Data Collection Procedures and Revised Hypotheses

Some of the data collection procedures and hypotheses discussed up to this point were changed to accommodate difficulties with participant recruitment. Initially, the plan was to recruit survey responses from 75 mother-daughter dyads through in-person visits to scoliosis clinics in the local community. Once it became apparent that data collection was progressing more slowly than anticipated, participant incentives (e.g., lottery drawing to win gift certificates) were added. In addition, an online data survey option was added to allow recruitment from scoliosis clinics across the United States and to make it more convenient for local families to participate. However, after coordinating recruitment efforts with treatment providers and scoliosis researchers in hospitals and scoliosis clinics across the country, it became apparent that

data collection was still proceeding much more slowly than expected. At this point, recruitment efforts broadened considerably to include scoliosis websites, local print media sources, and local community gathering places (e.g., coffee shops, gymnastics and dance studios, libraries, restaurants, pet stores, grocery stores). Although this last broadening helped considerably, data collection was still progressing at a much slower rate than expected. Therefore, the decision was made to end data collection once responses from 25 families were obtained.

The decision to stop collection at 25 mother-daughter dyads was based on guidelines outlined in common dyadic data analysis procedures (Kenny, Kashy, & Cook, 2006). With this sample size, meaningful contributions to the mother-daughter scoliosis literature could still be made with the survey material collected, while allowing data collection to be completed in a timely manner. As a result, however, the sample size was too small to perform a factor analysis, and, as such, Hypothesis 1 and the proposed exploratory factor analysis with the SRS-22r could not be tested. The remaining hypotheses were addressed as initially planned. An additional hypothesis was added (Hypothesis 6) that predicted there would not be significant differences in outcome measures between participants who completed the survey in person and online.

Research Design and Methodology

Participants

Female adolescents diagnosed with AIS and their mothers were recruited from scoliosis clinics, research centers, scoliosis websites, and local community gathering places. The attrition process (Appendix A) left 58 total participants who completed the survey (either in-person or online) including 26 matched dyads, 4 mothers (without their daughters), and 2 daughters (without their mothers). Given that the focus of the present study is to understand more about the mother-daughter relationship, and that an absence of a response from half of the dyad may be significantly related to the constructs being investigated in the present study, responses from either mothers or daughters, not matched with the other member of the dyad, were eliminated from the analyses (i.e., responses from 6 people). The final sample consisted of 26 matched dyads ($n = 52$). In all cases, either mothers or daughters reported that bracing was the current treatment for daughters' AIS.

Mothers. The average age of mothers ($n = 26$) was 43.8 years ($SD = 4.66$). Mothers in this study self-identified their ethnicity as Caucasian (76.9%), African-American (11.5%), Middle Eastern (7.7%), or multiracial (3.8%). The majority of mothers reported being married or cohabitating with a domestic partner (88.5%), having attained at least some college (96.2%), and being from an upper-middle class socioeconomic background (84.8%; defined as \$50,000 or more annual income). Thirty-eight percent of mothers described their family's current economic situation as having "definitely enough of everything." Mothers' level of education was positively correlated with the family's household income [$r(25) = 0.50, p < .01$].

Daughters. The average age of daughters who completed the online survey was 12.9 years ($n = 14; SD = 1.1$). The average age of daughters who completed the in-person survey is

not available because that question was inadvertently deleted from the original paper survey. Similarly, information on daughters' self-identified ethnicity is not available because it was not included in either version of the survey. Participating daughters reported very low rates of substance use to manage their spine condition. Most daughters reported they "never" use alcohol (96.2%), and all participants reported that they never use illegal drugs (100%) or misuse prescription drugs (100%) to cope with their spine condition. The one adolescent who did endorse alcohol use as a method of coping reported "rarely" using.

Mother-Daughter dyad. The majority of daughters (96.2%) in the sample had some form of health insurance, and most mothers (76.9%) reported being satisfied with their daughters' health insurance coverage. Some mothers (19.2%), however, reported being dissatisfied with their daughters' health insurance coverage. A few of these mothers cited high co-pays as their predominant complaint. Other demographic statistics about the families, as reported by mothers, are shown in Appendix B.

In describing their own experiences with childhood illness, five mothers (19.2%) reported having a childhood diagnosis of AIS. Mothers were treated with close monitoring ($n = 2$), bracing ($n = 2$), or a combination of both close monitoring and bracing ($n = 1$). Four out of the five mothers with AIS described their treatment as relatively uncomplicated. The majority of mothers denied having any other major childhood illnesses (90.5%). Additional demographic statistics about mothers' experiences with major childhood illnesses are shown in Appendix C.

Ten mothers (38.5%) reported having a female relative – other than their daughter who participated in the present study with them – diagnosed with AIS. Mothers' female relatives with AIS consisted of a second daughter who did not participate in the study ($n = 1$), sisters ($n = 2$), mother ($n = 1$), cousins ($n = 2$), aunt ($n = 1$), and nieces ($n = 3$). Of these mothers, five reported

knowing “some information” about their relatives’ treatment, eight described their relatives’ treatment as relatively uncomplicated, and six did not recall any strong emotional reactions to their relatives’ treatment. Additionally, four mothers (15.4%) reported having more than one child who was diagnosed with AIS. Of those, 50% described their other child’s AIS treatment as relatively unremarkable, although the recommended treatment varied considerably including close monitoring (3.8%), close monitoring and physical therapy (3.8%), surgery (3.8%), and close monitoring, bracing, physical therapy, and surgery (3.8%). Other demographic statistics about the siblings’ AIS diagnosis and treatment, as reported by mothers, are shown in Appendix E.

To a great extent, mothers and daughters provided highly reliable data with regard to the daughters’ AIS diagnosis and treatment. The average length of time since daughters were diagnosed with AIS was approximately 2 years and 5 months ($SD = 1$ year, 9 months) according to mothers, and 2 years and 4 months ($SD = 1$ year, 8 months) according to daughters. The average size of the daughters’ spinal curve was 32.2° ($SD = 6.09$) according to mothers, and 32.5° ($SD = 7.23$) according to daughters. The difference between mothers’ and daughters’ estimates about the length of time since diagnosis and estimates about the daughters’ spinal curve were not significant (all $ps > .05$). In other words, on average, mother-daughter dyads appeared to share an adequate understanding of daughter’s AIS.

Regarding treatment recommendations for the daughters’ AIS, the majority of mothers (88.5%) and daughters (96.2%) reported that “bracing” was the currently prescribed treatment. These data are expected given that current bracing was one of the inclusion criteria for the present study. During the informed consent process, mothers from each dyad confirmed that their daughters were currently wearing a brace. However, there was a significant association between

membership in the dyad and reported current treatment [$\chi^2(1) = 7.97, p < .01$]. Daughters were significantly more likely than mothers to report they were receiving bracing as their current treatment. It is not clear why there were discrepancies during mothers' reports during the consent process and dyads' responses on the actual survey.

Regarding previous treatment recommendations, 19.2% of daughters and 23.1% of mothers reported both close monitoring and bracing in the past, while 15.4% of both mothers and daughters reported close monitoring, bracing, and physical therapy were all previous treatment recommendations.

Both mothers (84.6%) and daughters (92.3%) noted that daughters were following their doctor's recommendations "most of the time," and these reports were not statistically significantly different ($p = .33$). However, 7.7% ($n = 2$) of daughters reported wearing the brace only "sometimes." In other words, on average, mothers and daughters agreed on how adherent daughters' brace wearing behavior was with their treatment recommendations. Other demographic statistics about daughters' AIS diagnosis and treatment, as reported by both mothers and daughters, are shown in Appendix D.

Procedure

Broadly speaking, the present project included five main steps: (1) development of the AIS Dyadic Assessment Scale, (2) data collection, (3) statistical analysis of the AIS Dyadic Assessment Scale, (4) hypothesis testing, and (5) statistical analysis of the novel use of the SRS-22r.

AIS Dyadic Assessment Scale Development

The AIS Dyadic Assessment is the measure that was developed in the current study. The initial pool of items is presented in Appendices J (parent version) and K (adolescent version). As

mentioned earlier, these items were based on the existing relevant literatures and findings from an unpublished dissertation (Lynch, 2006). The items were designed to assess three domains pertinent to the parent-adolescent relationship affected by AIS: Communication Skills, Emotional Regulation, and Mutual Agreement about AIS. A graphical representation of the specific steps of scale development is included in Figure 2, followed by a written explanation of the process.

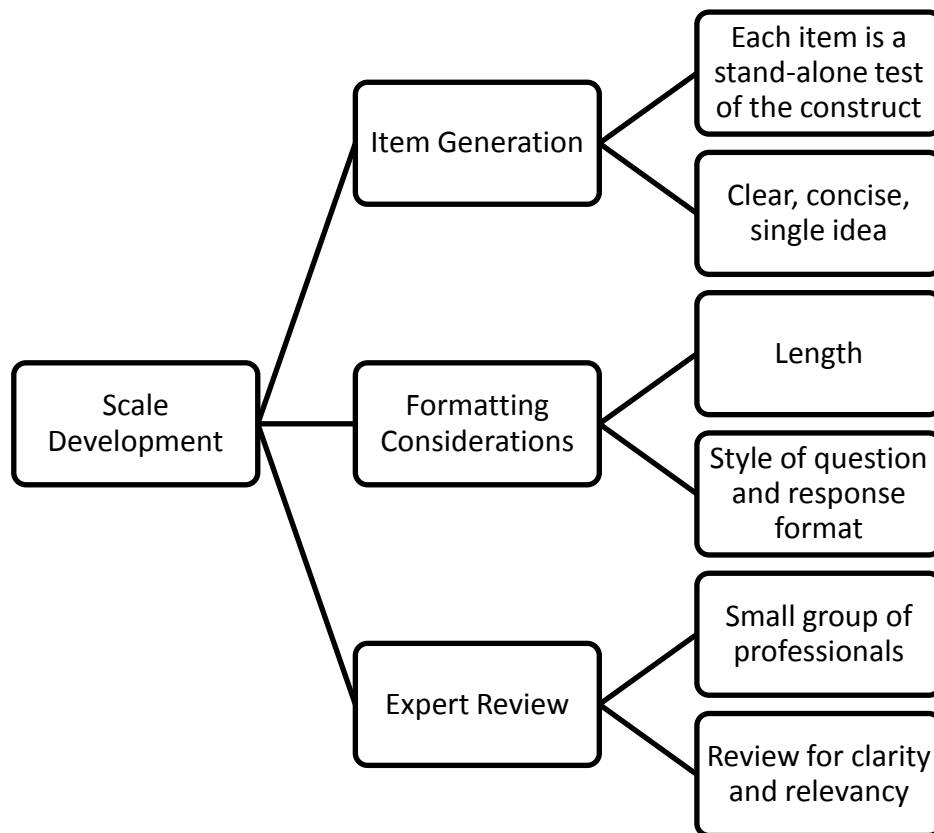


Figure 2. Steps in Scale Development

Item generation. Each of the items was written as though it were a stand-alone test of the parent-adolescent relationship affected by AIS (i.e., the latent construct) with the goal of generating redundancy of the construct when all the items were administered simultaneously (DeVellis, 2003). Each item reflected a single idea that is clear and concise to avoid “double-barreled responses” (DeVellis, 2003).

In keeping with research guidelines for dyadic assessments, the items were written to be “directed-relationship” items (Cook, 2005). This means that the items were phrased to assess one of the three components of the parent-adolescent relationship: (1) individual factors related to parent, (2) individual factors related to adolescent, or (3) factors that develop in the context of the parent-adolescent relationship (L. Thompson & Walker, 1982). Thus, items designed to assess parents’ and adolescents’ individual perceptions were included, as well as items that asked participants to assess their relationship.

To ensure the reading level of the instrument was between a 5th and 7th grade reading level (DeVellis, 2003), the reading level function in Microsoft Word was used.

Length of questionnaire. Although the axiom of “the more items the better” is often touted in instrument development, an initial item pool that is 3-4 times larger than the desired final scale is adequate (DeVellis, 2003). Additionally, larger item pools require larger samples. In order to strike a balance between sound research design principles and logistical concerns about sampling, the initial item pool was limited to 45 items for the AIS Dyadic Assessment.

Formatting considerations. The formatting of the measure was written using a Likert scale with five response options for each item. The Likert scale option was chosen for the present study because it has the ability to assess a continuum of responses with meaningful differences between responses (DeVellis, 2003). Each item was weighted equally, and the average was taken to create the final scale “score.”

In general, higher scores represent more functional outcomes for the dyad. For example, higher scores on the Communication Skills subscale reflect a style that is effective and proactive. Higher scores on items on the Emotion Regulation subscale reflect awareness and respect of both self’s and other’s emotions. Scores on the Mutual Agreement about AIS subscale reflect

agreement about what adherence with treatment and consequences of not adhering look like. Higher scores suggest the individual responding to the items believes that both she and the mother-daughter dyad are functioning effectively as a unit to manage the daughters' AIS treatment.

Expert review. The AIS Dyadic Assessment was reviewed by an orthopedic surgeon and licensed orthotist. They were asked to review each item for its relevancy and clarity, as well as to point out any aspects of the construct they believed were missing (DeVellis, 2003). Based on feedback from the experts, no changes were made to any items.

Data Collection

The principal investigator obtained approval from Eastern Michigan University HSRC and relevant medical facilities for all procedures, including informed consent, before beginning data collection. Both in-person (12 dyads) and online (14 dyads) data collection methods were used; in-person procedures are described first.

When in-person data collection took place in scoliosis clinics, HIPPA procedures were followed accordingly to protect participants' privacy; a representative of the orthotist made initial contact with potential participants to inquire about their interest in participating in a research study. Dyads who indicated they wanted to participate were then introduced to the principal investigator or a graduate level research assistant who obtained informed consent. Mothers were asked to provide written informed consent for themselves and their child; adolescents were asked to provide written assent (See Appendices F & G for Consent and Assent Forms, respectively). The consent and assent forms are stored in a locked file cabinet separately from the response forms at the Eastern Michigan University Department of Psychology. The questionnaires were made available to mothers and daughters in private sections of the waiting

rooms of scoliosis clinics (or in private rooms) or in waiting areas of public places at the request of the mothers (e.g., their local McDonald's restaurant). There were no perceived risks associated with participating in this study.

Regarding online data collection procedures, potential participants were contacted through scoliosis research centers, scoliosis websites across the U.S., and local community gathering places. Interested participants then called or e-mailed the principal investigator to discuss any questions or concerns they had about the study and to obtain the URL to access the online survey. Once it was verified that a mother provided informed consent, dyads were given a unique code to enter into the survey; this code was later used to link each dyad's responses together within the data set.

The content of the online survey was the same as the in-person survey except that the online survey included a question asking daughters their age. The online survey was created using SurveyMonkey[®], a secure and well-respected online research tool. It is endorsed by the Better Business Bureau and has been awarded a Trustee designation (e.g., it complies with the U.S. Department of Commerce recommendations for online services). It is protected with SSL encryption services (VeriSign Secured[™]) and McAfee[™] security software, programs that test the website on a daily basis to ensure security/encryption compliance. The website does not collect information on its users.

Each mother-daughter pair who decided to participate in the study was eligible to win a participant incentive. Ten mother-daughter pairs won a \$50.00 gift certificate to a store of their choosing. Winners were drawn randomly, and gift certificates were awarded at the end of the study.

Measures

A graphical representation of the measures used in the present study is provided in Figure 3. The left side of the figure includes the three main hypothesized subscales of the AIS Dyadic Assessment. The right side of the figure includes information on measures that were given, as well as who completed them, in order to investigate the validity of the AIS Dyadic Assessment. Table 1 is followed by a written description of each measure.

Table 1

Measures Included in the Present Study

Domain	Corresponding Items on the AIS Dyadic Assessment	Additional Measure Given to Compare Validity	Who Completes
Communication Skills	1-11	PARQ (subscale) HHI	Mothers + Daughters Mothers
Emotion Regulation	12-31	DERS	Mothers + Daughters
Mutual Agreement about AIS	32-45	SRS-22r Brief IPQ	Mothers + Daughters Daughters

Demographic questionnaire. A demographic questionnaire was created to assess demographic variables including age, gender, race, socioeconomic status, and education. This questionnaire was completed by mothers only, and information from it was used to verify that the sample in the present study was similar to samples in other AIS studies for the purposes of generalizing the present study's findings. Unfortunately, questions that asked daughters about their self-identified ethnicity were not included in the demographic questionnaire, and a question that asked daughters about their age was not included in the paper version of the survey. Additional questions pertaining to medically relevant information (e.g., degree of curvature, current treatment) were given to both parents and adolescents. See Appendix H for questions for parents and Appendix I for questions for adolescents.

Parent-Adolescent Relationship Questionnaire (PARQ). In the present study, only the Problem-Solving and Communication Skills subscales were administered. These items are not included in the appendices because they are protected by copyright laws. However, sample items from the relevant subscales include: “My teenager provokes me into an argument at least once a week” and “My teenager and I usually reach an agreement” (Robin et al., 1990). These subscales were used in the present study to assess general communication style within the dyad and to examine the validity of the Communication Skills subscale of the AIS Dyadic Assessment Scale. For additional information on the psychometric properties and utility of the PARQ, please refer to an earlier discussion of this measure (i.e., starting on page 21).

Difficulties in Emotion Regulation Scale (DERS). This scale was included in the present study to assess emotion regulation within the dyad and to examine the validity of the Emotion Regulation subscale of the AIS Dyadic Assessment Scale. For additional information on the psychometric properties and utility of the DERS, please refer to an earlier discussion of this measure (i.e., starting on page 23). See Appendix L for individual items on the DERS.

Scoliosis Research Society-22 Health Related Questionnaire (SRS-22r). The SRS-22r was used in a novel way in the present study: In addition to giving the SRS-22r in the standardized manner, parents completed a modified version, which was compared to adolescents’ responses. As consistent with the original instrument, the focus of the modified version was still on the AIS patient’s experience. The only difference was that the modified version assessed parents’ perceptions of how AIS impacted their adolescents’ quality of life. Parents’ and adolescents’ responses were compared to determine to what degree parents and adolescents agree about the impact of AIS on the adolescent’s quality of life. For additional information on the psychometric properties and utility of the SRS-22r, please refer to an earlier

discussion of this measure (i.e., starting on page 24). See Appendices M & N for Parents and Adolescents versions, respectively.

Helping for Health Inventory (HHI). The HHI was used in the present study to assess general perceived intrusiveness; parents' responses from the HHI were compared to their responses on the Communication Skills subscale of the AIS Dyadic Assessment. The language of the HHI was modified for the purposes of the present study. The HHI's original language referred to "child's illness." In the present study, the word illness was replaced with "spine condition." The wording was changed to make the responses more relevant for participants in the present study and to maintain consistent language throughout the entire survey. For additional information on the psychometric properties and utility of the HHI, please refer to an earlier discussion of this measure (i.e., starting on page 25). See Appendix O for individual items on the HHI.

The Brief Illness Perception Questionnaire (Brief IPQ). In the present study, the Brief IPQ was used to assess general beliefs about AIS; adolescents' responses from the Brief IPQ were compared to their responses on the Mutual Agreement about AIS subscale of the AIS Dyadic Assessment. The language of the Brief IPQ was modified for the purposes of the present study. The Brief IPQ's original language referred to "illness" throughout the measure. In the present study, the word illness was replaced with "spine condition." The wording was changed to make the responses more relevant for participants in the present study and to maintain consistent language throughout the entire survey. For additional information on the psychometric properties and utility of the Brief IPQ, please refer to an earlier discussion of this measure (i.e., starting on page 26). See Appendix P for individual items on the Brief IPQ.

Results

Data Analysis

Missing data. In general, there was a minimal amount of missing data. However, items that were missing appeared to be centered on two particular areas: daughters' estimates of time since diagnosis and curve size, and individuals' responses on the DERS. For example, one mother skipped one page of the paper survey in the middle of the DERS, and a couple of daughters skipped some individual items on the DERS. There was no apparent pattern or connection between these missing responses.

In all analyses, missing data were excluded, case wise, from the relevant statistical procedures. Subsequent sample sizes for each analysis are presented throughout the document. Although it is a common practice to impute the mean score for missing items, this approach may “suppress the true value of the standard deviation” and, consequently, increase the probability of a Type I error (Field, 2005, p. 184). Given that a smaller sample size, like the one in the present study, would be more susceptible, the decision was made to adopt a more conservative approach and exclude cases with missing data. In practice, minimal data were excluded from the analysis, with hypothesis testing being conducted with the majority of the sample.

