

Running head: IS CHRONIC SORROW PRESENT IN MATERNAL CAREGIVERS?

Is Chronic Sorrow Present in Maternal Caregivers
Of Attention Deficit Hyperactivity Disordered
Children?

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By

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Abstract

The adverse impact of Attention Deficit Hyperactivity Disorder (ADHD), one of the most prevalent childhood psychiatric disorders, goes beyond the individual's symptoms of hyperactivity, impulsivity and inattentiveness. It is chronic and persistent, frequently impacting academic, social and family interactions and outcomes. Research indicates that maternal caregivers are especially vulnerable experiencing increased levels of stress, anxiety, marital discord and depression (West, Houghton, Douglas, Wall & Whiting, 1999). These same mothers also appear to be experiencing chronic sorrow: persistent, pervasive and episodic guilt, pain and sadness that at times is mediated by times of pleasure and satisfaction in being with their child (Roos, 2002). This paper reviews current research and literature on mothers of ADHD children, defines chronic sorrow, proposes its relevance to mothers of ADHD children, seeks to identify its presence in the maternal caregiver, shows its applicability to Adlerian psychotherapy and discusses these findings and the implications for future research.

Outline

IS CHRONIC SORROW PRESENT IN MATERNAL CAREGIVERS OF ATTENTION DEFICIT HYPERACTIVITY DISORDERED CHILDREN?

| | |
|--|----|
| Introduction | 3 |
| Background and Relevant Components | 5 |
| <i>Attention Deficit Hyperactivity Disorder</i> | 5 |
| <i>Impact of ADHD on Primary Caregiver</i> | 5 |
| <i>Depression in the Maternal Caregiver</i> | 6 |
| <i>Attributions Causing Stress in the Maternal Caregiver</i> | 7 |
| <i>Other Maternal Attributions</i> | 14 |
| <i>Treatment Approaches and Parents Training (PT)</i> | 16 |
| <i>Current Needs and Direction for the Maternal Caregiver of the ADHD Child</i> | 18 |
| <i>Chronic Sorrow</i> | 18 |
| <i>Differences Between Chronic Sorrow and Bereavement</i> | 19 |
| <i>Distinctions Between Chronic Sorrow and Depression</i> | 20 |
| <i>Models and Theories of Chronic Sorrow</i> | 21 |
| <i>Chronic Sorrow: Current Research</i> | 23 |
| <i>Chronic Sorrow and Adlerian Theory and Application</i> | 28 |
| <i>Background</i> | 29 |
| <i>Organ Inferiority and the Role of the Maternal Caregiver of an ADHD Child</i> | 29 |
| <i>Adlerian Theory: Application to Maternal Caregivers of ADHD Children</i> | 30 |
| <i>Adlerian Theory as it Relates to the Current Study</i> | 31 |
| Current Study | 32 |
| <i>Research Procedure and Process</i> | 32 |
| <i>Volunteer Selection and Mother/Child Prerequisites</i> | 32 |
| <i>Hypothesis and Prediction</i> | 34 |
| <i>Definition of Chronic Sorrow for Current Study</i> | 34 |
| <i>Attributions of Chronic Sorrow of Current Study</i> | 34 |
| <i>Methods and Designs</i> | 35 |
| <i>The Demographic Study</i> | 36 |
| <i>Survey Rationale</i> | 36 |
| <i>Interviews with Mothers of ADHD Children</i> | 37 |
| <i>Interview Rationale</i> | 37 |
| <i>The Maternal Value and Expectation Scale</i> | 40 |
| <i>Survey Rationale</i> | 40 |
| <i>Reaction and Impact</i> | 41 |
| Results | 42 |
| <i>Participant Awareness of Research Topic</i> | 42 |
| <i>Participant Demographics</i> | 42 |
| <i>Participant Characteristics</i> | 42 |
| <i>Characteristics of Biological Father</i> | 45 |
| <i>Characteristics of ADHD Child</i> | 46 |
| <i>Maternal Values and Expectations Survey</i> | 48 |

| | |
|---|--------|
| <i>Maternal Values and Expectations for the ADHD Child</i> | 48 |
| <i>Qualitative Interviews with Mothers</i> | 50 |
| <i>How Child was Diagnosed</i> | 50 |
| <i>Mother's Emotion Upon ADHD Diagnosis</i> | 50 |
| <i>Mother's Realization to the Extent of the Disorder</i> | 51 |
| <i>The First Time You Realized the Extent of the Disorder and the Emotions You Felt</i> | 51 |
| <i>Personal and Parental Adjustment After Realizing the Extent of the Disorder</i> | 52 |
| <i>What has Been Most Helpful in Dealing with ADHD</i> | 53 |
| <i>What has not Been Helpful in Dealing with ADHD</i> | 53 |
| <i>Emotions of Participant</i> | 54 |
| <i>Significant Findings</i> | 57 |
| <i>Differences Between Mothers Aware of Research Topic and Those Who Were Not</i> | 57 |
| <i>Mother's Employment Status</i> | 58 |
| <i>Education Level of the Child</i> | 58 |
| <i>Father of ADHD Child Diagnosed with ADHD</i> | 59 |
| <i>Mother's Diagnosis of Anxiety and Depression</i> | 59 |
| <i>Mother has ADHD</i> | 60 |
| <i>Impressions: Mother of ADHD Children Interview</i> | 61 |
| <i>Participant Interview Summary</i> | 63 |
| Implications for Future Research | 64 |
| The Impact of Chronic Sorrow and the Adlerian Therapist | 69 |
| Summary and Conclusions | 72 |
| APPENDIX | 73 |
| Appendix A | |
| <i>Informed Consent for Research</i> | 73 |
| Appendix B | |
| <i>The Demographic Survey</i> | 75 |
| Appendix C | |
| <i>Chronic Sorrow Questionnaire for Mothers of ADHD Children</i> | 78 |
| Appendix D | |
| <i>Maternal Expectations for the ADHD Child</i> | 81 |
| Appendix E | |
| <i>Human Subject/Interview Results: Mothers #1-25</i> | 83-164 |
| <i>Mother #1</i> | 83 |
| <i>Mother #2</i> | 87 |
| <i>Mother #3</i> | 90 |
| <i>Mother #4</i> | 94 |
| <i>Mother #5</i> | 97 |
| <i>Mother #6</i> | 100 |
| <i>Mother #7</i> | 103 |
| <i>Mother #8</i> | 107 |
| <i>Mother #9</i> | 110 |
| <i>Mother #10</i> | 113 |

| | |
|-------------------------|---------|
| <i>Mother #11</i> | 116 |
| <i>Mother #12</i> | 119 |
| <i>Mother #13</i> | 122 |
| <i>Mother #14</i> | 125 |
| <i>Mother #15</i> | 128 |
| <i>Mother #16</i> | 132 |
| <i>Mother #17</i> | 135 |
| <i>Mother #18</i> | 139 |
| <i>Mother #19</i> | 142 |
| <i>Mother #20</i> | 145 |
| <i>Mother #21</i> | 148 |
| <i>Mother #22</i> | 151 |
| <i>Mother #23</i> | 155 |
| <i>Mother #24</i> | 159 |
| <i>Mother #25</i> | 162 |
| Appendix F | |
| <i>Cronbach's alpha</i> | 165 |
| References | 166-174 |

Introduction

ADHD, a common childhood neurological behavioral disorder affects 4-8% of children in the worldwide population (Bull & Whelan, 2006) and 7.4- 9.9% of children in the United States; in studies using criteria from the DSM-IV (Barkley, P. 104, 2006). ADHD is chronic and persistent, frequently impacting academic, social and family interactions and outcomes. The adverse impact of the disorder goes beyond the individual's symptoms of hyperactivity, impulsivity and inattentiveness. ADHD children's disabilities often negatively impact their parental relationships (Barkley, P. 480, 2006). Especially, impacted are mothers as primary caretakers, who experience increased levels of stress, anxiety, marital discord and maternal depression (West, et al., 1999).

At times these same mothers appear to be experiencing symptoms of Chronic Sorrow: persistent, pervasive and episodic guilt, pain, and frustration over the loss of the normal child (Cameron, Snowdon & Orr, 1992; Eakes, 1995) and sadness that at times is mediated by pleasure and satisfaction in the child's achievements and interactions (Gravelle, 1997; Hewson, 1997; Isaksson, 2007). Seemingly unaware of the existence and meaning of chronic sorrow, medical and psychiatric professionals attempt to address and increase maternal caregiver efficacy and wellbeing in parenting these disordered children through various treatments, short and long term approaches, health care teams and Parent Training Programs.

However, the long-term value of many of these treatments and programs lacks empirical support. Consistencies of study and research parameters have been highly variable meaning that true utility and merit is uncertain (Barkley, 1998, pp. 282-283; Barkley, 2006, p. 457). These approaches seek to address various parent issues such as depression, stress, anxiety, improved child behavior, improved family and parent relations, etc. Multimodal treatment for parents and their ADHD children is often difficult to achieve, where schools are dealing with competing mandates, clinicians lack necessary time, and parents may not only lack knowledge regarding the disorder, they may also not have the necessary skill sets to assist the child. Additionally, they may not have financial resources or the wherewithal to coordinate professional care (Komaroff, 2008). Chronic Sorrow is introduced to better and more accurately describe and account

for the emotional status and continuous parental challenges and difficulties that the mother of an ADHD child encounters.

Chronic Sorrow is by no means a new term, but rather a type of identified grieving that has been identified and studied since Olshansky first developed the concept in the 1960's (Teel, 1991). Since then it has become relatively well known and is applied in the field of nursing. Since the early 1990's empirical statistical design and analysis have demonstrated the existence of Chronic Sorrow in various individuals who love and care for individuals with conditions that significantly and permanently impair daily functioning (Roos, 2002). Chronic Sorrow is described as a pervasive sadness that is permanent, periodic and progressive in nature.

The identification of Chronic Sorrow in maternal caregivers of ADHD children would prove beneficial on several levels. First, it would assist mothers in interpreting and understanding their own reactions to trigger events, stress and the child's challenges in attempting to successfully transition through life stages. Second, it would affirm the maternal caregiver's daily emotional state, thereby acknowledging the situation, its challenges and the fact that their reactions are not pathological in nature. Third, it would assist health care providers in understanding and offering more effective maternal treatment. Fourth, it would improve maternal caregiver's efficacy in caring for the ADHD child by preparing and increasing knowledge regarding maternal responses and ways to appropriately deal with them as they relate to self and the ADHD child.

The presence and recognition of Chronic Sorrow in the maternal caregiver as a natural response to her ADHD child's disorder would be particularly significant as it relates to the Adlerian perspective on Organ Inferiority. ADHD is a neurobiological disability impacting the inhibitory system, causing developmental delays and often various and numerous challenges in areas of Executive Functioning. Individuals with the disorder can be highly and negatively impacted by the disability. Adlerians could easily correlate the inherent influence this would have on the maternal parent. The presence of Chronic Sorrow in the mother of an ADHD child would challenge the mother's Teleology, Life Style and ability to successfully complete Life Tasks, thereby causing feelings of inferiority and discouragement.

Background and Relevant Components

Attention Deficit Hyperactivity Disorder

Attention Deficit Hyperactivity Disorder (ADHD) is one of the most prevalent childhood psychiatric disorders (Barkley, 2006). It is a common neurological behavioral disorder affecting 4-8% of the childhood population worldwide (Bull, 2006). The disorder can persist from childhood through adolescence and even into adulthood. ADHD is chronic and persistent in nature, developmentally disabling and often negatively impacting academic and social outcomes. Essential features of ADHD that clearly distinguish it from other psychiatric and developmental disorders involve disinhibition, poor self-regulation and poor Executive Functioning. Attention-Deficit/Hyperactivity Disorder has three sub-types. They include Combined Type, Predominantly Inattentive Type and Predominantly Hyperactive-Impulsive Type (DSM-IV-TR, 2000). Individuals with the disorder have difficulty with tasks such as homework, schoolwork, and unpleasant activities that require sustained attention. The disorder is also associated with organizational difficulties and the ability to filter out extraneous stimuli. ADHD can be a disabling impairment. A high percentage of other co-morbid conditions such as Depression, Anxiety, Obsessive Compulsive Disorder, Tourett's Syndrome, learning disabilities, drug and alcohol addictions, Oppositional Defiant Behavior and Conduct Disorder, may accompany the diagnosis (Barkley, 2006).

Impact of ADHD on the Primary Caregiver

The adverse impact of ADHD is not limited to the child. The impairments associated with the disorder extend far beyond its elemental diagnostic symptoms of impulsivity, inattention and over activity (Hinshaw, 2004). Parents of ADHD children often experience clinically significant stress. This stress is much greater than the level of stress found among families of normal controls (Breen & Barkley, 1988; Mash & Johnson, 1983). Research and clinical experience suggests that maternal stress is related to the increased caretaking demands and challenges of caring for ADHD children. Some of the common caretaking stressors include: more frequent displays of noncompliance, which are related to challenges in following parent requests and instructions, frequent interventions and challenges on the academic level, peer and sibling issues in childhood through adolescence. Additionally numerous other emotional and related conditions exist

such as low self-esteem, anxiety and depression (Anastopoulous, Shelton, DuPaul & Guevremont, 1993). Research indicates that in addition to normal parenting stress, parents of ADHD children also experience increased levels of depression, anxiety, marital discord and maternal depression (West, 1999; Roizen, 1996). Roizen reported that compared with parents of Down Syndrome children, ADHD parents were significantly more likely to experience alcoholism, drug abuse, nervous breakdowns, delinquency, depression, learning disabilities and ADHD (Roizen, Blondis, Irwin, Rubinoff, Kieffer, & Stein, 1996). When a child or adolescent is diagnosed with ADHD the primary caregiver, most often the mother, is also dramatically influenced by the disorder.

Depression in the Maternal Caregiver. A diagnosis of ADHD means that the already challenging maternal role takes on additional complex dimensions. Managing the disorder is a responsibility demanding time, attention, skill, patience, marital/family accord, and physical and emotional health beyond normal parenting. Previous studies suggest that mothers of ADHD disordered children experience higher levels of depression than do mothers of normal children (Chi & Hinshaw, 2002). In Baldwin's 1995 study, mothers endorsed symptoms of depression, marital discord and difficulties with adjustment (Baldwin, Brown & Milan, 1995). Data in a 1997 study conducted by Boyle suggested that maternal depressive symptoms are associated with emotional disorders in girls. In boys maternal depressive symptoms correlated with mothers rating errors suggesting maternal bias (Boyle & Pickle, 1997).

Mother's of ADHD children are negatively impacted by depression, stress, self-blame, social isolation and feelings of incompetent parenting (Baldwin, et al., 1995). In 1998, Cunningham's research suggested that maternal depression is linked to both child behavior problems and family dysfunction. Mothers described themselves as more depressed than their husbands described (Cunningham, Benness & Siegel, 1998). Research by Boyle concurred that mothers' ability to effectively protect, nurture and supervise their children may be undermined by the presence of depression (Boyle, et al., 1997). In 1999, West, et al. sought to identify levels of depression in mothers' with ADHD children. Using the Beck Depression Inventory (BDI), 80 mothers were self-tested. The study concluded that these mothers had elevated levels of depressive severity and that the severity was related to their children's ADHD sub-type and to the number of

children and ADHD children in the family (West, et al., 1999). McKee's 2004 study confirmed the link between maternal depression, dysfunctional parenting and child maladjustment (McKee, Harvey, Dandorth, Ulaszek & Friedman, 2004). In Kashdan's 2004 research he noted that depressed caregivers have a tendency to ruminate about their mistakes and parental ineffectiveness (Kashdan, Jacob, Pelham, Lang, Hoza, Blumenthal & Gnagy, 2004).

Attributions Causing Stress in the Maternal Caregiver. ADHD mothers parenting efficacy is not solely impacted by the presence of depression. Other negative attributes frequently associated with mothers of ADHD children include, stress, anxiety, social isolation and marital discord. Fischer suggests that that parenting stress (indicated by the Parenting Stress Index) is a general characteristic of parents who have children with psychopathology, especially those with externalizing behaviors, such as those found in ADHD children (Fischer, 1990). Yet, in later research Baldwin found that caregivers of ADHD children have an increased risk of stress, which is not related to children's psychopathology. Stress disrupts effective parenting and thereby increases development of behavioral disturbances in the ADHD children. This in turn causes disrupted parent-child interactions and relations causing further stress in caregivers. Results of his study demonstrate that caregivers in lower socio-economic situations routinely experience greater stress, which is the cause for an increase in the ADHD child's symptom display (Baldwin, 1995).

ADHD children's non-compliance due to an inability to carry out parental requests is often cited as a cause for stress. Additionally, these parents become stressed when they must frequently intervene and resolve various, medical, academic, sibling, and peer problems throughout childhood and adolescence. Parental stress is greater and clinically significant in those with ADHD children than in those with normal children (Anastopoulous, Guevremont, Shelton & DuPaul, 1992). Baker's 1994 study suggests that being mothers of ADHD children contributes significantly to parental stress as measured by the Child Domain Scale. According to this study, problem behavior is the primary cause of parents stress (Baker, 1994). Another important determinant of parental stresses are the demands placed on the parent of an adolescent with ADHD. Mash found maternal stress to increase in situations where child compliance is necessary, time

constraints are present and the child is distracted (Mash, 1990 b). Depressed mothers experience increased stress in their parenting role and regarding their physical and mental health (Breen & Barkley, 1988). McCleary found that parents experience increasing stress during the time when their teen transitions through the developmental tasks of autonomy and individualization. Additionally, the severity of the behavior disturbance is an important factor in this heightened level of stress (McCleary, 1999). Johnson's 2002 study suggests high levels of parenting hassles have been related to decreased life satisfaction, more negative mood and affect and increased maternal distress (Johnson & Reader, 2002).

Fischer's 1990 critical review of previous research examines stress related to parenting ADHD children and identified four directions of study. Past research has focused on stress assessment in parents, especially mothers. A study conducted by Gillberg, Carlstrom, and Rasmussen (1983) found that within a one-year period, mothers sought treatment for personal psychopathology more frequently than mothers of normal children. They also found a correlation in the severity of the disordered child's ADHD and those mothers that sought treatment. One noted trend was that mothers of older ADHD children sought assistance more often than mothers of younger disordered children.

Several of the studies that Fischer reviewed used the Parenting Stress Index (PSI) in their investigations (Lyod & Abidin, 1985). The PSI attempted to pinpoint parent stress contributors by examining maternal characteristics, child characteristics and situation/demographic life stressors. Through use of the PSI, Mash and Johnson's 1990 study, found that hyperactive children cause mothers much greater stress than mothers of normal children experience (Mash & Johnson, 1990). Additionally, this stress was due to the children's distractibility and amount of bother plus the mother's feelings of self-blame, social isolation, depression and ineffectual parenting skills. Mash and Johnson's study indicate that younger children caused greater levels of stress than older children, but Gillberg's 1983 study demonstrated that mothers of older ADHD children sought mental health assistance more often (Gillberg, 1983).

In another study, Mash and Johnson found that another stressor for mothers of ADHD children was sibling interactions and conflict (Mash & Johnson. 1983). They

found that sibling interaction with ADHD disordered children was characterized by four times the amount of negative behavior as normal children when involved in unsupervised play. This finding strongly correlated with reports of low levels of parent self-esteem and parenting stress.

In a 1988 study conducted by Breen and Barkley, they examine maternal stress in parenting hyperactive girls, boys and non-hyperactive children and normal girls. This study concluded that parenting girls and boys did not change the degree of maternal stress. These results disagreed with previous studies. Breen and Barkley's study found that reported maternal stresses were associated with maternal depression. Maternal stress was also associated with the severity of the children's psychopathology; especially aggression, conduct problems, and hyperactivity. They also found that these stresses were consistent between hyperactive girls and clinic referred girls who had externalizing psychopathology (Breen & Barkley, 1988).

According to Fischer, it is difficult to ascertain whether or not the child's behaviors come before or after parental stress and low self-esteem. In addition to stress, Fischer's review finds a high correlation between parental stress and parental psychopathology. Fischer finds marital discord to be a contributing factor for stress. However, what remains unclear is causality. Research by O'Leary, Emery and Porter (1981) argues that marital discord may lead to more behavioral disturbances in the hyperactive child.

Others have suggested that the behavior problemed child is the cause of marital dysfunction (Berfera & Barkley, 1985). An 8-year longitudinal study supports this finding (Barkley, Fischer, Deelbrock, & Smalish, 1990). Fischer concludes that the symptoms of impulsivity, hyperactivity and inattentiveness directly affect the quantity and quality of parent/child interaction. Studies conducted by Barkley over a decade indicate the child is less compliant to immediate commands, less able to sustain compliance and more oppositional. These parents are more negative and reprimanding, give more commands and directions and are less responsive to their child's social initiatives than parents of a normal child. Additionally, this pattern is evident in mother/child relations with the adolescent with ADHD and seems to be a continuous factor from childhood (Fischer, 1990). Finally, Fischer concludes that the hyperactive

child causes significantly greater caregiver stress, feelings of parent in-competency, and marital discord than in parents of the normal child.

A recent and somewhat incompatible finding in Psychogios' recent research with 192 mothers found that ADHD mothers parenting ADHD children create a more positive parenting context, called "similarity fit". This is interesting and surprising considering ADHD symptoms and characteristics that may differ between these children and their mothers (Psychogios, L., Daley, D., Thompson, M., & Sonuga-Barke, E. 2008).

The study conducted by Anastopoulos, et al. endeavored to determine what factors would cause caregiver stress. They explored whether psychosocial factors would affect the degree of stress on the caregiver. Other factors would include severity of the child's ADHD, various parental characteristics plus environment and family characteristics. They hypothesized that these many characteristics would impact the ADHD child who would respond in a collective manner. Available evidence suggested that various types of caretaker psychopathology and depression occurred more frequently among ADHD families than normal family populations. Most likely these factors contributed to and exacerbated paternal stress (Anastopoulos, et al. 1992).

Assessments were conducted on 104 clinic-referred children diagnosed with ADHD. Collected data applied to a hierarchical, multiple-regressions analyses used the PSI as its criterion. Their results demonstrated parent/child characteristics account for the majority of the variance in overall parenting stress. The severity of the children's ADHD is also a major factor in predicting parental stress. Other important predictors of parental stress include caretakers' psychopathology and the children's oppositional defiant behavior (Anastopoulos, et al. 1992).

In a study conducted by Barkley, Anastopoulos, Guevremont and Fletcher (1992), mothers and ADHD adolescents were examined to ascertain family beliefs, conflicts, maternal psychopathology and adolescent interactions. Eighty-three ADHD disordered adolescents and their mothers were divided into two groups. The first group, made up of ADHD (27) adolescents and the second group made up of ADHD and Oppositional Defiant Disordered (56) adolescents were compared to one another and to a control group (77) on the aforementioned characteristics as they related to neutral and conflict discussions. Mothers of both ADHD groups believed relations with their teens to be more

negative, had more issues involving conflict with each other, and contained greater intensity of anger during communications than did mothers in the control group. These mother/teen interactions and communication patterns were reported by mothers of ADHD adolescents regardless of the presence of co-morbidity. Barkley, et al. speculated that these conflicted relations may have been the result of the impulsive, inattentive and generally developmentally delayed self-regulatory behaviors that were found in ADHD that increased disagreement between mothers and ADHD adolescents (Barkley, et al. 1992).

The ADHD/ODB (Oppositional Defiant Behavior) groups demonstrated greater negative behaviors during neutral discussions and reported significantly higher levels of unreasonable and rigid beliefs about others. However, when Oppositional Defiant Behavior was present it was associated with greater risks for negative communication, angry interactions and conflicts and extreme and rigid beliefs about each of their relationships.

Teens in the ADHD group did not exhibit communication problems, family conflicts, anger intensity or unreasonable beliefs. Additionally, the ADHD only group did not display negative behavior or communication styles during neutral mother/teen interactions. The ADHD only teens when placed between the control group and the ADHD/ODB group did not vary in any noteworthy way from either group. It became apparent that although conflict existed in the ADHD only group: the presence of Oppositional Defiant Behavior added risk for angry family discourse, negative patterns of communication and unreasonable, extreme family beliefs about the ADHD child. Interestingly, all groups engage in negative communications with their mothers during conflict conversations. All mothers use put downs, commands, defending, and complaining statements during conflict discussions. Evidently, parents and teens with and without ADHD have similar types of behavior patterns and communication during conflict issues. There are important differences among the ADHD groups. For instance, the ADHD groups had a greater number of family issues, greater levels of anger and anger intensity. Also, the ADHD groups engage in negative communication even during neutral conversations. This is not the case with the control group. This negative style of interactions most likely contributes to further conflict on an ongoing basis. Additionally,

mothers and teens of both ADHD groups have more unreasonable and extreme beliefs about the other. Mothers feel their child's behaviors have malicious intent and will be ruinous to their overall outcome in life. The ADHD and ODB adolescents attribute more ruinous self-outcomes due to the actions of their parent. This same group holds more extreme attitudes about their autonomy from their parent. This group also demonstrates significantly greater numbers of conflict, higher levels of anger, and extreme cognitions about one another.

In this study results demonstrated that mothers of ADHD with ODB teens have greater levels personal psychological distress. Regression analysis suggested that these mothers internal anger might contribute to the level of parent/teen conflict. Mothers in the ADHD groups experienced marital discord, higher levels of obsessive-compulsive behaviors, greater levels of anxiety, higher levels of interpersonal hostility, and higher levels of depression. The results of this study illustrated the need for more complex and concentrated treatment for ADHD and ODB individuals and their families.

Barkley, et al. believe that because of the strong association of maternal psychological distress, marital discord, and perhaps parental antisocial behavior with parent-adolescent conflicts that treatment must address these parent difficulties in order to effectively treat the disordered child (Barkley, et al. 1992).

As noted by Fischer, most research examined stress in mothers of ADHD children (Fischer. 1992). He recommended that continued research include fathers. Baker recognized the importance of fathers in the family system and felt that including them in research could further expand understanding of the family system and dynamic and lead to improved treatment and intervention.

Baker's study examined 20 middle-upper middle class mostly Caucasian married couples and their male ADHD children. Baker utilized the The Child Behavior Checklist (Achenbach & Edelbrock, 1983) and the Parenting Stress Index (Abidin, 1986). Regression analysis determining what parent and child variables add to parental stress was conducted.

Findings indicated that child internalizing and externalizing behaviors accounted as a 45% predictor of parent stress. Additionally, sex of the parent, age of the ADHD child, number of children in the family, years married and socio-economic status were all

parental stress factors. Results demonstrated that mothers believed their ADHD children to be more stressful than did fathers. Fathers also reported feeling significantly less attached to their children than did mothers. Mothers and fathers both reported similar child behaviors. This finding conflicted with 1983 studies done by Mash and Johnston which determined that mothers found the behaviors of their ADHD children more challenging than did fathers. It also conflicted with Cunningham's 1988 study finding that although mothers reported more hyperactivity and learning problems among their ADHD children that there was little difference in reports of conduct problems between the two. Baker's study established that both mothers and fathers of ADHD children experience similar levels of parental stress. However, fathers felt less attachment toward their disordered child and problem behaviors among ADHD children are a predictor of parental stress.

Baldwin's 1995 research examined the caregivers of 30 ADHD children; ranging in age from 5 to 14 years (Baldwin, 1995). Not surprisingly, their findings indicated that 42%, the largest variance percentage, was due to family income and financial stress. Only 18% of the percentage variance for stress prediction was due to the child's ADHD symptom behavior. A limitation of this study was the examined population. Baldwin, et al. recruited children that were referred to an outpatient child psychiatric clinic at major inner city teaching hospital.

It is not surprising to find that the largest predictor of stress in this instance was income and financial stress as all of participating children were from lower socioeconomic status families (80% of the families making less than \$20,000 annually) (Baldwin, et al., 1995). This study is not consistent with previous findings that indicated a strong correlation between stress moderation, social support and problem solving skills (Dubow, Tisak, Causey, Hryshko & Reid. 1991). However, it is consistent with a 1992 study by Abidin, which finds a strong correlation between problem behaved children and a high risk for parental stress (Abidin, 1992) and Mash suggests that maternal stress is based on the important role of cognitions which may vary in different family structures (Mash, 1990 a) . Research demonstrates stress predictors for caregivers of ADHD children may appear conflictual. One finding appears to remain consistent from the reviewed research, that being the high rates of stress among maternal caregivers.

Other Maternal Attributions. Maternal attributions are the focus of much research in attempting to identify and understand how care giving inherently influences the child with ADHD. Attributions are examined as ways that parents are impacted as a result of their life long experience with their child (dependent variables). For instance parents are more likely to feel out of control and to blame their child for their behavior when the child demonstrates various behaviors such as noncompliance or oppositional defiant behavior (Bugental, Blunt, Johnston, New & Silvester, 1998). Within linear models the direction of attribution is blurred; making it difficult to determine whether parental attributions are responses to the child or whether parents bring a pre-determined set of attributes to their parenting style. Most often the confusion is settled by the notion of reciprocation between parent and child. In an effort to gain better and more accurate knowledge longitudinal studies are being used. Additionally a multi-dimensional approach assists in more accurate determination of findings. For instance, the use of stimulus-dependent measures, stimuli-elicitation and response formats are all ways to lend more credence to data.

In a 1997 study parents of ADHD children viewed opposition, inattentiveness and hyperactivity as stable and less controllable characteristics than did parents of non-problem children (Bugental, et al., 1997). Kashdan notes that clinically anxious mothers are significantly less warm and positive in their parenting behaviors (Kashdan, 2004). Yet, another complicating factor in effective parenting is the presence of ADHD symptoms in the mother. Chronis-Tuscano suggests the ADHD mother is compromised in her ability to effectively parent her child with ADHD (Chronis-Tuscano, Ragi, Clarke, Rooney, Diaz & Pian. 2008).

Bull & Whelan attempted to find common perceptions among parents of ADHD children. They identified and tested eight schemata: a sense that the children were different, expectations to overcome the abnormality, the importance of medication, the limitations of management techniques, the rejection of parental authority, the subordinate position of fathers, the high self-expectations of participants and the limitations of community support in an effort to find these parental attributes. Using taped individual

interviews, data was compiled and themes and units of meaning were assigned. Validity was established through parent validation.

Findings regarding views that their children are intrinsically different were in line with Barkley's 1998 findings that parents believed that ADHD is a unified biologic condition. Within the second schemata parents believed that stimulant medication as well as cognitive and behavioral treatments were necessary in decreasing the ADHD child's symptom-ology. This supported the notion that parents believe ADHD is a medical condition. In regards to managing the ADHD child the majority report using contingency management as their main approach; although they believed it to be difficult to implement and usually ineffective. They also held that emotional support and reasoning are ineffectual and that physical punishment is unacceptable. Participants were doubtful about using authority, because the ADHD child most often does not respond to an authoritative approach. Some participants were unwilling to consider the authoritative schemata secondary to issues of morality.

In regards to the schemata on fathering the ADHD child, all but two of the participant mothers felt themselves to be responsible for child management. They also felt their spouses should have been involved in child management but had demonstrated an inability to do so effectively. Mothers saw the father's management role as being subordinate to theirs. At one end of the spectrum some believed the fathers to be "absolutely useless", while at the other end was, "he does not do it the way I do it" and "he disciplined her along my guidelines". Generally, mothers objected to the fathers punitive rather than reasoning methods of management.

Schema supporting mothering the child with ADHD; revealed that mothers had expected a lot out of themselves and felt a large sense of responsibility for their child's well being. Many mothers reported a considerable amount of stress in relation to parenting an ADHD child. This stress negatively impacted their social, marital, physical and emotional health. Although, caretaking a disordered child all mothers were absolutely committed to their child and the parenting role.

Schema that supported parents with ADHD children illustrated the need for child management courses. Although it also showed a need for emotional support the participants had little hope that this could actually occur. Finally, the author suggested

that the parent mindsets in these eight schemata limit their options and choices when faced with issues within these areas (Bull & Whelan, 2006).

Treatment Approaches and Parent Training. One therapeutic approach that attempts to address the needs of both the caregiver(s) and the child is Parent Training. Parent Training has been utilized to educate, improve cognitions, and assist parents in learning new skills and methods for parenting the ADHD child. When these approaches are consistently and effectively carried out one of the additional benefits is thought to be an increase in parental efficacy; thereby promoting overall parent well-being. In a 1993 study Anastopoulos, et al. examined the effect of a nine-session Parent Training on the functioning of parents with ADHD children and on the control group of wait-listed parents who do not attend the treatment sessions (Anastopoulos, Shelton, DuPaul & Guevremont. 1993). Parent Training sessions include an overview of ADHD, discussion of the disorder, positive reinforcement techniques (utilizing positive and ignoring skills), a token reward system for child compliance, skills for consequencing inappropriate child behaviors and modification of parental skills for use in public domains.

Their findings conclude that parents do benefit from behavioral parent training immediately following treatment and after a two- month follow-up. Parents report reduced stress, increased parenting self-esteem and an overall change in the severity of their child's ADHD symptoms. The study does concede to a limitation in using Parent Training as a treatment, especially when used by it self. This research also emphasizes the need to examine what parent or child characteristics might predict and who might best be suited for this therapeutic approach. This is an important finding considering the broad spectrums of symptomatology in both the maternal caregiver and the ADHD child and perhaps other family members.

Empirical support for the efficacy of Parent Training of ADHD children is lacking. Still, Barkley (2006) is optimistic and advocates the importance of Parent Training as part of a multimodal approach (Barkley, 2006 b). In an earlier book, Barkley points out that marital discord may cause more severely defiant and aggressive behaviors in children and that these parents may be less successful in Parent Training. He also notes that these same parents may be depressed which could negatively impact Parent Training (Barkley, 1998, pp. 282-283). Additionally, other factors such as adult ADHD may

decrease effectiveness of training. Still, Barkley is optimistic and advocates the importance of Parent Training programs (Barkley, 2006, p. 457).

In her thesis and extensive review of parent training programs, Chandler finds a positive impact on the well-being of the parent. However, she documents Weinberg's 1991 study, which found that although parental knowledge was increased, that there was not evidence that child behavior had changed. She went on to say that Hechtman's 2004 study identified no change in parental behaviors during interactions with their children, in spite of an increase in knowledge (Chandler, 2004).

In 1981, Forehand and McMahon suggested that depression in the caregiver of children with behavior problems negatively impacted Parent Training as part of a multimodal approach (Barkley, 2006, p. 457). Parent Training programs (Fischer, 1990). Evidently, depression can heighten the parent's perception of child noncompliance, thereby increasing the number of parent commands and the amount of parent controlling behavior. Presumably, the existence of depression acted to maintain adverse child response, parent stress and treatment outcome (Fischer, 1990).

