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A Mixed Method Study of Mood Disorders in Mothers of Children with Autism Spectrum
Disorder and Mothers of Typically-Developing Children

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of Towson University

in Partial Fulfillment of the Requirements of the Degree of
Doctor of Science in Occupational Science

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Towson, Maryland

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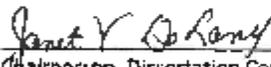
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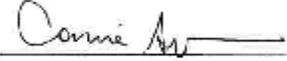
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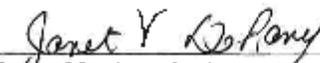
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Dedication

This work is dedicated to all husbands, whom with their selfless love and support get their wives to achieve an ultimate level of success. May this work encourage you to give your wives the support to follow their dreams for their well-being. Since my husband is one of those, I also dedicate this work to you Souheil for all of your unconditional sacrifices and endless motivation. I love you greatly. And to my lovely daughters, Yara and Nataly who bear the weight of the extra challenge with me. I love you dearly.

“All things are possible to him who believes”...Mark 9:23

Abstract

A Mixed Method Study of Mood Disorders in Mothers of Children with Autism Spectrum Disorder and Mothers of Typically-Developing Children

Haifa S Batarseh

This mixed method study examined mood disorders in mothers who were rearing a child with ASD.. The objective of the quantitative section of the study was to examine the occurrence of maternal depression and bipolar disorders in mothers of children with ASD compared to mothers of typically developing (TD) children. The Depression History Questionnaire that was adapted from Interactive Autism Network (IAN) at Kennedy Krieger Institute (KKI) database was used for this comparison. The qualitative section of the study explored the meaning of the lived experience of mothers who concurrently were depressed and rearing a children with ASD using a phenomenological approach.. Results of the quantitative inquiry indicated that mothers of children with ASD report a history of: (a) depression and bipolar disorder; (b) treatment for depression or bipolar disorder; (c) suicidal ideation or suicidal attempts; and (d) depression, bipolar disorder, and suicide among the participants' first and second-degree relatives more frequently than mothers of TD children. The following five emerged themes emerged from the qualitative exploration: a) Regardless of when I was first diagnosed, having a child with ASD contributed to and intensified my depression; b) I feel a lack of support and understanding either from my husband, the extended family, or the community; c) Challenges and stressors of rearing a child with ASD are ongoing; what I do is never enough and is physically and mentally exhausting; d) It is difficult to balance all aspects of my life; it may be less demanding if I sacrifice one of my roles; and finally, e) There is a history of mental health challenges in my

family. These findings provide valuable insight about concurrently coping with depression and rearing a child with ASD and propose interventions to address the challenge.

KEY WORDS: ASD, mood disorders, mothers, occupational engagement

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Chapter 1: Introduction

The intent of this chapter is to introduce the background of the research problem, the purpose of the study, and the need for and significance of the study within general population and to the occupational science discipline in particular. To begin, this chapter introduces a background of the research topic, the research questions and hypotheses, terms/definitions, assumptions, and their significance related to the discipline of occupational science.

Additionally, an overview of the research method and occupation-based theoretical framework used to guide the study is presented.

Background

Throughout this paper, the term “mood disorder” refers to depression and bipolar disorders. Depression and bipolar disorders are leading forms of mental illness on a global scale. Depression and bipolar illness are among the 20 leading causes of disability worldwide (World Health Organization [WHO], 2008). Weissman et al. (1996) found that the lifetime prevalence of bipolar disorder was approximately consistent across the five following investigated countries. The lifetime prevalence of bipolar disorder ranged from a low of 0.3% in Taiwan to a high of 1.5% in New Zealand. However, in a large scale study done by the WHO (2008), the prevalence (millions of cases) of bipolar disorder among the WHO regions was found to be as follows: worldwide 92.5, Western Pacific 8.9, South East Asia 7.2, Europe 4.4, the Americas 4.1, Africa 2.7, and Eastern Mediterranean 2.1. Bipolar disorder is considered one of the top twenty diseases that cause of disability worldwide (WHO, 2008).

Typically, the onset of bipolar disorder occurs earlier than depression by 6 years on average. According to APA (2013), the mean age of bipolar onset is between 18-to-mid 20s years old. The female-to-male ratio is approximately 1:1 for having bipolar disorder during one’s

lifetime (APA, 2013). While bipolar disorder shares some of the same features as major depression, it is a different disorder. According to the Diagnostic Statistical Manual-5 (DSM-5), a bipolar disorder is considered a bridge between depressive disorders and psychotic disorders in terms of symptomatology, family history, and genetics (American Psychological Association [APA], 2013). Bipolar disorder (formerly called manic-depressive illness) is characterized by episodes of major depression and episodes of mania. Mania is defined as periods of abnormally and persistently elevated mood or irritability and persistent and abnormally elevated energy levels present throughout the duration of at least one week. Additionally, these symptoms must be accompanied by at least three of the following: overly-inflated self-esteem; decreased need for sleep; increased talkativeness; racing thoughts; distractibility; increased goal-directed activity or physical agitation; or excessive involvement in pleasurable activities that have a high potential for painful consequences (APA, 2013). In contrast, depression is defined as a mental disorder that is marked by “the presence of sad, empty, or irritable mood, accompanied by somatic and cognitive changes that significantly affect that individual’s capacity to function” (APA, 2013, p.155).

Depressive disorder is an umbrella term that includes disruptive mood disorder, major depressive disorder, persistent depressive disorder, premenstrual dysphoric disorder, substance/medication-induced depressive disorder, depressive disorder due to another medical condition, other specific depressive disorder, and finally, unspecified depressive disorder (APA, 2013). Depression is a major mental health problem worldwide as it is indicated by the WHO (2008) report of the prevalence of depression among the WHO regions. The prevalence of depression worldwide (by millions of diagnosed cases) is as follows: worldwide 151.2, South East Asia 40.9, Western Pacific 39.3, the Americas 22.7, Europe 22.2, Africa 13.4, and finally,

Eastern Mediterranean 12.4. Depression, as a form of mental illness, ranks third worldwide, eighth in low-income regions and first in middle- and high-income countries in the frequency of occurrence (WHO, 2008). In a study that compared the prevalence of major depressive episode between high-income countries and low- to middle-income countries, Bromet et al. (2011) found that the average lifetime prevalence in high-income countries to be 14.6% and in low- to middle-income countries to be 11.1%. However, the average 12-months prevalence was found to be 5.5% in high-income countries and 5.9% in low- to middle-income countries. It is one of the three leading causes of mental illness in the Americas, Europe, and the Western Pacific (WHO, 2008).

According to the APA, a major depressive disorder must include either a depressed mood or marked loss of interest or pleasure (the first two symptoms listed below) over the course of a two-week period and present a change in the previous functional activities. In addition, individuals must have a total of at least five of the following symptoms over the same two-week period:

- Depressed mood most of the day, nearly every day, as indicated by either subjective report (e.g., feels sad, empty, hopelessness) or observation made by others (e.g., appears tearful).
- Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated by either subjective account or observation).
- Significant weight loss when not dieting or weight gain (e.g., a change of more than 5% of body weight in a month), or decrease or increase in appetite nearly every day.
- Insomnia or hypersomnia nearly every day.

- Psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down).
- Fatigue or loss of energy nearly every day.
- Feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick).
- Diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others).
- Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt, or a specific plan for committing suicide (APA, 2013, pp. 160-161).

Three major epidemiological studies have assessed the impact of depression and other mental disorders in the U.S. population. The first study was the Epidemiological Catchment Area study, which was conducted, in the early 1980s by Robins and Regier (1991). The results of this Epidemiological Catchment Area study indicated that between 3.0% and 5.9% of the people in the U.S. experienced depressive episodes sometime during their lifespan and that 0.7% to 3.4% of the U.S. population experienced a depressive episode during the past 12-months (Robins & Regier, 1991). The second study was the National Comorbidity Survey in 1990-1992, which was conducted by Kessler et al. (1994). The results of this study indicated that 17.1% of the people in the U.S. experienced major depression sometime during their lifetime and more than 10.3% of the population reported an episode in the past 12 months, making depression the most common psychiatric disorder in the U.S. (Kessler et al., 1994). Almost ten years later, from 2001 to 2002, a replication study of the National Comorbidity Survey was conducted by Kessler et al. (2003). The authors found that 6.6% of the U.S. adult population experienced a major mood disorder

(MDD) during the year preceding the study and 16.2% of adults experienced MDD as a chronic condition at some point in their lives (Kessler et al., 2003).

The results of the National Comorbidity Survey in the early 1990s and its replication in 2003 in the U.S population indicate that the prevalence of depression ranges from 6.6% to 10.3% during a 12 month period and ranges from 16.2% to 17.1% over the course of a person's lifetime (Kessler et al., 1994, Kessler et al., 2003). A comparison between the Epidemiological Catchment Area study and the revised National Comorbidity Survey suggests that the diagnoses of lifetime depression and 12-month prevalence nearly doubled during the period of 1980-2003. The prevalence has been increasingly rising between the 1980s and 2000s.

According to a number of studies, women often are more affected by depression than men (Ford & Erlinger, 2004; Kroenke et al., 2009; Piccinelli & Wilkinson 2000; Kessler, 2006). Kessler (2006) found that 6%-17% of women experience a major depression episode at some point in their lifetime, which is about one-and-a-half to three times higher than the occurrence in men. According to WHO (2008), women experience a higher rate of depression than men by 50%. This increased level of depression in women compared to men occurs across economic status and age groups. The results of a study by Piccinelli and Wilkinson (2000) indicated that depression is a major leading cause of mental illness for women in high-income and low- and middle- income countries. In their population-based survey about the prevalence of depression in the U.S., Kroenke et al. (2009) found that women reported depression more frequently than men even in older age groups

The higher rate of depression reported by women compared to men may be associated with differences in their care giving responsibilities. For men and women, the responsibility of care giving has been reported to have a negative impact on physical, emotional, and

psychological health compared to non-caregivers (Given & Sherwood, 2006; Zhang, Vitaliano, & Hsin-Hua, 2006). However, the impact and amount of care giving differs between women and men. For example, women caregivers were reported to have increased physical health problems and more psychological distress compared to men as caregivers. In contrast, male caregivers were reported to have better physical health but worse physiological risk compared to female caregivers (Zhang et al., 2006).

In addition, women assume more caregiving responsibilities than men. As explained in the National Alliance for Caregivers Executive Report (2009), women spend more time providing care than do men. Women spend on average 21.9 hours per week caring for children while men spend 17.4 hours per week care giving for children (National Alliance for Caregivers Executive Report, 2009). These findings may help to explain why women report depression more than men. According to Wilhelm (2006), childbearing years were found to be significant for a greater risk of major depression for the mothers. Olsson and Hwang (2001) found that the mothers had higher depression scores than the fathers across age and socio-economic groups regardless of whether they were rearing typically-developing (TD) children or children with disabilities. According to Mausbach et al. (2012), care giving stress that results from reduced personal resources and /or increased maladaptive responses can contribute to depression.

Mothers of children with disabilities have additional care giving responsibilities and thus have a greater likelihood of being depressed. Crowe and Florez (2006) found that in comparing the spent hours in the care giving responsibilities, mothers of children with disabilities spent more hours taking care of their children compared to mothers of TD children. In another study that was done in Estonia parents of children with disabilities were compared with parents of children who did not have a disability. The children with disabilities' group consisted of 151

mothers and 57 fathers. For the control group, 101 mothers and 55 fathers participated. The authors of this study found that mothers of children with disabilities reported significantly higher depression symptoms compared with the control group. However, the authors of this study did not mention what kind of disability the children had (Veisson, 1999). Because the term disability includes a wide spectrum of medical, social, and neurodevelopmental conditions that influence what a person can do (WHO, 2002), the reported stress and depression scores vary from one kind of disability to another. The literature shows that parents of children with disabilities report increased stress levels compared with parents of TD children (Baker, Blacher, Crnic, & Edelbrock, 2002; Innocenti, Huh, & Boyce 1992). Blacher and Lopez (1997); Hoare et al. (1998); and Veisson (1999) showed that depression was more prevalent in mothers of children with disabilities compared with control groups of parents who had TD children.

In particular, care giving for individuals with ASD is associated with decreased psychological well-being (Rizk, Pizur-Barnekow, & Darragh, 2011). Based on a comparison between a national sample of mothers with adolescents and adults without disabilities and mothers of adolescents and adults with ASD, the latter spent significantly more time providing care for their children including, daily care and daily chores, and less time engaging in leisure activities (Smith et al., 2010). Lin (2011) reported that the inability of individuals with ASD to take care of their daily living activities was the main characteristics of increased burden of care giving of their mothers.

Those mothers of children with ASD have mood disorders at higher rates than mothers of TD children may be related to: a) the high stress associated with rearing a child with ASD and b) a genetic predisposition to mood disorder in families where an individual has ASD. Research has shown that there is a higher frequency of mood disorders in families of individuals with ASD

(Lajiness-O'Neill & Menard, 2008; Piven et al., 1991; Piven et al., 1999). Holroyd & McArthur (1976) reported that mood disturbances in mothers, including depression, were related to the type of disability of their children. Another study showed that mothers of children with ASD reported the highest depression scores compared with mothers of children with other neurodevelopmental disabilities. Estes et al. (2009) compared maternal depression between mothers with children with developmental disabilities and mothers of children with ASD; the results showed that the latter reported significantly increased maternal depression. In addition, Olsson and Hwang (2001) found that mothers of children with ASD reported higher depressive scores compared with mothers of children with intellectual disabilities without autism.

Because the high prevalence of mood disorders in mothers of children with ASD also could be a result of the disability's characteristics, it is important to understand them. ASD is a neuro-developmental disorder marked by impairments in social communication and social interaction and by repetitive and restricted patterns of behavior, activities, and interests (APA, 2013). The symptoms of ASD must be evident in the early developmental stages. Also, the symptoms have to cause impairments in social, occupational, and essential areas of life in a significant way (APA, 2013). The social communication and social interaction diagnostic criteria consists of three major pervasive and sustained difficulties that affect social-emotional reciprocity, nonverbal communicative behaviors, and relationships. Deficits of the social-emotional reciprocity may include insufficient conversational skills to initiate, respond, and conduct a back-and-forth conversation. Nonverbal communication problems may include difficulty making eye contact with people, difficulty following the attention bids of others, and delays or deficits in integrating verbal and nonverbal communication. Limited ability to establish

and maintain relationships implies difficulty in making friends and a lack of interest in peers (APA, 2013).

The repetitive and restricted behaviors, activities, or interests that are part of the diagnostic criteria of ASD include stereotyped or repetitive motor movement, insistence on sameness, interest fixations, and hyper- or hyporeactivity to sensory stimuli. Stereotyped or repetitive motor movement may include motor mannerisms such as flapping arms and stereotypical interests including an excessive interest in a specific topic or object. Insistence on sameness may include rigid adherence to specific verbal and nonverbal behaviors. It also may reflect difficulty in transitioning from one activity, idea, or place to another. Highly restricted and fixated behaviors may include preservative focus of an unusual object (APA, 2013). Hyper- or hyporeactivity to sensory stimuli is manifested in “unusual interest in sensory aspects of the environment” (APA, 2013, p. 50).

Autism is a spectrum disorder; the symptom severity can vary from individual to individual. Additionally, symptoms of ASD appear to vary between males and females (Autism Speaks, 2013; Banach et al., 2009; Carter et al., 2007; Erikssona, Westerlund, Anderlid, Gillberg, & Fernell, 2012; Hartley & Sikora, 2009; Holtmann, Bolte, & Poustka, 2007; Janine, Lemon, Gargaro, Enticott, Rinehart, 2011; Mandy et al., 2012; Solomon et al., 2012). These variations may have important implications on the reported depression in mothers of children with ASD.

Because an individual with ASD typically lives within a family unit, it is important to discuss how rearing a child with ASD may change the dynamics among the family members. Family dynamics are defined as "the forces at work within the family that produce particular behaviors or symptoms" (Mosby's Medical Dictionary, 2009, p. 700). The family dynamics are defined as the way all of the family members interact. Every family member contributes to that

dynamic. According to Werner-DeGrace (2004), the dynamics of family members who have children with ASD are altered because the demands of addressing issues related to ASD are ongoing. Werner-DeGrace (2004) reported that parents and family members are often unable to engage in desired activities and occupations of their own because of the continual need to take care of the daily living demands of the child with ASD.

Problem Statement

Maternal depression, when parenting a child with ASD, has not been studied extensively (Singer, 2006). There have been studies done on depression and ASD; however, the rate of depression of mothers of children with ASD is typically compared with the base rate of depression of women in the population. Some studies have compared mothers with ASD to other mothers of children with developmental disorders or other medical conditions. The results of most of these studies have shown that mothers who are parenting children with ASD are more likely to report depression and increased stress compared with other mothers who are parenting children with other disabilities such as Down syndrome. Dissimilar to many developmental disabilities, children with ASD communicate using unusual language, exhibit stereotypical speech, display behavior problems, and show some ritualistic behaviors. The clusters of all these unique characteristics underlie the increased stress level among mothers of children with ASD compared to other developmental disabilities (Estes, et. al., 2009). The literature has shown the reported increased stress and increased mood disorders among mothers with children with ASD and other developmental disabilities. However, to the author's knowledge, the majority of studies that investigated the rate of mood disorders in mothers of children with ASD are not compared with the rate of mood disorders in mothers with TD children. This limitation will be discussed in detail in the literature review section.

As a result, little is known about mothers who are coping with depression while rearing a child with ASD in relation to mothers who are rearing a TD child. It is important to investigate the maternal stress and reported depression of mothers with children with ASD compared to a matched group of mothers with TD children. Such information is important to understand the percentage of women affected and ultimately the size and impact of this issue. It also is important to document the lived experiences of mothers who are simultaneously coping with depression and rearing a child with ASD. Exploring those mothers' lived experience will help reveal the complexity of their challenges and thus aid in the design of effective, system wide interventions. There are a number of interventions designed to reduce the symptoms of depression in mothers by enhancing the mothers' abilities to manage the challenges brought about by depression. However, because depression in mothers of children with developmental disabilities is not being addressed on a large-scale, few interventions focus on their specific needs (Singer, 2006).

Purpose of the Study

The objectives of this study were twofold. The first objective was to investigate whether the mood disorders reported by mothers, occur more frequently in families that have a child with ASD than in families that do not have a child with ASD. The second objective of this study was to explore the lived experience of mothers who cope with depression and to understand the impact of mood disorders on their daily life and parenting while rearing a child with ASD. No studies were found that give a qualitative description of what it is like for a mother to concurrently rear a child with ASD with autism and cope with depression. Therefore, it is important to explore in detail the lived experience of these mothers. Understanding the daily life challenges associated with the depression, recognizing the causes of the stress that stem from

being a mother of a child with ASD, identifying the support systems for the mothers, and discussing strategies that empower the mothers are also important issues.

Overview of Research Method

A mixed method explanatory sequential approach was used to accomplish the objectives of the study. To accomplish the first objective, questionnaire-based data was used to: (a) examine self-reported depression and bipolar disorder among mothers who have children with ASD versus mothers of TD children; (b) compare reported family history of mood disorder among first and second-degree relatives of mothers with children with ASD and mothers of TD children; and (c) compare the frequency of mood disorders of mothers who have daughters with ASD and mothers who have sons with ASD. For the sake of the comparison between mothers with children with autism and mothers with TD children, the two groups were matched on state of residence, chronological age of the children, and data collection method. The use of a comparison group consisting of mothers with TD children helped get comparable results of the rate of the reported mood disorders between mothers who have children with ASD and mothers who do not have children with ASD.

The original Depression History Questionnaire was designed and distributed nationally by IAN Research Database at the Kennedy Krieger Institute and Johns Hopkins Medical School (Interactive Autism Network [IAN], 2013). Four thousand six hundred and seventy seven mothers and fathers of children with ASD completed the Depression History Questionnaire. Of those, 2569 reported a professional diagnosis of depression, self-diagnosed of depression, or being treated for depression without a diagnosis. Of those, 14% reported having been hospitalized. The present study contrasted the total response of mothers with children ASD who

live in Maryland with a control group consisting of mothers of TD children who live in Maryland also.

The second objective of this study was to explore the meaning of the lived experience of mothers who cope with depression in order to understand the impact of mood disorders on daily life and parenting tasks while rearing a child with ASD. There are some studies that examine the lived experiences either of mothers who are coping with depression or of mothers who are rearing a child with ASD (Hall, 2006; Kuhaneck, Burroughs, Wright, Lemanczyk, & Darragh, 2010, Smith et al., 2010; Woodgate, Ateah, & Secco, 2008), but none have examined the lived experience of those mothers who are coping with both challenges. Thus, this current study examined the lived experience of depressed mothers who are rearing children with ASD to explore the impact of depression and ASD on their performance of activities of daily living.

In order to explore the essence of the meaning of the lived experience of mothers who are depressed and rearing a child with ASD, a phenomenological approach employing interviews was utilized. The phenomenological approach facilitated the exploration of how these mothers perceive their daily routines in relation to coping with depression and taking care of their child with ASD. The phenomenological design was an appropriate inquiry tool because it allows for the gathering detailed descriptions from the participants to examine their perceptions about their lives as challenged by both depression and ASD.

Research Questions and Hypotheses

For the quantitative part of this study, the research questions and hypotheses were as follows:

Aim 1: To determine if mothers of children with ASD reported a history of mood disorders more frequently than mothers of TD children.

Hypothesis 1: Mothers of children with ASD will report a history of mood disorder more frequently than mothers of TD children.

Aim 2: To determine if mothers of children with ASD reported a family history of mood disorders among first and second-degree relatives more frequently than mothers of TD children.

Hypothesis 2: Mothers of children with ASD will report a family history of mood disorders among first and second-degree relatives more frequently than mothers of TD children.

Aim 3: To determine if mothers of girls with ASD reported a history of mood disorder more frequently than mothers who have boys with ASD.

Hypothesis 3: Mothers of girls with ASD will report a history of mood disorder more frequently than mothers who have boys with ASD.

The research questions for the qualitative part explored the broader perspective of “what is it like for a mother who copes with depression to rear a child with ASD” through the following questions.

1. How do depressed mothers of a child with ASD describe their lived experience of coping with depression and rearing a child with ASD?
2. How do depressed mothers of a child with ASD describe their daily life activities and occupations?
3. What factors or life events do the mothers feel have contributed to their depression?
4. What factors or life events bring joy and satisfaction to the mother?
5. What are the mother’s current occupational patterns, including eating and sleeping since the child was diagnosed with ASD?

Occupation-based Theoretical Framework

The person-environment-occupation (PEO) model served as the theoretical framework for this study. The model was first published in 1996 by Mary Law, Susan Strong, Patricia Rigby, Barbara Cooper, Deborah Stewart, and Lori Letts. It is a client-centered model that focuses on the transaction between the person, the environment, and occupations in order to maximize occupational performance. The PEO model emphasizes the complexity of relationships of people engaging in occupations within broad environments. The person, environment, and occupation “interact continually across time and space in ways that increase or diminish their congruence” (Law et al., 1996, p. 17).

According to the model, the person is a dynamic, motivated, and ever developing being that constantly interacts with the environment. The person has many different, concurrent dynamic roles, such as being a mother, an employee, and/or a student. Qualities defining the individual will influence the way in which the person interacts with the environment and carries out occupational performance. Law et al. (1996) state: “The person brings a set of attributes and life experiences to bear on the transaction described as occupational performance, including self-concept, personality style, cultural background, and personal competencies” (p. 21).

The environment includes the household, neighborhood, or community of the person. Environment influences the behavior of the people. Peachy-Hill and Law (2000) stated that the ability for a person to be engaged in meaningful activities within a context can be supported or limited by the environment. According to AOTA (2008) environment can be defined as a group of different interrelated conditions that surround people and can positively or negatively influence performance of daily life occupations. The environment influences occupational performance and the time spent in engaging in self-care daily activities, work, and leisure

occupations (Peachy-Hill & Law, 2000). Different environments can provide various resources and/or obstacles to maintain or impede engagement in desirable occupations and occupational performance. According to Law et al. (1996), the balance between self-care activities, work, and leisure occupations can be influenced by the environment relative to time spent in the major daily occupations by people (Peachy-Hill & Law, 2000).

Occupations are activities and tasks that are meaningful to the person. Occupations meet the person's needs for self-maintenance, expression, and fulfillment within the context of his or her personal roles and environment (AOTA, 2008; Law et al., 1996). In the PEO model, activity, task, and occupation intertwine within each other. Activity is the basic unit of a task; a task is a set of purposeful activities in which a person engages. Occupation is a group of self-directed, functional tasks and activities in which the person engages over the lifespan (Law et al., 1996).

Finally, occupational performance is viewed as a complex, dynamic phenomenon that requires the ability to balance occupation and views of self and environment. Occupational performance is the outcome of the transaction of the person, the environment, and the occupation. Because the relationship between the PEO components is dynamic not linear, any change in the components will cause a change in the occupational performance (Law et al., 1996). Occupational performance can be measured by the outcome results of the transactional relationship between the PEO components. Occupational performance outcomes can range from maximum fit of occupational performance to minimal fit of occupational performance. Outcomes of the PEO can be a good fit or optimal occupational performance, which is referred to as the adaptive behavior and positive affect of satisfaction, pleasure, and desire to continue. On the other hand, a poor fit or inadequate occupational performance can be a dysfunctional outcome (Law et al., 1996). For example, when the competence of the person is too low in relation to the

occupational demands, maladaptive behaviors, failures in performance, or a negative affect and stress can result (Lawton, 1996). Strong et al. (1999) assert, “The quality of person’s experience, with regard to level of satisfaction and functioning, is the outcome of the fit between the person-environment-occupation” (p. 124). The person-environment-occupation fit is in harmony and interacting across time when the persons’ capabilities are supported by the environment to accomplish the desired occupation (Law et al., 1996). Similarly, Law et al. (1996) emphasize “focusing on the transaction between the client, his/her occupation and the environment, [so that] the therapist can choose from a broad range of interventions from either [the occupation or the environment or both]” (p. 21).

To understand the lived experience of mothers coping with depression while rearing a child with ASD, it is important to examine the interaction between the mothers being depressed and taking care of a child with ASD, the occupations that they engage in, and how all aspects of their environment either facilitates or hinders their occupational performance. The model of the PEO provides a framework for systematic interactional analysis between the depressed mothers of a child with ASD and (a) their environment, (b) the occupations they engage in, and (c) their child’s environment and how this environment supports or limits engaging in occupations. This model shifts the focus of examining the person, the occupations, and the environment as a single element into a more interactional and holistic analysis of all the nested aspects of person, environment, and occupation that can support or impede the occupational performance (Law et al., 1996). According to the model, increasing the relationship between the mothers themselves, their smaller and larger environment, and occupational elements of their life stories can maximize occupational performance of depressed mothers of a child with ASD. The current

study utilized the PEO model to explore the needs of depressed mothers of a child with ASD as they cope with their depression and provide care for their child with ASD.

Terms/Definitions

- Autism Spectrum Disorder (ASD): the term used for a group of neurodevelopmental disorders characterized by impaired social communication and social interaction as well as restrictive repetitive and stereotyped behaviors and interests (APA, 2013).
- Broad Autism Phenotype: “abbreviated BAP, this refers to the finding that relatives of people with autism often have mild autism-like characteristics including difficulty reading social cues, social anxiety, or obsessive-compulsive traits.” (Autism Science Foundation, 2014, para 1) These characteristics were noticed as early as Kanner and Eisenberg (1957) and Folstein and Rutter (1977) in their studies about twins.
- First-degree relatives include the following: mother, father, brother, sister, son, and daughter. Second –degree relative are maternal grandmother (mother's mother), maternal grandfather (mother's father), maternal aunt (mother's sister), maternal uncle (mother's brother), first cousin on the mother's side, paternal grandmother (father's mother), paternal grandfather (father's father), paternal aunt (father's sister), paternal uncle (father's brother), and first cousin on the father's side.
- Mood disorders: this term will be used throughout this paper to include the DSM-5 definitions of depressive disorders and bipolar disorders.
- Occupational performance: “the act of doing and accomplishing a selected activity or occupation that results from the dynamic transaction among the client, the context, and activity (AOTA, 2008, p. 672-673).

- Occupations: “chunks of culturally and personally meaningful activity in which humans engage that can be named in the lexicon of our culture” (Clark et al., 1991, p. 301).
- Participation: “involvement in a life situation” (WHO, 2001, p. 10).

Assumptions

For the quantitative portion of this study, it was assumed that mothers would be as truthful as they could when completing a paper-and-pencil questionnaire and that they may in fact be more honest and truthful because of the anonymity of the online environment. The web-based users can feel the anonymity while filling out an online survey. This feeling can enhance participants for more honest, truthful, and thus more accurate responses (Ahem, 2005). In the qualitative part, the methodologies were focused on capturing the lived experience of the mothers. Objectives truth is less important than the mothers’ narratives.

Significance of the Study to Occupational Science

The qualitative inquiry of this study helped to explore the link among the qualities of coping with depression for mothers of children with ASD, occupational performance, and occupational engagement in daily life occupations. Examining the relationship between qualities of being a mother who is depressed and rearing a child with ASD may yield significant information that affects occupational performance, which ultimately affects the occupational engagement. Findings may help guide intervention that targets the mothers’ needs. By investigating the extra challenges that mothers who are depressed and rearing a child with ASD face in their occupational engagement, occupational scientists may develop better interventions that promote these mothers occupational engagement. “All people need to be able or enabled to engage in the occupations of their need and choice, to grow through what they do, and to

experience independence or interdependence, equality, participation, security, health, and well-being” (Wilcock & Townsend, 2008, p. 198). Participation through engagement in occupations is considered one of the key elements to support health (AOTA, 2008). Therefore, listening to the unique needs of mothers who are depressed and taking care of a child with ASD is a solid foundation for the interventionist to better serve them. Guided by the PEO model, occupational scientists can assess the factors that affect the transaction of the mothers who are depressed, their responsibilities toward their children with ASD, their environment obstacles and supporters, and their desired occupations. By exploring these interrelated components, a health promotion intervention could be derived that supports the mothers and promotes their occupational engagement and well-being.

Summary

Research clearly shows that there is an interaction between care giving responsibilities of rearing a child with ASD and the reported increased stress level and sometimes increased likelihood of reported mood disorders. Therefore, one of the main objectives of this study was to understand the relationship between rearing a child with ASD and maternal mood disorders. The other main objective was to document the perspective of those mothers regarding how having a child with ASD and coping with depression affect their lifestyle and their occupational engagement. The following chapter reviews the literature that is related to the transaction relationships between stress, maternal mood disorders, and motherhood of a child with ASD and the factors that influence the mothers’ well-being and occupational participations.