Descriptive statistics of measures of interest. Means and standard deviations were calculated for each measure. Mean scores for each measure were compared to mean scores for adults and adolescents, respectively, in the normative samples, when available, using one sample t-tests. The normality of each measure's distribution was evaluated with a Kolmogorov-Smirnov test. Internal consistency reliability estimates (e.g., Cronbach's alpha) were also calculated for each measure, when applicable. See Table 2 for descriptive statistics related to the AIS Dyadic

Assessment, Table 3 for descriptive statistics on the other measures, and Appendix Q for additional descriptive statistics on the *subscales* of measures of interest.

Table 2

Descriptive Statistics for the AIS Dyadic Assessment

Subscale	<i>n</i>	Mean	Std. Deviation	<i>α</i>
Mothers				
Total Scale	25	126.9	13.9	0.81
Communication Skills	25	31.0	5.49	0.67
Emotion Regulation	25	55.8	6.87	0.71
Mutual Agreement About AIS	25	40.1	3.75	0.29
Daughters				
Total Scale	25	121.6	23.7	0.93
Communication Skills	25	33.5	6.63	0.82
Emotion Regulation	25	49.8	11.1	0.84
Mutual Agreement About AIS	25	38.3	7.71	0.80

The AIS Dyadic Assessment. The AIS Dyadic Assessment, a multidimensional assessment of the parent-adolescent relationship affected by AIS, was developed for the present study. This measure was intentionally designed to contain parallel forms for parents and adolescents, so that each member of the dyad could provide her own opinion without the overt influence of the other member. Thus, functionally speaking, the measure was intended to yield separate scores for parents and adolescents that could subsequently be compared to determine level of agreement on key issues related to adherence with treatment. As such, mothers' and daughters' responses on the AIS Dyadic Assessment were intended to be examined separately in the analysis.

To examine whether mothers' and daughters' responses on the AIS Dyadic Assessment were, indeed, as statistically independent as conceptualized, correlations between mothers' and

daughters' responses, respectively, on subscales of the AIS Dyadic Assessment were conducted. The choice of statistic was based on widely accepted guidelines for examining the assumption of independence in dyadic research (Kenny et al., 2006).

Results were non-significant for all three subscales of the AIS Dyadic Assessment: Communication Skills ($p = .19$) Emotion Regulation ($p = .95$), Mutual Agreement About AIS ($p = .19$). In other words, mothers' and daughters' responses on the AIS Dyadic Assessment scale were independent. Importantly, this finding supports the conceptual idea of assessing parents' and adolescents' perspectives separately, rather than on relying on either individual to accurately characterize dynamics of the dyad.

Means and standard deviations for mothers' and daughters' responses on the total AIS Dyadic Assessment score and for each individual subscale scores are presented in Table 2. As noted earlier, higher scores on this measure were intended to represent more functional outcomes for the dyad. Thus, the higher the scores on the total AIS Dyadic Assessment score, the more united the parent-adolescent dyad was thought to be. Broadly speaking, the sample characterized their relationship as having abilities to (1) be effective and proactive in their communication style; (2) cultivate awareness and respect for each other's emotional experiences, and (3) function effectively as a unit to manage the daughters' AIS treatment. As this is the first and only study to use the AIS Dyadic Assessment, some caution is warranted in interpreting these scores, particularly given the relatively small sample size.

Scores on the AIS Dyadic Assessment were normally distributed for mothers' and daughters' responses, respectively, on the total AIS Dyadic Assessment scale and each of the subscales, with one exception: Mothers' responses on the Mutual Agreement about AIS subscale were not normally distributed [$D(25) = 0.20, p < 0.05$]. The internal consistency reliability

estimates for mothers' total scores on the AIS Dyadic Assessment was "good" ($n = 25$; $\alpha = .81$). However, when Cronbach's alpha was examined for each of the subscales, estimates were acceptable for the Emotion Regulation ($n = 25$; $\alpha = .71$) subscale, somewhat less than acceptable for the Communication Skills ($n = 25$; $\alpha = .67$), and quite poor for the Mutual Agreement about AIS ($n = 25$; $\alpha = .29$) subscales. For daughters, internal consistency reliability estimates were good for the total AIS Dyadic Assessment Scale ($n = 25$; $\alpha = .93$) and for each of the three subscales: Communication Skills ($n = 25$; $\alpha = .82$), Emotion Regulation ($n = 25$; $\alpha = .84$), and Mutual Agreement about AIS ($n = 25$; $\alpha = .80$) subscales.

Table 3

Descriptive Statistics on Measures of Interest

Measure	<i>n</i>	Mean	Std. Deviation	Normative Mean	Normative Std. Deviation	<i>t</i>	α
PARQ: Communication							
Mothers	26	48.8	6.82	50.0	10.0	-0.86	0.64
Daughters	25	50.0	9.99	50.0	10.0	0.00	0.82
PARQ: Problem-Solving							
Mothers	26	46.2	5.33	50.0	10.0	-3.67 ^a	0.45
Daughters	25	49.6	9.28	50.0	10.0	-0.19	0.73
DERS: Mothers	22	81.2	6.09	78.0	20.7	2.45	0.49
DERS: Daughters	23	88.2	14.3	n/a	n/a	n/a	0.83
SRS-22r: Mothers	25	91.2	11.5	n/a	n/a	n/a	0.92
SRS-22r: Daughters	25	86.8	11.7	n/a	n/a	n/a	0.88
HHI	25	32.0	11.2	47.4	11.4	-6.83 ^a	0.92
Brief IPQ	25	41.5	10.7	n/a	n/a	n/a	n/a

^at-test is significant at the 0.01 level (2-tailed)

Parent-Adolescent Relationship Questionnaire (PARQ). The present study only used two of the subscales of the broader PARQ instrument; as such, there is no total score for the PARQ for either mothers or daughters. Thus, for the purposes of examining descriptive statistics

in the present study, mothers' and daughters' responses, respectively, were compared to appropriate normative samples' responses on the subscales of interest.

Mothers' mean T scores ($M = 48.8$, $SD = 6.82$) on the Communication Skills subscale were not significantly different ($p = .40$) than the mean T score for mothers in the normative sample. This means that mothers perceived the mother-daughter relationship as having average communication abilities. The mean T score for mothers on the Problem-Solving subscale, however, was significantly different [$t(25) = -3.67$, $p < .01$]. Mothers in the present sample ($M = 46.2$, $SD = 5.33$) reported statistically significantly lower scores on the Problem-Solving subscale than did mothers in the normative sample ($M = 50.0$, $SD = 10.0$). As noted earlier, lower scores on the Problem-Solving subscale reflect parents' beliefs that the parent-adolescent relationship has an adaptive problem-solving approach. Mothers' responses on both the Communication [$D(24) = .19$, $p < .05$] and Problem-Solving [$D(26) = .24$, $p < .01$] subscales were not normally distributed. The internal consistency of both the Communication ($n = 25$; $\alpha = .64$) and the Problem-Solving ($n = 26$; $\alpha = .45$) subscales were less than acceptable.

Daughters' mean T scores on the Communication ($M = 50$; $SD = 9.99$) and Problem-Solving ($M = 49.6$; $SD = 9.28$) subscales were not significantly different (all $ps > .05$) than the mean T scores for adolescents in the normative sample on each subscale, respectively. In other words, daughters in the present study characterized the communication and problem-solving styles within their mother-daughter relationship as average. Daughters' responses for both the Communication [$D(25) = .22$, $p < .01$] and Problem-Solving [$D(25) = .21$, $p = .01$] subscales were not normally distributed. The internal consistency reliability estimates were "good" for the Communication subscale ($n = 25$; $\alpha = .82$) and "adequate" for the Problem-Solving subscale ($n = 25$; $\alpha = .73$). Based on responses to the PARQ, participants in the present sample, in general,

characterized their mother-daughter relationship as having “good” communication and problem-solving skills (See Figure 3).

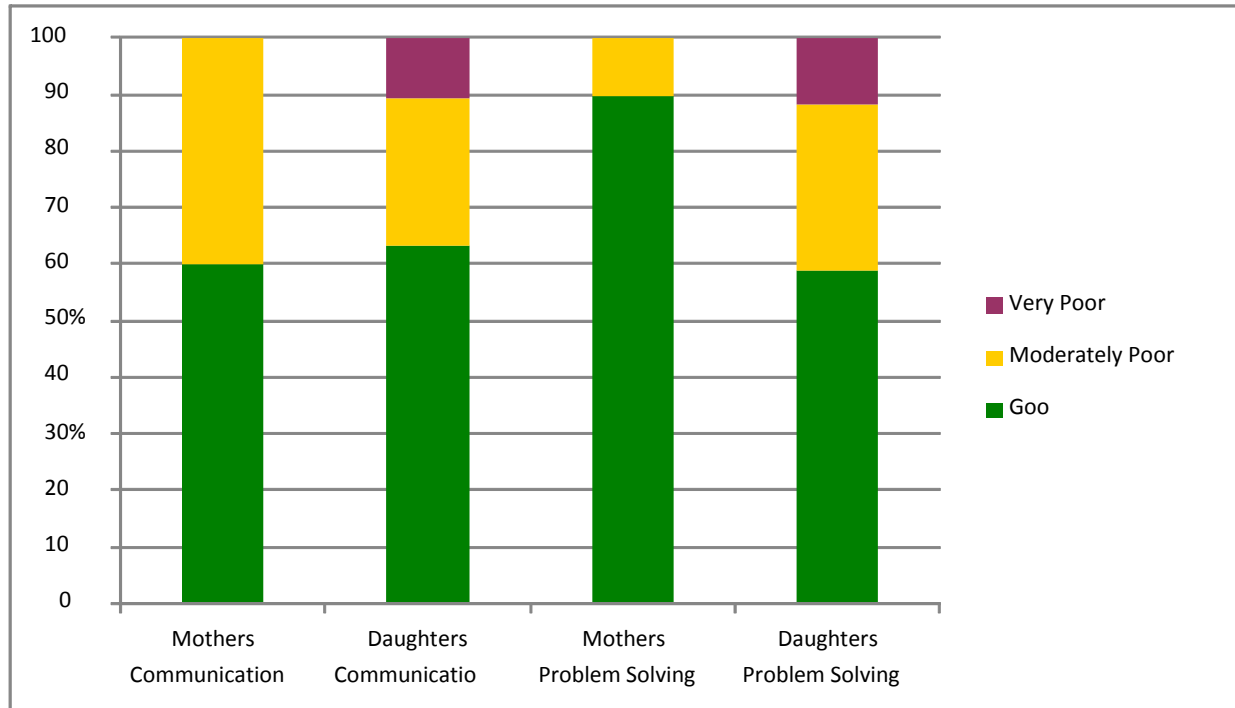


Figure 3. Dyadic Communication and Problem-Solving Skills

Difficulties in Emotion Regulation Scale (DERS). Mothers’ mean scores on the DERS ($M = 81.2$, $SD = 6.09$) were significantly higher [$t(22) = 2.45$, $p < .01$] than the mean score for undergraduate women in the normative sample ($M = 78.0$, $SD = 20.7$). As noted earlier, higher scores on the DERS reflect worse emotion regulation abilities. Mothers’ responses were normally distributed ($p > 0.05$), and the internal consistency was less than acceptable ($n = 22$; $\alpha = .49$). Daughters’ mean scores on the DERS ($M = 88.2$, $SD = 14.3$) could not be compared to a normative sample because total DERS scores were not reported in the developmental article. However, mean scores for subscales were reported and, as such, were compared to daughters’ responses on subscales in the present study. As can be seen by examining the results from t-test

comparisons in Appendix Q, daughters rated their emotional awareness and ability to engage in goal-directed behavior when distressed higher than did adolescents in the normative sample. In contrast, they reported less clarity about and acceptance of unwanted emotions, and greater difficulty controlling impulses and accessing emotion regulation strategies when distressed. Daughters' responses on the DERS total scale were not normally distributed ($p < 0.05$) but had a "good" internal consistency reliability estimate ($n = 23$; $\alpha = .83$).

Collectively, both mothers and daughters in the present sample had significantly lower average scale scores for each of the subscales of the DERS (See Appendix Q). As noted earlier, lower scores on the DERS reflect better emotion regulation abilities. Therefore, this pattern indicates that participants in the present study characterized their emotion regulation abilities as relatively high functioning compared to the normative samples.

Scoliosis Research Society-22 Health Related Questionnaire (SRS-22r). Mothers' mean scores on the SRS-22r ($M = 91.2$, $SD = 11.5$) could not be compared to any normative sample because the present study is the first study to administer the SRS-22r to a parental sample, and, as such, normative data for how parents might respond on this measure are unavailable. However, considering that higher scores represent more functional outcomes in samples with adolescents, and the relatively high total mean score reported by mothers in the present sample, it seems reasonable to conclude that mothers in the present sample rated their daughters' functioning levels across all five domains of the SRS-22r as highly functional.

Mothers' scores on the SRS-22r were normally distributed and had "good" internal consistency reliability estimates ($n = 25$; $\alpha = 0.92$). Daughters' mean scores on the SRS-22r ($M = 86.8$, $SD = 11.7$) were not compared to the normative sample because total scale scores were not included in the development article (Asher et al., 2006). However, means for subscales were

included in the development article and, as such, were compared to daughters' mean scores on subscales of the SRS-22r in the present study.

As can be seen by examining the results of t-test comparisons in Appendix Q, daughters' mean scores on the Functioning/activity and Pain ($M = 3.98$; $SD = 0.81$) subscales were not significantly different (all $ps < .05$) than adolescents' mean scores on these subscales, respectively, in the normative sample. This suggests that daughters in the present sample were fairly consistent with the literature with respect to self-reported physical activity and pain levels. They were, however, significantly different on the Self-image/appearance [$t(25) = -3.39$, $p < .01$], Mental health [$t(25) = -7.27$, $p < .01$], and Satisfaction with management of symptoms [$t(25) = -2.43$, $p < .05$]. Daughters had significantly lower scores on all three subscales than adolescents in the normative sample. As noted earlier, higher scores on the subscales of the SRS-22r are associated with better outcomes; therefore, the significantly lower mean scores in the present sample suggests that daughters in the present sample had a lower self-image, lower mental health, and less satisfaction with their AIS treatment than samples of AIS teens in the literature.

Helping for Health Inventory (HHI). Mothers' mean scores on the HHI were significantly different [$t(24) = -6.83$, $p < .01$] than mothers' mean scores in the normative sample (Harris et al., 2008). Mothers in the present study ($M = 32.0$, $SD = 10.7$) had significantly lower scores than mothers of adolescents with diabetes did in the normative sample ($M = 47.4$, $SD = 11.4$). As noted earlier, lower scores on the HHI reflect the parents' perception that they are engaging in a less overly intrusive communication style (e.g., less "miscarried helping"); this suggests mothers in the present sample believed they were engaging in an effective communication style. Mothers' responses in the present sample were not normally distributed

[$D(25) = .18, p < .05$], and the internal consistency ($N = 25; \alpha = .92$) of their responses was “good.”

The Brief Illness Perception Questionnaire (Brief IPQ). As noted earlier, the Brief IPQ consists of 8 Likert scale items and one qualitative response item. As such, an overall total scale score is not available for comparison purposes. However, the means of items 1-8 in the normative sample were available and, as such, were compared to daughters’ means on items 1-8 in the present sample. For the present study, the individuals with diabetes group in the normative sample were chosen for comparison purposes because the self-management behaviors for each illness are thought to be similar (as discussed in the literature review).

As can be seen by examining the t-test results in Appendix Q, daughters’ mean scores on the Consequences, Concern, Emotional Response, and Understanding items were not significantly different (all $ps > .05$) from adolescents’ mean scores on the same items in the normative sample. This means daughters in the present sample had similar expectations as individuals with diabetes regarding how severely their illness affects their life; how concerned they were about their illness, in general; how affected their emotional state is by the illness; and, how well they feel they understand their back condition.

However, daughters’ mean scores on the Personal Control, Treatment Control, Timeline, and Identity items were all significantly lower than adolescents’ mean scores on the items in the normative sample. This means that daughters in the present sample, compared to individuals with diabetes, felt like they had less control over their illness; believed treatment would be less helpful; felt their illness would not last for a long time; and did not experience many symptoms. No descriptive statistics were calculated for item 9 because it is a qualitative response item. Daughters’ scores on items 1-8, collectively, were normally distributed. Cronbach’s alpha was

not calculated for items 1-8 because they were conceptualized as distinct constructs in the developmental article.

Preliminary Analyses

To investigate whether there were any significant relationships between demographic variables and responses on outcome measures, correlations between demographic variables and mothers' and daughters' responses, respectively, on outcome measures used in the present study were conducted (See Appendix R: Correlation Matrices for Mothers and Daughters). The type of correlation was adjusted to account for normality of the distribution (e.g., Pearson's versus Spearman's) and level of data (e.g., bivariate versus point-biserial). Additional correlations (not included in the tables) between demographic variables and mothers' and daughters' responses, respectively, on *subscales* of the measures were also conducted. The collective results of all the *statistically significant* correlations are described below, starting with demographic information reported by mothers.

Mothers' demographic variables. Mothers' age was positively correlated with mothers' responses on the SRS-22r [$r(25) = 0.40, p < .05$] and with daughters' responses on the Functioning/activity [$r_s(25) = 0.43, p < .05$] subscale of the SRS-22r. Mothers' age was negatively correlated with daughters' responses on the Consequences item [$r(26) = -0.43, p < .05$] on the Brief IPQ, and with daughters' responses on the Limited Access to Emotion Regulation Strategies [$r(26) = -0.40, p < .05$] subscale of the DERS.

Family's household income, as reported by mothers, was negatively correlated with mothers' responses on the Limited Access to Emotion Regulation Strategies subscale of the DERS [$r_s(24) = -0.42, p < .05$]. Mothers' childhood diagnosis of AIS was positively correlated with mothers' responses on the AIS Dyadic Assessment [$r(24) = 0.45, p < .05$]. Mothers'

childhood diagnosis of AIS was positively correlated with mothers' responses on the SRS-22r [$r(24) = 0.49, p < .05$], including mothers' responses on the Functioning/activity [$r_s(24) = 0.51, p < .05$], Pain [$r(24) = 0.43, p < .05$], and Self-image/appearance [$r(24) = 0.42, p < .05$] subscales. Mothers' childhood diagnosis of AIS was negatively correlated with mothers' level of education [$r(25) = -0.40, p < .05$]. Mothers who reported having a childhood diagnosis of AIS were also more likely to report having more than one female relative who was also diagnosed with AIS [$r(25) = -0.41, p < .05$].

Daughters' demographic variables. Daughters' ratings of current adherence with brace wearing were positively correlated with daughters' responses on the DERS [$r_s(23) = 0.44, p < 0.01$] and Brief IPQ [$r(25) = 0.40, p < 0.05$] but were negatively correlated with daughters' responses on the SRS-22r [$r(25) = -0.45, p < 0.05$].

The AIS Dyadic Assessment. Although the sample size was too small to conduct the planned factor analysis (e.g., Hypothesis 1), it was large enough to investigate whether there were significant differences between mothers' and daughters' responses on the subscales of the AIS Dyadic Assessment. A multivariate analysis of variance (MANOVA) was conducted with participants' responses on the subscales of the AIS Dyadic Assessment as the three outcome variables (e.g., Communication Skills, Emotion Regulation, and Mutual Agreement about AIS) and membership in the dyad as the single predictor variable (e.g., two levels: mother or daughter).

Although the present sample met the assumption of independence required for a MANOVA (e.g., mothers' and daughters' responses were not significantly correlated with each other), it is likely the assumption of multivariate normality was violated because two of the subscales were not normally distributed: Emotion Regulation [$D(50) = 0.18, p < 0.01$] and

Mutual Agreement about AIS [$D(50) = 0.13, p < 0.05$]. However, the MANOVA can withstand violations in normality provided there are at least 20 degrees of freedom in the sample (Tabachnick & Fidell, 2001). As the present sample had 48 degrees of freedom for the univariate test, it is likely the MANOVA was robust against these violations of normality. To assess for homogeneity of covariance, a third assumption of the MANOVA, Levene's Tests of Equality of Variance was calculated, and this assumption was met for all three subscales (all $ps > 0.05$).

There was a significant difference between mothers' and daughters' responses on the Communication Skills subscale of the AIS Dyadic Assessment [$F(1,50) = 4.49, p < 0.05, \eta^2 = 0.08$]. Non-significant differences were found for the Emotion Regulation [$F(1,50) = 2.45, p = 0.12, \eta^2 = 0.05$] and Mutual Agreement about AIS [$F(1,50) = 0.17, p = 0.68, \eta^2 = 0.00$] subscales. Adjusted means on dependent variables for mothers and daughters are provided in Table 4.