Chronis-Tuscano's study examines the impact of maternal ADHD symptoms on parenting the ADHD child. She notes that when a caregiver demonstrates ADHD symptoms that Parent Training rarely has an impact on either the child or the parent (Chronis-Tuscano, et al. 2008). Additionally, families with parents that have evident ADHD symptoms themselves may demonstrate less improvement as a result of Parent Training (Barkley, 2006). Psychogios' research supports the fact that Parent Training is far less effective when mothers have high levels of ADHD symptoms because they have difficulty implementing a structured and organized approach necessary for successful treatment (Psychogios, 2008). Additionally, the clinician may determine that Parent Training may not be an appropriate intervention immediately given various complicating factors. Parent Training has its limitations, but is generally an accepted and therapeutic intervention. However, relatively few advances have been made due to a lack of systematic approach in research. In fact, Parent Training and its integration and follow-through are highly dependent on the mother's ability to carry out specific skills and approaches particular to ADHD. Maternal ability is elemental to her efficacy as a parent. As previously mentioned, there are any number of reasons a mother's ability to parent is

disrupted. These factors continue to confound the effective treatment of the child with ADHD.

The above research supports Parent Training, especially when the mother has the ability to carry out the behaviors and skills necessary to impact the necessary change in the ADHD child. However, it is obvious that various circumstances, skill sets and attributions can disqualify some maternal caregivers. Mothers with ADHD and/or depression apparently are not successful with Parent Training. There is an obvious need to focus attention on maternal caregivers suffering from depression, stress and various symptomatology in order to promote their wellbeing thereby improving their ability to effectively parent their ADHD child.

Current Needs and Direction for the Maternal Caregiver of the ADHD Child.

Parenting and the primary caregiver are elemental factors to the overall outcome of the ADHD individual. It therefore becomes imperative to explore issues or alternatives that may positively or negatively impact the maternal caregiver. Research has found the mother to experience, isolation, marital discord, depression, anger, frustration and anxiety in addition to parental ineffectuality (West, et al., 1999). In her research review, Fischer speculated about whether there may exist, “some sources of stress that could be specific to parenting a child with ADHD” (Fischer, 1990). She emphasizes this notion by citing Ross and Ross’ 1982 study that describe the disorder as, “unique among the child behavior disorders in that the whole field is characterized to an unusual degree by uncertainty, contradiction, the unexpected and the bizarre” (Fischer, 1990).

It may appear inherently obvious that the mother of an ADHD child experiences periods of sadness. Surprisingly, no research has been located that addresses possible sadness that may be experienced by the ADHD mother.

Chronic Sorrow

Nursing and Social Work fields have examined issues of grief as it relates to families and individuals who experience disease, chronic and terminal illness. Over time they have developed working models that go beyond Kübler-Ross’ significant contributions to our understanding of death, dying and the stages of grief. In 1962, Simon Olshansky, a physical rehabilitation researcher suggested that chronic sorrow was

experienced by parents of mentally retarded children and should be viewed as a normal response to their situation rather than a neurotic response.

Olshansky described chronic sorrow as a sadness that reoccurs throughout the lifetime of the chronically disabled, disordered or ill child. He went on to say that the intensity may vary across situations and at different times and in different ways by the individuals and family members. Olshansky asserted that parents, “will always be burdened by the child’s unrelenting demands and unabated dependency”, and that the natural and understandable response will be Chronic Sorrow, that is a prolonged grief-like state (Davis & Schultz, 1998). This sadness was not continuous but was triggered at critical times in the child’s development. These triggers forced the parent to realize the disparity between their own child and the child they had hoped for. According to Olshansky’s original work, chronic sorrow was an expected pattern of response with recognizable characteristics. “A critical attribute of chronic sorrow has been the experience of episodic sadness that lasts the lifetime of the child or the parent, regardless of the physical proximity of the disabled child to the parents (Teel, 1991)”.

Olshansky believed that parenting disabled children daily brings up issues of guilt, shame, and anger. Joy for the child’s accomplishments, however modest, are intertwined with these issues and a sense of continual sorrow (Wittert & Burdette, 2008). Olshansky suggests that sorrow does not decrease in intensity over time and periodically re-occurs, especially during critical developmental stages (Teel, 1991). Yet, Hewson explains that individuals may experience different intensity of emotions from situation to situation, “...a changing phenomenon, with peaks of sorrow and stress and valleys of calm and happiness (Hewson, 1997)”. Depending on the situation the individual may return to denial, which instead of being abnormal is a helpful coping mechanism.

Differences Between Chronic Sorrow and Bereavement. Chronic sorrow is distinctly different from bereavement grief and mourning. Bereavement generally involves individuals who experience the death of a loved one. These individuals go through the stages that Kubler-Ross established. They include: shock, denial, anger, bargaining and finally acceptance. Individuals can move back and forth through the stages, re-experience various stages and/or skip stages. However, the last stage, acceptance, is finally achieved which allows the griever to move forward in their life.

Chronic sorrow, on the other hand, refers to individuals that are continually living the loss of a loved one. The loved one may have a disability, chronic illness, or injury. In chronic sorrow there is no end or cure to the loved one's plight. For this reason, although they may experience times of happiness with the impaired individual, they routinely experience a type of lasting grief that is triggered by specific and re-occurring events. Their episodic and continual sorrow is considered a normal emotional response to an on-going chronic situation.

Distinctions between Chronic Sorrow and Depression. Although depressive states do not lead to Chronic Sorrow, chronic sorrow can lead to clinical depression and more often to dysthymic disorder or what is observed as a depressive personality. Depressive states are characterized by, self-deprecating thinking and various life-long schemas of one's personal inability to make changes, in order to improve one's situation and feelings of hopelessness. In major depression there are also physical symptoms such as sleep disturbances, lack of energy, weight loss, etc.

Dysthymic disorder and Chronic Sorrow are more difficult to distinguish, especially during initial contact with the client. In chronic sorrow there is the characteristic and ongoing sense of a living loss. Additionally, the individual experiencing Chronic Sorrow is able to maintain high levels of functioning even during episodes when sadness and sorrow are escalated. Interestingly, the individual who is experiencing Chronic Sorrow is able to differentiate the line that separates depression and Chronic Sorrow. In such instances individuals often report and are aware of the shift that is being made from the state of Chronic Sorrow to Depression (Roos. p. 32, 2002).

Teel's 1993 study demonstrates separate factors for initial and current grief, recurrent sorrow and depression. These results suggest a difference between Depression and Chronic Sorrow. One element of Hobdell's research differentiates depression and chronic sorrow in parents of children with neural tube defects. Her findings indicate that of the 132 parents studied, only 14% (18) demonstrated adequate criteria for clinical Depression (Hobdell, 2004). In Isaksson's doctoral thesis she found that sixty-two percent of her 61 patients experience Chronic Sorrow and the group, in general is not Depressed, as only 4 of the participants experienced mild symptoms of Depression. She

suggests that this finding demonstrates that Chronic Sorrow is a distinct form of emotional stress (Isaksson, 2007).

Boyle discusses the limitations of previous research measurements in his study on maternal depressive symptoms. His concern is that Depression can be conceptualized as either diagnostic (qualitative phenomenon) or it can be a continuum of psychological distress (quantitative phenomenon) and these in turn can be acute, chronic or episodic. He cautions that failure to incorporate these elements of Depression lead to measurement heterogeneity and a misrepresentation of the research (Boyle, 1997). Consideration of the research and related concerns means that making distinctions between Chronic Sorrow and depression becomes important in the effective care and treatment of individuals who are in situations of continuous grief. The professional caregiver must be cautious to not label an individual as depressed because of their apparent depressed affect and inability to improve their situation. Medical/psychiatric professional must familiarize themselves with the many distinctions between depression and Chronic Sorrow.

Models and Theories of Chronic Sorrow. Cameron has described the initial response of parents to the diagnosis of a chronic or terminal illness as shock, disbelief, anger, denial and guilt (Cameron, Snowdon & Orr, 1992). These emotions have been described as responses to loss of the normal child. Over time discussions have focused on whether these emotions are a part of the grieving process that was time-bound ending with acceptance or whether they were instead a state of Chronic Sorrow as previously proposed. These fields of knowledge have initiated various working models that addressed the role of grief and Chronic Sorrow as it related to chronic and terminal illness, and disabilities.

Theorists and researchers in the fields of behavioral science, social work and nursing recognize that parents who face the challenges of raising a child with a disability or chronic disease or disorder tend to neither have a time-bound response or to attain acceptance. These disciplines have built on Olshansky's original concept of chronic sorrow to more appropriately describe what parents of disabled children experience. Hewson suggests that the word chronic is problematic because it indicates that grieving is unresolved and therefore pathologic. The word also co-notates that the grief is continuous and unrelenting. Research continually demonstrates that there are episodes of sorrow and

happiness (Hewson, 1997). Hewson proposes that the word episodic be utilized for this purpose instead of chronic. Additionally she suggests that stress is an underlying factor in grief responses. Toward that notion she proposes an Episodic Stress Response Model. In this model emotional, behavioral, physical and cognitive responses to loss of ability are seen as cyclic episodes of coping strategies to meet the appraised stress demands (Hewson, 1997). She writes:

The coping process involves continual shifting back and forth between confrontation or struggle and retreat or denial/avoidance and... the retreat phase is viewed as an important, natural means of preventing breakdown by allowing temporary withdrawal into safety (Hewson, 1997, p. 1133).

In 1997, Gravelle explored the daily experience of caring for a child during the chronic stage of a progressive illness. Eleven parents (five mothers and three couples) participated in the study. These individuals were initially interviewed using a set of open-ended trigger questions in order to initiate participant reflection on their care giving experience. Second interviews were conducted to clarify and validate information from the first interviews. Gravelle's findings revealed that the caregivers conceptualized their parenting experience as an unending process of "facing adversity".

Adversity has two distinct elements. The first element is defining the nature of the adversity and the second element is managing the adversity. Gravelle illustrates this adversity as a set of spirals that are linked horizontally. This linked spiral demonstrates that while the caregiver may learn from past experience and insight and problem solving skills that at the same time they are subject to a continuous burden of care, exhaustion and over time, a decreased ability to effectively cope. These parents continually redefine and manage their child's illness. Gravelle suggests that mothers are especially impacted by the challenges and burden of the caretaker role (Gravelle, 1997). Another model by suggests that parents may be unable to achieve acceptance as long as their child lives, but may achieve "restitution" or a point at which they adjust to having a child with a disability.

Researchers in the nursing field developed a social process theory called "transformed parenting" to describe the ongoing emotional process parents went through in raising a child with a disability. These parents dealt daily with the responsibility of

raising their child and simultaneously dealt with the emotional adjustment of having a child with a disability. In this model parents adjusted their parenting practices in order to be effective. “Transformation”, described by other researchers, identified the positive changes that parents of disabled children made in care-giving their child. Frequently, positive transformations occurred secondary to experiences of grief. These positive transformations included: personal growth (greater compassion and personal growth), relational growth (strong relationships in family and friends), and philosophical/spiritual growth (important aspects of life) (Wittert & Burdette, 2008).

The process of adaptation in another model is called “normalization”. This occurs after the initial diagnosis when families attempt to balance the demands of their disabled child with the daily responsibilities of family. Common attributes in “normalization” include: family acknowledgement of the illness and its potential to disruption to the family, family redefinition of what is normal, family focus on normal aspects of family life, family interaction with others based on their own view of their family as normal and then having expectations that others treat their family and child as normal. Some families with disabled children view normalization as an inappropriate or impossible goal. These families often view their child as burdensome or as being different, making the child’s disorder the central focus of family life (Witter & Burdette. 2008).

Hobdell’s study theorizes that there are four different components of Chronic Sorrow. They include: a. Cyclical-intermittent presence of sorrow interspersed with times of feeling fine, b. Intensity-depth or degree of sorrow response, c. Mood state- the variety of emotion/moods used to describe the sorrow, and d. Progression –the worsening or deepening of sorrow over time (Hobdell, 2004). Chronic Sorrow theory and related models all reflect the belief that maternal support and wellbeing are imperative in the treatment of a child with an illness or disability and must include identification and treatment of this area of concern.

Chronic Sorrow: Current Research. Byrne and Cunningham’s (1985) research identifies more progressive approaches to research Chronic Sorrow. The study characterizes various coping strategies by families, examination of service needs of families and research which discounts the notion of parental pathology and instead seeks to recognize attributions and vulnerabilities in the parent (Cunningham. 1985). Several

large studies conducted in England during the 1980's work from a parental need based assumption. These studies identify five overlapping but distinct areas of caretaking need. They include: a need for information, access to resources opportunity for social interaction, support and advice (Burden & Thomas, 1986).

In her 1991 study, Teel, proposes that the response to an ongoing loss is different from bereavement because the relationship deprivation is not due to physical death, but due to a "symbolic" loss of a loved one. For this reason she calls for an understanding reaction to ongoing loss that is extremely significant to the individual that is experiencing the grief. She also suggests a less restrictive, non-linear model for ongoing loss should act as a substitution for the linear bereavement model of loss (Teel. 1991).

A 1992 study conducted by Cameron, supports the notion that mothers of developmentally disabled children do not experience a time bound grief rather an unpredictable variety of emotions including, sadness, guilt, anger and frustration. Their research supports Chronic Sorrow as a maternal response to a child with a developmental disability (Cameron, 1992).

Atkinson's 1994 research compares grief among parents of schizophrenic children and parents who lost children through death or a chronic organic personality disorder from a head injury. Their findings reveal that parental loss of a child through schizophrenia results in a pattern of chronic grieving, while parental loss of a child due to death or head trauma creates a greater initial grief reaction. Additionally, parents of children with schizophrenia may experience fluctuations in their chronic grief pattern during exacerbation of child symptomatology. Thinking about, "How their child could have been if not for the disease," is higher during these periods of disease exacerbation (Atkinson, 1994). To date, their research on maternal response includes various afflictions such as mental retardation, cancers, muscular diseases and deaths, but it does not include the maternal response to the chronic developmental disorder ADHD.

The premise of a 1986 study by Burden is examination of parental assessment to their own responses towards caretaking a disabled child. Burden calls for a theoretical framework that can incorporate varied caretaker situations, response and emotion. He cites the need for information, support, advice and access to opportunities and resources for social adjustment. To this end, Burden proposes a theoretical framework that involves

parental adjustment to the child's life transitions. The first element in the framework is recognition of individual differences and reactions to stress; the second is the severity of the disability; and the third is community tolerance to the disability (Burden et al., 1986).

In 1995, Eakes investigated the occurrence of Chronic Sorrow in the parents of mentally ill children. Using the Burke/NCRC's Chronic Sorrow Questionnaire a qualitative research approach demonstrated that 8 of 10 parents interviewed evidenced Chronic Sorrow. These parents articulated an array of grief feelings that were related to being informed of their child's diagnosis and also gave accounts of numerous circumstances and experiences over time when these emotions were repeated. These emotions included shock, disbelief, grief, anger, frustration, sadness, confusion, and other feelings associated with grief. One parent of a Bi-Polar son described their experience with sorrow as:

It has been about 5 years, so grief is an emotion that abates but it does not die.

The grief has abated somewhat, but it certainly does not leave. When the phone rings at night, maybe he's in the hospital. It's still a fear and it will be for as long as I live. The grief isn't on the surface, but it's there (Eakes, 1995. p. 79)

The most common emotions experienced initially and over time were anger, frustration and confusion. Intensity of recurrent feelings varied from more intense than the time of diagnosis to less intense than those at the time of diagnosis. They also cited that triggers of these emotions were related to situations having to do with "unending care responsibilities". These included a lack relief, impact on family/ family life and members, and extreme demands of time, energy and finances. One parent explained, "You really don't have a life outside of your preoccupation with the illness. It is a preoccupation; 24 hours a day for most people. It is an awesome, awesome task. (Eakes, 1995)" Other triggers reported included: management crises (such recognition of the disparity between their situations and social norms) and confrontation with their child's failure to achieve developmental norms. Eakes' study also suggested that Chronic Sorrow was a normal response to a never-ending loss rather than a pathological state. It was widely accepted that grief and the grieving process was a necessary element in the survivor's healing process. Eakes suggested that the recurrent experience of grief might have a healing

quality. Therefore, the recognition of Chronic Sorrow validated the parent experience and assists the professional in providing appropriate and adequate support.

In order to explore maternal emotional responses and experiences in caring for a developmentally disabled child, Cameron, et al., utilized a retrospective approach. Eighty- six mothers participated by filling in questionnaires and sixty-three agreed to partaking in an interview. Children of these participant mothers ranged from 5 to 21 years (mean=12.9) and all were residing at home with their families. They had variety of disabilities including cerebral palsy, chromosomal abnormalities, Down's Syndrome and other conditions with unknown origins (there were no ADHD children in this study). Social status was mixed. All of the interviews were performed by the same individual, were taped, and consisted of a semi-structured round of open-ended questions. Questions focused on the thoughts, feelings and reactions experienced relative to learning about their child's diagnosis, and how these emotions and experiences changed over the life of the child.

Cameron's findings indicated that mothers identified feelings of shock, disbelief, sadness, guilt, anger, loss, isolation and frustration on a frequent and ongoing basis. Some of the mothers reported some memory loss in relation to the initial reaction to hearing of their child's diagnosis. Another finding was that mothers routinely reported feeling isolated and alone. Guilt was experienced on an on-going basis and mothers did not believe it would ever be resolved. Mothers also routinely reported going over their pregnancy and wondering what went wrong, if they should have noticed problems and whether they caused their child's disability. Mothers also described feelings of profound loss and sadness and grieving over the loss of a "normal" child. They routinely expressed the need for periods of distance in order to cope. However, they were unable to do so because of the demands of caring for their disabled child. Yet, another common emotion was the sadness and loss; they experience daily with constant reminders of their child's limitations, especially in relation to other normal same aged children.

Profound sadness and loss experiences occurred when transitioning milestones were not reached at the age appropriate times. As the child aged, mother's reported anger and frustration. Much of the anger and frustration was focused around community reaction, expectations and the lack of community understanding and available resources.

Although all the mothers had an acceptance of the diagnosis itself, acceptance of the implications of what that would mean for them, their child and their family were more difficult. Some mothers claimed to have reached acceptance while others claimed to sometimes experience periods of acceptance. Cameron's study clearly supported the notion of Chronic Sorrow characterized by reoccurring sadness and stress over a prolonged period of time (Cameron et al., 1992).

A study conducted with caretakers of children with Diabetes found that although Chronic Sorrow was not explicitly referred to, findings indicated an emotional state closely relating to the concept. The study encouraged professionals to be aware of and sensitive to the possibility and presence of Chronic Sorrow that were secondary to the loss that parents of chronically ill children faced (Lowes, 2000).

The objective of Bonner's 2005 research is to develop and implement methodology, which assists in caretaking the child with a chronic illness. The study utilizes the Experience of Child Illness (PECI) scale, to ascertain the level of paternal adjustment when caring for a child with chronic illness. Although behaviors and various coping strategies are well-studied, other variables such as believed parent effectiveness and thoughtful interpretation of internal response has not been identified in populations of caretakers of children with chronic illnesses. Their factor analysis reveals four factors which include: guilt, worry, emotional resources, unresolved sorrow and anger and long-term uncertainty. Unresolved sorrow and anger appears to be most related to Chronic Sorrow as described by Burke (Burke, et al. 1992). Parents scoring high in this scale feel a sense of ongoing loss due to their child's chronic illness. Specifically, parents scoring high in this scale experience notions of anger and grief regarding the loss of a healthy child and the perceived loss of happiness and a normal course for their lives. They suggest that parents scoring high in this area of unresolved sorrow and anger may show less adaptive parenting that may negatively impact their child. Reliability scales ranged from .72 to .89, acceptable reliability (Bonner, Hardy, Guill, McLaughlin, Schweitzer & Carter, 2005).

Chronic Sorrow theory, research and related models reflect the belief that maternal support and wellbeing are imperative in the treatment of a child with an illness or disability. Early studies superficially appear helpful in their intent to sensitize

healthcare providers to the plight and emotional situation of the parent caretaking a chronically ill or disabled child. These studies lend insight and legitimacy to issues of Chronic Sorrow. It also becomes evident that identification and therapeutic intervention may vary depending on the type of chronic condition and the care takers personal situation.

Whether or not mothers of ADHD children experience grief or Chronic Sorrow is unclear. However, it is clear that many experience varying degrees of stress, depression, marital discord, and social isolation. The research used to identify Chronic Sorrow and its symptoms among mothers of children with chronic disorders seems consistent with the research, symptoms, and experiences of mothers' caretaking ADHD children. If relationship between ADHD mothers and the Chronic Sorrow experience can be determined it could be an important aspect and consideration in affirmation of the mothers' situation thereby increasing her wellbeing and her ability to consistently and effectively parent the ADHD child. It could also have implications for the treatment, care and parenting skills that are necessary in raising an ADHD child. This, in turn, would have huge ramifications and impact on the child's life skills, level of functioning and ability to successfully achieve short and long-term transitions and outcomes.

Chronic Sorrow and Adlerian Theory and Application

Adlerian theory and practice is a central and integral element to this research, development and potential for a new approach in thinking and assisting mothers with ADHD children. ADHD is a unique disorder because its neuro-biological basis is strongly associated with psychiatric diagnosis and symptomatology. This correlation prompts the obvious necessity for further discussion of what Adler originally described as Organ Inferiority (Oberst & Stewart, 2003, pp. 3-5) and its impact on a mother's ability to effectively parent.

The maternal view of the ADHD disorder, the provision and development of her own and the child's teleology, her life style and her view of her accomplishment of basic life tasks are all inherent Adlerian elements that require careful consideration and examination. A basic understanding of Adler's background and theory are necessary in order to understand how it relates to the maternal caregiver of an ADHD child.

Background. Adler was sickly as a child. Adler's early recollections are of death and continual ill health. He developed rickets when he was four years old and relates watching his brother move around without effort while he was bedridden and unable to move or care for himself. At five he contracted pneumonia and a very poor prognosis. Adler's life movement was shaped by the impact of these experiences and he became steadfast in his decision to become a doctor. Later he faced academic challenges in mathematics. His professor suggested that he drop out of school and become a cobbler. Adler's father scoffed at his instructor and Adler, himself, determined to prove his teacher wrong, rose to the top of his class. This experience was instrumental in the development of Adler's theory about personality development and striving from a place of inferiority toward superiority. He later developed the term "organ deficiency," self-image and personality. In 1918, Adler developed child guidance clinics in Vienna. Here, he gained a wealth of information about personality development and dysfunction. He believed that "organ dysfunction" was an important element of personality problems. "Pampering", "neglect", and birth order were three other factors that he identified as integral to personality development.

Organ Inferiority and the Role of the Maternal Caregiver of an ADHD Child. As a medical practitioner, Alfred Adler, the founder of Individual Psychotherapy, had a strong foundation and belief in the importance of biological determinants. During his transition from medicine to psychology he utilized a medical model to negotiate the complex notion of the psyche. His initial research, *A Study of Organ Inferiority and Its Psychological Compensation* (1907), he offered a biological basis for psychological theory. Basically, Adler believed that the way an individual was influenced by a vulnerable organ was a reflection of their physical self. The weaker organ may or may not always have been involved in necessary daily functioning. Its weakness may not always have been recognized, however, consciously or unwittingly the individual may have believed the infirmity significantly prevented the fruition of his potential. How individuals approached and maneuvered their impairment may in large part have been determined by parenting and environment (Manaster & Corsini, 1995). In this way, mothers as primary care givers become significant elements in rearing the child with ADHD.

Adlerian Theory: Application to Maternal Caregivers of ADHD Children.

Teleology, an important Adlerian concept gives meaning to behavior. For Adlerian thinkers, all behavior is goal directed; although, individuals may not always be aware of their goals. For healthy individuals goals are aligned with social interest, and useful and positive actions. Unhealthy individuals are concerned with finding superiority, which is often approached, in useless strivings. For mothers with ADHD children goal directed behavior becomes muddled and confused. As parents, they determine and most often witness and acknowledge their children's appropriate behaviors, responses and performances. As parents with children having ADHD they acknowledge these age-appropriate markers but are confused in the execution, determination and suitability of these parenting goals when faced with their children's disability. Caretaking ADHD children often becomes frustrating and exasperating because there are no outward signs that something is physically wrong with the child's brain and central nervous system. These children look capable but are often unable to perform the basic age-appropriate tasks. Confounded and confused parents attempt to differentiate whether they should demand more or less of their children. Are they being too critical or not critical enough? Should they be assisting their children or leaving them alone to fail? What should they say and when should she say it? For this reason ADHD children may be parented in ways that Adler might deem "pampered" or "neglected". Frustration, guilt, shame and inadequacy are emotions that frequently accompany parenting these ADHD children. Because of the nature of the disorder mothers are in a heightened emotional state. Their goal directed behavior is thwarted by their children's performance and disability and may become unhealthy for both of them due to their inability to recognize, sort and manage behaviors associated with ADHD. Confusion and observation of their ADHD child's failures leads to the parents own feelings of inadequacy and inferiority, which negatively impact maternal and personal goal directed behavior.

A child's diagnosis of ADHD immediately or eventually challenges a mother's Life Style. The Adlerian life style is a compilation of the basic principles guiding an individual's process through life and the world. Mosak described the life style as a cognitive map which contains the individual's organized pattern of coping skills and unique set of apperceptions (how new ideas are perceived based on individual previous

experience) which determines his view of what life requires of him and how best he can achieve life's demands (Beames, 1992). It consists of methods of behavior, cognitions, private logic, and strategies that move the individual towards the life goals. As the mother of an ADHD disordered child, the mother's past notions of what she "is" and what the world "is" are radically altered. Her coping skills and apperceptions are not only challenged, but are often ineffectual. This often means that desired outcomes are less controllable and frequently unobtainable.

Adlerian life tasks consist of categories, which address various challenges of life. They include: work, love, social interest, sense of self, spirituality and existential efforts to develop life meaning (Oberst & Stewart, 2003, p. 202). One's success in meeting these tasks is measured through the degree of social interest that is exhibited by the individual. An individual who is unable to meet the challenges of the life tasks becomes discouraged which inevitably leads to a behavior disruption. For the mother with an ADHD child all of the Adlerian life tasks can be challenged regularly. The mother frequently finds herself socially isolated, experiencing marital discord, feeling ineffectual as a parent (which may be her primary or secondary occupation). Additionally, these failures may lead the primary care giver to question herself and her meaning of life. The ADHD mother may frequently experience overwhelming confusion and turmoil. Often the mother feels discouraged, angry, guilty and sad. Discouragement prevents her from fulfilling Life Tasks and unfulfilled Life Tasks can cause greater discouragement and more ineffectual parenting and questionable outcomes for her ADHD child.

Adlerian Theory as it Relates to the Current Study. Previous research has identified the negative impact of depression, stress, marital discord and isolation on the mother of an ADHD child. Although ADHD Parent Training and various other therapeutic interventions have been used in treatment and caring for the ADHD child and parents, there are obvious gaps in the research and application as it pertains to degrees of effectiveness.

Other fields of study, including nursing and social work have examined issues of Chronic Sorrow and sadness in mothers of children with various chronic illnesses, diseases and disorders. Adlerian theory would support the identification of what has

previously been recognized as “organ inferiority” in the ADHD individual and the potentially unmet needs of the mother of the ADHD child.

This study seeks to study and identify the presence or absence of feelings of chronic sadness or sorrow; which lead to maternal discouragement as it relates to Adlerian theory and parenting the ADHD child.

Current Study

Research Procedure and Process

Volunteer Selection and Mother/Child Prerequisites

Research was conducted with 25 mothers of ADHD children. Twenty-five mothers were randomly selected from a pool consisting of the author’s current clients. These mothers were contacted and solicited for the study. No mothers refused or were uninterested in participation. However, if unable to participate due to scheduling conflicts additional names were randomly selected from a pool of past clients and clients from one Mother’s of ADHD Teens Support Group. Mothers were asked to volunteer their time for the purpose of this study. In return for their time mothers were offered one free coaching/counseling session with the author. The final participant group was made up of 25 mothers who were either current or past clients or support group mothers.

All interviewed mothers discussed a child who had been diagnosed with ADHD through psychometric testing by a neuro-psychologist. In some cases additional diagnosis had been made through other sources such as family physicians, psychiatrists, school special education teams who did not necessarily or usually do psychometric testing including Executive Functioning Assessment. When mothers had more than one ADHD child, they were asked to choose the child they would like to discuss. The research included children of any age over 7, having any of the ADHD Types and any co morbid conditions.

The Consent to Research (see Appendix A) was explained and read by each participant. This document clarified the author’s qualifications, reasons for research, confidentiality, their ability to withdraw from the study at any time, potential emotional risk and consequences that could occur as a result of their participation in the study. It also encouraged them to stay for a debriefing session, and encouraged the use of a complimentary coaching/counseling session. Once the participant had a clear

understanding of the Consent it was signed. All portions of the mother's research was conducted and completed in the author's office at the participant's scheduled time.

Research Approach and Method

The mother was asked to fill out the first portion of the research, The Demographic Survey (see Appendix B). Before the Interview portion of the session began, the participant was informed that the author would be taking word for word notes on their responses. This method was preferred over taping to increase the mother's comfort level and spontaneity. The participant was informed regarding the interview procedure and told that no comments or additional information, other than to clarify questions, would take place during the interview portion of the research. The participant was offered time to ask questions prior to the initiation of the interview (see Appendix C). The last portion of the research involved the Maternal Expectations and Values Survey (see Appendix D). At the end of each interview, participants were allowed and encouraged to take additional time to debrief for questions, comments, and/or concerns in case any adverse emotional impact occurred secondary to their participation in the research.

After completion, the research was reviewed and spreadsheets were compiled with data from The Demographic Survey, The Mother's Values and Expectations Survey and from several portions of the Chronic Sorrow Interview. Additionally transcripts of the Mother's Interviews were translated into written form and pertinent information was highlighted in an effort to identify common themes and topics. All data was submitted for analysis by CDE Consulting (CDE Consulting, Coral Gables, Florida).

All participants were contacted for reading, review, correction, additions/deletions to their transcribed interview sessions. Twelve mothers reviewed their transcripts and agreed to the written information, several made small changes or additions. Thirteen mothers declined the opportunity to read the transcripts feeling the information was adequately communicated and transcribed. Two of these mothers declined saying that they did not wish to review what they felt was a difficult emotional experience, but felt comfortable with leaving the wording and report standing. Both of these mothers commented that they hoped the information would in some way be helpful to others.

Hypothesis and Predictions

The hypothesis underlying this research is that mothers of an ADHD child who are unaware of the presence or definition of Chronic Sorrow will demonstrate a greater presence of the symptoms when compared with their more educated counterparts.

Definition of Chronic Sorrow for Current Study

For the purpose of this study the working definition and critical attributes of Chronic Sorrow will include criteria as described by Eakes: numbers 1 through 4 (Eakes, 1995), and number 5 as identified by various research studies (Gravelle, 1997; Hewson, 1997; Isaksson, 2007):

1. A perception of sorrow or sadness resulting from a perceived loss continues over time in a situation that has no predictable end.
2. The loss and resulting sorrow or sadness is cyclic or recurrent.
3. The sorrow or sadness is triggered either internally or externally and brings to mind the person's losses, disappointments, or fear.
4. The sadness or sorrow is continual and can intensify even years after the initial sense of loss, disappointment, or fear.
5. A sense of happiness or joy, in spite of the loss, is experienced in relation to the disabled child and their accomplishments, however modest, are intertwined with a sense of recurrent sadness, sorrow and grief.

Attributions of Chronic Sorrow for Current Study

Attributions of Chronic Sorrow in Mothers of ADHD children are devised from various reports, research and books which have contributed to this study and which are especially salient to the studied population.

1. Undue stress
2. Undue anxiety
3. Continual or periodic sadness
4. Undue guilt
5. Undue disappointment
6. Hope for the child's future
7. Undue feelings of failure in one's ability to effectively parent
8. Undue depression (not diagnostic in nature)

9. Social isolation
10. Marital discord secondary to issues regarding the loss of the child
11. Intermittent happiness
12. Loss of the imagined child
13. Loss of one's parental ideals
14. Necessary change in one's perceptions, expectations and goals for self and child
15. Undue worry and fear for child and their future
16. Episodes of grief
17. Intermittent sadness and sorrow

Methods and Designs

The research is designed around the individual interviewing and form filling of adapted surveys given to maternal caregivers of ADHD children. Twenty-five mothers were recruited and interviewed for the purpose of the study. Mothers were contacted by phone and asked to participate in the study. If mothers agreed, appointments were set. Participants were told that a 2-hour allotment was offered, but that the time used by the participant could vary.

Prior to the study some of the mothers were familiar with the concept of Chronic Sorrow secondary to therapeutic, coaching or educational sessions. Because of this knowledge and because all mothers upon hearing about the concept of Chronic Sorrow immediately identified with its major characteristics; a control group was established with participant mothers who were unaware of the Chronic Sorrow concept. Eleven of the participants had pre-existing knowledge or were given information about Chronic Sorrow prior to their interview. The remaining participants fourteen had no knowledge of the concept and were told that the purpose of the research was to explore the experiences and emotions of mothers with ADHD children. Having almost half of the participants know the nature of the study and the definition of Chronic Sorrow offered the research a unique examination of an educated and expectant response versus an unknowing or unaware response. The uninformed response of the control mothers would hopefully clarify and support the Chronic Sorrow experience among maternal caregivers of ADHD children.

The Demographic Survey. The purpose of the Demographic Survey was to identify the characteristics and unique qualities of the surveyed population (see Appendix B). For instance, on the survey the age, grade level and gender of the ADHD child was identified. Additionally, co-morbid disorders were identified along with information about whether or not the child was medicated. Information was gathered regarding any diagnosis of the biological father and caretaking mother. Other information included mother's race, age, level of education, marital status, and the family's annual income, and whether and how much the mother worked outside of the home. Social isolation and social contribution were ascertained through designation of time commitment.

Survey Rationale. Much of the gathered information on the Demographic Survey was necessary to the research, such as the mother's age, race, socio-economic standing, level of education, and whether they worked inside and/or outside the home. However, several parts of the survey were developed to support and/or clarify various important aspects and characteristics of the ADHD mother's daily experience. Additionally, several areas of interest were examined as a result of previous research results and accepted beliefs about mothers of ADHD children. For instance, it was widely accepted that mothers of ADHD children frequently suffer from depression (Anastopoulos, et al., 1994; Biederman, Faraone, Keenan, et al., 1992; West, et al., 1999). However, Roos has reported that mothers suffering from chronic sorrow, although they may appear so, did not necessarily experience depression and/or dysthymia. Furthermore, she claimed that a therapist could make a clear delineation between the two. Additionally, Roos' stated that an individual with Chronic Sorrow would be able to self identify when they had crossed the line into a state of Depression (Roos, 2002. p. 32).

For this reason a series of 3 questions was asked regarding whether the mother suffered from Depression and/or anxiety, whether she thought she might be depressed and whether or not she was medicated for Depression. Later in the Chronic Sorrow Interview the mother was again asked this question to support past research or to ascertain how it might relate to Roos' belief that individuals with Chronic Sorrow did not suffer from Depression, but suffered from a despair that was unique to chronic sorrow.