Chapter 2: Literature Review

Introduction

This chapter presents a comprehensive review of the literature related to the purposes of the study. In particular, this chapter contains literature that addresses the relationship between motherhood and having a child with ASD, and motherhood and depression. This literature review explores factors related to mothers who cope with depression/bipolar and rear a child with ASD at the same time, including an overview of: (a) the relationship of depression in mothers and children with ASD, (b) motherhood and the experience of having a child with ASD, (c) causes of stress for mothers with children with ASD, (d) effect of stress on mothers' lives, (e) motherhood and depression, (f) mothers' depression and effects on children, (g) occupation and well-being of depressed mothers with children with ASD, (h) gender differences of children with ASD, and (i) a history of depression of the mothers of children with ASD. Investigating these factors were pertinent to fully understanding the complex relationship between rearing a child with ASD and the maternal depression.

Overview of Research on Children with ASD and Maternal Stress and Depression

The following section provides an overview of the literature that addresses the relationships among all the variables of this study including stress, depression, motherhood, and children with ASD. Also, this section includes a discussion of what has been researched in relation to the above-mentioned variables and how this current study addressed a gap in regard to knowledge.

Previous research has shown depression, motherhood, and having a child with ASD to be related. A study in the southwest of Sweden compared three groups of mothers and fathers of children with a primary diagnosis of ASD, primary diagnosis of intellectual disability without

ASD, and a control group (Olsson & Hwang, 2001). The sample consisted of 151 children with intellectual disabilities without autism and 65 children with autism and 214 children of the control group. The overall results showed that 47% of 216 families of children with disabilities had one parent with a significantly elevated depression score, compared to 24% of 214 families in the control group. Also, the results showed that mothers of children with ASD had significantly higher depression scores than mothers of children with intellectual disabilities without autism and the control group. Prevalence of depression in mothers of children with ASD was 16% compared with 8% for mothers of children with intellectual disability without ASD and 4% for mothers in the control group. As mentioned above, the study sample was divided into three groups, children with intellectual disabilities without ASD, children with ASD, and a control group. However, the children in the ASD group also have intellectual disabilities. It seems that intellectual disabilities were a common factor between both groups of children. In addition, the authors did not mention any common set of the inclusion characteristics criteria between the study groups. According to Portney and Watkins (2009), a study sample is a group of individuals, objects, or events that meet a particular set of criteria. The sample of children with disabilities and the sample of children with ASD had overlapping sets of criteria related to cognitive capacities; therefore, results of a study of children with ASD and intellectual disabilities cannot be generalized to children with ASD without intellectual disabilities.

A more recent study was a population-based case-control Swedish study. Daniels et al. (2008) studied a group of children born between 1977 and 2003. The purpose of the study was to investigate whether the rate of hospitalization for psychiatric diagnoses was higher among parents of children with ASD compared to a control group. The study sample consisted of 1,227 parents of children with ASD, Asperger's, or PDD-NOS and 30,693 parents of children in the

control group. The study showed that parents of children with ASD had a higher rate of hospitalization for a psychiatric condition compared with parents of the control participants. The study also showed that depression was more common among the participants' mothers than among the participants' fathers. Those results may show the increased need for psychiatric intervention for parents of children with ASD.

Another study done in Southwestern Ontario of the parents of 31 children with ASD, 31 children with Down syndrome, and 62 TD children compared mothers' depression, stress, and marital intimacy. The study results showed that depression, greater stress, and lower marital intimacy were found to be more significant for mothers of children with ASD than compared to the other study groups (Fisman, Wolf, & Noh 1989). Again, in southwestern Ontario, another study investigated parenting stress, child behavior, and depression in families who had children with ASD, Down syndrome, behavior disorders, and normal development. The sample consisted of families of 30 children with ASD, 30 children with Down syndrome, 30 children with behavioral disorders, and finally, 60 TD children. The results showed that mothers of children with ASD and behavior problems reported higher maternal dysphoric depression scores, which appeared to be related to parenting stress of those children compared to mothers in the other two groups (Dumas, Wolf, Fisman, & Culligan, 1991). These findings may suggest that mothers of children with ASD and children with behavior disorder, in particular, face a cascade of challenges taking care of their children. Most mothers of children with other disabilities might face these challenges, which can include an increased stress level, lower intimacy, and depression. However, the difference is that those challenges are amplified for mothers of children with ASD compared to mothers who have children with other disabilities.

A more recent study of depression in mothers with children with ASD that used a control group was conducted by Ingersoll et al. (2011). Seventy-one mothers of children with ASD and 94 non-ASD mothers were recruited through various online services. Mothers of children with ASD were recruited through the IAN research database. Mothers of children without ASD were recruited through an online service that connects researchers with people who are willing to complete surveys. The purpose of the study was to investigate whether mothers of children with ASD exhibited higher levels of depression symptoms, parenting stress, and characteristics of the broader autism phenotype than non-ASD mothers. The results showed that mothers of children with ASD reported significantly higher rates of depression, parental stress, and broader autism phenotype. However, maternal broader autism phenotype was a predictor for both mothers with and without children with ASD, which suggests that the broader autism phenotype may increase vulnerability to depression in the general population rather than just in mothers with children with ASD (Ingersoll et al., 2011). It is worth mentioning that since the participants were recruited through online services and the geographical location was not matched between both groups, a bias in the means of recruiting participants may be present and could lead to invalid results.

It is important for a study with a larger sample size to match the participants on the place of residence since mental health distresses are more common in some states compared to others. The 10 states with the highest rate of depression and psychological distress include Arkansas, Indiana, Kentucky, Michigan, Mississippi, Missouri, Nevada, Oklahoma, Tennessee, and West Virginia (health.com, 2013). For the above-mentioned study, it is not guaranteed that the sample was representative of the states with the highest and the lowest rates of depression and psychological distress. Consequently, it is important to compare the rate of the reported mood

disorders of mothers of a child with ASD with the reported mood disorders of mothers without a child with ASD within the same geographical location. To clarify the importance of selecting a sample within a particular geographical location, an example of ASD prevalence will be utilized. Often, prevalence is a function of factors besides the 'real' occurrence of a condition; prevalence rate of ASD is dependent on many factors, such as socio-economic status, access to health care, clinician expertise. Although Alabama has the lowest rate of ASD among the states CDC counts (CDC, 2012a) it may be that ASD is under-identified because clinicians aren't as trained to diagnosis ASD and people have limited access to healthcare (Singer, 2012). Therefore, it was wise to select the sample of mothers of children with ASD within the same geographical location where the health care practices and the degree of the practitioners' expertise are similar.

A few studies that used a control group to compare mood disorders in parents of children with ASD were conducted in other countries outside the U.S. as mentioned above. Therefore, it is important to investigate the rate of reported mood disorders in mothers who reside in the U.S. Weissman et al. (1996) found a wide variation of the life-time prevalence and 12-month prevalence for major depression depending on location. For example, the lifetime prevalence was 1.5% in Taiwan, 9.2% in West Germany, 9.6% in Canada, and 19.0% in Lebanon. However, the 12-month prevalence for major depression ranged from 0.8% in Taiwan, 3.0% in U.S., 4.5% in France, and to 5.8% in New Zealand. Adding to this, there are variations on the reported depression within the same country. The reported depression studies showed differences of the prevalence of depression within the U.S. (health.com, 2013) and across countries (Weissman et al., 1996). Because of the variation of the reported depression within the different regions within the U.S., it is important to compare the reported depression of mothers with children with ASD to the base prevalence of depression in the same region. There is a need to study health and

health-related issues across regions (Murray & Lopez, 1996), however, it was important to use the same methodology and measures in every circumstance. Most of the rates of the depression of mothers who rear children with ASD came from vastly different methods. One might be based on a telephone survey, another might be based on medical records, and others might be based age groups, 8-year old versus adults. However, in this study, the same methods and the same regions were used for this study comparison. Therefore, studying the variation of reported mood disorder of mothers of children with ASD across regions can help to understand this issue comprehensively.

Summary of Gaps in the Literature

A few studies have compared the depression of mothers of children with ASD with that of mothers of TD children. However, these studies have some methodological challenges regarding sampling size and matched groups. For example, some of these studies have a small sample size for mothers of children with ASD (Dumas et al., 1991). One study that investigated the rate of reported depression among mothers of children with ASD did not have a set of inclusion criteria of the study sample (Olsson & Hwang, 2001). In another study, the groups of mothers of children with ASD and mothers of TD children were not matched in some variables affecting the validity of the results (Ingersoll, Meyer et al., 2011). Other studies are relatively old (Dumas et al., 1991); therefore, it is worthwhile to investigate more recent occurrence of mood disorders in mothers of children with ASD compared to those studies. Finally, the findings of the few studies conducted in other countries such as Sweden (Daniels et al., 2008), have yet to be compared with findings about mothers with children with ASD in the U.S. who are coping with depression.

In mothers who have children with ASD, understanding the size and the impact of the mood disorders, including depression and bipolar disorder, is a key factor. The information can be beneficial for developing intervention more directly targeted for the population of mothers who are depressed and rearing children with ASD. In order to do so, the perspectives of depressed mothers of children with ASD should be taken into consideration to understand the impact of being depressed. The mothers themselves need help because of the challenges associated with depression; yet at the same time, these mothers are committed to provide help and take care of their children with ASD.

Motherhood and Experience of Having a Child with ASD

Motherhood is a unique journey full of different fascinating experiences. The common emotions of joy, happiness, and unlimited giving, frustration, and fear are associated with being a mother. However, mothers who rear a child with ASD often experience-demanding challenges that differ from the joys and difficulties associated with having a neurotypical child (Anderson, 2007). This following section reviews the causes of the stress rooted in rearing a child with ASD and its relationship to mothers. Despite these considerable challenges, it is common for the whole family to dedicate a great deal of its time, effort, and resources to enhance the development and fulfill the needs of their children with ASD (Altiere & Von Kluge, 2009; Fletcher, Markonlakis, & Bryden, 2012; Sen & Yurtsever, 2007).

Causes of stress for mothers with children with ASD. There is usually a mystery that surrounds the diagnosis process (Anderson, 2007). The severe and pervasive nature of this disorder also creates an extra emotional burden on families who are rearing a child with ASD (Bishop, Richler, Cain, & Lord, 2007; Fletcher et al., 2012). According to Anderson (2007); Dale, Jahoda, and Knott (2006); and Stein, Foran, and Cermak, (2011), the uncertainty of

scientific knowledge regarding the etiology and prognosis of ASD produces feelings of confusion and guilt because the parents may question whether they are responsible for their child's disorder.

Altieri and Von Kluge (2009) found that the stress, depression, and frustration that are associated with having a child with autism negatively affect the family in some way. The authors interviewed 26 married couples who had children with ASD: 26 mothers and 26 fathers. They found that parents viewed the discovery of their child's ASD diagnosis as a "life-altering" event (p. 145). According to Altieri and Von Kluge, (2009) and Stein et al. (2011), the participating families in their studies experienced feelings of despair, sadness, denial, confusion, anger, insecurity, and incompetence after a confirmation of the diagnosis. In addition, the ability of parents to envision their children's future is more difficult for parents of children with ASD compared to parents of children with Down syndrome (Seltzer, Krauss, Orsmond, & Vestal, 2000). All of these reasons contribute to the mothers' varied feelings of doubt, uncertainty, and worry and put them at risk for high levels of stress and depression.

An increased frequency, severity, and diversity of the core ASD symptoms is associated with increased stress and depression level and decreased levels of positive affect for mothers of individuals with ASD (Benson, 2006; Ekas & Whitman, 2010; Ekas & Whitman, 2011; Smith et al., 2010). Parenting a child with ASD increases the possibilities of maternal stress (Werner-DeGrace, 2004; Hoffman et al., 2008; Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009; Montes & Halterman 2007, 2008; Woodgate, Ateah, & Secco, 2008). Donovan (1988) found that mothers who have children with ASD report greater stress, lower levels of social support, and less positive views of their children compared to mothers who have children with other kinds of disabilities such as cognitive disabilities. Also, they reported that they experienced

loss of friends, strained relationships with friends, and social stigma (Fletcher et al., 2012; Tunali & Power, 2002). In regards to the mother-child relationship, mothers of a son or daughter with ASD reported less closeness in the relationship compared to mothers with Down syndrome (Abbeduto et al., 2004). Similarly, Estes et al. (2009) found that mothers who have children with ASD have higher stress levels compared with mothers who have children with other disabilities. Their psychological distress, as indicated by increased mean scores of depression, was significantly higher than the mothers of children with a developmental delay. In a more recent study conducted by Fletcher et al. (2012), mothers of children with ASD reported increased stress, fatigue, depression, and weight gain. According to Wilhelm (2006), there is a significant relationship between stressors and an increased risk of the depression. Parenting a child with ASD is a stressful experience and a leading cause of depression in mothers (Phentrasuwan & Miles, 2009).

Other researchers have investigated the relationship among stress, the community, and health support. Montes, Halterman, and Magyar (2009) studied the parents of 2123 children with varying disabilities to investigate their satisfaction with the school and community health resources. The results showed that parents of children with ASD were more likely to experience dissatisfaction with the provided service across all settings compared to parents of children with other conditions. Mothers of children with ASD were more dissatisfied with the service provided for their children compared to mothers without children with ASD (Montes et al., 2009). This dissatisfaction may contribute to the high stress level and negative psychological functioning compared to children without ASD.

Impaired adaptive functioning and increased demand for help from the mothers to perform daily living activities also are potential causes of increased maternal stress (Estes et al.,

2009). They also are important determinants of stress and higher rates of symptoms of depression in mothers and fathers (Seltzer, Greenberg, & Krauss, 1995). Individuals with ASD showed more impaired adaptive functioning than individuals with other disabilities such as Down syndrome (Pueschel, 1996; Seltzer et al., 2000). Hall & Graff (2011) found a significant association between the decreased level of adaptive functioning in children with ASD and the increase in maternal stress. In contrast, higher levels of a child's adaptive functioning were a significant predictor of parental psychological well-being (Fidler, Hodapp, & Dykens, 2000; Friedrich, Wiltner, & Cohen, 1985; Hodapp, Dykens, & Masino, 1997; Hodapp, Fidler, & Smith, 1998).

Behavioral difficulties in children with ASD also contribute to maternal stress and depression. After analyzing a group of variables that effect parenting stress, Estes et al. (2009) and Phetrasuwan and Miles (2009) found that behavioral problem symptoms of children with ASD were found to be the primary source of maternal stress. Hasting (2003) also found an association between the increased maternal stress and the behavior problems of children with ASD. Dumas et al. (1991) reported higher levels of stress in parents of children with ASD children with behavior disorders compared to parents of children with Down syndrome and typically developing. From mothers' perspectives, children with ASD and children with behavior disorders were found to present more behavior problems compared to other children (Dumas et al., 1991). According to Phetrasuwan and Miles (2009), a child's emotional responses, expressions of fear or nervousness, verbal communication issues, relations with people, behavior management in public places, and problem behavior management were the most symptom-related stressors for mothers with children with ASD. These characteristics also have an impact

on the mother-child relationship. Hoffman et al. (2009) found that the more severe the children with ASD behaviors were, the less emotional closeness there was between mother and child.

Families who have children with ASD also face long-standing financial difficulties associated with seeking out high-cost evaluation and best treatment services for their children (Altiere & Von Kluge, 2009; Anderson, 2007). Yet, according to Fletcher et al. (2012), mothers of children with ASD reported that costs of rearing a child with ASD extend beyond the added financial burden and include compromises to their employment and social life. Compared to mothers of TD children, mothers of children with ASD place more emphasis on the parental role; they are more likely to stay home to take care of their children (Tunali & Power, 2002).

The aforementioned section shed light on some of the causes of the increased level of stress for mothers with children with ASD. Some of those causes stem from the challenges associated with the extra care needed for the children with ASD. Other causes were rooted in the changed parental role and social supports. Also, the adaptive functioning challenges and behavioral problems that are associated with ASD have a distinct role in the increased stress level of mothers of children with ASD. Finally, financial burden as well as dissatisfaction of the school and community health resources for children with ASD contributes to the stress.

Effect of stress on mothers' lives. High levels of stress and depression also can lead to problems with parenting. Extreme parenting stress may result in harsh or withdrawn parenting styles (McEwen & Lasley, 2002). Moreover, stressed parents are usually less likely to see an optimal future for their children (Abbeduto et al., 2004; Deater-Dechard, 2004). Mothers who are depressed and have children with ASD are less likely to advocate and utilize the resources that are available, thus further limiting the potential success of their children's future (Mazefsky, Williams, & Minshew, 2008).

Mothers of children with ASD are more likely to emphasize their parental role than their career (Tunali & Power, 2002). In the comparison of mothers of children with and without ASD, Tunali and Power (2002) found that the idea of sacrificing a job is a process of redefining the maternal roles of “being a good mother” (p. 26). Mothers of children with ASD stated that both groups of mothers should stay home; in contrast, mothers with children without ASD did not affirm the idea of staying home in order to be a good mother.

Providing day-to-day care for children with disabilities often depletes parents’ time and energy, which can lead to limited or diminished social and cultural activities and depression. Mothers of children with ASD stated that the responsibility of rearing children with ASD is “a 24-hour, 7-day-a-week task” (Altiere & Von Kluge, 2009, p. 146). The more the children with disabilities are dependent on their mothers the less their mothers engaged in outside the home activities (Breslau, Staruch, Mortimer, 1982). Similarly, in their qualitative study Kuhaneck et al. (2010) found that the time mothers spent taking care of their children with ASD was “emotionally and physically draining, and all consuming” (p. 344). This all-consuming parental responsibility and limited participation in other daily life activities can lead to depression which, in turn, can compromise the ability of these mothers to successfully parent their children with ASD (Goodman & Gotlib, 1999).

Benson (2010) found that mothers of children with ASD used distraction and disengagement as coping strategies in order to modulate the stress stemmed from rearing their children with ASD. Distraction involves the mother’s efforts to stay away from the source of the stress associated with rearing their child with ASD. Distraction can include humor, self-blame, and venting. However, disengagement involves withdrawal from the source of the stress by using strategies such as denial or substance abuse (Benson, 2010). These strategies can have an

influence on the ability of those mothers to parent their children. Disengagement of mothers of children with ASD may lead to a greater tendency of disengagement by children with ASD themselves (Mazefsky et al., 2008). The mothers who use the avoidant strategies such as distraction and disengagement were found to report increased level of maternal anger and depression (Benson, 2006). In addition, depression in mothers was found to negatively affect their ability to parent children with or without ASD. On the other hand, some children with ASD are not very responsive to their mothers, which can be very hard for the parent. This may be a vicious pattern because it begins with a child with ASD who is not being responsive, which makes the mother feel hopeless and consequently less able to reach out to her child with ASD.

The effects of stress on mothers are multifaceted. Several studies have established that chronic stress can lead to serious health problems in mothers of children with ASD (Abbeduto et al., 2004; McEwen & Lasley, 2002). In addition to depression (Korszun, Altemus, & Young, 2006) high levels of stress also have been associated with health-related problems such as cardiovascular diseases, sleep disturbance, memory problems, and increased weight for mothers in general, regardless of the ability status of their children (McEwen & Lasley, 2002; Sapolsky, 2004). For mothers of children with ASD increased stress levels can lead to difficulty sleeping, parenting problems, and reduced ability to engage in advocacy initiatives compared to mothers of TD children (Hoffman et al., 2009). Despair, sadness, denial, confusion, anger, insecurity, and incompetence after a confirmation of the diagnosis are common feelings among mothers of children with ASD (Altiere & Von Kluge, 2009; Stein, et. al., 2011). Other studies of mothers of children with ASD also have shown that mothers with children with ASD are at risk to report fatigue (Fletcher et al., 2012; Smith, et. al., 2010), stress (Abbeduto et al., 2004; Dąbrowska & Pisula, 2010; Duarte, Bordin, Yazigi, & Mooney, 2005; Estes, et. al., 2009; Montes &

Halterman, 2007; Shu, 2009), sleep problem (Hoffman et al, 2008), anxiety (Estes et al., 2009; Hasting, 2003), anger (Benson & Karlof, 2009), pessimism (Abbeduto et al., 2004; Lin, 2011), weight gain (Fletcher et al., 2012), mental health problems (Ekas & Whitman, 2011; Fletcher et al., 2012; Montes & Halterman, 2007; Smith, et. al., 2010; Wilhelm, 2006), isolation and loneliness (Marcus, 1977; Woodgate et al., 2008), marital disharmony or breakdown (Dunn, Burbine, Bowers, & Tantleff, 2001). Because depression on a wide scale is considered as a stress-related condition (Korszun et al., 2006), it is discussed in more detail in a following section that highlights the relationship between motherhood and depression and its effect on the children with ASD. However, prior to doing so, an important issue to be discussed is the relationship between the depression on mothers and the gender of their children with ASD. The following section provides a discussion of the developmental variation of the boys and girls with ASD. Also, the purpose of the following section is to investigate if there is a pre-established connection between having a boy or a girl with ASD and the reported depression of their mothers.

Gender Differences of Children with ASD

Several studies suggest wide developmental variations between boys and girls with ASD within physical, mental, social, cognitive, and behavioral domains, as well as across ages (Autism Speaks, 2013a; Banach et al., 2009; Solomon et al., 2012; Erikssona, Westerlund, Anderlid, Gillberg, Fernell, 2012; Hartley & Sikora, 2009; Holtman et al., 2007; Janine et al., 2011; Mandy et al., 2012; Solomon et al., 2012). In general, studies showed that girls with ASD were found to have more physical difficulties, internalizing behaviors problems, sleep problems, emotional struggles, anxiety difficulties, and communicational impairment than boys with ASD (Banach et al., 2009; Carter et al., 2007; Hartley & Sikora 2009; Mandy et al., 2012; Solomon et

al., 2012). In a sample of high-functioning participants of 23 matched males with 23 females with ASD, females showed significant ‘social problems’, ‘thought problems’, ‘attention problems’ and ‘total problems scores’ which “reflect peer relation impairments, social immaturity, social dependency, and inattentive, impulsive and hyperactive as well as compulsive and bizarre” (Holtmann et al., 2007, p. 363).

In addition, there are physical differences between the genders with children with ASD. Boys show better motor skills than girls do. In contrast, Mandy et al. (2012) found that girls with ASD have better fine motor skills and dexterity than boys with ASD across the age range (3-18) of the study sample. However, Tsai, Stewart, and August (1981) reported that abnormal movements such as dystonic posturing of hands and fingers and hand flapping were more common in girls than boys (Carter et al., 2007). The findings shows that girls had more impaired gross motor functioning than boys based on both parental reports and direct assessments. These findings may be viewed as consistent with an early report by Tsai and Beisler (1983), who also reported that boys tended to develop better physical skills than girls upon direct assessment. In another a study of six 16 year old children with ASD, female participants with ASD displayed considerable increase in stopping time, which is indicative of poorer inhibition control compared to the other group of males with ASD (Janine et al., 2011). On the other hand, boys showed greater deficits on the visual perception relative to girls (Carter et al., 2007).

In addition to the physical abilities, boys and girls with ASD develop differently socially and behaviorally. In a sample consisting of 22 girl and 68 boy toddlers with ASD who had higher cognitive abilities, toddler boys exhibited higher scores in communication and language as well as social functioning (Carter et al., 2007). Banach et al. (2009) and Hartley and Sikora (2009) supported the notion that girls with ASD are more likely to have communicational impairment

than boys with ASD, which is particularly for those in the lower functioning end of the autism spectrum. Another dimension of the gender differences between girls and boys with ASD is the internalizing symptoms. In a study done by Solomon et al. (2012), internalizing symptoms were more prevalent in girls than boys with ASD. On the other hand, externalizing behaviors and interpersonal problems were more likely to be prevalent in boys with ASD than girls with ASD (Baker et al., 2002; Mandy et al., 2012). Furthermore, results of this study showed significant differences between boys and girls with ASD in engaging in interested activities. Boys were more likely to have restricted interests compared to girls. Hartley and Sikora (2009) and Mandy et al. (2012) found similar results that boys with ASD are more likely to exhibit more restricted, stereotyped, and repetitive interest than girls with ASD.

Furthermore, differences in emotional behaviors were seen between boys and girls with ASD. Girls with ASD had more sleep problems than boys. In addition, girls with ASD had considerably increased anxiety and depression scores than boys with ASD (Hartley & Sikora, 2009). In contrast, Mandy et al. (2012) obtained differing results, depending on whether they interviewed parents or teachers. Though the parents reported that girls had significantly worse emotional difficulties than boys with ASD, teachers reported that boys had higher levels of psychopathology than girls with ASD.

Lastly, cognitive development varies with gender for individuals with ASD. In a sample study across Canada of 50 families with one affected girl with ASD and 144 families with one affected boy with ASD, females with ASD were over-represented in the intelligent quotient (IQ) below 50. More than 50% of females with ASD were below 50 IQ level, and just 20.3% of males were below the 50 IQ level (Banach et al., 2009). These findings were supported by a national study conducted by the CDC in 14 states, which indicates that girls were more likely to have

cognitive impairment than boys with ASD (CDC, 2007). However, it is worth mentioning that girls are often under-diagnosed, which would mean that only the most severely symptomatic girls get an ASD diagnosis and end up participating in those studies (Dworzynski, Ronald, Bolton, & Happé, 2012).

To the author's knowledge, no studies have focused on or examined gender differences in children with ASD and the reported mood disorders of mothers who are rearing their children with ASD. The closest study was conducted in Sweden and investigated the gender differences of the young children with ASD and the reported psychiatric/developmental disorder in first-degree relatives. Broader autism phenotype symptoms, dyslexia, speech-and language impairment, and attention deficit and hyperactivity disorder (ADHD) dominated among males with ASD first-degree relatives. In contrast, in females with ASD, mood disorders, including depression and bipolar disorder, and other psychiatric disorders dominated (Erikssona et al. 2012). The fact that autism-like features appear in members of the same family supports the notion that there could be a genetic basis for autism (Autism Science Foundation, 2014, para 1). This study helped to reveal if part of this complex relationship between ASD and mood disorder is a stress-based relationship.

Investigating and examining gender differences in children with ASD and the reported mood disorders of the mothers is important as it has not been studied in the literature before. One of this study's aims was to address this important gap in the literature. The goal was to investigate whether mothers of girls with ASD report a history of mood disorder more likely than mothers who have boys with ASD. Even though the research has shown the above-mentioned differences do exist, there is counter evidence that only severe cases of girls with ASD get a diagnosis. The literature has found that girls with ASD are more likely to be misdiagnosed

(Dworzynski et al., 2012). Girls are under identified; those with the most severe cases of ASD get diagnosed but not those who are higher functioning. The results of a study done by Dworzynski et al. (2012) showed significant gender differences between boys and girls who did not get an ASD diagnosis. Girls but not boys were found to be less likely to meet the criteria for the ASD diagnosis. As cited in Janine et al. (2011), girls with ASD may be able to “camouflage” their symptoms, which could support the idea of misdiagnosis among girls with ASD. When compared with boys with ASD, girls seem to exhibit fewer challenging behaviors, have greater social and communicative abilities, and have fewer and more ‘typical’ special interests (p. 352). Also, there is a delay in time before girls with ASD get diagnosed. Begeer et al (2013) found that during childhood, females with ASD were likely to get a diagnosis of Asperger 1.8 years later than males. During adulthood, females were likely to get a diagnosis of ASD 4.3-years later than males (Begeer et al., 2013). The relationship of gender of children with ASD and the reported mood disorders of their mothers has not been studied yet. This study sought to investigate whether gender has any impact on the reported mood disorders among their mothers. Studying the relationship of gender and occurrence of mood disorder may help to reveal some confusion about this controversial topic. However, paying attention to the fact that girls with high functioning ASD are more likely to be misdiagnosed is important to acknowledge. In addition, studying the relationship between gender of the children with ASD and reported mood disorders of their mothers provides a useful framework for examining various psychological issues based on the gender differences.

Motherhood and Depression

Depression can negatively affect the mothers themselves, their ability to carry out their daily occupations, and their parental responsibilities toward their children with or without

disabilities. According to the novelist Honore De Balzac, "The art of motherhood involves much silent, unobtrusive self-denial, an hourly devotion which finds no detail too minute" (Quotes Archive, 2011, para 1). Unconstructive consequences such as negative cognitions, behaviors, and effects of depressed mothers limit the mothers' ability to parent their children. Pratt and Brody (2008), in their study about the depression in the United States for the years 2005–2006, found that approximately 80% of individuals with depression reported some level of functional impairment and 27% reported serious difficulties in work and home life. Pelaez, Field, Pickens, & Hart (2007) studied the parenting style of depressed and non-depressed mothers and the behaviors of the toddlers of those mothers. In comparison to non-depressed mothers, depressed mothers showed more authoritarian and more disengaged behaviors over a greater percentage of the time with their toddlers. According to Pelaez et al. (2007), authoritarian mothers are those mothers who show "verbal or physical rejection or control and lack positive encouragement (p. 146)." In contrast, a disengaged mother is "uninvolved, unresponsive or avoidant, rarely vocalizes and displays flat affect" (p. 146).

Lovejoy, Graczyk, O'Hare, and Neuman (2000), in their meta-analytic review of maternal depression and parenting behavior, analyzed the results of 46 observational studies of mothers who were depressed and their children. The focus of this meta-analysis was to compare and contrast mothers who are depressed to mothers who are non-depressed from a maternal depression and parenting behavior stand point. The results showed a moderate effect size for the negative/coercive maternal behaviors ($d = .40$) and disengaged maternal behaviors ($d = .29$), which were significantly higher in depressed mothers than in non-depressed mothers. In contrast, the results showed a small effect size ($d = .16$) for the positive maternal behavior measure, which was significantly less in depressed mothers compared to non-depressed mothers. The results

showed modest effect size for the negative parenting behaviors and the weakest effect size for the positive parenting behaviors.

Mothers' depression and its effects on children. Children of mothers who are depressed are less likely to have their social and emotional needs fulfilled, which may affect their development (Goodman & Gotlib, 1999). According to Goodman and Gotlib (1999) “there is no question that children are adversely affected by their mothers' depression” (p. 458). Moreover, children of depressed mothers have significantly higher rates of externalizing and internalizing problems and other difficulties in emotional and behavioral development compared to children whose mothers are not depressed (Goodman et al., 2011). Guttmanova, Szanyi, and Cali (2007) reviewed the previous literature of Achenbach and Edelbrock (1978), Hinshaw (1992), and McCulloch, Wiggins, Joshi, and Sachdev (2000) and defined internalizing and externalizing behavior problems in the following way. Externalizing behavior problems refer to the behaviors represented by an under-control of emotions and include difficulties with interpersonal relationships, rule breaking, and displays of irritability and aggression. Internalizing behavior problems, on the other hand, involve an over-control of emotions and include social withdrawal, demand for attention, feelings of worthlessness or feeling of inferiority, and dependency. Connell and Goodman (2002) argued that children's internalizing and externalizing disorders are associated with a range of negative outcomes, including peer rejection, impaired social–cognitive development, the development of academic challenges, and difficulty with emotion regulation. Because children of mothers with maternal depression are at risk for internalizing and externalizing problem behaviors (Goodman et al., 2011), behavior problems of children with ASD can be influenced by maternal depression (Goodman et al., 2011); moreover, the mothers increased level of stress can be triggered or increased by the problem behaviors of the child with

ASD (Baker et al., 2002; Beck et al., 2004; Hodapp et al., 2003). For example, stereotypical behaviors of children with ASD were found to be associated with increased maternal stress (Hoffman et al., 2009). In a study sample of 44 children with ASD, parental stress was predicted from problem behaviors such as self-injury (Konstantareas & Homatidis, 1989). Both the children with ASD outcomes and the mothers' mental well-being can be influenced by each other. Consequently, intervening as early as possible with mothers who are depressed is important to decrease the negative consequences on their children with ASD.