Table 4

Adjusted Means for Dependent Variables on the AIS Dyadic Assessment

	Mothers		Daughters	
	M	Std. Error	M	Std. Error
Communication Skills	22.3	0.91	25.0	0.91
Emotion Regulation	46.4	1.23	43.6	1.23
Mutual Agreement about AIS	30.2	1.06	29.5	1.06

Tests of Hypotheses

Hypothesis 1. Hypothesis 1 predicted that a factor analysis of responses on the AIS Dyadic Assessment would yield three subscales related to communication, emotion regulation, and mutual agreement about AIS. Due to a limited sample size, however, it was not possible to conduct a factor analysis. Therefore, Hypothesis 1 could not be tested, as originally planned.

Hypothesis 2. Hypothesis 2 predicted mothers' responses on the Helping for Health Inventory (HHI), a measure of parents' perceptions of their own misguided or overly intrusive helping behaviors, would be significantly correlated with mothers' responses on the Communication Skills subscale of the AIS Dyadic Assessment. As noted earlier, mothers' responses on the Communication Skills subscale were normally distributed ($p = 0.06$), while their responses on the HHI were not [$D(25) = .18, p < .05$]; therefore, the decision was made to use a Spearman's correlation because the data violated parametric assumptions of the Pearson's statistic. Hypothesis 2 was supported; mothers' responses on the Communication Skills subscale were negatively correlated with mothers' responses on the HHI [$r_s(24) = -0.62, p < .01$]. As mothers reported a more efficient and proactive communication style (e.g., higher scores on the Communication Skills subscale), they reported less overly intrusive helping behaviors (e.g., lower scores on the HHI).

Hypothesis 2a predicted there would be higher rates of endorsement on the Communication Skills subscale of the AIS Dyadic Assessment than on the HHI. In order to compare scores from two different measures, raw scores on both measures were converted to z scores. As noted earlier, the data for the HHI was not normally distributed; therefore, the decision was made to use a Wilcoxon signed-rank test because the data violated parametric assumptions about the dependent t-test (i.e., the test typically chosen to measure differences in means in a repeated measures design). Hypothesis 2a was not supported; mothers' responses on the Communication Skills subscale and HHI were not significantly different ($p = 0.69$).

Hypothesis 3. The third hypothesis suggested mothers' and daughters' responses on the DERS, a measure of how well participants identify and cope with "unwanted emotions," would be significantly correlated with mothers' and daughters' responses, respectively, on the Emotion

Regulation subscale of the AIS Dyadic Assessment. This hypothesis was tested with a series of correlations. First, a Pearson's correlation between mothers' responses on the Emotion Regulation subscale of the AIS Dyadic Assessment and mothers' total score on the DERS was non-significant ($p = 0.91$). Mothers' responses on the Difficulty Controlling Impulsive Behavior subscale, however, were negatively correlated with mothers' responses on the Emotion Regulation subscale of the AIS Dyadic Assessment [$r_s(24) = -0.42, p < 0.05$]. In other words, as mothers reported higher endorsement of scores on the Emotion Regulation subscale of the AIS Dyadic Assessment, they reported greater difficulty controlling impulsive behavior when distressed.

Second, a Spearman's correlation between daughters' responses on the Emotion Regulation subscale of the AIS Dyadic Assessment and daughters' total scores on the DERS was non-significant ($p = 0.64$). However, daughters' responses on the Emotion Regulation subscale of the AIS Dyadic Assessment were positively correlated with their responses on the Lack of Emotional Clarity subscale [$r(25) = 0.62, p < 0.01$] and negatively correlated with their responses on the Difficulty Controlling Impulsive Behavior subscale [$r(23) = -0.54, p < 0.01$] of the DERS. As daughters reported higher endorsement of scores on the Emotion Regulation subscale of the AIS Dyadic Assessment, they reported greater ability to control impulsivity when distressed, but less clarity about their emotional experiences. Therefore, Hypothesis 3 was partially supported.

Hypothesis 3a predicted that mothers and daughters would have higher rates of endorsement on the Emotion Regulation subscale of the AIS Dyadic Assessment than on the DERS. In order to compare scores from two different measures, raw scores on both measures were converted to z scores. A paired samples t test revealed that Hypothesis 3a was not

supported for mothers ($p = 0.98$). As noted earlier, daughters' responses on the DERS were not normally distributed [$D(23) = 0.23, p < 0.01$]; therefore, the decision was made to use a Wilcoxon signed-rank test because the data violated parametric assumptions about the dependent t-test. Hypothesis 3a was not supported for daughters either ($p = 0.76$). Mothers' and daughters' responses on both the Emotion Regulation subscale of the AIS Dyadic Assessment and the DERS were not significantly different.

Hypothesis 4. The fourth hypothesis suggested daughters' responses on the Brief IPQ, a measure of "cognitive and emotional representations of illness," would be significantly correlated with daughters' responses on the Mutual Agreement about AIS subscale of the AIS Dyadic Assessment. A Pearson's correlation between daughters' responses on the Mutual Agreement about AIS subscale and the Brief IPQ (i.e., items 1-8 only) was non-significant ($p = 0.47$). However, daughters' responses on the Mutual Agreement about AIS subscale were negatively correlated with their responses on the Consequences [$r(25) = -0.50, p < .05$] and Emotional Response [$r(25) = -0.45, p < .05$] items, and positively correlated with the Treatment Control [$r(25) = 0.55, p < .01$] item on the Brief IPQ. As daughters endorsed greater belief that their mother-daughter relationship was successfully navigating AIS treatment, they reported greater belief that their back condition will have a minimal impact on their life (e.g., Consequences), belief that treatment will be helpful (e.g., Treatment Control), and reported that their back condition does not affect them very much emotionally (e.g., Emotional Response). Therefore, Hypothesis 4 was partially supported.

Hypothesis 4a predicted daughters would have higher rates of endorsement on the Mutual Agreement about AIS subscale than on the Brief IPQ. In order to compare scores from two different measures, raw scores on both measures were converted to z scores. (For this analysis,

the total mean for items 1-8 on the Brief IPQ, rather than means on individual items, was used). A paired samples t test revealed that Hypothesis 4a was not supported; daughters' responses on the Mutual Agreement about AIS subscale and on the Brief IPQ were not significantly different ($p = 0.82$).

Hypothesis 5. It was predicted there would be discrepancies between parents' and adolescents' reports on the SRS-22r. To test this hypothesis, a MANOVA was conducted with participants' responses on each of the subscales of the SRS-22r as the five outcome variables (e.g., Functioning/activity, Pain, Self-image/appearance, Mental health, Satisfaction with treatment) and membership in the dyad as the single predictor variable (e.g., two levels: mother or daughter). Mothers' and daughters' responses on the Pain [$r_s(25) = -0.40, p = 0.05$], Self-image [$r_s(25) = -0.43, p < 0.05$], and Satisfaction with Management of Symptoms [$r_s(26) = -0.41, p < 0.05$] subscales of the SRS-22r were significantly related, thus violating the assumption of independence required for the MANOVA. The assumption of multivariate normality was also likely violated, as the distributions for the Functioning/Activity [$D(50) = 0.23, p < 0.01$], Pain [$D(50) = 0.22, p < 0.01$], Mental Health [$D(50) = 0.17, p < 0.01$], and Satisfaction with Management of Symptoms [$D(50) = 0.16, p < 0.01$] subscales were all not normally distributed. To assess for homogeneity of covariance, a third assumption of the MANOVA, Levene's Tests of Equality of Variance, was calculated, and this assumption was met for all five of the subscales (all $p_s > 0.05$). Although the present sample violated the assumptions of independence, and likely the assumption of multivariate normality, as well, given the references cited above, the MANOVA was likely robust to these violations.

Results were non-significant for all five subscales: Functioning/activity [$F(1,48) = 0.36, p = 0.55, \eta^2 = 0.01$], Pain [$F(1,48) = 2.63, p = 0.11, \eta^2 = 0.05$], Mental Health [$F(1,48) = 0.03, p$

= 0.86, $\eta^2 = 0.00$], Self-image [$F(1,48) = 1.93, p = 0.17, \eta^2 = 0.04$], and Satisfaction with Management of Symptoms [$F(1,48) = 2.62, p = 0.11, \eta^2 = 0.05$]. Therefore, Hypothesis 5 was not supported; there were no significant differences between mothers' and daughters' responses on the subscales of the SRS-22r. Adjusted means on dependent variables for mothers and daughters are provided in Table 5.

Table 5

Adjusted Means for Dependent Variables on the SRS-22r

	Mothers		Daughters	
	M	Std. Error	M	Std. Error
Functioning/activity	13.5	0.28	13.3	0.28
Pain	10.0	0.45	11.1	0.45
Mental Health	14.6	0.31	14.7	0.31
Self-image/Appearance	10.4	0.73	11.8	0.73
Satisfaction with Symptom Management	4.04	0.30	4.72	0.30

Hypothesis 6. The sixth hypothesis predicted that method of data collection (i.e., in person or online) would not be associated with significant differences in participants' responses on outcome measures. To determine whether there were any *a priori* differences in demographic variables between the dyads who participated in the in-person data collection and dyads who participated in online data collection, chi square and independent t-tests were run, as appropriate, among demographic variables.

Looking at demographic variables reported by mothers, there were no significant differences between in-person and online data collection samples with respect to any demographic variables with the exception of prior experience with AIS. There was a significant difference between in-person and online data collection samples with respect to mothers' having been diagnosed with AIS in childhood [$\chi^2(1) = 4.91, p < .05$]. In other words, mothers who reported having a childhood diagnosis of AIS were 2.22 times more likely to have completed the

survey online. There was also a significant difference between in-person and online data collection samples with respect to a second child in the family being diagnosed with AIS [$\chi^2(1) = 4.05, p < .05$]. In other words, families with two children diagnosed with AIS were 2.20 times more likely to have completed the survey online. Given that online recruitment occurred via scoliosis websites, mothers who have had more familial involvement with AIS may have been more likely to have been involved with these resources and, subsequently, more likely to participate online.

With regard to demographic variables reported by mothers and daughters, there were no significant differences between in-person and online data collection samples with respect to reports of daughters' adherence with brace wearing and identification of AIS treatment prescribed in the past (all $ps > .05$). There was, however, a significant difference between in-person and online data collection samples with respect to the daughters' currently recommended treatment [$\chi^2(1) = 3.71, p = .05$]. In other words, participants were 2.00 times more likely to report that the daughters' current treatment was "close monitoring" in the online survey.

Collectively, the significant differences observed between in-person and online samples on some demographic variables suggest there may be some key differences between dyads who completed the survey in-person and online. To investigate whether there were significant differences between in-person and online responses on outcome measures, a MANOVA was conducted. Participants' responses on the AIS Dyadic Assessment, PARQ Communication and Problem-Solving subscales, SRS-22r, and DERS were the outcome variables while method of data collection was the single predictor variable (e.g., level: in-person or online). There were statistically significant differences between in-person and online responses with respect to daughters' responses on the DERS [$F(1,16) = 6.62, p < 0.05, \eta^2 = 0.29$] and with respect to

mothers' responses on the AIS Dyadic Assessment [$F(1,16) = 6.80, p < 0.05, \eta^2 = 0.30$].

Adjusted means on dependent variables for mothers and daughters are provided in Table 6.

Table 6

Adjusted Means for Dependent Variables

	In-Person		Online	
	M	Std. Error	M	Std. Error
AIS Dyadic Assessment – Mothers	133.1	3.77	118.4	4.21
AIS Dyadic Assessment – Daughters	123.3	7.36	114.4	8.23
PARQ Communication – Mothers	50.9	2.19	48.8	2.45
PARQ Communication – Daughters	51.7	3.20	46.5	3.58
PARQ Problem-Solving – Mothers	47.7	1.90	45.4	2.12
PARQ Problem-Solving – Daughters	53.0	3.20	47.8	3.58
DERS – Mothers	80.5	1.79	82.5	2.00
DERS – Daughters	82.7	4.23	99.0	4.72
SRS-22r – Mothers	91.1	3.74	87.1	4.18
SRS-22r – Daughters	89.0	3.75	81.5	4.19

Additionally, separate one-way ANOVAs were conducted with the HHI and Brief IPQ as the outcome variables. The decision was made to examine these scales separately because only mothers completed the HHI and only daughters completed the Brief IPQ. There were no significant differences between in-person and online participants' responses on either the HHI or the Brief IPQ (all $ps > .05$). Therefore, Hypothesis 6 was partially supported.

Power analysis. An *a priori* power analysis was conducted to determine the sample size required for adequate power when detecting group differences with an ANOVA. The power analysis was done using G* Power 3.1.2 software program (Faul, Erdfelder, Buchner, & Lang, 2009). Twenty participants per group were required if a medium effect size ($f = 0.25$) were to be found (Cohen, 1977). Therefore, it was estimated 40 total participants would be needed to have adequate power for the ANOVA.

Exploratory analysis: statistical analysis of the SRS-22r. The original proposal planned to further investigate parents' responses on the SRS-22r by performing a confirmatory factor analysis to determine if the factor structure in the present sample yielded the same five subscales of the original SRS-22r. Due to sample size limitations, however, it was not possible to perform this analysis; therefore, the exploratory analysis could not be tested.

To further explore potential relationships between the AIS Dyadic Assessment and the SRS-22r, additional correlations (either Pearson's or Spearman's) were conducted. Difference scores between mothers' and daughters' responses on the five subscales of the SRS-22r were calculated. These difference scores were then correlated with mothers' and daughters' responses, respectively, on the three subscales of the AIS Dyadic Assessment. As can be seen in Table 7, as daughters endorsed greater responses on the Emotion Regulation subscale of the AIS Dyadic Assessment, the dyads reported less disagreement on scores on the Self-Image [$r(24) = -0.42, p < 0.05$] and Mental Health [$r(24) = -0.41, p < 0.05$] subscales of the SRS-22r. Similarly, as daughters' responses on the Mutual Agreement about AIS subscale increased, dyads reported less disagreement on the Self-Image [$r(24) = -0.54, p < 0.01$] and Mental Health [$r(24) = -0.43, p < 0.01$] subscales of the SRS-22r, as well.

Table 7

Correlation Matrix for the SRS-22r and AIS Dyadic Assessment [r(n)]

	Function	Pain	Self-Image	Mental Health	Satisfaction
Communication: Mother	0.35(23)	-0.16(24)	0.10(24)	0.13(25)	-0.17(25)
Communication: Daughter	-0.15(24)	-0.31(25)	-0.27(25)	-0.25(26)	-0.35(26)
Emotion Regulation: Mother	0.36(24)	-0.11(25)	0.38(25)	0.30(26)	0.24(26)
Emotion Regulation: Daughter	-0.17(23)	-0.28(24)	-0.42(24) ^a	-0.41(25) ^a	-0.32(25)
Mutual Agreement: Mother	0.35(24)	-0.09(25)	-0.02(25)	-0.03(26)	-0.02(26)
Mutual Agreement: Daughter	-0.18(23)	-0.18(24)	-0.54(24) ^b	-0.43(25) ^b	-0.23(25)

^a Correlation is significant at the 0.05 level (2-tailed).

^b Correlation is significant at the 0.01 level (2-tailed).

Summary of Results

To summarize, results in support of the proposed hypotheses were mixed. Hypothesis 1 could not be tested due to a smaller than anticipated sample size. Hypothesis 2 was partially supported: Mothers' responses on the Communication Skills subscale of the AIS Dyadic Assessment were significantly correlated with mothers' responses on the HHI; however, mothers did not have higher rates of endorsement on the Communication Skills subscale than on the HHI. Hypothesis 3 was partially supported: Mothers' and daughters' responses on the Emotion Regulation subscale of the AIS Dyadic Assessment were correlated with mothers' and daughters' responses, respectively, on subscales of the DERS. Neither mothers nor daughters had greater rates of endorsement on the Emotion Regulation subscale of the AIS Dyadic Assessment than on the DERS. Hypothesis 4 was partially supported: Daughters' responses on the Brief IPQ were significantly correlated with daughters' responses on the Mutual Agreement about AIS subscale of the AIS Dyadic Assessment. However, daughters did not have higher rates of endorsement on the Brief IPQ than on the Mutual Agreement subscale. Hypothesis 5 was not supported: There were no significant differences between mothers' and daughters' responses on the SRS-22r. Hypothesis 6 was partially supported: There were significant differences between mothers' responses on the AIS Dyadic Assessment and daughters' responses on the DERS between in-person and online administrations, but not on any other outcome measures.

Discussion

The main focus of the present study was to examine the mother-daughter relationship in the context of the daughters' diagnosis of AIS. This included developing a measure, the AIS Dyadic Assessment, that could be used to systematically measure the functioning of the mother-daughter dyad in clinical settings and potentially identify families who might benefit from a

referral to a mental health professional as an adjunctive intervention to typical AIS treatment. The AIS Dyadic Assessment endeavored to assess three dimensions of the mother-daughter relationship thought to be affected by diagnosis and treatment of AIS including how well the dyad communicated about adherence, how well the dyad regulated their emotional experiences in the context of AIS treatment, and to what degree the dyad reached consensus about key components of adherence to brace-wearing and consequences for non-adherence.

Secondary aims of the study included novel use of the SRS-22r as an avenue for assessing parents' perceptions of adolescents' quality of life within the context of wearing a brace for the treatment of AIS. Additionally, the present study proposed a theoretical model of the parent-adolescent relationship affected by AIS, and although the model was not explicitly tested in the present study, results did lend some preliminary support for this model.

The Utility of the AIS Dyadic Assessment: An Evaluation of its Psychometric Performance

The AIS Dyadic Assessment consists of three subscales – Communication Skills, Emotion Regulation, and Mutual Agreement about AIS – that were derived from the AIS, parent-adolescent, and adolescent with chronic illness literatures. Although the relatively small sample size of the present study precluded the planned statistical analysis that would further explore the proposed factor structure of the AIS Dyadic Assessment, other analyses provided tentative and preliminary support for the convergent validity and utility of the AIS Dyadic Assessment.

One of the benefits of using the AIS Dyadic Assessment is that it provides both parents' and adolescents' perspectives on treatment, something that is not produced by any other existing measure in the AIS and/or related literatures. This is important because both mothers' and daughters' perceptions about AIS treatment are not always congruent. For example, parents have historically been more worried about their daughter needing surgery (Gratz & Papalia-Finlay,

1984), while adolescents have been more concerned about day-to-day hassles associated with effective bracing: things like choosing what clothes to wear and whether wearing a brace will affect participation with extracurricular activities (Bridwell et al., 2007; Lynch 2006). Moreover, parents' and adolescents' *perceptions* about long-term outcomes of treatment are associated with *actual treatment and psychological outcomes*. For example, mothers' optimism about treatment is associated with better outcomes (Kahanovitz & Weiser, 1989; Olafsson, et al., 1999), while adolescents' pessimism about AIS prognosis is associated with increased depression (Kahanovitz & Weiser, 1989). Practically speaking, then, relying on a measure that only assesses parents' or adolescents' perspectives – like the extant measures discussed in the literature review – may not accurately characterize the parent-adolescent relationship affected by AIS or identify important barriers to adherence and may not correctly identify families who may benefit from adjunctive psychological services in the course of AIS treatment.

Additionally, considering that the results from the AIS Dyadic Assessment were statistically independent in the present sample, there can be some tentative confidence in assuming the AIS Dyadic Assessment will continue to adequately characterize differences in opinion within parent-adolescent dyads. Although it is possible that the test for statistical independence was underpowered due to a relatively small sample size, given the statistically significant difference between mothers' and daughters' responses on the Communication Skills subscale of the AIS Dyadic Assessment, however, it seems more likely that members of the dyad had genuine differences of opinion. As the AIS Dyadic Assessment is the only measure that explicitly examines the parent-adolescent relationship within the context of AIS treatment, information provided by the AIS Dyadic Assessment represents a unique contribution to the

literature and, following further empirical investigation and refinement, has the potential to make clinically meaningful predictions.

The reliability of the AIS Dyadic Assessment. To examine the reliability of the AIS Dyadic Assessment, estimates of internal consistency (e.g., Cronbach's alpha) were calculated for mothers' and daughters' responses, respectively, on the total AIS Dyadic Assessment, as well as for each of the subscales.

Broadly speaking, the total AIS Dyadic Assessment had "good" internal consistency when completed by either mothers or daughters. This trend continued for daughters' responses on the three subscales of the AIS Dyadic Assessment, suggesting that the subscales adequately reflected the separate constructs thought to be crucial to the parent-adolescent relationship navigating AIS treatment (e.g., as discussed in the literature review).

For mothers' responses, however, estimates of the internal consistency varied considerably by subscale, including adequate estimations for the Emotion Regulation subscale, slightly less than adequate for the Communication Skills subscale, and quite poor for the Mutual Agreement about AIS subscale. It seems reasonable to posit that the lower internal reliability estimates for mothers may improve with a larger sample size. However, it is also possible that for mothers' responses on the Mutual Agreement about AIS subscale, the construct being assessed in this scale may be less unidimensional than anticipated. Future investigations with larger sample sizes would allow more sophisticated analyses (e.g., factor analysis, structural equation modeling) to help address this question. Examining how participants' responses change over time (e.g., test-retest reliability) may also be helpful.