Additionally, this survey examined issues surrounding anxiety (Biederman, et al., 1992), social isolation (Barkley, 2006) and marital discord (Anastopoulos, et al., 1993) as

it related to previous reports that mother's of ADHD children frequently report these experiences (West, et al., 1999; Anastopoulos, et al., 1993). These issues were revisited in the Chronic Sorrow Interview in an effort to support previous research and how it might relate to Chronic Sorrow. Another question in the Demographic Survey asked about the number of hours spent volunteering outside the home. This was placed on the survey in an effort to identify any tie between social isolation and social contribution as an aspect of Adlerian Theory regarding social consciousness and health.

Gathering information about whether or not the biological father had ADHD was done in order to see if its presence might somehow impact the mother's caretaking experience. For instance a positive response could have perhaps made maternal caretaking more challenging or create or contribute to the presence of marital discord (Anastopoulos, et al., 1993).

Information taken regarding the child discussed is necessary for understanding where and what stage the mother is experiencing in relation to her ADHD child. For example, a mother with a teen-age child having several co morbid conditions and not medicated, and not getting assistance at school will most likely be experiencing their child's daily life as more difficult and challenging. This perhaps can have some impact or determination on whether or not they experience Chronic Sorrow.

Interviews with Mothers of ADHD Children. The purpose of the Interview with Mothers of ADHD Children (see Appendix C) was to gain insight into the experience of mother's caretaking ADHD children and specifically to determine whether Chronic Sorrow was present among this population. The interview was specifically designed for mothers of ADHD children. In order to validate the presence of Chronic Sorrow in these maternal caregivers, questions on Burke/NCRCS Chronic Questionnaire (Caregiver Version) (Burke, 1992) were used as a guide, but revised to suit the population of study. In addition several questions were added to confirm information in other studies and to examine whether Chronic Sorrow was a part of various other characteristics that maternal caregivers frequently report.

Interview Question Rational. Interview questions were specifically designed to address the various key components characteristics, and attributes in Chronic Sorrow as they related to the emotions and experience in the maternal caretaking of an ADHD child.

The interview began with questions about how the mother's ADHD child was diagnosed and her recollection of that experience and the emotions surrounding the ADHD diagnoses. This question specifically related to information regarding how news of the diagnosis of an illness or disorder was perceived by a parent who was experiencing Chronic Sorrow.

In other identified cases of Chronic Sorrow the loved one has most often experienced initial emotions as shock, disbelief, denial. Due to the author's experience that caregivers often responded to the diagnosis with indifference due to a lack of knowledge and understanding regarding the diagnostic implications; this question was asked in order to follow Chronic Sorrow research, but was later followed with additional questions clarifying and comparing their first response to when they realized the true impact of the disorder.

If Chronic Sorrow was found in maternal caregivers of ADHD children, their initial response might have differed secondary to the disorder's symptoms and process. Another question asked was for the mother to discuss the type of personal adjustments she has made since the time of diagnosis. This question sought to identify how the maternal Life Style is altered in relation to the added demands of the disorder, how her Life Style was different from that of a mother without an ADHD child and how this related to the experience of other mothers who have experienced Chronic Sorrow.

Questions sought to identify what had been most and least helpful to them in relation to parenting the ADHD child. This question examined whether the mothers studied had similar experiences to other ADHD mothers and to mothers reporting Chronic Sorrow. Another question asked the mother to identify five emotions that she routinely experienced with her ADHD child. This question examined whether mothers of ADHD children would use adjectives similar to those that describe attributions of Chronic Sorrow as defined for the purpose of this study; such as: sadness, sorrow, intermittent happiness, guilt, loss, ineffectual parenting etc. Two questions asked the mother to describe instances when she had similar feeling to those described as adjectives. Yet, another question asked the mother to describe how she was feeling about her ADHD child during the interview. The intent of these questions was to further identify or support issues of Chronic Sorrow. Trigger events were also discussed in an

effort to identify similarities in response to other ADHD mother's trigger events, past research and Chronic Sorrow.

Mother's were also asked to compare the intensity of their current experiences with their child to experiences they had at the time of diagnosis or before they received support. This question was used in order to support or negate information that indicated that individuals experiencing Chronic Sorrow frequently report emotional response that is just as intense as initial responses to diagnosis.

Next mothers were asked to describe their emotional responses to their ADHD child in comparison to what they believed would be a response to a child without ADHD. Seventeen emotional responses were listed separately and the mother was asked to respond with either a "yes" or "no" answer. Emotional responses listed included emotional characteristics of Chronic Sorrow: continual or periodic sadness, guilt, disappointment, hope for the future, intermittent happiness, loss of the imagined child, loss of ideals, change in perceptions, grief, intermittent sadness and sorrow, depression that it was not diagnostic in nature, marital discord, isolation, feelings of isolation, anxiety, feelings of failure in parenting.

It should be noted that although, many of these characteristics were attributions found in research done on ADHD caretakers that only two of them, guilt and sadness, were categories that were found on the Beck Depression Inventory categories (Beck, 2006, P.189). ADHD mothers who reported experiencing marital discord, isolation, anxiety, feelings of failure in parenting, and even feelings of depression were not necessarily experiencing diagnosable depression of the various types. Instead, they were ADHD caretaker attributions that may contribute to a formal diagnosis of depression. This was an important distinction that will assist in the overall goal of identifying whether ADHD maternal caregivers experience Chronic Sorrow.

The final question was asked to gather final thoughts, concerns and advice. The rationale behind this question was simply to gather additional important information from the maternal perspective for use in therapeutic intervention.

Answers ascertained and revealed common themes among ADHD mothers regarding how they may or may not experience Chronic Sorrow. Additionally it revealed

if there were unique characteristics of mother response as it related to the topic of Chronic Sorrow.

The Maternal Values and Expectations Scale. The Maternal Values and Expectations Scale is a Likert scale survey that seeks to identify those life skills and transition areas that are of particular concern to the mothers of ADHD children. An ADHD individual's developmental delay and inability or difficulty in performing various tasks has a huge impact on life skills and the individual's ability to transition into different life stages. Mother's of these children could appropriately have high levels of concern for the specific areas covered within the survey. It is important to know these levels in order to better serve such caregivers, but it also serves as important as a comparison to their Chronic Sorrow Interviews results.

Survey Rational. The survey asks the maternal caregiver to identify her levels of concern using the choice of: 1. not at all, 2. sometimes, 3. often, or 4. most of the time. ADHD children have been identified as having difficulties and being challenged by peer relations (Barkley, 2006, pp. 198, 263, 355, 590-91) One of the questions asks: I am concerned that my child will have or has had difficulty with peer relations: 1-not at all, 2-sometimes, 3-often, 4-most of the time. The mother is asked to identify the answer that most closely matches her level of concern. Some other areas that are covered include academic success, attendance and graduation from high school and college, finding and keeping a job, completion of things that are important to these children, handling their life in the future, remembering to take medication independently, getting hurt or getting in trouble secondary to the disorder.

The Maternal Worry Scale for Children with Chronic Illness (DeVet & Ireys, 1998), a psychometric testing instrument was considered in designing The Maternal Values and Expectation Scale in order to focus on commonly held areas of concern for the mothers of ADHD children. This is exemplified by questions asked regarding issues common to ADHD children such as peer relationships, relationships with significant others, ability to perform academically, ability to live and work independently and successfully, abilities to consistently take daily medication and to keep themselves safe possibly refraining from impulsive behaviors.

Analysis of data gathered on this scale may offer some insight into areas that are of greater and lesser concern to mothers with ADHD children. There may be some comparison of result levels to issues of Chronic Sorrow and specifics of Demographic data.

Reaction and Impact. The interviews were all completed without interruption in my office and took from twenty-five minutes to an hour and a half each; depending on the mother, the detail and length of the information she disclosed. It was anticipated that all the participants would experience familiar emotions regarding their ADHD child, themselves and their experience as the mother of an ADHD child. However, the extent of impact was larger than anticipated. Many mothers cried during various portions of the interview. Some expressed that the interview was difficult because of the condensed view of their child and their parenting experience. Others felt reviewing their issues regarding their child, their disorder, the challenges and their maternal role could be sad and leave them feeling discouraged. Mothers were given the opportunity to debrief and to have additional sessions if they desired. Much time was spent with many mothers after the completion of the interview. Two mothers, however, refused to debrief or to return for additional session(s).

The author did not anticipate that the interviews and the process would impact mothers to any greater degree than what she experiences during regular therapeutic sessions or groups. However, the majority of the interviews were difficult because of the over-riding sadness and at times hopelessness that was contained within each.

The last question on the interview did appear to be helpful to many mothers, especially those that offered advice. These mothers seemed more encouraged when they offered advice that might be helpful to other primary caregivers of ADHD children. In many instances these mothers seemed better able to debrief very quickly. These same mothers had no need for additional or lengthened sessions to deal with concerns or adverse emotional response. Three of the twenty-five participants had lengthy debriefing sessions. None of the mothers opted to return for an additional session to further assist with emotion responses secondary to the interview.

Because the interviews caused emotional response greater than anticipated all mothers were contacted several weeks post interview to assess their status and to again

offer additional sessions. All mothers believed they were fine and that discomfort was temporary.

RESULTS

Participant Awareness of Research Topic

Prior to beginning the session participants were asked if they knew or were familiar with the topic of research for the study. Many of the participants had been familiarized with the Theory of Chronic Sorrow for the therapeutic intervention during parent counseling/coaching sessions. The remainder of the participants were unaware of the topic and theory of chronic sorrow. These participants were informed that the session was for the purpose of better understanding the emotions and experiences of mothers of ADHD children.

Table 1 Topic of Study Awareness

| CHARACTERISTIC/QUESTION | N | % |
|--|----------|----------|
| Participant knows the topic of research | | |
| Yes | 11 | 44 |
| No | 14 | 56 |

Participant Demographics

Participant Characteristics. Twenty-five female participants were interviewed for this study. The participants in this study were asked to report on demographic characteristics. These characteristics are displayed in Table 2. The mean age of the participants was 49.96, the median age was 50. The participant's age ranged from 40-61 and was almost evenly split over the ages of 40-49 (48%) and 50 and older (52%). Twenty-four participants (96%) reported that they were Caucasian, one participant was Pacific Islander (4%). Most of the participants were currently married (88%). The participants were highly educated, 88% reported having at least a baccalaureate degree.

Participants were asked to report on their work status and whether or not they volunteered in the community. Fifty-two percent reported that they worked full-time inside of their homes. In a separate question 60% were employed outside of their home and 32% worked full-time outside of the home. Sixty-eight percent of participants reported that they volunteered in the community, 24% reported that they volunteered at

least 8 hours per week. The reported family income for participants was quite high; 28% reported annual incomes of \$1000-200,000 and 36% reported a family income of >\$2000,000. Four participants chose to not report an income, 2 participants chose to not report their income, but indicated that finances were not an issue and one reported that finances were an issue.

Participants were asked to report on the ADHD status of their children. A slight majority of participants (13) reported that they had one child with ADHD, 10 participants reported that they had 2 children with ADHD and 2 participants had three children with ADHD.

The participants were asked about their own ADHD status. Five of the 25 participants (20%) reported that they believed that they had ADHD. Of these five participants, three participants had been diagnosed with ADHD and two were currently on ADHD medication.

Participants were asked if they had been diagnosed with anxiety or Depression. Interestingly, while 7 of 25 participants (28%) reported a diagnosis of anxiety or Depression, 84% of participants reported that they were currently taking anti-anxiety or anti-depressant medication.

Participants were asked about social support of friends and how often they spent time with friends. Fifty-six percent of participants reported that they spent time with friends at least once a week.

Table 2. Demographic Survey Results/Characteristics of Participants (N= 25)

| <u>CHARACTERISTIC/QUESTION</u> | <u>N</u> | <u>%</u> |
|--------------------------------------|----------|----------|
| Age at the time of the survey | | |
| 40-44 years old | 5 | 20 |
| 45-49 years old | 7 | 28 |
| 50-54 years old | 7 | 28 |
| 55-59 years old | 5 | 20 |
| 60 years or older | 1 | 4 |
| Race | | |
| Caucasian | 24 | 96 |
| Pacific Islander | 1 | 4 |
| Marital Status | | |

| | | |
|---|----|----|
| Married | 21 | 84 |
| Divorced | 3 | 12 |
| Remarried | 1 | 4 |
| Education Level | | |
| High School | 1 | 4 |
| College | 15 | 60 |
| Graduate School | 7 | 28 |
| Other higher education | 2 | 8 |
| Works in home | | |
| Full- time | 13 | 52 |
| Part-time | 11 | 44 |
| Neither | 1 | 4 |
| Works outside the home | | |
| Full-time | 8 | 32 |
| Part-time | 7 | 28 |
| Neither | 10 | 40 |
| Participates in Volunteer Services | | |
| Not at all | 8 | 32 |
| Less than 8 hours per week | 11 | 44 |
| 8 hours per week | 2 | 8 |
| Greater than 8 hours per week | 4 | 16 |
| Family Income Level | | |
| Less than \$50,000 | 1 | 4 |
| \$50,000-\$100,000 | 2 | 8 |
| \$100,000-\$200,000 | 7 | 28 |
| > \$200,000 | 9 | 36 |
| >\$500,000 | 2 | 8 |
| I would rather not say, but finances are an issue | 1 | 4 |
| I would rather not say, but finances are not an issue | 2 | 8 |
| No Answer | 1 | 4 |
| Number of Children with ADHD | | |
| One | 13 | 52 |
| Two | 10 | 40 |
| Three | 2 | 8 |
| Participant believes she has ADHD | | |
| Yes | 5 | 20 |
| No | 13 | 52 |
| Maybe | 7 | 28 |
| Participant diagnosed with ADHD | | |
| Yes | 3 | 12 |

| | | |
|--|----|----|
| No | 22 | 88 |
| Participant on ADHD medication | | |
| Yes | 2 | 8 |
| No | 23 | 92 |
| Participant diagnosed with anxiety or depression | | |
| Yes | 7 | 28 |
| No | 18 | 72 |
| Participant currently on medication for depression or anxiety | | |
| Yes | 3 | 12 |
| No | 21 | 84 |
| Yes, but did not specify type | 1 | 4 |
| Participant time spent with friends | | |
| Once a month | 11 | 44 |
| Once a week | 8 | 32 |
| More than once a week | 6 | 24 |

Characteristics of the Biological Father. Participants were asked to report on the biological father of their child with ADHD. As shown in Table 3, only 4 of 25 participants (16%) reported that the biological father had been diagnosed with ADHD, and the mothers reported that two fathers were on ADHD medication. However, when asked about their perception of whether the biological father has ADHD, 14 of 25 mothers (56%) indicated that was their belief. Therefore, the perception of the mothers was that the ADHD was under-diagnosed in both themselves and in the biological fathers of the ADHD children. However, when asked if participants believed they themselves had ADHD, only 20% believed that she did. Mother participants believed more often (56% versus 20%) that the biological father had ADHD.

Table 3. Demographic Survey Results cont./ Characteristics of biological father as reported by participant.

| CHARACTERISTIC/QUESTION | N | % |
|--|----------|----------|
| Biological father diagnosed with ADHD | | |
| Yes | 4 | 16 |
| No | 19 | 76 |
| No answer | 2 | 8 |
| Biological father on ADHD medication | | |
| Yes | 14 | 56 |

| | | |
|--|----|----|
| No | 7 | 28 |
| No answer | 4 | 16 |
| Participant believes biological father has ADHD | | |
| Yes | 14 | 56 |
| No | 7 | 28 |
| No answer | 4 | 16 |

Characteristics of the ADHD Child. Participants were asked a series of questions about their ADHD child. Their responses are shown in Table 4. Fourteen of 25 children (56%) were male, while 11 (44%) were female. The reported age of the ADHD child ranged from 7 to 33, with a mean age of 17.08 and a median age of 17. Three of 25 children (12%) were in grades five through eight, 76% of all children were in a public institution (elementary middle or high school, higher education institution).

The mothers were asked whether their ADHD child was getting or had received the help that they needed. Twenty-four percent of mothers reported that their child was not receiving necessary help.

While all mothers reported that their child had been diagnosed with ADHD through psychometric testing, 7 of 25 mothers (28%) reported their child had also been diagnosed by a physician. Five of 25 mothers (20%) reported that someone at their child's school had also diagnosed them with ADHD.

The participants reported several types of ADHD in their children. The largest proportion of mothers (52%) reported that their child had ADHD Predominantly Inattentive Type, followed by ADHD Combined Type (32%). Eight percent of mothers ($n=2$) reported that they were not sure which type of ADHD their child had. Twenty-one of 25 children (84%) were on ADHD medication.

The mothers reported that their ADHD child had been diagnosed with a variety of other conditions related to ADHD. The largest proportion of children had also been diagnosed with depression (56%), followed by anxiety (48%), and learning disabilities (28%); 52% of ADHD children were on medication for other diagnosed conditions, most often anxiety (44%) and depression (40%).

Table 4. Demographic Survey Results cont./Responses to questions regarding participant's ADHD child

| QUESTION | N | % |
|---|----------|----------|
| Gender of ADHD child? | | |
| Male | 14 | 56 |
| Female | 11 | 44 |
| Age of ADHD child? | | |
| 5-9 | 2 | 8 |
| 10-14 | 6 | 24 |
| 15-19 | 11 | 44 |
| Over 20 | 6 | 24 |
| Education level of ADHD child? | | |
| Elementary school grades 1- 5 | 1 | 4 |
| Middle school grades 6-8 | 2 | 8 |
| High school grades 9-12 | 9 | 36 |
| College or trade school | 8 | 32 |
| Other | 1 | 4 |
| No answer | 4 | 16 |
| Type of school? | | |
| Public | 19 | 76 |
| Private | 5 | 20 |
| No answer | 1 | 4 |
| Child with ADHD is getting or has received the help he or she needs? | | |
| Yes | 16 | 64 |
| No | 9 | 36 |
| Type of help ADHD child is getting? | | |
| IEP | 8 | 32 |
| 504 | 6 | 24 |
| Other | 4 | 16 |
| No help | 6 | 24 |
| No answer | 1 | 4 |
| Child diagnosed with ADHD? | | |
| Yes | 25 | 100 |
| No | 0 | 0 |
| Child diagnosed with ADHD through (multiple responses allowed) | | |
| Psychometric testing | 25 | 100 |
| Physician | 7 | 28 |
| School | 5 | 20 |
| Type of ADHD? | | |
| ADHD Combined Type | 8 | 32 |
| ADHD Predominantly Inattentive Type | 13 | 52 |
| ADHD Predominantly Hyperactive Impulsive Type | 2 | 8 |
| Not sure | 2 | 8 |
| Child on medication for ADHD? | | |
| Yes | 21 | 84 |
| No | 4 | 16 |
| Other diagnosed conditions related to ADHD (multiple responses allowed)? | | |
| Depression | 14 | 56 |
| Anxiety | 12 | 48 |
| Drug or alcohol abuse | 2 | 8 |
| Obsessive Compulsive Disorder | 1 | 4 |
| Bipolar Disorder | 1 | 4 |
| Oppositional Defiant Disorder | 6 | 24 |
| Learning Disabilities | 7 | 28 |
| Tourettes | 0 | 0 |
| ADHD child on medications for other diagnosed conditions? | | |
| Yes | 13 | 52 |
| No | 9 | 36 |
| No answer | 3 | 12 |

*Maternal Values and Expectations Survey**Maternal values and expectations for the ADHD child.*

The mothers were asked to respond to the Maternal Values and Expectations for the ADHD Child survey instrument. A reliability analysis was performed to determine the internal consistency for this instrument. Three participants were excluded from reliability analysis because they did not respond to all the instrument items. The reliability analysis determined that the instrument had an acceptable internal consistency, Cronbach's alpha= 0.73 (Appendix F).

As shown in Table 5, 44% of mothers reported that they were concerned "often" or "most of the time" that their ADHD child would have problems getting along with their peers. Thirty-six percent of mothers reported that they were concerned "often" or "most of the time" that their ADHD child would have relationship difficulty with a significant other.

Table 5 indicates that mothers also reported that they had concerns about their ADHD child and academic success. Fifty-six percent of mothers reported that they were concerned "often" or "most" of the time" that their ADHD child would have academic success. Twenty-four percent of mothers reported that they were concerned "often" or "most of the time" that their ADHD child would have difficulty graduating from high school. Twenty-eight percent of mothers reported that they were concerned "often" or "most of the time" that their ADHD child would be able to attend and/or graduate from college.

As shown in Table 5, mothers expressed other concerns about their ADHD child's future. Twenty-eight percent of mothers reported that they were concerned "often" or "most of the time" that their ADHD child would have difficulty with a job situation. Thirty-six percent of mothers reported that they were concerned "often" or "most of the time" that their ADHD child would have difficulty completing goals. Twenty-four percent of mothers reported that they were concerned "often" or "most of the time" that their ADHD child would have difficulty handling life in the future as an adult.

Table 5 depicts other concerns that the mothers expressed about their ADHD child. Forty percent of the participants reported the they were concerned "often" or "most

of the time” that their ADHD child would not take their medication. Twelve percent of mothers reported that they were concerned “often” or “most of the time” that their ADHD child would not learn independent living skills. Finally, 24% of mothers reported that they were concerned “often” or “most of the time” that their ADHD child would get in trouble or be hurt due to their ADHD.

Interestingly, mothers responded with highest percentages in an answer of *sometimes* in seven of the eleven questions. In two of the eleven questions equal percentage answers were *sometimes* and *often*. In only one question was the highest percentage answer *not at all*.

Table 5: Maternal Expectations and Values for the ADHD child

| QUESTION | N | % |
|---|----------|----------|
| I have (had) concerns that my child will have difficulty with peer relations | | |
| Most of the time | 6 | 24 |
| Often | 5 | 20 |
| Sometimes | 11 | 44 |
| Not at all | 3 | 12 |
| I have (had) concerns that my child will have difficulty finding and maintaining a relationship with a significant other | | |
| Most of the time | 5 | 20 |
| Often | 4 | 16 |
| Sometimes | 11 | 44 |
| Not at all | 5 | 20 |
| I have (had) concerns that my child will have difficulty being successful academically at school | | |
| Most of the time | 6 | 24 |
| Often | 8 | 32 |
| Sometimes | 10 | 40 |
| Not at all | 1 | 4 |
| I have (had) concerns that my child will have difficulty graduating from high school | | |
| Most of the time | 1 | 4 |
| Often | 5 | 20 |
| Sometimes | 7 | 28 |
| Not at all | 12 | 48 |
| I have (had) concerns that my child will be unable to either attend or graduate from college | | |
| Most of the time | 3 | 12 |
| Often | 12 | 48 |
| Sometimes | 12 | 48 |
| Not at all | 6 | 24 |
| I have (had) concerns that my child will have difficulty finding and/or keeping a job | | |
| Most of the time | 4 | 16 |
| Often | 3 | 12 |
| Sometimes | 12 | 48 |
| Not at all | 6 | 24 |
| I have (had) concerns that my child won't be able to do or complete things that he/she wants to | | |
| Most of the time | 2 | 8 |
| Often | 7 | 28 |
| Sometimes | 13 | 52 |
| Not at all | 3 | 12 |
| I have (had) concerns that my child won't be able to handle their life in the future when he or she is on their own | | |
| Most of the time | 3 | 12 |

| | | |
|--|----|----|
| Often | 3 | 12 |
| Sometimes | 15 | 60 |
| Not at all | 4 | 16 |
| I have (had) concerns that my child won't take or will forget to take their medications | | |
| Most of the time | 3 | 12 |
| Often | 7 | 28 |
| Sometimes | 7 | 28 |
| Not at all | 5 | 20 |
| I have (had) concerns that my child won't learn the skills necessary to live independently | | |
| Most of the time | 2 | 8 |
| Often | 1 | 4 |
| Sometimes | 8 | 32 |
| Not at all | 14 | 56 |
| I have (had) concerns that my child will get into trouble or get hurt because of their disorder | | |
| Most of the time | 1 | 4 |
| Often | 5 | 20 |
| Sometimes | 11 | 44 |
| Not at all | 8 | 32 |

Qualitative Interview with Mothers

How Child was Diagnosed. Although in the survey items, all mothers reported that their ADHD child had been diagnosed with ADHD through psychometric tests, when asked how they had learned that their child had ADHD there were various responses. Thirteen of the 25 mothers reported that they first learned of the ADHD diagnosis through testing, two mothers of 25 reported that it took multiple tests to diagnosis their child as ADHD. Seven mothers reported that their child's teacher suggested the diagnosis. Four of the 25 mothers reported that their child was first diagnosed in a clinical setting by a doctor or therapist. Three mothers reported that they suspected that their child had ADHD and one mother reported her child came to her and reported the child's suspicion that she had ADHD.

Mothers' Emotions Upon ADHD Diagnosis. The mothers were asked to recall their feelings when their child was diagnosed with ADHD. A considerable range of emotions were reported, some positive and some negative. The most commonly reported emotions were relief (40%), sadness (20%), not surprised (20%), denial/disbelief/shock (20%), disappointment (16%), guilt (12%), surprise (12%), and happiness (8%). Other

negative emotions that were recalled included: self-blame (“What did I do wrong”), worry, troubled, confusion, grief, anger, and resentment. Positive emotions that were recalled were clarity and focus.

Mother’s Realization of the Extent of the Disorder. The participants were asked if they realized the extent of the disorder when their child was diagnosed with ADHD. Ninety-six percent of the mothers reported that they did not realize the extent of the disorder. Four of 25 mothers reported that they believed that medication would be the answer, and 4 of 25 mothers reported that the disorder was much more pervasive than they realized. Twelve percent (3 of 25) of mothers reported that co-morbidity of ADHD with other diagnoses, especially Depression, had made the diagnosis of ADHD even more problematic. One mother reported that she believed that their child’s ADHD would react positively to medication like her other son with ADHD but has not. Another mother reported that her other children have suffered at the hands of the ADHD child, both by his behavior and by the excess attention that must be paid to the ADHD child. Another mother proclaimed that her child’s ADHD diagnosis was “200 times worse than we thought.”

The First Time you Realized the Extent of the Disorder and Emotions you Felt. The mothers gave a range of responses when asked to identify when they realized the extent of their child’s ADHD. Three of 25 mothers reported that they realized the extent of the diagnosis upon diagnosis or immediately thereafter; two additional mothers reported it was when their child was diagnosed with co-morbid disorders (i.e., Depression and anxiety). Two mothers reported that they realized the extent of the disorder prior to diagnosis; two mothers of 25 reported that it was when their child was in junior high

school (i.e., grades six through eight). The remaining mothers reported a variety of responses such as when her child: was in 5th grade, was in 11th grade, got older, started treatment with medication, displayed a complete lack of organization, could not complete tasks or follow directions, started counseling, and changed schools. One mother reported that they realized the extent of ADHD when she and her husband attended a lecture on the ADHD brain.

The mothers reported a number of emotions upon the realization of the extent of their child's ADHD. The most commonly reported emotions were: sadness/wrenching sadness (28%), anger (12%), guilt (12%), worry (12%), denial (8%), fear (8%), and hopelessness (8%). Other reported emotions were: "I thought I could cure it," concern, depression, desperation, devastation, empathy, exhaustion, failure, frustration, helplessness, inadequacy, overwhelmed, panic, relief, and shame.

Personal and Parental Adjustments After Realizing the Extent of Disorder. The mothers again reported a variety of responses to this interview question. The most common responses were: a change in parenting style and co-parenting with spouse including stricter schedules and consistent consequences for behavior (48%), working more closely with child's school (20%), lowering expectations or changing hopes and dreams for ADHD child (16%), realizing that the ADHD diagnosis is not a reflection on them (12%), distancing and/or detaching from others (12%), practicing empathy (8%), working with an ADHD coach (8%), having more patience and understanding (8%), and making daily adjustments (8%). Other responses included: focusing on the positive qualities of the ADHD child, changing everything, learning to not be disappointed, making daily adjustments, changing work schedule, getting therapy, home-schooling the

ADHD child, living with the ADHD as a chronic illness, and changed family relationships. Mothers also reported a number of emotions such as: anger, rage, powerlessness, fear, frustration, sadness, depression, guilt, inadequacy, and a feeling of increased accountability. One mother reported that she has not adjusted after realizing the extent of the disorder.

What has been Most Helpful in Dealing with ADHD? There was more consensus from the mothers in response to this question; however, most mothers gave multiple answers. Sixty-eight percent reported that getting an ADHD coach was helpful; getting informed and educated was cited by 36% of mothers; 34% reported that joining a support group, a 12-step program, or talking to others was helpful; and 28% reported that counseling for themselves or their child was helpful. Twenty percent of mothers reported that ADHD medications were helpful, 20% cited getting professional assistance such as enlisting the help of a doctor or taking parenting classes, while 16% reported working with the child's school was helpful. Twelve percent of mothers reported that getting rid of negative emotions such as guilt, shame, and a feeling of failure was an important step in dealing with the ADHD diagnosis. Eight percent of mothers reported that lowering expectations for their ADHD child was helpful and other mothers cited family dinners and listening to their ADHD child as useful tools in dealing with the ADHD.

What has not Been Helpful in Dealing with ADHD? Thirty-six percent of the mothers reported as unhelpful, people who: do not understand, compare the ADHD child to other children, and judge and give unsolicited opinions of the ADHD child. Thirty-two percent of participants reported that schools had not been helpful in dealing with their child's ADHD. Other unhelpful things that were reported were: thinking they can do it all

and not asking for help, “parenting coaching” with a professional who does not understand ADHD, setting unclear boundaries, authoritarian parenting style, their spouses, poor communication, others not recognizing the unique skills and talents of the ADHD child, not accepting the ADHD diagnosis, their daughter no longer attending her ADHD coaching, negative emotions (i.e., nagging, worrying, anger), media reports on ADHD medication, and alternative diets.

Emotions of Participants. During the interview the participants were asked to identify five emotions that they routinely experience as the primary caregiver of an ADHD child. Emotional responses of the mothers are depicted in Table 6. Emotions that were characteristic of chronic sorrow are noted. The most commonly reported emotions reported by the majority of the mothers were frustration (80%) and sadness (64%). Anger (36%), fear (32%), and joy (32%) were also common emotional responses reported by the mothers.

Table 7 illustrates that mothers with ADHD children had emotions consistent with chronic sorrow (e.g., sadness, sorrow, grief, disappointment, anxiety, and periodic pride), they also reported a set of additional complex negative emotions, which may relate or overlap with the concept of chronic sorrow (e.g., frustration, loss of support, guilt, self-blame, guilt, stress, and anger). Seventy-two percent of participants reported that their emotional responses were as intense as or more intense than when their child was initially diagnosed with ADHD as exemplified in Table 8.

Table 6: Emotional Responses as a Parent of an ADHD Child

| <u>QUESTION</u> | <u>N</u> | <u>%</u> |
|---|----------|----------|
| As the primary caregiver can you list or identify 5 emotions that you routinely experience? | | |
| Frustration | 20 | 80 |
| Sadness | 16 | 64 |
| Anger | 9 | 36 |
| Fear | 8 | 32 |
| Joy | 8 | 32 |
| Disappointment | 5 | 20 |
| Love | 5 | 20 |
| Pride | 5 | 20 |
| Worry | 4 | 16 |
| Anxiety | 3 | 12 |
| Extreme sadness/overwhelming sadness/ sorrow | 3 | 12 |
| Helplessness | 3 | 12 |
| Compassion | 2 | 8 |
| Concern | 2 | 8 |
| Exhaustion/Tired | 2 | 8 |
| Guilt | 2 | 8 |
| Hope | 2 | 8 |
| Humor | 2 | 8 |
| Ineffectiveness | 2 | 8 |
| Despondent/ "being down" | 2 | 8 |
| Uncertainty | 2 | 8 |
| Confusion | 1 | 4 |
| Defeat | 1 | 4 |
| Empathy | 1 | 4 |
| Encouragement | 1 | 4 |
| Enlightenment | 1 | 4 |
| Exasperation | 1 | 4 |
| Excitement | 1 | 4 |
| Failure as a parent | 1 | 4 |
| Gratitude (that things are not worse) | 1 | 4 |
| Heartbreak | 1 | 4 |
| Helplessness | 1 | 4 |
| Impatience | 1 | 4 |
| Irritation | 1 | 4 |
| Kindness towards his gentle spirit | 1 | 4 |
| Hopelessness | 1 | 4 |
| Need to give demonstrative love (to the child) | 1 | 4 |
| Overwhelmed | 1 | 4 |
| Panic | 1 | 4 |
| Patience | 1 | 4 |
| Unpredictability | 1 | 4 |
| Wonder | 1 | 4 |

Table 7. Responses from Table 6 that are Emotions/Characteristics Characteristic of Chronic Sorrow

| Emotion/Characteristic of Chronic Sorrow | N | % |
|---|----------|----------|
| Sadness | 16 | 64 |
| Fear | 8 | 32 |
| Joy | 8 | 32 |
| Disappointment | 5 | 20 |
| Pride | 5 | 20 |
| Worry | 4 | 16 |
| Anxiety | 3 | 12 |
| Extreme sadness/overwhelming sadness/sorrow | 3 | 13 |
| Guilt | 2 | 8 |
| Hope | 2 | 8 |
| Ineffectiveness | 2 | 8 |
| “Being down”/despondent | 2 | 8 |
| Uncertainty | 2 | 8 |
| Defeat | 1 | 4 |
| Failure as a parent | 1 | 4 |
| Heartbreak | 1 | 4 |
| Helpless | 1 | 4 |
| Hopelessness | 1 | 4 |
| Overwhelmed | 1 | 4 |

Table 8. Comparing Later Experiences to Original Feelings

| Comparisons | N | % |
|-------------------------|----------|----------|
| Usually more intense | 9 | 36 |
| Usually just as intense | 9 | 36 |
| Usually less intense | 7 | 28 |

The mothers of the ADHD children were also asked to compare their emotional responses to parenting an ADHD child with the normal emotional responses of a parent who had a child who did not have ADHD. As shown in Table 9, participants reported that compared to normal emotional responses of parents with children who do not have ADHD, they have greater emotions of: “intermittent happiness when spending time with their child” (100%), “undue worry and fear for my child and their future” (96%), intermittent sadness and sorrow” (96%), “continual or periodic sadness” (92%), “hope for their future” (92%), and a “necessary change in my perceptions, expectations, and goals for my ADHD child” (92%). With the exception of “hope for their future,” the most

endorsed items were characteristic of chronic sorrow.