Maternal depression also affects play behaviors. In comparison to the play behaviors of toddlers of non-depressed mothers, toddlers of mothers who are depressed showed less time in following their mothers' instruction. In addition, those toddlers exhibited aggressive play behaviors and less on-task-behaviors a greater proportion of time when compared to toddlers of non-depressed mothers (Hipwell, Murray, Ducournau, & Stein, 2005). Extrapolating from the studies of children of mothers with maternal depression, it is likely that giving support to depressed mothers of children with ASD is crucial in improving relations with their children and helping with their children's emotional and behavioral well-being. In this regard, mothers receiving help for their well-being may positively affect the well-being of their children with ASD as well.

It is well established that post-natal depression is associated with some negative disturbances of the mother-infant interaction (Murray, Fiori-Cowley, Hooper, & Cooper 1996; Stein et al., 1991), aggressiveness during children's peer play (Hipwell et al., 2005), and an increased vulnerability for depression of the offspring (Murray, 2009). Depression in mothers has been associated with less effective parental practices and negative maternal thought processes and behaviors (Goodman & Gotlib, 1999). According to Murray et al. (1996),

depressed mothers interact significantly less than non-depressed mothers with their infants. Depressed mothers showed fewer affirmations and greater negations of their infants' behaviors. Moreover, mothers who were depressed were rated as less sensitive. Murray, Halligan, & Cooper (2010) refer to insensitivity that ranges from some kind of intrusive and hostile communication at one end, to some kind of a withdrawn, flat, and disengaged behavior at the other end. The results showed that the more sensitive the mother the more active engagement was going on between the mothers and their children in regards to mother child communication and interaction (Murray et al., 1996). Collectively, these studies substantiate that, the nature of interaction between depressed mothers and their infants were found to be different than that of those who are not depressed. In summary, the main differences between children of depressed and non-depressed mothers are represented by overall decreased sensitivity, less affirmation, and finally more negation. For example, infants of depressed mothers showed some kind of disrupted behavior represented by being sober, still, and showing a negative affect after being exposed to their mothers' negating behaviors (Murray et al., 1996). From the perspective of the maternal depression and children's peer play, Hipwell et al. (2005) found that girls who were exposed to maternal depression (81.8%) were more likely to use verbal aggression compared to girls who were not exposed to maternal depression (50%). On the other hand, boys who were exposed to maternal depression were significantly found to act using physical aggression (76%) compared to a non-exposed control group (52%).

Mood Disorders and Family History of Children with ASD

Investigating the reported family history of mood disorders can reveal very important information about the connection between having a child with ASD and mood disorders. Daniels et al. (2008); Larsson et al. (2005); Lauritsen, Pedersen, & Mortensen (2005); Piven et al. (1991);

Yirmiya & Shaked (2005) reported that history of parental psychiatric disorders has been associated with an increased risk for ASD in the future generation (as cited in Erikssona, Westerlund, Anderlid, Gillberg, & Fernell, 2012). Piven et al. (1999) found that major depression in grandparents of children with ASD was significantly higher (17.7%) than those of children with Down syndrome (8.4%). Also, the results showed that major depression was significantly higher in aunts and uncles of children with ASD compared to children with Down syndrome (13.2% versus 5.4%).

Erikssona et al (2012) found a variation between the reported familial developmental disorders and neuropsychiatric disorders among first-degree relatives based on the gender of the child with ASD. Broader phenotype, speech-and language impairment, dyslexia, and ADHD were dominant diagnoses of first-degree relatives of a male with ASD. In contrast, a history of depression or bipolar disorder was common among female first-degree relatives of females with ASD. Mazefsky, Folstein, and Lainhart (2008) studied a sample of 17 of adults with ASD and their first-degree relatives. The results showed that the rate of major depressive disorder was prevalent among almost 60% of at least one parents of adults with ASD.

DeLong (2004); Piven and Palmer (1999); and Vasa et al. (2012) found that prior to the birth of a child with ASD, mood and anxiety disorders were found to be higher among maternal first-degree relatives. Lajiness-O'Neill and Menard (2008) found a significantly higher rate of mood disorders and anxiety disorder among first-degree relative. In this study, the authors defined first-degree relative as those who are “one meioses away from the parent” including aunts, uncles, or grandparents (p. 983). However, in the current study, first-degree relatives include the following: mother, father, brother, sister, son, and daughter. Second-degree relatives include aunts, uncles, or grandparents.

In addition, some studies found variation between the relationship concerning mood disorders and type of ASD. For example, Vasa et al. (2012) found an association between children with high functioning ASD and maternal mood disorder. The authors stated that having a child with Asperger was strongly associated with maternal lifetime history of depression and bipolar disorder compared to having a child with autism. Moreover, DeLong and Dwyer (1988) found that first and second-degree relatives of individuals with ASD are more likely to report bipolar disorder. Erikssona et al. (2012) found there was significantly higher antidepressant and psychoactive drugs usage in mothers of children with ASD compared to a control group.

In addition, DeLong and Dwyer (1988) studied the rate of psychopathology among first- and second-degree relatives of probands diagnosed with autism and pervasive developmental disorder. The results showed a more specific pattern between the relationship of mood disorders and probands with ASD who have an IQ greater than 70. Cohen and Tsiouris (2006) found significantly higher likelihood association between maternal history of depression disorder and Asperger disorder versus autism phenotype in offspring.

For the purpose of this study and depending on the above-mentioned criteria for the comparison, which includes controlling other variables such as the state of residence, the reported family history of the depression and bipolar disorder of first and second-degree relatives was studied and compared between families with children with ASD and families with TD children.

Interventions for ASD and Depression

There are many interventions that are available for children with ASD. Likewise, there are some other interventions for mothers with depression. However, there is nothing specific that targets mothers with mood disorders who are rearing a child with ASD.

Interventions for children with ASD. Various studies have investigated the best practices for evaluating and providing intervention for individuals with ASD from a very early age through adulthood. A wide variety of behavioral, educational and sensory-based therapies for individuals with ASD can be found in the literature (Baranek, 2002; Dawson & Burner, 2011; Strain, Schwartz, & Barton, 2011). These interventions differ in their emphasis as to behavioral, educational, cognitive, social, medical, and sensory-based approaches. No one approach has been proven beneficial for all individuals with ASD since the impact of ASD is relatively different among individuals with ASD. However, the following section will introduce two of the most commonly used interventions in treating individuals with ASD.

Applied behavioral analysis (ABA) has been proven to be one of the most effective interventions for individuals with ASD. ABA can help to teach individuals with ASD social and communicational skills, and some activities of daily living as well as play skills. The main premise of the ABA is to understand behaviors represented by actions and skills and the effect of the environment of behaviors represented by the physical or social influence that may affect or be affected by one's behavior. The main principle of the ABA is that positive reinforcement by using some kind of reward is more likely to result in positive behaviors being repeated over and over (Autism Speaks, 2013b).

Sensory integration as defined by Ayres (1979) is "the organization of sensory input for use" (p. 184). Ayres (1979) stated the importance of sensation as nutrient that "nourish(es) the brain" (p. 7). The basic principle of sensory integration is eliciting adaptive response by controlling and organizing sensory stimulation (Baranek, 2002). According to Baranek (2002) sensory processing dysfunction represented by difficulty in regulating response to different sensational stimuli is a common disorder among the population of the ASD. Therefore, sensory

integration intervention has been proven to be effective in some ways in treating the neurological processing of the individuals with ASD. For example, Pfeiffer, Koenig, Kinnealey, Sheppard, and Henderson (2011) found a significant effect of reducing autistic mannerism, and increasing fine motor skills, sensory processing and regulation, and finally social-emotional function among children with ASD who received sensory integration interventions.

Interventions for mothers with depression. Most of the interventions for mothers coping with depression do not take into consideration the unique circumstances of being a mother with children with special needs. As stated by Singer (2006), depression in mothers of children with developmental disabilities is not being addressed on an extensive scale. Because of this limitation, the following section examines the broader research about and interventions for mothers coping with depression. The intent of doing so is to provide a backdrop for understanding depression in mothers of children with ASD.

There are a number of interventions that target reducing the symptoms of depression in mothers by enhancing the mothers' ability to manage the challenges brought about by depression. According to National Institute of Mental Health (NIMH; n.d) the most common interventions for managing depression are medication and psychotherapy. Depression medications (antidepressants) primarily work on chemicals of the brain called neurotransmitters. Psychotherapy, also called "talk therapy," is an effective intervention used to help people who are coping with depression. Cognitive-behavioral therapy and interpersonal therapy are the two main kinds of psychotherapies. The main focus of cognitive-behavioral therapy is to restructure negative thoughts that are associated with depression. This process assists individuals who are depressed to recognize the factors that may be contributing to depression and finally assist to change behaviors that are associated with depression. Interpersonal therapy helps people

understand and work through troubled relationships that may be causing or exacerbating their depression.

Serious medical illnesses such stroke, heart disease, cancer, diabetes, or HIV/AIDS, may occur with depression. Those medical conditions along with depression tend to intensify the symptoms for both conditions. In addition, the combination of depression with another medical illness creates more complexity for the individuals to adapt to their medical conditions. Also, the medical costs are higher when treating the co-existing depression (NIMH, n.d.).

As does the complexity of depression become more severe when occurring concurrently with other medical illness, so may the complexity of depression become more severe when rearing a child with ASD. As it was mentioned in the previous section, rearing a child with ASD can be a source of enormous stress and depression. The question is: are the therapies that target depression for people in general also beneficial for addressing the unique challenge of mothers who concurrently are depressed and rearing a child with ASD? Interventions are needed for mothers to successfully cope with the emotional, physical, and social difficulties created by the challenges associated with being depressed and parenting a child with ASD.

Occupation and Well-being of Depressed Mothers with Children with ASD

People's occupations can give meaning to their lives and reveal to others who they are (Christiansen, 1999; Clark et al., 1991). When people disclose to others what they do, they reveal aspects of their personal identities. People might be able to know about others by observing what their occupations are. According to Wilcock (1999a), how people create themselves basically depends on the process of doing, being and becoming through occupations. According to Clark et al. (1991), human beings are occupational beings; having an occupation is one of the main foci of a person's life. According to Zemke and Clark (1996), occupations are defined as "chunks of

daily activity that can be named in the lexicon of the culture" (p. vii). Accordingly, occupation can be any activity that people do to occupy themselves such as cooking, studying, gardening, and grooming. The importance of doing through engaging in meaningful occupations has been recognized as early as the late 70s by Fidler and Fidler (1978) when they acknowledged the relationship between self-actualization and self-identity and what people actually do. Even as early as nineteen hundred, Dunton (1919) recognized the importance of occupation to heal the humans' bodies, minds, and souls when he stated that

Occupation is necessary to life as food and drink

Every human being should have both physical and mental occupations

All should have occupations which they enjoy, or hobbies

Sick mind, sick bodies and sick souls may be healed thru occupation (p. 10)

The dynamic balance between doing and being appears to be central to having a healthy life and contributes whatever people are best fitted to become in their contexts (Wilcock, 1999a). Wilcock (1999a) considers human occupations as the natural biological mechanism for health where a very strong relationship exists between occupation and health. Finding meaning in what people do is positively related to both biological needs and natural health. Hence, health and well-being are influenced by the ability to engage and perform meaningful activities in a person's life (Wilcock, 2006). Engagement in occupations is a basic foundation of life; it is through the active transaction with people, places, and things in an environment that people develop a sense of competence and self-efficacy (Matuska & Christiansen, 2008). Competency is the ability to respond to continually changing events and challenges in new ways that allow people to continue to adapt, grow, and renew (Matuska & Christiansen, 2008). Self-efficacy is the "people's

judgments of their capabilities to organize and execute courses of action required to attain designated types of performances" (Bandura, 1986, p. 391).

While Wilcock (1999b) acknowledges that what people do on a daily basis and throughout their lives is a dynamic factor that can positively influence their health and well-being, she also acknowledges that occupations that do not meet the needs of people can negatively affect their health and contribute to dysfunction, disease, disability or death. Illness, disasters, and difficult life circumstances can compromise the occupations available to people and alter how they engage in those occupations. This compromised or altered engagement can have a devastating effect by not meeting people's desires and needs.

Based on these philosophical premises, it can be assumed that the well-being of mothers of children with ASD is very important. Decreased emotional well-being can be related to stress and depression (Wilhelm, 2006). On the other hand, positive feeling can play an important role in improving the quality of life of mothers who have children with ASD (Shu, 2009). As mothers, to a large extent, they are the primary caregivers for their children with ASD. Parents of children with ASD are more likely to have difficulty in maintaining a balanced lifestyle (Stein et al., 2011). Negative effects of rearing a child with ASD on maternal psychological well-being have been documented. Rizk (2011) found a significant difference between the mental health- of mothers who have children with ASD and who don't have children with ASD, thus negatively impacting their well-being and quality of life. In addition, the well-being of mothers with children with ASD is affected by the social and family support. For example, Ekas, and Whitman (2010) found that partners, family, friends, and social support for mothers with children with ASD were found to be associated with positive maternal well-being outcomes. In particular, the

family support that was provided for mothers with children with ASD is crucial in lowering the levels of emotional turmoil and loneliness that those mothers could face (Shu, 2009).

The occupations of all family members, particularly those of the mothers, can be significantly impacted by the high stress associated with rearing and managing the behavior problems of a child with ASD (Werner-DeGrace, 2004). An increasing number of studies indicates that high overall depressive symptoms, lower sense of wellbeing, and increased care demand have significantly impacted the time mothers of children with ASD engage in activities of choice or desirable activities (Phetrasuwan & Miles, 2009). However, still missing from the research are large population-based studies that address how taking care of a child with ASD has a negative impact on the mothers' psychological well-being (Montes & Halterman, 2007). Therefore, understanding the factors that may be influential in impeding the occupational engagement of mothers who are depressed and taking care of a child with ASD is important to provide a better intervention and to enhance those mothers' occupational participation.

Summary

The literature review presented above highlights the relationships among stress, depression, rearing a child with ASD, and struggles that mothers could have in engaging in their daily occupations. First, the chapter provided an overview of motherhood experience including the effects on mothers and having a child with ASD. It also described how depression is associated with negative maternal functioning and how mothers' depression affects children with or without ASD. Next, the effects of having a son or a daughter with ASD and its impact on mothers and the effect of depression on family history and depression of mothers who have children with ASD was discussed. Finally, the occupational engagement and well-being of those mothers who are depressed and have a child with ASD was discussed.

Chapter 3: Methods

Introduction

This chapter introduces the methods and procedures of both the quantitative and qualitative parts of the mixed method design of this study. It includes an explanation of the: (a) research design and rationale, (b) participants and sampling methods, (c) instrument and data collection methods, (d) data analysis methods, and (e) validation strategies used to ensure the validity and reliability of the study. This chapter concludes with a discussion of ethical issues related to the quantitative and qualitative components and the researcher's qualifications for conducting the research.

Research Design and Rationale

This current study used a mixed method research design that can be simply defined as a process for collecting, analyzing, and “mixing” the methodologies of both quantitative and qualitative research inquiries into one single study to comprehend a research problem or question (Creswell & Plano Clark, 2007, p. 66). However, mixed method research can also be defined “as research in which the investigator collects and analyzes data, integrates the findings, and draws inferences using both qualitative and quantitative approaches or methods in a single study or a program of inquiry” (Tashakkori & Creswell, 2007, p. 4). Mixed method research extends beyond collecting two distinct quantitative and qualitative inquiries to merge, integrate, and link the two inquiries together. According to Creswell (2008), the basic supposition of using a mixed method design is that neither qualitative nor quantitative methods are satisfactory by themselves, but a mixed method approach provides a better understanding of the research problem or question.

This study employed an explanatory sequential mixed method design to (a) test the relationships between the variables in order to compare mood disorders frequency in mothers of children with ASD and mothers of TD children; and (b) explore the lived experience of mothers who are concurrently coping with depression and rearing a child with ASD. An explanatory sequential mixed method design begins with quantitative and moves to qualitative inquiry. It is the most straightforward design of all other mixed method designs and allows the researcher to collect and analyze both quantitative and qualitative data for a more comprehensive understanding of the research problem (Creswell & Plano Clark, 2011). This explanatory sequential mixed method design allowed the researcher to address the questions, which focus on the reported mood disorders of mothers of children with ASD.

The quantitative part of this study helped to explain the relationship between motherhood, depression, and having a child with ASD. The objective was to investigate the frequency of depression and bipolar disorder in mothers of a child with ASD and in mothers who have TD children. Understanding the relationship revealed whether mood disorders occur with the same frequency in both groups of mothers or occur more frequently in mothers of children with ASD.

The qualitative part of this study explored the lived experience of those mothers who are depressed and rearing a child with ASD. Studies exist that examine the lived experience either of mothers who are coping with depression or of mothers who are rearing a child with ASD (Hall, 2006; Kuhaneck, Burroughs, Wright, Lemanczyk, & Darragh, 2010, Smith et al., 2010; Woodgate, Ateah, & Secco, 2008), but none exist that examine the lived experience of those mothers who are coping with both challenges. The objective of the qualitative phase of the study was to capture and understand the perceptions of the lived experience of mothers who cope with

depression while rearing a child with ASD in general, and with rearing a son versus daughter with ASD in particular. A phenomenological design was used for this part of this study. A phenomenological study is a common research design in health related sciences (Nieswiadomy, 1993). Phenomenology can be defined as finding the essence of the common meaning for several persons of their lived experiences of a concept or phenomenon (Creswell, 2007, 2013).

Phenomenological studies, therefore, accurately describe the broad meaning of a lived experience for particular subjects (Creswell, 2007, 2013). Phenomenology in this research study documents the perceptions of depressed mothers who are concurrently rearing a child with ASD rather than explaining it. Using a phenomenological approach, qualitative data was gathered from a select group of mothers, using interviews to understand the impact of mood disorders on daily life and parenting tasks.

Participants

Quantitative. Many mothers of children with ASD participating in the IAN Research Project volunteered to complete the Depression History Questionnaire that focused on mood disorders IAN is the nation's largest online autism research project funded by Autism Speaks, the Simons Foundation, and the National Institute of Mental Health (NIMH). IAN provides qualified researchers free access to their data set (IAN, 2011). Of the 4779 individuals who completed the Depression History Questionnaire, one hundred eighty five were mothers of children, ages 3 to 17.99, with ASD in Maryland. The study sample was created by merging MD IAN subjects (N=1783) with all who had completed the Depression History Questionnaire nationally (N=4779) which resulted in a preliminary sample of N=227 mothers and fathers. Twenty-five (25) fathers were then excluded for a total of 202 Maryland mothers who had taken the Depression History Questionnaire. These mothers were then paired with their oldest affected

child between the ages of 3 and 17.99 years. Seventeen (17) mothers were excluded because they had no affected child in the designated range resulting in a final sample of 185 mother-child dyads (See Figure 3.1). Three years old was selected as the minimum age because this is the age when the diagnosis of ASD is frequently is confirmed (Autism Speaks, 2014). The age of 17.99 represents the end of childhood (National Conference of State Legislature, 2014).

Figure 3.1

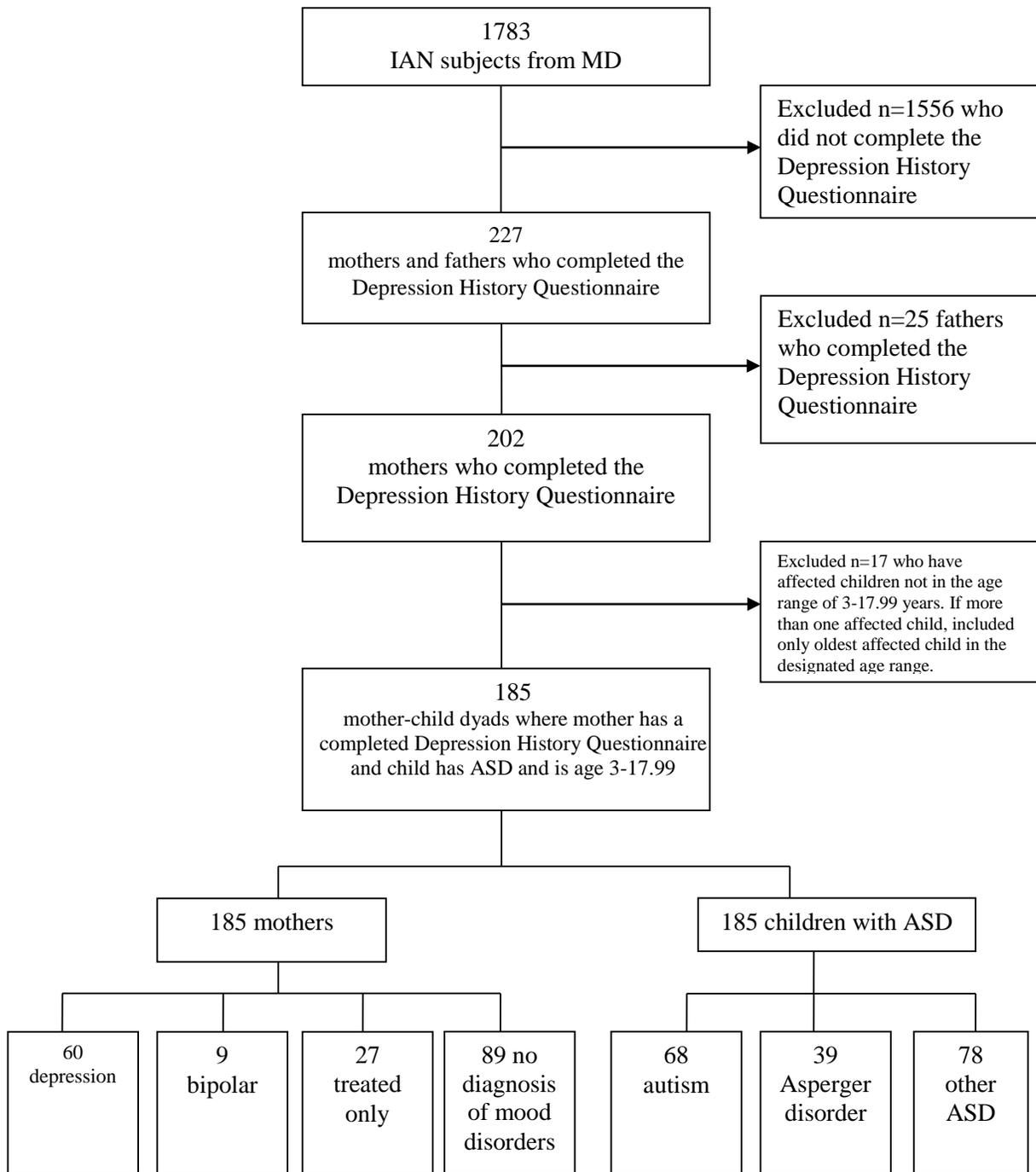


Figure 3.1. The Eligibility of the Sample of Mothers and their Children with ASD

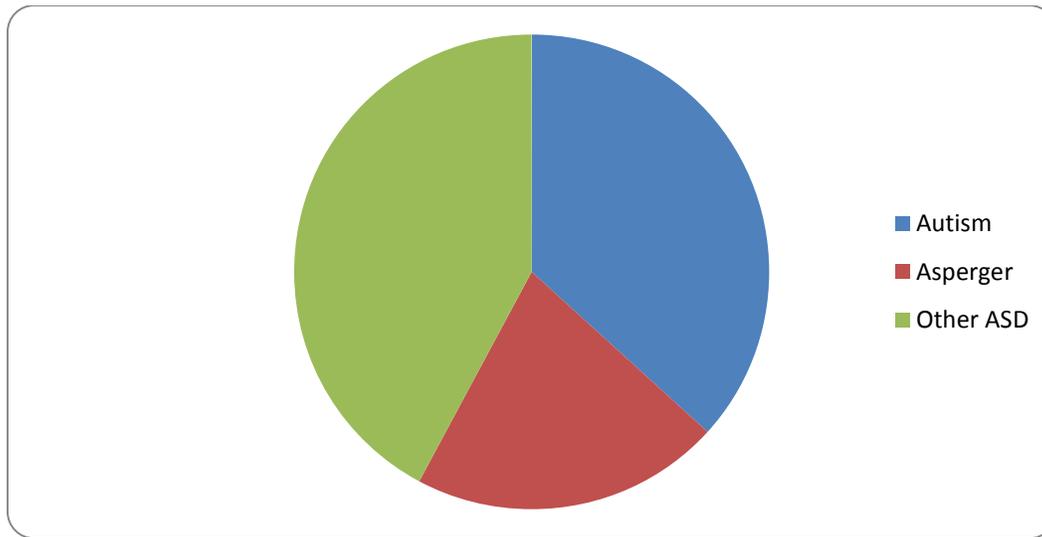
Because IAN data on maternal Depression History Questionnaire does not include information from a control group of mothers of children unaffected by ASD, a similar questionnaire was electronically disseminated to mothers in Maryland of children who are TD. Permission to use the Depression History Questionnaire for this purpose was granted by the IAN Research Project (See Appendix A). The aim was to collect similar information from mothers who live in Maryland and whose children are TD, and to compare it with the existing data. Therefore, the quantitative phase of the study involved recruiting a large sample of mothers of TD children in Maryland to compare the frequency and effect of mood disorders in those with children who have ASD versus those with children who are typically developing. The group of mothers who have TD children included approximately 200-300 mothers who self-identified that their biological children are: (a) between the ages of 3 and 17.99 years; (b) are developing typically; and (c) do not have ASD. In addition, mothers needed to have access to a computer and internet in order to be able to participate.

The sample of mothers whose children are TD was chosen from Maryland to control for the variable of the place of residence for the purpose of the comparison. In order to match data nationally, the researcher would require financial funds, more time, and extra efforts, which are not available for a doctoral student. In addition, it would be difficult to match the number of mothers with TD children, collected by the researcher, with the number of mothers with children with ASD that already exists in IAN's database. For the purpose of this study, the children were between the ages of 3 and 17.99 years, which matched with the children with ASD. TD children were defined as those who do not have a diagnosis of autism, developmental delay, or other chronic physical or mental health challenges.

Data from both the IAN Depression History Questionnaire and the TD depression history questionnaire were used to compare (a) demographics of reported history of mood disorder, (b) reported mood disorders, and (c) reported family history of mood disorder. Finally, mothers of TD children who completed the survey had a chance to win a \$50 Amazon gift card. Those participants who wished to participate in the drawing to earn a \$50 Amazon award card did so by filling a separate entry form on Survey Monkey ® that was linked to their responses.

Demographic and clinical characteristics of children with ASD. Based on the preliminary analysis of the IAN data, children with ASD's ages ranged from 3 to 17 years. The children's mean age was 8.55 years with a standard deviation of 4.15. Children with ASD comprised 153 (82.7%) males and 32 (17.3%) females, which closely matches the approximate ratio of 4-to-1 male to female of the population of ASD (APA, 2013). Out of the 185, autism (N=68), Asperger disorder (N=39), and other ASD (N= 78; see Figure 3.2). A substantial minority of the affected children in the study sample had an SRS t-score (138 out of 185). The mean SRS t-score for these children was 86.31. As stated by Constantino and Gruber (2005) a total t-score of the range of 76 or higher is interpreted to indicate severe clinical ASD diagnosis. The SRS is a measure of social disability in ASD, which will be explained further in the validity and reliability section. Consequently, the t-score of this study sample confirmed the diagnosis of ASD. Descriptive characteristics of the sample of the children with ASD and for TD children are found in Table3.1.

Figure 3.2.

*Figure 3.2. Children with ASD Diagnoses Percentages*

Demographic and clinical characteristics of mothers of children with ASD. Mothers of children with ASD ranged in age from 26.91 to 57.29 years with a mean of 38.84 and a standard deviation of 6.07. The majority of the mothers of the children with ASD were non-Hispanic (n=180, 97.3%) and the remaining were Hispanic (n=5, 2.7%). White mothers constituted the majority of mothers of children with ASD (n=156, 84.3%) followed by Black/African-American mothers (n=20, 10.8%). The remaining mothers comprised Asians, other races, and American Indian/Alaskan Native in order. No mother was of Native Hawaiian/Pacific Islander or of unknown race. The highest level of education completed by the mothers was classified into six levels, ranging from less than high school to doctoral or professional degree. Average maternal education was bachelor's degree, which was located between some college or associate degree and master's degree. The descriptive characteristics of

the sample of mothers with children with ASD and for mothers of TD children are found in Table 3.2.

Characterizing the sample of mothers with children with ASD. Because of a diagnosis of bipolar disorder is very specific and usually includes depressive components, those who reported both a diagnosis of depression and bipolar disorder were counted as bipolar. Those who reported a diagnosis of depression but not bipolar disorder were counted as depressed. Those who had not been diagnosed with bipolar disorder or depression but did report receiving treatment, (for example, those who were given antidepressant medications by a general doctor), were counted as treated only. Finally, those who fit none of the above categories were counted as no history of mood disorders at all (See Figure 3.3).

Figure 3.3

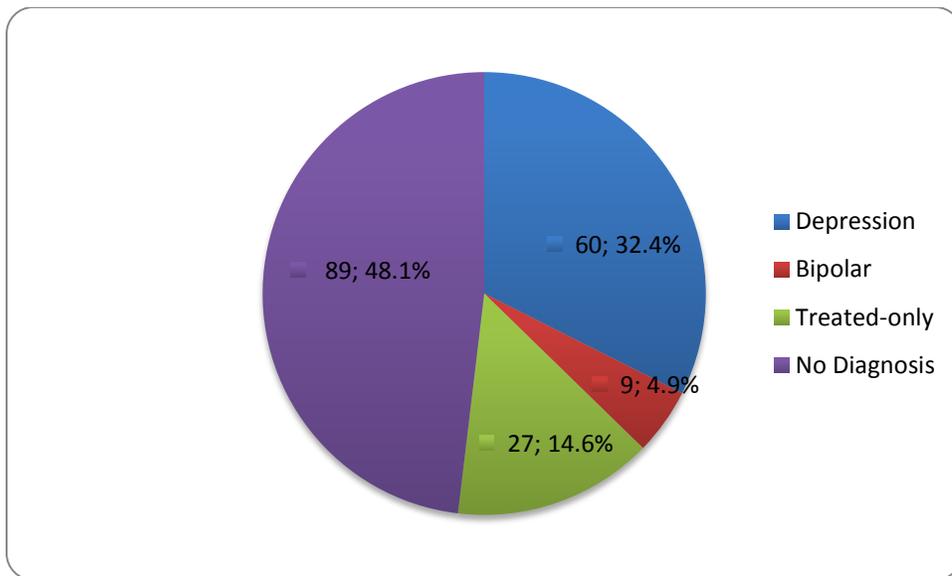


Figure 3.3. Categorizations of Mood Disorders of Mothers with children with ASD

Table 3.1.