The validity of the Communication Skills subscale of the AIS Dyadic Assessment. In examining the convergent validity of the AIS Dyadic Assessment, participants' responses on

subscales of this measure were compared to their responses on more established measures within the adolescent and adolescent chronic illness literatures. More specifically, mothers' responses on the Helping for Health Inventory (HHI) were compared to the Communication Skills subscale of the AIS Dyadic Assessment. Additionally, although not included as a formal hypothesis, participants' responses on the Communication and Problem-Solving subscales of the Parent-Adolescent Relationship Questionnaire (PARQ) were compared to participants' responses on the Communication Skills subscale of the AIS Dyadic Assessment in exploratory analyses.

Discussion on the HHI is presented first.

As predicted, mothers' responses on the HHI, a proxy measure of misguided or overly intrusive helping behaviors by parents, and the Communication Skills subscale of the AIS Dyadic Assessment were significantly related. More specifically, as mothers reported a more efficient and proactive communication style (e.g., higher scores on the Communication Skills subscale of the AIS Dyadic Assessment), they reported less overly intrusive helping behaviors (e.g., lower scores on the HHI). This is important because higher family conflict, particularly between parent and adolescent, is associated with poorer outcomes in the adolescent diabetes literature – a treatment regimen that is similar in many ways to AIS treatment. More specifically, greater conflict between parents and teens is associated with poorer glycemic control (Anderson et al., 2009; Anderson et al., 1981; Anderson et al., 2002; Bobrow et al., 1985; Hauser et al., 1990; Jacobson et al., 1994; Miller-Johnson et al., 1994; Wysocki, 1993), and parental behavior that is perceived as being overly intrusive (e.g., nagging, controlling, overly critical) by adolescents is associated with poorer adherence to diabetes regimens (Schafer et al., 1983; Schafer et al., 1986).

Although the HHI is only a proxy measure of conflict and overly intrusive parental helping behavior (e.g., it measures parents' perceptions of their own behavior rather than a neutral third party's observation), it has demonstrated predictive validity in the adolescent diabetes literature (Harris et al., 2008). It seems reasonable, therefore, to conclude that mothers' perceptions of their helping behavior in the present study, then, are at least somewhat consistent with their actual helping behavior in the context of AIS treatment. Moreover, this finding suggests that in the present study, a lack of nagging, controlling, and overly critical helping behaviors by mothers is associated with the perception of a "good" communication style by both mothers and daughters. Additionally, although possible causal relationships between communication and adherence were not measured directly in the present study, it seems reasonable to posit that the relatively effective communication style reported by dyads in the present study may be a contributing factor to the higher than usual rates of adherence reported in the present study. The predictive utility of measuring communication styles within the parent-adolescent relationship in order to predict adolescent's adherence with brace-wearing, then, may be an important area for future investigation.

The direction of the relationship between these two different communication measures makes sense within the context of instrument development. For example, higher scores on the Communication Skills subscale of the AIS Dyadic Assessment were designed to represent more effective communication skills; therefore, it makes sense from a theoretical perspective that higher scores would be significantly correlated with less overly intrusive helping behaviors – a presumably less effective communication approach.

Contrary to expectation, however, the relationships between mothers' and daughters' responses, respectively, on the Communication subscale of the PARQ and the Communication

Skills subscale of the AIS Dyadic Assessment were not significantly related. On the surface, this suggests that the Communication Skills subscale of the AIS Dyadic Assessment is, perhaps, not a valid assessment of the construct communication. An alternative explanation, however, is that the Communication Skills subscale of the AIS Dyadic Assessment is measuring different aspects of communication in the mother-daughter dyad than is the Communication subscale of the PARQ. This second explanation seems more likely considering that each of the questions on the AIS Dyadic Assessment is specifically tailored to assess communication in the context of managing AIS treatment, while the items on the PARQ Communication and Problem-Solving subscales reflect broader patterns of communication related to a plethora of topics that frequently arise in the parent-adolescent relationship (Robin, Koepke, Moye, & Gerhardstein, 2009). Considering these differences in focus between the two measures, it seems possible, then, that dyads may, in general, have “good” communication skills but may still struggle with talking about topics related to AIS, although in the present study, at least, it appears dyads believed they were able to successfully communicate about both general and AIS specific issues. Future research examining patterns of communication, both broadly speaking and targeted to AIS management specifically, may be helpful in further pinpointing possible communication struggles for dyads.

In summary, then, the significant relationship between mothers’ responses on the Communication Skills subscale of the AIS Dyadic Assessment and Helping for Health Inventory provides tentative evidence of convergent validity for the parental version of the Communication Skills subscale of the AIS Dyadic Assessment, while evidence of the convergent validity of daughters’ version of the Communication Skills subscale of the AIS Dyadic Assessment remains to be tested in future investigations.

The validity of the Emotion Regulation subscale of the AIS Dyadic Assessment. To examine the convergent validity of the Emotion Regulation subscale of the AIS Dyadic Assessment, participants' responses on this subscale were compared to their responses on the Difficulties in Emotion Regulation Scale (DERS), a measure of problems related to identifying, accepting, or effectively dealing with so-called "difficult" or unwanted emotions (Grazt & Roemer, 2004).

Mothers' responses on the Emotion Regulation subscale of the AIS Dyadic Assessment were not significantly related to mothers' responses on the broader DERS but were related to their responses on the Difficulties Controlling Impulsive Behavior subscale. As mothers' reported greater awareness and respect for self's and other's emotions (e.g., higher endorsement of scores on the Emotion Regulation subscale of the AIS Dyadic Assessment), they reported a better ability to control impulsive behavior when distressed (e.g., lower scores on the Impulse subscale of the DERS). Although the construct of behavioral impulsivity in response to unwanted or negative emotional responses was not explicitly included in the Emotion Regulation subscale of the AIS Dyadic Assessment, it makes sense, from an instrument development perspective, that more functional responses on the Emotion Regulation subscale would be associated with a better ability to control impulsivity when faced with emotional distress.

Daughters' responses on the Emotion Regulation subscale of the AIS Dyadic Assessment and daughters' responses on the broader DERS scale were not significantly related, either. However, daughters' responses on the Emotion Regulation subscale of the AIS Dyadic Assessment were significantly correlated with daughters' responses on some of the *subscales* of the DERS, including a positive correlation with the Lack of Emotional Clarity subscale and a negative correlation with the Difficulties Controlling Impulsive Behavior subscale. The direction

of the relationship between the Emotion Regulation subscale and the Lack of Emotional Clarity subscale is particularly puzzling, as greater awareness and respect for self's and other's emotions (e.g., higher scores on the Emotion Regulation subscale of the AIS Dyadic Assessment), should, from an instrument development perspective, include clarity about what emotions one is experiencing. Perhaps this finding reflects the relatively young age of the daughters in the present sample, in that they may be becoming more aware of their responses but have not yet developed clarity about the causes and potential coping mechanisms associated with these experiences.

It is also possible that the specific focus on the Emotion Regulation subscale of the AIS Dyadic Assessment – awareness of emotions entirely within the context of AIS treatment – accounted for the difference in this finding in that, perhaps, for unexplored reasons, daughters in the present sample were more finely attuned to their emotional responses related to AIS than they were more broadly speaking. Another difference in scale construction may also have accounted for this odd finding: Items on the Emotion Regulation subscale of the AIS Dyadic Assessment refer to daughters' perceptions of the *dyads'* emotion regulation abilities within the context of AIS treatment, while items on the DERS focus solely on the perspective of the *individual's* own emotion regulation abilities. Perhaps the emphasis on the dyad's ability to regulate emotions, rather than on the individual's ability, accounted for this unexpected finding.

A significant negative correlation between daughters' responses on the Emotion Regulation subscale of the AIS Dyadic Assessment and daughters' responses on the Difficulties Controlling Impulsive Behavior subscale of the DERS provides tentative evidence of convergent validity for the adolescent version of the Emotion Regulation subscale of the AIS Dyadic Assessment. As daughters endorsed greater awareness and respect for self's and other's emotion

experiences within the context of AIS treatment (e.g., responses on the Emotion Regulation subscale of the AIS Dyadic Assessment), they also reported greater ability to control impulsive behaviors (e.g., responses on the Difficulties Controlling Impulsive Behavior subscale of the DERS). The direction and significance of this relationship provides tentative evidence of convergent validity for the adolescent version of the Emotion Regulation subscale of the AIS Dyadic Assessment because, from an instrument development perspective, these two emotion regulation characteristics should be *conceptually* related: Greater awareness for emotions seems like a reasonable precursor to accessing emotion regulation strategies.

In summary then, significant correlations between the Emotion Regulation subscale of the AIS Dyadic Assessment and subscales of the DERS provides preliminary evidence of the convergent validity of the Emotion Regulation subscale in the present study. However, the unanticipated and puzzling direction of one of those relationships indicates the need for further investigation of the Emotion Regulation subscale before it is possible to speak with confidence about the subscales validity. Differences in the breadth and scope of the Emotion Regulation subscale and the DERS may explain the lack of correspondence in some cases and suggests that further investigation of the Emotion Regulation subscale of the AIS Dyadic Assessment is warranted to firmly establish the validity of this subscale.

The validity of the Mutual Agreement about AIS subscale of the AIS Dyadic Assessment. To examine the convergent validity of the Mutual Agreement about AIS subscale of the AIS Dyadic Assessment, daughters' responses on this subscale were compared to daughters' responses on the Brief Illness Perception Questionnaire (Brief IPQ), a measure of beliefs about illness.

Daughters' responses on the Mutual Agreement about AIS subscale of the AIS Dyadic Assessment were not related to daughters' responses on the total Brief IPQ (e.g., items 1-8). They were, however, correlated with *individual items* on the Brief IPQ. More specifically, as daughters endorsed greater belief that their mother-daughter relationship was successfully navigating AIS treatment (e.g., Mutual Agreement about AIS subscale), they reported greater belief that their back condition will have a minimal impact on their life (e.g., Consequences), that treatment will be helpful (e.g., Treatment Control), and that their back condition does not affect them very much emotionally (e.g., Emotional Response). From an instrument development stance, the direction of these relationships is consistent with the initial conceptualization of the Mutual Agreement about AIS subscale in that higher scores on this subscale were thought to reflect the dyad's successful navigation of challenges associated with treatment, and successful teamwork should, from a theoretical perspective, be associated with more optimistic outcomes.

For reasons that are unclear, there was not complete correspondence between the Mutual Agreement about AIS subscale and all the items of the Brief IPQ. It is possible that a difference in focus may have accounted for this lack of correspondence in that items on the Brief IPQ were directed towards the adolescents' perspectives about their spine condition without any consideration for relationship variables. Perhaps this emphasis on the self, rather than on the mother-daughter relationship, allowed adolescents to feel more comfortable rating their opinions more strongly and thus accounted for the lack of significant association among some items. Collectively, the results of the present study provided tentative and preliminary support of evidence of convergent validity of the adolescent version of the Mutual Agreement about AIS subscale of the AIS Dyadic Assessment.

In summary, the AIS Dyadic Assessment performed, psychometrically speaking, as expected. There was evidence of good reliability for both the parent and adolescent versions of the measure. Future research, with larger sample sizes, would likely help to strengthen the evidence for the internal consistency reliability estimates of the individual subscales of the parent version and provide opportunities to examine the measures performance over time (e.g., test/re-test reliability). By examining how well the subscales of the AIS Dyadic Assessment correlated with more established measures of the same/similar constructs in the literature, the present study provided some preliminary evidence of the convergent validity of the AIS Dyadic Assessment. Future research that examines the ability of the AIS Dyadic Assessment to predict treatment outcomes (e.g., predictive validity) and capture information not accounted for by other measures (e.g., incremental validity) is warranted.

High-Functioning Mother-Daughter Dyads Affected by AIS

In general, dyads in the present sample appeared to be relatively “high functioning.” For example, they rated their overall communication and problem-solving skills highly. To a great extent, they provided highly reliable data with regard to the daughters’ AIS diagnosis and treatment, suggesting mothers and daughters “were on the same page” regarding basic facts related to diagnosis and treatment. Additionally, estimates of adherence with brace-wearing were higher in the present study than in previous studies (Morton, Riddle, Buchanan, Katz, & Birch, 2008; Rahman, Bowen, Takemitsu, & Scott, 2005). Collectively, this pattern of findings suggests that the mother-daughter dyads in the present sample were relatively high functioning and, presumably, coping well with AIS treatment.

Communicating and problem-solving within the mother-daughter relationship. In general, dyads in the present sample characterized their overall communication and problem-

solving skills as being generally high functioning. As was seen in Figure 3, 34.6% of mothers and 48% of daughters characterized their mother-daughter relationship as having “good” communication skills, and 65% of mothers and 40% of daughters characterized their relationship as having “good” problem-solving skills.

Interestingly, these results are somewhat contrary to patterns of parent-adolescent communication cited in the parent-adolescent literature. For example, between the ages of 11-15, adolescents’ negative affect towards their parents generally increases substantially (Kim et al., 2001), and parent-adolescent dyads become notable for their “marked deterioration” in communication, including increased conflict and difficulty solving problems (McGue et al., 2005). The average age of adolescents in the present sample was at the beginning of the typical conflict period and perhaps too early in the developmental course to be consistent with parent-adolescent communication patterns seen in the literature. However, given that the age of daughters is not known for those who completed the survey in-person, it is difficult to draw strong conclusions about the possible influence of age on communication and problem-solving abilities within the mother-daughter dyad.

Regulating emotions within the mother-daughter relationship. Both mothers and daughters in the present sample characterized their individual emotion regulation abilities as relatively high functioning, including greater awareness about negative emotional responses (daughters), greater acceptance of negative emotional responses (mothers), less difficulty engaging in goal-directed activities when distressed (mothers and daughters), and greater access to emotional regulation strategies when distressed (mothers).

Well-functioning emotion regulation abilities within the parent-adolescent relationship, although not studied extensively in the AIS literature, are thought to be an important component

of successful adherence. For example, as noted earlier, parents of adolescents with AIS reported being aware that their adolescents felt embarrassed about wearing a brace and admitted to giving their child permission to remove the brace against medical advice (Lynch, 2006), presumably as a consequence of their inability/unwillingness to tolerate their child's emotional discomfort. In line with this finding, in a cystic fibrosis study, greater family cohesiveness was associated with better treatment adherence in children (White et al., 2009; Wolman et al., 1994). Additionally, children/adolescents with chronic illnesses admitted to hiding important illness-related information from parents, in part because they did not want to worry their parent or their parent was in a "bad mood" (Hafetz & Miller, 2010). These findings suggest that emotional interactions within the parent-adolescent dyad play an important role in the dyad's ability to navigate challenges associated with chronic illness management.

Although the present study did not explicitly examine potential causal mechanisms between emotion regulation within the dyad and adherence, it seems reasonable to posit, considering the aforementioned findings in the literature, that the high rates of adherence reported in this study may be related to the high ratings of emotion regulation abilities reported by mothers and daughters. Future investigations that aim to directly assess potential causal mechanisms may be helpful in identifying if and what aspects of emotion regulation abilities predict adherence with brace wearing in adolescents.

Despite the seeming positive aspects of high ratings of emotion regulation abilities in the present study, these high ratings are somewhat surprising, as difficulties with emotion regulation are typically associated with earlier stages of adolescence (Loeber et al., 2000; McGue et al., 2005), and the present sample of daughters appears to be relatively young. Perhaps the younger age of the present sample explains why daughters in the present sample reported less acceptance

of unwanted emotions, greater difficulty controlling impulsive behavior when distressed, and less clarity about unwanted emotional experiences than the normative sample.

It is possible also, given the limitations of self-report survey methodology, that participants in the present study are over- or underestimating their emotion regulation abilities. Indeed, it should be acknowledged that the overall pattern of high functioning on the other constructs of interests – communication, problem-solving, and degree of agreement, and rates of adherence – may all be accounted for by overestimations of abilities and minimizations of problems by dyads in the present sample. Inclusion of third party observer report, as well as physiological indicators of these variables (when possible), would help to investigate these seemingly positive associations further. Additionally, given the limited information about daughters' age in the present sample, it would be interesting for future research to examine patterns of communication, problem-solving, and emotion regulation among mother-daughter dyads affected by AIS with a broader sampling of adolescent ages to more fully elucidate possible interactions between mothers and daughters throughout the developmental course of adolescence.

Successful navigation of AIS treatment within the mother-daughter relationship.

Administration of the Scoliosis Society-22 Health Related Questionnaire (SRS-22r), as well as targeted questions related to basic facts about diagnosis and treatment to both mothers and daughters, allowed for the direct comparison of mothers' and daughters' perceptions on key aspects of AIS treatment. To a great extent, mothers and daughters provided highly reliable data with regard to the daughters' AIS diagnosis and treatment, including agreement about time since diagnosis, degree of curve, adherence, and, for the most part, bracing as the current treatment recommendation. They were in agreement about daughters' level of physical activity, back pain,

self-image, mental health, and satisfaction with AIS treatment (e.g., the SRS-22r) and had comparable levels of agreement about how to navigate challenges associated with AIS treatment (e.g., the Mutual Agreement about AIS subscale).

Although possible causal mechanisms between mutual agreement about treatment and adherence with treatment were not explicitly assessed in the present study, it seems reasonable to posit that a high degree of agreement about how to manage AIS treatment may be associated with the high rates of reported adherence with brace wearing in the present study. For example, as noted earlier, parent-child agreement about responsibility for diabetic care tasks was associated with greater glycemic control among preteens in the juvenile diabetes literature (Anderson et al., 2009). Given the previously mentioned similarities between diabetes and AIS self-care behaviors, it seems likely that similar associations between mutual agreement about treatment and subsequent outcomes exist for dyads' with AIS. Future research that explicitly assesses potential causal mechanisms between mutual agreement and adherence could help shed light on this finding.

In conclusion, mother-daughter dyads in the present sample appear to be relatively high functioning in terms of their communication, problem solving, and selected emotion regulation abilities. They were in agreement about key facts related to daughters' AIS diagnosis, had similar perceptions about daughters' quality of life, and reported comparable levels of mutual agreement about their ability to navigate challenges associated with AIS treatment. They also reported high rates of adherence with brace wearing. Collectively, the pattern of results in the present study provides some preliminary support for the influence of mother-daughter relationship variables on adherence, although the present study did not explicitly examine potential causal mechanisms, and the results must be considered within the context of limitations due to self-report survey

methodology. Future investigation focusing on the functioning and adaptability of the mother-daughter relationship on daughters' adherence with brace wearing is warranted.

The Utility of Online Data Collection Methods

Anecdotally, when the principal investigator reached out to coordinators of online scoliosis support groups and websites, there was a very strong positive reaction from “grassroots” groups. Indeed, one coordinator noted she had been hoping to collaborate with healthcare providers to support scoliosis research but had often met with resistance and uncertainty about how to network with interested scoliosis researchers. A perceived lack of collaboration between community groups (either in-person or online) and researchers is unfortunate, considering that online survey methodology may be a way to reach families who might otherwise not be invited to participate in research (e.g., families with limited access to healthcare). Perhaps concerns about the feasibility of obtaining consent, recruiting families, and the perception that data gathered from an online methodology would be significantly different than more traditional methods of data collection are contributing factors. Hopefully, results from the present study will help to alleviate some of those concerns and support future collaboration between AIS grassroots communities and researchers.

Strengths and Limitations of the Present Study

The emphasis on the dyadic relationship represented a strength of the present study. The majority of AIS family-oriented research focuses on either the perspective of the parent or the adolescent, not both. The inclusion of the dyadic relationship within the present study made it possible to begin taking preliminary steps towards examining the impact of the family relationship on AIS treatment.

The incorporation of findings from the AIS and other adolescent illness literature into the conceptual model presented in the present study is another strength. Being grounded in the research allowed the present study to take a preliminary step towards consolidating the literature on the mother-daughter relationship affected by AIS and propose a theoretical model against which to test further research. Additionally, a thorough examination of the literature identified a gap in the mother-daughter literature – no standardized measure of the parent-adolescent relationship affected by AIS exists – and guided this study in taking preliminary steps towards developing such a measure.

As noted earlier, a relatively small sample size that prohibited further instrument development (e.g., factor analysis) is a limitation of the present study. Additionally, a larger sample size would have made it possible to examine mother-daughter relationship variables across the span of adolescence. Another limitation of the present study is that a measure was not included to examine the convergent validity of mothers' responses on the Mutual Agreement about AIS subscale. The time commitment and relative burden placed on families to complete the survey was weighed against the possible utility of including another measure, and ultimately it was decided to err on the side of reducing participants' time commitment. As noted earlier, other limitations include the regrettable exclusion of items addressing daughters' ages on the in-person survey, and daughters' ethnicity on both versions.