Table 9. Characterizing Maternal Experience of Caring for an ADHD child

| <u>Comparisons</u> | <u>N</u> | <u>%</u> |
|---|----------|----------|
| In relation to what you view as normal emotional responses in parenting a child without ADHD: how would you characterize and/or compare your experience of caring for your ADHD child? | | |
| Intermittent happiness when spending time with your child | 25 | 100 |
| Undue worry and fear for my child and their future | 24 | 96 |
| Intermittent sadness and sorrow | 23 | 92 |
| Continual or periodic sadness | 23 | 92 |
| Hope for their future | 23 | 92 |
| Necessary change in my perceptions, expectations, and goals for my ADHD child. | 23 | 92 |
| Undue anxiety | 22 | 88 |
| Undue stress | 22 | 88 |
| Episodes of grief | 19 | 76 |
| Loss of my parental ideals | 18 | 72 |
| Undue disappointment | 17 | 68 |
| Undue feeling of failure in your ability to effectively parent | 17 | 68 |
| Loss of the child I imagined | 16 | 64 |
| Undue guilt | 15 | 60 |
| Marital discord | 14 | 56 |
| Undue depression | 14 | 56 |
| Social isolation | 11 | 44 |

Significant Findings

Differences Between Mothers Aware of Research Topic and Those Who Were Not.

A qualitative analysis was performed to analyze responses to the Chronic Sorrow Questionnaire. Recurring and divergent themes were noted and compared between those mothers who were aware of the research question (n=11) and those who did not (n=14).

Themes were analyzed and where appropriate statistical testing was employed to determine if a significantly different percentage of mothers in the two groups endorsed a particular theme. A summary of the analysis appears below.

The interviewer asked the mothers what adjustments had to be made both personally and as a parent subsequent to their child's diagnosis of ADHD and recognition of the extent of the disorder. The group of mothers who were not aware of the research question were significantly more likely to report that they had to change their parenting style (57%) than mothers who were aware the research question (9%), $t(23) = 2.48, p = .02$.

The interviewer asked the mothers what had been least helpful to them as a mother of an ADHD child. The group of mothers who were not aware of the research question were significantly more likely to report that teachers did not understand their child's disorder (50%) than mothers who were aware of the research question (9%), $t(23) = 2.18, p = .04$.

Mother's Employment Status. There was a significant relationship detected between whether the research topic was known by the mother and the mother's work status in the home, either full-time or part-time, $X^2(2) = 7.12, p = .03$. Participants who knew the research topic were significantly more likely to report working full-time inside of the home (82%) and participants who did not know the research topic were significantly more likely to report working part-time in the home (64%) than was expected.

Education Level of the Child. There was significant relationship detected between the education level of the child and mother reporting having undue worry and fear about

my ADHD child and his or her future, $X^2(4) = 11.98, p = .02$. Mothers with a child in middle school were more likely than expected to report that they did not have undue worry and fear about their ADHD child and his or her future, 50% reported they had undue worry and fear, 50% reported that they did not.

There was a significant relationship detected between the education level of the child and the ADHD child's gender, $X^2(4) = 9.61, p = .05$. Mothers were more likely than expected to report that their middle school (100%) and high school child with ADHD (87.5%) was a male.

Father of ADHD Child Diagnosed With ADHD. There was a significant relationship detected between whether the mother reported that she had hope for her ADHD child's future, $X^2 = 8.02, p = .02$. Mothers were more likely than expected (75%) to report hope for their ADHD child's future when the father also had ADHD.

There was a significant relationship detected between whether the father of the ADHD child also had ADHD and whether the mother reported that she had intermittent sadness and sorrow, $X^2(2) = 11.98, p < .01$. One hundred percent of mothers reported that they experienced intermittent sadness and sorrow and this was higher than expected, especially for those mothers who reported that their ADHD child's father did not ADHD.

Mother's Diagnosis of Anxiety or Depression. There was a significant relationship detected between whether the mother reported being diagnosed with anxiety or Depression and the mother's own diagnosis of ADHD, $X^2(1) = 8.77, p < .01$. One hundred percent of mothers who have not been diagnosed with anxiety or Depression also do not have ADHD and this is higher than was expected.

There was a significant relationship detected between whether the mother

reported being diagnosed with anxiety or Depression and whether the mother reported that their child was getting the help that they need, $X^2(1) = 5.30, p = .02$. Mothers who reported that they were diagnosed with anxiety or Depression were more likely to report that their child was not getting the help that he or she needed (71% versus 22%).

There was a significant relationship detected between whether the mother reported being diagnosed with anxiety or Depression and whether the mother reported that they believed their ADHD child would have difficulty finding and/or keeping a job, $X^2(3) = 9.29, p = .03$. Mothers who were not anxious or Depressed were more likely to report that they were sometimes concerned than was expected (61% versus 14%).

There was a significant relationship detected between whether the mother reported being diagnosed with anxiety or Depression and whether the mother reported that they have concerns about how their ADHD child will handle their life in the future, $X^2(3) = 12.10, p < .01$. Mothers who were not anxious or depressed were more likely to report that they sometimes were concerned (78% versus 14%).

There was a significant relationship detected between whether the mother reported being diagnosed with anxiety or Depression and whether the mother reported marital discord, $X^2(1) = 4.71, p = .03$. One hundred percent of mothers who reported anxiety or depression also reported marital discord compared to 50% of the mothers not diagnosed with anxiety or depression.

Mother has ADHD. There was a significant relationship detected between whether the mother reported having ADHD and the number of children the mothers reported that they had with ADHD, $X^2(4) = 12.13, p = .02$. Mothers who had ADHD were more likely to report having three children with ADHD (40%). This was not expected.

Impressions: Mother of ADHD Children Interviews

All the mothers participating in the research were familiar with their child's diagnosis and were experiencing the parenting of the ADHD child at various ages and developmental stages. All mothers were familiar with their child's diagnosis, its implications, and challenges. All mothers had participated in numerous hours of one on one parent education about ADHD, its specific impact on their child (as indicated on their child's psychometric testing results), skills necessary to assist their child, and in many cases the mothers participating had also been involved in a support group for mothers of ADHD children. Nonetheless, all mothers appeared emotional during the interviews. Many mothers cried, especially during questions 8 through 14 in the Mothers of ADHD Children Interview. These questions focused on personal experience emotions and characteristics of Chronic Sorrow. Many mothers waved away tears explaining it was what they experienced on an ongoing basis. Other obvious emotions included anger over their child's situation and sadness.

Almost all mothers were able to identify times of pride and joy in their child and their accomplishments and many used these instances as the focal point of questions 8 through 13 on the Mother's Interviews. Question 15 was left unasked until after the end of the Values and Expectations Survey in an effort to allow the participants to regroup and to examine positive suggestions that might be helpful to other mothers with ADHD children. The Mothers of ADHD Values and Expectations Survey seemed to underscore, for these participant mothers, their child's disability and their own realization of how that influenced their own expectations for them. In many cases this was a difficult and sad situation.

Question 15 became a timely and beneficial question for most mothers. Being able to contribute in some positive and broader scope seemed to assist mothers in bridging their emotions and self-reflection. In many cases this last portion of the interview, assisted in preparing mothers to exit the interview in a more healthy state. Other mothers remained emotional and sad at the end of the session and were offered extra time to debrief. Twelve mothers (48%) stayed when offered the additional debriefing time. Fifty-two percent (13 mothers) felt fine and left. Two of the 13 mothers left feeling angry and refusing to debrief or talk longer about their situation.

Return calls were made to all mothers approximately two weeks post interview asking about their emotional status and if they would like an additional debriefing session. Mothers who were reached during these calls stated that they were doing well and that they did not need follow up sessions. Six mothers stated that the research sessions had been helpful because it helped them articulate and clarify their situation and how they might move forward. In some instances phone messages were left asking mothers to call back with information on how they were doing post interview. All mothers who were left messages called back and refused additional time stating they were in a suitable state secondary to participation in the research. One mother returned the call and left a message that she was angry about the interview and she didn't like to think about how her child and herself were impacted by the disorder. She further stated that the experience was not positive for her. She refused additional time for debriefing.

It is worth noting that as the researcher and interviewer, these twenty-five sessions with mothers of ADHD children were exceptionally and unexpectedly sad. It was speculated that this might be due to the intense focus of the topic Chronic Sorrow.

Additionally, the clinical setting may have been made easier for this researcher because of the therapeutic setting and the possibility of offering information, education and skills that might improve situations for the ADHD individual and their family member(s).

During the actual participant sessions no information was rendered that might serve to improve the emotional status of the mothers. Inability to intervene during these sessions was frustrating and sad for the researcher, herself.

Participant Interview: Summary

Overall, the emotions reported in the interview with the mothers were consistent and more in-depth than the emotions reported in response to the survey item. It was clear that these interviews provide support for the supposition that the mothers of ADHD children in this sample report emotions that are consistent with the definition of chronic sorrow. These mothers reported a whole range of negative emotions, which was particularly striking because the majority (72%) of the mothers denied a diagnosis of anxiety or Depression and 84% were not on anti-anxiety and anti-depressant medications. While the mothers reported emotions consistent with Chronic Sorrow (e.g., sadness, sorrow, grief, disappointment, and periodic pride), they also reported a set of additional complex negative emotions, which have related or over-lapped with the concept of chronic sorrow (e.g., loss of support, guilt, self-blame, stress, anxiety, anger).

This sample of mothers is clearly struggling with all of the negative emotions that accompany a diagnosis of ADHD. In addition, some participants are struggling with guilt not only because they believe that their child inherited ADHD from them but also because they are not as supportive of their ADHD child as they would like to be. This is a heavy burden for these women to bear.

There are some positive signs that some of these women are successfully dealing with their child's ADHD. Several women reported positive emotions when thinking about their ADHD child and pride in their child's uniqueness and gifts. One participant, in particular, used very positive language when discussing her ADHD child.

Overall, participant interviews provide evidence for the existence of the concept of Chronic Sorrow and the unique characteristics that accompany it.

Implications for Future Research

The participant interviews clearly substantiate the presence of Chronic Sorrow in the maternal caregivers of ADHD children. Mothers scored highest percentages on attributes of Chronic Sorrow (Intermittent happiness with child: 100%; Undue worry and fear for child: 96%; Intermittent sadness and sorrow: 92%; Continual or periodic sadness and sorrow: 92%; Hope for child's future: 92%; Necessary change in perceptions, expectations and goals of child: 92%; Episodes of grief: 76%; Loss of child imagined: 64%, etc.) Interestingly, many characteristic attributes routinely assigned and recognized by ADHD research, scored lower in the presence of Chronic Sorrow (Marital discord: 56%; Undue depression: 56%; Social Isolation: 44%). Undue anxiety (88%) and stress (88%) both held high percentages and are characteristic attributes of maternal caregivers in Chronic Sorrow and ADHD research. It seems apparent that Chronic Sorrow is an overriding concern for mothers of ADHD children. Although, other attributes may be present in mothers of ADHD children, they may be of lesser concern when compared to the overriding presence of Chronic Sorrow. This is an important yet, unexplored area in the field of ADHD. Potentially it may have implications for a different type of therapeutic intervention when dealing with primary caregivers. Future research with

larger test groups should duplicate these findings and also compare and correlate various attributes of Chronic Sorrow and past ADHD research. Efforts to more accurately understand the maternal caregivers daily situation, how it impacts her parental efficacy, self esteem and overall well being are important elements in the delivery of care to her ADHD child.

An interesting finding in the Demographic Study revealed that 7 of 25 participants (28%) had been diagnosed with anxiety or Depression, but that only 12% of the test-group were currently taking anti-anxiety or anti-depression medication. These results may demonstrate that mothers are not aware of a diagnosis of either anxiety or Depression. In her book, Roos goes into lengthy discussion about the presence of anxiety or depression in those individuals who had Chronic Sorrow. Evidently, individuals can differentiate between sadness and depression. They are also able to identify when sorrow might cross over into Depression. Additionally, although Depression may be present in instances of Chronic Sorrow, Chronic Sorrow does not necessarily mean that Depression is present. Does this mean the participants in this study requested medications for attributes and symptoms of Chronic Sorrow and did the healthcare professionals recognize a different yet unrecognized type of sadness and anxiety? If it is possible to make the differentiation between the two; how will this be done and what will be the most effective treatment for individuals impacted by Chronic Sorrow? Future research should examine these questions in an effort to better serve this maternal population.

Barkley found that studies on the prevalence of ADHD in various socio-economic classes are not particularly consistent. Yet, the Socio-economic status of the family and the child's level of intelligence are correlated with outcomes as they relate to success in

academics, advanced education and eventual types of employment. Children from lower socio-economic status have slightly higher ADHD levels (Barkley, 2006, p. 263). Some studies did indicate the prevalence of ADHD among a lower socio-economic strata when hyperactive children had to be identified as such when two of three sources had to concur. Additionally, he cited Szatmari's 1992 study that identified higher rates of ADHD among the lower class families (Barkley, 1998, p. 84).

In the current study the reported family income was high with 76% reporting a family income of > \$200,000. The median family income of those reporting was greater than \$200,000. Yet, these participants obviously were subject to some of the same emotions and challenges of those with lower annual incomes. This seems to imply that in the presence of Chronic Sorrow socio-economic status may be irrelevant in relation to a mother's sadness and sorrow. Research addressing this possibility would need to examine degrees or levels of Chronic Sorrow attributions as they relate to annual income. Finding common ground in this area could be to some extent encouraging for mothers. It also might mean that a therapeutic approach might be identified that is more applicable and universal to Chronic Sorrow.

Fifty-two percent of the mother's reported that their children had Inattentive Type ADHD, while 32% had Combined Type, and 8% were unsure of the type of ADHD their child had. Since slightly over half of the children of the mother participants are of the Inattentive Type of ADHD it would be interesting to study the level of Chronic Sorrow that mothers of ADHD children have given their ADHD type. Correlation of attributions and levels of severity of Chronic Sorrow could be beneficial in treatment and care of the maternal caregiver. Additionally, in this population over half of the ADHD children had

been diagnosed with depression, followed by 48% with anxiety, and 28% with Learning Disabilities. What ramifications are there for the instance, degree and level of Chronic Sorrow in mother's whose children have ADHD with co-morbidity?

Chronic Sorrow research and books consistently describe the initial reaction of caregivers to a loved ones diagnosis. Most often these reactions are of shock, denial and anger (Cameron, et al., 1992). Yet in this study, the most commonly reported reaction during initial diagnosis was relief (40%). This may be understandable given that ADHD children, for the most part, appear to be "normal." Side by side a non-ADHD child and a child suffering the disorder look the same. It is during function and performance that the developmental delay and the faulty inhibitory response becomes evident. It is therefore understandable that initially a mother may find some relief in finding some reason for her child's difficulties. Many mothers actually feel that once the diagnosis had been made that they can correct the problem with medication or appropriate therapy. When they finally realize the true extent of the disorder, 96% are deeply and emotionally impacted by this recognition. Can this eventual recognition and deep emotional impact be compared with the initial response that Chronic Sorrow studies refer to? The implications of this finding may be that the attributions of Chronic Sorrow for specific disorders may vary slightly. Perhaps there exist different levels, types or time frames of occurrence of Chronic Sorrow that have not been investigated.

In reporting what was most helpful to them in dealing with their ADHD child 68% reported that having an ADHD coach was most beneficial. There may have been some limitation to this finding given that the interviewer and author of this study specializes in and coaches and counsels ADHD children and their families. Should

further research reveal similar findings it would be prudent to discover ways that more children and parents could find and afford ADHD coaches; which currently are not covered by insurance. The shortage and cost of ADHD coaches makes issues of socio-economic status important. Although in the current study it appeared that economics had little to do with presence of Chronic Sorrow.

Interestingly, the level of worry based on the results of the Maternal Expectations and Values for the ADHD Child is relatively low. Majority percentages are most often found in answers of *sometimes*. Only twice are equal percentages listed and those are found in answers of *often and sometimes*. In one question the highest percentage answer is listed as *not at all*. It appears that when mothers applied their situation to future potential concerns that they are *sometimes* but not *most of the time* expecting or having concerns about what could occur as their child transitions into different life stages. This is a pertinent finding considering the high levels of frustration, sadness, anger and fear that are documented in mother interviews. These responses and results might indicate that maternal caregivers are too busy dealing with current issues to consider the long term ramifications of their ADHD child's disorder

Consideration should be given to the possibility that mothers have not considered the future secondary to over involvement in their present situation. Consideration should also be given to the possibility that in spite of detailed and reinforced education regarding their child's ADHD, mothers do not understand the ramifications of the disability or deny what the future could hold for their ADHD child.

There are flaws inherent in this research. The sample size (25) is small meaning that it may not be a good representation of maternal caregivers with ADHD children and

common experience. The median family income is greater than \$200,000 and the average annual income was \$100,000. This is not an accurate representation of the greater population and may skew the results as they compare to middle and lower socio-economic groups. The surveys and interviews are specifically designed for mothers with ADHD children using ADHD and Chronic Sorrow research. This means that not all test measures align with other psycho-metrics used in past research. As a result duplication and comparison are purely speculative. Finally, the author and researcher of this study offers professional care as an ADHD counselor, coach and educator to the mothers used in the study. It is possible that although over half of the participants were unaware of the topic of study that they were inclined in some way to answer for the author's benefit. It might be that knowing mothers inadvertently answer in favor of Chronic Sorrow attributes given the nature of the questions and the relationship with the author. In spite of its limitations this study does give clear indication that Chronic Sorrow exists in participant maternal caregivers.

The Impact of Chronic Sorrow and the Adlerian Therapist

The present research documents the presence of Chronic Sorrow among participant mothers with ADHD children. ADHD is a neuro-biological disability impacting approximately 7.4 to 9.9 % of children in the US population. The disorder is chronic and persistent causing developmental delays, impairment in inhibitions, and often an impact on one's ability to carry out various Executive Functions. ADHD negatively affects academics, social and family relationships, interactions and outcomes. The mother of the ADHD child is inadvertently and deeply involved in the care and upbringing of her disabled child. Although the child appears physically normal, the mother is well aware of

her child's impairment (organ inferiority). The awareness of her child's imperfection has a huge impact on the maternal caregiver as a parent, a mother and an individual.

As discussed previously a mother with an ADHD child confronts, daily, her own Phenomenology, Teleology, Private Logic, Life Style and Life Tasks as they relate to her disabled child. Previous research has often described marital discord, social isolation, depression and stress as attributes of the primary caregiver of ADHD children. This research supports many of these characteristics but goes beyond by identifying Chronic Sorrow in these mothers. A chronic state of sadness, intermittent grieving and sorrow intermingled with episodes of happiness in their child's successes is easily seen as a place of discouragement and frustration in the care-giving mother.

The detrimental impact occurs in maternal caregivers when they attempt to come to terms with the obvious disparity between their disordered child and the child without ADHD. It is during these times of confusion that the maternal caregiver confronts her Phenology as it applies to a new perception and reality (her child's disorder) and the loss of the child she imagined. As her expectations of her child change so must her values and expectations for her parenting and her self as an individual in a new difficult and challenging role.

Application of the new found knowledge obtained through this research must be applied to Adlerian theory in order to assist the maternal caregiver. Individual Psychology can be utilized to encourage the mother of an ADHD child to improve her parental efficacy and her own sense of self.

Among the participant mothers, almost half of the group were knowledgeable about Chronic Sorrow. When these mothers were educated about Chronic Sorrow they all

identified with its attributions. They also expressed relief in knowing that they were not crazy or mentally ill and that their experience was something that actually existed and was documented through research and theory. It appears that being aware of the existence and likelihood of the presence of Chronic Sorrow among these individuals promotes a sense of relief. This allows mothers to experience their sadness as a normal part of childrearing. They are then allowed to incorporate rather than ignore, deny or hide their emotions about their children, their parenting and themselves. In this way they move out of a place of discouragement and inferiority into a place where they can feel more encouraged and better able to handle their situation, their children and all the far reaching implications of the diagnosis.

Additionally, specific intervention for these mothers can be further developed to more consistently move them toward positive goals for themselves and their children. Since Chronic Sorrow is a grieving experience that does not subside during the life of the child, mothers must be given tools, skills and education enabling them to deal with exacerbations and transitions that will occur throughout the child's life. It will also be important to identify whether or not the mother is actually experiencing diagnosable Depression and/or anxiety. Although all mothers in this study were on anti-depressants, some mothers in this study did have Depression; others felt depressed but did not believe that they actually had depression. Depression is different from Chronic Sorrow, and intervention must also be different in order to effectively treat the maternal caregiver. Unless, Chronic Sorrow is identified and integrated into therapeutic intervention sadness and sorrow will not be examined and the mother will be viewed as having pathological Depression.

Individual Psychology considers the person as a whole entity. An individual's personality is "fundamentally an organ of self-realization (Manaster & Corsini, 1995 p. 3)". As Adlerian therapists we must endeavor to encourage the individual towards holism in order that they may serve themselves in a way that is appropriate and acceptable to themselves, their loved ones and society. In recognizing and treating the mother of an ADHD child who is experiencing Chronic Sorrow according to Adlerian principles and theory the therapist can promote this noteworthy goal.

Summary and Conclusion

This research confirms the presence of Chronic Sorrow in maternal caregivers of ADHD children, both those aware and those unaware of Chronic Sorrow Theory. It discusses the implications and necessity for identification of Chronic Sorrow in the maternal caregiver in order to promote wellbeing and parental efficacy in caring for the ADHD disordered child. The paper also examines ways that Individual Psychology may incorporate these findings and encourages further integration of the Chronic Sorrow theory into the therapeutic approach.

APPENDIX

Appendix A

Informed Consent for Research

This form will introduce you to the structure specific to this research and inform you of your rights as a participant. It will also familiarize you with my qualifications and the reason for this analysis.

Deborah Borkon: Counselor/Coach/Registered Nurse Specializing in ADHD and Related Conditions. I am a Registered Nurse, A Certified Life Styles Coach and a Counselor having specialized training, interest and expertise in ADHD and related conditions. I graduated from St. Mary of Nazareth School of Nursing in Chicago, Illinois. I received my Bachelor's degree from Macalester College in St. Paul, Minnesota. I am currently completing my Masters Degree in Counseling at Adler Graduate School, Richfield, Minnesota in preparation for a license in Marriage and Family Counseling. As a participant you are assisting and contributing valuable information that will be included in my final thesis and research project.

The Study

The purpose of this study is to examine the experience, thoughts and emotions of mother's as primary caregivers of ADHD children. In an effort to accomplish this you have voluntarily agreed to participate in a Demographic Survey, a Questionnaire and a private interview. You may excuse yourself from completing this process at any time.

I will be conducting these three portions of the study. The study will take place in the privacy of my office (34 Water St., Suite B, Excelsior, MN. 55331). It is my intent to protect your privacy and the confidentiality of the information you give me. In order to do this your form and interview will be identified by number only. Additionally, the information will be shredded at the conclusion of this research.

As one of my clients and/or as a past participant in the Mom's of ADHD Children Support Group, you are already knowledgeable about ADHD, its related conditions, your child's, your family's and your own experience and response. Most likely the information questions and emotional response in this study will be familiar. It is unlikely, but possible that you will experience some new or unexpected emotional response. Should this occur and should you or myself deem it necessary; you will be offered opportunity for counseling in order to alleviate any negative impact from your participation in this project.

Addressing Your Concerns

As previously stated I am currently seeking my Masters Degree from Adler Graduate School. Inherent to this process and the process of my research is my continuous and rigorous supervision by qualified and licensed professionals in the fields of counseling and education. This means that my research has been approved and monitored. It also means final compiled data will be discussed with my professors and may be submitted for publication. Should you at any time become concerned with any

portion of this research please do not hesitate to contact Sue Pye Brokaw, Adler Graduate School, Richfield, Minnesota.

Signed Consent for Research

I, _____, am a voluntary participant in research being conducted by Deborah Borkon; for the partial fulfillment of her Masters Thesis. I understand that I may excuse myself from participation at any time during the study process. I further understand that my privacy and confidentiality will be protected as I will be assigned a number for identification. I further understand that all my information will be shredded when the research is completed. Furthermore, I have read, been given opportunity to ask questions and understand my role and the Informed Consent.

Signed, _____

Date, _____

Appendix B

Demographic Survey

Mother # _____

1. Your age _____
2. Your race _____

ADHD and you:

3. Do you think you are ADHD: ___ yes ___ no ___ maybe
4. Have you been diagnosed with ADHD: ___ yes ___ no
5. If yes, are you currently on ADHD medication: ___ yes ___ no ___ not applicable

DEPRESSION and or ANXIETY and you:

6. Have you been diagnosed recently or in the past for depression and/or anxiety: ___ yes ___ no
7. Are you currently on medication for depression and/or anxiety: ___ yes ___ no
8. If untreated, do you think you might have depression or/an anxiety disorder: ___ yes ___ no ___ not applicable

BIOLOGICAL FATHER and ADHD:

9. Has the biological father of your ADHD child been diagnosed with ADHD: ___ yes ___ no
10. Is he currently on ADHD medication: ___ yes ___ no
11. Do you think he is ADHD: ___ yes ___ no ___ not applicable

OTHER INFORMATION about you:

12. Are you currently: ___ married ___ divorced ___ separated ___ remarried
13. What is your highest level of education: ___ high school ___ college ___ graduate school ___ other _____
14. Are you:
 - A. Working in the home: ___ full time ___ part time

B. Working outside the home: full time part time neither

C. Participating in volunteer service: not at all

less than 8 hours per week

8 hours per week

greater than 8 hours per week

D. Spending time with friends: rarely

once a month

once a week

more than once a week

INCOME:

15. Which best describes your annual family income:

less than \$50,000

\$50,000 to \$100,000

\$100,000 to \$200,000

greater than \$200,000

greater than \$500,000

I rather not say, but finances are an issue

I rather not say, but finances are not an issue

ADHD AND YOUR CHILDREN:

16. How many of your children are ADHD: one two three other

ADDITIONAL INFORMATION ABOUT THE ADHD CHILD I WILL BE DISCUSSING IN THIS INTERVIEW:

17. My

A. male female child

B. is years old

C. and in or going into grade(K-8th) HS(9-12th) College(13-16th) other

18. Most recently my child with ADHD is/was in a public private school

19. My child with ADHD is getting/or has received the help they need ___yes___no

20. Through an ___IEP___504___other___nothing

21. Has your child been diagnosed with ADHD: ___yes___no

22. Was the diagnosis made through: A. psychometric testing ___yes___no

B. Physician ___yes___no

C. School ___yes___no

D. Other ___yes___no

23. What type of ADHD does your child have:

___ADHD Combined Type (Inattentive, Hyperactive and Impulsive)

___ADHD Predominantly Inattentive Type

___ADHD Predominantly Hyperactive-Impulsive Type

___I'm not sure

24. Is your ADHD child on medication for ADHD: ___yes___no

YOUR CHILD and RELATED CONDITIONS:

25. Has your ADHD child been diagnosed with other conditions related to ADHD?

___a. Depression ___b. Anxiety ___c. Drug or Alcohol Abuse

___d. Obsessive Compulsive Disorder (OCD) ___e. Bi-polar Disorder

___f. Oppositional Defiant Disorder(ODD) ___g. Conduct Disorder

___h. Tourette's Syndrome ___i. Learning Disabilities

26. Is your ADHD child medicated for any of these other related conditions: ___yes___no

Appendix C

Chronic Sorrow Questionnaire for Mothers with ADHD Children

Mother ___does___does not know the topic of this research

I would like to ask you some questions about some of the thoughts and feelings you have experienced since _____(name) was diagnosed with ADHD (condition). I am interested in learning your point of view so that health care providers can become more sensitive and helpful to people like yourself.

1. How did you first learn that _____(name) has ADHD?
2. Can you recall your feelings when you first learned about it? (may add: What went through your mind?)
3. When you learned the diagnosis did you realize the true extent of the disorder?
4. If not, when was the first time you realized the true extent and impact of your child's disorder and what were your feelings at that time? (may add: what went through your mind?)
5. What kind of adjustments have you personally and as a parent had to make since the time of diagnosis or since you realized the extent of the disorder?
6. As the mother of an ADHD child what has been most helpful to you in dealing with _____'s (child's name) ADHD?
7. In your position as the mother of an ADHD child, what has not been helpful?

8. As the primary caregiver could you list or identify 5 emotions that you routinely experience:
 - a.
 - b.
 - c.
 - d.
 - e.

9. Thinking back to that time when you fully felt the impact of your child's ADHD diagnosis, has there been a time since then when something happened and you had those same feelings of _____ (read the mother's 5 identified emotions in question #8) as you described above?

10. What feelings do you have right now when you think about _____'s ADHD?

11. Can you tell me about other specific times when you felt these same emotions as you just described?

12. Are there certain types of trigger events that tend to bring up these feelings repeatedly?

13. How would you compare these later experiences to the feelings you originally had?
 - a. Usually more intense___
 - b. Usually just as intense___
 - c. Usually less intense___

14. In relation to what you view as normal emotional responses in parenting a child without ADHD; how would you characterize and/or compare your experience of caring for your ADHD child?
 - a. Undue Stress:___yes___no
 - b. Undue Anxiety:___yes___no
 - c. Continual or periodic sadness:___yes___no
 - d. Undue Guilt:___yes___no
 - e. Undue Disappointment:___yes___no
 - f. Hope for his/her future:___yes___no

- g. Undue feeling of failure in your ability to effectively parent: ___yes___no
- h. Undue Depression (not diagnostic, but feeling continually down in relation to your ADHD child): ___yes___no
- i. Social Isolation: ___yes___no
- j. Marital Discord secondary to issues regarding your ADHD child: ___yes___no
- k. Intermittent happiness when spending time with your ADHD child: ___yes___no
- l. Loss of the child I imagined: ___yes___no
- m. Loss of my parental ideals: ___yes___no
- n. Necessary change in my perceptions, expectations, and goals for my ADHD child: ___yes___no
- o. Undue worry and fear for my child and their future: ___yes___no
- p. Episodes of grief: ___yes___no
- q. Intermittent sadness and sorrow: ___yes___no.

15. Are there any other comments, thoughts and/or advice that you would like to add regarding your experience as the primary caregiver to a child with ADHD that you think might benefit other mothers with ADHD children?

This interviewing questionnaire has been specifically designed for application to maternal caregivers of ADHD Children in order to identify the presence of Chronic Sorrow.

Appendix D

Maternal Expectations and Values for
the ADHD Child

DIRECTIONS: Please circle the numbered answer that best describes your level of concern in relation to the expectations and values you have for your ADHD child.

- 1. I have (had) concerns that _____ (child's name) will have difficulty with peer relations:**

1-not at all 2-sometimes 3-often 4-most of the time

- 2. I have (had) concerns that _____ (child's name) will have difficulty finding and maintaining a relationship with a significant other (ie., boyfriend or girlfriend):**

1-not at all 2-sometimes 3-often 4-most of the time

- 3. I have (had) concerns that _____ (child's name) will have difficulty being successful academically at school:**

1-not at all 2-sometimes 3-often 4-most of the time

- 4. I have (had) concerns that _____ (child's name) will have difficulty graduating from high school:**

1-not at all 2-sometimes 3-often 4-most of the time

- 5. I have (had) concerns that _____ (child's name) will be unable to either attend or graduate from college:**

1-not at all 2-sometimes 3-often 4-most of the time

- 6. I have (had) concerns that _____ (child's name) will have difficulty finding and/or keeping job:**

1-not at all 2-sometimes 3-often 4-most of the time

7. I have (had) concerns that _____(child's name) won't be able to do or complete things that he/she wants to:

1-not at all 2-sometimes 3-often 4-most of the time

8. I have (had) concerns that _____(child's name) won't be able to handle their life in the future when he or she is on her own:

1-not at all 2-sometimes 3-often 4-most of the time

9. I have (had) concerns that _____(child's name) won't take or will forget to take their medication:

1-not at all 2-sometimes 3-often 4-most of the time

10. I have (had) concerns that _____(child's name) won't learn the skills necessary to live independently:

1-not at all 2-sometimes 3-often 4-most of the time

11. I have (had) concerns that _____(child's name) will get into trouble or get hurt because of their disorder:

1-not at all 2-sometimes 3-often 4-most of the time

This Values and Expectations Survey was adapted from the Maternal Worry Scale and specifically designed for application to maternal caregivers of ADHD children.

Appendix E

Human Subject Research/ Interview Results Mothers #1- 25

#1 MOTHER talking about her ADHD child (C).

QUESTION #1. How did you first learn that C has ADHD?

ANSWER. By doing testing. I knew something was going on but thought that it was a Learning Disability. But this came out instead. I didn't understand ADHD at that time. I knew he was smart, but could not understand why he didn't do the schoolwork.

QUESTION #2. Can you recall your feelings when you first learned about it?

ANSWER. I didn't really think he had it. He was border-line (demonstrates with hands the levels). He wasn't hyperactive like everyone thinks ADHD is. I denied it... maybe not denial but something else was going on. It was interesting. I thought, "What do you do for that?" The first time he was diagnosed, I felt I was given a "label" for my child, but no tools to help.

QUESTION #3. When you learned diagnosis did you realize the true extent of the disorder?

ANSWER. Absolutely not.

QUESTION #4. If not, when was the first time you realized the true extent and impact of your child's disorder and what were your feelings at that time?

ANSWER. Probably when he got older. Really, he could do the homework, intellectually, but he was just not doing it! We tried medications but he had adverse reactions to them. It is really just so sad... he is so bright. He is an amazing kid... but can't put it together. So then, I researched. I thought I could solve or cure the problem... his ADHD. I wanted to do that without meds but the problems he was having became more pronounced in Middle School. I was actually relieved after the second testing with Dr. C. After those results I knew he had it.

All along I kept thinking that I could change this with me being more organized. In many ways, I found myself looking for a better "system", so he could pull himself together and stay on task. I drove myself to a point of exhaustion, always trying to be more organized and efficient. When my efforts failed, I became frustrated, which made him feel guilty. But I kept running into problems and thinking, "Why can't he remember?" I felt guilty and sad because I'm always nagging. Sad because I realized he would try to avoid me. So, it was like: I stay on top of him. I know he has homework. I check, but he wants to avoid me because it increases his stress. I get mad. He gets mad. I feel guilty. He feels guilty. I feel sad. He feels sad. I go back to the guilt, "There is something I should be doing. Let's try homework in another room, maybe that will work."

QUESTION #5. What kind of adjustments have you personally and as a parent had to make since the time of diagnosis or since you realized the extent of the disorder?

ANSWER. I've lowered my expectations. I have done a lot of soul searching... it is not a direct reflection on me. Now, if he gets a C-, I think, "Good, he's not failing!" I used to

think he was a reflection of me...A's, the Honor Roll, that kind of thing...not any more. I try to focus more on his wonderful qualities...humor, creativity, compassion and kindness. He is a wonderful person, even if his school grades don't always show it.

QUESTION #6. As the mother of an ADHD child what has been most helpful to you in dealing with A's. ADHD?

ANSWER. Information. A lot of symptoms are not typical. Talking to professionals and other parents of ADHD kids. It goes back to the guilt. I used to take it on as my own. I started to become more open to it. In a way, his diagnosis is a blessing because I can get him the help he needs. I don't make excuses for him.

QUESTION #7. In your position as the mother of an ADHD child, what has not been helpful?