Characteristics of Children with ASD

<i>Characteristics</i>	<i>Children with ASD</i>
	<i>N=185</i>
Demographics	
Children age, mean (SD)	8.55 (4.15)
Children gender n (%)	
Male	153 (82.7%)

Table 3.2.

Characteristics of Mothers of Children with ASD

<i>Characteristics</i>	<i>Mothers of Children with ASD N=185</i>
Demographics	
Mothers age, mean (SD)	38.84 (6.07)
Ethnicity n (%)	
Non-Hispanic	180 (97.3%)
Race n (%)	
White	156 (84.3%)
Black/African-American	20 (10.8%)
Native Hawaiian or Pacific Islander	0 (0%)
Asian	6 (3.2%)
American Indian or Alaskan Native	1 (0.5%)
Unknown	0 (0%)
Others	4 (2.2%)
Educational Level n (%)	
Did not complete high school	1 (0.5%)
High school or graduate equivalent	9 (4.9%)
Some college associate degree	55 (29.7%)
Bachelor's degree	58 (31.4%)
Master's degree	44 (23.8%)
Doctoral or Professional degree	18 (9.7%)

Qualitative. The qualitative part utilized purposeful sampling in which the participants who had experienced the central phenomenon were intentionally selected (Creswell & Plano Clark, 2011). The original intent was to have a minimum purposeful sample of four mothers: one mother of an adolescent age son, one mother of an adolescent age daughter, one mother of an elementary age son, and one mother of an elementary age daughter. Nine mothers of school-aged children with ASD who self-identified as having depression, currently being treated for depression (taking medication or receiving psychotherapy), having a child with ASD and living in Maryland volunteered to participate in the study. They were interviewed in a location of their choosing and shared their daily life experiences of being a mother with a child with ASD and coping with depression. That nine mothers agreed to be interviewed resulted in saturation of themes and contributed to the knowledge base about the relationship between maternal depression and parenting a child with ASD.

Recruitment of Participants

Quantitative. A number of methods were used to recruit mothers of TD children. First, the link to the questionnaire was posted on Autism Society of Maryland's Facebook page. The Autism Society's Baltimore-Chesapeake Chapter and Autism Society Harford County Chapter had agreed to disseminate an announcement with a print out that requested mothers with children with ASD to assist with identifying mothers of TD children who were willing to participate to support research for ASD. Using Autism Society Chapters, the researcher invited mothers of TD children to complete the online questionnaire. The reason why mothers of children with ASD were asked to help seek mothers of TD children was because mothers of children with ASD were more likely to be motivated to contribute to ASD research. Second, an invitation was sent to Towson University students, staff, and faculty through Towson Tigers Today, asking the

qualified population to participate in this survey. Third, the researcher used email to contact mothers of children with ASD who are known to her as well as in the researcher's contact list and ask them to share the email with their friends who are mothers of children who are TD. Finally, an advertisement about the study was posted on the bulletin board and webpage of a local church to ask the qualified target population to participate (See Appendix D).

Qualitative. Most participants were solicited through chapters of the Autism Society in Maryland via their support groups and advertisement posted on the societies' Facebook page. The Autism Society Baltimore-Chesapeake Chapter and Autism Society Baltimore-Harford Chapter agreed to advertise the study flyers at their support group and on Facebook. A flyer about the qualitative section of this study was displayed, informing mothers of children with ASD and who were coping with depression of the purpose and procedure of the research study and asking them to participate (See Appendix E). In addition, a mother of a child with ASD known to the researcher agreed to participate. This mother also agreed to ask other mothers to participate.

Data Collection and Analysis

Quantitative. The data for the mothers' Depression History Questionnaire from IAN was obtained in an Excel file. The cases that met the inclusion criteria were imported into a Statistical Package of Social Sciences (SPSS) file. The IAN Project provided a codebook for the Depression History Questionnaire; the data of mothers of TD children were coded to match and compared with the data from IAN. SPSS version 21 for Windows was used for the statistical analysis. Descriptive statistics were used to report on key variables for both groups of mothers. Binary logistic regression analysis was used to predict the reported maternal history of mood disorders (e.g. diagnostic status) and family mood disorder history between mothers of children

with ASD and mothers of TD children. Similarly, binary logistic regression was used to predict the gender differences of the children with ASD on the reported mood disorder among mothers of children with ASD.

Qualitative. The interviews were transcribed and then coded in order to produce a picture of the processes and strategies used to develop the course material. In addition, the participants had the right to review and make edits to the transcripts of the interviews if they wish. The phenomenological study method, as applied in this study, allowed for the discovery of a deep understanding of the complex realities experienced by mothers who are depressed and rearing a child with ASD.

In order to capture the meaning of the lived experience of mothers with children with ASD who also have depression, Mousstakes (1994) approach was used for analyzing the results. According to Creswell (2013), Mousstakes' data analysis procedure was considered a structured approach. It has organized procedures, steps, and guidelines for assembling the common lived experiences through the participants' description. Mousstakes (1994) stated the major procedural steps of conducting phenomenological research as follows: (1) determining the suitability of phenomenological approach to qualitatively explore the research problem, (2) identifying the phenomenon of the interest, (3) understanding and recognizing the broader philosophical assumption of phenomenology as a research inquiry, 4) collecting-depth data via interviewing the target participants, (5) asking the participants open-ended questions that answer the main essence of the phenomenon including what they have experienced in relation to the phenomenon of the inquiry and what situations have influenced the participants' experience, 6) analyzing data, which consists of transcription, and formulating themes.

In regards to the data reduction process of a phenomenon, Mousstakes (1994) suggested the following bracketing, horizontalization, and clustering techniques. Bracketing is defined as placing those statements of the study focus within brackets. Horizontalization is the ability of the researcher to give an equal value to all statements even for the redundant ones. In addition, the data was reduced by deleting all the repetitive and overlapping statements leaving only the relevant irredundant textual meaning. Finally, clustering all the pieces of the phenomenon description into themes provided a “Coherent Textual Description” of the central phenomenon (p. 97). Utilizing Mousstakes procedures and guidelines, the researcher equally considered all the mothers’ statements. The descriptions that were most pertinent to the central phenomenon were bracketed. Finally, the points of views of mothers of children with ASD who are coping with depression were gathered to explore the common meaning for their lived experience.

Validity and Reliability for the Quantitative Study

The Depression History Questionnaire was developed at the IAN project by a multidisciplinary team including autism researchers, mental health professionals, and parents of children with ASD. The questionnaire was meant to further explore an early finding of the project: that more than 40% of the thousands of mothers of children with ASD participating in the project reported having been ‘diagnosed with or treated for depression’ (IAN, 2013).

The IAN data set as a whole does demonstrate external validity, reflecting ratios that would be expected based on the literature. For example, the male-to-female ratio of children with ASD in the IAN sample closely approximates that reported in the DSM-5: 4 males to 1 female (APA, 2013). This is true of both the overall IAN sample and the sample of IAN families in Maryland used for the current study.

One key issue for the IAN study was establishing the accuracy of ASD diagnoses reported by parents. This was accomplished in two ways. First, Daniels et al. (2012) verified the diagnosis reported by 116 IAN families based upon the child's diagnostic documentation. They found that the diagnoses that parents with ASD had reported were confirmed by diagnostic documentation such as medical or school records.

Second, as part of IAN's questionnaires, families were invited to complete the Social Responsiveness Scale (SRS). The SRS is a widely used 65-item screening tool that addresses communication, interpersonal behaviors, and repetitive and stereotypic behaviors that are associated with ASD (Constantino & Gruber, 2005). It is a widely used, valid, and reliable instrument based on a parent's report of a child's social behaviors (Constantino & Gruber, 2005; Constantino, et. al., 2009). A t-score of less than 60 does not suggest an ASD diagnosis. A T-score of 60-75 is expected for children with high-functioning ASD such as Asperger's Disorder, while a T-score of 76 or higher is expected for more severe cases of ASD. Even individuals with ASD with average or even high IQ will score poorly on the SRS as it captures their social deficits (Constantino & Gruber, 2005). Although SRS scores are not available for every IAN participant, they are available for many. To demonstrate the validity of the ASD diagnosis, a t test was used to compare the SRS t-scores of children with ASD and their unaffected siblings in the Maryland IAN subsample. As expected, the mean SRS t-scores for the children with ASD (86.07) and unaffected siblings (46.24) were statistically significantly different ($p < .001$) and fall into the anticipated ranges for 'affected' and 'unaffected.' This provides additional support for the validity of the parent-reported diagnosis.

Authenticity and Trustworthiness of Qualitative Data

This qualitative study incorporates key strategies to ensure authenticity and trustworthiness of the data. According to Holloway and Wheeler (2010) the terms trustworthiness and authenticity are more often used than the terms validity and reliability in qualitative research. Thus, according to Creswell and Miller (2000) various validation strategies was utilized to assure the credibility and rigor. Qualitative validity can be captured through trustworthiness, which includes credibility, transferability, dependability, and confirmability. Also validity can be achieved by authenticity, which includes fairness as well as personal and other constructions (Creswell & Miller, 2000, Holloway & Wheeler, 2010). In order to assure authenticity and trustworthiness of the data, a qualitative researcher can utilize triangulation, member checking, peer reviews/peer debriefing, thick description, external audits, and identifying the negative cases and alternative explanation (Creswell & Miller, 2000; Holloway & Wheeler, 2010). For the purpose of the qualitative inquiry of this study, the researcher used the following procedures, member checking, peer review, audit trail, thick description, and reflexivity.

The interviews were recorded and then they were transcribed verbatim. Then there was a second time of listening for the interviews to insure accuracy of the transcripts. In order to establish internal validity, participants were asked to verify the recorded information and to make sure that the transcript reflected what they meant (“member checking”). A member check allows the subject to agree or disagree with the information that was stated about them (Ratcliff, 1995). The participants’ feedback helped insure the authenticity of the mothers’ perception about their experiences. In addition, the chairperson of the dissertation committee served as second reader of the transcripts to do the analysis of themes.

In order to demonstrate validity of the results, the researcher maintained an ongoing audit trail of all the documentation of the research process (Mile & Huberman, 1984). According to Creswell (2007) an audit trail consists of the “chronological narratives entries of research activities, including pre-entry conceptualization, entry into the field, interviews, group activities, transcription, initial coding efforts, analytic activities, and the evolution of the survival and coping theoretical model” (p. 291). Audit trail helps to evaluate study validity (Holloway & Wheeler, 2010). Rice and Ezzy (2000) stated that “maintaining and reporting an audit trail of methodological and analytic decisions allows others to assess the significance of the research” (p.36).

Ethical Issues

The IAN Project’s protocols and practices, including its collection and distribution of Depression History Questionnaire data, was approved by the Johns Hopkins University Institutional Review Board (IRB) (See Appendix F). All precautions were taken to assure the protection of mothers of children with ASD as well as their children with ASD. The researcher received de-identified data containing only the year of birth of the mothers and their children and the states of residence were listed. Prior to the start of data collection, an application for Towson University IRB was submitted and approved for this mixed method design study (See Appendix G).

Quantitative. Towson University approved this study to collect data for mothers with TD children. The target population of this study was informed that participation was absolutely voluntary. In order to assure the protection of human subjects in this study, participants were asked to sign an electronic consent form (See Appendix H), in which all the study’s objectives, procedures, risks, and the participants’ rights are stated. In this online consent form, it was

clearly stated that the mothers have the right to answer the questions they would like to. Signing the permission to participate indicated that the mothers had read the purpose and procedures for the study and agreed to participate. However, mothers had the right to withdraw from filling out the survey at any point. Mothers of TD children only were asked to provide their date of birth, zip code, and state. Those participants who wanted the summary of the study results to be sent to them were asked to send a separate email to make that request. Therefore, nobody would be able to match their contact information with their data. The quantitative data were stored on the researcher's computer, which is password protected. At the completion of the quantitative part of the study, the data was removed from the computer to a disk and stored in a locked cabinet of the chair of the dissertation committee for three years, as per Towson University policy.

Qualitative. To protect the mothers' confidentiality, the mothers of children with ASD who are currently coping with depression were informed that their identity would not be revealed to anyone except the investigator. The participants were asked to sign a consent form, which outlined the purpose of and procedures for the study (See Appendix I). They were informed that they can choose which questions to answer and could terminate the interview at any time. Participation in this study was voluntary. All identification information that was reported by the mothers was changed for example, name of a doctor, name of a teacher, or name of a school etc. Pseudonyms rather than the mothers and their children real names were used in all reports. No personal identification was revealed except to the researcher. The interviews were audio taped and transcribed verbatim. At the completion of the qualitative part, the recordings were saved on a CD. All participants' transcriptions and recording materials were coded with participant ID numbers to ensure confidentiality. The recording and the transcripts were to be stored in a locked cabinet of the chair of the researcher's dissertation committee for three years, as per Towson

University policy. There were no known risks for human participants. In addition, upon request, the participants would be provided with a list of counselors from the community who specialize in family counseling and ASD. One of the mothers had asked for a list of counselors. Therefore, she was provided with that list that is close where she lives.

The Qualifications of the Researcher

The investigator of this study has been practicing occupational therapy for thirteen years in the Hashemite Kingdom of Jordan. For the first eight years, the researcher worked as an occupational therapy practitioner, treating pediatric cases including ASD. For five years of practice, the investigator has served as a faculty instructor in the Occupational Therapy department at the Hashemite University in Jordan. For the past five years, the investigator has been engaged in the graduate studies. In 2009, the researcher completed her Master of Arts in Occupational Therapy from New York University. Her master's thesis focused on a comparison of social participation between children with high-functioning autism and those who are typically developing. In 2009, the journey for her doctorate degree started at Towson University. Since that time, the researcher has focused on courses and internships that are related to ASD.

Additionally, the investigator completed an internship focusing on planning and implementing online survey research in the field of autism with the IAN Project at Kennedy Krieger Institute. Through fulfilling the course requirement, the researcher was introduced to the IAN questionnaires. The Depression History Questionnaire was one of the IAN questionnaires, which inspired this study.

The Role of the Researcher

The researcher is considered the primary mean of data collection, data interpretation, and data analysis processes in a qualitative research (Creswell, 2009). In order for a researcher to

conduct a qualitative inquiry, the following aspects of self-evaluation that contains assumptions, biases, experiences, and expectation should be considered (Greenbank, 2003). Therefore, the researcher was as objective as possible and took the role of active listener who sought additional information from the participants in the interviews while being aware of her own biases and assumptions. In order to reduce the potential bias, the researcher consistently reviewed any biases or standpoints that she had that might have affected the validity of this study. Reflexivity is very important issue to take into consideration while conducting a qualitative study.

Reflexivity can be defined as “the writer is conscious of the biases, values, and experiences that he or she brings to a qualitative research study” (Creswell, 2013). According to Morrow and Smith (2000), utilizing a reflective journal adds rigor to qualitative inquiry, as the researchers are able to document their assumptions, reflections, expectations, and biases about the research procedure. Therefore, a reflective journal describing the reflections and insights of the researcher was kept along with the qualitative data collection and analysis processes.

Limits of the Research Design

Quantitative. Self-report data was considered one limitation in relation to data collection. The quantitative part of this study relied on pre-existing maternal self-reported data of mood disorders rather than in-clinic assessment conducted as part of the study or confirmed by a medical institution. The researcher took what the participants stated at face value. As cited in Paulhus and Vazire (2006, p. 224) “Despite its popularity and demonstrated utility, the self-report method has been a frequent target of criticism from the early days of psychological assessment (Allport, 1927) right up to the present (Dunning, Heath, & Suls, 2005)”. In self-report method, the key disadvantage is that individuals are not always honest and the collected data is personal and “may bear little relationship to reality,” therefore, data could be subject to

validity issues (Barker et al., 2002, p. 95). However, self-report method for a quantitative inquiry helps the researcher to collect data involving large number of participants in a quick way. Self-report method for the qualitative research assist the researcher to get the participants to describe their experiences, own views, and perceptions in details (Barker, Pistrang, and Elliott, 2002).

In addition, the population of this study was limited to the Maryland state area, which may influence the generalizability of the findings to other states. However, because of the variation among the reported depression within the U.S. it was more beneficial to match for the place of residence for the sake of a solid comparison. In addition, the data from mothers with children with ASD were collected via an online questionnaire though IAN. Also, the data of mothers of TD children was also collected online via Survey Monkey ®. The process – online data collection – is substantially the same.

Although there has been come criticism of online data collection, including the notion that a ‘digital divide’ means only those with access to a computer and internet connection can participate (McDonald & Adam, 2003), there are some major advantages as well. Goslin, Vazire, Srivastava, and John (2004) stated that web-based collected data is proven to be a powerful strategy and a reliable means for different types of research inquiries including health-related studies. Web-based surveys have their own advantages such as, faster data collection, low cost, fewer occurrences of item-missing data, and more accessibility especially for people from rural areas, and finally anonymity (Boyer, Olson, & Jackson, 2001; McDonald & Adam, 2003; Zlomke, 2009). Moreover, current research supports the increased usability of the internet especially among American individuals of parenting age, which was the target group of this current study. The age range of 18-to-44 was found to be over half of the adult internet users and also the rate of the internet users has been increased almost 75% in the 18-to-54 year old age

group (Jones & Fox, 2009). At the same time, traditional data collection methods have their own disadvantages such as the lack of anonymity and restricted access by lifestyle (parents who work and can't take time off to visit a clinic when it is open for business) or geography (parents who live far from any research institution). These factors may create bias as well (Goslin et al. 2004). To conclude, both web-based and traditional data collection methods have their own pros and cons, however, web-based method has been found to be a reliable mean for collecting data.

Qualitative. For the qualitative part of this study, the phenomenological design, although it is an appropriate approach to gather in-depth and rich information, has its own limitations. Since the researcher is the primary source of collecting and analyzing data, the process is subjective and liable to researcher biases, which affect the reliability and validity of the results. For researchers, it is difficult to be aware of all the personal biases or to prevent bias from interfering with the results. There are some ways where the bias can be on the conscious level and can be minimized. In order to reduce the subjectivity of the findings and establish a solid foundation of the reliability and validity, the researcher followed Patton's (2002) suggestions to "explore one's predispositions, making biases explicit, to the extent possible, and engaging in mental cleansing processes" (p. 553). The researcher kept a journal of her experiences and discussed them with the dissertation committee members to minimize personal bias.

The recruiting procedure might have contributed to another limitation of this part. Since the sample for the qualitative part of this study was recruited through purposeful criterion sampling, the generalizations as well as the control for selection bias could be influenced. However, the aim of phenomenology studies is not to produce generalizable data but to explore the lived experience of the target population.

Summary

This chapter described the mixed methods approach that was used to complete the study. In summary, this study used quantitative methods to compare the reported bipolar/depression among mothers with or without children with ASD. It also described the relationship between a family history of mood disorders and the reported mood disorders among mothers with or without children with ASD. Finally, the quantitative part also described the relationship of the gender of the child with ASD and the reported bipolar/depression of their mothers. Inclusion criteria required mothers to have TD children between the ages of 3-17.99 who reside in Maryland. The data on mothers of children with ASD is pre-existing; data on mothers of TD children was gathered through an online questionnaire through Survey Monkey ® and analyzed using SPSS version 21 for Windows.

For the qualitative part, a phenomenological research design was utilized in order to explore the daily experiences of mothers who are depressed and having a child with ASD. Mothers who are depressed and rearing an elementary school or high school aged child with ASD are considered in the inclusion criteria. The data was collected through a face-to-face, semi-structured, audio-taped interview. The data was transcribed verbatim and analyzed using Mousstakes' (1994) approach. This mixed study with its two parts was approved by the IRB by the researcher's academic institution. Sample recruitment consisted of a snowball design by posting flyers, advertising through the Facebook of Autism Society Baltimore-Chesapeake, Autism Society-Harford, Autism Society-Howard, and local churches.

Chapter 4: Results

Introduction

The purpose of this study was to examine experiential coping differences between mothers of ASD children and mothers of TD children. The study included two types of research methodology. The quantitative portion of the study compared the differences in the reported mood disorder between mothers who have at least one child with ASD and mothers whose children all are developing typically. The qualitative portion expanded upon the quantitative to describe the lived experiences of mothers who are coping with depression while rearing a child/children with ASD. The following sections present the results of the quantitative and qualitative studies and then an integration of results of both methods.

Quantitative Results

Sample Characteristics. The sample consisted of a total of 355 mothers: 185 mothers who have children with ASD and 170 mothers of TD children. Independent sample t-tests and chi square tests examined differences in demographic characteristics for mothers who have children with ASD and mothers of TD children. (See Table 4.1.) The mean age of mothers of TD children was 40.7 with 7.4 SD while the mean age of mothers of children with ASD was 38.8 with 6.1 SD ($p < .05$). Compared to mothers of TD children, more mothers of children with ASD were white (84.3% vs. 73.5%), chi-square (1)=6.26, $p < .05$ and non-Hispanic (97.3% vs. 90.9%), chi square (1)=6.61, $p < .05$. Education level differed somewhat between the two groups of mothers. More mothers of TD children failed to complete high school (1.8% vs. 0.5%) or held high school diplomas (8.8% vs. 4.9%), Bachelor's degrees (33.5% vs. 31.4%), Master's degrees (29.4% vs. 23.8%), or Doctoral degrees (11.2% vs. 9.7%), while mothers of ASD children held more Associate's degrees (29.7% vs. 11.3%), chi-square (5)=12.69, $p < .05$. Mothers were paired

with their oldest child with ASD under the age of 18 (in the case of the mothers of children with ASD), while mothers of TD children were simply paired with their oldest child under 18. The mean age of TD children was 11.3 years with 4.7 SD; the mean age of children with ASD was 8.5 years with 4.2 SD, ($p < .05$). The sample of TD children was 46.5% male and the sample of children with ASD was 82.7% male, chi-square (1)=51.36, $p < .001$. (See Table 4.1 for descriptive statistics). Of those children with ASD, 37% were diagnosed with autism, 21% were diagnosed Asperger's syndrome, and 42% were diagnosed with other ASD diagnoses.

Table 4.1.

Sample Characteristics

	TD Children and Their Moms n=170	Children with ASD and Their Moms n=185	p value of chi- square, Fisher's exact or t-test
Mean maternal age (SD)*	40.7 (7.5)	38.8 (6.1)	p<.05
Maternal race (% white)	125 (73.5%)	156 (84.3%)	p<.05
Maternal Ethnicity (% Non-Hispanic)	149 (90.9%)	179 (97.3%)	p<.05
Maternal Education %			
Did not complete high school	3 (1.8%)	1 (0.5%)	
High school or graduate equivalent	15 (8.8%)	9 (4.9%)	
Some college associate degree	26 (15.3%)	55 (29.7%)	
Bachelor's degree	57 (33.5%)	58 (31.4%)	

Master's degree	50 (29.4%)	44 (23.8%)	
Doctoral or Professional degree	19 (11.2%)	18 (9.7%)	
Mean Child Age	11.3 (4.7)	8.5 (4.15%)	p<.05
Child Gender (% Female)	91 (53.5%)	32 (17.3%)	p<.05

More mothers of children with ASD had been professionally diagnosed with depression or a mood disorder at some point during their lives than mothers of TD children. In the sample of mothers of children with ASD 33% had been diagnosed with depression; 4.9% had been diagnosed with bipolar disorder; and 62.2% had never had a diagnosis. In the sample of mothers with TD children 12.9% had been diagnosed with depression; 0.6% had been diagnosed with bipolar disorder; and 86.5% had never had a diagnosis. The results of a chi-square test that examines the associations among the reported mood disorder variables and ASD status (mothers of children with ASD vs. mothers of TD children) can be found in Table 4.2. The rationale for using the chi-square test is described in the statistical procedures section. More detailed analyses of the findings can be found in the analysis of quantitative data section below. Maternal mood disorder diagnoses for mothers of children with ASD added up to 101% due to a rounding error (See Table 4.2).

Table 4.2.

Percentages of Mood Disorders of Mothers who have Children with ASD and Mothers of TD Children

	Moms of TD Children	Moms of ASD Children	Chi-square/Fisher's exact/t-test p values
Maternal Mood Disorder Diagnosis*	n=170	n=185	
Depression	22 (12.9%)	61 (33.0%)	p<0.001
Bipolar Disorder	1 (0.6%)	9 (4.9%)	p<0.001
No Diagnosis	147 (86.5%)	115 (62.2%)	p<0.001
Professionally diagnosed with depression	23 (13.5%) n=170	70 (37.8) n=185	p<0.001
Ever treated	42(24.7%)	98 (53%)	p<0.001
Ever hospitalized	2 (1.2%) n=170	12 (6.5%) n=185	p<0.05
Suicidal Ideation	20 (12%) n=166	61 (33%) n=185	p<0.001
Suicidal attempts	7 (4.2%) n=166	22 (12%) n=184	p<0.05
Any depression	55 (32.4%) n=170	105 (56.8%) n=185	p<0.001
Had depression	14 (30.4%)	73 (71.6%)	p<0.001

before having children	n=46	n= 102	
Professionally diagnosed with manic disorder	1 (0.6%)	9 (4.9%)	p<0.05
If diagnosed with any bipolar diagnosis	n=166	n=183	
Family history of depression	1 (0.6%)	9 (4.9%)	p<0.05
Family history of manic disorder	n=170	n=185	
Family history of depression	39 (23.5%)	98 (53.8%)	p<0.001
Family history of manic disorder	n=166	n=82	
Family history of suicide	13 (7.8%)	46 (25.6%)	p<0.001
Family history of suicide	n=166	n=180	
Family history of suicide	17 (10.2%)	49 (26.9%)	p<0.001
Family history of suicide	n=166	n=182	

Validity and Reliability for the Quantitative Study

As discussed in chapter three, external validity of the data is supported by the fact that several prevalence ratios of demographic variables were similar to those established in published research. For example, the male-to-female ratio of children with ASD in the IAN Maryland subsample closely approximated that reported in the DSM-5: 4 males to 1 female (APA, 2013). In contrast, the female-to-male ratio of children in the TD subsample approached 1:1, with 53.5% being female. This closely approximates the proportion of females in the U.S. reported by the World Bank (2015): 50.8%.

Also, as discussed in chapter three of this study, the accuracy of the ASD diagnosis was established in a study done by Daniels et al. (2012). In addition, families who completed IAN's questionnaires were invited to complete the SRS, which confirmed that the children had ASD. The SRS is a highly respected assessment tool for measuring social responsiveness problems that include communication, interpersonal behaviors, and repetitive and stereotypic behaviors associated with ASD (Constantino & Gruber, 2005). In order to validate diagnosis of ASD in the current study, a t-test was used to compare the SRS scores of children with ASD relative to their unaffected siblings. The results confirmed the parents' reported diagnosis of ASD. The difference between the mean SRS T-scores for the children with ASD (86.07) and unaffected siblings (46.24) was statistically significant ($p < .001$) and fell into the anticipated ranges for 'affected' (≥ 76) and 'unaffected' (< 76). As a reminder, a total T-score of 76 or higher is interpreted to indicate severe clinical ASD diagnosis (Constantino & Gruber, 2005)

Statistical Procedures

This study included a number of predictor and outcome variables. The predictor variables included the following:

- ASD Status (mothers of children with ASD vs. mothers of TD children)
(Hypotheses 1 and 2)
- Child gender (male vs. female)
(Hypothesis 3)

In addition, a number of demographic covariate variables were investigated, including:

- The mothers' age, race, ethnicity, and education,
- The children's age, and gender.

The outcome variables addressed whether the mothers:

- Had ever been professionally diagnosed with depression
- Had ever been self-diagnosed with depression
- Had ever been treated for depression
- Had ever had suicidal ideation
- Had ever attempted suicide
- Had ever been hospitalized for depression
- Had ever had any depression (professionally diagnosed, self-diagnosed, or treated)
- Had experienced depression before having their children
- Had been professionally diagnosed with a manic disorder
- Had ever been hospitalized for a manic disorder
- Had a family history of depression
- Had a family history of a manic disorder
- Had a family history of suicide.

Student's t tests were used to compare the ASD vs. TD groups on several scale variables (See Table 4.1). Chi-square and Fisher's exact tests were performed to explore associations between categorical variables including ASD status and reported mood disorders. The results are presented in Table 4.2.

Next, a binary logistic regression analysis assessed the probability that mothers of children with ASD would report mood disorders more frequently than mothers of TD children. This analysis was chosen because the outcome measures were dichotomous and involved a comparison of two groups: mothers with children with ASD vs. TD children (in the case of Hypothesis 1 and 2) and gender of children with ASD (in the case of Hypothesis 3) (See Table 4.3).

Table 4.3.

Binary Logistic Regression

Outcome Variables	R Squared	Odds Ratio	Bootstrap Confidence Interval Significance
Professionally Diagnosed Depression	.123	ASD Status (4.765)	Yes
Ever Treated	.115	ASD Status (3.650)	Yes
Suicidal Ideation	.087	ASD Status (3.447)	Yes
Any Depression	.083	ASD Status (2.951)	Yes
Having Depression Before Children	.260	ASD Status (5.925)	Yes
Family History Depression	.136	ASD Status (4.163)	Yes
Family History Manic	.108	ASD Status (4.148)	Yes
Family History Suicide	.097	ASD status (3.710)	Yes

The table contains only those variables that were significant predictors. The odds ratios are included in parentheses.

Analysis of Quantitative Data

Mood disorders and associated issues of mothers of children with ASD vs. TD. Aim

1: To determine if mothers of children with ASD reported a history of mood disorders more frequently than mothers of TD children.

Hypothesis 1: Mothers of children with ASD will report a history of mood disorder more frequently than mothers of TD children.

The analyses examined the relationship between the outcome variables and the predictor variables. Results of Chi square or Fisher's exact analyses testing this hypothesis are reported in Table 4.2. In addition, a series of binary logistic regression analyses were performed on the same set of variables. Results are reported in Table 4.3. The data support the hypothesis. The findings indicate a statistically significant difference between mothers of ASD and mothers of TD children with regard to frequency of professionally diagnosed depression (37.8% vs. 13.5%), chi-square (1) = 27.07, $p < .001$. Also, Mothers of ASD children were far more likely to have been treated for depression than mothers of TD children (53.0% vs. 24.7%), chi-square (1) = 29.64, $p < .001$.