Minimal assessment of adolescents' adherence with brace wearing was also a limitation in that the present study focused on the dyads' self-report of adherence rather than a behavioral or physiological indicator of adherence. Considering that this study endeavored to take preliminary steps to investigate associations between the mother-daughter dyad and adherence, the use of a self-report indicator was appropriate. However, once evidence for particular aspects

of the mother-daughter relationship are strong enough to warrant more targeted examination of adherence, it would be helpful to include a behavioral/physiological indicator. The inclusion of more objective measures of adherence would have allowed the researcher to draw stronger conclusions about the associations between dyadic variables and adherence in the present study.

Statistical procedures chosen to examine the utility of the AIS Dyadic Assessment, conceptualized as “rates of endorsement” in the present study, were also a limitation. A statistically sounder approach to instrument development would have been to examine the incremental validity of the scale with hierarchical regression techniques (Haynes & Lench, 2003; Johnston & Murray, 2003; Nelson-Gray, 2003; Smith, Fischer, & Fister, 2003). Such an approach would have made it possible to speak more explicitly about the relative contributions of the AIS Dyadic Assessment in predicting AIS outcomes compared to more established measures like the SRS-22r. Future investigations of the AIS Dyadic Assessment would benefit from examining the incremental validity of the measure in this way, along with examining the factor structure of the subscales (as originally proposed in this study).

Conclusion

In conclusion, the present study sought to examine how the mother-daughter relationship and daughters’ AIS treatment impacted each other. Primary aims of the study focused on developing a measurement tool, the AIS Dyadic Assessment, specifically designed to assess the mother-daughter relationship in the context of AIS treatment. The AIS Dyadic Assessment included three subscales based on the literature: Communication Skills, Emotion Regulation, and Mutual Agreement about AIS. When compared to more established measures of the parent-adolescent relationship, generally speaking, and aspects of treatment related to managing chronic diseases in adolescence, the AIS Dyadic Assessment had preliminary and tentative evidence of

reliability, convergent validity, and utility. However, these results are akin to pilot data, and future research on the AIS Dyadic Assessment is needed before strong conclusions related to its applicability in research and utility in clinical settings can be determined.

Secondary aims included novel use of the SRS-22r; both mothers and daughters completed the measure, and results were compared to help examine how well mothers and daughters were in agreement about AIS treatment. Dyads were in complete agreement on this scale, as well as on basic facts about diagnosis and treatment. Collectively, this suggests mothers and daughters, in the present sample, were in agreement about many factors related to daughters' AIS treatment. Although not directly assessed in the present study, such a level of agreement may have contributed to the higher than anticipated rates of adherence with brace wearing.

Understanding how families interact and cope with AIS diagnosis and treatment are important aspects of both AIS research and psychosocial assessments conducted in clinical settings. A comprehensive assessment of the mother-daughter relationship may be helpful in identifying families who are experiencing significant emotional distress, communicating about and/or coping with AIS, and who may benefit from referral to adjunctive mental health services. Future research about adherence with brace wearing may be better informed by the inclusion of parent-child interaction variables. It is important to consider the broader social systems that surround an individual who is living with a chronic illness, like AIS. Doing so will likely inform research and clinical interventions, help improve the efficiency of treatment, and may even alleviate psychological distress secondary to living with a chronic illness.

References

- Abidin, R. R. (1995). *Parenting Stress Index Professional Manual* (3rd ed.). Lutz, FL: Psychological Assessment Resources, Inc.
- Alborghetti, A., Scimeca, G., Costanzo, G., & Boca, S. (2010). The prevalence of eating disorders in adolescents with idiopathic scoliosis. *Eating Disorders, 16*, 85-93.
- Anderson, B. J., Auslander, W. F., Jung, K. C., Miller, J. P., & Santiago, J. V. (1990). Assessing family sharing of diabetes responsibilities. *Journal of Pediatric Psychology, 15*, 477-492.
- Anderson, B. J., & Coyne, J. C. (1991). "Miscarried helping" in families of children and adolescents with chronic diseases. In J. H. Johnson & S. B. Johnson (Eds.), *Advances in child health psychology*. Gainesville, FL: University of Florida Press.
- Anderson, B. J., & Coyne, J. C. (1993). Family context and compliance behavior in chronically ill children. In N. A. Krasnegor, L. Epstein, S. B. Johnson & S. J. Yaffe (Eds.), *Developmental aspects of health compliance behavior* (pp. 77-89). Hillsdale, NJ: Lawrence Erlbaum.
- Anderson, B. J., Holmbeck, G. N., Iannotti, R. J., McKay, S. V., Lochrie, A., Volkening, L. K., et al. (2009). Dyadic measures of the parent-child relationship during the transition to adolescence and glycemic control in children with type 1 diabetes. *Families, Systems, & Health, 27*(2), 141-152.
- Anderson, B. J., Miller, J., Auslander, W. F., & Santiago, J. V. (1981). Family characteristics of diabetic adolescents: Relationship to metabolic control. *Diabetes Care, 4*, 586-594.
- Anderson, B. J., Vangsness, L., Connell, A., Butler, D., Goebel-Fabbri, A., & Laffel, L. M. (2002). Family conflict, adherence, and glycaemic control in youth with short duration type 1 diabetes. *Diabetic Medicine, 19*, 635-642.

- Anderson, F. J., Asher, M. A., Clark, G. M., Orrick, J. M., & Quiason, E. P. (1979). Adjustment of adolescents to chronic disability. *Rehabilitation Psychology, 26*(4), 177-185.
- Apter, A., Morein, G., Munitz, H., Tyano, S., Maoz, B., & Wijsenbeeck, H. (1978). The psychological sequelae of the Milwaukee brace in adolescent girls. *Clinical Orthopaedics and Related Research, 131*, 156-159.
- Ascani, E., Bartolozzi, P., Logroscino, C. A., et al. (1986). Natural history of untreated idiopathic scoliosis after skeletal maturity. Symposium on epidemiology, natural history and non-operative treatment of idiopathic scoliosis. *Spine, 11*, 784-789.
- Asher, M. A., Lai, S. M., Burton, D. C., & Manna, B. (2003). Discrimination validity of the Scoliosis Research Society-22 Patient Questionnaire: Relationship to idiopathic scoliosis curve pattern and curve size. *Spine, 28*, 74-78.
- Asher, M. A., Lai, S. M., Glattes, C., Burton, D. C., Alanay, A., & Bago, J. (2006). Refinement of the SRS-22 Health-Related Quality of Life Questionnaire Function Domain. *Spine, 31*(5), 593-597.
- Barnes, H., & Olson, D. H. (1982). *Parent-Adolescent Communication Scale*. St. Paul, MN: University of Minnesota.
- Bell, K. L., & Calkins, S. D. (2000). Relationships as inputs and outputs of emotion regulation. *Psychological Inquiry, 11*, 160-163.
- Benli, I. T., Uzumcugil, O., Aydin, E., Ates, B., Gurses, L., & Hekimoglu, B. (2006). Magnetic resonance imaging abnormalities of neural axis in Lenke type 1 idiopathic scoliosis. *Spine, 31*, 1828-1833.
- Bienvenu, M. J. (1969). *A Parent-Adolescent Communication Inventory*. Natchitoches, LA: Northwest Publications.

- Bjure, J., & Nachemson, A. (1973). Non-treated scoliosis. *Clin Orthop Rel Res*, 93, 44-52.
- Bobrow, E. S., Avruskin, T. W., & Siller, J. (1985). Mother-daughter interaction and adherence to diabetes regimens. *Diabetes Care*, 8, 146-151.
- Bridwell, K. H., Anderson, P. A., Boden, S. D., Vaccaro, A. R., & Wang, J. C. (2007). What's new in spine surgery. *J Bone Joint Surg*, 89, 1654-1663.
- Bridwell, K. H., Shufflebarger, H. L., Lenke, L. G., Lowe, T. G., Betz, R. R., & Bassett, G. S. (2000). Parents' and patients' preferences and concerns in idiopathic adolescent scoliosis. *Spine*, 25(18), 2392-2399.
- Broadbent, E., Petrie, K. J., Main, J., & Weinman, J. (2006). The Brief Illness Perception Questionnaire. *Journal of Psychosomatic Research*, 60, 631-637.
- Burwell, R. G. (2003). Aetiology of idiopathic scoliosis: Current concepts. *Pediatric Rehabilitation*, 6, 137-170.
- Calkins, S. D., & Johnson, M. C. (1998). Toddler regulation of distress to frustrating events: Temperamental and maternal correlates. *Infant Behavior and Development*, 21, 379-395.
- Campos, J. J. (1995). Foreword. In J. P. Tangney & K. W. Fischer (Eds.), *Self-conscious Emotions: The Psychology of Shame, Guilt, Embarrassment, and Pride*. New York: Guilford.
- Chu, W. C., Lam, W. W., Chan, Y. L., Ng, B. K. W., Lam, T., Lee, K., et al. (2006). Relative shortening and functional tethering of spinal cord in adolescent idiopathic scoliosis: Study with multiplanar reformat magnetic resonance imaging and somatosensory evoked potential. *Spine*, 31, E19-E25.

- Clayson, D., Luz-Alterman, S., Cataletto, M. M., & Levine, D. B. (1987). Long-term psychological sequelae of surgically versus nonsurgically treated scoliosis. *Spine, 12*, 983-986.
- Cohen, J. (1977). *Statistical Power Analysis for the Behavioral Sciences*. Orlando, FL: Academic Press, Inc.
- Cook, W. L. (2005). The SRM approach to family assessment: An introduction and case example. *European Journal of Psychological Assessment, 21*(4), 216-225.
- Danielsson, A. J., & Nachemson, A. L. (2003a). Back pain and function 22 years after brace treatment for adolescent idiopathic scoliosis: a case-control study-part I. *Spine, 28*, 2078-2085.
- Danielsson, A. J., & Nachemson, A. L. (2003b). Back pain and function 23 years after fusion for adolescent idiopathic scoliosis: a case-control study-part II. *Spine, 28*, E373-383.
- Danielsson, A. J., Wiklund, I., Pehrsson, K., & Nachemson, A. L. (2001). Health-related quality of life in patients with adolescent idiopathic scoliosis: a matched follow-up at least 20 years after treatment with brace or surgery. *Eur Spine J, 10*, 278-288.
- DeCato, L. A., Donohue, B., Azrin, N. H., Teichner, G. A., & Crum, T. (2002). Adolescents and their parents: A critical review of measures to assess their satisfaction with one another. *Clinical Psychology Review, 22*, 833-874.
- Dekel, Y., Tenenbaum, G., & Kudar, K. (1996). An exploratory study on the relationship between postural deformities and body-image and self-esteem in adolescents: the mediating role of physical activity. *Int. J. Sport. Psychol., 27*, 183-196.
- DeVellis, R. F. (2003). *Scale Development: Theory and Applications* (2nd ed. Vol. 26). Thousand Oaks, CA: Sage Publications, Inc.

- Dickson, J. H., Mirkovic, S., Noble, P. C., Nalty, T., & Erwin, W. D. (1995). Results of operative treatment of idiopathic scoliosis in adults. *J Bone Joint Surg*, 77(A), 513-523.
- DiRaimondo, C. V., & Green, N. E. (1988). Brace-wear compliance in patients with adolescent idiopathic scoliosis. *Journal of Pediatric Orthopaedics*, 8, 143-146.
- Dolan, L. A., & Weinstein, S. L. (2007). Surgical rates after observation and bracing for adolescent idiopathic scoliosis: An evidence-based review. *Spine*, 1(32(19 Suppl)), S91-S100.
- Drench, E. M. (1994). Changes in body image secondary to disease and injury. *Rehabilitation Nursing*, 19(1), 31-36.
- Edwards, A. J., & Pfeiffer, S. I. (2004). Parent-Adolescent Communication Scale. Mental Measurements Yearbook, from Board of Regents of the University of Nebraska
- Eliason, M. J., & Richman, L. C. (1984). Psychological effects of idiopathic adolescent scoliosis. *Journal of Developmental and Behavioural Pediatrics*, 5(4), 169-172.
- Emery, E., Redondo, A., & Rey, A. (1997). Syringomyelia and Arnold Chiari in scoliosis initially classified as idiopathic: Experience with 25 patients. *Eur Spine J*, 6, 158-162.
- Erikson, E. (1968). *Identity, Youth, and Crisis*. New York, NY: W.W.Norton.
- Fairbank, J. C., Couper, J., Davies, J. B., & O'Brien, J. P. (1980). The Oswestry Low Back Pain Disability Questionnaire. *Physiotherapy*, 66, 271-273.
- Fallstrom, K., Cochran, T., & Nachemson, A. (1986). Long-term effects on personality development in patients with adolescent idiopathic scoliosis. Influence of type of treatment. *Spine*, 11, 756-758.

- Faul, F., Erdfelder, E., Buchner, A., & Lang, A.-G. (2009). Statistical power analyses using G*Power 3.1: Tests for correlation and regression analyses. *Behavior Research Methods*, *41*, 1149-1160.
- Feise, R. J., Donaldson, S., Crowther, E. R., Menke, J. M., & Wright, J. G. (2005). Construction and validation of the scoliosis quality of life index in adolescent idiopathic scoliosis. *Spine*, *30*, 1310-1315.
- Field, A. (2005). *Discovering Statistics Using SPSS Second Edition*. London: SAGE Publications Ltd.
- Foster, S., Prinz, R. J., & O'Leary, K. D. (1983). Impact of problem solving communication training and generalization procedures on family conflict. *Child and Family Behavior Therapy*, *5*(1), 1-23.
- Fox, N. A., & Calkins, S. D. (2003). The development of self-control of emotion: Intrinsic and extrinsic influences. *Motivation and Emotion*, *27*, 7-26.
- Freidel, K., Petermann, F., Reichel, D., Steiner, A., Warschburger, P., & Weiss, H. R. (2002). Quality of life in women with idiopathic scoliosis. *Spine*, *27*(4), E87-E91.
- Fulgini, A. J., & Eccles, J. S. (1993). Perceived parent-child relationships and early adolescents' orientation toward peers. *Developmental Psychology*, *29*, 622-632.
- Ginsburg, H., & Opper, S. (1979). *Piaget's Theory of Intellectual Development* (2nd ed.). Englewood Cliffs, NJ: Prentice-Hall.
- Goldberg, M. S., Mayo, N. E., Politas, B., Scott, S., & Hanley, J. (1994). The Ste-Jastine adolescence idiopathic scoliosis cohort study, Part II, perception of health, self and body image and participation in physical activities. *Spine*, *19*(14), 1562-1572.

- Gottman, J., & Silver, N. (2000). *The Seven Principles for Making Marriage Work*. London, UK: Orion Publishing Group.
- Gratz, K. L., & Roemer, L. (2004). Multidimensional assessment of emotion regulation and dysregulation: Development, factor structure, and initial validation of the Difficulties in Emotion Regulation Scale. *Journal of Psychopathology and Behavioral Assessment*, 26(1), 41-54.
- Gratz, R. R., & Papalia-Finlay, D. (1984). Psychosocial adaptation to wearing the Milwaukee brace for scoliosis. A pilot study of adolescent females and their mothers. *Journal of Adolescent Health Care*, 5, 237-242.
- Grimard, G., Lacroix, G., Mayo, N. E., Vandal, S., Labelle, H., & Poitras, B. (2002). *Long-term evaluation of the quality of life of subjects with adolescent idiopathic scoliosis*. Paper presented at the Scoliosis Research Society Annual Meeting, Seattle.
- Gross, J. J., & John, O. P. (2003). Individual differences in two emotion regulation processes: Implications for affect, relationships, and well-being. *Journal of Personality and Social Psychology*, 85(2), 348-362.
- Guo, X., Chau, W. W., Chan, Y. L., & Cheng, J. C. Y. (2003). Relative anterior spinal overgrowth in adolescent idiopathic scoliosis: Results of disproportionate endochondral-membranous bone growth. *Journal of Bone & Joint Surgery*, 85-B, 1026-1031.
- Hafetz, J., & Miller, V. A. (2010). Child and parent perceptions of monitoring in chronic illness management: A qualitative study. *Child: Care, Health and Development*, 36(5), 655-662. doi: 10.1111/j.1365-2214.2010.01102.x

- Harris, M. A., Antal, H., Oelbaum, R., Buckloh, L. M., White, N. H., & Whysocki, T. (2008). Good intentions gone awry: Assessing parental "miscarried helping" in diabetes. *Families, Systems, & Health, 26*(4), 393-403.
- Hashimoto, H., Sase, T., Arai, Y., Maruyama, T., Isobe, K., & Shouno, Y. (2007). Validation of a Japanese version of the Scoliosis Research Society-22 patient questionnaire among idiopathic scoliosis patients in Japan. *Spine, 32*, E141-E146.
- Hauser, S. T., Jacobson, A. M., Lavori, P., Wolfsdorf, J. I., Herskowitz, R. D., Wertlieb, D., et al. (1990). Adherence among children and adolescents with insulin-dependent diabetes mellitus over a four-year longitudinal follow-up: II. Immediate and long-term linkages with the family milieu. *Journal of Pediatric Psychology, 15*, 527-542.
- Haynes, S., N., & Lench, H. C. (2003). Incremental validity of new clinical assessment measures. *Psychological Assessment, 15*(4), 456-466. doi: 10.1037/1040-3590.15.4.456
- Hood, K. K., Butler, D. A., Anderson, B. J., & Laffel, L. M. B. (2007). Updated and revised Diabetes Family Conflict Scale. *Diabetes Care, 30*, 1764-1769.
- Huynh, A. M., Aubin, C. E., Rajwani, T., Bagnall, K. M., & Villemure, I. (2007). Pedicle growth asymmetry as a cause of adolescent idiopathic scoliosis: A biomechanical study. *Eur Spine J, 16*, 523-529.
- Inoue, M., Minami, S., Nakata, Y., Otsuka, Y., Takaso, M., Kitahara, H., et al. (2005). Preoperative MRI analysis of patients with idiopathic scoliosis: A prospective study. *Spine, 30*, 108-114.
- Jacob, T., & Seilhamer, R. A. (1985). Adaptation of the Areas of Change Questionnaire for parent-child relationship assessment. *American Journal of Family Therapy, 13*, 28-38.

- Jacobson, A. M., Hauser, S. T., Lavori, P., Willett, J. B., Cole, C. F., Wolfsdorf, J. I., et al. (1994). Family environment and glycemic control: A four-year prospective study of children and adolescents with insulin-dependent diabetes mellitus. *Psychosomatic Medicine, 56*, 401-409.
- Johnston, C., & Murray, C. (2003). Incremental validity in the psychological assessment of children and adolescents. *Psychological Assessment, 15*(4), 496-507. doi: 10.1037/1040-3590.15.4.496
- Kahanovitz, N., & Weiser, S. (1989). The psychological impact of idiopathic scoliosis on the adolescent female. A preliminary multi-center study. *Spine, 14*, 483-485.
- Kamphaus, R. W., & Reynolds, C. R. (2006). *Parenting Relationship Questionnaire Manual*. Minneapolis, MN: Pearson Assessments.
- Kenny, D. A., Kashy, D. A., & Cook, W. L. (2006). *Dyadic Data Analysis*. New York, NY: The Guilford Press.
- Kesling, K. L., & Reinker, K. A. (1997). Scoliosis in twins. A meta-analysis of the literature and report of six cases. *Spine, 22*, 2009-2014.
- Kim, K. J., Conger, R. D., & Lorenz, F. O. (2001). Parent-adolescent reciprocity in negative affect and its relation to early adult social development. *Developmental Psychology, 37*, 775-790.
- Kopp, C. B. (1992). Emotional distress and control in young children. In N. Eisenberg & R. A. Fabes (Eds.), *Emotion and Its Regulation in Early Development*. San Francisco: Jossey-Bass.
- Kotzer, A. M., & Foster, R. (2000). Children's use of PCA following spinal fusion. *Orthopaedic Nursing, 19*, 19-30.