ANSWER. Well, when I don't let go...thinking I can do it all. When I didn't ask the school for help. Not asking the school and the professionals in to lighten my load, that wasn't helpful for me emotionally or physically. It wasn't helpful for C, either. I had to try to turn my thinking around. Feeling guilty doesn't help. I have to keep reminding myself that it is not something that I did or did not do.

QUESTION #8. As the primary caregiver, could you list or identify 5 emotions that you routinely experience.

ANSWER.

- a. frustrated
- b. sad
- c. overwhelmed
- d. tired
- e. pride

QUESTION #9. Thinking back to that time when you fully felt the impact of your child's ADHD diagnosis, has there been a time since then when something happened and you had those same feelings of being frustrated, sad, overwhelmed, tired and/or pride as you described above?

ANSWER. Yes. I got everything in place, meds, testing a great team of professionals. He believed he could pull it through. I believed he could do it for the 7th grade. Then I realized. I felt beaten down when he couldn't make it work. I thought, "Nothing helps." Actually, it really does help, but it just goes back to those changed expectations. But, yes, it felt hopeless. I was frustrated and anxious.

QUESTION #10. What feelings do you have right now when you think about C's ADHD?

ANSWER. That's a tough question. Its so general I wish I could make it go away. I think about how stupid he feels. I wish he could have a moment when he said, "This is my disability", and use it as an inspiration. This has to come from him. But my thing is that I want to make it right for him.

QUESTION#11. Can you tell me about other times when you felt this way?

ANSWER. Just all the time when something with the ADHD comes up. Maybe it's a mom thing or just a female thing...mom wants to solve all of it, all of the time.

QUESTION #12. Are there certain types of trigger events that tend to bring up these feelings repeatedly?

ANSWER. Report cards, conferences, Ed Line (C's school internet on line continuous grade location), missing assignments...thinking, "If you just get caught up", waiting for him to get this realization. When he is being dishonest or sneaky...I know he is disappointed in himself. I know it's his coping mechanism...but, I carry such a burden for him. I often just don't confront his difficulty, I just get frustrated and tired.

QUESTION #13. How would you compare these later experiences to the feelings you originally had?

ANSWER. a. usually more intense. Because I didn't understand what I would be dealing with...but, maybe for C it's less intense because now I have changed my thinking and expectations. I've lowered them. It used to be, "Why did you do this? or Why didn't you do that?"...today, those are the least of my worries....now I am focused on the impulsive or inappropriate choices and the future.

QUESTION #14. In relation to what you view as normal emotional responses in parenting a child without ADHD; how would you characterize and/or compare your experience of caring for your ADHD child?

ANSWERS.

- a. Undue stress: yes
- b. Undue anxiety: yes
- c. Continual or periodic sadness: yes
- d. Undue guilt: yes
- e. Undue disappointment: probably, yes
- f. Hope for his/her future: yes
- g. Undue feeling of failure in your ability to effectively parent: yes, sometimes
- h. Undue depression (not diagnosed): no
- i. Social isolation: yes
- j. Marital discord secondary to issues regarding ADHD child: yes
- k. Intermittent happiness when spending time with your ADHD child: yes
- l. Loss of the child I imagined: yes
- m. Loss of my parental ideals: yes
- n. Necessary change in my perceptions, expectations and goals for my ADHD child: yes
- o. Undue worry and fear for my child and their future: yes
- p. Episodes of grief: yes
- q. Intermittent sadness and sorrow: yes

Actually, this has been good for me. It's made me a better person. I hate that. I wish it could be left for someone else to be a better person, but you have to work with what you have. I remember thinking in our support group...and this was the turning point for me, "You mean he's always going to have this?" This is when I began to actually cope with it in a different way.

So, first the realization, then some level of acceptance-the meds were huge, then get more help, then cope- changed my mindset...and there is a lot of hope within that.

QUESTION #15. Are there any other comments, thoughts and/or advice that you would like to add regarding your experience as the primary caregiver to a child with ADHD that you think might benefit other mothers with ADHD children?

ANSWER. In Mom's Group I thought I could make it go away. But that was the lowest point when I realized I couldn't. Then I've been better since I gave it up. I fluctuate though, I go back and forth on these feelings, "I hate ADHD. There's always an issue. I worry."

#2 MOTHER talking about her ADHD child (C).

QUESTION #1. How did you first learn that C has ADHD?

ANSWER. I think I was aware of the issues in pre-school. C couldn't sit in a circle with other kids; he wasn't social with the other kids in his class. He had no interest in what they were doing in class. That was a red flag. In first grade there were a lot of symptoms: impulsivity, anxiety, he couldn't complete a full day in school. In the spring of his first grade year we had some testing done and the results were inconclusive because C couldn't sit still to complete the test. When we had him tested for a second time that year, the results were that he had ADHD.

QUESTION #2. Can you recall your feelings when you first learned about the diagnosis?

ANSWER. Exactly! My first thought was, "What did I do wrong?" I also remember feeling, "Why us? Why him? Why do we have to deal with this? Why do we have to go through this?"

QUESTION #3. When you learned the diagnosis did you realize the true extent of the disorder?

ANSWER. No. I thought the medication would wrap it up and tie it with a neat bow and put it away. I also hoped it would get better with maturity and age. I kept questioning: could this just be immaturity, or he's just a boy, could this just be a phase?

QUESTION #4. If not, when was the first time you realized the true extent and impact of your child's disorder and what were your feelings at that time?

ANSWER. Before C's diagnosis, when he started at Blake...when C ran out of the building. I felt shame, guilt. I was desperate. How can I help him? There was just a lot of guilt and shame. I thought, "Maybe I put him in this position...maybe I did something wrong." There were just so many mixed feelings.

QUESTION #5. What kind of adjustments have you personally and as a parent had to make since the time of diagnosis or since you realized the extent of the disorder?

ANSWER. EVERYTHING. Just everything. There was, actually is, just so much to learn, ...the research, how can I be a good parent to C. Then trying to constantly remember not to be disappointed, not to wish he was different,being sorry for what he goes through. Then, adjusting my life to meeting his needs, everyday...adjusting my schedule, the appointments. Daily adjustments. It effects every single day.

QUESTION #6. As the mother of an ADHD child what has been most helpful to you in dealing with C's ADHD?

ANSWER. Well, books. I read some...but that takes a chunk of time...and then the information is gone. I guess, talking. Talking to others...having resources, being aware of what the resources are and then using them. Being able to be open and talk. Not being ashamed. That was the biggest hurdle. Having an ADHD coach...who knows...talking and learning. Going over it again and again.

QUESTION #7. In your position as the mother of an ADHD child what has not been helpful?

ANSWER. Parenting coaching. We tried that. It doesn't apply if it's not about ADHD. It was useless. And then, comparing my child to other children. That does not do me any good and it is a waste of my time and destructive.

QUESTION #8. As the primary caregiver could you list or identify 5 emotions that you routinely experience?

ANSWERS.

- a. anger
- b. frustration
- c. sadness
- d. anxiety
- e. hopefulness.

QUESTION #9. Thinking back to that time when you fully felt the impact of your child's ADHD diagnosis, has there been a time since then when something happened and you had those same feelings of anger, frustration, sadness, anxiety and/or hopefulness?

ANSWER. His 3rd grade year at Blake. It was so sad. I was so sad. I was wishing that he was different...that it could be different for him....that I was not doing enough and what more can I do to make this better. And then the blame. I put all the blame on the teacher. I felt angry and frustrated.

QUESTION #10. What feelings do you have right now when you think about C's ADHD?

ANSWER. Mad. I'm really mad the he has to go through this and then sad, so sad. It is just sad.

QUESTION #11. Can you tell me about other times when you felt this way?

ANSWER. So many times. Many times, even this past week-end. C was acting out at his grandparent's. Again, I felt shameful. I felt guilty and shameful. He was acting out and his Grandfather said, "Has he had his meds?" I hate that! How sad is that? I mean, his Grandfather is wonderful and loves C. Its not that...I do it, too. If he starts acting up in the afternoon, the first thing I think now, is, "His meds are wearing off." That is just sad. But sometimes C even knows it's about his meds. I hate that. I hate that we are dependent on medication.

QUESTION #12. Are there certain types of trigger events that tend to bring up these feelings repeatedly? Social events with other families. Events with social expectations. Like C must sit quietly. Gatherings of any type. I might not think of it until we get there and then I am reminded, "I need to be prepared...just in case."

QUESTION #13. How would you compare these later experiences to the feelings you originally had?

ANSWER. Usually less intense. I'm more prepared. I can kick in and know how to deal with it.

QUESTION #14. In relation to what you view as normal emotional responses in parenting a child with ADHD; how would you characterize and/or compare your experience of caring for your ADHD child?

ANSWERS.

- a. Undue stress: yes
- b. Undue anxiety: yes
- c. Continual or periodic sadness: yes
- d. Undue guilt: yes
- e. Undue disappointment: yes
- f. Hope for his/her future: yes
- g. Undue feeling of failure in your ability to effectively parent: yes
- h. Undue depression (undiagnosed): yes
- i. Social isolation: no
- j. Marital discord secondary to issues regarding your ADHD child: yes
- k. Intermittent happiness when spending time with your ADHD child: yes
- l. Loss of the child I imagined: yes
- m. Loss of my parental ideals: yes
- n. Necessary change in my perceptions, expectations, and goals for my ADHD child: yes
- o. Undue worry and fear for my child and their future: yes
- p. Episodes of grief: yes
- q. Intermittent sadness and sorrow: yes

QUESTION #15. Are there any other comments, thoughts and/or advice that you would like to add regarding your experience as the primary caregiver to a child with ADHD that you think might benefit other mothers with ADHD children?

ANSWER. I just want to comment on the intermittent happiness. My feelings are always flat, now. When C is laughing and happy, I think I should feel happy right now and I don't feel happy because I always just feel its not going to last.

As far as advice: seek out as many resources as available. An ADHD coach, an ADHD psychiatrist. Talk to people and professionals that know about ADHD. Get over the idea that it is shameful, it is nothing you did. Help others to understand your child. Get a network of others who have kids with ADHD.

#3 MOTHER talking about her ADHD child (C).

QUESTION #1. How did you first learn that C has ADHD?

ANSWER. Actually, she came to me and said she thought she might have it since her older brother has it and she is so much like him. She was 15, I think and I was somewhat surprised; however, I didn't doubt her at all.

QUESTION #2. Can you recall your feelings when you first learned about it?

ANSWER. Relieved. I felt relieved...knowing what it was and finding a method to help her. And in a way I guess I was surprised. I began to notice how slow she was to answer questions. It increased my understanding of what she must have quietly been going through. There is always a sadness in realizing your child has a struggle. Looking back to 8th grade, she had all A's. Then 9th grade a 3.9 GPA and then her grades began to slip. She hid a lot from us, so I was unaware. There was the ADHD and then came the depression. I think I was beside myself with worry for her safety and happiness. That child had gone that far, so many years and I didn't realize her suffering and struggles...how hard she was pushing herself. She was doing well until 5th grade. 5th grade seemed to be pivotal...her brother got cancer. Because she is just so pleasant and kind and wonderful. I had no idea. There's guilt.

QUESTION #3. When you learned the diagnosis did you realize the true extent of the disorder?

ANSWER. No. Even now, I can't believe she has this. I just have a hard time putting my arms around it. I had to change the way I parent. I had to become so cautious and careful with my wording...what I said to C, the way I presented things. I just had no idea. I knew it was attention problems, but didn't realize how it permeated her life....socially, the procrastination, following through; things like that.

QUESTION #4. If not, when was the first time you realized the true extent and impact of your child's disorder and what were your feelings at that time?

ANSWER. I felt really sad, almost depressed. Angry...not at C. I always have difficulty just being angry, but I felt that way about the ADHD and what it was doing to C...the way it was affecting her. It was inconceivable. It can't be happening. I had and have a lot of long-term concerns. I feel panic when she gets secretive. I know or I think, she must be struggling with something. For me, for mothers it is just this feeling of being helpless and hopeless.

QUESTION #5. What kind of adjustments have you personally and as a parent had to make since the time of diagnosis or since you realized the extent of the disorder?

ANSWER. There have been a lot of adjustments and for the good. I have learned a lot about the disorder and come to understand that it is complicated. I have learned a lot and I believe all the entities that go along with the ADHD. And parenting techniques...underline parenting techniques. I worked really hard at home to not react right away, but to take the time and think about how I will react. I always have to be "on". I have felt anger and rage over it being so much work on my part. When she is quiet and nothing comes out. I'm powerless, fear based, and frustrated. Also, we parent

as a couple now. We have different parenting styles. Before we would be exhausted. Now, with things being better, you forget how really difficult it was. It was really hard to change my footing and let go and let her grow up. I've also had to take really good care of my self . Al-anon helps me pace myself. I am always taking a deep breath...basically, this is a lot of effort.

QUESTION #6. As the mother of an ADHD child what has been most helpful to you in dealing with C's ADHD?

ANSWER. Counseling. Working with an ADHD coach and therapist, specifically, _____(coaches name)...the explanation of what it really is. Other people we worked with didn't explain all that is part of ADHD. They felt C was done getting extra help. Fortunately, the assistant principle at C's school wouldn't help with the 504 Plan unless C saw _____ (coach). Learning techniques for parenting an ADHD child is helpful. C knows and appreciates me coming to meetings with her and on my own. She knows I am trying. It helps me be stronger and not so wishy-washy. The boundaries and limit setting has really helped me not be a constant nag. Al-anon, of course has helped tremendously because I am quietly doing what she needs me to do. She's working hard. It creates a positive cycle. She has become more outspoken and that's good because I know where she is coming from and what I need to do next.

QUESTION #7. In your position as the mother of an ADHD child, what has not been helpful?

ANSWER. That list is a mile long! Being an authoritarian. Not helpful. To decide something negative about one of C's friends and then say something. Not helpful. Doing things for her, like cleaning her room, getting books, that kind of thing. Not helpful. Instead, I say, "I'm here what do you need?" If I am unclear or do not define boundaries. Not helpful. I have to be clear. If I make a big deal over something and keep going over and over it. Not helpful. I have to make it clear that it is a safety issue and not an issue of trust. Another thing happened in 3rd grade in dance. It had to do with the instructor moving her to the back of the line. It was done in a way that was detrimental to C...that kind of thing...important people in C's life that have not handled her appropriately. Then the counselor at school kept discouraging us from doing anything because C's grades were always OK. But she was struggling. These kinds of things are not helpful.

QUESTION #8. As a primary caregiver could you list or identify 5 emotions that you routinely experience?

ANSWERS.

- a. sadness
- b. concern
- c. fear
- d. panic
- e. joy in who she is

QUESTION #9. Thinking back to that time when you fully felt the impact of your child's ADHD diagnosis, has there been a time since then when something happened and you

had those same feelings of sadness, concern, fear, panic and/or joy that you described above?

ANSWER. Yes, this spring. Then everything comes back, the fear, the sadness, the worry the helplessness, the panic. C's behavior had changed the last two months of her senior year. She was more withdrawn, irritable, and confusing.

QUESTION #10. What feelings do you have right now when you think about C's ADHD?

ANSWER. I'm still very sad about it. At least I feel hopeful. I have concern. I can't tell you that I have accepted this...maybe I won't...it's just really frustrating.

QUESTION #11. Can you tell me about other times when you felt this way? What were your feelings?

ANSWER. It comes and it goes. I'm always on the edge waiting for the other shoe to drop.

QUESTION #12. Are there certain types of trigger events that tend to bring up these feelings repeatedly?

ANSWER. Yes. Seeing her let things slip at school, selections of friends that give me, as a mom, a bad vibration and then her mute moments; when she just doesn't talk. Those times always bring up those feelings.

QUESTION #13. How would you compare these later experiences to the feelings you originally had?

ANSWER. They are, (b.) usually just as intense...maybe at the beginning of all this they were a little more intense, but basically, just the same.

QUESTION #14. In relation to what you view as normal emotional responses in parenting a child with ADHD: how would you characterize and/or compare your experience of caring for your ADHD child?

- a. Undue stress: no, in some ways each child has their own stress
- b. Undue anxiety: no
- c. Continual or periodic sadness: yes
- d. Undue guilt: yes
- e. Undue disappointment: no
- f. Hope for his/her future: yes
- g. Undue feelings of failure in your ability to parent: no (sometimes)
- h. Undue depression (not diagnosed): yes
- i. Social isolation: no
- j. Marital discord secondary to issues regarding your ADHD child: no
- k. Intermittent happiness when spending time with you ADHD child: yes
- l. Loss of the child I imagined: yes
- m. Loss of my parental ideals: no
- n. Necessary change in my perceptions, expectations and goals for my ADHD child: yes
- o. Undue worry and fear for my child and their future: yes
- p. Episodes of grief: yes

q. Intermittent sadness and sorrow: yes

QUESTION #15. Are there any other comments, thoughts and/or advice that you would like to add regarding your experience as the primary caregiver to a child with ADHD that you think might benefit other mothers with ADHD children?

ANSWER. Each child is so individual. I put a lot of effort into every one of them. Mothers of ADHD children would benefit by understanding the total scope of ADHD and to get help from a great counselor/coach on how to parent the ADHD child.

#4 MOTHER talking about her ADHD child (C).

QUESTION #1. How did you first learn that C had ADHD?

ANSWER. He was having tremendous difficulty in school in the 1st and 2nd grade. There was such tremendous tension and a lot of fighting between me and C and his father when it came to doing his home-work. We ended up doing a lot of yelling. It was very tense. There was such an incredible sense of tension that we had him tested.

QUESTION #2. Can you recall your feelings when you first learned about it?

ANSWER. I was very disappointed when I found out that his intelligence was average. I remember that very distinctly...there is a lot of importance put on education and intelligence in my family of origin. But I was happy to have a diagnosis, something that we could work with.

QUESTION #3. When you learned the diagnosis did you realize the true extent of the disorder?

ANSWER. No.

QUESTION #4. If not, when was the first time you realized the true extent and impact of your child's disorder and what were your feelings at that time?

ANSWER. Well, he didn't go on medication until the 5th grade. So he would regularly score in the 13th-15th percentile on standardized testing. Then we finally realized that we needed more testing and then we put him on meds. Then he scored in the 85 percentile on his testing. That is when I felt the true magnitude of his ADHD. The difference was just so stunning because of the meds. The test showed his intelligence to be in the average range and we had no idea that he could actually perform so well.

QUESTION #5. What kind of adjustments have you personally and as a parent had to make since the time of diagnosis or since you realized the extent of the disorder?

ANSWER. Well, really we haven't actually made enough adjustments. We still are not parents who do homework with our kids. We sought out an ADHD coach and initially a 504. That eventually led to and resulted in an IEP. I have also had to change my hopes and dreams about my child. Education and intelligence are a real score card in my family. That doesn't mean that I value or love my kid less though.

QUESTION #6. As the mother of an ADHD child what has been most helpful to you in dealing with C's ADHD?

ANSWER. The benefit of the treatment we received in the medication would be the first thing because it actually helped him...not that he accepts his ADHD or likes being medicated or even always chooses to take his med. He doesn't and he tries to hide it. Then the professionals around us helped to establish a framework. That helped him use tools that make him feel better about his self.

QUESTION #7. In your position as the mother of an ADHD child, what has not been helpful?

ANSWER. The schools have not met the challenge of C. My husband has not been helpful. We parent very differently. He's a conflict avoider and a giver...always positive. It's hard for him to see me being angry at C or setting down limits. He is much more flexible than I am.

QUESTION #8. As the primary caregiver could you list or identify 5 emotions that you routinely experience?

ANSWERS.

- a. fear
- b. anxiety
- c. love
- d. humor
- e. frustration

QUESTION #9. Thinking back to that time when you fully felt the impact of your child's ADHD diagnosis, has there been a time since then when something happened and you had those same feelings fear, anxiety, love, humor and/or frustration that you described above?

ANSWER. Continuously. Every school year is a new hope and a disappointment. He starts out great, then gets a little behind...then it all snowballs and he crashes. He crashed down every time. Every time we hope and hope for positive results and try to be supportive and every time our hopes are dashed.

QUESTION #10. What feelings do you have right now when you think about C's ADHD?

ANSWER. Panic. I think he is severely impairing his future with his actions. I think he is expressing his own fear of moving forward. I don't know what to do. I'm trying to just let go.

QUESTION #11. Can you tell me about other times when you felt this way? What were your feelings?

ANSWER. Panic. To this extent, no, because there was always next year, next year, next year. Now we're looking at senior year. What about a year from now, two years. I have to think to myself, "Just let it unfold." Try to stop my panic.

QUESTION #12. Are there certain types of trigger events that tend to bring up these feelings repeatedly?

ANSWER. Yes. Every time C avoids doing what he should be doing. And when I see his pattern of behavior is unchanged. When I see his continued denial of his disability. When people ask and when I hear him tell people the names of colleges that he won't attend because he could never get into them. His avoidance and denial are triggers.

QUESTION #13. How would you compare these later experiences to the feelings you originally had?

ANSWER. a. Usually more intense.

QUESTION #14. In relation to what you view as normal emotional responses in parenting a child without ADHD: how would you characterize and/or compare your experience of caring for your ADHD child?

ANSWERS.

- a. Undue stress: yes
- b. Undue anxiety: yes
- c. Continual periodic sadness: yes
- d. Undue guilt: yes
- e. Undue disappointment: yes
- f. Hope for his/her future: no
- g. Undue feeling of failure in your ability to effectively parent: yes
- h. Undue depression: yes
- i. Social isolation: yes
- j. Marital discord secondary to issues regarding your ADHD child: yes
- k. Intermittent happiness when spending time with your ADHD child: yes
- l. Loss of the child I imagined: yes
- m. Loss of my parental ideals: yes
- n. Necessary change in my perceptions, expectations and goals for my ADHD child: yes
- o. Undue worry and fear for my child and their future: yes
- p. Episodes of grief: yes
- q. Intermittent sadness and sorrow: yes

QUESTION #15. Are there any other comments, thoughts and/or advice that you would like to add regarding your experience as the primary caregiver to a child with ADHD that you think might benefit other others with ADHD children?

ANSWER. No.

#5 MOTHER talking about her ADHD child (C).

QUESTION #1. How did you first learn that C has ADHD?

ANSWER. She had so many troubles in school. In 2nd grade the teacher thought she should be tested. We didn't think she needed it but we tested her and the tests were inconclusive. During her freshman year in high school she had emotional and academic problems. We had her tested again by a psychologist who did a history and then we went to the pediatrician for Stratera (non-stimulant ADHD medication). Then, when she was 16 the nurse at school called and said she suspected cutting. We had to find a psychiatrist. She monitored C's ADHD and depression. We asked for a referral for testing, again. The tests showed a very high IQ, ADHD and possibly pre-emergent Bipolar.

QUESTION #2. Can you recall your feelings when you first learned about it?

ANSWER. Denial, especially in 2nd grade because her grades were all fine. Her friendships were fine so, no social issues...but, I didn't see her in the classroom. She always had a hard time transitioning. Because her Dad probably has it, I knew it was a possibility but I didn't want to believe it.

QUESTION #3. When you learned the diagnosis did you realize the true extent of the disorder?

ANSWER. No. I thought meds would cover all the bases and that she would function like any other normal person. I didn't know about all the emotional battering she had all these years because of the ADHD. She was feeling like an emotional outcast. That was the biggest misconception that the med will take care of everything.

QUESTION #4. If not when was the first time you realized the true extent and impact of your child's disorder and what were your feelings at that time?

ANSWER. Probably when she was diagnosed with depression and anxiety, knowing it goes hand in hand with ADHD. Its life long. This would be life long for her and I was just sad that she would have to deal with it for the rest of her life.

QUESTION #5. What kind of adjustments have you personally and as a parent had to make since the time of diagnosis or since you realized the extent of the disorder?

ANSWER. My whole parenting style had to change in that I didn't hold her to the same standards. I couldn't tell her to do something and think that I didn't have to remind her over and over. We let a lot of things slide. We didn't consequence her because she was a social outcast. So anything that required a punishment we didn't do because it would have a negative impact on her social life. Grounding was out of the question.

QUESTION #6. As the mother of an ADHD child what has been most helpful to you in dealing with C's ADHD?

ANSWER. Her attending ADHD coaching and therapy because her ADHD coach understands her and we don't. This has helped her.

QUESTION #7. In your position as the mother of an ADHD child, what has not been helpful?

ANSWER. That people don't understand how this disease encompasses your whole life. So much of this is out of your hands. They think you should fix the non-compliance. The embarrassment of having an ADHD child and the guilt is a lot. She is the way she is. You just have to accept her the way she is. She really is not going to change.

QUESTION #8. As the primary caregiver could you list or identify 5 emotions that you routinely experience?

ANSWERS.

- a. disappointment
- b. overwhelming sadness
- c. helplessness
- d. frustration
- e. ineffectiveness

QUESTION #9. Thinking back to that time when you fully felt the impact of your child's ADHD diagnosis, has there been a time since then when something happened and you had those same feelings of disappointment, overwhelming sadness, helplessness, frustration and/or ineffectiveness that you described above?

ANSWER. All the time. I mean, she tells me all the time, "You don't understand." For her, everything has to be so in the right order for things to happen.

QUESTION #10. What feelings do you have right now when you think about C's ADHD?

ANSWER. Helplessness and what kind of a parent am I? You can't help them. She just tunes me out. She is just so sick of hearing me.

QUESTION #11. Can you tell me about other times when you felt this way?

ANSWER. All the time because she will never cease to amaze me at what she does without any forethought. Like her medications...giving it to her girlfriend because she had run out and couldn't afford to get more. We had gone over this before about your medications and not sharing them. She did it anyway and this was hugely disappointing.

QUESTION #12. Are there certain types of trigger events that tend to bring up these feelings repeatedly?

ANSWER. Anytime she doesn't do what we're expecting of her. She has one job and that's school and she doesn't stick with it. There's no reasoning with her; no turning her off the track she might be on that won't work. She has to experience it all herself.

QUESTION #13. How would you compare these later experiences to the feelings you originally had?

ANSWER. a. Usually more intense.

QUESTION #14. In relation to what you view as normal emotional responses in parenting a child without ADHD; how would you characterize and/or compare your experience of caring for your ADHD child?

ANSWERS.

- a. Undue stress: yes
- b. Undue anxiety: yes
- c. Continual or periodic sadness: yes
- d. Undue guilt: yes
- e. Undue disappointment: yes
- f. Hope for his/her future: no
- g. Undue feeling of failure in your ability to effectively parent: yes
- h. Undue depression: yes
- i. Social isolation: yes
- j. Marital discord secondary to issues regarding your ADHD child: yes
- k. Intermittent happiness when spending time with your ADHD child: yes
- l. Loss of the child I imagined: yes
- m. Loss of my parental ideals: yes
- n. Necessary change in my perceptions, expectations, and goals for my ADHD child: yes
- o. Undue worry and fear for my child and their future: yes
- p. Episodes of grief: yes
- q. Intermittent sadness and sorrow: yes

QUESTION # 15. Are there any other comments, thoughts and/or advice that you would like to add regarding your experience as the primary caregiver to a child with ADHD that you think might benefit other mothers with ADHD children?

ANSWER. No.

#6 MOTHER talking about her ADHD child (C)

QUESTION #1. How did you first learn that C has ADHD?

ANSWER. It was because she was having difficulty in school. She couldn't read and was having trouble learning in school. I was kind of suspicious because of a family history of ADHD. She was very hard to control, hyperactive, very stubborn.

QUESTION #2. Can you recall your feelings when you first learned about it?

ANSWER. I wasn't surprised because of the family history. I felt a little sad.

QUESTION #3. When you learned the diagnosis did you realize the true extent of the disorder?

ANSWER. No. I just thought she had the regular ADHD. But she also has depression and anxiety. I had no idea how complicated this would mean her ADHD would be.

QUESTION #4. If not, when was the first time you realized the true extent and impact of your child's disorder and what were your feelings at that time?

ANSWER. It was in 5th grade. I knew she was depressed. Things got complicated. I felt hopeless, sad and worried.

QUESTION #5. What kind of adjustments have you personally and as a parent had to make since the time of diagnosis or since you realized the extent of the disorder?

ANSWER. It has meant hours of therapy for C. Then there was the juggling...trying to find the correct professionals to put in place. Then learning about and managing the medications. I have withdrawn from social interaction with others it is hard for them to understand the whole thing. Learning to work with my husband as a team has been an adjustment. Learning how to work with the school has been a learning experience. Then there is the fear...always listening for the running bathtub (the bathroom was the place where she previously cut), reading her papers...knowing she is depressed again. I have had to relearn how to parent.

QUESTION #6. As the mother of an ADHD child what has been most helpful to you in dealing with C's ADHD?

ANSWER. Talking with the appropriate people on a regular basis has been helpful. Attending the Mom's Support Group. Learning about and understanding how to handle things...knowing how to do what you are supposed to do when things come up.

QUESTION #7. In your position as the mother of an ADHD child, what has not been helpful?

ANSWER. Well, trying to use my own experience growing up to understand what she is feeling. That's impossible...no help what so ever. The school system at times is not helpful.

QUESTION #8. As the primary caregiver could you list or identify 5 emotions that you routinely experience?

ANSWERS.

- a. sadness
- b. anger
- c. helplessness
- d. feeling afraid
- e. frustrated.

QUESTION #9. Thinking back to that time when you fully felt the impact of your child's ADHD diagnosis, has there been a time since then when something happened and you had those same feelings of sadness, anger, helplessness, feeling afraid and/or being frustrated that you described above?

ANSWER. Yes. I get those same feelings every time she gets worse.

QUESTION #10. What feelings do you have right now when you think about C's ADHD?

ANSWER. The same feelings that I just mentioned...the sadness, being afraid, helpless...all those...all those every time.

QUESTION #11. Can you tell me about other times when you felt this way?

ANSWER. Again, every time she gets worse....all those feelings and desperation and disbelief that this is happening to her...to me...all of us.

QUESTION #12. Are there certain types of trigger events that tend to bring up these feelings repeatedly?

ANSWER. Hearing that she has been misunderstood, that someone is upset with her. The depression and the cutting, her morbid writings, seeing blood (she smears on her poems from cutting).

QUESTION #13. How would you compare these later experiences to the feelings you originally had?

ANSWER. a. Usually more intense

QUESTION #14. In relation to what you view as normal emotional responses in parenting a child without ADHD; how would you characterize and/or compare your experience of caring for your ADHD child?

ANSWERS.

- a. Undue stress: yes
- b. Undue anxiety: yes
- c. Continual or periodic sadness: yes
- d. Undue guilt: yes
- e. Undue disappointment: yes (Mom answered misplaced disappointment)
- f. Hope for his/her future: no
- g. Undue feeling of failure in your ability to effectively parent: yes

- h. Undue depression: yes
- i. Social isolation: yes
- j. Marital discord secondary to issues regarding your ADHD child: no not any more
- k. Intermittent happiness when spending time with your ADHD child: yes
- l. Loss of the child I imagined: yes
- m. Loss of my parental ideals: yes
- n. Necessary change in my perceptions, expectations and goals for my ADHD child:
yes
- o. Undue worry and fear for my child and their future: yes
- p. Episodes of grief: yes
- q. Intermittent sadness and sorrow: yes

QUESTION #15. Are there any other comments, thoughts and/or advice that you would like to add regarding your experience as the primary caregiver to a child with ADHD that you think might benefit other mothers with ADHD children?

ANSWER. No, not now.

#7 MOTHER talking about her ADHD child (C).

QUESTION #1. How did you first learn that C has ADHD?

ANSWER. His 4th grade teacher recommended testing and he was tested at the end of 4th grade. But even before that his 2nd grade teacher had said, “Something’s going on.”

QUESTION #2. Can you recall your feelings when you first learned about it?

ANSWER. I wasn’t surprised if that’s what you mean. In retrospect at the end of 1st grade, even going back before that I knew that something was going on, so no, I wasn’t surprised. Things made more sense once we had the test results. Looking back, in hindsight, he was so non-combative, gentle, not at all social, withdrawn. He’s never liked conflict. I was relieved when we got the diagnosis. Now we knew, this was concrete.

QUESTION #3. When you learned the diagnosis did you realize the true extent of the disorder?

ANSWER. No. Probably it wasn’t until the 6th grade when it became more and more apparent with the letter grading. So, maybe I noticed it to some extent in the 5th grade but the whole thing really ramped up in the 6th grade with the homework issues and problems. I thought the pill would make it better...but then I started thinking, “Gee we’re taking the medicine why is everything falling apart?”

QUESTION #4. If not, when was the first time you realized the true extent and impact of your child’s disorder and what were your feelings at that time?

ANSWER. It all didn’t make sense to me. Things were not getting done. The things that were getting done, weren’t getting handed in. He didn’t know if he did or didn’t have homework. He couldn’t organize. That is when I felt it.

QUESTION #5. What kind of adjustments have you personally and as a parent had to make since the time of diagnosis or since you realized the extent of the disorder?

ANSWER. When he gets home at 4PM I pretty much have to have my day complete because he needs my attention. Things, noises, commotion, are very distracting to him. Like if I’m making dinner. I pretty much have to have things done so I can review things with him, go over his day. Things around the house are pretty much quiet during this time of the day. His sister isn’t home, yet, and that probably works well for C. I also now stay in close contact with his teachers phoning them, e-mailing, meeting with them in person...and getting him all the help I can with a tutor or anything else he needs. I just have had to keep up with all he’s doing.

QUESTION #6. As the mother of an ADHD child what has been most helpful to you in dealing with C’s ADHD?

ANSWER. I have a couple of adult friends that are ADHD they are really helpful. They tell me what exactly it was like for them. It’s been helpful for me to better understand what C is going through daily. One friend tells me, “This is my world.” They remember being buried and overwhelmed with work if they missed an assignment. It has been a little bit of a check for me when things are not going well.

Also, getting an ADHD coach because at the onset of all this he was so emotional. He told the coach things that he wouldn't tell us. That was helpful in understanding his situation and in correcting those things that we or he could.

Then, too, there is a lot of camaraderie at school between teachers, students, staff. The school has worked with us very well.

QUESTION #7. In your position as the mother of an ADHD child what has not been helpful?

ANSWER. It is not helpful when he is in an environment that assumes he can't take a leadership role because he is quiet. For instance, in Boy Scouts. That's why I have become involved and on the board. What I find is that people don't realize the nuances and assets of boys with personalities like C. Because they're quiet they don't think they can take leadership roles or that they wouldn't be interested. People just assume you can't do it...and that isn't necessarily true.

QUESTION #8. As the primary caregiver could you list or identify 5 emotions that you routinely experience?

ANSWERS.

- a. love
- b. patience
- c. frustration
- d. kindness towards his gentle spirit
- e. fear.

QUESTION #9. Thinking back to that time when you fully felt the impact of your child's ADHD diagnosis, has there been a time since then when something happened and you had those same feelings of love, patience, frustration, kindness towards his gentle spirit and/or fear that you described above?

ANSWER. Yes, whenever he begins to struggle.