Note that the percentage of mothers of children with ASD who were professionally diagnosed with depression was more than four times greater than the percentage of mothers with TD children. Similarly, the percentage of mothers with ASD children that had been hospitalized due to depression and/or manic disorders was significantly higher for mothers of ASD children (6.5% vs. 1.2%), chi-square (1) = 6.59, $p < 0.05$. (See Table 4.2). In addition, mothers of children with ASD were more likely to report a history of suicidal ideation (33.0% vs. 12.0%), chi-square (1) = 21.58, $p < 0.001$) and suicidal attempts (12% vs. 4.2%, chi-square (1) = 6.87; $p < 0.05$). (See Table 4.2),

Mothers of children with ASD were significantly more likely than mothers of TD children to report “any depression”, defined as a professionally diagnosed depression, self-diagnosed depression, or any treatment for depression (56.8% vs. 32.4%), chi-square (1) =21.31, $p<0.001$, as well as to report being depressed before having any children (71.6% vs 30.4%), chi-square (1) =22.14, $p<0.001$. In addition, significantly more mothers of ASD children had been professionally diagnosed with bipolar disorder (4.9% vs. 0.6), chi-square (1) =28.05, $p<0.05$. (See table 4.2).

The findings from the binary logistic regression model, including odds ratios, are displayed in Table 4.3 and indicate that mothers of children with ASD were significantly more likely to have experienced mood disorders and associated issues than were the mothers of TD children.

First of all, odds of being professionally diagnosed with depression were more than four times higher for mothers of children with ASD compared to mothers of TD children (OR=4.76; 95% CI = 0.92-2.38). For the professionally diagnosed depression group, 93.0% of the people in the “no” group were correctly classified while 23.1% of those in the “yes” group were correctly classified, and an overall of 74.6% were correctly classified.

Second, mothers of children with ASD had almost 4 times the odds of being treated for depression compared with mothers of TD children (OR =3.65; 95% CI = 0.78-2.00). Almost three-fourths of the mothers who did not receive treatment for depression were correctly classified and 50.0% of the mothers who did were correctly classified, and an overall of 63.1% were correctly classified. In addition, mothers of children with ASD had nearly 3 times the odds of having any history of depression (i.e. professionally diagnosed depression; self-diagnosed depression, or depression treatment) compared with mothers of TD children (OR=2.95; 95% CI

= 0.57-1.68). If participants claim that they were professionally diagnosed, self-diagnosed, or treated with depression, 62.4% of the people in the “no” group were correctly classified and 57.6% of the mothers of the “yes” group were correctly classified, and an overall of 60.2% were correctly classified.

Mothers of children with ASD were also much more likely to experience depression before having children compared with mothers of TD children (OR=5.92; 95% CI = 0.794-3.312). For having depression before having children group 56.7% of the people in the “no” group were correctly classified and 86% of the mothers of the “yes” group were correctly classified, and an overall of 74% were correctly classified.

Likewise, mothers of children with ASD had more than three times the odds of having thoughts of suicide compared with mothers of TD children (OR=3.45; 95% CI = 0.56-2.19). For this variable, the model is biased toward the no category with 99.6% of the people in the “no” group correctly classified but only 1.2% of those in the “yes” group correctly classified. However, 76.5% were correctly classified overall.

Reported history of family mood disorders among first and second-degree relatives of mothers of children with ASD vs. TD. Aim 2: To determine if mothers of children with ASD reported a family history of mood disorders among first and second-degree relatives more frequently than mothers of TD children.

Hypothesis 2: Mothers of children with ASD will report a family history of mood disorders among first and second-degree relatives more frequently than mothers of TD children.

As a reminder, first-degree relatives included: mother, father, brother, sister, son, and daughter. Second-degree relative included maternal grandmother (mother's mother), maternal grandfather (mother's father), maternal aunt (mother's sister), maternal uncle (mother's brother),

first cousin on the mother's side, paternal grandmother (father's mother), paternal grandfather (father's father), paternal aunt (father's sister), paternal uncle (father's brother), and first cousin on the father's side. The findings from chi-square and binary logistic regression analyses supported the hypothesis.

The results of the chi-square analysis showed that significantly more mothers of children with ASD reported family histories of depression (53.8% vs. 25.6%), $\chi^2(1)=33.50$, $p<.001$, manic disorder (26.9% vs. 23.5%), $\chi^2(1)=19.18$, $p<.001$, and suicide (7.8%, 10.2%), $\chi^2(1)=15.72$, $p<.001$ among first and second-degree relatives. (See Table 4.2).

The results of the binary logistic regression analysis also indicated that, compared with mothers of TD children, mothers of children with ASD have significantly higher odds of having a maternal family history for depression (OR=4.16; 95% CI = 0.91-2.14). For family history of depression group 79.6% of the people in the “no” group were correctly classified and 51.9% of the mothers of the “yes” group were correctly classified, and an overall of 68.6% were correctly classified.

Likewise, these mothers had more than 4 times the odds of having a first and second-degree relative who had been diagnosed with manic disorder relative to those who are mothers of TD children (OR=4.14; 95% CI =0.60-2.52). For the family history of manic disorder, the model is biased toward the no category. The model predicted the “no” category well, but not the “yes” category. For the family history of mania, 98.9% of the people in the “no” group were correctly classified and 6.8% of the mothers of the “yes” group were correctly classified, and an overall of 82.9% were correctly classified.

Lastly, mothers of children with ASD had nearly 4 times the odds of having a first and second-degree relative who had attempted suicide than those who are mothers of TD children

(OR=3.71; 95% CI = 0.60-2.29). For the family history of suicide, the model is biased toward the “no” category, that is, the model predicted the “no” category substantially better than it did the “yes” category. For the family history of suicide, 99.3% of the mothers in the “no” group were correctly classified and 7.6% of the mothers of the “yes” group were correctly classified however, an overall of 81.5% were correctly classified.

Reported mood disorders in mothers who have girls vs. boys with ASD. Aim 3: To determine if mothers of girls with ASD reported a history of mood disorder more frequently than mothers who have boys with ASD.

Hypothesis 3: Mothers of girls with ASD will report a history of mood disorder more frequently than mothers who have boys with ASD.

The findings did not indicate a statistically significant difference in the depression status of mothers of children with ASD based on child’s gender. Therefore, the third hypothesis was not supported.

Summary

The statistical analysis clearly showed a significant difference in reported mood disorders in mothers of children with ASD compared to mothers with TD children. Likewise, there was a marked difference in family history of depressive illness, manic illness, or suicide between the two groups. Both hypotheses of the reported mood disorders of mothers and their first-degree relatives were supported through chi-square, Fisher’s exact, and binary logistic regression analyses. Specifically, mothers of children with ASD were more likely to report mood disorders in themselves and in their first-degree relatives than mothers of TD children. However, the hypothesis that child’s gender would influence reported mood disorders in mothers of children with ASD was not supported.

Qualitative Results

The purpose of this phenomenological qualitative portion of the study was to explore the perceptions of lived experiences of a select group of mothers coping with depression while rearing a school age child with ASD. This section contains an overview of the study participants and an analysis of the data gathered from in-depth audiotaped interviews with them. All interviews took place in a convenient place for the mothers between July 2014 and August 2014. Some mothers preferred their homes; others chose public libraries, while others decided to meet in a coffee shop or a restaurant. The interviews were transcribed verbatim, coded, and categorized using Mousstakes' approach (Mousstakes, 1994). Categories that were related were chunked into themes that reflected the perspectives that the mothers shared during the interviews. Interviews continued until saturation of themes was achieved. The data collected via interviews assisted the researcher in answering the central question of this phenomenological study.

Figure 4.1.

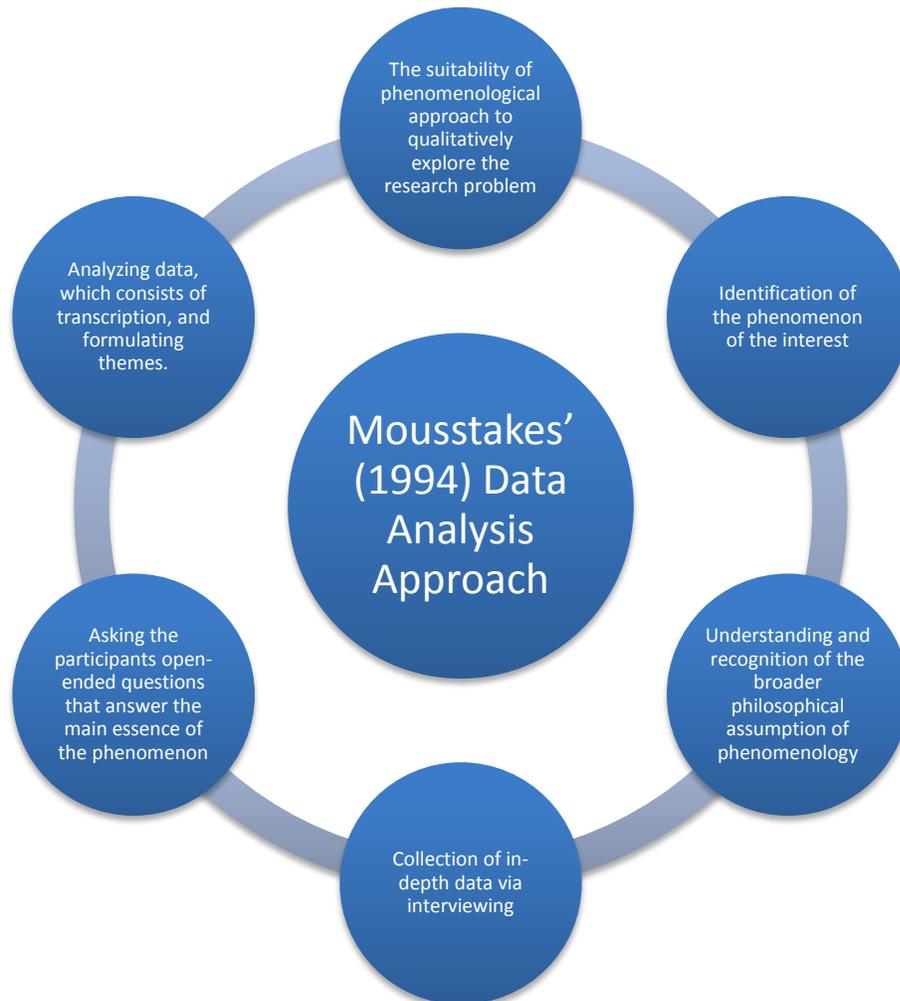


Figure 4.1. Mousstakes's Data Analysis Approach (Mousstakes, 1994)

Authenticity and Trustworthiness of Qualitative Data

To ensure authenticity and trustworthiness of the data, the interviews with the participants were recorded and transcribed verbatim. The researcher then listened to the recorded interviews a second time and compared them with the transcripts to ensure accuracy of the transcriptions. A document copy of the transcribed interview was emailed to all the participants- nine mothers- for member checking. Five mothers got back to the researcher. Four of them

completed the member check and agreed with the transcribed information. The fifth mother said, “I can’t read the document.” It seems that the topic of the interview was upsetting to her. The remaining four mothers did not inform the researcher as to whether they completed the member check request. The researcher used the mothers’ narratives to get to their personal meaning to identify codes and categories and propose emerging themes. The chairperson of the dissertation committee served as an expert consultant. In this role, she separately read and coded the transcripts, clustered the codes into categories, then identified emerging themes. The researcher then compared her codes, categories and themes with those of the expert consultant to identify discrepancies and to reach consensus. Finally, the researcher maintained an ongoing audit trail of the research process and a journal of her reflective analysis.

Participants

The participants were mothers who identified themselves as rearing a school age child/children with ASD while concurrently coping with depression. They were recruited using a purposeful sampling technique. This enabled the researcher to intentionally select the participants who had experienced the central phenomenon (Creswell & Plano Clark, 2011), and to gain a more comprehensive understanding of the lived experience (Patton, 1990) of rearing a school age child/children with ASD while concurrently coping with depression.

As part of the original study design a total of four mothers who were coping with depression, rearing school-aged children with ASD, and living in Maryland were to be recruited as study participants. The researcher received a total of 10 responses from mothers interested in participating in the study. One of the 10 mothers was excluded from the study because she was not coping with depression. Nine mothers met the inclusion criteria and participated in the study. Seven mothers have a son with ASD between the ages of 6-16 years old. One has a teen-age

daughter with ASD, and one mother has twin, elementary school-aged daughters with ASD.

Mother-child dyad demographic information are described by the mothers and presented in the order in which they were interviewed (see table 4.4).

Table 4.4.

Demographic Information of Depressed Mothers who have Children with ASD

Mother - Pseudonym	Mother Year of Birth	Child with ASD Year of Birth	Marital Status	Employed	Gender of the Child with ASD	Number in Household
Ruby	1970	2005	Married	No	Boy	4
Jane	1975	2000	Married	Yes	Boy	5
Suzan	1957	1998	Married	No	Boy	5
Emily	1964	2001	Married	Yes	Girl	3
Naomi	1976	2000	Divorced/ In a relationship	Yes	Boy	3
Judy	1965	1998	Divorced	Yes	Boy	2
Rilee	1972	2001	Married	No	Boy	5
Sue	1970	2002	Married	Yes	Boy	4
Dorsey	1972	2008	Married	No	Twin girls	5

Ruby. Ruby's family consists of her husband and two children. Ryan is 9 years old and her oldest child. Ruby also has a younger daughter in the elementary school. According to Ruby, Ryan was diagnosed with ASD when he was two and a half years old. Ruby considers Ryan to be high functioning but has a lot of language delays. Because it is difficult for him to communicate what he wants, he exhibits aggressive behaviors. She explained, "[Ryan] was very aggressive with my daughter so I could not leave him alone at all in the house." Also, Ryan has apraxia, extreme obsessive-compulsive disorder, and separation anxiety. Ryan needs help with "pretty much everything" including his activities of daily living and self-hygiene. Ryan has a very hard time sleeping, which negatively affects Ruby's emotional and physical health. Ruby is 45 years old. Ruby spends much of her time helping Ryan with self-hygiene and self-maintenance skills and keeping her daughter safe from him. Ruby is a stay-at-home mother. She tried to work outside the home but found it "too much with my children's schedules and with my son's issues." Ruby was diagnosed with depression years before having any children. However, Ruby stated "there is never a time where autism is off of my mind completely. ... There is always something to worry about for my son with autism." When Ruby was asked about the time she gives for her children and herself, she explained "for myself, it's a very slim percentage; I would say maybe 90% is my children and the rest fits in everything else... 80% for my son and 20% for my daughter." Ruby explained that autism and depression are similar in that they cause a lack of energy and affect one's mood. Ruby talked about the impact of depression on herself by "my body gets extremely fatigued. I feel that I'm in a fog. I can't think clearly. I can't remember things. I have very low energy. I am short-tempered so it's not fun." Ruby explained that her mother and brother have suffered from depression. Ruby has some great friends to spend time with. She enjoys reading and shopping. (Ruby, personal conversation, July 2014).

Jane. Jane's family includes her husband, and her three children. Andrew is the middle child and is 14 years old. Jane's older daughter is in high school and her youngest daughter is in elementary school. Andrew was diagnosed with pervasive developmental disorder-NOS when he was 5 years old. The doctors wanted to diagnose him with Asperger disorder but he developed language at a late age. He demonstrated growth personally and academically between first and fifth grades. According to Jane, Andrew can do almost all his self-hygiene skills by himself but "needs reminders about everything" and requires a lot of attention. Jane is 41 years old. Jane identifies that her major responsibility is to help her son control his aggressiveness behaviors and to ensure safety of her daughters. She keeps thinking of how she is going to get through the next day and explained that she needs support to take care of her son because "it's him and I 24/7." For many years Jane has coped with anxiety and ADD; her "anxiety increased significantly due to the stress of raising a child on the spectrum." Jane was diagnosed with depression in 2010; since then she has been taking antidepressant medications. She works as assistance at a school. She prefers to work in a school system because of the flexibility it affords in case her son needs her. She explained that she used to leave her work frequently because her son needs her. She talked about how her body reacted to the stress in her life by "exhausted, my skin broke out, I had acne, I had diabetic and my blood sugar went sky high. They said it is stress-related." When asked about what she wished to change in her life, she answered, "I would change about myself the stress of raising [Andrew]... [It] has been very difficult." Also, she wants to be financially independent from her husband. "My husband and I are roommates rather than husband and wife." Jane enjoys doing something with her family or her friends, listening to music, shopping, and reading (Jane, personal communication, July 2014).

Suzan. Suzan's family consists of her husband, and 3 children. Her son, James, is the middle child and is 15 years old. Her oldest daughter is in her first year of college. Her youngest is in middle school and has a learning disability. James originally was considered to have borderline autism. James was officially diagnosed with autism spectrum in February of 2014 after the definition was revised in DSM-5. James also has ADHD and dysgraphia. Suzan describes James as a picky eater and very sensitive to touch, smell, and taste. He struggles language and short-term memory challenges. One of Suzan's major roles is to advocate for her son's rights within the school system. She provides James "tremendous support at home" so that he can succeed academically in school. His homework is almost "equivalent to school work." Suzan is 58 years old. Suzan was diagnosed with depression and was put on antidepressant medication when she was 45, a year after the birth of her third baby. She said that the lack of support from her husband especially in critical times is a major contributor to her depression. Suzan stated that her husband "does not have the psychological matter to deal with the great issues of autism." She explained her relationship with her husband currently is like that of bookends. "I want to stay bookends, there is nothing in the middle. If you pull the kids out, there's nothing in the middle." She also mentioned that she doesn't enjoy her husband's company because "I am married to my children and husband is married to his job." That she had all her children at a late age, runs the house mostly by herself, and takes care of her son who has autism also contribute to her depression. Finally, her oldest child's hostility contributes to her increased stress level and depression. Suzan is a stay-at-home mother. She stated, "I don't like my day job" doing what she does every day. She would like to work outside her home, not in her former area of national security but with families with children with ASD. Suzan tries "to find

solutions through exercise and diet” to her depression. Reading and exercising brings Suzan joy and satisfaction (Suzan, personal communication, July 2014).

Emily. This family consists of Emily, her husband, and her 13 years-old daughter, Celina. Celina was diagnosed with ASD when she was two years old. According to Emily, Celina can communicate verbally but has difficulty using language. Even though she can complete many self-hygiene skills by herself but “she can’t do any of them without supervision.” She needs physical assistance with some of her daily life skills. She also becomes violent when she gets frustrated, upset, worried, or angry. Celina doesn’t have a sense of safety or danger. Emily’s major concern for her daughter is her safety and social life. Emily’s long-term goal is to find permanent housing for Celina so that she has a place to live after Emily and her husband die. Emily is 50 years old. Emily was diagnosed with depression and anxiety when she was 14 years old after she took a large quantity of pills from the family’s medicine cabinet to permanently put herself “out of her misery.” Emily explained that her mother coped with depression and alcoholism. Her mother used to blame Emily for the family difficulties; though Emily tried to please her mother, she could not do so. Emily explained, that to this day “If I am not taking medications, my instincts would want me to commit suicide... I go to some very dark place.” Emily felt that her depression lifted in the first years of Celina’s life before she was diagnosed with ASD. Emily believes that her current depression is a reaction to the stress and anxiety in her life - “my daughter, my marriage, my marriage is tough” and her parents’ divorce. Emily described that autism makes her sad, really sad and that rearing a child with ASD makes it very difficult to get leisure time for herself. She considers herself to be active mother in Celina life but believes that whatever she does “is never enough.” Emily works part-time outside the home. Inside her house, Emily assumes most of the family responsibility. Her husband does a few

things when he has time. Emily enjoys having a good conversation with her husband, writing, and making her daughter giggle (Emily, personal communication, July 2015).

Naomi. Her family consists of herself and her two children. Naomi's youngest son, Justin, was diagnosed with ASD when he was two years old. He now is 14 years old. Her older son, 16 years old, has a learning disability that negatively affects his working memory. Also, Naomi thinks that her older son battled from depression for years. Naomi considers Justin to be high functioning. He can accomplish most tasks independently but struggles with the social aspects of his life. Though he gets along well with his brother, he would rather play by himself than interact with people. He struggles academically and needs reminders to do things that he does not like to do. She believes that her major role is to advocate for Justin at school. Naomi is 38 years old. She is a full time teacher. She was clinically diagnosed with depression and anxiety in summer of 2013. She explained that it was very hard for her to get out of the bed, feeling sick. She used to take many days off work. She shut down. She could not remember so many things in her life. She could not think straight. She cried. "Everything in [her] life was falling apart." She had some suicidal thoughts, was admitted to a hospital for four weeks, and was medicated immediately. She believes that her depression stemmed from being sexually abused, being married to a controlling husband, being part of unstable home when she was a child, and coping with a child with autism. "I hate to even think that I have to do something with my son but there are days when I am just like why was I given this child ... that almost I have to work three times as hard as everybody to make sure that everything was taking care of." She explained that her husband was "Mr. Tough and nothing bothered him. I never knew what was going on his head.... I wish that he was more involved in raising [Justin]." She thinks that he was embarrassed by some of their son's behaviors such as acting out, falling in the floor, hitting, and

making noises. Her marriage to Justin's father was supposed to officially end two weeks after the date of this interview. Spending time with her children, going to movies, or watching a movie at home bring Naomi joy and satisfaction. (Naomi, personal communication, July 2014).

Judy. Judy lives with her son, Isaac, who is 17 years old. Isaac originally was diagnosed with a genetic syndrome. His condition involved multiple heart defects, low muscle tone, developmental delay, severe speech delay, inappropriate social behaviors, self-injury, and obsessive-compulsive behaviors. These medical issues coupled with severe intellectual delay led to a diagnosis of autism by age 6. Isaac needs help with most self-care tasks. He "requires 100% supervision and a baby-proofed setting." Judy is 50 years old single mother who works full time outside the home. Judy encountered recent health problems resulting from the stress of her situation such as insomnia, high blood pressure, high cholesterol, weight gain, and depression. Judy experienced deep depression in 2013 resulting in medical difficulties and her request for respite time away from work to regain her health and to have time to prepare for her son's transition from the public school system to adulthood. She believes that her depression also was a consequence of a difficult childhood experience, demanding life at work, a difficult marriage and divorce. Judy explained that there were "cracks" in her relationship with her husband but "when the baby came with all the medical and other problems, the marriage finally crumbled." Her husband did not want their baby. Judy describes that having a child with autism "has been the most profound thing that's ever happened to me. I wish it never happened." Judy elaborated that she finds herself resentful toward her son at times, and definitely toward her ex-husband due to his abdication of his responsibilities and leaving her to deal with all of it alone. She lamented, "I hate my life and don't know how to go on." On the other hand, sometimes she "feels a deep gratitude to the Lord for giving me the challenges my son represents and for how it allowed me

to grow as a person in profound ways...really necessary for my salvation.” Judy’s “strong Christian faith helps [her] with [her] situation, along with individual counseling and newly prescribed medicinal therapy designed to help reduce the effects of stress. When Judy was asked about things that bring her joy and satisfaction. She answered “I struggle to find joy at this point in my life. However, I am satisfied when I get things done... She does find joy in the reality of her child, even though the situation is very difficult and has even caused me to feel real resentment at times. She enjoys time with her close friends, even if that time is hard to come by due to busy lives. She finds joy in her faith, the love of my mother and family, and the sheer wonder of the love I know God has for me and all mankind.” (Judy, personal communication, July 2014).

Rilee. Rilee’s family includes her husband, and three children. Leo, who has ASD, is the oldest and is 13 years old. Rilee also has a nine-year-old daughter and six year old son who has a processing disorder and attends special education classes. Leo was officially diagnosed when he was 3 years old. However, his parents suspected a problem when he was two years old. Rilee stated that Leo is considered to be a high functioning child with ASD. ‘He is quite independent and can do many things.’ Rilee’s job is to keep him on task and to make sure that he is doing what he is supposed to be doing in a timely manner. Though Leo is very verbal, his language is not always appropriate. Because Leo has a lot of food allergies, he is on a very specialized diet. He also takes a number of medicines and supplements. Rilee explained that she is “like a playmate” to Leo and that her responsibilities toward him are “never ending.... That is why I keep forgetting anything outside my four walls.” However, Leo was a sickly child, “he was never a sleeper,” and he was not as good as he is now. Rilee explained that autism “affects everything. It is constant. It’s everywhere in my house. It’s there from a hole in the wall from where he

picked it from his anxiety and the paint is gone because he does not like things that pop out... I have gotten my living room decorated by a little child with autism.” Rilee is 43 years old. Rilee was diagnosed with situational depression in 2011 and has been taking medication since then. She had a hard time moving. She was tired all the time. Leo’s autism contributed to her depression. To her it was a traumatic experience in her life. Her depression worsened when her younger child started to exhibit symptoms similar to those of Leo. Rilee previously worked as a teacher. She quit her job after she had her third baby. It was hard to take care of three children and keep working, with lack of support from her husband. She explained that her husband “was not helping. “ I had a lot of resentment of not working [and] pictur[ing] myself as a stay home mother. I always had plans to work. My husband was not helping me. He was supposed to do but he didn’t do it at all.” She explained, “people get glassy eyes. They don’t want to know. They want to know that you are okay and you are not okay because life is not okay.” However, Her children’s birthdays as well as Christmas bring her a lot of joy and satisfaction (Rilee, personal communication, August 2014).

Sue. Sue’s family consists of her husband, her son Adam, and her brother-in-law who lives with them. Adam is 13 years old. Sue and her husband suspected a problem when Adam was nearing his second birthday. Sue stated that this was traumatic time for her. Adam was officially diagnosed with ASD when he was 2 years and 6 months. Adam is high-functioning child with ASD. He is independent in most self-hygiene skills. He is able to convey his basic needs using language but has difficulty expressing his feelings. He struggles socially and does not have friends outside school. Adam has food allergies and is picky eater. Sue worries about Adam’s future. Sue is 44 years old. She became depressed overtime ago. Her depression started three or four years. “I just noticed that I get more depressed overtime. I have been going to a

parent supportive group for parents of child/children with autism. So eventually I decided to make an appointment with the lady that runs the group. She sees people individually.” She explained “I think [depression] just make everything a little bit harder because it's harder to get up in the morning, it's harder to stay focused on things, it's harder to be optimistic. Sue works from home. Her work is very flexible but she had to turn down promotions to advance in her career. She stated that ASD affects her connections to others; as a result, she is becoming “more introverted... we do spend so much time at home” “Having my world get small make the biggest difference...when Adam has a good day I have a good day. When he’s having a good day everyone is having a good day. If he has a bad day the world is having a bad day.” Sue is satisfied with the support she gets from her husband. Also, she was pleased with the help she gets from her brother in law once a month so she can go watch a movie with her husband. Sue enjoys doing things outside her home when Adam is having a good day. She likes going to the gym. On the other hand, Sue does not spend time with friends because “most my friend that have typical kids decided to put away and most my friends who have children on the spectrum all sort of all over the place. I have more Facebook friends than I have local” (Sue, personal communication, August 2014).

Dorsey. Dorsey lives with her husband and daughters. Dorsey has three daughters- twin daughters and an older daughter in the elementary school. Her oldest daughter copes with speech and language problems and academic challenges. The older twin daughter, Silvia, is diagnosed with pervasive developmental disorder. The younger one, Linda, is diagnosed with autism. Silvia and Linda are 5 years old and attend an inclusion classroom. According to Dorsey, they have progressed in their development and can complete most self-hygiene tasks independently, though have difficulty with social interactions. Silvia can accomplish more tasks than Linda. Linda has a

lot of anxiety and struggles with cognitive challenges. She needs contextual clues to recall situations and repeat directions. All of her daughters have sensitivity issues. Dorsey assists her daughters emotionally more than physically, “it is a lot of emotional handholding. It’s a lot of nurturing. It’s a lot of encouraging” Her major role is to “keep them from killing each other.” Silvia has a temper and is aggressive with her sisters. “She can go from 0-100 in a matter of seconds. She explained, “by the time I dropped [my daughters] off [to school], I am exhausted... It’s a constant juggle in the morning trying to keep everyone on the same even, calm level.” Dorsey is 43 years old. She was diagnosed with major depression in her early 20s and began taking medication at that time. Currently, she finds it very difficult to get up in the morning. Her childhood was tumultuous. She is a social worker by profession but stopped working when she became pregnant with her twin daughters. Currently, she does not work but plans to do so. Her husband has an un-medicated attention deficit disorder. She stated that her husband is “like a fourth kid.... He is addicted to his phone and laptop [which is] a bone of contention.” Her husband doesn’t understand how to parent his daughters. He does not see their special needs. Dorsey stated that her husband and she “are more roommates than anything now.” She thinks that her marital relationship “has gotten worse after having the twins because I don’t get support and he doesn’t understand. So I am by myself.” Dorsey gets her joy and satisfaction from watching her daughters excel at something. She has nothing outside of her daughters. She loves going to movies. She likes volunteering at her daughters’ school, which helps her “to be connected to other people other than [her] kids” (Dorsey, personal communication, August 2014).

Demographic Summary of Participants

To conclude, nine mothers were interviewed. They answered open-ended questions that addressed the lived experience of concurrently being a mother of a child with ASD and coping with depression. The mothers lived in Maryland and ranged in age between 40-58 years old. Seven mothers have a son with ASD; two mothers have a daughter with ASD. Of those two mothers, one has twin daughters with ASD. Seven mothers are married and two are divorced. Of those mothers who are married, four indicate that the marriage is difficult. Their children with ASD age range between 8-16 years old. Five mothers are working either full time or part time. Four mothers quit their jobs because of the increased demand of rearing a child with ASD along with their other responsibilities.

Thematic Description and Data Analysis

Utilizing Mousstakes' (1994) data analysis approach (See Figure 4.1), the researcher developed thematic descriptions of the key elements of the central phenomenon of the lived experience of these nine mothers. Bracketing, horizontalization, and clustering (Mousstakes, 1994), which were defined and discussed in chapter three were used in the data analysis to extract the themes.

This section presents the five themes that emerged from analyzing data. The themes are as follows:

- a) Regardless of when I was first diagnosed, having a child with ASD contributed to and intensified my depression.
- b) Challenges and stressors of rearing a child with ASD are ongoing. What I do is never enough. It is physically and mentally exhausting.

- c) I feel a lack of support and understanding either from my husband, the extended family, or the community.
- d) It is difficult to balance all my life aspects; it may be less demanding if I sacrifice one of my roles.
- e) There is a history of mental health challenges in my family.

Each of these themes is described in detail in the following section.