- LaMontagne, L. L., Hepworth, J. T., Johnson, B. D., & Cohen, F. (1996). Children's preoperative coping and its effects on postoperative anxiety and return to normal activity. *Nursing Research, 45*, 141-147.
- Laursen, B., Coy, K. C., & Collins, W. A. (1998). Reconsidering changes in parent-child conflict across adolescence: A meta-analysis. *Child Development, 69*, 817-832.
- Lerman, J. A., Sullivan, E., & Haynes, R. J. (2002). The Pediatric Outcomes Data Collection Instrument (PODCI) and functional assessment in patients with adolescent or juvenile idiopathic scoliosis and congenital scoliosis or kyphosis. *Spine, 27*(18), 2052-2057.
- Lerner, R. M., Lerner, J. V., von Eye, A., Ostrom, C. W., Nitz, K., Talwar-Soni, R., et al. (1996). Continuity and discontinuity across the transition of early adolescence: A developmental contextual perspective. In J. A. Graber, J. Brooks-Gunn & A. C. Petersen (Eds.), *Transitions Through Adolescence* (pp. 3-22). Mahwah, NJ: Erlbaum.
- Liskey-Fitzwater, N., Moore, C. L., & Gurel, L. M. (1993). Clothing importance and self perception of female adolescents with and without scoliosis. *Clothing and Textiles Research Journal, 11*, 17-22.
- Loeber, R., Drinkwater, M., Yin, Y., Anderson, S. J., Schmidt, L. C., & Crawford, A. (2000). Stability of family interaction from ages 6 to 18. *Journal of Abnormal Child Psychology, 28*, 353-369.
- Lonner, B. S., Auerbach, J. D., Sponseller, P., Rajadhyaksha, A. D., & Newton, P. O. (2010). Variations in pelvic and other sagittal spinal parameters as a function of race in adolescent idiopathic scoliosis. *Spine, 35*(10), E374-E377.

- Lowe, T. G., Edgar, M., Margulies, J. Y., Miller, N. H., Raso, J., Reinker, K. A., et al. (2000). Etiology of idiopathic scoliosis: Current trends in research. *Journal of Bone & Joint Surgery* 82-A(8), 1157-1168.
- Lowe, T. G., Lawellin, D., Smith, D., Price, C., Haheer, T., Merola, A., et al. (2002). Platelet calmodulin levels in adolescent idiopathic scoliosis: Do the levels correlate with curve progression and severity? *Spine*, 27(7), 768-775.
- Lynch, T. (2006). *Adolescent Adherence to Wearing Orthopedic Brace*. Dissertation. Eastern Michigan University. Ypsilanti, MI.
- Lyons, B., Boachie-Adjei, O., Podzius, J., & Podzius, C. (1999). *Scoliosis: Ascending the Curve*. New York NY: M. Evans and Company, Inc.
- MacDermott, S. T., Gullone, E., Allen, J. S., King, N. J., & Tonge, B. (2010). The Emotion Regulation Index for Children and Adolescents (ERICA): A psychometric investigation. *J Psychopathol Behav Assess*, 32, 301-314.
- MacLean, W. E., Green, N. E., Pierre, C. B., & Ray, D. C. (1989). Stress and coping with scoliosis, psychological effects on adolescents and their families. *Journal of Paediatric Orthopaedics*, 9(3), 257-261.
- Maiocco, B., Deeney, V. F., Coulon, R., & Parks, P. F., Jr. (1997). Adolescent idiopathic scoliosis and the presence of spinal cord abnormalities: Preoperative magnetic resonance imaging analysis. *Spine*, 22, 2537-2541.
- Mayo, N. E., Goldberg, M. S., Poitras, B., Scott, S., & Hanley, J. (1994). The Ste-Justine adolescent idiopathic scoliosis cohort study. Part III: back pain. *Spine*, 19, 1573-1581.
- McGue, M., Elkins, I., Walden, B., & Iacono, W. G. (2005). Perceptions of the parent-adolescent relationship: A longitudinal investigation. *Developmental Psychology*, 41(6), 971-984.

- Miller-Johnson, S., Emery, E., Marvin, R. S., Clarke, W., Lovinger, R., & Martin, M. (1994). Parent-child relationships and the management of insulin-dependent diabetes mellitus. *Journal of Consulting and Clinical Psychology, 62*, 603-610.
- Misterska, E., Glowacki, M., & Latuszewska, M. (2012). Female patients' and parents' assessment of deformity-and brace-related stress in the conservative treatment of adolescent idiopathic scoliosis. *Spine, 37*(14), 1218-1223.
- Modi, A. C., & Quittner, A. L. (2006). Barriers to treatment adherence for children with cystic fibrosis and asthma: What gets in the way? *Journal of Pediatric Psychology, 31*(8), 846-858.
- Molina, B. S. G., & Chassin, L. (1996). The parent-adolescent relationship at puberty: Hispanic ethnicity and parent alcoholism as moderators. *Developmental Psychology, 32*, 675-686.
- Morton, A., Riddle, R., Buchanan, R., Katz, D., & Birch, J. (2008). Accuracy in the prediction and estimation of adherence to bracewear before and during treatment of adolescent idiopathic scoliosis. *Journal of Pediatric Orthopaedics, 28*(3), 336-341. doi: 10.1097/BPO.obo13e318168d154
- Nathan, S. W. (1977). Body image of scoliotic adolescents before and after surgery. *Maternal-Child Nursing Journal, 6*, 139-149.
- National Scoliosis Foundation. (2010). Information and support Retrieved 9-19-2010, from <http://www.scoliosis.org/info.php>
- Nelson-Gray, R. O. (2003). Treatment utility of psychological assessment. *Psychological Assessment, 15*(4), 521-531. doi: 10.1037/1040-3590.15.4.521

- Neumann, A., van Lier, P. A. C., Gratz, K. L., & Koot, H. M. (2010). Multidimensional assessment of emotion regulation difficulties in adolescents using the Difficulties in Emotion Regulation Scale. *Assessment, 17*(1), 138-149.
- Neuwirth, M., & Osborn, K. (2001). *The Scoliosis Sourcebook*. Chicago, IL: Contemporary Books.
- Nichols, M. P., & Schwartz, R. C. (2001). *Family Therapy Concepts and Methods* (5th ed.). Needham Heights, MA: Allyn and Bacon.
- Noonan, K. J., Dolan, L. A., Jacobson, W. C., & Weinstein, S. L. (1997). Long-term psychosocial characteristics of patients treated for idiopathic scoliosis. *Journal of Paediatric Orthopaedics, 17*, 712-717.
- Olafsson, Y., Saraste, H., & Ahlgren, R. M. (1999). Does bracing affect self-image? A prospective study on 54 patients with adolescent idiopathic scoliosis. *Eur Spine J, 8*, 402-405.
- Paikoff, R. L., & Brooks-Gunn, J. (1991). Do parent-child relationships change during puberty? *Psychological Bulletin, 110*, 47-66.
- Papalia, D. E., Olds, S. W., & Feldman, R. D. (2004). Part 5: Adolescence *Human Development* (9th ed., pp. 382-453). Boston, MA: McGraw Hill.
- Parent, S., Newton, P. O., & Wenger, D. R. (2005). Adolescent idiopathic scoliosis: etiology, anatomy, natural history, and bracing. *Instr Course Lect, 54*, 529-536.
- Payne, W. K., Ogilvie, J. W., Resnick, M. D., Kane, R. L., Transfeldt, E. E., & Blum, R. W. (1997). Does scoliosis have a psychological impact and does gender make a difference? *Spine, 22*(12), 1380-1384.

- Prinz, R. J., Foster, S., Kent, R. N., & O'Leary, K. D. (1979). Multivariate assessment of conflict in distressed and nondistressed mother-adolescent dyads. *Journal of Applied Behavior Analysis, 12*, 691-700.
- Rahman, T., Bowen, J. R., Takemitsu, M., & Scott, C. (2005). The association between brace compliance and outcomes for patients with idiopathic scoliosis. *Journal of Pediatric Orthopaedics, 25*(4), 420-422. doi: 10.1097/01.bpo.0000161097.61586.bb
- Rajwani, T., Bagnall, K. M., Lambert, R., Videman, T., Kautz, J., Moreau, M., et al. (2004). Using magnetic resonance imaging to characterize pedicle asymmetry in both normal patients and patients with adolescent idiopathic scoliosis. *Spine, 29*, E145-E152.
- Reamy, B. V., & Slakey, J. B. (2001). Adolescent idiopathic scoliosis: Review and current concepts. *American Family Physician, 64*, 111-116.
- Roberts, M. W., & Sines, J. O. (2004). A Parent-Adolescent Communication Inventory. Mental Measurements Yearbook, from Board of Regents of the University of Nebraska
- Robin, A. L., & Foster, S. (1989). *Negotiating parent-adolescent conflict*. New York: Guilford Press.
- Robin, A. L., Koepke, T., & Moye, A. (1990). Multidimensional assessment of parent-adolescent relations. *Psychological Assessment, 2*(4), 451-459.
- Robin, A. L., Koepke, T., Moye, A., & Gerhardstein, R. (2009). *PARQ Parent Adolescent Relationship Questionnaire Professional Manual*. Lutz, FL: Psychological Assessment Resources, Inc.
- Sanders, J. O., Harrast, J. J., Kuklo, T. R., Polly, D. W., Bridwell, K. H., Diab, M., et al. (2007). The Spinal Appearance Questionnaire: Results of the reliability, validity, and responsiveness testing in patients with idiopathic scoliosis. *Spine, 32*(24), 2719-2722.

- Sapountzi-Krepia, D., Psychogiou, M., Peterson, D., Zafiri, V., Iordanopoulou, E., Michailidou, F., et al. (2006). The experience of brace treatment in children/adolescents with scoliosis. *Scoliosis, 1*(8). Retrieved from doi:10.1186/1748-7161-1-8
- Schafer, L. C., Glasgow, R. E., McCaul, K., & Drecher, M. (1983). Adherence to IDDM regimens: Relationship to psychosocial variables and metabolic control. *Diabetes Care, 6*, 493-498.
- Schafer, L. C., McCaul, K., & Glasgow, R. E. (1986). Supportive and nonsupportive family behaviors: Relations to adherence and metabolic control in persons with type I diabetes. *Diabetes Care, 9*, 179-185.
- Schatzinger, L. H., Brower, E. M., & Nash, C. L. J. (1979). The patient with scoliosis. Spinal fusion: emotional stress and adjustment. *Am J Nurs, 79*, 1608-1612.
- Smith, G. T., Fischer, S., & Fister, S. M. (2003). Incremental validity principles in test construction. *Psychological Assessment, 15*(4). doi: 10.1037/1040-3590.15.4.467
- Southam-Gerow, M. A., & Kendall, P. C. (2002). Emotion regulation and understanding-implications for child psychopathology and therapy. *Clinical Psychology Review, 22*, 189-222.
- Steinberg, L. (1988). Reciprocal relation between parent-child distance and pubertal maturation. *Developmental Psychology, 24*, 122-128.
- Tabachnick, B. G., & Fidell, L. S. (2001). *Using Multivariate Statistics* (4th ed.). Boston: Allyn & Bacon.
- Thompson, L., & Walker, A. J. (1982). The dyad as the unit of analysis: Conceptual and methodological issues. *Journal of Marriage and the Family, 44*(4), 889-900.

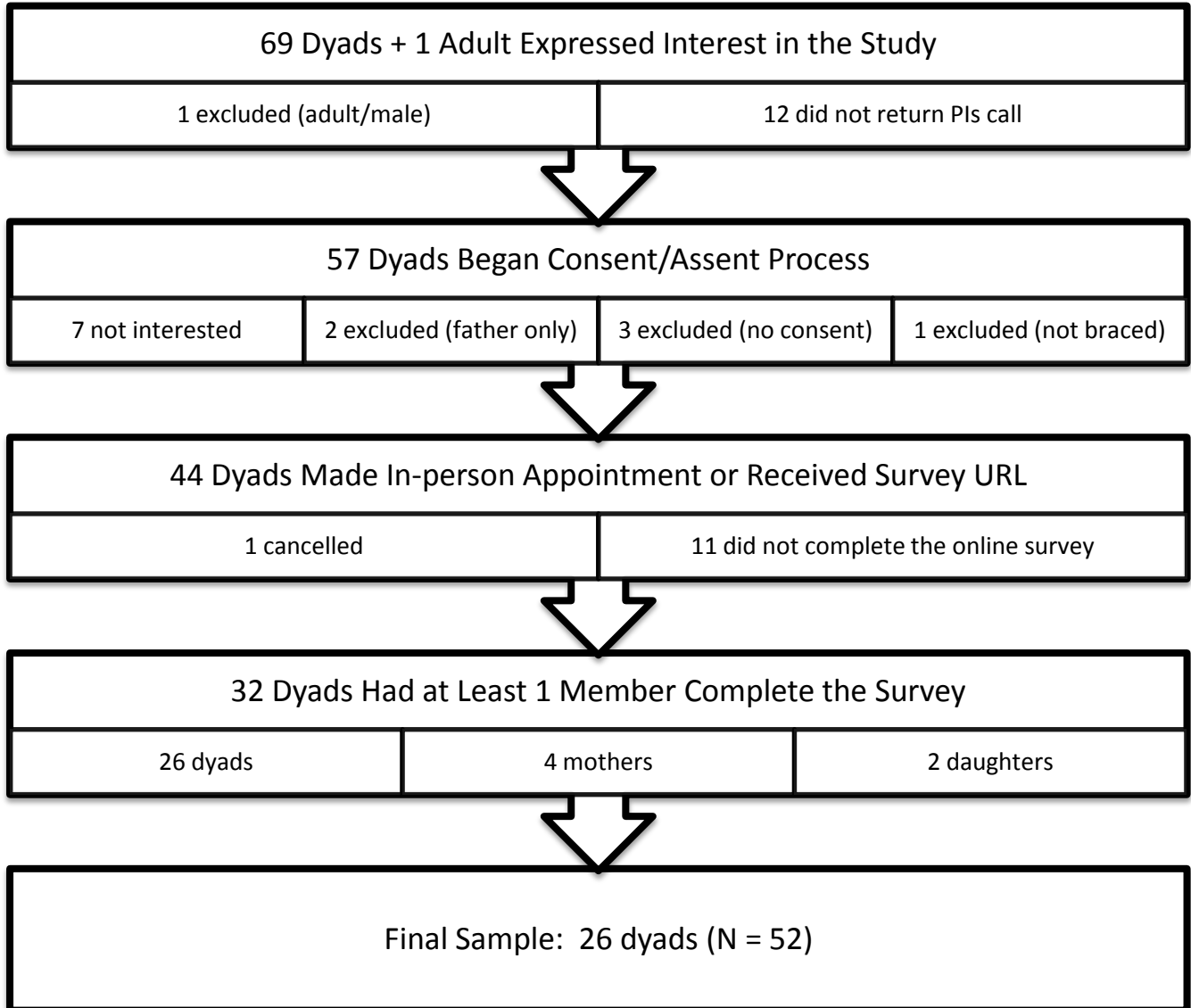
- Thompson, R. A. (1994). Emotion regulation: A theme in search of definition. *Monographs of the Society for Research in Child Development, 59*(2-3), 25-52.
- Tones, M., Moss, N., & Polly, D. W. (2006). A review of quality of life and psychosocial issues in scoliosis. *Spine, 31*, 3027-3038.
- Ugwonali, O. F., Lomas, G., Choe, J. C., Hyman, J. E., Lee, F. Y., Vitale, M. G., et al. (2004). Effect of bracing on the quality of life of adolescents with idiopathic scoliosis. *The Spine Journal, 4*, 254-260.
- Villemure, I., Aubin, C. E., Dansereau, J., & Labelle, H. (2004). Biomechanical simulations of the spine deformation process in adolescent idiopathic scoliosis from different pathogenesis hypotheses. *Eur Spine J, 13*, 83-90.
- Weinstein, S. L., Dolan, L. A., Cheng, J. C. Y., Danielsson, A., & Morcuende, J. A. (2008). Adolescent idiopathic scoliosis. *Lancet, 371*, 1527-1537.
- Weinstein, S. L., Dolan, L. A., Spratt, K. F., Peterson, K. K., Spoonamore, M. J., & Ponseti, I. V. (2003). Health and function of patients with untreated idiopathic scoliosis: a 50-year natural history study. *JAMA, 289*, 559-567.
- White, T., Miller, J., Smith, G. L., & McMahon, W. M. (2009). Adherence and psychopathology in children and adolescents with cystic fibrosis. *Eur Child Adolesc Psychiatry, 18*, 96-104. doi: 10.1007/s00787-008-0709-5
- Wiebe, D. J., Berg, C. A., Korbel, C., Palmer, D. L., Beveridge, R. M., Upchurch, R., et al. (2005). Children's appraisals of maternal involvement in coping with diabetes: Enhancing our understanding of adherence, metabolic control, and quality of life across adolescence. *Journal of Pediatric Psychology, 30*, 167-178.

- Wolman, C., Resnick, M. D., Harris, L. J., & Blum, R. W. (1994). Emotional well-being among adolescents with and without chronic conditions. *Journal of Adolescent Health, 15*, 199-204.
- Wysocki, T. (1993). Associations among teen-parent relationships, metabolic control, and adjustment to diabetes in adolescents. *Journal of Pediatric Psychology, 18*, 442-452.
- Wysocki, T., Greco, P., Harris, M. A., Bubb, J., & White, N. E. (2001). Behavior therapy for families of adolescents with diabetes. *Diabetes Care, 24*(3), 441-446.

APPENDICES

Appendix A

Recruitment and Attrition Figure



Appendix B
Family Demographics as Reported by Mothers

	Number Reporting	%
Mother's Marital Status		
Married and/or Living with a Partner	23	88.5%
Separated	0	0%
Divorced	1	3.8%
Single	2	7.7%
Mother's Level of Completed Education		
High School Diploma or GED	1	3.8%
Some College	10	38.5%
Bachelor's Degree	8	30.8%
Master's Degree	3	11.5%
Doctoral Degree	1	3.8%
Professional Degree (e.g., MD, JD, etc)	3	11.5%
Family's Current Household Income		
Under \$10,000	1	3.8%
\$10,000-\$19,000	0	0%
\$20,000-\$29,000	1	3.8%
\$30,000-\$39,000	1	3.8%
\$40,000-\$49,000	1	3.8%
\$50,000-\$74,000	4	15.4%
\$75,000-\$99,999	5	19.2%
\$100,000-\$150,000	8	30.8%
Over \$150,000	4	15.4%
"I do not wish to share this information"	1	3.8%
Family's Current Economic Situation		
"Almost enough to get by"	4	15.4%

“Enough to get by, but no more”	5	19.2%
“Definitely enough of everything”	10	38.5%
“Plenty of extras, but no luxuries”	3	11.5%
“Plenty of luxuries.”	3	11.5%
No response	1	3.8%
Does the Daughter Have Health Insurance?		
Yes	25	96.2%
No	0	0%
No response	1	3.8%
Is the Mother Satisfied with Her Daughter’s Health Insurance?		
Yes	20	76.9%
No	5	19.2%
No response	1	3.8%
Mothers Ethnic Background		
African-American	3	11.5%
Asian-American	0	0%
Caucasian or Euro-American	20	76.9%
Hispanic American; Latino, Latina	0	0%
Middle Eastern	2	7.7%
Native American	0	0%
Multiracial	1	3.8%
Daughters’ use of alcohol to cope with AIS		
“all of the time”	0	0%
“most of the time”	0	0%
“sometimes”	0	0%
“rarely”	1	3.8%
“never”	25	96.2%
Daughters’ use of illegal drugs to cope with AIS		

“all of the time”	0	0%
“most of the time”	0	0%
“sometimes”	0	0%
“rarely”	0	0%
“never”	26	100%

Daughters' misuse of prescription drugs to cope with AIS

“all of the time”	0	0%
“most of the time”	0	0%
“sometimes”	0	0%
“rarely”	0	0%
“never”	26	100%

Appendix C
Mothers' Experiences with Major Childhood Illnesses

	Number Reporting	%
Was Mother Diagnosed with AIS as a Child?		
Yes	5	19.2%
No	20	76.9%
No Response	1	3.8%
What AIS Treatment Were Mothers Prescribed?		
Close monitoring	2	7.7%
Bracing	2	7.7%
Close monitoring & bracing	1	3.8%
Physical therapy	0	0%
Surgery	0	0%
Not applicable	21	80.8%
How Did Mothers Describe Their AIS Treatment?		
“Very easy; little to no problems”	1	3.8%
“Somewhat easy; a few problems”	1	3.8%
“Neither easy nor difficult”	2	7.7%
“Somewhat difficult; more than a few problems”	1	3.8%
Not applicable	21	80.8%
What Other Major Childhood Illnesses Did Mothers Have?		
None	19	73.1%
Asthma	2	7.7%
No Response	5	19.2%
Mothers' Relatives Who Were Diagnosed with AIS		
Sister	2	7.7%
Mother	1	3.8%
Grandmother	0	0%

Cousin	2	7.7%
Another daughter	1	3.8%
Aunts and cousins	1	3.8%
Niece	3	11.5%
None	16	61.5%

How Much Did Mothers Know About Their Relatives' Treatment?