QUESTION #10. What feelings do you have right now when you think about C's ADHD?

ANSWER. That we're on the right track. I'm nervous...nervous about upper school. The new challenges, grades count now...that makes me nervous. But I feel confident that we're on the right track. I'm glad that entering into the 9th grade that his father and I are on the right track...together making boundaries around the household structure and academics.

QUESTION #11. Can you tell me about other times when you felt this way?

ANSWER. Yes, in 8th grade I felt happy and confident because he started the year with a bang. ...I thought...then by January he shut down. That is frustrating and nerve wracking. He either shuts down at the beginning or towards the end. My goal is that he doesn't shut down or maybe even that he would actually like school.

QUESTION #12. Are there certain types of trigger events that tend to bring up these feelings repeatedly?

ANSWER. Yes. Whenever there is a missing assignment...even more of a trigger is when he does the work and then doesn't hand it in...and then he doesn't seem to know why he didn't turn it in. He shrugs his shoulders acting like he doesn't care.

QUESTION #13. How would you compare these later experiences to the feelings you originally had?

ANSWER. c. Usually less intense

QUESTION #14. In relation to what you view as normal emotional response in parenting a child without ADHD; how would you characterize and/or compare your experience of caring for your ADHD child?

ANSWERS.

- a. Undue stress: yes
- b. Undue anxiety: yes
- c. Continual or periodic sadness: no
- d. Undue guilt: no
- e. Undue disappointment: no
- f. Hope: no
- g. Undue feeling of failure in your ability to effectively parent: no
- h. Undue depression (not diagnostic): no
- i. Social isolation: yes
- j. Marital discord secondary to issues regarding your ADHD child: no
- k. Intermittent happiness when spending time with your ADHD child: yes
- l. Loss of the child I imagined: no
- m. Loss of my parental ideals: no
- n. Necessary change in my perceptions, expectations, and goals for my ADHD child: no
- o. Undue worry and fear for my child and their future: yes
- p. Episodes of grief: no
- q. Intermittent sadness and sorrow: no

QUESTION #15. Are there any other comments, thoughts and/or advice that you would like to add regarding your experience as the primary caregiver to a child with ADHD that you think might benefit other mothers with ADHD children?

ANSWER. I think that if economics provided having the support of ADHD an ADHD coach/therapist in conjunction with schools, tutors, the like. Proper diagnosis with a psychologist and testing is important. It's so important to form a team around the ADHD child. When this is done at a young age it is so much more acceptable to the child. When it becomes a part of life it is perceived by the child as normal; just a part of the routine. A team of support around them is so essential to success. That is why I'm not afraid of him going out into life on his own, because I think he will have mastered these skills. Making this diagnosis and all it involves positive at a young age-even medications....C takes them on his own now.

There are, of course, periods of rebellion. But we continuously talk about our plan, evaluate it and restructure it. In the 8th grade, H (husband) became more involved & I really appreciated that. He's great as far as being involved. That helps.

#8 MOTHER talking about her ADHD child (C).

QUESTION #1. How did you first learn that C has ADHD?

ANSWER. We had him tested in 10th grade. It was a battery of tests outside of school. We were seeing a child psychiatrist who recommended the testing.

QUESTION #2. Can you recall your feelings when you first learned about it?

ANSWER. It's interesting because C had a multi-faceted report where there were other things. So, the ADHD was actually a relief but the other diagnoses were devastating. If it had just been the ADHD diagnosis it would have been easier to cope with. It just seemed overwhelming with all the other problems.

QUESTION #3. When you learned the diagnosis did you realize the true extent of the disorder?

ANSWER. No absolutely not. We had no idea of the extent of emotion that would be attached. I was angry, upset every time he acted out. I had no idea he could be oppositional but we were starting to see a part of that. We still didn't understand the extent of the disorder. We still grapple with that.

QUESTION #4. If not, when was the first time you realized the true extent and impact of your child's disorder and what were your feelings at the time?

ANSWER. Being devastated, overwhelmed, concerned. It hit us at different times...in pieces. At times there was such heart wrenching sadness. The sadness that our child was struggling with so many issues. We kept trying to figure out what to do. Once we did find help, it became more intense and we felt the full extent of the disability... and I felt so incredibly sad, not depressed, but some feelings like that. But I felt that as a parent we had somehow failed him. There was a lot of worry as a parent if we were doing the right thing for him, if we were getting him the right help, if we had located the right resources. The piece that made it so difficult was that he was oppositional and rejected everything that was put forward. That was exhausting.

QUESTION #5. What kind of adjustments have you personally and as a parent had to make since the time of diagnosis?

ANSWER. We now live day by day in the moment, not in planning. I've become more of an assistant to C, not a mom. He demands us to execute and track his schedule and to time manage for him. It's changed our whole family and the way we operate. It's just who he is. I guess we've reached a level of acceptance. C's issues have also changed relationships in the family. He prefers to do things on his own- separate from the family. It's changed us.

QUESTION #6. As the mother of an ADHD child what has been most helpful to you in dealing with C's ADHD?

ANSWER. An ADHD coach, being given resources and ideas about how to deal with all the challenges, family and individual therapy for all of us was great. I can't imagine that we'd be healthy without it. This is where the frustration lies, there weren't a lot of resources. We had the data, but now what were we suppose to do with it. The other thing

that has really helped has been our faith...it has given us hope. This has been such an important component...to have prayer...the comfort and feeling like God will make it better. He's watching over C. He's going to take care of him. Such a deep sense of power and strength. I know that C is safe.

QUESTION #7. In your position as the mother of an ADHD child, what has not been helpful?

ANSWER. As I mentioned, we had all these results from the testing, but what were we to do with it. The schools tried to be helpful. I was amazed at how we had to advocate for him. We had been to 3 counselors before the ADHD coach and we were looking for experts in the area and still it was difficult to find resources. Also, we live in a community of over achievers. When a child, like C, has a challenge it takes a toll on his self-esteem. There needs to be a way for every student to flourish.

QUESTION #8. As the primary caregiver could you list or identify 5 emotions that you routinely experience?

ANSWERS.

- a. worry
- b. sadness
- c. frustration
- d. uncertainty
- e. hope

QUESTION #9. Thinking back to that time when you fully felt the impact of your child's ADHD diagnosis, has there been a time since then when something happened and you had those same feelings of worry, sadness, frustration, uncertainty and/or hope that you described above?

ANSWER. Yes. Just when I think, "OK, everything's under control." You know things are going along relatively well, then if he begins to struggle or goes back...that takes me back to that time and I think all over again, "What do I do now?" There are times when I do go back. It's not as intense now. Now I have tools and skills and am more understanding of what C is going through.

QUESTION #10. What feelings do you have right now when you think about C's ADHD?

ANSWER. I am not as devastated as I was a year ago because I've seen him be successful in other areas of his life. I've seen how he is managing his daily life. He has some great skills. I can now actually visualize him living independently. Of course, maturity has also been a factor and a blessing.

QUESTION #11. Can you tell me about other times when you felt this way? What were your feelings?

ANSWER. I have seen it more this summer...he will ask to use the car to drive himself to work later in the day. There is a little bit of pre-planning, a little bit of forethought is there. He has done really well with his part-time job. He is always on time. He's done

well. He's even been given raises. He has a sense of accomplishment. He can hold down a job, that's a relief.

QUESTION #12. Are there certain types of trigger events that tend to bring up these feelings repeatedly?

ANSWER. I notice if C is tired he is more argumentative and abusive. Then you start feeling the despair, again...or if he begins to get bored...then it can get bad. If he is at a low or not doing well, it brings up those feelings again. These emotions are totally tied to his happiness. If he's doing well, then I'm doing well.

QUESTION #13. How would you compare these later experiences to the feelings you originally had?

ANSWER. c. Usually less intense.

QUESTION #14. In relation to what you view as normal emotional responses in parenting a child without ADHD; how would you characterize and/or compare your experience of caring for your ADHD child?

ANSWERS.

- a. Undue stress: yes
- b. Undue anxiety: yes
- c. Continual or periodic sadness: yes
- d. Undue guilt: yes
- e. Undue disappointment: yes
- f. Hope for his/her future: yes
- g. Undue feeling of failure in your ability to effectively parent: yes
- h. Undue depression (not diagnostic): no
- i. Social isolation: yes
- j. Marital discord secondary to issues regarding your ADHD child: no
- k. Intermittent happiness when spending time with your ADHD child: yes
- l. Loss of the child I imagined: yes
- m. Loss of my parental ideals: yes
- n. Necessary change in my perceptions, expectations, and goals for my ADHD child: yes
- o. Undue worry and fear for my child and their future: yes
- p. Episodes of grief: yes
- q. Intermittent sadness and sorrow: yes

QUESTION #15. Are there any other comments, thoughts and/or advice that you would like to add regarding your experience as the primary caregiver to a child with ADHD that you think might benefit other mothers with ADHD children?

I don't feel like I was able to effectively articulate my experience because it was so intense and because something like this is about your child. It is a very intense experience that words and explanation can not describe.

9 MOTHER talking about her ADHD child (C).

QUESTION #1. How did you first learn that C has ADHD?

ANSWER. After school was not going well her freshman year in high school we decided to have her tested. Also, in 4th grade, her teacher suggested that we have her tested. But we didn't think she was because she didn't have the typical things you think about when you think of ADHD. She wasn't at all hyperactive...the teacher said she was slow to finish her work, easily distracted; that kind of thing. None of those things meant anything to us. We blew it off thinking, "That's the way C is, always in her own little world"...but now it's C's own ADHD world.

QUESTION #2. Can you recall your feelings when you first learned about it?

ANSWER. Yes, I was relieved and happy for her because she was really struggling. Now we could figure out how to address it and assist her through meds and an ADHD coach...the things that she needed.

QUESTION #3. When you learned the diagnosis did you realize the true extent of the disorder?

ANSWER. No.

QUESTION #4. If not, when was the first time you realized the true extent and impact of your child's disorder and what were your feelings at that time?

ANSWER. We went and saw a lecture on the How the ADHD Brain Works about a month after her diagnosis. We were like, "Wow!" It made so much sense; the difficulties she had with processing, organization skills, taking in information and then being able to use that information, all the executive functioning stuff.

QUESTION #5. What kind of adjustments have you personally and as a parent had to make since the time of diagnosis or since you realized the extent of the disorder?

ANSWER. Reading, I've done some reading. We sought out an ADHD coach/counselor for her and then both my husband and I spent time learning and being educated by her. A lot of that time was spent learning new ways to communicate, what to say, how to say it. We did a lot of work on boundaries, consequences...putting those in place. When you have a kid with ADHD you have to parent differently.

QUESTION #6. As the mother of an ADHD child what has been most helpful to you in dealing with C's ADHD?

ANSWER. Working with an ADHD coach, keeping C consistently on her medication...making sure she is taking it every day.

QUESTION #7. In your position as the mother of an ADHD child, what has not been helpful?

ANSWER. When I don't communicate with C in the proper manner. You know, keep it short, unemotional, matter of fact. That was the really big thing. Trying to argue with her the old way, that never worked.

QUESTION #8. As the primary caregiver could you list or identify 5 emotions that you routinely experience?

ANSWERS.

- a. frustration
- b. sadness
- c. worry
- d. anger
- e. feeling ineffective

QUESTION # 9. Thinking back to that time when you fully felt the impact of your child's ADHD diagnosis, has there been a time since then when something happened and you had those same feelings of frustration, sadness, worry, anger, and/or feeling ineffective that you mentioned above?

ANSWER. Yes. Just recently when she moved out abruptly. There wasn't an argument or anything. She was just ready to go back to school and said so and then left. It caught me by surprise. I was bummed all day. Sad. She gets so focused that she doesn't think about others or how her actions affect them.

QUESTION #10. What feelings do you have right now when you think about C's ADHD?

ANSWER. Well, she's all grown up now and independent. I don't worry about her because she has learned to be good at taking care of her self. Sometimes I do wonder if she will get to her college classes on time or get her homework done.

QUESTION #11. Can you tell me about other times when you felt this way?

ANSWER. Just mostly when she was in high school. She is really good about her job. She never missed a day of her high school job. She liked that. For all ADHD kids you have to find something that they love, something they can be passionate about...so they will stick with it. I guess I do worry a little bit about C being in a very small group of friends...not getting involved...just always in her own little world. But, its OK for her if it makes her happy.

QUESTION #12. Are there certain types of trigger events that tend to bring up these feelings repeatedly?

ANSER. Yes, that would always happen with her drinking or smoking pot...when we would find out about it that is when I would feel that way.

QUESTION #13. How would you compare these later experiences to the feelings you originally had?

ANSWER. c. Usually less intense.

QUESTION #14. In relation to what you view s normal emotional responses in parenting a child without ADHD: how would you characterize and/or compare your experience of caring for your ADHD child?

ANSWER.

- a. Undue stress: yes
- b. Undue anxiety: yes
- c. Continual or periodic sadness: yes
- d. Undue guilt: yes
- e. Undue disappointment: yes
- f. Hope: yes
- g. Undue feeling of failure in your ability to effectively parent: yes
- h. Undue depression (not diagnostic): yes
- i. Social isolation: no
- j. Marital discord secondary to issues regarding your ADHD child: yes
- k. Intermittent happiness when spending time with your ADHD child: yes
- l. Loss of the child I imagined: no
- m. Loss of my parental ideals: no
- n. Necessary change in my perceptions, expectations, and goals for my ADHD child: yes
- o. Undue worry and fear for my child and their future: yes
- p. Episodes of grief: yes
- q. Intermittent sadness and sorrow: yes

QUESTION #15. Are there any other comments, thoughts and/or advice that you would like to add regarding your experience as the primary caregiver to a child with ADHD that you think might benefit other mothers with ADHD children?

ANSWER. No, not right now.

#10 MOTHER talking about her ADHD child (C).

QUESTION #1. How did you learn that C has ADHD?

ANSWER. We knew he had something like ADHD in grade school. He couldn't sit still. He was in an open classroom and the teacher picked up on his hyperactivity and let him stand and walk around his chair 4-5 times when he got antsy. As school got harder he was diagnosed...right after junior high.

QUESTION #2. Can you recall your feelings when you first learned about it?

ANSWER. No, I don't remember exactly because I had already figured it out on my own when he was younger...in about third grade. So, I don't think it was a big surprise.

QUESTION #3. When you learned the diagnosis did you realize the true extent of the disorder?

ANSWER. No. No...not even close.

QUESTION #4. If not, when was the first time you realized the true extent and impact of your child's disorder and what were your feelings at that time?

ANSWER. We managed OK through grade school, junior high, high school and even college. But, after college it got bad. It became really hard for him to function. He couldn't function in life. It is always up and down. He is so intense- he can't let things go and then he just can't succeed. If he had had this much focus on learning this stuff, these life skills, when he was younger, he would be a success.

QUESTION #5. What kind of adjustments have you personally and as a parent had to make since the time of diagnosis or since you realized the extent of the disorder?

ANSWER. Its like you have a kid with Juvenile Arthritis...its there you have to live with it. It's like a chronic illness. It just doesn't go away. It's always there...every day. I pray he will develop maturity and other skills.

QUESTION #6. As the mother of an ADHD child what has been most helpful to you in dealing with C's ADHD?

ANSWER. If you get to a point where you just can't handle it get therapy. Talking to someone who knows about ADHD really helps because you can vent and get some helpful suggestions. You know you just don't want to tell everyone about your dirty laundry-so to speak. People tend to be judgmental...and that just doesn't help.

QUESTION #7. In your position as the mother of an ADHD child, what has not been helpful?

ANSWER. A lot of times, you know, with anything like ADHD you tend to not want to tell anyone about it. People judge. People really judge. Sometimes family members even judge and that's really hurtful. That kind of thing is not helpful.

QUESTION #8. As the primary caregiver could you list or identify 5 emotions that you routinely experience?

ANSWERS.

- a. gratitude (that it's not worse)
- b. sadness
- c. extreme sadness
- d. failure as a parent
- e. worry and fear for his future

QUESTION #9. Thinking back to that time when you fully felt the impact of your child's ADHD diagnosis, has there been a time since then when something happened and you had those same feelings of gratitude, sadness, extreme sadness, parental failure and/or worry and fear that you described above?

ANSWER. Probably, but I can't think of one specific time...it can be continuous or not so often.

QUESTION #10. What feelings do you have right now when you think about C's ADHD?

ANSWER. I used to have trouble sleeping after he moved out. Just not knowing what he was doing, if he was in trouble or needed help. Along with the ADHD he has a little depression and a lot of anxiety and hyperactivity. He doesn't like to be by himself. So, I would worry a lot.

QUESTION #11. Can you tell me about other times when you felt this way?

ANSWER. Besides his ADHD, his biggest problem is the anxiety. He just can't let things go. He is very black and white and things need to be perfect. The way he sees things...I just shake my head. And another problem is trying to teach him to manage his money...live within his means. He doesn't have this skill. This is really hard for me. I have a lot of concern.

QUESTION #12. Are there certain types of trigger events that tend to bring up these feelings repeatedly?

ANSWER. He has this big sense of what is right or wrong. He's black and white. He is going to get to the bottom of it and nothing is going to stop him. I feel very concerned and worried.

QUESTION #13. How would you compare these later experiences to the feelings you originally had?

ANSWER. b. Just as intense

QUESTION #14. In relation to what you view as normal emotional responses in parenting a child without ADHD; how would you characterize and/or compare your experience of caring for your ADHD child?

ANSWERS.

- a. Undue stress: yes
- b. Undue anxiety: yes
- c. Continual or periodic sadness: yes
- d. Undue guilt: no
- e. Undue disappointment: no
- f. Hope for his/her future: yes
- g. Undue feeling of failure in your ability to effectively parent: no
- h. Undue depression: no
- i. Social isolation: no
- j. Marital discord secondary to issues regarding your ADHD child: yes
- k. Intermittent happiness when spending time with your ADHD child: yes
- l. Loss of the child I imagined: yes
- m. Loss of my parental ideals: no
- n. Necessary change in my perceptions, expectations, and goals for my ADHD child: yes
- o. Undue worry and fear for my child and their future: yes
- p. Episodes of grief: no
- q. Intermittent sadness and sorrow: yes

QUESTION #15. Are there any other comments, thoughts and/or advice that you would like to add regarding your experience as the primary caregiver to a child with ADHD that you think might benefit other mothers with ADHD children?

ANSWER. I might add that as an ADHD adult, if you are having a lot of issues with your disorder you should consider therapy to help with the sadness you probably have.

#11 MOTHER talking about her ADHD child (C).

QUESTION #1. How did you first learn that C has ADHD?

ANSWER. In 8th grade he started to become suddenly defiant, oppositional, nervous and then I did some research. There kept being evidence that this was more than teenage angst. A woman at the Teen Clinic said that he should be on meds for ADHD.

QUESTION #2. Can you recall your feelings when you first learned about it?

ANSWER. Disbelief...because I just didn't want it to be true.

QUESTION #3. When you learned the diagnosis did you realize the true extent of the disorder?

ANSWER. No.

QUESTION #4. If not, when was the first time you realized the true extent and impact of your child's disorder and what were your feelings at that time?

ANSWER. I don't mean to be evasive, but I'm not sure that I even now realize the true extent. He's an adult now so it's different. It's difficult because where is my responsibility? I make suggestions, but there is no way to help him. It's like I feel sad. Sad. Mad.

QUESTION #5. What kind of adjustments have you personally and as a parent had to make since the time of diagnosis or since you realized the extent of the disorder?

ANSWER....a loss of dreams. I've had to detach, put up a shield around myself. Just his frustration plays into my sadness about how hard it is for him everyday. So that puts him in a position to take it out on me...even take it out on himself, "What did you expect?" He tells me every single day he wants to die when he wakes up. It's always hard.

QUESTION #6. As the mother of an ADHD child what has been most helpful to you in dealing with C's ADHD?

12 step work.

QUESTION #7. In your position as the mother of an ADHD child, what has not been helpful?

ANSWER. Someone saying it is going to be OK. That is not helpful...or, he's going to grow out of it. People have even told me to move. People will always judge...so, I am supposed to move someplace else. Thinking about giving up isn't helpful. Saying that he can change isn't helpful. It's very personal.

QUESTION #8. As the primary caregiver could you list or identify 5 emotions that you routinely experience?

ANSWER.

- a. joy
- b. pride
- c. wonder
- d. fear

e. sadness

QUESTION #9. Thinking back to that time when you fully felt the impact of your child's ADHD diagnosis, has there been a time since then when something happened and you had those same feelings of joy, pride, wonder, fear and/or sadness that you described above?

ANSWER. Many times. In 8th grade he was at a school camp and they called me and told me he had fashioned a noose out of rope. They put him on suicide watch at camp. I have a lot of fear, sadness, helplessness, heaviness. I feel as if I'm not sure enough, I'm not smart enough, I'm not up to dealing with it.

QUESTION #10. What feelings do you have right now when you think about C's ADHD?

ANSWER. I feel empathy, resignation, hope...I keep hoping maybe he will learn enough where things will turn around. I'ts really out of my hands.

QUESTION #11. Can you tell me about other times when you felt this way?

ANSWER. It's always these things. Always the same thing. Other kids can not have this, it's C who has it. It's always there, these 3 things: empathy, resignation, hope. That's my stuff. He still doesn't even think he has the disorder.

QUESTION #12. Are there certain types of trigger events that tend to bring up these feelings?

ANSWER. It's really always under the surface. When he calls right away there's terror. I feel terror. I try not to talk about these things because thoughts become alive. When I see his name on the screen e-mailing me...its terror. Always.

QUESTION #13. How would you compare these later experiences to the feelings you originally had?

ANSWER. b. Usually just as intense

QUESTION #14. In relation to what you view as normal emotional responses in parenting a child without ADHD: how would you characterize and/or compare your experience of caring for your ADHD child?

ANSWERS.

- a. Undue stress: yes
- b. Undue anxiety: yes
- c. Continual or periodic sadness: yes
- d. Undue guilt: no
- e. Undue disappointment: no
- f. Hope for his/her future: yes
- g. Undue feelings of failure in your ability to effectively parent: yes
- h. Undue depression (not diagnosed): yes
- i. Social isolation: yes
- j. Marital discord secondary to issues regarding your ADHD child: NA
- k. Intermittent happiness when spending time with your ADHD child: yes

- l. Loss of the child I imagined: yes
- m. Loss of my parental ideals: yes
- n. Necessary change in my perceptions, expectations, and goals for my ADHD child: yes
- o. Undue worry and fear for my child and their future: yes
- p. Episodes of grief: yes
- q. Intermittent sadness and sorrow: yes

QUESTION #15. Are there any other comments, thoughts and/or advice that you would like to add regarding your experience as the primary caregiver to a child with ADHD that you think might benefit other mothers with ADHD children?

ANSWER. If you're in Al-anon you learn to give these feelings and issues over. So, any disorder, addiction, etc. might seem like an individual choice. But with ADHD people there is also the exceptions and happiness that comes along with the disasters.

#12 MOTHER talking about her ADHD child (C).

QUESTION #1. How did you first learn that C has ADHD?

ANSWER. When I took her to be tested for her reading ability. She said that she was reading too slowly. I didn't realize that they were testing her for more than her reading ability. The results showed that she had ADHD.

QUESTION #2. Can you recall your feelings when you first learned about it?

ANSWER. Surprised...it knocked my socks off. Shocked but also my immediate feeling was to see what we could do for C. We started coaching. I wasn't going to go right for medication. She went to someone for coaching. She didn't do that well with that first person. I was hoping the coaching was going to do it...I didn't know that much about ADHD at the time.

QUESTION #3. When you learned the diagnosis did you realize the true extent and impact of your child's disorder and what were your feelings at that time?

ANSWER. No. I tried to learn more about it and read about it and I would get a little feedback from the old coach. The way I was able to truly understand was when I began to reflect on myself and then how it related to C. This was such a gift for her to learn about it early on and how to deal with it rather than learn at my age. I had been wondering what's wrong with me...and of course, I have ADHD, too.

QUESTION #4. If not, when was the first time you realized the true extent and impact of your child's disorder and what were your feelings at that time?

ANSWER. I never doubted that she had ADHD when I heard the diagnosis. When she had some last minute things due and she didn't do it and had meltdowns. When I gave her lists and she had all day to do them and didn't do them. I could understand, but I could also see how badly things were for her.

QUESTION #5. What kind of adjustments have you personally and as a parent had to make since the time of diagnosis or since you realized the extent of the disorder?

ANSWER. It's more like I could draw from my own experience so I could understand what was happening to her. She had a couple of meltdowns in college and I literally went to help her in the middle of the night...because I understood the ADHD. She thanked me the next day. As the parent of an ADHD kid, I didn't do everything for her...like organize, plan, that kind of thing...because I didn't know. But I let her try and fail or succeed.

QUESTION #6. As the mother of an ADHD child what has been most helpful to you in dealing with C's ADHD?

ANSWER. My own experience has helped me recognize things that happen to her were things I had gone through. ADHD coaching for C and then the last 15 minutes of the session being able to go in and visit with C and the ADHD coach and see what to do in the up coming week to support C in her efforts...and then getting her meds. Getting myself an ADHD coach has been really helpful for me.

QUESTION #7. In your position as the mother of an ADHD child, what has not been helpful?

ANSWER. I can't really think of anything...well, I guess in a round-a-bout way...since leaving high school her choice has been to not see her ADHD coach. That has not been a helpful choice for herself.

QUESTION #8. As the primary caregiver could you list or identify 5 emotions that you routinely experience?

ANSWER.

- a. heartbreak
- b. pride in C
- c. frustration
- d. guilt
- e. love

QUESTION #9. Thinking back to that time when you fully felt the impact of your child's ADHD diagnosis, has there been a time since then when something happened to you and you had those feelings of heartbreak, pride, frustration, guilt, and/or love as you described above?

ANSWER. Yes, a few times. Those school situations, those last minute things and she gets behind...so far behind. I knew why. It was the ADHD and it brought up how I felt when I got behind and felt lost...total despair. I couldn't even think how to get myself out of it. Feeling alone, not knowing what to do or where to get help. We now know all that, but it still doesn't take away the heartbreak and pain.

QUESTION #10. What feelings do you have right now when you think about C's ADHD?

ANSWER. Sad. Just sad. Really a lot of pain and just really sad.

QUESTION #11. Can you tell me about other times when you felt this way?

ANSWER. I've gotten into these same types of situations at work. I don't know why or why I can't get motivated. Crying...totally out of control. Or when C has been in a rut. I would just absorb it and be back in that same painful, sad place.

QUESTION #12. Are there certain types of trigger events that tend to bring up these feelings repeatedly?

ANSWER. Trigger events can happen for me being ADHD. For instance, when my sister would talk about her kids. She would talk about the issues she's putting up with and the pain she's going through. It's not easy for me to tell her because she doesn't have ADHD. She just doesn't know. I guess the issues are the triggers.

QUESTION #13. How would you compare these later experiences to the feelings you originally had?

ANSWER.

- b. Usually just as intense (but short lived).

QUESTION #14. In relation to what you view as normal emotional responses in parenting a child without ADHD; how would you characterize and/or compare your experience of caring for your ADHD child?

ANSWERS.

- a. Undue stress: no
- b. Undue anxiety: yes
- c. Continual or periodic sadness: yes
- d. Undue guilt: no
- e. Undue disappointment: yes
- f. Hope for his/her future: yes
- g. Undue feeling of failure in your ability to effectively parent: no
- h. Undue depression (not diagnosed): no
- i. Social isolation: no
- j. Marital discord secondary to issues regarding you ADHD child: NA
- k. Intermittent happiness when spending time with you ADHD child: yes
- l. Loss of the child I imagined: no
- m. Loss of my parental ideals: yes
- n. Necessary change in my perceptions, expectations and goals for my ADHD child: yes
- o. Undue worry and fear for my child and their future: yes
- p. Episodes of grief: yes
- q. Intermittent sadness and sorrow: yes

QUESTION #15. Are there any other comments, thoughts and/or advice that you would like to add regarding your experience as the primary caregiver to a child with ADHD that you think might benefit other mothers with ADHD children?

ANSWER. I didn't know about her ADHD until pretty late in her childhood. So, I only really dealt with issues in her later years. There was a lot of having to make sure she was attending school or getting there on time...a lot of meltdowns and not getting her homework done.

Also, I'm continuously reminded of very successful people with ADHD. I keep thinking there might be a little spark in her to make her move forward. I think about that all the time. That's the hope.

#13 MOTHER talking about her ADHD child (C).

QUESTION #1. How did you first learn that C has ADHD?

ANSWER. We first learned after testing done with a psychologist in December of 2007. There was just a suspicion on our part. There had been many incidents leading up to the testing. He was having problems in school with the work and sometimes behaviors.

QUESTION #2. Can you recall your feelings when you first learned about it?

ANSWER. Very mixed. There was some relief. I remember saying, "I would be surprised if he doesn't have something." I guess there was some sadness thinking he will have to deal with this and we will have to deal with it, too.

QUESTION #3. When you learned the diagnosis did you realize the true extent of the disorder?

ANSWER. No. It's much more far reaching in the likes of people that have it and more involved in various aspects of his life. I didn't realize how it might impact so much....driving, college, the future.

QUESTION #4. If not when was the first time you realized the true extent and impact of your child's disorder and what were your feelings at that time?

ANSWER. I guess that came as we got started with counseling and coaching and met with the psychiatrist. That is when we learned more and began to get a better understanding of the real impact.

QUESTION #5. What kind of adjustments have you personally and as a parent had to make since the time of diagnosis?

ANSWER. The adjustments are in a different kind of communication with his teachers and just adjusting routines and the various methods we use around the house and in his everyday life. I would say also, the way we lay out expectations and examples for situations in advance, being as clear and consistent with consequences. Also, rearranging his room, his desk, his backpack the way it works best for him...just so that he has the best chance to succeed.

QUESTION #6. As the mother of an ADHD child what has been most helpful to you in dealing with C's ADHD?

ANSWER. First of all just understanding what ADHD is. I understand how his brain works because of the ADHD; so I'm not as frustrated as I was. Working with a coach has been helpful. And then getting the outside support to help his organization...like at school.

QUESTION #7. In your position as the mother of an ADHD child, what has not been helpful?

ANSWER. I haven't felt like the school's been too helpful. They seemed to have a lack of information. Maybe my expectations were too high. I was glad we had resources to bypass school and get help and information on our own. For many years we had suggested to teachers the possibility of ADHD but they just blew it off. They seemed to

have excuse like, “Its an active class” or “He’s fine once he gets focused”. There was such inconsistency. When I read *Driven to Distraction* it clarified so much. I thought every parent of a child should read this. Then last year once we got closer and closer to feeling like we needed to get to the bottom of this, no one at school seemed to know how to pursue this through the school. Luckily we have the finances and the where-with-all to pursue this on our own. If someone were to be less persistent it would be a lot more difficult.

QUESTION #8. As the primary caregiver could you list or identify 5 emotions that you routinely experience?

ANSWERS.

- a. frustration
- b. confusion
- c. anger
- d. sadness
- e. exhaustion

QUESTION #9. Thinking back to that time when you fully felt the impact of your child’s ADHD diagnosis, has there been a time since then when something happened and you had some of the same feelings of frustration, confusion, anger, sadness and/or exhaustion as you described above?

ANSWER. Last night and since school started. The whole bedtime routine. The medication has worn off and I’m tired, too. It’s so difficult for him to move forward. He’s so distracted. I feel like I’m nagging him. We need to figure this one out soon. It just makes me feel frustrated and angry.

QUESTION #10. What feelings do you have right now when you think about C’s ADHD?

ANSWER. Hopeful and happy we figured out what’s going on. Things are so improved over last year. I have some fears about the future...how we’re going to deal with that and how he’s going to deal with that.

QUESTION #11. Can you tell me about other times when felt this way?

ANSWER. We felt really hopeful last year a couple of months after we started all his treatment. Seeing the changes. He was better able to complete tasks and feel better about himself. We felt hopeful to get things turned around and back on track.

QUESTION #12. Are there certain types of trigger events that tend to bring up these feelings repeatedly?

ANSWER. Other than bedtime would be those times when he makes poor choices on the computer. We’ve given him a little freedom and he’s made poor choices because he is so impulsive and then I think, “Here we go again.” He’s been a little deceptive with his computer use. Like one time I forgot to log out and he saw that and just used the computer and went to some sites...not porno, but girly stuff. We have a structure around the computer. He knows the rules. He gets impulsive. We have to log him in and of course he has to ask to be on the computer...that kind of thing.

QUESTION #13. How would you compare these later experiences to the feelings you originally had?

ANSWER. b. Usually just as intense

QUESTION #14. In relation to what you view s normal emotional responses in parenting a child without ADHD: how would you characterize and/or compare your experience of caring for your ADHD child?

ANSWERS.

- a. Undue stress: yes
- b. Undue anxiety: yes
- c. Continual or periodic sadness: yes
- d. Undue guilt: yes
- e. Undue disappointment: yes
- f. hope for his/her future: yes
- g. Undue feeling of failure in your ability to effectively parent: yes
- h. Undue depression (not diagnosed): no
- i. Social isolation: yes
- j. Marital discord secondary to issues regarding your ADHD child: no
- k. Intermittent happiness when spending time with your ADHD child: yes
- l. Loss of the child I imagined: no
- m. Loss of my parental ideals: no
- n. Necessary change in my perceptions, expectations, and goals for my ADHD child: yes
- o. Undue worry and fear for my child and their future: yes
- p. Episodes of grief: no
- q. Intermittent sadness and sorrow: yes

QUESTION #15. Are there any other comments, thoughts and/or advice that you would like to add regarding your experience as the primary caregiver to a child with ADHD that you think might benefit other mothers with ADHD children?

ANSWER. No.

#14. MOTHER talking about her ADHD child (C).

QUESTION #1. How did you first learn that C has ADHD

ANSWER. I think I suspected it in 4th grade. I talked with an ADHD coach and then we set up an appointment to have him tested by a neuro-psychologist.

QUESTION #2. Can you recall your feelings when you first learned about it?

ANSWER. Aahhhha! But also, I was disappointed. Knowing that he would have a rough road to hoe. It would be more of a challenge for him....school, the social stuff...everything. But, it also explained a lot...his struggle with math and reading. The results of the testing explained a lot.

QUESTION #3. When you learned the diagnosis did you realize the true extent of the disorder?

ANSWER. No. I thought it would be like my other son's ADHD. I thought he gets some meds...settles down and performs almost as well as his peers.

QUESTION #4. If not, when was the first time you realized the true extent and impact of your child's disorder and what were your feelings at that time?

ANSWER. In 7th and 8th grade that's when it was becoming more and more obvious. I thought, "OK, now we have to take this really seriously....give me a "fix-it", please, somebody!" Then all that came up again when we ended up having him retested this past school year.

QUESTION #5. What kind of adjustments have you personally and as a parent had to make since the time of diagnosis?

ANSWER. I've had to be more accountable for him. I have had to constantly check on him...and then worry. Lots of worry.