Theme one: Regardless of when I was first diagnosed, having a child with ASD contributed to and intensified my depression. All of the mothers discussed the association between having depression and rearing a child with ASD. Mothers who were diagnosed with depression before having their children with ASD described how having a child with ASD intensified or retriggered their depression. Mothers who were diagnosed with depression after having their children explained that rearing a child with ASD was a major cause of stress in their lives, contributed to their depression, and in some circumstances, led to or intensified their marital difficulties.

Three of the nine mothers were diagnosed with depression before having their child/children with ASD. For example, Ruby was diagnosed with depression when she was 18 years old, before having her children. When Ruby was asked to describe how having depression affected her life, she answered explicitly “autism intensifies my depression....there is never time where autism is off of my mind completely.” Emily talked about her experience of being depressed since she was 14 years old and how she planned to commit suicide to end her misery at that time of her life. She shared that her depression was and still is a reaction to stressors in her life and that rearing a child with autism is the major stressors in her life. The third mother who was diagnosed with major depression before she had her children was Dorsey. She became

aware of her depression in her early 20s. She described that her childhood was surrounded “with a lot of turmoil... and pressure.” Her pregnancy with her twin daughters was “miserable” due to multiple medical issues and contributed to her depression. Currently, Dorsey always worries about her daughters. Dorsey explained that her relationship with her husband got “worse after having the twins because I don’t get support and doesn’t understand. So I am by myself.”

Two of these mothers, Ruby and Dorsey described how their children’s violent behaviors exacerbated their depression. Ruby described that because of her son’s aggressive behaviors she always has “to be aware of him hurting [her] daughter. He was extremely violent and aggressive, so I was terrified for my daughter to be around him. I was trying to protect her also trying to calm him down at the same time. It was just really hard.” Similarly, Dorsey explained that one of her major roles was to keep her twins with autism “from killing each other.” One of the twins has a temper tantrum. “She can go from 0-100 in a matter of seconds” therefore, “it is a must to keep an eye on her all the times.”

Six mothers were diagnosed with depression after having their children with ASD. Depression was associated with the difficulty of rearing the child. Jane was diagnosed with anxiety when she was 22 years old. She explained that her anxiety level increased significantly due to the stress of rearing her son, Andrew, who has autism. For her it is the biggest stress in her life. Similar to Ruby and Dorsey, Jane explained that her son’s escalated and extreme violence increased her anxiety significantly. His aggressive behaviors started in 2008-2009; she was officially diagnosed with depression in 2010. “[Andrew’s] aggression threatened the safety of my other children.” His behaviors escalated from hitting, pushing, to chasing his sisters with a big kitchen knife.

Rilee was diagnosed with situational depression in 2011. She explained that her son, Leo, “wasn’t a good ... sleeper so I never slept...autism behaviors kept him awake ... I never slept but I did my job and my kids were taken care of.” She believes that having a child with ASD has affected all aspects of her life. “It’s everywhere in my house.” She believes that of all of the life events that contributed to her depression, her son’s autism was the most significant. . “It affects everything.”

Judy described that the pressure of caring for her son reached a critical point last year: I only recently admitted to suffering from deep depression. The toll of stress and depression were taking on me came to a head within the last year, resulting in medical difficulties and my request for respite time away from work to regain health and work on tasks related to the child's school placement and preparation for eventual transition from the public school system upon reaching adulthood.

Similarly, Naomi was diagnosed with depression in 2013. She had suicidal thoughts and was hospitalized for three weeks. When asked about the factors that contributed to her depression. She answered:

I hate to even think that is has to do something with my son but there are days when I’m just like why was I given this child? Why am I giving these two kids that have disabilities that almost I have to work three times as hard as everybody to make sure that everything was taking care of?

Suzan was diagnosed with depression in 2003-2004. She identified that her son’s autism was the major life event that contributed to her depression. She discussed how hard was it to watch other children thrive and to know that it will never be the same for her son:

When I go to bed at night you put your head down on the pillow and you silently grieve. You grieve. It was harder when he was younger because I would come to Barnes and Noble to pick up ... a Life magazine up in the lobby. And you would see a nice little boy loaded with the soccer pants and soccer shins all ready to put on and I would grieve because I realize that's never going happen now. The neurotypical development isn't going to happen. I think those were the lowest points.

Theme two: Challenges and stressors of rearing a child with ASD are ongoing. What I do is never enough. It is physically and mentally exhausting. The mothers described how caring for their children with ASD is a never-ending responsibility. The care extends beyond providing physical assistance, nurturance and supervision to include protecting their children from harm within extended family units, and school and community systems. The mothers assumed additional responsibilities beyond those associated with parenting a typically developing child to include longer periods time assisting with self- care and daily life tasks, controlling their children's behaviors, being hyper vigilant about their safety, and advocating for their rights within the community and educational systems. The mothers spent a substantive amount of their time and energy fighting for educational services, supervising their children's play activities and social opportunities, and escorting their children to doctor and therapy appointments. They argued that their roles as mothers, wives, and employees were more complex than those of mothers of typically developing children because of the extra work of taking care of and managing all the pertinent issues of their children with ASD.

Almost all the mothers stated that they devoted the majority of their time to their child with ASD and explained that their child with ASD received more of their attention than the siblings. Some mothers discussed that their weekdays were demanding because their children

had full schedule with therapy appointments and activities. For example, Ruby stated that “I am always mentally and physically tired...I’m just drained.” She said there are “so many worries” that come from the ongoing stress of rearing a child with ASD and that at times her depression become severe because of trying to cope with her son’s issues. For example, when her son got sick, he became violent and aggressive. He could not sleep so neither did she. Even when her son is healthy Ruby has difficulty falling asleep because her “brain is thinking of autism related issues. ...There is always something to worry about for my son with autism.”

Jane also spoke of the ongoing demands of caring for a child with ASD and calculates that she devotes two thirds of her time caring for her son, Andrew. Jane talked about eating fast food because of all the doctors’ appointments that he has.

There is no time after school to sit and eat....it is constant and it is every night.... I keep thinking of how I am going to get through the next day with Andrew’s schedules and appointments. I even have to think of how I am going to keep him entertained.... it’s a struggle every day.”

Rilee also talked about how her son’s special diet was a consistent challenge. Because her son, Leo, has a lot of food allergies, she needs to be in charge of what he eats on a daily basis. From the mental aspect, caring for her son “never stops. What am I going be doing tomorrow? What has got to be finished tomorrow?”

Judy, a single parent expressed that “nothing in my life right now is easy except for one thing: loving this child. I hate and resent the situation on a regular basis, and can find myself overwhelmed with all the demands to the point of shut[ting] down.” She describes herself as a:

Fifty-year old, single mother who works full time.... I attempt to manage the demands of having a disabled child, an intense work environment, and all normal home maintenance

requirements. I have a limited support network and very limited social life. Medical and therapeutic care expenses and time required to be away from work due to the child's medical and behavioral conditions cause deep strain on the family from income and stress points of view.... [I] have encountered recent health problems resulting from the stress of this situation -insomnia, high blood pressure, high cholesterol, weight gain, depression.

Emily discussed a crucial issue of rearing a daughter with ASD related to puberty. When Celina gets her menstrual cycle, Emily the mother stated:

She screams her head off and she tries to know what's going on. She can't tell you. It can be very scary. And it can be very depressing because you want to help somebody feel better, your own child feels better and can't. You can't explain to them because they can't hear you. They can't understand what you're saying.

Naomi talked about her major role as an advocate in the school system. She stated:

I advocate for him at school more than anything else and that can be a battle...I feel that I am always arguing. It is still a battle in progress and that can be very stressful especially when I am by myself.”

Naomi summarized that it is “just hard to juggle it all and to take care of your kids with disabilities.”

Dorsey stated that in a typical school day, “by the time I dropped everyone off, I am exhausted.” Dorsey described her mornings with her twins as “a constant juggle. It is very chaotic in the morning.” Adding to the chaos in the morning are her daughter's scalp sensitivity and food allergies.

It makes it more difficult for them to be able to go to school with a nice, calm, ...rested, refreshed, and ready for learning....I am just trying to work within their personalities while taking into consideration their sensitivity issues and it is just going to be difficult.”

Dorsey also discussed her struggle with having them clean after themselves. ”So I do almost all the household chores by myself.” She concluded, “I am always worried about them. I am always worried about that someone is not going to understand what they want ... and how they are going to deal with that.... All of my energy, all of everything is put into my kids and keeping myself float. So that I am pretty much depleted.”

All nine mothers discussed their concerns about the futures of their children with ASD. Will they be able to live independently without the help they get especially from their mothers? The mothers became stressed when thinking of their children’s future especially after the age of 21 because of limited support for long-term housing. Emily discussed that finding long-term housing for her daughter, Celina, is an ongoing concern for her. Sue talked about her constant worry for her son, Adam’s future. Judy stated that when she wakes up every day “fear grips me, fear of the future, fear of the unknown for my child and myself, fear of not getting it "right" for my child. It is debilitating on a regular basis.”

Rilee explained

I think [Leo] will be living with me for the rest of his life but what I would like is for him to be able to be independent enough to hold down a job and live by himself. That would be an ultimate goal. After I went to those meetings, for adults with autism there is nothing out there ... When I think of it, if he doesn't get any better than where he is right now he is going to need major support. Will I be able to trust anybody to take care of him? Well, probably not. That will be a whole issue. ... to find housing specifically for a child with

autism is different than with an adult just with a physical disabilities who has other capacities. You don't need a physician. You don't need somebody who's going to be there overnight because they may elope. Or what if their OCD doesn't allow them to have a roommate and then it's really a different factor than just dealing with just a physical or just a mental disability and that what I think people didn't get yet. Sometimes I don't think about it. I have to live in such denial. But when I go to those meetings it takes me 2 days to recover, to recover from that because I am thinking 'oh my God, he is going to live with me forever. We are never going to travel. We are not going to be able to go to Italy. I will never see the Vatican.' Because there is nothing there for him... So his future, the last year he has been in my mind every day.

Moreover, the mothers stated that they get sad from not being able to celebrate their children's achievements and successes throughout their lives. Ruby shared

I think that every parent just assumes that when you have a child that they will not have this difficult life or they will attend their children's celebration like high school graduation, going to college, then getting married. I am not sure if that will ever happen with my son, I am not sure he will ever be able to live on his own so I worry about that, I worry about anything ever happened to my husband and me, what he would do without us, I don't know if he will ever have a job where he can support himself.

Jane shared similar ideas in this regard.

[Andrew] fortunately is extremely high-functioning and very intelligent. I think he will always probably live with me but I know he will have a job and he will be successful. I have yet to see him have a relationship with anyone outside the family. So I would hope that he will meet someone or at least have a friend but I feel like as long as I can steer

him in the right direction and he has a career not people-oriented more a routine or in a lab. I think he would be able to do it. But I worry about him doing the daily banking and everyday life as an adult. I just worry that he asks for a lot of my help. I think he is capable a lot but his disorder will stop him from like, what I said banking, talk to a bank teller any kind of social interaction would be difficult, going to the doctor he has a hard time talking to anyone outside the.

The majority of the mothers lamented that what they do it is never enough. The needs of their children with ASD, and the challenges from their partners, families, school system, and community create ongoing demands that the feel they can never fulfill.

Theme three: I feel a lack of support and understanding either from my husband, the extended family, or the community. All of the mothers felt that they did not get enough support. Sometimes it was lack of support from their husbands; other times, it was lack of support from extended family, friends, or the community. Lack of support from their husbands was particularly troublesome. The mothers expected their husbands to be actively involved in taking care of their children with ASD and to share household responsibilities. Two out of the nine mothers were satisfied with the support they received from their husbands. Two mothers were divorced, and two had separated from their spouses for a least a period of time. Three mothers described their marital status as a roommate or “business arrangement.”

Ruby and Sue were the two mothers who were grateful for the support that they received from their husbands. Ruby stated,

My husband is wonderful; we seem to balance each other out. He knows when I need a break so he steps in. He gives me time when I need it. Just to regroup or to get some time, or time alone. So he is great in that way.

On the other hand, Ruby and her husband don't get any assistance from extended their family members. "So it's been difficult because it's just me and my husband" as Ruby described it.

Likewise, Sue was pleased with the support she gets from her husband. Sue and her husband divide the work based on who has the time and energy. Sue explained that "[my husband] tends to do more than what I do." In addition, Sue gets help from her brother-in-law who lives with them. Sue considers his involvement a "big help." However, Sue discussed that there is a lack of community support. For example, Sue explained, "If there were more community based special needs programs that are affordable it would be really good."

Similarly, Judy shared that

We think people shouldn't be so-called takers. Evidently, my son is a taker, but he has no choice. If the supporting agencies cut supports to people like my son, what is he going to do? Where is he going to go for help and support, especially after he either leaves my home or after I die? I look to the government and its part in all this, along with public-private partnerships, to support our society in our need to provide for the job training, occupational therapy, and life skills training needed for the children/adults in this population. It is imperative we as a society put more resources against this problem set. We cannot continue to balance our budgets on the backs of these, our most vulnerable citizens. I want support and recognition from the governor on down that these issues are critical for society. Disabled children are only increasing in population. Government who puts its "head in the sand" on this topic is wrong and will face huge budgetary issues over the long term.

Though Emily received help from her husband, she felt that he criticized her for not working as hard as he did. In addition to caring for their daughter and taking care of their home,

Emily has a part-time job. In addition to working, her husband does the grocery shopping and organizes the drawers when they get messy. Her husband

Works a lot and he takes on projects and extra business ... he almost works nonstop, he is almost like a workaholic and or he is a workaholic ... there are times where he sort of feels like if everybody is not working as hard as he is ..., so he tends to get on me... because I don't work as hard as he does....I feel like I do enough and I don't want to work myself crazy. I want to make sure I have time for exercise and relax and socialize. [My husband] doesn't like to socialize with anybody ever. He doesn't really understand why I go to a friend's house, just to hang out with a friend ... that sometimes causes a conflict.

Suzan feels little support from her husband. "My husband...relies squarely on me as the air traffic controller... He has been able to continue doing the fun activities he usually does and I manage the three children and I run the house."

Even though Suzan physically lives with her husband she said "it's so hard being a single parent." Also, she explained that her husband "wants to be the fourth child and would leave her to deal with the three children at critical time. For example, her husband left her and traveled on the first day of school. As she stated

First day of school is tough...especially her son with ASD does not like to wake up in the morning.... He does not like to get dressed, brush his teeth, eat his breakfastIt crushes my spirit and I think there is just no way I am staying married to this person. I will keep in there till [my son] gets closer to his diploma.

Jane stated she is responsible for almost everything in house including taking care of Andrew. "I pretty much do everything." Her biggest concern is that she and her husband

Are not always on the same pagemy husband doesn't want to rock the boat, he will give in to [Andrew] ... whatever he wants, I can spend my entire day saying no to something because it is the right thing ... then my husband will come in and override it, allow to happen.

Dorsey raised concerns similar to those of Jane regarding the quality of care her husband provides to their children with autism and stated that he does not contribute to any kind of decision-making process in regards to them.

[My husband] is rarely home after work most times he is on his phone. He's addicted to his phone and his lap top ... he can't be without texting...when he does come home if the kids are still awake, he will play with them for a little while which is bad for me because it is the time I am trying to get them settled down and he comes in and ramps them up. Then he goes to bed and that is his involvement It's hard when you are in two different pages....My husband doesn't understand. He understands that [our daughters] have some quirks but he doesn't understand what that means in terms of working with them...he still sees them as kids who are just like every other kid ... So I have to do a lot of educating him, and his mom.

Two mothers received more help from their husbands after they were separated. Naomi's husband started to take the children every other weekend, which she considered helpful. Naomi elaborated by saying

I do wish that my [husband] would have participated more in the early days as far as working with my son's speech, taking him to different places to give him more experience. I think he was embarrassed by something that my son would do in the early age because he would act out when he was young because he was not able to

communicate so he would fall in the floor and he would throw things. He would make noises that nobody would understand ... He would get very frustrated so I wish that my husband was able to be there more in that way, teaching him how he should speak or how he can communicate. Like I said taking him to different places as far as men's concern, what men do. I am a mom and I can't teach him what men do.

When they were living together, Naomi felt that she had to guide her husband in making decisions about how to manage their son. Since living apart, he is making decisions more independently.

In the past, I guided the decision-making. I would have to convince my husband that is a good route to go. It would take a lot to do that until he had to handle my son on his own. For example, the whole thing with the gastro ...he would throw up and he would throw up for days because it bothered him so much. So my husband when I tell him about this. It was kind of like 'just give him some soda.' ...But when he had to take off his work to deal with it then it's "we need to go and get him to a doctor we need so and so." I am like "I said that already" but it was that kind of thing when I had to convince him or show him, or let him experience for himself.

Rilee also received more help from her husband after separation. Currently, Rilee and her husband are together; however, they were separated for almost a year. As she explained

I used to do [everything] ... physically in the house and [my husband] was still not there ... I was just doing the same things. He just left. There was no difference. So I had been doing it all by myself all alone. The only difference when we when we separated was that I got a break every Wednesday because he had to come and see his children. But I was doing everything else.

Two mothers discussed how their faith open their eyes to accept their children with ASD even with the limited or lack of support they received for taking care of their children with ASD. As Judy stated “my strong Christian faith helps with this situation...help reduce the effects of stress.” Also she explained that faith helped her not to be delved into “very dark thoughts” of suicide. Judy believes that having a child with autism has enabled her

To grow to be the woman God intended her to be, even if she has much more needed growth ahead of her.... Many other days, I feel a deep gratitude to the Lord for giving me the challenges my son represents and for how they have allowed me to grow as a person in profound ways, ways that are, really, necessary for my salvation. Being that he is a permanent innocent, my son's salvation is already assured, which makes me happier than I can say.

Jane also expressed how her faith helped her to be less negative and to be stronger.

I had a moment of change in my thinking rather than thinking about myself ‘What have I done that this is my life’ and being negative. I looked to faith and kind of thought instead of being negative that I was chosen. I think when you think that way it makes it much easier that I am strong enough, and I am the best mom for him and God chose me to be his mother and rather than being mad, I should take it as an honor and it humbles me that he choose me and I had that moment with a women a friend of mine, we were discussing it and in that moment it is when a whole bunch of things started to make sense in my life. It changed my outlook in [Andrew].

The mothers with children with ASD have been greatly influenced by the support they received, particularly from their spouses. A few mothers received ongoing support from their spouses. Others received limited to no support. A few found that some of their burdens lifted and

that they had more free time after separating from their husband. Regardless of the support from their spouses, the mothers had to continuously educate themselves and others about the unique challenges of ASD in order to get the supports their children needed. For two mothers, faith was a source of comfort, enabling them to accept their children and the lives they were leading.

Theme four: It is difficult to balance all my life aspects; it may be less demanding if I sacrifice one of my roles. Balancing the demands of all of their competing roles while concurrently caring for their children with ASD was difficult for the mothers. Often they sacrificed leisure time for themselves and social time with friends. Four of the nine mothers quit their jobs because they found it too difficult to currently work and to accomplish all of their parenting and household responsibilities, especially if they received little support from their partners. One mother chose to work only part-time because it allowed her the flexibility she needed to meet the demands for rearing her child with autism. Four mothers worked full-time jobs; and one of them worked from her home but turned down promotions to maintain the flexibility her current job afforded her.

Ruby shared that

I don't work outside the home. I have tried to but it is just too much with my children's schedule and my son's issues. He was not sleeping for a while so none of us were sleeping and having to go to a job was stressful. Before I had my children, I had my own business... and that was great. I tried to get back to it when the kids were younger but it was just hard.

Dorsey stated a similar story to Ruby's.

I stay at home now. When I started out I worked.... I stopped working when I was pregnant with the twins because I had so many complications with the pregnancy. I was

working from home at the time but I wasn't able even to do that. So by the time I had the twins, I couldn't go back to work. That job had been eliminated. So I have been in the home ever since. My plan is to go back soon.

Rilee shared her story of resenting staying home. She explained I had a lot of resentment of not working and pictur[ing] myself as a stay-at-home mother. I always had plans to work. I actually had to give up two positions because of [my husband]. He was not helping me. He was supposed to do but he didn't do it all. So I was working every day and night and did everything around the house every weekend. And that built a lot of anger, a lot of anger. I did not deal with the disability well either. I dealt with it anyhow. I just took care. I just. I can shut him out completely and he did the same to me, yeah.

Suzan was able to work a total of two years after she had her children. She stopped because it was hard on her children to have nannies and baby sitters especially with the special needs of her son, James, and her other child who has dyslexia and attention deficit hyperactivity disorder (ADHD). Currently, Suzan is looking to find a job not related to her former area of specialty but one related to her "passion and [her] expertise [which] is really now more with special education kids and rearing special kids."

In contrast to these four mothers, Sue works a full time job from home. She has been in the same position for the past 12 years.

I had to turn down promotions so I can work from home. [I] sort of kept in same position for the past 12 years because the position that I have is very flexible but if I want to move up or even around I would not have that flexibility. So I'm very lucky that the position I have is so flexible but like I said there's no, I can't move around.

Emily works a part-time job. Even though it is her choice to work, she shared that I don't think that I am very well balanced. It is a daily struggle to be balanced. I would have to say not that great, not that well. But it's something you can work on. I don't think that I give enough to my work. And I don't think that I give enough to my child's health and my health. ... So these are things that I struggle with. I find it challenging.

Naomi reiterated similar struggles with trying to balance of her responsibilities.

I don't think I balance it well. This is another reason why I had issues last year...I don't think I balanced well enough. I do juggle but a lot of things fall into the cracks. I try to recover as best as I can. My older son has been a big help and tries to help me with that you know. He takes care of his brother at times when I am lacking in that area. He will make sure he has food. I am just like 'This is something your mom should be doing but it is hard.' Really [my work] is hard also. Just hard to juggle it all, keeping your career, taking care of your kids with disability but we still are floating.

When Judy was asked how she balance her daily responsibilities, she answered

I am not sure I balance them very well at all. I struggle daily with the stress of the demands on me, of the financial strain, of fear of the unknown regarding my son's future, of the worries about how I will be able to arrange and pay for the right care for him over time, of my concern as to whether I will be able to continue to work once he exits the school system, which would be financially catastrophic for me and him, and related concerns. It has gotten so bad that I was forced to pursue a respite from my work, paid for by an emergency medical leave policy, due to severe depression and other mental health issues I have been experiencing over the last several years but which came to a head this past year.

In addition, Judy explained that

Balance is very hard, especially when that small autistic person stands there, looking up at me, with big eyes, a happy smile, and complete faith in that I will always be there, and that I will always continue to make things right. To go to sleep knowing what you know he doesn't know - that you will not always be there and you will not always know how to or be able to make things right - kills me on a regular basis.

Clearly mothers of children with ASD who cope with depression struggle with balancing their multiple roles and responsibilities. Some of the mothers found it necessary to quit their jobs to keep up with the continuous demands of rearing their child with ASD. Those who continued to work often felt they compromised their parenting and their work responsibilities, performing neither role as well as they thought they should. All sacrificed leisure and social activities to attend to the ongoing needs of their children. Fear of the future added to the struggle.

Theme five: There is a history of mental health challenges in my family. Three mothers, 33% of those interviewed, stated that there is a history of mental health challenges among their family including their parents and siblings. Two mothers reported that they had a family member who struggled from bipolar depression. Dorsey reported that her spouse coped with attention deficit disorders.

Emily family has a history of mood disorder. As Emily shared “my mother was bipolar and when I was 14 years she was hospitalized.” Also, Ruby stated, “my mother suffered from depression ... and my brother suffered from depression too.” Ruby and Emily were diagnosed with depression before they had children with ASD. Naomi has suspicions that her older child has depression. As she shared

I think my older son has battled with it for years, dealing with depression. He is tired all the time. He will sleep all day. I don't know if this is a teen thing or if it is depression or a combination of both. His mood is very somber with me. He can't be happy and he can't show emotions. We talk but he will not [talk] with anybody else. Sometimes, they will say, 'what is wrong with him? He does not smile. He moves very slowly. He cannot do this. He cannot do that.'" So I think that my depression did affect him in that way. He could not figure out what's wrong with mom and how can I help my mom. He used to tell me years ago, 'You have to leave Dad.' When he was nine, he told me 'You just need to leave'. He is 16 and I'm just now leaving so he had to deal with it all these years.

In the quantitative part of this study, mothers of children with ASD reported 53.8% family history of depression compared to 23.5% mothers of TD children. Moreover, 25.6% of mothers with children with ASD reported family history of bipolar compared to 7.8% of mother of TD children. These results of the quantitative inquiry supported what was explored from the qualitative research.

The Relationship between Quantitative and Qualitative Inquiries

In this explanatory sequential design, the research began with quantitative analysis of a survey sent to mothers of children with ASD and mothers with TD children. The results substantiated the hypothesized differences between groups. Next, in-depth interviews were used to gather rich descriptions of the lived experience from a group of nine mothers who were concurrently rearing a child with ASD and coping with depression. The analysis of the themes that emerged from the interviews supported and expanded upon the quantitative results.

Regarding the quantitative analysis, the results indicated that mothers of children with ASD reported a history of mood disorder at a significantly higher rate than mothers of TD

children. The mood disorders included depression and bipolar disorders. The mothers of children with ASD also reported a family history of mood disorders among first and second-degree relatives at a significantly higher rate than did mothers of TD children. In addition, that data indicated that the mothers of children with ASD had higher odds than mothers of TD children for having a mood disorder and having other family members with mood disorders. The qualitative themes gathered from the interviews with the nine mothers added rich detail and meaning to the quantitative results (Creswell & Plano-Clark, 2010). By exploring the lived experiences of these mothers, a deeper understanding of the complexity of concurrently being a mother of a child with ASD and coping with depression that was missing from the quantitative data emerged. Several themes emerged from these narratives: a) having a child with ASD contributed to and intensified the mothers' depression regardless of when they were diagnosed with depression; b) a lack of support and understanding either from their husband, their extended family, or their community affected their relationships and their mental health; c) the challenges and stressors of rearing a child with ASD were ongoing; d) balancing all aspects of their lives was difficult; and e) mental health challenges affected other family members.

To fully understand the frequency with which depression occurs in mothers who are rearing children with ASD and the impact of depression and ASD on their lives, it was critical to gather and integrate these quantitative and qualitative results. The meaning of these findings will be explored in greater detail in chapter 5.

Summary

This chapter investigated the reported mood disorders comparing mothers who have children with ASD and mothers who do not have children with ASD. Also, this chapter provided an in-depth view and understanding of the lived experience of those mothers who concurrently

cope with depression and rear a child with ASD. Significant differences were found in the reported mood disorders between mothers who have children with ASD and mother who have TD children. Also, significant difference were found in the reported frequency of mood disorders among first and second generation relatives by mothers of children with ASD when compared with mothers of TD children. On the other hand, the hypothesis that mothers of girls with ASD will report a history of mood disorder more frequently than mothers who have boys with ASD was not supported.

The qualitative portion of the study provided additional insight into the central phenomenon of the lived experience of those mothers of children with ASD. Five themes emerged that highlighted the complexity and interrelatedness of coping with depression and rearing a child with ASD in the lives of these mothers.

Finally, the significance of the sequential mixed method design has been shown through the connection of the results of both sections. As discussed, the quantitative results substantiated that a significant number of mothers are coping with depression while rearing a child with ASD. Thus, this is an area of concern that needs to be addressed. The stories gathered from the interviews illuminated the pervasiveness of the challenges these women confront, and support the need for additional support from health care practitioners, educators, and governmental agencies. These issues will be discussed further in chapter 5.

Chapter 5: Discussion

The results of this mixed method study were reported in two parts. The quantitative findings were gathered from the Depression History Questionnaire completed by 185 mothers of children with ASD and 170 mothers of TD children. The purpose of the quantitative study was to investigate whether mood disorders reported by mothers occur more frequently in families that have a child with ASD than in families with TD children. The qualitative findings were gathered from in-depth interviews with nine mothers who concurrently were coping with depression and rearing a child with ASD. The purpose of the qualitative study was to explore the lived experiences of these mothers and to understand the impact of mood disorders and rearing a child with ASD on their daily life occupations. This chapter provides a discussion of the findings from an occupations perspective and from the PEO theoretical framework as described in the occupational science literature.

As explained in the previous chapter, the results of the quantitative data suggest that mothers who have children with ASD were more likely than mothers of TD children to report a history of mood disorders. These include: (a) depression and bipolar disorder; (b) treatment for depression or bipolar disorder; (c) suicidal ideation or attempted suicide; and (d) depression, bipolar disorder, and suicide among the participants' first and second-degree relatives. From the qualitative data the following five themes emerged: a) Regardless of when I was first diagnosed, having a child with ASD contributed to and intensified my depression; b) I feel a lack of support and understanding either from my husband, the extended family, or the community; c) Challenges and stressors of raising a child with ASD are ongoing, what I do is never enough and is physically and mentally exhausting; d) It is difficult to balance all aspects of my life; it may be

less demanding if I sacrifice one of my roles; and finally, e) There is a history of mental health challenges in my family.

Though a blend of positive, neutral and negative prompts were used to conduct the interviews during the qualitative phase of the study, the themes that emerged emphasized primarily the difficulties rather than the pleasures the mothers experienced in their daily life occupations. Positive and neutral prompts included questions such as: “Describe your child;” “What brings you joy and satisfaction?” “What types of supports do you receive?” These were followed by negative prompts such as “Describe something difficult” and “Tell me about your depression.” (See appendix B). Thus, it is likely that the emphasis on difficulties that emerged in the five themes stemmed primarily from the mothers’ interpretation of their lived experience framed within the context of their depression rather than from any negative bias in the prompts. In addition, it seemed to the researcher that the mothers needed to tell someone about their challenges, possibly contributing to the themes about difficulties within their occupational lives.

In the following section these quantitative and qualitative findings are analyzed in detail within the PEO framework. Research cited in chapter 2 of this study is used to substantiate this analysis.

Analysis of the Study’s Results in Relation to the Theoretical Framework Guiding the Study

The PEO model (Law et al., 1996) served as the theoretical framework guiding the structure of this study. As explained in the discussion about PEO in Chapter 1, occupational performance is influenced by the interaction of person, environment, and occupation factors. Consistent with the construct of the PEO model, the data gathered from this study indicate that these factors interacted across time and space, contributing to and challenging the mothers’

occupational performance and influencing their current health and well-being. (See figure 5.1).

Figure 5.1.