"Nothing"	0	0%
"Very little"	1	3.8%
"Some information"	5	19.2%
"Almost everything"	1	3.8%
"Everything"	2	7.7%
No response	1	3.8%
Not applicable	16	61.6%

Mothers Description of Relatives' Treatment

"Very well; little to no problems"	3	11.5%
"Somewhat well; a few problems"	3	11.5%
"Neither well nor difficult"	2	7.7%
"Somewhat difficult; more than a few problems"	1	3.8%
No response	1	3.8%
Not applicable	16	57.5%

How Did Mothers Feel About Their Relatives' Treatment?

"Fearful/anxious about my relative's health"	2	7.7%
"I do not recall any strong emotional reactions to my relative's experiences"	6	23.8%
"Scared something like this would happen to me" and "Angry that something like this would happen to my relative"	1	3.8%
"Other" (no further description)	1	3.8%
Not applicable	16	61.5%

Appendix D
Information about Daughters' AIS Treatment as Reported by both Mothers and Daughters

	Number Reporting	%
Mothers: Treatment Recommended Currently for Daughters		
Close monitoring	3	11.5%
Bracing	23	88.5%
Close monitoring and bracing	0	0%
Physical therapy	0	0%
Surgery	0	0%
Mothers: Daughters' Adherence to Current Treatment		
“Most of the time”	22	84.6%
“Sometimes”	4	15.4%
“Rarely”	0	0%
“Never”	0	0%
“I'm not sure”	0	0%
Mothers: Treatment Recommended in the Past for Daughters		
Close monitoring	2	7.7%
Bracing	13	50.0%
Close monitoring and bracing	6	23.1%
Bracing and physical therapy	1	3.8%
Close monitoring and bracing and physical therapy	4	15.4%
Daughters: Treatment Recommended Currently		
Close monitoring	1	3.8%
Bracing	25	96.2%
Close monitoring and bracing	0	0%
Physical therapy	0	0%
Surgery	0	0%
Daughters: Adherence to Current Treatment		

“Most of the time”	24	92.3%
“Sometimes”	2	7.7%
“Rarely”	0	0%
“Never”	0	0%
“I’m not sure”	0	0%

Daughters: Treatment Recommended in the Past

Close monitoring	3	11.5%
Bracing	10	38.5%
Close monitoring and bracing	5	19.2%
Physical therapy	0	0%
Close monitoring and physical therapy	1	3.8%
Bracing and physical therapy	2	7.7%
Close monitoring, bracing, and physical therapy	4	15.4%
Surgery	0	0%
Close monitoring, bracing, and surgery	1	3.8%

Appendix E
Information about Siblings' AIS Treatment as Reported by Mothers

	Number Reporting	%
Do you have other children who have been diagnosed with AIS?		
Yes	4	15.4%
No	22	84.6%
How many other children have AIS?		
One child	2	7.7%
Two children	1	3.8%
No response	1	3.8%
Not applicable	22	84.6%
Has it been difficult to manage the other child's AIS?		
“Very easy; little to no problems”	1	3.8%
“Somewhat easy; a few problems”	2	7.7%
“Somewhat difficult; more than a few problems”	1	3.8%
“Very difficult; lots of problems”	0	0%
Not applicable	22	84.6%
What type of treatment did your other child receive for AIS?		
Close monitoring	1	3.8%
Bracing	0	0%
Physical therapy	0	0%
Close monitoring and physical therapy	1	3.8%
Surgery	1	3.8%
Close monitoring, bracing, physical therapy, and surgery	1	3.8%
Not applicable	22	84.6%

Appendix F
Informed Consent (Parent)

Project Title: The Development of a Dyadic Assessment for Families Experiencing
Adolescent Idiopathic Scoliosis

Principle Investigator: Sarah Wice, M.S., Doctoral Fellow

Co-Investigator: Michelle Byrd, Ph.D., L.P., Associate Professor

Purpose of the Study: The purpose of this **research** study is to better understand how families cope with and communicate about Adolescent Idiopathic Scoliosis. Information gathered in this dissertation will help create a measurement tool about the parent-child relationship affected by Adolescent Idiopathic Scoliosis. You are being asked to participate in this study because you are the parent of a child who has Adolescent Idiopathic Scoliosis.

Procedure: A research assistant will explain the study to you, answer any questions you may have, and witness your signature to this consent form. You will be providing written informed consent for your own participation as well as for the participation of your child. Your child will be asked to complete an assent form, which asks their permission to participate, but does not replace legal informed consent. In order to be eligible to participate in this study, you must be (a) the mother of a child who has Adolescent Idiopathic Scoliosis, (b) be 18 years of age or older, and (c) be able to read and speak English. In order for your child to participate, they must be (a) diagnosed with Adolescent Idiopathic Scoliosis, (b) currently braced for their condition, (c) aged 12-17, (d) be able to read and speak English, and (e) not be diagnosed with any other significant medical condition such as Duchenne's muscular dystrophy or cerebral palsy.

You will be asked to complete questionnaires about your demographic information, your relationship with your child, and your child's Adolescent Idiopathic Scoliosis treatment. Your child will be asked to complete questionnaires about their general well-being and coping style, including any alcohol or drug use, your relationship with them, and their treatment for Adolescent Idiopathic Scoliosis. You will not be able to see her answers, and she will not be able to see your answers.

Upon completing the questionnaires, you will be given a duplicate copy of this informed consent, which includes follow-up contact information, if needed. The approximate total time to complete the questionnaires should be about 50 minutes.

Confidentiality: Only a code number will identify your questionnaire responses. All answers you or your child give on the questionnaires will remain private and will only be seen by the principle investigator and members of the research team. Medical staff who work at this facility, including your doctor, are NOT members of the research team and will NOT have access to your individual responses. Once all of the data has been collected and de-identified, group responses may be shared with the medical staff.

The results will be stored separately from the consent form, which includes your names. At no time will your names be associated with your responses to the questionnaires. Information you or your child give will not and cannot be used for any reason other than research. All related materials will be kept in locked file cabinets in the researcher's office and electronic data will be stored in a password-protected computer.

Expected Risks: There are no foreseeable risks to you or your daughter by completing this survey, as all results will be kept confidential. We do not anticipate that answering the questionnaires will lead to more discomfort than talking about Adolescent Idiopathic Scoliosis in other contexts.

Expected Benefits: There are no known personal benefits to you or to your daughter as a result of participating in this study. However, your participation will contribute to our understanding about how the diagnosis and treatment of Adolescent Idiopathic Scoliosis may affect the parent-child relationship and this information may be used in the future to help other families cope with this condition.

Potential Compensation: Each mother-daughter pair who chooses to participate will be eligible to win 1 of 10 gift cards to a local retail store of your choosing (as a mother, you will have the final say about which store). The gift cards will each be worth \$50. Only ten mother-daughter pairs will win a gift card. Even though you might choose to participate, you might not win a gift card. Names of mother-daughter pairs will be drawn randomly at the end of the study and the winning pairs will be contacted by the principal investigator, Sarah Wice, to receive their gift card.

Voluntary Participation: Participation in this study is voluntary. You may choose not to participate. If you do decide to participate, you can change your mind at any time and withdraw from the study without negative consequences. Your choice to participate (or not participate) will in no way impact the medical care your daughter currently receives or will receive at this medical facility in the future.

Use of Research Results: Results from this study will be presented in aggregate form only. No names or individually identifying information will be revealed. However, direct quotes from open-ended questions may be used. Results may be presented at research meetings and conferences, in scientific publications, and as part of a doctoral dissertation being conducted by the principal investigator.

Questions: If you have any questions concerning your participation in this study now or in the future, you can contact the principal investigator, Sarah Wice, by phone (810-701-7484) or via e-mail (swice@emich.edu), or her supervisor, Dr. Michelle Byrd, by phone (734-487-1155) or via e-mail (mbyrd@emich.edu).

Human Subjects Review Board: This research protocol and informed consent document has been reviewed and approved by the Eastern Michigan University Human Subjects Review Committee (UHSRC) for use from 8/4/2011 to 8/4/2012. If you have any questions about the approval process, please contact Dr. Deb de Laski-Smith (734-487-0042, Interim Dean of the

Graduate School and Administrative Co-chair of UHSRC, e-mail to:
human.subjects@emich.edu).

Consent to Participate: I have read or had read to me all of the above information about this research study, including the research procedures, possible risks, side effects, and the likelihood of any benefit to me. The content and meaning of this information has been explained and I understand. All of my questions, at this time, have been answered. I hereby consent for myself and my child to participate and do voluntarily offer to follow the study requirements and take part in the study.

YOUR NAME (Please print): _____

YOUR CHILD'S NAME (Please print): _____

Signatures:

Participant (your signature): _____ Date: _____

Investigator or Specified Designee: _____ Date: _____

Appendix G

Informed Assent (Adolescent)

Project Title: The Development of a Dyadic Assessment for Families Experiencing Adolescent Idiopathic Scoliosis

Principle Investigator: Sarah Wice, M.S., Doctoral Fellow

Co-Investigator: Michelle Byrd, Ph.D., L.P., Associate Professor

Purpose of the Study: The purpose of this **research** study is to better understand how families cope with and communicate about Adolescent Idiopathic Scoliosis. You are being asked to participate in this study because you have a diagnosis of Adolescent Idiopathic Scoliosis and currently wear a brace for this condition.

Procedure: If you decide that you want to participate in this study, a research assistant will explain the study to you, answer any questions you may have, and watch you sign this form. In order to participate in this study, you must (a) have your parent's permission to participate, (b) be female, (c) have been told to wear a back brace by your doctor, (d) have a diagnosis of Adolescent Idiopathic Scoliosis, and (e) be able to read and speak English.

You will be asked to read and answer questions about how you are doing, your relationship with your mother, and how you deal with your Adolescent Idiopathic Scoliosis treatment. Answering all of these questions will take you a little less than an hour.

Confidentiality: All the answers you give on the questionnaires will remain private and will only be seen by the people running this study and not anyone else, even your doctor or mother. Your name will not be with any of your answers, so no one will know what you said. We will keep all of your answers locked up so that no one can read them that isn't allowed to.

Expected Risks: We do not think that you will feel bad or be hurt in any way because of answering these questions.

Expected Benefits: You won't get anything in return if you decide to answer these questions. Your answers might be used to help other children who are going through the same thing in the future, though, which could be very helpful to those children and their families.

Potential Compensation: If you and your mom decide to answer these questions, there is a chance you could win 1 of 10 gift cards to a local retail store. If you win, you and your mom get to pick the store, but your mom has the final say about which store. The gift cards will each be worth \$50. Only ten families will win, so, even though you might chose to answer the questions, you might not win a gift card.

Voluntary Participation: Only you get to decide whether or not you want to answer these questions and no one can make you answer them if you don't want to. If you decide that you

want to and then change your mind, you can stop at any time without negative consequences. Whether you decide to answer the questions or not, the quality of care you receive from your doctor will not be affected by your decision, either today or in the future.

Use of Research Results: Results from this study will be presented in group form only. This means that no names or individually identifying information will be revealed. However, direct quotes from open-ended questions may be used. Results may be presented at research meetings and conferences, as well as in scientific writing.

Questions: If you have any questions concerning your participation in this study now or in the future, you can contact the principal investigator, Sarah Wice, by phone (810-701-7484) or via e-mail (swice@emich.edu), or her supervisor, Dr. Michelle Byrd, by phone (734-487-1155) or via e-mail (mbyrd@emich.edu).

Human Subjects Review Board: This research protocol and informed consent document has been reviewed and approved by the Eastern Michigan University Human Subjects Review Committee (UHSRC) for use from 8/4/2011 to 8/4/2012. If you have any questions about the approval process, please contact Dr. Deb de Laski-Smith (734-487-0042, Interim Dean of the Graduate School and Administrative Co-chair of UHSRC, e-mail to: human.subjects@emich.edu).

Assent to Participate: I have read or had read to me all of the above information about this research study. This information has been explained to me and I understand what I am being asked to do. All of my questions, at this time, have been answered.

By writing and signing my name below I am saying that I want to answer the questions as part of this research today.

PRINT NAME: _____

Signatures:

Participant (your signature): _____ Date: _____

Investigator or Specified Designee: _____ Date: _____

Appendix H

Demographic Questionnaire (Parent)

1. What is your current age? _____
2. Please select your marital status:
 - Married Living with a Partner
 - Separated
 - Divorced
 - Single
 - Other: _____
3. How many total children are living in your home? _____
4. Please select your ethnic background (check all that apply):
 - African-American
 - Asian-American (including Indian and Pacific Island regions)
 - Caucasian or Euro-American
 - Hispanic American; Latino, Latina
 - Middle Eastern
 - Native American
 - Other: _____
 - Multiracial: _____
5. What is the highest level of education you have completed?
 - Elementary School
 - High school or equivalent
 - Vocational/technical school (2 year)
 - Some college
 - Bachelor's degree
 - Master's degree
 - Doctoral degree
 - Professional degree (MD, JD, etc.)
 - Other: _____

6. What is your current household income in U.S. dollars?

- Under \$10,000
- 10,000-\$19,000
- \$20,000-\$29,000
- \$30,000-\$39,000
- \$40,000-\$49,000
- \$50,000-\$74,000
- \$75,000-\$99,999
- \$100,000-\$150,000
- Over \$150,000
- I do not wish to share this information

7. Does your child have health insurance?

- Yes
- No

8. If yes, are you satisfied with your child's health insurance?

- Yes, please explain why:

- No, please explain why not:

9. How would you describe your economic situation now?

- Almost enough to get by
- Enough to get by, but no more
- Definitely enough of everything
- Plenty of extras, but no luxuries
- Plenty of luxuries

10. Were YOU diagnosed with AIS as a child or adolescent?

- Yes. How old were you at the time? _____
- No. Please skip to question #13.

11. If yes, what type of treatment did you receive for AIS? Please check all that apply.

- Close monitoring to see if your curve got larger
- Bracing
- Surgery
- Physical Therapy
- Other, please specify: _____

12. If yes, how would you describe your treatment? Please check only one.

- Very easy; little to no problems
- Somewhat easy; a few problems
- Neither easy nor difficult
- Somewhat difficult; more than a few problems
- Very difficult; lots of problems

13. Did you have any major childhood illnesses? If yes, please list all:

14. Other than your daughter, do you have any other female relatives who have been diagnosed and treated for AIS? Please check all that apply.

- Sister(s)
- Mother
- Grandmother(s)
- Aunt(s)
- Cousin(s)
- Other, please specify: _____

15. If yes, how much do/did you know about their treatment? Please check only one.

- Nothing
- Very little
- Some information
- Almost everything
- Everything

16. If yes, how did you feel about your relative's AIS? Please check all that apply.

- Fearful/anxious about my relative's health
- Scared something like this would happen to me
- Angry that something like this would happen to my relative
- Other, please describe: _____
- I do not recall any strong emotional reactions to my relative's experiences.

17. If yes, how would you describe their treatment? Please check only one.

- Very well; little to no problems
- Somewhat well; a few problems
- Neither well nor difficult
- Somewhat difficult; more than a few problems
- Very difficult; lots of problems

18. How long has your daughter been diagnosed with AIS? _____

19. What is the size of your daughter's curve right now? _____

20. What treatment is your doctor CURRENTLY recommending for your daughter AT THE PRESENT MOMENT? Please check only one.

- Close monitoring of her curve
- Bracing
- Surgery
- Physical Therapy
- Other, please specify: _____

21. My daughter is following her doctor's recommendations. Please check only one.

- Most of the time
- Sometimes
- Rarely
- Never
- I'm not sure

22. What treatment has your daughter's doctor recommended in the PAST? Please check ALL that apply.

- Close monitoring of her curve
- Bracing
- Surgery
- Physical Therapy
- Other, please specify: _____

23. Do you have any other children who have been diagnosed with AIS?

- Yes. How many? _____
- No. Please skip to the next section.

24. If yes, how difficult has it been to manage the other child's AIS treatment? Please check only one.

- Very easy; little to no problems
- Somewhat easy; a few problems
- Somewhat difficult; more than a few problems
- Very difficult; lots of problems

25. If yes, what type of treatment did your other child receive for AIS? Please check all that apply.

- Close monitoring to see if your curve got larger
- Bracing
- Surgery
- Physical Therapy
- Other, please specify: _____

Note: This question and statement will appear at the end of the survey.

Is there anything else you would like us to know about your relationship? Or about your daughter's spine condition?

Thank you for your time!

Appendix I

Additional Questions (Adolescents)

1. How long have you had a spine condition? _____
2. What is the size of your curve right now? _____
3. What treatment is your doctor CURRENTLY recommending AT THE PRESENT MOMENT? Please check only one.
 - Close monitoring of her curve
 - Bracing
 - Surgery
 - Physical Therapy
 - Other, please specify: _____
4. I am following my doctor's recommendations. Please check only one.
 - Most of the time
 - Sometimes
 - Rarely
 - Never
 - I'm not sure
5. My doctor has recommended these treatments in the PAST? Please check ALL that apply.
 - Close monitoring of her curve
 - Bracing
 - Surgery
 - Physical Therapy
 - Other, please specify: _____
6. I use alcohol to help cope with my spine condition.
 - All of the time
 - Most of the time
 - Sometimes
 - Rarely
 - Never

7. I use illegal drugs (or inhale household chemicals) to help cope with my spine condition.

- All of the time
- Most of the time
- Sometimes
- Rarely
- Never

8. I misuse prescription medications to help cope with my spine condition.

- All of the time
- Most of the time
- Sometimes
- Rarely
- Never

Note: This question and statement will appear at the end of the survey.

Is there anything else you would like us to know about your relationship? Or about your spine condition?

Thank you for your time!

Appendix J

AIS Dyadic Assessment: Parent's Version¹

Instructions: Please select on how much you agree or disagree with each statement.

- Strongly disagree
- Disagree
- Neither disagree nor agree
- Agree
- Strongly Agree

Communication Skills Items

1. My daughter hides things about her condition from me.*
2. I am honest with my daughter about her scoliosis.
3. We argue about medical appointments.
4. We disagree about what to tell her friends about scoliosis.
5. We fight about missing extracurricular activities (e.g., sports).*
6. It is easy to talk to each other about scoliosis.
7. We are able to resolve disagreements about scoliosis effectively.*
8. I communicate effectively about scoliosis.*
9. We agree about the consequences of not wearing the brace as recommended.*
10. We fight about taking care of the brace (e.g., keeping it clean).
11. My daughter expresses her feelings about the brace clearly.*

Emotion Regulation Items

12. I am a source of comfort to my daughter during medical appointments.*
13. My daughter's back problems have become the main focus of our relationship.

¹ Note: Items are divided by components of the proposed model. Formatting will be changed for participants.

* Reverse scored items

14. My feelings make it difficult for us to talk about her treatment.*
15. My daughter's emotions make it difficult for us to talk about scoliosis.*
16. Sharing our feelings helps us resolve disagreements about treatment.
17. We share everything related to my daughter's treatment.
18. Our relationship has not changed since my daughter was diagnosed with scoliosis.*
19. I trust my daughter to wear her brace, even when I'm not there to make sure she is wearing it.
20. My daughter relies on me to make healthy choices.
21. Scoliosis has strained our relationship.*
22. The smallest thing about my daughter's brace starts a fight between us.
23. I can't stand to see my daughter in pain.
24. My daughter does not seek my advice about problems related to wearing her brace.*
25. I am worried about my daughter's ability to function in the future.*
26. My daughter is hopeful the brace will help her scoliosis.
27. We have an optimistic outlook about treatment.
28. Talking to my daughter about her medical condition makes me fearful or anxious about the state of my own health.*
29. I am frustrated by my daughter's behavior and management of her medical condition.
30. I feel helpless about how I can help my daughter get through this tough time.
31. I am optimistic my daughter's condition will improve.

Mutual Agreement About AIS Items

32. I know how often my daughter is wearing her brace.
33. It is my daughter's responsibility to wear her brace as prescribed.*

34. It is my job to make sure my daughter is wearing her brace.*
35. My daughter is responsible for scheduling her medical appointments.*
36. I do not know how much I should be helping my daughter manage her scoliosis.
37. Unless my daughter's scoliosis is corrected, she will have a decreased quality of life as an adult.*
38. My daughter's biggest concern about wearing a brace is finding clothes to wear with it.
39. My daughter worries that wearing a brace will make it difficult to date.
40. I've reduced or changed my daughter's responsibilities (e.g., chores) at home because of her brace.
41. My daughter is able to solve problems about wearing her brace effectively.*
42. I am confident I am helping my daughter be healthy.
43. My daughter would say I am helping her treatment.
44. I know what is the best medical treatment for my daughter.*
45. I am helping my daughter manage her illness.

Appendix K

AIS Dyadic Assessment: Adolescent's Version²

Instructions: Please select on how much you agree or disagree with each statement.