QUESTION #6. As the mother of an ADHD child what has been most helpful to you in dealing with C's ADHD?

ANSWER. His ADHD coach. His caseworker in Special Ed.and the medication.

QUESTION #7. In your position as the mother of an ADHD child, what has not been helpful?

ANSWER. Nagging. Nagging and worrying does not help. Becoming upset at or with him. Getting angry when he doesn't follow through with things- its all, just part of it.

QUESTION #8. As the primary caregiver could you list or identify 5 emotions that you routinely experience?

ANSWERS.

- a. frustration
- b. disappointment
- c. a little sadness
- e. irritation
- f. exasperation

QUESTION #9. Thinking back to that time when you fully felt the impact of your child's ADHD diagnosis, has there been a time since then when something happened and you had some of the same feelings of frustration, disappointment, a little sadness, irritation and/or exasperation that you described above?

ANSWER. The tail end of school last year- a great example. He would say, "I'm doing fine", and he wasn't. He'd say, "I'm pushing myself harder", and he wasn't. It was a lie...no, no, a deception. He was avoiding dealing with it and helping me to avoid dealing with it. I felt a lot of anger and frustration. Mostly frustration. It felt like I didn't get through to him. I just wanted to get through to him and this is something that just doesn't happen.

QUESTION #10. What feeling do you have right now when you think about C's ADHD?

ANSWER. GRRRRRR. I wish it wasn't there. I know he can not over come it because I know he'll always have it, but, hopefully he will learn to cope.

QUESTION #11. Can you tell me about other times when you felt this way? What were your feelings?

ANSWER. I feel that way all the time. When its –the ADHD- right in front of me, which is all the time. He's there...or there is something that I have to fix or nag him about. When I'm awake its there. Sleeping...when I sleep, then its gone until the next morning.

QUESTION #12. Are there certain types of trigger events that tend to bring up these feelings repeatedly?

ANSWER. When grades come in. The dread of going on line and looking at his grades at mid-quarter, semester...being frustrated. And then, there I am again, saying, "Try a little harder. Do more please." Then I go back and remember it's the ADD...and then I have to take action. Gear up and be more pro-active.

QUESTION #13. How would you compare these later experiences to the feelings you originally had?

ANSWER. a. Usually more intense

QUESTION #14. In relation to what you view as normal emotional responses in parenting a child without ADHD; how would you characterize and/or compare your experience of caring for your ADHD child?

ANSWERS.

- a. Undue stress: no
- b. Undue anxiety: no
- c. Continual or periodic sadness: yes
- d. Undue guilt: no
- e. Undue disappointment: yes
- f. Hope: yes
- g. Undue feeling of failure in your ability to effectively parent: yes
- h. Undue depression: yes
- i. Social isolation: no

- j. Marital discord secondary to issues regarding your ADHD child: no
- k. Intermittent happiness when spending time with your ADHD child: yes
- l. Loss of the child I imagined: no
- m. Loss of my parental ideals: yes
- n. Necessary change in my perceptions, expectations, and goals for my ADHD child: yes
- o. Undue worry and fear for my child and their future: yes
- p. Episodes of grief: no
- q. Intermittent sadness and sorrow: yes

QUESTION #15. Are there any other comments, thoughts and/or advice that you would like to add regarding your experience as the primary caregiver to a child with ADHD that you think might benefit other mothers with ADHD children?

ANSWER. I feel that with ADD it is just always there...that little grinding thing...the worry. Because if you're a parent with an ADD kid, you have it- its just always there. With ADHD there is always something more...more worry, more frustration.

15 MOTHER talking about her ADHD child (C).

QUESTION #1. How did you first learn that C has ADHD?

ANSWER. We learned through Dr. G. through a professional diagnosis. We got a notification by the school in 1st or 2nd grade that she was having problems keeping up, especially in Math.

QUESTION #2. Can you recall your feelings when you first learned about it?

ANSWER. We sort of had a hunch. My first feelings though were, "We're finally getting a handle on this." Relief isn't the right word...something like that...maybe clarity. It wasn't a total surprise because we have ADHD on both sides of the family.

QUESTION #3. When you learned the diagnosis did you realize the true extent of the disorder?

ANSWER. No. I didn't know how...ADHD was thrown around as if it was a personality trait. It's not it's a disorder that causes difficulties with life...management skill, emotions, relationships, school, social relations, self esteem, family...every area of your life. And that, I wasn't aware of at all. Socially they seem like, "Wow,...wonderful." But then beyond that there are a lot of struggles.

QUESTION #4. If not, when was the first time you realized the true extent and impact of your child's disorder and what were your feelings at that time?

ANSWER. I realized it within the first year of her diagnosis. I realized she had more of a mountain to climb. Initially, I was just thinking she has a lot of ground to cover to make up for being behind in school. But it's not just a matter of putting your nose to the grindstone. All the tutors in the world would not be able to get her back on track. It's not a matter of getting back on track. It's more a matter of starting over learning a different way. But I was still 100% optimistic...we're going to find a way.

QUESTION #5. What kind of adjustments have you personally and as a parent had to make since the time of diagnosis or since you realized the extent of the disorder?

ANSWER. Initially it was a struggle to get up to speed, as a parent, on what to do. There were a lot of changes I had to make as a parent. I had to provide more structure for my ADHD child. I had to become more co-dependent with her. As she got older I had to structure her social time. I had to shape free time out of school. I should have also spent extra steps to get her to spell out the process she needed to get things accomplished. You know, spell it out on the black board, so to speak. I always wanted to cut to the chase. I should have let the consequences happen more often. It has always been the fight between protecting her and letting her go to have age appropriate and safe consequences.

QUESTION #6. As the mother of an ADHD child what has been most helpful to you in dealing with C's ADHD?

ANSWER. Spelling things out has been helpful, providing a structure that isn't demeaning and at the same time is helpful. Boosting her self-esteem. Sharing positive experiences. Family dinners are huge and important. We didn't do enough of them, but these were very important and very good. Working with teachers, having her on an IEP.

Her getting treatment as early as possible contributed to the process and then her finally being able to be mainstreamed. Also, trusting C's feelings about her special-ed teachers. She was usually right about how things were going to go for her and I learned to listen. And that made her a part of the process, too. Having her feel like we trusted and listened to her input. Trusting her instincts. The IEP and the diagnosis shouldn't be a prison sentence. Also, putting forward things that work in her favor.

QUESTION #7. In your position as the mother of an ADHD child, what has not been helpful?

ANSWER. I have struggled with her Adderall (stimulant medication used for the treatment of ADHD) and the medical approach. I'm not crazy about that stuff. The fact that a child is dependent on a pill really in some ways prevents a thought process. There is some personality change that she experiences. She would be agitated on it and this could eb and flo. The med scared the hell out of me. The dependency on it and then some of the abuses of it...taking it to stay awake all night to study for tests in college, that kind of thing. I am talking about the using it for things other than its purpose. I just don't like it.

QUESTION #8. As the primary caregiver could you list or identify 5 emotions that you routinely experience?

ANSWERS.

- a. joy
- b. concern/compassion
- c. worry
- d. excitement/ energy
- e. need to give her demonstrative love

QUESTION #9. Thinking back to that time when you fully felt the impact of your child's ADHD diagnosis, has there been a time since then when something happened and you had some of the same feelings of joy, concern/compassion, worry, excitement/energy, and/or the need to give her demonstrative love that you described above?

ANSWER. Some of her creative things She put together a collage of magazine photos for my mom. It was about love. I look at it and think, "Wow." It's the energetic exciting piece and then the theme of love and her need for demonstrative love. I was envious that she could do something like that collage. There's a joy. It just flows for her...its nothing that an organized mind would do. She doesn't get some of those mental blocks...she creates in a different way.

QUESTION #10. What feelings do you have right now when you think about C's ADHD?

ANSWER. Very positive thoughts and feelings. A very happy proud moment as a parent. I hope she looks at it (the collage) and that it boosts her pride. I have sorrow when I think of her self-esteem being low.

QUESTION #11. Can you tell me about other times when you felt this way?

ANSWER. I've had other moments. The way she interacts with people. She's very socially gifted. She treats people well. I'm very proud as a parent. She has a good sense of people and the world. But, I'm not sure that she has that same gift for herself.

QUESTION #12. Are there certain types of trigger events that tend to bring up these feelings repeatedly?

ANSWER. How she brings things up to me. Her tone of voice is what triggers things. There are certain patterns. Times of uncertainty, when she's anxious and worried. Like when there was a party...in her later school years when there would be drinking. So, there are actually categories of things that are triggered for me by her tone and voice.

QUESTION #13. How would you compare these later experiences to the feelings you originally had?

ANSWER. b. Usually just as intense

QUESTION #14. In relation to what you view as normal emotional responses in parenting a child without ADHD; how would you characterize and/or compare your experience of caring for your ADHD child?

ANSWERS.

- a. Undue stress: yes
- b. Undue anxiety: yes
- c. Continual or periodic sadness: yes
- d. Undue guilt: yes
- e. Undue disappointment: no
- f. Hope for his/her future: yes
- g. Undue feeling of failure in your ability to effectively parent: no
- h. Undue depression (not diagnosed): no
- i. Social isolation: no
- j. Marital discord secondary to issues regarding your ADHD child: yes
- k. Intermittent happiness when spending time with your ADHD child: yes
- l. Loss of the child I imagined: no
- m. Loss of my parental ideals: yes
- n. Necessary change in my perceptions, expectations, and goals for my ADHD child: yes
- o. Undue worry and fear for my child and their future: yes
- p. Episodes of grief: no
- q. Intermittent sadness and sorrow: yes

QUESTION #15. Are there any other comments, thoughts and/or advice that you would like to add regarding your experience as the primary caregiver to a child with ADHD that you think might benefit other mothers with ADHD children?

ANSWER. Yes. The nutritional piece. In 2004 I took a nutrition class. I think looking back I should have worked on C's blood sugar levels. When she is low on blood sugar her mood changes, things become more difficult. I think there is a big bio-chemical piece here. Then more fats....good fats...omega 3s are necessary. C was difficult with her

eating and then there was her alcohol intake. She seems to have this need for sugar. I think the fats are actually more important-you know the brain is 60% fat. It needs good fat.

Also, another important thing is setting up a structured environment when an ADHD child is young. I like the book about the 12-steps of ADHD. C and my husband both say, "I have ADHD, deal with it." Really, it should be, "You have ADHD, you should deal with it." Really, they have no awareness on this type of thing...sometimes they are socially inept. But having a structure right away is important and it helps them deal with these attitudes and ways of thinking about things.

#16 MOTHER talking about her ADHD child (C).

QUESTION #1. How did you first learn that C has ADHD?

ANSWER. We took her to a psychiatrist. She was being treated for depression and the psychiatrist thought she might be ADHD. So then we went and had her tested. She was just going into high school when we started the process. But it was not until sophomore year until she was actually tested.

QUESTION #2. Can you recall your feelings when you first learned about it?

ANSWER. My immediate feeling was relief knowing “something” was there and that she could get some help. I had a lot of questions. We needed answers. I had deep feelings...a lot of guilt. Why didn't we know sooner? Why wasn't it brought up? She was in the gifted and talented program for in elementary and middle school. None of this was there or at least showed up.

QUESTION #3. When you learned the diagnosis did you realize the true extent of the disorder?

ANSWER. No. And it was a difficult situation. My husband was on board for C to see a counselor when she was depressed. But the ADHD...he believed the test results but thought she could or she should just rise above it. After we saw the lecture on *How the ADHD Brain Works* he could see C in it and then he got on board.

QUESTION #4. If not, when was the first time you realized the true extent and impact of your child's disorder and what were your feelings at that time?

ANSWER. The one thing that came flying at me were her grades. I saw how her grades had slipped dramatically from freshman to junior year. I struggled with a lot of the behavior issues, but the grades were different. She had gone from A's to D's. At first I thought drugs and drinking...and that is what the school was saying. If she was doing that; maybe it was because of the ADHD...and maybe that caused the rest....I didn't know. But it came flying at me.

QUESTION #5. What kind of adjustments have you personally and as a parent had to make since the time of diagnosis or since you realized the extent of the disorder?

ANSWER. I have to be more understanding, more patient. We had to try to keep track of her schedule, her homework, her entire daily routine. Not control it, but keep track of it. We let a lot of little stuff go.

QUESTION #6. As the mother of an ADHD child what has been most helpful to you in dealing with C's ADHD?

ANSWER. Seeing her counselor and going to an ADHD coach. Just having a 3rd party...being her mother not a watch dog. Without that we wouldn't have the relationship we have now. It was stressful for my husband and I to be more open with each other before we got help for all of us. Then we got on the same page, got a game plan- with help- and we usually ended up in agreement.

QUESTION #7. In your position as the mother of an ADHD child, what has not been helpful?

ANSWER. My emotions get in the way big time. The IEP meetings at the high school were intimidating. I always do better with a one on one with the counselor. But in the IEP meeting you're in front of a firing squad. My husband and I agreed that he would do the talking because I just couldn't get it out. I was too emotional. The other thing that was not at all helpful was the online grades for each course from the teachers. They are never up to date. No one but C really knew whether or not she had handed it in. She would say I handed it in and the teacher just hasn't recorded the grade yet. Who knew? It wasn't accurate or up to date. It started a lot of home struggles. H. couldn't keep himself out of it. He was always looking on line trying to track C's progress. It just doesn't work when you have an ADHD kid. That was hell for us.

QUESTION #8. As the primary caregiver could you list or identify 5 emotions that you routinely experience?

ANSWERS.

- a. frustration
- b. compassion
- c. anger
- d. sadness
- e. being down....it was all I could do to put my jeans on and get to work everyday.

QUESTION #9. Thinking back to that time when you fully felt the impact of your child's ADHD diagnosis, has there been a time since then when something happened and it brought up those same feelings of frustration, compassion, anger, sadness and/or being down that you described above?

ANSWER. Yea, all the time. The whole high school thing was pretty bad. And now with her doing the college thing its all coming back. I have those feelings all over again.

QUESTION #10. What feelings do you have right now when you think about C's ADHD?

ANSWER. Feeling frustrated. She's doing the best she can to take the medication. She's trying really hard. It's not nearly as intense as in high school. And maybe I'm feeling a little frustrated with which way should we go to make her successful with college.

QUESTION #11. Can you tell me about other times when you felt this way?

ANSWER. Yes. I always felt like we were battling the school. I would get pretty down when I felt that C was getting down. I usually felt that way after every school meeting. They would always say, "We just don't know what to do with your child." I would be frustrated with the fact that teachers would accuse her of being lazy. They should know better. There was just a lot of frustration. A lot of sadness....a lot of that. It was just very sad and I guess I had some guilt that I just wasn't doing enough.

QUESTION #12. Are there certain types of trigger events that tend to bring up these feelings repeatedly?

ANSWER. Well, the college thing...feeling those same things all over. Then she is living at home, so all those same issues...messy child stuff. She does try to work at that. Then, the frustration with her moodiness. All those things are triggers.

QUESTION #13. How would you compare these later experiences to the feelings you originally had?

ANSWER. c. Usually less intense.

QUESTION #14. In relation to what you view as normal emotional responses in parenting a child without ADHD; how would you characterize and/or compare your experience of caring for your ADHD child?

ANSWERS.

- a. undue stress: yes
- b. Undue anxiety: yes
- c. Continual or periodic sadness: yes
- d. Undue guilt: yes
- e. Undue disappointment: yes
- f. Hope for his/her future: yes
- g. Undue feeling of failure in your ability to effectively parent: yes
- h. Undue depression (not diagnosed): yes
- i. Social isolation: no
- j. Marital discord secondary to issues regarding your ADHD child: yes
- k. Intermittent happiness when spending time with your ADHD child: yes
- l. Loss of the child I imagined: yes
- m. loss of my parental ideals: yes
- n. Necessary change in my perceptions, expectations, and goals for my ADHD child: yes
- o. Undue worry and fear for my child and their future: yes
- p. Episodes of grief: yes
- q. Intermittent sadness and sorrow: yes

QUESTION #15. Are there any other comments, thoughts or advice that you would like to add regarding your experience as the primary caregiver to a child with ADHD that you think might benefit other mothers with ADHD children?

ANSWER. Get as much help as you can. Try to get a third party so you can step back and not be the drill sergeant. If we had had C diagnosed earlier I would have tried to be much more consistent. I just always thought she was a little quirky. Testing is obviously very necessary. ADHD coaching was huge...just huge for us. Get as much information as you can about ADHD and then you will become more compassionate and less frustrated and angry. Advocate for your child.

#17 MOTHER talking about her child (C).

QUESTION #1. How did you first learn that C has ADHD?

ANSWER. Mostly by observation. I thought he had it. I just wanted to wait as long as possible to take him for an evaluation. . Then I researched it to see what tests were necessary. My opinion was that lots of doctors just say, "He's hyper, here are some medications." I didn't want that.

QUESTION #2. Can you recall your feelings when you first learned about it?

ANSWER. I was sad and disappointed. I hoped that I was wrong and that maybe it was something that he would grow out of. But what I was observing was that when other boys his age would only go to step B.; C would go on to step C. When C wouldn't change the other kids would get mad at him. But, I was also relieved. I also felt guilty because I knew it came straight down from my side.

QUESTION #3. When you learned the diagnosis did you realize the true extent of the disorder?

ANSWER. No. Even after reading about it I didn't realize how very interrelated it is with other things. I didn't realize the scope... and how long this would take. I also didn't realize how it would impact the family. I knew how it was affecting me and my husband, but it also impacted his younger sister. For a time I took him off of medication. One day his sister asked me to please put him back on his meds. She was just feeling slighted and left out because I was always wrapped up in trying to take care of C. So, my other kids got left behind. As a result his younger sister became more self-sufficient and more of a starter. She knew there would be less stress if she was ready even if C wasn't. She would pick up his shoes and take them with her to the car if C forgot to put them on or if I ran out of time. I did this clapping thing 15 minutes before it was time to go. She just knew she had to pull things together so that I wouldn't get mad. And as a result she became somewhat of a pleaser.

QUESTION #4. If not, when was the first time you realized the true extent and impact of your child's ADHD disorder and what were your feelings at that time?

ANSWER. I guess in kinder-garden. When he went to kinder-garden and it wasn't just our family. Here were all these people that were totally qualified...when they came out and talked to me about how he was impacting the class...I thought, "Oh boy, twelve more years of dealing with this!" And then last Friday, it hit me again, "It's not just getting him through high school, it's going to be like this through college, too." He's very bright. He was asked to be in advanced classes this year. We made requests for more specific accommodations and they weren't in place for the beginning of the year. So, of course, it wasn't going well in those harder classes. He got a D on one of the tests and the teacher suggested that he drop out. It's always a struggle and in the mean time C feels bad about himself and discouraged. He had a lot of anxiety in the class...it was my fault, I didn't prepare him for what the advanced class would be like. So, it hits you hard.

QUESTION #5. What kind of adjustments have you personally and as a parent had to make since the time of diagnosis or since you realized the true extent of the disorder?

ANSWER. Well, I have made adjustments in structure like the 15 minute warning clap and teaching all my kids to organize by color. I home schooled C from first to fourth grade because of his ADHD. He had experienced a lot of abuse at the public school so we thought home schooling would be best. Also, I print up schedules daily for C and all the kids.

QUESTION #6. As the mother of an ADHD child what has been most helpful to you in dealing with C's ADHD?

ANSWER. Getting and working with an ADHD coach and counselor. I always tell other parents with ADHD kids to get an ADHD coach. Other counselors that we tried weren't helpful because they seemed frustrated with C's hyperactivity. Another helpful thing was that our whole family went to an ADHD workshop.

QUESTION #7. In your position as the mother of an ADHD child, what has not been helpful?

ANSWER. It was not helpful when other people would blame him and say, "If he would just try harder." Or, they would judge my parenting. But when they would judge him that would be the most difficult. We also got questionable direction from healthcare providers who are not familiar with ADHD. I would ask a question about a med and then after their response it would be very obvious that they know nothing. I'm a teacher and a parent and when you have a child with ADHD you educate yourself. I would think to myself, "Why did I even ask?"

QUESTION #8. As the primary caregiver could you list or identify 5 emotions that you routinely experience?

ANSWERS.

- a. laughter/joy
- b. frustration
- c. disappointment
- d. guilt
- e. anger

QUESTION #9. Thinking back to that time when you fully felt the impact of your child's ADHD diagnosis, has there been a time since then when something happened and you had the same feeling of laughter/joy, frustration, disappointment, guilt, and/or anger that you described above?

ANSWER. Yes, in dealing with C's teachers. Except when we finally got him into a charter school. I was so frustrated when he was in first grade in the public school. The teachers would continually put him in the "Stop and Think Room". He was in there all the time and for very long periods of time. During that time I had all of those feelings but joy. But in the charter school they did appreciate his happiness and joy and then I could also feel that.

QUESTION #10 What feelings do you have right now when you think about C's ADHD?

ANSWER. Sadness. I think things are pretty OK when the meds are being managed. But today, he forgot his meds. If I'm at work I spend time the entire day wondering what his day will be like. How can I help get him to a point where he can do it himself. I've given him the tools... but what about the future?

QUESTION #11. Can you tell me about other times when you felt this way?

ANSWER. Last year he had an incident and pushed a kid against the wall. I was so scared for so many days thinking about what will happen to him in the future. Will he end up in the juvenile system? Will he go down the wrong road? I worried if would happen again. C has a good heart. He would never just be mean. I worried over how this incident would make him feel about himself. That's why I so often say, "I'll drive your med to school."

QUESTION #12. Are there certain types of trigger events that end to bring up these feelings repeatedly?

ANSWER. Last night is a perfect example. His meds had completely worn off and he didn't want to take an afternoon dose and I was still at work so I can't make him take them. He's in the room where I am working on homework with the girls and he comes in acting silly, making a lot of noise, playing with the dog and I think, "Oh God, please just stop being here so I can concentrate on the girls." It's 6PM. I can't give him more medication or he will be up all night. I don't want to deal with this, I just want him to stop. If we leave the room he follows us...he is just being hyper and funny, but its not funny. That kind of thing is a trigger. Worry is a trigger, too.

QUESTION #13. How would you compare these later experiences to the feeling you originally had?

ANSWER. b. Usually just as intense. Initially, I didn't have enough skills to calm myself. So, I've had to change my approach. For instance, talking more slowly and planning ahead of time what I want to say. Sometimes I write down what I want to say so that I stay focused. Talking slowly helps me to stay calm and rational. I've also changed how I react to things.

QUESTION #14. In relation to what you view as normal emotional responses in parenting a child without ADHD; how would you characterize and/or compare your experience of caring for your ADHD child?

ANSWERS.

- a. Undue stress: yes
- b. Undue anxiety: yes
- c. Continual or periodic sadness: yes
- d. Undue guilt: yes
- e. Undue disappointment: yes
- f. Hope for his/her future: yes
- g. Undue feelings of failure in my ability to effectively parent: yes
- h. Undue depression: yes

- i. Social isolation: yes
- j. Marital discord secondary to issues regarding your ADHD child: yes
- k. Intermittent happiness when spending time with your ADHD child: yes
- l. Loss of the child I imagined: yes
- m. Loss of my parental ideals: yes
- n. Necessary change in my perceptions, expectations, and goals for my ADHD child: yes
- o. Undue worry and fear for my child and their future: yes
- p. Episodes of grief: yes
- q. intermittent sadness and sorrow: yes

QUESTION #15. Are there any other comments, thoughts or advice that you would like to add regarding your experience as the primary caregiver to a child with ADHD that you think might benefit other mothers with ADHD children.

No... well, maybe. I did a lot of visuals that were really helpful. The clapping 5 minutes before it was time to go or be finished with something. I did the Shoe Garden at the front door. That is arranging the shoes like a garden in pairs and rows. When it's messy it's a Weed Garden. That was very helpful to keeping things in order. Then I did a lot of signing. I would signal on my nose for C to make eye contact. Then I had one for calm down, sit down, please and thank you. Then I didn't have to repeat or yell. The book, *Baby Signs*, really helped me to not be irritated and yell. I also did a lot of car games and singing and word games. Play dates were very important and having them over at my house was good because I could keep an eye on C and see how he was doing. I always coached him on his behavior ahead of time...how to play and how to get along. Everything was a teaching moment.

#18 MOTHER talking about her child (C).

QUESTION #1. How did you first learn that C has ADHD?

ANSWER. Through a therapist that was engaged after C had an episode of acute depression. She was concerned that C had ADHD because she said, many kids with depression have ADHD.

QUESTION #2. Can you recall your feelings when you first learned about it?

ANSWER. I was feeling pretty focused on what I could do to help her get the extended time she might need for college entrance exams. The therapist had encouraged us to get C testing prior to college in case she needed extra time for testing. My consciousness has expanded so much since that time. I knew so little.

QUESTION #3. When you learned the diagnosis did you realize the true extent of the disorder?

ANSWER. No. It's been an education process for me. I've been getting an education while C has been getting educated. It's been a real experience for me.

QUESTION #4. If not, when was the first time you realized the true extent and impact of your child's disorder and what were your feelings at that time?

ANSWER. Probably when she needed to get out of the CIB program (honors course). And she ended up leaving her school and going to a charter school. I was worried about her ability to be successful academically and everything that translates to for her future.

QUESTION #5. What kind of adjustments have you personally and as a parent had to make since the time of diagnosis or since you realized the true extent of the disorder?

ANSWER. I've had to take more time to reinforce her good qualities and occasionally help her with school-work. And then, too, I've had to remind her when she's having difficulty how the ADHD factors into this. Also, her working memory problems get in the way of her doing well easily in Spanish. I've had to take time, be alert and focused when her mind is doing two things at once.

QUESTION #6. As the mother of an ADHD child what has been most helpful to you in dealing with C's ADHD?

ANSWER. Well, the first thing would be reading the psychometric testing results because I didn't know anything about the disorder before that. And then getting an ADHD coach/counselor because there was a big focus on the ADHD and the depression. Then there has been a lot of education about this. That has been helpful.

QUESTION #7. In your position as the mother of an ADHD child, what has not been helpful?

ANSWER. I'm struck by how if a child like her didn't have a smart articulate pushy parent, like myself, how C would still be in a really bad place. I've had to be her advocate. I feel for kids that have the disorder and the things they go through. It's taken a lot of time and energy to get her into school...a college that works for her. There aren't

any ADHD coaches around where we live. The capacity of the system does not meet the need.

QUESTION #8. As the primary caregiver could you list or identify 5 emotions that you routinely experience?

ANSWERS.

- a. sadness
- b. worry
- c. frustration
- d. empathy
- e. humor

QUESTION #9. Thinking back to that time when you fully felt the impact of your child's ADHD diagnosis, has there been a time since then when something happened and you had those same feelings of sadness, worry, frustration, empathy and/or humor that you described above?

ANSWER. When I submitted the application to the ACTs for extended time. I was worried about whether or not we would get it and I knew that C would need that to be successful.

QUESTION #10. What feelings do you have right now when you think about C's ADHD?

Sadness. Just that.

QUESTION #11. Can you tell me about other times when you felt this way?

I felt this same way each time her Dad has denied that she even has ADHD. I feel sad that someone you'd expect to understand or learn about the disorder wouldn't be supportive. It gives me a look into the world and how others won't cut her slack or be sympathetic and don't get it. The extent she'll have to be an advocate for her self. As it is she doesn't like to draw attention to her self. So it's very hard.

QUESTION #12. Are there certain types of trigger events that tend to bring up these feelings repeatedly?

ANSWER. Academics. There are multiple academic related concerns. I guess it comes up in her relations, too. She gets burnt out quickly...but that is sort of wrapped up with her depression. It's hard for me to sort it all out. It's the ups and downs. She tries really hard and gets tired. She tries too hard and crashes. She's not calm or OK with who she is...

QUESTION #13 How would you compare these later experiences to the feelings you originally had?

ANSWER. a. Usually more intense

QUESTION #14. In relation to what you view as normal emotional responses in parenting a child without ADHD; how would you characterize and/or compare your experience of caring for your ADHD child?

ANSWERS.

- a. Undue stress: yes
- b. Undue anxiety: yes
- c. Continual or periodic sadness: yes
- d. Undue guilt: no
- e. Undue disappointment: no
- f. Hope for his/her future: yes
- g. Undue feelings of failure in your ability to effectively parent: no
- h. Undue depression: no
- i. Social isolation: no
- j. Marital discord secondary to issues regarding your ADHD child: NA
- k. Intermittent happiness when spending time with your ADHD child: yes
- l. Loss of the child I imagined: no
- m. Loss of my parental ideals: no
- n. Necessary change in my perceptions, expectations, and goals for my ADHD child: yes
- o. Undue worry and fear for my child and their future: yes
- p. Episodes of grief: yes
- q. Intermittent sadness and sorrow: yes

QUESTION #15. Are there any other comments, thoughts and/or advice that you would like to add regarding your experience as the primary caregiver to a child with ADHD that you think might benefit other mothers with ADHD children?

It's hard to say...Learn as much as you can about the variations your child has in relation to their disorder. You need this so you don't make your child feel bad about something that is not their fault.

Adjust one's own expectations. You need to adjust your time frame and how much time you'll have available for your child or for your stuff. Parenting is going to take more time. That's a big one. But not everyone has that amount of time available or even maybe determination.

#19 MOTHER talking about her child (C).

QUESTION #1. How did you first learn about C's ADHD?

ANSWER. She was diagnosed in 5th grade. The teacher told us she thought she might have it because she couldn't stay focused.

QUESTION #2. Can you recall your feelings when you first learned about it?

ANSWER. I think I was surprised and happy because now we had something to work with. But we didn't know what was ahead and there would be medications and at first I thought those would be a great idea.

QUESTION #3. When you learned the diagnosis did you realize the true extent of the disorder?

ANSWER. No. It was probably 200 times worse than we thought...probably because we didn't initially know anything about it. You know, the disorder, the pills, and everyday all the time spent dealing with it.

QUESTION #4. If not, when was the first time you realized the true extent and impact of your child's disorder and what were your feelings at the time?

ANSWER. Well, the depression was a big part of this, too. It was when she wrote her suicide letter. She always cried every night before bed. She was very unhappy. Things seemed to get even worse when we started the ADHD medication. It seemed to change her personality. At times we called her the scorpion. She was crabby, moody, unhappy, irritated. When my husband found the suicide note we took her to the Emergency Room. We sat there for hours...a full day and part of a night. We thought about that letter. It was really well written. Initially I thought all this was caused by the ADHD not the med, but now, I've changed my mind...anyway, that is when it hit me that this is going to be a really long road.

QUESTION #5. What kind of adjustments have you personally and as a parent had to make since the time of diagnosis?

ANSWER. We've had to watch her a lot closer. We tightened our grip which isn't the same as doing everything for her...it was just tighter rules. We constantly second guessed her, which isn't good...and my husband and I have had to get therapy. That is when I first realized that I have ADHD.

QUESTION #6. As the mother of an ADHD child what has been most helpful to you in dealing with C's ADHD?

ANSWER. An ADHD coach and counselor. The group therapy, the Mom's Support Group. But, number one would be our faith because we just knew the Lord has been with us through everything, every day. He's put good people in our path and I know that C prays, too.

QUESTION #7. In your position as the mother of an ADHD child, what has not been helpful?

ANSWER. The staff at the high school where she used to go. They could have cared less. She transferred to a different high school because of that and at the new high school they really did care and that really helped. And then our ADHD coach helped us through the 504 and IEP that she eventually needed.

QUESTION #8. As the primary caregiver could you list or identify 5 emotions that you routinely have?

ANSWERS.

- a. love
- b. disappointment
- c. sadness
- d. great joy
- e. fear

QUESTION #9. Thinking back to that time when you fully felt the impact of your child's ADHD diagnosis, has there been a time since then when something happened and you had those same feelings of love, disappointment, sadness, great joy and/or fear that you described above?

ANSWER. Yes. The night she ended up at the hospital and then on the psychiatric unit. We were going to have a girls bonding night, you know C and I. When I got home she was so drunk she could hardly talk. Then we got into an argument, she ended up running away...and it was so cold that night...the police picked her up. That night there was disappointment, fear, love...everything but great joy.

QUESTION #10. What feelings do you have right now when you think about C's ADHD?

ANSWER. I feel like we're coming out of this...plateauing you might call it. That makes me feel wonderful. I'm very happy that I'm too old to have children. I wouldn't want to go through this, again. I saw my grandchildren recently. One of them has ADHD. It reminded me.

QUESTION #11. Can you tell me about other times when you felt this way?

ANSWER. Mother's Day. We told her we would trust her to be home alone for one night while we went to the cabin. We were clear that we were testing, "...you to see how you can do." She had a party, she got drunk, had unprotected sex with a guy she just met on my bed. Things were stolen...my computer, jewelry...I felt hate for C. I felt betrayed, sad. C was upset and felt horribly embarrassed and like a loser. It's very sad and difficult.

QUESTION #12. Are there certain types of trigger events that tend to bring up these feelings?

ANSWER. When she was younger she used to hug the dog. As she got older I could tell by the tone of her voice that we were going to be in for problems. I guess the triggers are

the tone of her voice and the way she looks away or when she yells at me. Those are signals.

QUESTION #13. How would you compare these later experiences to the feelings you originally had?

ANSWER. a. Usually more intense.

QUESTION #14. In relation to what you view as normal emotional responses in parenting a child without ADHD; how would you characterize and/or compare your experience of caring for your ADHD child?

ANSWERS.

- a. Undue stress: yes
- b. Undue anxiety: yes
- c. Continual or periodic sadness: yes
- d. Undue guilt: yes
- e. Undue disappointment: yes
- f. Hope for his/her future: yes
- g. Undue feeling of failure in your ability to effectively parent: yes
- h. Undue depression: yes
- i. Social isolation: yes
- j. Marital discord secondary to issues regarding your ADHD child: yes
- k. Intermittent happiness when spending time with your ADHD child: yes
- l. Loss of the child I imagined: no
- m. Loss of my parental ideals: yes
- n. Necessary change in my perceptions, expectations, and goals for my ADHD child: yes
- o. Undue worry and fear for my child and their future: yes
- p. Episodes of grief: yes
- q. Intermittent sadness: yes

QUESTION #15. Are there any other comments, thoughts and/or advice that you would like to add regarding your experience as the primary caregiver to a child with ADHD that you think might benefit other mothers with ADHD children.

ANSWER. It would be important to look for another way to help your child in another way than through medication like diet, vitamins...something different. Mother's should get therapy and the child, too. Also, both parents and kids need to learn to, "ride the waves." And you need to teach your child to, "use your wise mind," in order to make good choices.

Finally, good luck.

#20 MOTHER talking about her child (C).

QUESTION #1. How did you first learn that C has ADHD?

ANSWER. I have wondered about it for a long time. I began to notice in kinder-garden and first grade that I was always nagging, "Put on your coat." In fourth grade it became more of an issue. I brought up to the fourth grade teacher and she was all over it and then we had her evaluated. We had mentioned it to the third grade teacher. She had noticed some behaviors but didn't feel like there was anything that was really a problem.