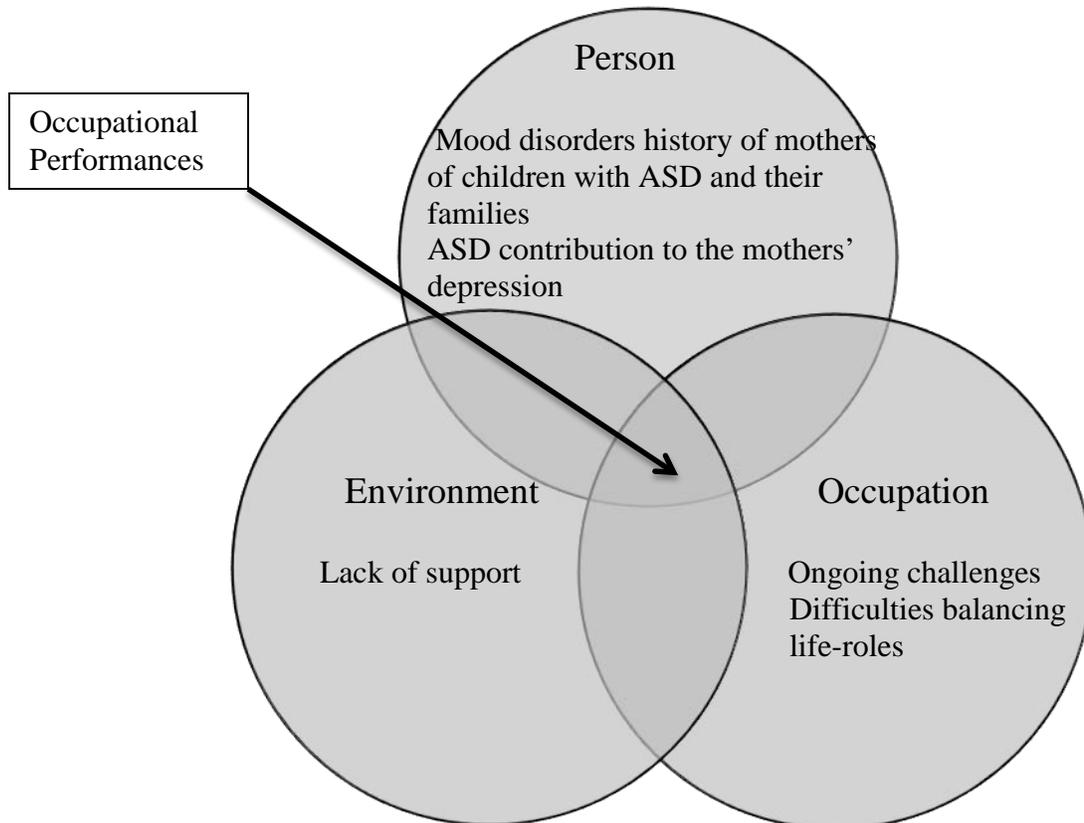


Figure 5.1. *Integration of the findings from the study with the PEO model, adapted from Law et al. (1996)*

Person. Initially, data about person factors were gathered from the Depression History Questionnaire. The findings indicated a significant difference in lifetime history of depression and bipolar disorder between mothers who were rearing children with ASD and mothers of TD children. The information from the interviews contributed to a deeper understanding of the

person factors and elucidated some of the environment and the occupation factors. It was through the mothers' stories that the researcher was able to gain insight into the interaction among the person, environment, and occupation factors and the influence of this interaction on the mothers' occupational engagement and well-being.

Person factors from quantitative data. The quantitative part of the study resulted in significantly relevant data that were reported by the mothers about the following person factors: their history of mood disorders, their treatment for mood disorders, their history of attempted suicide and suicidal ideation, and their family history of mood disorder. As related to history of mood disorders, the mothers of children with ASD in this current study reported being professionally diagnosed with depression and bipolar disorder more frequently than mothers of TD children. These findings are consistent with those of Ingersoll et al. (2011), Fisman, Wolf, and Noh (1989), and Dumas, Wolf, Fisman, and Culligan (1991) who found that mothers of children with ASD were more likely to struggle with depression than other groups of mothers. In addition, the findings of this current study expand upon those of previous studies by comparing the incidence of mood disorders in mothers of children with ASD to mothers with TD children and by using a larger sample.

Compared with mothers of TD children, the mothers of children with ASD in this study reported more suicidal ideation and suicide attempts (4.2% vs 12.0%) than mothers of TD children. Suicide does occur frequently in our society. The CDC (2012b) reported 0.5% of the U.S. population attempted suicide in the year of 2012. Suicide is the 10th leading cause of death in our nation, and its prevalence is increasing (Kochanek, Murphy, Xu, & Arias, 2014). Still, the lifetime prevalence of suicidal ideation and suicide attempts among the mothers of children with ASD appears to be startlingly high, even in this context. No studies could be found that

investigated the relationship between suicide and rearing a child with ASD or that compared the frequency of suicidal ideation or suicide attempts between mothers of children with ASD and mothers of TD children. The current study contributes to this needed knowledge base; according to the findings, mothers of children with ASD had more than three times the odds of thinking about or attempting suicide than mothers of TD children.

Also, the mothers of children with ASD in this current study were more likely than mothers of TD children to report a family history of depression, manic illness, and suicide (attempted or completed) in their first and second-degree relatives. These results add to the work of Bolton, et al. (1998) who found that the rates of major and minor depression and bipolar disorder were significantly elevated in the relatives of an ASD group compared to the relatives of a Down syndrome group.

Person factors from qualitative data. Two of the qualitative themes also address person factors. These include the influence of a child's diagnosis on a mother's depression and the family history of mood disorders among the mothers' families.

Regardless of when I was first diagnosed, having a child with ASD contributed to and intensified my depression. All mothers in the present study discussed in detail how rearing a child with ASD contributed to their stress and depression. Mothers who were depressed before having their child with ASD argued that having the child intensified their depression. Mothers who were diagnosed with depression after having their child with ASD believed that rearing that child was a major cause of stress in their lives and led to the depression. Often using emotionally laden words that were sometimes accompanied by tears, the mothers described their concurrent challenge of being a mother of a child with ASD and coping with depression. They identified learning about their child's diagnosis of ASD as one of the major traumatic events in their lives.

Issues related to ASD intensified their depression. Safety of siblings because of the violent and aggressive behaviors of their child with ASD was a major concern. Their and their child's sleep deprivation and the extra demands of rearing a child with ASD caused added stress. Furthermore, the majority of mothers described the grief they felt from believing that their child with ASD would not live life or celebrate major milestones such as high school graduations and marriages in the same way as TD children.

These findings are consistent with the work of other researchers who found that mothers of children with ASD struggle with stress, negative affect, and depression (Bolton et al., 1998; Carter, Martinez-Pedraza, Gray, 2009; Ekas, Whitman, & Shivers, 2009), and to a greater degree than did mothers of children with other disabilities (Abbeduto et al., 2004, Barker et al., 2011, Lounds et al., 2007). The unique impairments and behavioral challenges associated with ASD heightened the susceptibility of family members, particularly mothers, to psychological and emotional distress (Lee et al., 2009, Tehee, Honan, & Hevey, 2009). Increased levels of stress and distress were associated with the severity level of the impairments (Ekas & Whitman, 2010), and with the degree of behavioral problems of the child with ASD (Abbeduto et al., 2004; Hating, 2003). High levels of stress correlated with high levels of negative affect (Smith et al., 2010) and with low levels of well-being (Abbeduto et al., 2004; Hasting et al., 2005; Wang, Michaels, & Day, 2007). Conversely, mothers of children with ASD who reported daily negative affect were more likely than mothers with positive affect to negatively perceive their children's behavioral, emotional, cognitive, motor, sensory, communication, and social status (Lickenbrock, Ekas, & Whitman, 2011). Such findings are consistent with the supposition proposed earlier in this chapter that the depression of the mothers who were interviewed may have influenced their tendency to dwell on themes about difficulties in the current study. A few

mothers of children with ASD revealed that they considered committing suicide. They explained that because of their depression and the high level of demands associated with rearing their child with ASD, they go to a “very dark place” where suicide is a comfortable solution for escaping their high levels of stress.

There is a history of mental health challenges in my family. Consistent with the quantitative findings of this study a few of the interviewed mothers reported a family history of mental illness. One mother stated that her mother and her brother struggled with depression. Another mother reported that her mother struggled with bipolar disorder. This is consistent with the work of Bolton, et al. (1998) who noted a significant increase in the rate of affective disorder among first-degree relatives of individuals with ASD, and with the work of DeLong and Dwyer (1988) who found increased rates of bipolar disorder in first and second-degree relatives of individual with ASD, specifically Asperger’s syndrome. It is worth-mentioning that the two mothers who spoke about a family history of mood disorders were diagnosed with depression before having their children with ASD. This may indicate some link between a genetic predisposition for mood disorder and for ASD.

Environment

The environment most discussed by the mothers during the interviews was the social environment. The intensity of the stress and depression that the mothers experienced was mitigated or exacerbated by the level of support they received from others within their social environment. Conversely, the mother’s stress and depression influenced their ability to engage with and receive support from others in the social environment.

As depicted in the theme *I feel a lack of support and understanding either from my husband, the extended family, or the community*, most of the mothers felt they received limited or

no support from their spouses, extended family, friends, schools, and community. This lack of support hindered their occupational performance within the home, community and workforce. Of the nine mothers, only two expressed satisfaction with the support they received from their spouses and appreciated their spouses' investment in shared decision making. A few of the mothers also received periodic support from other family members and from friends. The support from their spouses, family members, or friends afforded respite from the ongoing demands of rearing the child with ASD and provided opportunities to engage in a few self-nurturing leisure occupations and satisfying work occupations.

The rest of the mothers experienced limited support. These mothers either were separated or divorced from their spouses, or co-habited as roommates with them. The marital strain detailed by the mothers was consistent with the meta-analysis conducted by Risdal and Singer (2004) which revealed an increase in the rate of marital difficulties, separation, and divorce among parents of children with disabilities including parents of children with ASD. Similar to findings of Gray (2003) and Hasting (2003), the mothers in the current study explained that spouses or ex-spouses remained emotionally aloof, relying on the women to take care of the child, navigate school and health care issues, and manage the household. Extended family support also was sporadic. Friends were few and drifted away as personal interests and the needs of their families followed divergent paths. If the fathers or extended family members did spend time with their child with ASD, they frequently did so in a manner that undermined the therapeutic protocol established by the mother and the health care professional or educator. These mothers felt that they needed to continuously educate their husbands, family members, and the community about ASD and how to manage the pertinent issues associated with ASD.

The limited support provided to mothers of children with ASD by their spouses, family members, and friends contributed to the mothers' stress and depression. They felt alone as they dealt with the ongoing responsibilities for their children without a sufficient support system. The needs of their children became their priority, leaving little time to engage in personal and leisure occupations that could contribute positively to their health and well-being. Rather, to cope with their stress and depression several of them isolated themselves from social contacts; most sought psychotherapy and medication.

Occupation

Qualitative findings also illuminated the occupations of these mothers. Influencing and influenced by the person and environment factors, the occupations associated with rearing their child with ASD were ongoing and physically and mentally exhausting. To sustain engagement in them, the mothers felt that they needed to forgo engagement in other desired occupations.

Challenges and stressors of rearing a child with ASD are ongoing. What I do is never enough. It is physically and mentally exhausting. The majority of the mothers spoke about the continuous challenges and non-stop caregiving responsibilities associated with rearing their child with ASD. For some of the mothers, the extra demands of these caregiving occupations, coupled with their depression, sapped their energy to engage in other daily life occupations. In addition to the physical assistance they provided to help their children complete self-hygiene and other daily living activities, the mothers provided emotional assistance and ongoing supervision to nurture and support their children, and protect them from harm. A number of the mothers needed to remain routinely vigilant to manage and control their child's special diet, sensitivity issues, and violent and aggressive behaviors. Several mothers needed to assume advocacy roles

to fight for educational, health, and community services they believed their child was entitled to receive.

As a result of juggling the occupational demands of caring for their child with the demands from other family members, the school system, and the community, the mothers were exhausted. Yet, they felt that what they did was never enough. Always there was something to do. This finding is consistent with those of Crowe and Florez (2006) and Smith et al. (2010) who found that mothers of children with disabilities spent more time providing care for their children compared to mothers of TD children.

Many of the mothers interviewed also mentioned sleep deprivation. Their sleep deprivation stemmed from the disruptive sleeping patterns of their child with ASD, their depression, and their chronic stress about the daily caregiving tasks they needed to complete. Hoffman et al. (2008) found a correlation between the sleeping difficulties of children with ASD and those of their mothers. Hoffman et al. (2008) and Sweeney et al. (2003) also found an inverse relationship between the increased stressed experienced by the mothers and the sleeping difficulties experienced by their children with ASD.

Smith et al. (2010) found that mothers of individuals with ASD experienced significantly more occurrences of stressful events at home or work, or involving a friend or a relative, compared to mothers with non-ASD children, which they labeled “network stress” (p.172). Specifically, the mothers of children with ASD experienced at least twice as many days filled with stressful events at home, at work, or with family or friends compared to mothers who did not have children with ASD. In addition, they found the mothers of children with ASD were likely to experience a stressful situation three times more frequently than mothers of children without ASD. According to Gerstien, Crnic, Blachet, and Baker (2009), parenting stress

continues to increase over time for mothers of children with disabilities but remains constant for the fathers of children with disabilities.

It is difficult to balance all my life aspects; it may be less demanding if I sacrifice one of my roles. The mothers interviewed for this study assumed primary or full responsibility for the care of their child with ASD. This required that they also perform the roles of negotiator, monitor, supporter, and advocate in the educational program for their child with ASD. According to Stoner and Angell (2006), mothers of children with ASD perform these roles to a greater degree than mothers of other children. The mothers in this current study found it challenging to balance all these occupational roles particularly if they received only limited support and understanding from their spouses. Yet they continued to absorb the responsibilities rather than lean on someone else for support usually because they did not believe anyone qualified and willing was available to provide such support. As a result, most of them sacrificed the time they might have otherwise allocated to engaging in personal and leisure occupations. The personal and leisure occupations they pursued tended to be more sedentary such as writing, reading a book, watching a movie, or Facebooking. These occupations tended to occur only occasionally or for short periods, or involved celebratory activities with the children. Brown (2007) and Smith et al. (2010) found that mothers of children with disabilities spent less time engaging in recreational activities of choice compared to mothers of TD children. Smith et al. (2010) also found that mothers of children with ASD spent one hour less on a daily basis engaging in leisure activities; yet engagement in leisure activities of choice was a predictor of higher positive affect.

Most of the mothers in the current study also had ceased or reduced engagement in paid work occupations that they found meaningful in order to fulfill their caregiving roles. Those who continued to work did so on a part time basis or performed work that was less meaningful to

them to maintain the flexibility they needed to care for their child. These findings are consistent with the research conducted by Gray (2003) who reported that half of the mothers who participated in the study were unemployed and that the majority of the employed mothers were working part-time to permit them to manage their demanding life and to maintain the flexibility they needed to rear their children with ASD.

Summary of the Analysis of the Study from a PEO Perspective

Concurrently coping with depression and rearing a child with ASD presented significant challenges for the interviewed mothers. Though the mothers needed support from others within their social environment, and opportunities to engage in occupations that brought them meaning and pleasure to successfully cope with their depression, most felt that they received little support and could afford little time to engage in self-nurturing and other meaningful occupations. Rather, they believed that they needed to allocate most of their time to the occupation of caring for their child with ASD. In spite of doing so, they felt that what they did for their child, that is, their level of occupational performance, was never enough. Their sense of chronic caregiving that they judged as never sufficient and their feelings of limited support resulted in or exacerbated their original stress and depression.

As related to PEO, the mothers coped with difficulties in all of the factors, person, environment, and occupation factors. As a transactional model, PEO emphasizes the interdependence of the three factors and their resultant effect on occupational performance. Thus, each of the factors affected and was affected by the other two, and resulted in the mothers' perceived and actual levels of occupational performance. As regarding to the person factors, the surveyed mothers of children with ASD were more likely to report a history of mood disorder. The interviewed mothers talked about their ongoing depression, low energy levels, limited

interests, chronic stress, and occasionally their joys. These person factors affected, and were affected by, the supports the mothers needed and received from the social environment and the occupations they felt obligated or chose to perform, or abandoned

Embedded within their environments, the mothers also discussed the supports they did or did not receive from their nuclear family, extended family and friends, community, school, and health care systems. Consistent with the transactional construct of PEO, the supports mothers did and did not receive were affected by their person factors, particularly the depression and stress they described and the occupations they performed.

Finally, the mothers spoke about their engagement and participations in daily occupations. They talked primarily about their success, survival, and frustrations with their parenting efforts, daily life routines, and advocacy initiatives. They also discussed their past or present paid work experiences, and their constrained social and leisure occupations. Comments about their level of physical and mental exhaustion permeated their descriptions. The occupations the mothers chose or felt obligated to perform, the occupations they abandoned, and their actual and perceived level of occupational performance were affected by, and affected, the person and environment factors described above.

From an occupational science perspective, engagement in meaningful occupations contributes to health and well-being. Conversely, the lack of participation in meaningful occupations negatively impacts health (AOTA, 2008). Wilcock (1999) considered human occupations the natural biological mechanism for health, and believed that finding meaning in occupations contributed positively to both biological needs and health. He believed health and well-being were determined by "being through doing," that is, the ability and opportunity to engage and perform meaningful occupations (Wilcock, 2006).

Implications for Practice

The study's findings have implications for occupational therapy practice and suggest the importance of interventions that enhance the strengths and target the particular challenges of depressed mothers who are rearing a child with ASD. If the ultimate goal is to improve the well-being of these mothers, then a comprehensive look through the lens of PEO at the interactions among the mothers' personal characteristics (strength and needs), environment factors (supports and hindrances), and occupation (roles, required and chosen occupations, and opportunities to engage in meaningful occupations) provides a holistic view for accomplishing it. It is through addressing the interaction of the person, environment, and occupations that well-being may be achieved. Carter, Martinez-Pedraza, and Gray (2009) found that depressive symptoms are a very important target for intervention. Consistent with the work of Gerstien, Crnic, Blachet, & Baker (2009), lowering the daily parenting stress levels experienced by mothers of children with ASD would promote greater maternal well-being. Consistent with the findings of Shu (2009), strengthening the roles of other family members and providing the mothers of children with ASD the needed support would reduce the mothers' loneliness and emotional turmoil. Similar to the recommendations of Hall and Graff (2011), providing the mothers with a family support network, encouragement, and physical assistance to care for their children with ASD would allow the mothers can take care of their personal needs and engage in activities of choice also is critical. According to Lampinen, Heikkinen, Kauppinen, and Heikkinen (2006) positive mental health and well-being is predicated on engagement in recreational and leisure occupations. Thus, the more opportunity the mothers have to engage in leisure occupations the more positive their mental health and sense of well-being may become.

Previous researchers have shown positive effects of engagement in meaningful occupations

on health and well-being (Dunton (1919); Wilcock, 1999a; Wilcock, 199b, Wilcock, 2006). Creating opportunities to enhance occupational performance of the mother can be achieved by strengthening supportive environments and respite services, promoting the mothers' identification and engagement in self-nurturing and meaningful occupations, and facilitating the mothers' positive assessment of their occupational performance. The findings from this current study may provide guidance for occupational scientists and occupational therapists to help facilitate occupational performance by maximizing the optimal fit between mothers' characteristics, their environment factors, and the occupations that are meaningful to them. In addition, it provides a structure for encouraging occupational therapists and occupational scientists to engage in similar research initiatives using conceptual frameworks such as PEO for assessing the comprehensiveness of the person's strengths and needs, the environments and occupations the influence health and well-being and efficacy of interventions.

Designing a successful intervention depends on a variety of factors including the nature of the depressive symptoms of the mother, the characteristics of the child with ASD, and the dynamics of the family system. All these variables may determine what a mother with depression wants and needs. Rather than placing additional burdens and expectations on the mothers, the interventions need to be designed, in collaboration with the mothers, take into consideration their ongoing caregiving demands and challenges as well as their strengths, desires, and aspirations.

Limitations of the Study

Quantitative. Despite the methodological strengths of this mixed methods study, a number of limitations exist. First, in order to create a control group of mothers of TD children, the original Maternal Depression History Questionnaire was re-launched. However, the data for

the mothers of TD children were collected seven years later than the data for the mothers of children with ASD (2014 vs. 2007).

Second, data were collected online, and it may be that mothers with less access to or knowledge of technology were not able to participate to the same degree as mothers with more resources. In addition, although the data gathering process was via the Internet for both groups, the method for contacting the mothers differed, potentially creating bias in the samples. The mothers of children with ASD for the 2007 study were contacted via email from the IAN project (for which they had registered); the mothers of TD children in the 2014 study were contacted through Autism Society chapters' Facebook pages and bulletin boards, Towson Tiger Today, a local church, and the researcher's email list.

A third limitation was a significant difference in maternal race, ethnicity, and age between the groups, with more diversity among the TD mothers. Compared to mothers of children with ASD, they were significantly more non-white (26.5% vs. 15.7%), more Hispanic (9.1% vs. 2.7%), and slightly older (mean age 40.8 vs. 38.8 years). Likewise, the TD children were significantly older than the children with ASD with a mean age of 11.3 years with 4.7 SD compared to 8.5 years with 4.2 SD. There may be a number of reasons for this. For one thing, recruitment methods differed. These were more locally targeted in the case of TD mothers, whereas the IAN Project's original recruitment campaigns were national. Perhaps mothers of color were more likely to respond to more local calls to action. It's also likely that the composition of the ASD group was inherently biased because African-American children are less likely to be diagnosed with ASD than white children (Mandell, et al., 2009). A CDC study (2010) counting ASD cases in Maryland found that 1 in 60 white children, 1 in 65 African-American children, 1 in 102 Hispanic children, and 1 in 84 Asian or Pacific Islander children

were identified with ASD. Clearly, a group of children with identified ASD might include fewer children of color than a typically developing group of children.

Fourth, even though the validity of the ASD diagnoses in the IAN sample was established through the SRS and the study by Daniels et al. (2012), the validity of mood disorder diagnoses was not. Mothers' mood disorders were self-reported, not based on a clinical assessment. This may have influenced the validity of the results. The questions were designed, however, to help participants reflect and choose a very specific status: not diagnosed, professionally diagnosed, self-diagnosed, and treated.

Qualitative. As is often the case in qualitative research, the subjectivity of the researcher who conducted the study could contribute to bias. As mentioned before, considerations were taken to minimize such bias by asking a blend of neutral, positive and negative questions. In addition, multiple reviews, codes, and creation of categories were conducted by the researcher and the chair of the dissertation committee. Member checking was completed by five participants to make sure that interview transcripts reflected what they meant to express about their lived experience. The researcher kept a journal in which she acknowledged and reflected upon her perspectives, assumptions and personal values and those of the interviewees.

Finally, the sampling of the qualitative part could be a limitation. The participants were obtained through criterion sampling, which has its own limitations. All participants who fit the criteria of this study may have had similar characteristics. Though this limits the generalizability of the findings, the main objective of this study was to gain an in-depth understanding of the lived experience of depressed mothers who rear children with ASD.

Recommendations for Future Research

This study has contributed to knowledge about the reported rate of depression and mood disorders and the lived experience of mothers who are concurrently depressed and rearing a child with ASD. The study leads to further questions and topics for study that will expand and refine insights about this phenomenon. The quantitative section of the study should be replicated in other states to determine whether the results from the Maryland sample are similar to those obtained in other geographic locales. The qualitative part of this study should be replicated with sample of lower income participants because most of the interviewed mothers were well-educated and from middle-income families. The current study cannot demonstrate how income and educational levels affected the support systems, the occupational options, and the available resources discussed during the interviews.

Further exploration of the lived experiences of mothers who cope with depression and rear a child with Asperger's disorder vs. a child with autism also is needed. ASD is a spectrum disorder and while there are factors common to children across the autism spectrum, there also are factors that differ depending on level of cognitive ability. Investigation of the lived experience of mothers who concurrently cope with depression and rear a child with Asperger's disorder vs. autism may add a different perspective to the essence of the phenomenon. Similarly, further investigation of the lived experience of mothers whose children are adults with ASD could reveal different perceptions and concerns. Exploring in greater detail the occupations and the meaning of engagement in occupation is important so occupational scientists understand how to effectively utilize occupations to support the mothers' health and well-being. In addition, research on the depressed fathers of individuals with ASD may provide nuanced insights about their lived experience, engagement of occupations, and health, and well-being

Summary

This mixed methods study incorporated the collection and analysis of quantitative and qualitative data. The purpose of the quantitative inquiry was to examine whether mothers of children with ASD and their first and second-degree relatives were more likely to report depression and bipolar disorder than mothers of TD children. The qualitative section of the study expanded upon the findings of the quantitative section to explore the lived experience of mothers who coped with depression while rearing a child with ASD. Findings were interpreted within the PEO theoretical framework. The results of the findings can be used to provide more effective and holistic interventions that promote health and well-being of the mothers through engagement in meaningful occupations.

The strength of the study was its mixed design, which enhanced the complexity of the two sections. A strength of the quantitative section was its large sample size. A strength of the qualitative section was its compilation of thick and in-depth descriptions of the lived experience of mothers who rear a child with ASD and cope with depression at the same time. Most importantly, the insights gained about the lived experience of mothers may help to guide practice. It is important for practitioners to be aware that mothers of children with ASD may be coping with high levels of stress and depression stemming from the responsibilities of caring for their child with ASD, their other children, their marriage, the support system and work obligations. Resources and interventions need to be available to support these mothers as their health and well-being significantly impacts that of their children.

As occupational scientists and occupational therapy professionals, there is a need to understand that these mothers confront more and different challenges than mothers of TD children. It is important to know the problems they are facing and the support they require to

overcome these challenges. It is also important to recognize and celebrate their strengths. It is crucial to acknowledge their need for specialized assistance and support arising from the dual challenges of being depressed and rearing a child with ASD. When working with individuals with ASD, it is important acknowledge that they are part of a family unit and that their health and well-being is interdependent with the health and well-being of the entire family.

For mothers who are rearing a child with ASD while coping with depression, it is this researcher's hope that this study will shed the light on your stories, and that your stories will be read by policy makers and care providers. As a result, they will advocate on your behalf to make available the support and services that you need to take care of your child with ASD and yourself. For the interventionist providing services, it is this researcher's hope that the findings of the study will expand your insights about the strengths and challenges of these families and provide you with a framework for designing best practice interventions that meet their needs and support their success.

Appendix A

Data Release Permission

Jay,

I have received the IRB approval and a signed data access agreement from Haifa.

Please could you release the data?

Thank you.

Alison

Alison R. Marvin, Ph.D.

Interactive Autism Network (IAN)

Department of Medical Informatics

Kennedy Krieger Institute -~~e~~mail: marvin@kennedykrieger.org phone: [443-923-4143](tel:443-923-4143) fax:

[443-923-4145](tel:443-923-4145)

www.IANproject.org

Appendix B

Depression History Questionnaire

Section 1: Informed Consent Form

Click on NEXT to continue.

Dear Participant,

I am a graduate student at Towson University and am conducting a study that compares the frequency of depression and other mood disorders in families with a child with an autism spectrum disorder (ASD) and in families where all children are typically developing. I am asking you as a mother whose biological children are typically developing to complete the Maternal Depression History Questionnaire. For the purpose of this study, a "typically developing child" is one who is between the ages of 3 and 17.99 years, and does not have autism, a developmental disability or a chronic physical or mental health challenge.

In a previous study conducted at Kennedy Krieger Institute, mothers of children with ASD completed a similar Depression History Questionnaire. To better understand if there is a possible genetic link between ASD and a family history of depression and mood disorders, results from the questionnaire completed by these mothers need to be compared with those of mothers of typically developing children. Unfortunately, there is no available information that compares the experiences of these two groups of mothers. That is why I am seeking mothers of typically developing children to complete the same survey. I want to learn whether mood disorders occur at the same frequency in both groups of mothers or occur more frequently in mothers of children with ASD.

The Maternal Depression History Questionnaire is an online survey asking questions about any history of mood disorder you or members of your extended family may have had. Participation will take 10-15 minutes of your time. The survey is anonymous so I will be able to see your answers but I will not know your identity. Your participation is voluntary. You do not have to complete any question that you do not feel comfortable completing. Mothers who complete the survey will have a chance to win a \$50 Amazon gift card.

There are no risks involved in participating in this project. At no time will your name be revealed. All data will be reported in aggregate form.

I am a Towson University graduate student in the Occupational Science Doctoral program. I am conducting this study under the supervision of my doctoral committee. I would be grateful for your valuable input and participation. If you have any questions about this project, please contact me, Haifa Batarseh at 516-551-4597. You also may contact Dr Janet DeLany, the Chair of my doctoral committee at 410-704-2078. Or Dr. Debi Gartland, Chairperson of the Institutional Review Board for the Protection of Human Participants at Towson University. Phone: 410-704-2236, or email: ours@towson.edu

THIS PROJECT HAS BEEN REVIEWED BY THE INSTITUTIONAL REVIEW BOARD FOR THE PROTECTION OF HUMAN PARTICIPANTS AT TOWSON UNIVERSITY.

*** 1. To begin the survey, please respond to the following question:**

No, I choose not to participate.

Yes, I affirm that I have read and understood the above statement and have had all of my questions answered. I also affirm that I am 18 years or older and am participating in this research voluntarily. I am the mother of a child/children between the ages of 3 and 17.99 years. My child/ children are typically developing and do not have autism, another developmental disability, or a chronic physical or mental health challenge.

No, I choose not to participate.

Section 2: State of Residence

***2. This study is about mothers living in Maryland. Do you live in the state of Maryland?**

- No
 Yes

Section 2: Your Date of Birth and Education

***3. What is your date of birth?**

Date / Time MM DD YYYY
 | | |
 | | |

***4. What is the highest level of education you have completed?**

- Did not complete high school
 High school or graduate equivalent
 Some college associate degree
 Bachelor's degree
 Master's degree
 Doctoral or Professional degree

Section 2: Mothers' Information Click on NEXT to continue.