- Strongly disagree
- Disagree
- Neither disagree nor agree
- Agree
- Strongly Agree

Communication Skills Items

1. I tell my mother everything about my back condition.
2. I am honest with my mother about my scoliosis.
3. We argue about medical appointments.*
4. We disagree about what to tell my friends about scoliosis.*
5. We fight about missing extracurricular activities (e.g., sports).*
6. It is easy to talk to each other about scoliosis.
7. We are able to resolve disagreements about scoliosis effectively.
8. I communicate effectively about scoliosis.
9. We agree about the consequences of not wearing the brace as recommended.
10. We fight about taking care of the brace (e.g., keeping it clean).*
11. I express my feelings about the brace clearly.

Emotion Regulation Items

12. My mother is a source of comfort to me during medical appointments.
13. My back problems have become the main focus of our relationship.*

² Note: Items are divided by components of the proposed model. Formatting will be changed for participants.

*Reverse scored item.

14. My feelings make it difficult for us to talk about treatment.*
15. My emotions make it difficult for us to talk about scoliosis.*
16. Sharing our feelings helps us resolve disagreements about treatment.
17. We share everything related to my treatment.
18. Our relationship has not changed since I was diagnosed with scoliosis.
19. I wear my brace, even my mother is not there to make sure I am wearing it.
20. I rely on my mother to help me make healthy choices.
21. Scoliosis has strained our relationship.*
22. The smallest thing about my brace starts a fight between us.*
23. My mother can't stand to see me in pain.
24. I do not ask advice from my mother about problems related to wearing my brace.*
25. I am worried about my ability to function in the future.*
26. I am hopeful the brace will help my scoliosis.
27. We have an optimistic outlook about treatment.
28. Talking to my mother about my medical condition makes me fearful or anxious about the
my health.*
29. I am frustrated by my mother's behavior and management of my scoliosis.*
30. I feel helpless about how I can get through this tough time.*
31. I am optimistic my condition will improve.

Mutual Agreement About AIS Items

32. My mother knows how often I am wearing my brace.
33. It is my responsibility to wear my brace as prescribed.
34. It is my mother's job to make sure I am wearing my brace.*

35. I am responsible for scheduling medical appointments.
36. I do not know how much my mother should be helping me manage scoliosis.*
37. Unless my scoliosis is corrected, I will have a decreased quality of life as an adult.*
38. My biggest concern about wearing a brace is finding clothes to wear with it.*
39. I worry that wearing a brace will make it difficult to date.*
40. I have less responsibilities (e.g., chores) at home because of my brace.
41. I am able to solve problems about wearing my brace effectively.
42. I am confident my mother is helping me be healthy.
43. My mother is helping my treatment.
44. I know what is the best medical treatment for me.
45. My mother is helping me manage my illness.

Appendix L

Difficulties in Emotion Regulation Scale [DERS; (K. L. Gratz & Roemer, 2004)]

Instructions: Please indicate how often the items apply to you using the following scale.

		1		2		3		4		5
		Almost never		Sometimes		About Half the Time		Most of the Time		Almost Always
1.	I am clear about my feelings.	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>
2.	I feel at ease with my emotions.	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>
3.	I pay attention to how I feel.	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>
4.	I experience my emotions as overwhelming and out of control.	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>
5.	I have no idea how I am feeling.	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>
6.	I have difficulty making sense out of my feelings.	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>
7.	I am attentive to my feelings.	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>
8.	I know exactly how I am feeling.	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>
9.	I care about what I am feeling.	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>
10.	I am confused about how I feel.	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>
11.	My emotions make me uncomfortable.	<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>

	1 Almost never	2 Sometimes	3 About Half the Time	4 Most of the Time	5 Almost Always
12. When I'm upset, I acknowledge my emotions.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. When I'm upset, I allow myself to feel that way.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. When I'm upset, I become angry with myself for feeling that way.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. When I'm upset, I become embarrassed for feeling that way.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. When I'm upset, I have difficulty getting work done.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. When I'm upset, I become out of control.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. When I'm upset, I believe that I will remain that way for a long time.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. When I'm upset, I become scared and fearful of those feelings.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. When I'm upset, I believe that I'll end up feeling very depressed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	1 Almost never	2 Sometimes	3 About Half the Time	4 Most of the Time	5 Almost Always
21. When I'm upset, I believe that my feelings are valid and important.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. When I'm upset, I have difficulty focusing on other things.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. When I'm upset, I feel out of control.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. When I'm upset, I can still get things done.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. When I'm upset, I feel ashamed with myself for feeling that way.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. When I'm upset, I know that I can find a way to eventually feel better.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. When I'm upset, I feel like I am weak.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. When I'm upset, I feel like I can remain in control of my behaviors.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. When I'm upset, I feel guilty for feeling that way.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- | | | | | | | |
|-----|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| 30. | When I'm upset, I have difficulty concentrating. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 31. | When I'm upset, I have difficulty controlling my behaviors. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 32. | When I'm upset, I believe that there is nothing I can do to make myself feel better. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 33. | When I'm upset, I become irritated with myself for feeling that way. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 34. | When I'm upset, I start to feel very bad about myself. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 35. | When I'm upset, I believe that wallowing in it is all I can do. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 36. | When I'm upset, I lose control over my behaviors. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 37. | When I'm upset, I know there are things I can do to manage my emotions. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 38. | When I'm upset, I have difficulty thinking about anything else. | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

	1 Almost never	2 Sometimes	3 About Half the Time	4 Most of the Time	5 Almost Always
39. When I'm upset, I take time to figure out what I'm really feeling.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. When I'm upset, it takes me a long time to feel better.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. When I'm upset, my emotions feel overwhelming.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix M

Scoliosis Research Society-22r Patient Questionnaire

[SRS-22r; Parents; (Asher, et al., 2006)]

Instructions: We are carefully evaluating the condition of your daughter's back and it is IMPORTANT THAT YOU ANSWER EACH OF THESE QUESTIONS YOURSELF. Please CHECK THE **ONE BEST ANSWER** to each question.

1. Which of the following best describes the amount of pain your daughter has experienced during the past 6 months.
 - None
 - Mild
 - Moderate
 - Moderate to Severe
 - Severe

2. Which of the following best describes the amount of pain your daughter has experienced over the last month.
 - None
 - Mild
 - Moderate
 - Moderate to Severe
 - Severe

3. During the past 6 months, has your daughter been a nervous person?
 - None of the time
 - A little of the time
 - Some of the time
 - Most of the time
 - All of the time

4. If your daughter had to spend the rest of her life with her back shape as it is right now, how would she feel about it?
 - Very happy
 - Somewhat happy
 - Neither happy nor unhappy
 - Somewhat unhappy
 - Very unhappy

5. What is your daughter's current level of activity?

- Bedridden
- Primarily no activity
- Light labor, and light sports
- Moderate labor and moderate sports
- Full activities without restriction

6. How does your daughter look in clothes?

- Very good
- Good
- Fair
- Bad
- Very bad

7. In the past 6 months, has your daughter felt so down in the dumps that nothing could cheer her up?

- Very often
- Often
- Sometimes
- Rarely
- Never

8. Does your daughter experience back pain when at rest?

- Very often
- Often
- Sometimes
- Rarely
- Never

9. What is your daughter's current level of work/school activity?

- 100% normal
- 75% normal
- 50% normal
- 25% normal
- 0% normal

10. Which of the following best describes the appearance of your daughter's trunk; defined as the human body except for the head and extremities?

- Very good
- Good
- Fair
- Poor
- Very poor

11. Which one of the following best describes your daughter's pain medication use for back pain?

- None
- Non-narcotics weekly or less (e.g., aspirin, Tylenol, Ibuprofen)
- Non-narcotics daily
- Narcotics weekly or less (e.g., Tylenol III, Lorocet, Percocet)
- Narcotics daily

12. Does your daughter's back limit her ability to do things around the house?

- Never
- Rarely
- Sometimes
- Often
- Very Often

13. Has your daughter felt calm and peaceful during the past 6 months?

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

14. Does your daughter feel her back condition affects her personal relationships?

- None
- Slightly
- Mildly
- Moderately
- Severely

15. Is your family experiencing financial difficulties because of your daughter's back?

- Severely
- Moderately
- Mildly
- Slightly
- None

16. In the past 6 months, has your daughter felt down hearted and blue?

- Never
- Rarely
- Sometimes
- Often
- Very often

17. In the last 3 months, has your daughter taken any sick days from work/school due to back pain and if so, how many?

- 0
- 1
- 2
- 3
- 4 or more

18. Does your daughter's back condition limit her going out with friends/family?

- Never
- Rarely
- Sometimes
- Often
- Very often

19. Does your daughter feel attractive with her current back condition?

- Yes, very
- Yes, somewhat
- Neither attractive or unattractive
- No, not very much
- No, not at all

20. Has your daughter been a happy person during the past 6 months?

- None of the time
- A little of the time
- Some of the time
- Most of the time
- All of the time

21. Is your daughter satisfied with the results of her back management?

- Very satisfied
- Satisfied
- Neither satisfied nor unsatisfied
- Unsatisfied
- Very unsatisfied

22. Would your daughter have the same management again if she had the same condition?

- Definitely yes
- Probably yes
- Not sure
- Probably not
- Definitely not

Appendix N

Scoliosis Research Society-22r Patient Questionnaire

[SRS-22r; Adolescents; (Asher, et al., 2006)]

Instructions: We are carefully evaluating the condition of your back and it is **IMPORTANT THAT YOU ANSWER EACH OF THESE QUESTIONS YOURSELF**. Please **CHECK THE ONE BEST ANSWER** to each question.

23. Which of the following best describes the amount of pain you have experienced during the past 6 months.
- None
 - Mild
 - Moderate
 - Moderate to Severe
 - Severe
24. Which of the following best describes the amount of pain you have experienced over the last month.
- None
 - Mild
 - Moderate
 - Moderate to Severe
 - Severe
25. During the past 6 months, have you been a nervous person?
- None of the time
 - A little of the time
 - Some of the time
 - Most of the time
 - All of the time
26. If you had to spend the rest of your life with your back shape as it is right now, how would you feel about it?
- Very happy
 - Somewhat happy
 - Neither happy nor unhappy
 - Somewhat unhappy
 - Very unhappy

27. What is your current level of activity?

- Bedridden
- Primarily no activity
- Light labor, and light sports
- Moderate labor and moderate sports
- Full activities without restriction

28. How do you look in clothes?

- Very good
- Good
- Fair
- Bad
- Very bad

29. In the past 6 months, have you felt so down in the dumps that nothing could cheer you up?

- Very often
- Often
- Sometimes
- Rarely
- Never

30. Do you experience back pain when at rest?

- Very often
- Often
- Sometimes
- Rarely
- Never

31. What is your current level of work/school activity?

- 100% normal
- 75% normal
- 50% normal
- 25% normal
- 0% normal

32. Which of the following best describes the appearance of your trunk; defined as the human body except for the head and extremities?

- Very good
- Good
- Fair
- Poor
- Very poor

33. Which one of the following best describes your pain medication use for back pain?

- None
- Non-narcotics weekly or less (e.g., aspirin, Tylenol, Ibuprofen)
- Non-narcotics daily
- Narcotics weekly or less (e.g., Tylenol III, Lorocet, Percocet)
- Narcotics daily

34. Does your back limit your ability to do things around the house?

- Never
- Rarely
- Sometimes
- Often
- Very Often

35. Have you felt calm and peaceful during the past 6 months?

- All of the time
- Most of the time
- Some of the time
- A little of the time
- None of the time

36. Do you feel your back condition affects your personal relationships?

- None
- Slightly
- Mildly
- Moderately
- Severely

37. Are you and/or your family experiencing financial difficulties because of your back?

- Severely
- Moderately
- Mildly
- Slightly
- None

38. In the past 6 months, have you felt down hearted and blue?

- Never
- Rarely
- Sometimes
- Often
- Very often

39. In the last 3 months, have you taken any sick days from work/school due to back pain and if so, how many?

- 0
- 1
- 2
- 3
- 4 or more

40. Does your back condition limit your going out with friends/family?

- Never
- Rarely
- Sometimes
- Often
- Very often

41. Do you feel attractive with your current back condition?

- Yes, very
- Yes, somewhat
- Neither attractive or unattractive
- No, not very much
- No, not at all

42. Have you been a happy person during the past 6 months?

- None of the time
- A little of the time
- Some of the time
- Most of the time
- All of the time

43. Are you satisfied with the results of your back management?

- Very satisfied
- Satisfied
- Neither satisfied nor unsatisfied
- Unsatisfied
- Very unsatisfied

44. Would you have the same management again if you had the same condition?

- Definitely yes
- Probably yes
- Not sure
- Probably not
- Definitely not

Appendix O

Helping for Health Inventory [HHI; Parents; (Harris, et al., 2008)]

	1 = Rarely	2	3	4	5 = Always
1. My child resists my involvement in her back condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I find that the more I try to help my child with her back condition, the more she resists my involvement.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I get upset with myself when my child's health doesn't improve.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. When my child doesn't take my advice or direction in managing her health, I do it or want to do it myself.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I get upset with my child when her health doesn't improve.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. My child and I argue about my helping her with managing her back condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I feel like the more I try to help my child with her back condition, the worse things get between us.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. My child says I "nag" her about managing her back condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I feel there is no limit to what I can do as a parent in helping my child manage her back condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. When my child's health does not improve, I feel like I have not been a good parent.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. I feel responsible for my child having a back condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I believe that if I do the right thing, my child's health will improve.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	1 = Rarely	2	3	4	5 = Always
13. I want to be a “good” helper when it comes to helping my child manager her back condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. I feel that I “nag” my child about how she manages her back condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. When my child has health setbacks, I feel that she is not trying hard enough.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. How concerned are you about your back condition?

0	1	2	3	4	5	6	7	8	9	10
not at all										extremely
concerned										concerned

7. How well do you feel you understand your back condition?

0	1	2	3	4	5	6	7	8	9	10
don't										understand
understand										very
at all										clearly

8. How much does your back condition affect you emotionally? (e.g., does it make you angry, scared, upset or depressed?)

0	1	2	3	4	5	6	7	8	9	10
not at all										extremely
affected										affected
emotionally										emotionally

9. Please list in rank-order the three most important factors that you believe caused your back condition. The most important causes for me:

1. _____
2. _____
3. _____

Appendix Q:

Descriptive Statistics for Subscales on Measures of Interest

Difficulties in Emotion Regulation Scale	<i>n</i>	Mean	Std. Deviation	Normative Mean	Normative Std. Deviation	<i>t</i>	<i>α</i>
Nonacceptance of Emotional Responses							
Mothers	25	9.28	2.75	11.7	4.72	-4.41 ^a	0.78
Daughters	25	13.8	3.42	11.0	4.31	4.04 ^a	0.76
Difficulties Engaging in Goal-Directed Behavior							
Mothers	25	11.7	2.67	14.4	4.95	-5.02 ^a	0.71
Daughters	26	12.2	2.48	15.3	4.45	-6.47 ^a	0.54
Impulse Control Difficulties							
Mothers	24	11.0	1.49	10.8	4.41	0.80	0.76
Daughters	26	14.8	3.42	10.7	4.30	5.81 ^a	0.66
Lack of Emotional Awareness							
Mothers	25	22.9	4.23	14.3	4.60	10.2 ^a	0.80
Daughters	24	14.2	2.31	17.3	4.81	-6.95 ^a	0.73
Limited Access to Emotion Regulation Strategies							
Mothers	24	14.0	2.39	16.2	6.19	-4.43 ^a	0.53
Daughters	26	17.3	5.73	16.4	6.17	0.84	0.61
Lack of Emotional Clarity							
Mothers	25	12.4	1.63	10.6	3.80	5.40 ^a	-0.08
Daughters	26	15.6	2.97	9.51	3.46	10.4 ^a	-0.01

^at-test is significant at the 0.01 level (2-tailed)

Scoliosis Research Society-22r Health Related Questionnaire	<i>n</i>	Mean	Std. Deviation	Normative Mean	Normative Std. Deviation	<i>t</i>	<i>α</i>
Functioning/activity level							
Mothers	25	4.58	0.54	n/a	n/a	n/a	0.78
Daughters	25	4.48	0.62	4.60	0.63	-0.97	0.71
Pain							
Mothers	25	4.30	0.62	n/a	n/a	n/a	0.84
Daughters	26	3.98	0.81	4.30	0.82	-1.99	0.81
Self-image/appearance							
Mothers		3.92	0.73	n/a	n/a	n/a	0.75
Daughters	26	3.56	0.81	4.10	0.66	-3.39 ^a	0.76
Mental Health							
Mothers	26	3.85	0.67	n/a	n/a	n/a	0.87
Daughters	26	3.63	0.89	4.90	0.45	-7.27 ^a	0.86
Satisfaction with Management of Symptoms							
Mothers	26	3.94	0.65	n/a	n/a	n/a	0.61
Daughters	26	3.60	0.85	4.00	1.05	-2.43 ^b	0.38

^at-test is significant at the 0.01 level (2-tailed)

^bt-test is significant at the 0.05 level (2-tailed)

The Brief Illness Perception Questionnaire	<i>n</i>	Mean	Std. Deviation	Normative Mean	Normative Std. Deviation	<i>t</i>
Consequences	26	4.62	2.42	4.7	2.9	-0.18
Timeline	25	5.08	2.55	9.2	1.9	-8.08 ^a
Personal Control	26	4.38	2.70	6.7	2.3	-4.37 ^a
Treatment Control	24	6.30	2.07	8.0	2.3	-4.16 ^a
Identity	26	2.85	2.56	4.6	2.8	-3.50 ^a
Concern	26	5.96	2.71	7.0	3.1	-1.96
Understanding	26	7.35	2.67	7.9	2.3	-1.06
Emotional Response	26	4.85	3.28	4.3	3.3	0.85

^at-test is significant at the 0.01 level (2-tailed)

Appendix R:

Correlation Matrices for Mothers and Daughters

Table 1. Correlation Matrix for Mothers [r(n)]

	1.	2.	3.	4.	5.	6.	7.	8.	9.
1. Age									
2. Family Income	-0.07(26)								
3. Childhood AIS	0.33(25)	-0.20(25)							
4. Relatives' AIS	-0.04(26)	0.24(26)	-0.41(25) ^a						
5. AIS Dyadic Assessment	0.18(25)	0.10(25)	0.45(24) ^a	0.06(25)					
6. PARQ:C	0.09(26)	0.14(26)	-0.09(25)	0.16(26)	-0.18(25)				
7. PARQ:PS	0.01(26)	-0.14(26)	-0.15(25)	-0.12(26)	0.01(25)	0.56(26) ^b			
8. DERS	-0.21(22)	0.06(22)	0.02(22)	0.18(22)	0.04(21)	0.04(22)	-0.21(22)		
9. SRS-22r	0.40(25)*	0.09(25)	0.49(24) ^a	-0.05(25)	0.57(24) ^b	-0.22(25)	-0.17(25)	-0.29(22)	
10. HHI	-0.31(25)	-0.19(25)	-0.29(24)	-0.13(25)	-0.62(24) ^b	0.26(25)	0.24(25)	0.12(22)	-0.69(25) ^b

^a Correlation is significant at the 0.05 level (2-tailed).

^b Correlation is significant at the 0.01 level (2-tailed).

Table 2. Correlation Matrix for Daughters [r(n)]

	1.	2.	3.	4.	5.	6.	7.	8.	9.
1. Age									
2. Curve Size	0.02(12)								
3. Time Since Diagnosis	-0.10(19)	0.34(19)							
4. Current Adherence	0.03(14)	-0.02(22)	-0.20(22)						
5. AIS Dyadic Assessment	-0.01(13)	-0.25(21)	0.05(21)	-0.16(25)					
6. PARQ:C	-0.47(13)	0.38(21)	-0.02(21)	0.11(25)	-0.59(24) ^b				
7. PARQ:PS	-0.20(13)	0.37(21)	-0.04(21)	0.17(25)	-0.55(25) ^b	0.77(24) ^b			
8. DERS	0.29(11)	-0.17(19)	-0.35(19)	0.67(23) ^b	-0.11(22)	0.01(23)	-0.37(22)		
9. SRS-22r	0.18(14)	-0.03(22)	-0.01(22)	-0.45(25) ^a	-0.49(24) ^a	-0.31(24)	-0.17(24)	-0.58(22) ^b	
10. Brief IPQ	-0.20(13)	0.23(21)	0.07(21)	0.40(25) ^a	-0.18(24)	0.18(25)	-0.06(24)	0.47(23) ^a	-0.31(24)

^a Correlation is significant at the 0.05 level (2-tailed).

^b Correlation is significant at the 0.01 level (2-tailed).