QUESTION #2. Can you recall your feelings when you first learned about it?

ANSWER. I wasn't surprised. But I was a little bit troubled because I didn't want any major response that is a part of ADHD like medications or that we would be compelled because of the diagnosis. You know the whole teacher or doctor pressure on us.

QUESTION #3. When you learned the diagnosis did you realize the true extent of the disorder?

ANSWER. I don't think so. I still don't feel like I know the true extent.

QUESTION #4. If not, when was the first time you realized the true extent and impact of your child's disorder and what were your feelings at that time?

ANSWER. I think I was aware well in advance of the diagnosis. I guess in a way I am still not really understanding the impact of the diagnosis...will it get better or worse? The criteria we're using for medications are grades or difficulties with friends.

QUESTION #5. What kind of adjustments have you personally and as a parent had to make since the time of diagnosis or since you realized the extent of the disorder?

ANSWER. We have become much more deliberate about setting limits, about staying on task and about time. Frankly, it's helped me to be more patient with timeliness, homework, funny behaviors. For instance when we go to a restaurant that we have been to numerous times and the waitress asks her what she wants to drink and she can't decide and spends forever making up her mind. She just can't get it done and I have had to become more tolerant, and more understanding of her situation with the ADHD.

QUESTION #6. As the mother of an ADHD child what has been most helpful to you in dealing with C's ADHD?

ANSWER. An ADHD coach and counselor. The direction and education about the disorder. But, the thing about the ADHD is the cluster of symptoms. Books are so general. So, direction and insight from a coach/counselor applied to C is so helpful and then the things that I can do are important.

QUESTION #7. In your position as the mother of an ADHD child, what has not been helpful?

ANSWER. I can't identify anything that's not helpful. We haven't implemented the 504, we're just waiting and looking at her school performance right now.

QUESTION #8. As the primary caregiver could you list or identify 5 emotions that you routinely experience?

ANSWERS.

- a. frustration
- b. more frustration
- c. anger
- d. despondency
- e. helplessness

QUESTION #9. Thinking back to that time when you fully felt the impact of your child's ADHD diagnosis, has there been a time since then when something happened and you had those same feelings of frustration, more frustration, anger, despondency and/or helplessness that you mentioned above?

ANSWER. Every day. Nearly every day the frustration is there and then the well...not really depression, but something like that.

QUESTION #10 What feelings do you have right now when you think about C's ADHD?

ANSWER. Frustration

QUESTION #11. Can you tell me about other times when you felt this way?

ANSWER. Last week. I started work on Monday. We have the same after school babysitter so she's completely plugged into our family and our routine. C should have been practicing her instruments after school while the babysitter was there for the past week. When I asked her to take out her music stuff it was clear she hadn't done anything. She had lied to me and to the nanny.

QUESTION #12. Are there certain types of trigger events that tend to bring up these feelings repeatedly? My threshold for things seems to be becoming lower. The nagging...a lot of the same thing every day. Getting dressed...making sure her socks are on. Stuff that we have worked on. I've insensitized the issue in order for her to comply, talked it over. It still falls apart.

QUESTION #13. How would you compare these later experiences to the feelings you originally had?

ANSWER. a. usually more intense.

QUESTION #14. In relation to what you view as normal emotional responses in parenting a child without ADHD; how would you characterize and/or compare your experience of caring for your ADHD child?

ANSWERS.

- a. Undue stress: yes
- b. Undue anxiety: no
- c. Continual or periodic sadness: yes, periodic
- d. Undue guilt: yes
- e. Undue disappointment: yes
- f. Hope for his/her future: yes

- g. Undue feeling of failure in your ability to effectively parent: yes
- h. Undue depression: yes
- i. Social isolation: no
- j. Marital discord secondary to issues regarding your ADHD child: yes
- k. Intermittent happiness when spending time with you ADHD child: yes
- l. Loss of the child I imagined: yes
- m. Loss of my parental ideals: yes
- n. Necessary change in my perceptions, expectations and goals for my ADHD child: yes
- o. Undue worry and fear for my child and their future: yes
- p. Episodes of grief: yes
- q. Intermittent sadness and sorrow: yes

QUESTION #15. Are there any other comments, thoughts and/or advice that you would like to add regarding your experience as the primary caregiver to a child with ADHD that you think might benefit other mothers with ADHD children?

ANSWER. No. I'm at a loss. I guess seek out the assistance of an ADHD coach.

21 MOTHER talking about her child (C).

QUESTION #1. How did you first learn about C's ADHD?

ANSWER. I feel like I knew it myself when he was 4. I was suspicious at a younger age, even at age 2. He couldn't finish age appropriate puzzles. He was clinically diagnosed at age 8. He struggled in Pre-K and through 1st grade. I felt like and regret this now, I worked through the medical setting because I didn't want him labeled. He was officially diagnosed with ADHD and I wanted to deal with it in a way that he wouldn't be viewed in a negative way. It was always the structured school environment that was the problem. Others didn't see what we saw. Like my brother...

QUESTION #2. Can you recall your feelings when you first learned about it?

ANSWER. Relief was the biggest one and sadness at the same time. Having the diagnosis made it something that we could deal with and then move forward. I think the whole family was different at the time. He and his older brother didn't get along. So, when we were able to tell him he wasn't as hard on C. He began to treat him in a different way.

QUESTION #3. When you learned the diagnosis did you realize the true extent of the disorder?

ANSWER. I think I did.

QUESTION #4. If not when was the first time you realized the true extent and impact of your child's disorder and what were your feelings at that time?

ANSWER. I always and probably still want to believe that this is something he'll learn to work around. He's smart enough to be able to learn to deal with this. It's as much about the way others and I react as it is about him.

QUESTION #5. What kind of adjustments have you personally and as a parent had to make since the time of diagnosis or since you realized the extent of the disorder?

ANSWER. What we didn't do right away and should have was to work with the school system. We didn't do that until fifth grade. We didn't like the way the teacher was interacting with C. So, we finally got them involved. We definitely spent a lot more time raising him than our other kids...school work wise.

QUESTION #6. As the mother of an ADHD child what has been most helpful to you in dealing with C's ADHD?

ANSWER. Just educating me about it. Learning the cause and effect...well, not the cause, but learning different approaches when I work with C. When I get frustrated it definitely doesn't help. Then I step back and let my husband work with him. In certain areas I've lowered my expectations. Like homework.

QUESTION #7. In your position as the mother of an ADHD child, what has not been helpful?

ANSWER. I think because of my mother-in-law we did try and alternative diet and environment...that kind of thing. She's really an environmentalist so... laundry

detergent...I switched to a different brand without chemicals. I didn't find any of these things helpful. I also tried some herbal products that a man at work recommended. That didn't help.

QUESTION #8. As the primary caregiver could you list or identify 5 emotions that you routinely experience?

ANSWERS.

- a. frustration
- b. anxiety
- c. love
- d. fun
- e. joy

QUESTION #9. Thinking back to that time when you fully felt the impact of your child's ADHD diagnosis, has there been a time since then when something happened and you had those same feelings of frustration, anxiety, love, fun and/or joy that you mentioned above.

ANSWER. Routine homework-every day frustration. There's stress. Sometimes I feel like I want to spend time doing other things I want. Homework just consumes a lot of time. He maybe has two hours of homework every night and that would be fine if his grades reflected that. But, he works hard on his homework and his grades don't show that.

QUESTION #10. What feelings do you have right now when you think about C's ADHD?

ANSWERS. The worry and anxiety of the future for him.

QUESTION #11. Can you tell me about other times when you felt this way?

ANSWER. Well, there is just always this same underlying concern that is always there.

QUESTION #12. Are there certain types of trigger events that tend to bring up these feelings repeatedly?

ANSWER. Homework and the whole life skills thing. Will he ever be able to live independently...get a job.

QUESTION #13. How would you compare these later experiences to the feelings you originally had?

ANSWER. b. Usually just as intense.

QUESTION #14. In relation to what you view as normal emotional responses in parenting a child without ADHD: how would you characterize and/or compare your experience of caring for your ADHD child?

- a. Undue stress: yes
- b. Undue anxiety: yes
- c. Continual or periodic sadness: no
- d. Undue guilt: no

- e. Undue disappointment: yes
- f. Hope for his/her future: yes
- g. Undue feelings of failure in your ability to effectively parent: yes
- h. Undue depression: no
- i. Social isolation: yes
- j. Marital discord secondary to issues regarding your ADHD child: yes
- k. Intermittent happiness when spending time with your ADHD child: yes
- l. Loss of the child I imagined: no
- m. Loss of my parental ideals: yes
- n. Necessary change in my perceptions, expectations, and goals for my ADHD child: yes
- o. Undue worry and fear for my child and their future: yes
- p. Episodes of grief: no
- q. Intermittent sadness and sorrow: yes

QUESTION #15. Are there any other comments, thoughts and/or advice that you would like to add regarding your experience as the primary caregiver to a child with ADHD that you think might benefit other mothers with ADHD children?

ANSWER. The thing I regret is trying to hide this from the school system. I think acknowledging and talking to him and everyone about it is a positive thing and makes it easier. And then I think, just let him be himself not what I expect him to be. But let him be who he is. Talk to other parents. Don't be afraid to get help. Ask for the help you need.

#22 MOTHER talking about her child (C).

QUESTION #1. How did you first learn that C has ADHD?

ANSWER. His kinder-garden teacher brought to our attention that he was more active than the other children in his class. She had experience in Special Education. We always knew that he was very active but I didn't have brothers. I just thought he was active like a boy.

QUESTION #2. Can you recall your feelings when you first learned about it?

ANSWER. It was more of a relief that I wasn't an inadequate parent. I was having trouble keeping up with him. He was always running away. It wasn't that I thought different parenting would have changed him. Like at his birthday party when he was 2 years old, he just wandered off. This was typical; he was just always walking off. I was always on the run.

QUESTION #3. When you learned the diagnosis did you realize the true extent of the disorder?

ANSWER. No. Everybody just thinks that its hyperactivity. There was a point in time when his behavior became more defiant and it became more of a behavioral issue. He would be angry and yelling about something but the next day that same thing wouldn't bother him. And then there was the issue that he just couldn't follow directions.

QUESTION #4. If not, when was the first time you realized the true extent and impact of your child's disorder and what were your feelings at that time?

ANSWER. I still don't know the true extent. We still are in the reaction mode. We deal with what we have at the moment. The episode we had with the Concerta is what comes to mind. He was totally out of control when he began that medication. He was out of control and I have these two other younger children. All I could think of was, "how am I going to care for them with this other little tornado racing around?" I had a lot of fear and anger towards him. It was really hard. There has always been a line and I don't know where one stops and the other begins. I kept thinking, "Why are you doing this to me?" Do I yell at him because he is out of control or do I empathize because he has ADHD and just let him run around and yell?

QUESTION #5. What kind of adjustments have you personally and as a parent had to make since the time of diagnosis or since you realized the extent of the disorder?

ANSWER. Well, you kind of change your expectations. That's such a gray area. I know in the back of my head that I have to make adjustments and keep C's best interest in mind. It's hard because other parents put a lot of pressure on you and the way you parent and the way your child performs. I've had to adjust the way I see my parenting and know that I am doing what I need to do in spite of how C might act or perform. So, it's not all about my failure. One of the adjustments is trying to determine these gray areas. There are lines where I'm not sure if it's the ADHD or the Alopecia piece that I am dealing with. I can't grasp where the ADHD starts...what is just normal boy stuff...what actions are the effect of the Alopecia. I think I'm pretty knowledgeable because I read a lot and I have educated my self about all these things, but it is still very difficult. Also, I am

constantly making adjustments for what I do with my husband. Trying to get a balance with my husband and the way we parent is tough. We are two different minds with two very different ideas of what is the right way to parent...then you add in the element of the ADHD and C's alopecia and it's very hard, very hard every day. I have tried to find out the strength of my ADHD child and then stick with that. Right now my adjustment is attempting to help him with social issues and that wasn't expected. As he goes through his day he starts to feel he isn't smart. So, I've tried to let him know he is smart like me. I am constantly trying to take him to a place where he will see his uniqueness. C is not going to be mainstream...what everyone else views as perfect.

QUESTION #6. As the mother of an ADHD child what has been most helpful to you in dealing with C's ADHD?

ANSWER. Medication is #1. It's such a major part of all this. I went to a CHADD (Children with Hyperactive Attention Deficit Disorder) conference that promoted a very structured rigid approach to parenting and ADHD child. Then I went to a seminar with a local ADHD speaker who said that ADHD kids can't help what they do and the way they act, so you can't really be rigid with your approach. Both of these were very good, but where does that leave me. I just need a plan, an approach that would be helpful. Something else that has been helpful has been an ADHD coach/counselor. That has been great for C and for my husband and I...but then I end up with the same problem and that's trying to apply it.

QUESTION #7. In your position as the mother of an ADHD child, what has not been helpful?

ANSWER. As I said, a lot of these things are very helpful, but there always seems to be the other side that isn't helpful. I am always looking for something black and white as far as an approach and maybe there isn't anything. I am an unstructured person trying to structure things for my ADHD child. Also, an uninformed opinion is really not helpful.

QUESTION #8. As the primary caregiver could you list or identify 5 emotions that you routinely experience?

ANSWERS.

- a. frustration
- b. hopelessness
- c. encouragement
- d. anger
- e. unpredictability

QUESTION #9. Thinking back to that time when you fully felt the impact of your child's ADHD diagnosis, has there been a time since then when something happened and you had those same feelings of frustration, hopelessness, encouragement, anger and/or unpredictability that you mentioned above?

ANSWER. Yes, most mornings I feel that unpredictability piece. Getting him up and going in the morning can be very frustrating because there are times when he'll just pop out of bed and then others when he won't. On those mornings that start badly breakfast becomes an issue because of his weight. I'll make him something that the day before he

said he loved and then that morning he'll yell and scream that he hates it. I'll get angry. I'll be patient as long as I can. I'll get very angry. I know I need to get him off to school. Another day he is fine and cooperative and that's where I'll feel encouraged, "Maybe we're done with those battles." But we never are.

QUESTION #10. What feelings do you have right now when you think about C's ADHD?

ANSWER. When his mood is under control I'm very protective and warm with him. I've experienced times of tremendous guilt. This time of day I have a good feeling because he is in a good place today. I also have feelings of dread about having to be his mom because it takes a lot out of you. Its just scary because I don't know where his age is going to take us with all of this. It's so painful to watch him as people realize he's different.

QUESTION #11. Can you tell me about other times when you felt this way?

ANSWER. No because I pretty much feel these on a daily basis. All of them. I wish there were more of a gap with the ADHD times. It's taken a big bite out of me and quite a few years off my life. I used to think I would live forever. I'm worried that I will start to get sick.

QUESTION #12. Are there certain types of trigger events that tend to bring up these feelings repeatedly?

ANSWER. His screaming and uncontrollable yelling about something inconsequential. When his whole world is tossed in the air. I can't stop him or rope him in.

QUESTION #13. How would you compare these later experiences to the feelings you originally had

ANSWER. a. Usually more intense

QUESTION #14. In relation to what you view as normal emotional responses in parenting a child without ADHD; how would you characterize and/or compare your experience of caring for your ADHD child?

ANSWERS.

- a. Undue stress; yes
- b. Undue anxiety: yes
- c. Continual or periodic sadness: yes
- d. Undue guilt: yes
- e. Undue disappointment: yes
- f. Hope for his/her future: yes
- g. Undue feeling of failure in your ability to effectively parent: yes
- h. Undue depression (not diagnosed): yes
- i. Social isolation: no
- j. Marital discord secondary to issues regarding your ADHD child: child
- k. Intermittent happiness when spending time with you ADHD child: yes
- l. Loss of the child I imagined: yes
- m. Loss of my parental ideals: yes

- n. Necessary change in my perceptions, expectations, and goals for my ADHD child: yes
- o. Undue worry and fear for my child and their future: yes
- p. Episodes of grief: yes
- q. Intermittent sadness and sorrow: yes

QUESTION #15. Are there any other comments, thoughts or advice you would like to add regarding your experience as a primary caregiver to a child with ADHD that you think might benefit other mothers of ADHD children?

ANSWER. Well, find out as much as you can. The disorder is so much more complex than others realize. Find out specifically how it affects your child because it's different for everybody. Medications...I don't know where we'd be without medication. There's a concern, of course, if it's the absolute right thing where his health is concerned. But I don't know how I'd mother him if he wasn't on medication...it's made that much of a difference. Find out different outlets for support: doctors, ADHD coach/counselor, teachers. It's really easy to not deal with it. It's a bomb waiting to go off if you don't deal with it, though.

#23 MOTHER talking about her child (C).

QUESTION #1. How did you first learn that C has ADHD?

ANSWER. It was first mentioned when C was in 1st grade. Her 1st grade teacher thought that it was a possibility. She said that she frequently had to get C's attention, that she was very active and distracting to other children in the class. She said that C must be learning from osmosis because she always getting her attention, but C always seemed to know what the topic and answer was. She brought this up as a consideration. In 2nd grade she had team teachers who never mentioned any of this. During a third grade conference in October I could tell from the door which desk was C's. It made my heart hurt...there were papers sticking out of the desk and the top wasn't even closed. We took the wheel and we did something. We went to her pediatrician who did some testing and the school did testing. It was such a process. It took so long. We didn't get a diagnosis until 3rd grade, almost. In 4th grade we started medication.

QUESTION #2. Can you recall your feelings when you first learned about it?

ANSWER. Confusion as to how it happened...how it took the school to recognize it. I felt it should have been me. I thought she was perfectly normal. I felt bad that I hadn't recognized it. I was disappointed. I knew there would be a stigma with her teachers, our relatives...dealing with others opinions.

QUESTION #3. When you learned the diagnosis did you realize the true extent of the disorder?

ANSWER. No. I was pretty ignorant. I didn't realize how many aspects of her life it would pertain to. I thought she would outgrow it and be like everyone.

QUESTION #4. If not, when was the first time you realized the true extent and impact of your child's disorder and what were your feelings at that time?

ANSWER. In junior high when she started an extracurricular activity. Her social group expanded, there was a lot of peer pressure. Her decisions and impulsivity impacted her and would take her down important and different roads. I was very scared. This was a very scary time. I was apprehensive.

QUESTION #5. What kind of adjustments have you personally and as a parent had to make since the time of diagnosis or since you realized the extent of the disorder.

ANSWER. I don't know that I have made these...I've just grown with her through her development. With her being the oldest I guess I just went with the flow.

QUESTION #6. As the mother of an ADHD child what has been most helpful to you in dealing with C's ADHD?

ANSWER. ADHD coaching. That took a huge load off of me and also helped with that feeling of failing as a mother. I was always looking for ways for her to adjust...different ways for her to get her homework done. The pediatrician was very helpful. Her pediatrician saw C from the time she was 3 and so the care was very consistent.

QUESTION #7. In your position as the mother of an ADHD child, what has not been helpful?

ANSWER. Other people's opinions. Other people telling me how things should be done. People mean well but just don't have any clue what I'm dealing with.

QUESTION #8. As the primary caregiver could you list or identify 5 emotions that you routinely experience?

ANSWERS.

- a. frustration
- b. joy
- c. pride
- d. sadness
- e. her enlightening me

QUESTION #9. Thinking back to that time when you fully felt the impact of your child's ADHD diagnosis, has there been a time since then when something happened and you had those same feelings of frustration, joy, pride, sadness and/or C enlightening you that you mentioned above?

ANSWER. Her first semester at college was very emotional for me. The day we took her I was really looking forward to it...I had dealt with her all through high school. I felt she was ready. Her roommate was from India. The first obstacle was her roommate who turned out to be suicidal. C had to deal with all that. She ended up with a private room. In one way that was good for her focus on schoolwork. On the other hand it isolated her. She had to find a good friend but this became a distraction. She was put on probation the 2nd semester. I experienced sadness, pride in her dealing with all the various issues. I was also frustrated with her procrastination with her homework and she didn't advocate for herself...even though she knew how to do these and had done these in high school.

QUESTION #10. What feelings do you have right now when you think about C's ADHD?

ANSWER. Fear, concern, pride...she's come a very long way. She keeps herself up beat. She is very strong and very determined.

QUESTION #11. Can you tell me about other times when you felt this way?

ANSWER. When she made dance team at college. She had taken the year off from college and done courses at the community college. She returned the next fall to a new college. She wanted to try out for the dance team, again. She's a dreamer. I thought, "Honey, you haven't danced for a long time." We told her this couldn't be a priority that her school work had to come first. She tried out one Saturday and called at noon and said the coach told her, "You can leave now, you already made it." I felt a tremendous amount of pride in her and her ability to recognize her strength and talent on her own.

QUESTION #12. Are there certain types of trigger events that tend to bring up these feelings repeatedly?

ANSWER. Just seeing any junior high girls brings back big emotions. I don't think she shared even half of what was going on and through. Hearing friends talk about their kids that are in junior high just brings all that impulsivity and focus on friends back to me. Also always at the end of a marking period or semester. She tells us what we want to hear. We know she is thinking in the back of her mind, "I'll pick it up." I can tell by the tone of her voice. When things are good, she shares everything. Her tone of voice is a trigger.

QUESTION #13. How would you compare these later experiences to the feelings you originally had?

ANSWER. b. Usually just as intense. There's more at stake on the horizon. She knows that and realizes the consequences of her choices. But during those times in 1st grade, it was just as intense.

QUESTION #14. In relation to what you view as normal emotional responses in parenting a child without ADHD; how would you characterize and/or compare your experience of caring for your ADHD child?

ANSWERS.

- a. Undue stress: yes
- b. Undue anxiety: yes
- c. Continual or periodic sadness: yes. There is just an underlying achiness...just for her to be normal and accepted. It's not fair.
- d. Undue guilt: no
- e. Undue disappointment: no
- f. Hope for his/her future: yes
- g. Undue feeling of failure in your ability to effectively parent: yes
- h. Undue depression: no
- i. Social isolation: yes
- j. Marital discord secondary to issues regarding you ADHD child: yes
- k. Intermittent happiness when spending time with your ADHD child: yes
- l. Loss of the child I imagined: no
- m. Loss of my parental ideals: yes
- n. Necessary change in my perceptions, expectations, and goals for my ADHD child: yes
- o. Undue worry and fear for my child and their future: yes
- p. Episodes of grief: yes
- q. Intermittent sadness and sorrow: yes

QUESTION #15 Are there any other comments, thoughts or advice that you would like to add regarding your experience as the primary caregiver to a child with ADHD that you think may be helpful to another mother with an ADHD child?

As a comment: "I will never be done with this."

Advice would be to accept your child and let them be who they are, as different as it may be from your expectations of who you want them to be. Never limit their goals even when you know their ability is not at that level.

It would have been much more frustrating going through this as a single parent. It takes a village with any child. But these kids need a lot of reassurance and encouragement. So as much as you can experience with them and as much interaction as you can have with them is so important.

Also, communication with your ADHD child is huge. You have to be accepting whether or not you agree. You've got to let them know they can talk to you and that you will listen and that you won't tip-toe around the crappy issues.

#24 MOTHER talking about her child (C).

QUESTION #1. How did you first learn that C has ADHD?

ANSWER. Through diagnosis at an ADHD Clinic. He was in the 7th or 8th grade. It was very challenging for him to get his homework done. And then his own feelings that other kids were thinking negatively about him because he didn't have his homework done. And then our own experience of sitting with him. A ten minute project would take way too long. And then his own doctor doing a rating scale. It was all there.

QUESTION #2. Can you recall your feelings when you first learned about it?

ANSWER. On the one hand I felt relieved, "We now know what this is, we can help." On the other hand a sense of grief or that he would have these challenges. Thinking it would not be as easy for him as other kids. So, I distinctly remember a dual response.

QUESTION #3. When you learned the diagnosis did you realize the true extent of the disorder?

ANSWER. No. I don't think so. I'm still learning about it. I had some ideas, but not much, not enough.

QUESTION #4. If not, when was the first time you realized the true extent and impact of your child's disorder and what were your feelings at that time?

ANSWER. I understood the impact when he was diagnosed, but I didn't understand very much about what you could do to intervene or what he would experience. It was more what it really did that resulted in the impact. Having more knowledge helped me to feel better and be better able to do something. This led to strategies for him...mostly positive ones. On the other hand understanding it made me feel, "That's got to be tough for him." Thinking about what his day to day experience is like makes me feel empathy and sadness.

QUESTION #5. What kind of adjustments have you personally and as a parent had to make since the time of diagnosis or since you realized the extent of the disorder?

ANSWER. Adjustments didn't come right away. I made adjustments to my work schedule as homework has become a big part of his school life. I don't have energy for the friendships I'd like to have. There are the day-to-day demands. Being more involved with his teachers at school has been an adjustment that has meant it is hard to fit in things for myself. The "me" time is not very abundant and sometimes just nonexistent.

QUESTION #6. As the mother of an ADHD child what has been most helpful to you in dealing with C's ADHD?

ANSWER. The parenting class at the clinic where C was diagnosed was good for understanding what ADHD is, what you can do. It was a 6 week class...once a week for six weeks. Then we went to some community ed classes. Now I'm starting a Mom's support group. Connecting with other moms will be good and supportive. The ADHD coach/counselor is good because she is a 3rd party who can be objective and make suggestions and help with what's too much or not enough. That line shifts back and forth.

Also, trying medication to see if it could be helpful. I was reluctant at first, but for C that's really helped.

QUESTION #7. In your position as the mother of an ADHD child, what has not been helpful?

ANSWER. Teachers who think you're babying your child. The stuff you hear in the media about medications. Information that you hear that makes you think you put your child at risk...the over diagnosis stuff, you know. It all makes you question, "Are we doing the right thing?" People that think they know but really don't...they are not helpful.

QUESTION #8. As the primary caregiver could you list or identify 5 emotions that you routinely experience?

ANSWERS.

- a. joy
- b. frustration
- c. pride
- d. sadness
- e. disappointment

QUESTION #9. Thinking back to that time when you fully felt the impact of your child's ADHD diagnosis, has there been a time since then when something happened and you had those same feelings of joy, frustration, pride, sadness and/or disappointment that you mentioned above?

ANSWER. Disappointment. That happened this year, first around the math homework. So, if you don't hand in your first group of 3 days homework you don't get credit. He didn't get any credit. So, the second group he got credit for one assignment, partial credit for another and the third he didn't hand in. So, frustration and sadness because you know how much he had to work on it and then to not get credit.

QUESTION #10. What feelings do you have right now when you think about C? We're going through some minor struggles...I feel sadness and frustration, mostly.

QUESTION #11. Can you tell me about other times when you felt this way?

ANSWER. To me, there is more on the positive side. Seeing him find the things he's good at. Seeing his face light up when he feels good about himself. The work he did last year on the school musical...working on the stage lights or a test he feels really good about...areas that he shines in. Those are good.

QUESTION #12. Are there certain types of trigger events that tend to bring up these feelings repeatedly?

ANSWER. The not getting his homework in, the homework that he has actually done. Being not really cognizant of time. He says he'll be home at 6:30 and it ends up being 7 or he's been in the bathroom for 30 minutes and hasn't showered...he's just in there looking around at things. So, those are some negative triggers. The positive ones are seeing him excited and talkative. That brings out my pride and joy.

QUESTION #13. How would you compare these later experiences to the feelings you originally had?

ANSWER. c. Usually less intense...but it goes in waves. Understanding it and him maturing and figuring out strategies. It's less intense and less often.

QUESTION #14. In relation to what you view as normal emotional responses in parenting a child without ADHD: how would you characterize and/or compare your experience of caring for your ADHD child?

- a. Undue stress: yes
- b. Undue anxiety: yes
- c. Continual or periodic sadness: yes
- d. Undue guilt: no
- e. Undue disappointment: yes
- f. Hope for his/her future: yes
- g. Undue feeling of failure in your ability to effectively parent: yes
- h. Undue depression: no
- i. Social isolation: no
- j. Marital discord secondary to issues regarding your ADHD child: no
- k. Intermittent happiness when spending time with your ADHD child: no
- l. Loss of the child I imagined: yes
- m. Loss of my parental ideals: no
- n. Necessary change in my perceptions, expectations, and goals for my ADHD child: yes
- o. Undue worry and fear for my child and their future: no
- p. Episodes of grief: yes
- q. Intermittent sadness and sorrow: yes

QUESTION #15 Are there any other comments, thoughts or advice that you would like to add regarding your experience as the primary caregiver to a child with ADHD that you think might benefit other mothers with ADHD children.

ANSWER. Yes. Focus on what is really important. Try to forget what you want and make sure that your ideals are really best for them. This might mean they're not in sports. Help them find something they really like where they can build confidence, self-esteem and energy. Find a support network...other parents with ADHD kids. Get an ADHD coach. Do your best to take care of your self spiritually and emotionally. Take some time for your self or take some alone time for your self. Fight the self-talk that tells you are being self-indulgent. If you don't you will get burnt out and have nothing to give. Stress will take you down a negative path and you won't be a positive influence on your child's life. I feel fortunate that my husband is very much a partner in raising C. You just can't do it all your self. Also, resist the temptation to do it all for them. Help them to be as independent as possible and to take responsibility for their own stuff. Let them have some consequences. This is really important.

#25 MOTHER talking about her child (C).

QUESTION #1. How did you first learn that C has ADHD?

ANSWER. It was in 1st grade during conferences. His teacher thought he might have the symptoms of ADHD. I had worked as a recreational therapist. I had experienced ADHD and had a very negative association with it. Since I had this negative association as a direct flashback when his teacher mentioned the symptoms I thought, "There's no way my son has ADHD." I was appalled.

QUESTION #2. Can you recall your feelings when you first learned about it?

ANSWER. Denial, anger, resentment

QUESTION #3. When you learned the diagnosis did you realize the true extent of the disorder?

ANSWER. No. He didn't get diagnosed until 4th grade. He was 9 years old. He started talking saying, "I should just die." His response to his life was just sadness, depression, he degraded himself, "I'm not any good." I started panicking. I started talking to my friends, special ed teachers, teachers. Finally I got the name of a doctor. She never actually said the word depression, but I was very aware that he was depressed. So much goes along with the ADHD...this was just a part.

QUESTION #4. If not, when was the first time you realized the true extent and impact of your child's disorder and what were your feelings at that time?

ANSWER. When the psychologist who did C's testing sat down with us and said this is the diagnosis and extent of C's ADHD. She gave a lot of explanation. I had only seen the extremes not the milder side that my son has. I had to be re-educated. I started getting depressed after he was diagnosed. My husband was in denial about C's ADHD. There was a lot of confusion for him and for me. I finally said if this is the diagnosis, lets just deal with it. The doctor said, "If your son had Diabetes what would you do?" That made sense. We needed to go forward, but it took my husband a long time to accept it.

QUESTION #5. What kind of adjustments have you personally and as a parent had to make since the time of diagnosis or since you realized the extent of the disorder?

ANSWER. The fact that I was depressed about it. I had to make adjustments for that. I had to get C counseling. I had to get over my guilt. I had to get over the fact that I gave my kid ADHD and that it is a diagnosis that I have to deal with. It's better than having cancer-right? I have done a lot of reading. Still, I have a sense of guilt in my stomach. I still feel very inadequate as a mom.

QUESTION #6. As the mother of an ADHD child what has been most helpful to you in dealing with C's ADHD?

ANSWER. The Mom's of ADHD Kid's Support Group to be honest. I know there's CHADD. But I get more out of the support group. Other mother's sharing how they deal with their child's ADHD is so reassuring and helpful. Also, it has been very helpful and necessary for me to educate my child's teachers about ADHD. I have to kiss ass to get

them to listen. It has helpful for me to bring down my expectations of C. I know that he is capable of more because of his intelligence, but unable to perform because of his ADHD.

QUESTION #8. As the primary caregiver could you list or identify 5 emotions that you routinely experience?

ANSWERS.

- a. helplessness
- b. anger
- c. frustration
- d. defeat
- e. sadness, fear, sorrow

QUESTION #9. Thinking back to that time when you fully felt the impact of your child's ADHD diagnosis, has there been a time since then when something happened and you had those same feelings of, helplessness, anger, frustration, defeat, sadness, fear and/or sorrow that you mentioned above?

ANSWER. When I dropped him off at college...there was a lot of fear. I was thinking, "Is he going to be able to do this by himself? Will he be able to feel like he's going to succeed? Will he advocate for himself, take his meds?" I know he has to do this by himself. If he doesn't grow up then I'm a failure...there will be a lot of self-blame.

QUESTION #10. What feelings do you have right now when you think about C's ADHD?

ANSWER. I have a lot of sadness and I feel scared.

QUESTION #11. Can you tell me about other times when you felt this way?

ANSWER. All the time. Like when he first got his drivers license. Like when I knew he was having sex. When he transitioned into middle school. All the time, every change.

QUESTION #12. Are there certain types of trigger events that tend to bring up these feelings repeatedly?

ANSWER. Conferences are big triggers...the beginning of the school year...report card time. Any time it involves a grade, that's a trigger.

QUESTION #13. How would you compare these later experiences to the feelings you originally had?

ANSWER. b. Usually just as intense. How do I approach this? How do I come across as caring? Will there be a blow-up? He always reacts to everything with anger, defensiveness in these situations.

QUESTION. #14. In relation to what you view as normal emotional responses in parenting a child without ADHD; how would you characterize your experience of caring for your ADHD child?

ANSWERS.

- a. Undue stress: yes
- b. Undue anxiety: yes

- c. Continual or periodic sadness: yes
- d. Undue guilt: yes
- e. Undue disappointment: yes
- f. Hope for his/her future: yes
- g. Undue feeling of failure in your ability to effectively parent: yes
- h. Undue depression (not diagnosed): yes
- i. Social isolation: yes
- j. Marital discord secondary to issues regarding you ADHD child: no
- k. Intermittent happiness when spending time with you ADHD child: yes
- l. Loss of the child I imagined: yes
- m. Loss of my parental ideals: yes
- n. Necessary change in my perceptions, expectations, and goals for my ADHD child: yes
- o. Undue worry and fear for my child and their future: yes
- p. Episodes of grief: yes
- q. Intermittent sadness and sorrow: yes

QUESTION #15. Are there any other comments, thoughts or advice that you would like to add regarding your experience as the primary caregiver to a child with ADHD that you think might benefit another mother with ADHD children?

ANSWERS. Educate, educate, educate yourself. Be able to talk about it to your support group, counselor. Pray, pray, pray. Believe in your Higher Power. This keeps me sane. Take care of yourself. Exercise.

Appendix F

Cronbach's alpha

Cronbach's alpha measures the internal consistency of an instrument. It informs how well the instrument has been constructed. It is a correlation that can run from .00 to 1.0. Like any correlation, it is acceptable for an instrument when it is at least .70 for Social Science research and when the sample is appropriate for the instrument. The instrument in this research produces a Cronbach's alpha = .73 indicating that there is acceptable internal consistency making it appropriate for use with these participants.

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