5. What is your race? Check all that apply

- White
 Black/African-American
 Native Hawaiian or Pacific Islander
 Asian
 American Indian or Alaskan Native
 Unknown

Other (please specify)

6. What is your ethnicity?

- Hispanic
 Not Hispanic

***7. How many children between the ages of 3 and up to (but not including) 18 do you have?**

Section 2: Confirming Children Don't Have Autism

***8. Can you confirm that all of your children are "typically developing," i.e. have not been diagnosed with autism, developmental delay, or other chronic physical or mental health challenges.**

No

Yes

Section 2: Child's Information

***9. For the rest of the survey, we are interested in your oldest child (between 3 and up to but not including 18). What is that child's gender?**

Female

Male

***10. What is that child's date of birth?**

Date / Time MM DD YYYY
 / /

Section 3: History of Depressive Illness

***11. Have you ever seen a medical or mental health professional because a) you felt sad, empty, or depressed, b) you felt discouraged about yourself, or c) you lost interest in most things you usually enjoy?**

No

Yes

*** 12. Have you ever diagnosed yourself with a depressive illness, perhaps through an Internet self-assessment tool, an informational brochure at the doctor' office, or symptoms listed in a medication advertisement?**

- No
 Yes

Section 3: History of Depressive Illness

*** 13. Which of the following diagnoses did you give yourself?**

- Major depressive disorder
 Dysthymic disorder
 Postpartum depression
 Depression associated with premenstrual syndrome, premenstrual Dysphoric Disorder, or Menopause
 Seasonal Affective Disorder (SAD)
 Bipolar Disorder (also known as Manic depression)
 Cyclothymic Disorder
 Not sure, but it was some type of depression

Other (please specify)

Section 3: Sought Help

*** 14. When you suspected you had a depressive illness, did you ever seek professional help?**

- No
 Yes

Section 3: History of Depressive Illness

*** 15. There are many reasons that a person coping with a depressive illness may not see a medical or mental health professional about their condition. Please tell us why you did not see a medical or mental health professional about your depressive illness. Check all that applies**

- No insurance for mental health issues
- Not enough money (whether insured or not)
- No time
- No energy
- Other family member in greater need
- Fear about impact of diagnosis on future health or life insurance eligibility
- Worry about what other will think of you
- Inability to find a medical or mental health professional you trust
- I did see a professional but they did not diagnose depression

Other (please specify)

Section 3: History of Depressive Illness

*** 16. Treatment for depressive symptoms may include medication and/or therapy. Whether or not you have been diagnosed by a medical or mental health professional, have you ever been treated for depressive symptoms?**

- No
- Yes

Section 3: History of Depressive Illness
Click on NEXT to continue.

***17. Have you used any of the following treatments or techniques to deal with a depressive illness? Check all that apply.**

- Medication
- Alternative medicine (herbs, homeopathic, remedies, acupuncture, vitamins, etc)
- Individual Therapy or Counseling (for example, talk therapy or cognitive behavioral therapy)
- Group Therapy
- Marital or Family Therapy
- Support Group, in person
- Support Group, online
- Spiritual practice (such as prayer or meditation)
- Speaking with a pastor, rabbi, etc.
- Life-style changes (such as diet or exercise)
- Self-help books
- None

Other (please specify)

***18. Are you currently being treated for depressive symptoms?**

- No
- Yes

Section 3: History of Depressive Illness

***19. Have you ever been diagnosed by a medical or mental health professional with a depressive illness (or a mood disorder with a depressive component)?**

- No
- Yes

Section 3: History of Depressive Illness

***20. When you were first diagnosed by a medical or mental health professional with a depressive illness... How old were you? Please enter a number such a "35".**

***21. What type of professional first diagnosed you with a depressive illness?**

- Physician other than a psychiatrist (family doctor, internist, etc.)
- Psychiatrist
- Psychologist
- Other Therapist or Counselor

Other (please specify)

Section 3: History of Depressive Illness***22. Which of the following diagnoses have you received from a medical or mental health professional? Check all that apply**

- Major Depressive Disorder
- Dysthymic Disorders
- Postpartum Depression
- Depression associated with Premenstrual Syndrome, Premenstrual Dysphoric Disorder, or Menopause
- Seasonal Affective Disorder (SAD)
- Bipolar Disorder (also known as manic depression)
- Cyclothymic Disorder
- Not sure, but it was some type of depression

Other (please specify)

Section 3: History of Depressive Illness***23. Over your lifetime, what pattern has your depressive illness tended to have? Check all that apply.**

- I go through long periods of a fairly constant level of depression.
- There are times when I have energetic "up" periods, and there are times when I have depressed "down" periods.
- I have had one or more distinct episodes of depression lasting at least 2 weeks.
- Other (please specify)

***24. How many periods of depressive illness do you estimate you have had?**

- 1
- 2
- 3
- 4 or more

Section 4: Depressive Episodes

***25. Think of the very first time in your life you experienced a depressive illness. How long did this episode last?**

- Less than 1 month
- 1-3 months
- 4-7 months
- 8-12 months
- More than 1 year

Section 4: Depressive Episodes

Click on **NEXT** to continue.

***26. Was there something going on in your life shortly before this first experience of depressive illness that you believe contributed to it? Check all that apply.**

- Major job or school related stress
- Job loss
- Divorce or end of close relationship
- Marital or relationship difficulties
- Abusive relationship
- Death of a loved one
- Violent crime (rape, mugging, carjacking, etc.)
- Illness or injury involving a loved one
- Illness or injury involving yourself
- Financial crisis
- Pregnancy

Other (please specify)

Section 4: Depressive Episodess

***27. Which of the following best describes your functioning during this first period of depressive illness?**

- I was so ill that I needed to spend time in an inpatient clinic or hospital.
- I was barely able to function, but was not hospitalized.
- I was somewhat able to function.
- I functioned fairly well.

Section 4: Depressive Episodes
Click on NEXT to continue.

***28. What type of symptoms did you experience during this first depressive illness?**

Check all that apply.

- Feeling sad or empty
- Loss of interest or pleasure in daily activities
- Weight loss or gain
- Sleeping problems (sleeping a great deal or being unable to sleep that is not due to child's sleep problems)
- Frequent crying
- Fatigue or low energy
- Feeling worthless or guilty
- Inability to concentrate, think, or make decisions
- Low sex drive
- Feeling isolated from others
- Digestive problems
- Restlessness
- Loss of interest in interaction with others
- Loss of appetite or eating too much
- Slowed speech and physical movement
- Drop in school or work performance
- Drug or alcohol abuse
- Thoughts about death or suicide

Section 4: Depressive Episodes

***29. Was this first experience of depressive illness also the worst experience of depressive illness that you have had?**

- No
- Yes

Section 4: Depressive Episodes

***30. Think of your worst experience of depressive illness. How old were you when this occurred? Please enter a number such a "35"**

Section 4: Depressive Episodes
Click on NEXT to continue.

31. Was there something going on in your life shortly before this worst experience of depressive illness that you believe contributed to it? Check all that apply.

- Major job or school related stress
- Job loss
- Divorce or end of close relationship
- Marital or relationship difficulties
- Abusive relationship
- Death of a loved one
- Violent crime (rape, mugging, carjacking, etc.)
- Illness or injury involving a loved one
- Illness or injury involving yourself
- Financial crisis
- Pregnancy

Other (please specify)

Section 4: Depressive Episodes

***32. Which of the following best describes your functioning during this worst period of depressive illness?**

- I was so ill that I needed to spend time in an inpatient clinic or hospital.
- I was barely able to function, but was not hospitalized.
- I was somewhat able to function.
- I functioned fairly well.

Section 4: Depressive Episodes
Click on NEXT to continue.

33. What type of symptoms did you experience during this worst depressive illness?*Check all that apply.**

- Feeling sad or empty
- Loss of interest or pleasure in daily activities
- Weight loss or gain
- Sleeping problems (sleeping a great deal or being unable to sleep that is not due to child's sleep problems)
- Frequent crying
- Fatigue or low energy
- Feeling worthless or guilty
- Inability to concentrate, think, or make decisions
- Low sex drive
- Feeling isolated from others
- Digestive problems
- Restlessness
- Loss of interest in interaction with others
- Loss of appetite or eating too much
- Slowed speech and physical movement
- Drop in school or work performance
- Drug or alcohol abuse
- Thoughts about death or suicide

Other (please specify)

Section 4: Hospitalization and Self-Harm
Click on NEXT to continue.***34. Did you experience a depressive illness before having any children?**

- No
- Yes
- Not applicable - I have never experienced a depressive illness.

***35. Have you ever been hospitalized due to depressive illness?**

- No
- Yes
- Not applicable - I have never experienced a depressive illness.

***36. Have you ever thought about hurting yourself?**

No

Yes

***37. Have you ever attempted to hurt yourself?**

No

Yes

Section 5: History of Manic Illness

***38. Some people have periods lasting several days or longer when they feel much more excited and full of energy than usual. Their minds go too fast. They talk a lot. They are very restless or unable to sit still and they sometimes do things that are unusual for them, such as driving too fast or spending too much money. Have you ever had a period like this lasting several days or longer?**

No

Yes

Section 5: History of Manic Illness

***39. When you first experienced a period of elevated mood, decreased need for sleep, racing thoughts, and intense bursts of activity...How old were you? Please enter a number such a "35"**

Section 5: History of Manic Illness

***40. Have you ever been diagnosed by a medical or mental health professional with manic depression, bipolar disorder, or cyclothymia?**

No

Yes

Section 5: History of Manic Illness

***41. When you were first diagnosed by a medical or mental health professional with manic depression, bipolar disorder, or cyclothymia...How old were you? Please enter a number such a "35"**

Section 5: History of Manic Illness

Click on NEXT to continue.

***42. What type of professional first diagnosed you with manic depression, bipolar disorder, or cyclothymia?**

- Physician other than a psychiatrist (family doctor, Internist, etc.)
- Psychiatrist
- Psychologist
- Other Therapist or Counselor

Other (please specify)

***43. Which of the following diagnoses have you received from a medical or mental health professional? Check all that apply.**

- Bipolar Disorder (also known as manic depression)
- Cyclothymic Disorder

Other (please specify)

***44. Have you ever been hospitalized due to manic depression, bipolar disorder, or cyclothymia?**

- No
- Yes

Section 6: Family History

***45. Has anyone in your immediate or extended biological family ever been diagnosed with or treated for a depressive illness, such as Major Depressive Disorder, Dysthymic Disorder, Postpartum Depression, Premenstrual Dysphoric Disorder, or Seasonal Affective Disorder (SAD)?**

- No
- Yes

Section 6: Family History
Click on NEXT to continue.

***46. Which of your biological relatives have been diagnosed with or treated for a depressive illness, such as Major Depressive Disorder, Dysthymic Disorder, Postpartum Depression, Premenstrual Dysphoric Disorder, or Seasonal Affective Disorder (SAD)? Check all that apply.**

- Mother
- Father
- Brother
- Sister
- Son
- Daughter
- Maternal grandmother (mother's mother)
- Maternal grandfather (mother's father)
- Maternal aunt (mother's sister)
- Maternal uncle (mother's brother)
- First cousin on your mother's side
- Paternal grandmother (father's mother)
- Paternal grandfather (father's father)
- Paternal aunt (father's sister)
- Paternal uncle (father's brother)
- First cousin on your father's side

Other (please specify)

Section 6: Family History

***47. Has anyone in your immediate or extended biological family ever been diagnosed with or treated for a manic illness, such as Bipolar Disorder (also known as Manic Depression)?**

- No
- Yes

Section 6: Family History

Click on **NEXT** to continue.

***48. Which of your biological relatives have been diagnosed with or treated for a manic illness, such as **Bipolar Disorder** (also known as **Manic Depression**)? Check all that apply.**

- Mother
- Father
- Brother
- Sister
- Son
- Daughter
- Maternal grandmother (mother's mother)
- Maternal grandfather (mother's father)
- Maternal aunt (mother's sister)
- Maternal uncle (mother's brother)
- First cousin on your mother's side
- Paternal grandmother (father's mother)
- Paternal grandfather (father's father)
- Paternal aunt (father's sister)
- Paternal uncle (father's brother)
- First cousin on your father's side

Other (please specify)

Section 6: Family History

***49. Has anyone in your immediate or extended biological family ever attempted or committed suicide?**

- No
- Yes

Section 6: Family History
Click on **NEXT** to continue.

*** 50. Which of your biological relatives have attempted or committed suicide? Check all that apply.**

- Mother
- Father
- Brother
- Sister
- Son
- Daughter
- Maternal grandmother (mother's mother)
- Maternal grandfather (mother's father)
- Maternal aunt (mother's sister)
- Maternal uncle (mother's brother)
- First cousin on your mother's side
- Paternal grandmother (father's mother)
- Paternal grandfather (father's father)
- Paternal aunt (father's sister)
- Paternal uncle (father's brother)
- First cousin on your father's side

Other (please specify)

Appendix C

Interview Questions

1. Tell me general information about yourself
2. Tell me about your child with ASD
3. When did you first learned about your depression and how did you become aware of it.
4. Tell me when you were diagnosed with depression and when you first learned your child had autism.
5. Tell me what a typical day is like.
 - a. What do you do for pleasure, leisure and relaxation?
 - b. What kind of work do you do at home and outside the home?
 - c. What other kind of other activities and tasks do you do inside and outside of your home?
 - d. What percentages of time do you devote to work, daily life, and leisure activities?
6. What kind of activities do you engage in for pleasure if any?
7. What factors or life events bring you joy and satisfaction?
8. Describe something that is easy for to do in your daily life and why.
9. Describe something that is difficult to do in your daily life and why.
10. What was your experience of having a child with ASD?
11. What was your experience after you got your depression diagnoses?
12. What was your experience of having a child with ASD and coping with depression at the same time?
13. Was there any changes in your occupational engagement after you had your child with ASD and if so in what ways.
14. What kind of support do you have to help in managing daily life responsibilities?
15. What kind of support do you wish you have but don't have?
16. Describe how having a child with ASD affects your daily life, leisure, and work activities
17. Describe how having depression affects your daily life, work, and leisure activities.
18. What factors or life events have contributed to your depression?
19. Can you describe any particular difficult or traumatic experience in your life?
20. What did you actually do when you felt depressed or down-How did your body react?
21. What activities or things you do ease your depression?
22. Tell me about your eating patterns.
23. Tell me about your sleeping pattern.
24. What age was your child when your depression was the most difficult for you?
25. What age was your child when the depression lifted or was easiest for you?
26. To what extent do you consider yourself active in your role as a mother of a child with ASD and your role as a mother to your other children?
27. What are your main responsibilities of caring for your child/children?
28. How do you see yourself today, in term of your leisure occupations?
29. What things can you observe about yourself that are different when you child diagnosed with ASD?
30. What kinds of decision do you make in regards to taking care of your child and yourself?
31. What, if any would you change about yourself if you could?

Appendix D

Quantitative Flyer

Dear Mothers,

I am looking for mothers whose children are between the ages of 3 and 17.99 years and who typically-developing to assist me with some important research about autism and family history of depression and bipolar disorder. By typically-developing I mean children who do not have autism, a developmental disability, or a chronic physical or mental health challenges. Participation involves completion of 10-15 minute online survey. **Mothers who complete the survey will have a chance to win a \$50 Amazon gift card.**

In a previous study conducted at Kennedy Krieger Institute, mothers of children with autism spectrum disorders (ASD) completed a similar survey. The results indicated that some of the mothers were coping with depression and their families had a history of bipolar mood disorders. It may be that there is a link between autism and a family history of bipolar mood disorders and depression. In other words, autism and mood disorders may be genetically linked.

To better understand if there is a possible link, results from the survey completed by mothers with children with ASD need to be compared with those of mothers of typically-developing children. Unfortunately, there is no available information that compares the experiences of these two groups of mothers. That is why I am seeking mothers of typically-developing children to complete a survey. I want to learn whether depression and bipolar mood disorders occur at the same frequency for both groups of mothers or occur more frequency for mothers of children with ASD. The survey is anonymous so I will be able to see your answers but I will not know your identity. Participation is voluntary. Answer only those questions you are comfortable completing.

I am a Towson University graduate student in the Occupational Science Doctoral program. I am conducting this study under the supervision of my doctoral committee. I would be grateful for your valuable input and participation. Please contact me if you have any questions. To begin the survey, click on the link below:

<https://www.surveymonkey.com/s/9DBB32S>

Best Regards.

If you have any questions about the study, you can contact:

Haifa Batarseh hatar1@students.towson.edu

Dr. Janet V. DeLany DEd
Dean, Office of Graduate Studies
Towson University, 8000 York Road
Towson, MD 21252
410-704-2078

jdelany@towson.edu

Dr. Debi Gartland, Chairperson of the Institutional Review Board for the Protection of Human Participants at Towson University. Phone: 410-704-2236, or email: ours@towson.edu.

Appendix E
Qualitative Flyer

Dear Mothers,

I am looking for mothers of school-aged children with autism spectrum disorder (ASD) to assist me with some important research about autism and depression/bipolar disorders. Those mothers are self-identified as having depression, currently taking medication for depression, and having an elementary or teen-age boy or girl with ASD. The purpose is to understand the daily life experiences of mothers who have a child with ASD and who are coping with depression. Such information should contribute to knowledge base about the relationship between maternal depression/mood disorders and parenting a child with ASD.

Though studies have been conducted to explore the daily life experiences of either mothers with depression or mothers of children with ASD, little is known about the daily life experience of mothers who are depressed and who have a child with ASD at the same time. That is why I am seeking mothers of children with ASD who are currently taking medication for depression/bipolar to participate on a face-to-face interview.

Participation in this study includes responding to some questions about your daily life experiences. Your participation is voluntary and you can choose which questions you want to answer. Your decision to participate, decline, or withdraw is completely voluntary. There are no known risks involved in participating in this project. You may choose to answer only those questions you are comfortable answering. To protect your privacy, a substitute rather than your real name will be used. At no time will your name or personal identification be revealed. Your answers to all questions will remain private and confidential. **Mothers who complete the interview will get a \$25 Amazon gift card.**

I am a Towson University graduate student in the Occupational Science Doctoral program. I am conducting this study under the supervision of my doctoral committee. I would be grateful for your valuable input and participation.

THIS RESEARCH STUDY HAS BEEN REVIEWED BY THE INSTITUTIONAL REVIEW BOARD FOR THE PROTECTION OF HUMAN PARTICIPANTS AT TOWSON UNIVERSITY.

Thank you in advance for your time and assistance. Looking forward working with you in the near future.

If you have any questions about the study, you can contact:

Haifa Batarseh: hbatar1@students.towson.edu

Dr. Janet V. DeLany DED
Dean, Office of Graduate Studies

Towson University, 8000 York Road
Towson, MD 21252
410-704-2078
jdelany@towson.edu

Or Dr. Debi Gartland, Chairperson of the Institutional Review Board for the Protection of Human Participants at Towson University. Phone: 410-704-2236,

Appendix F John Hopkins IRB



Office of Human Subjects Research
Institutional Review Boards

1620 McElderry Street, Reed Hall, Suite B-130
Baltimore, Maryland 21205-1911
410-955-3008
410-955-4367 Fax
e-mail: jhmirb@jhmi.edu

Date: February 28, 2013

CONTINUING REVIEW APPROVAL

Review Type: Expedited
PI Name: Paul Law
Study #: NA_00002750
Study Name: Interactive Autism Network Research Database
Committee Chair: Susan Bassett
Committee: JHM-IRB X

Date of review: February 28, 2013

Date of approval: February 28, 2013

Date of expiration: February 27, 2014

The JHM IRB approved the above-referenced Continuing Review.

Active enrollment.

IRB review included the following:

Use of an oral consent process.

45CFR46.404 and/or 21 CFR 50.51: This study has been approved for the inclusion of children as 'research not involving greater than minimal risk'. The permission of one parent is required.

Date of Approval and Expiration Date: The approval and expiration date for this research are listed above. If the approval lapses, the research must stop and you must submit a request to the IRB to determine whether it is in the best interests of individual participants to continue with treatment interventions.

Changes in Research: All proposed changes to the research must be submitted using an eIRB Change in Research application. The changes must be approved by the JHM IRB prior to implementation, with the following exception: changes made to eliminate apparent immediate hazards to participants may be made immediately, and promptly reported to the JHM IRB.

Continuing Review: Continuing Review Applications should be submitted at least 6 weeks prior to the study expiration date. Failure to allow sufficient time for review may result in a lapse of approval. If the Continuing Review Application is not submitted prior to the expiration date, your study will be terminated and a New Application must be submitted to reinstate the research.

Unanticipated Problems: You must inform the IRB of any unanticipated problems involving risks to participants or others.

If this research has a commercial sponsor, the research may not start until the sponsor and JHU have signed a contract.

The Johns Hopkins Institutions operates under multiple Federal-Wide Assurances: The Johns Hopkins University School of Medicine - FWA00005752, The Johns Hopkins University School of Nursing - FWA00006088, The Johns Hopkins Hospital and Johns Hopkins Health Systems - FWA00006087, Johns Hopkins Bayview Medical Center - FWA00006089, Howard County General Hospital - FWA00005743, Hugo W. Moser Research Institute at Kennedy Krieger, Inc. - FWA00005719, Johns Hopkins Community Physicians - FWA00002251, Suburban Hospital and Health System - FWA00005924

Appendix G
Towson University IRB



Date: Thursday, February 28, 2013

NOTICE OF APPROVAL

TO: Haifa Batarseh **DEPT:** OCTH

PROJECT TITLE: *A Mixed Methods Study of Mood Disorders in Mothers of Children With Autism Spectrum Disorder and Mothers of Typically Developing Children.*

SPONSORING AGENCY:

APPROVAL NUMBER: 13-A046

The Institutional Review Board for the Protection of Human Participants has approved the project described above. Approval was based on the descriptive material and procedures you submitted for review. Should any changes be made in your procedures, or if you should encounter any new risks, reactions, injuries, or deaths of persons as participants, you must notify the Board.

A consent form: is is not required of each participant

Assent: is is not required of each participant

This protocol was first approved on: 28-Feb-2013

This research will be reviewed every year from the date of first approval.

Patricia Alt, Member

Towson University Institutional Review Board

Appendix H
Quantitative Informed Consent

Informed Consent Form

Dear Participant,

I am a graduate student at Towson University and am conducting a study that compares the frequency of depression and other mood disorders in families with a child with an autism spectrum disorder (ASD) and in families where all children are typically developing. I am asking you as a mother whose biological children are typically-developing to complete the Maternal Depression History Questionnaire. For the purpose of this study, a “TD child” is one who is between the ages of 3 and 17.99 years, and does not have autism, a developmental disability or a chronic physical or mental health challenge.

In a previous study conducted at Kennedy Krieger Institute, mothers of children with ASD completed a similar Depression History Questionnaire. To better understand if there is a possible genetic link between ASD and a family history of depression and mood disorders, results from the questionnaire completed by these mothers need to be compared with those of mothers of typically-developing children. Unfortunately, there is no available information that compares the experiences of these two groups of mothers. That is why I am seeking mothers of TD children to complete the same survey. I want to learn whether mood disorders occur at the same frequency in both groups of mothers or occur more frequently in mothers of children with ASD.

The Maternal Depression History Questionnaire is an online survey asking questions about any history of mood disorder you or members of your extended family may have had. Participation will take 10-15 minutes of your time. The survey is anonymous so I will be able to see your answers but I will not know your identity. Your participation is voluntary. You do not have to complete any question that you do not feel comfortable completing. Mothers who complete the survey will have a chance to win a \$50 Amazon gift card.

There are no risks involved in participating in this project. At no time will your name be revealed. All data will be reported in aggregate form.

I am a Towson University graduate student in the Occupational Science Doctoral program. I am conducting this study under the supervision of my doctoral committee. I would be grateful for your valuable input and participation. If you have any questions about this project, please contact me, Haifa Batarseh at 516-551-4597. You also may contact Dr. Janet DeLany, the Chair of my doctoral committee at 410-704-2078. Or Dr. Debi Gartland, Chairperson of the Institutional Review Board for the Protection of Human Participants at Towson University. Phone: 410-704-2236, or email: ours@towson.edu

THIS PROJECT HAS BEEN REVIEWED BY THE INSTITUTIONAL REVIEW BOARD FOR THE PROTECTION OF HUMAN PARTICIPANTS AT TOWSON UNIVERSITY.

To begin the survey, please respond to the following question:

- Yes, I affirm that I have read and understood the above statement and have had all of my questions answered. I also affirm that I am 18 years or older and am participating in this research voluntarily. I am the mother of a child/children between the ages of 3 and 17.99 years. My child/children are typically-developing and do not have autism, another developmental disability, or a chronic physical or mental health challenge.
- No, I choose not to participate.

Appendix I
Qualitative Informed Consent

Informed Consent Form

To Participant,

I am asking you as a mother of a child with autism spectrum disorder (ASD) who is currently taking medication for depression/bipolar to participate in a study about your experience of coping with depression and raising a child with ASD. Those mothers are self-identified as having depression, currently taking medication for depression, and having an elementary or teen-age boy or girl with ASD. The purpose is to understand how being a mother with a child with ASD and coping with depression influences your daily life activities. Specifically, I am seeking four mothers with a boy or a girl with ASD to participate in the study

Though studies have been conducted to explore the daily life activities of either mothers with depression or mothers of children with ASD, little is known about the daily life experiences of depressed mothers who have a child with ASD at the same time

Participation in this study includes responding to some questions about how you cope with your daily life. The interviews will be conducted face-to-face format at a convenient place for you. The interview will be audiotape, then later transcribed. Your participation is voluntary. You can choose which questions you want to answer. Your decision to participate, decline, or withdraw is completely voluntary. The interview will take between 1 ½ -to- 2 hours of your time. A pseudonyms (alternative name) rather than your real name will be used to protect your confidentiality. No personal identification will be revealed in any report. At no time will your name be revealed. Please be reminded that your answers to all questions will remain private and confidential. **Mothers who complete the interview will get a \$25 Amazon gift card.**

There are no known risks involved in participating in this project. You may choose to answer only those questions you are comfortable answering. At any point during the interview, you may stop your participation. In addition, I will provide a list of counselors from the community who are specialized in families with ASD if you want to seek counseling support.

I am a Towson University graduate student in the Occupational Science Doctoral program. I am conducting this study under the supervision of my doctoral committee. I would be grateful for your valuable input and participation. If you have any questions about this project, please contact me, Haifa Batarseh at 516-551-4597. You also may contact Dr Janet DeLany, the Chair of my doctoral committee at 410-704-2078. Or Dr. Debi Gartland, Chairperson of the Institutional Review Board for the Protection of Human Participants at Towson University. Phone: 410-704-2236, or email: ours@towson.edu.

THIS RESEARCH STUDY HAS BEEN REVIEWED BY THE INSTITUTIONAL REVIEW BOARD FOR THE PROTECTION OF HUMAN PARTICIPANTS AT TOWSON UNIVERSITY.

Please indicate your decision regarding whether you would like to participate in this study. Check and sign the statement below. Thank you in advance for your cooperation and support.

Best wishes,

_____ I understand the description and purpose of this study and I
_____ would like to participate in it.

Participant Signature _____ Date_____

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CURRICULUM VITAE

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➤ **CRENENTIALS EDUCATION**

Towson University, Towson, Maryland, Doctor of Science in Occupational Therapy / Occupational Science (2009-Present)

New York University, New York, New York. Post-Professional Master's in Occupational Therapy (2008-2009)

The Hashemite University, Zarqa, Jordan. Bachelor of Science Degree in Occupational Therapy (2003)

Occupational Therapy College, Amman, Jordan. Three Years Diploma in Occupational Therapy (1995)

CERTIFICATIONS

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“USC/WPS Sensory Integration Certification # 2981”

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➤ **WORK EXPERINCE**

Additional assistant (Jan 2012-June 2012 and Sept 2014-June 2015), West Towson Elementary School, Towson, United States of America.

Instructor (2003-2008), Department of Occupational Therapy, Faculty of Allied Health Sciences, the Hashemite University, Zarqa, Jordan

Teaching the following courses:

Introduction to Occupational Therapy

Occupational Therapy Media 1

Occupational Therapy Media 2

Occupational Therapy Studies 2

Splinting in Occupational Therapy

Occupational Therapy for Developmental Disabilities

Occupational Therapy for Physical Dysfunction

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Staff Occupational Therapist (1996-2003), Al-Hussein Society for Habilitation and Rehabilitation of Physically Challenged Children, Amman, Jordan.

➤ **PROFESSIONAL MEMBERSHIPS**

World Federation of Occupational Therapy.
Administrative member in Jordanian Society of Occupational Therapy (2007-2008)
Jordanian Society of Occupational Therapy

➤ **COURSES and WORKSHOPS:**

“Making Learning Sensational” (one day workshop). Rondalyn Whitney. Kennedy Krieger Institute. Maryland, USA. July 20, 2011.

“Wheelchair Seating and Positioning for Function.” Eleanor’s Project. (Two days workshop). Tamara Kittelson. The Hashemite University, Zarqa, Jordan. August 11-12, 2008.

“Mobility and Orientation for Persons with Visual Disabilities Workshop.” (Eighteen days workshop). Shaden Oliwat. The Higher Council for the Affairs of Persons with Disabilities, Amman, Jordan. 11-29 May, 2008.

“Sensory Integration Intervention.” (Five days workshop). Stefanie Bodison. Amman, Jordan. July 7 – 11, 2008.

“From Interpretation to Intervention.” (Five days workshop). Suzan Knox. Amman, Jordan. March 28 – April 1, 2008.

“Specialized Techniques for Measuring Sensory Integration.” (Five days workshop). Shay McAtee. Amman, Jordan. November 6-11, 2007.

“The Sensory Integration Perspective.” (Five days workshop). Suzan Knox. Amman, Jordan. May 11-15, 2007.

“The First Jordanian Italian Congress for Orthotic and Prosthetics.” (Two days workshop). Amman, Jordan. June 27-28, 2007.

“Special Topics in Wheelchair Seating for Children.” Eleanor’s Project. (Full day workshop). Tamara Kittelson. Amman, Jordan. June 24, 2007.

“Introduction to Model of Human Occupation in the Physical Disability Setting.” (Full day workshop), Farazanh Yazdani. Amman, Jordan. December 9, 2006.

- “Specialized Wheelchair Seating and Positioning.” Eleanor’s Project. (Full day workshop). Tamara Kittelson. Amman, Jordan. September 9, 2006.
- “Vision Rehabilitation Workshop.” (Two days workshop), Lea Hyvarinen. Amman, Jordan. November 24-25, 2006.
- “Statistical Package for Social Sciences SPSS.” (Two weeks course). The Hashemite University, Zarqa, Jordan. June 25 – July 4, 2006.
- “Technology of Teaching and Evaluation Course.” (Five days course). The Hashemite University, Zarqa, Jordan. September 28 – October 2, 2003.
- “Healthy Environment for Children.” (One day lectures). Jordan University of Science and Technology, Irbid, Jordan. July 25, 2003.
- “A Rational Approach to Dynamic Hand Splinting.” (Full day workshop). Paul Vanlede. Amman, Jordan. July 29, 2003.
- “International Computer Driving License Course.” The Hashemite University, Zarqa, Jordan. January 11 –February 23, 2004.
- “Bobath Neurodevelopment Therapy.” (Eight weeks of post-graduate course). Stephanie Kemp, Amman, Jordan. June 30 - August 22, 2002.
- “A Rational Approach to Hand Splinting.” (Full day workshop). Paul Vanlede, Amman, Jordan. May 3, 2001.
- “Palestinian–Israel–Jordanian Workshop in Rehabilitation.” (Four days workshop). Ghazi Hanania, Dan Shanit, Michael Heim. Ramallah, Palestine. July 4-7, 1999.
- “Rehabilitation for Neurological Disorder.” (Three days workshop). Amman, Jordan. April 25-27, 1999.
- “Supervisor management / Data Structure.” (Three weeks workshop). Amman, Jordan. August 29 – September 23, 1998.
- “Normal and Abnormal Development.”(Five days workshop). Amman, Jordan. August 16 – 20, 1998.
- Bobath Neurodevelopment Techniques.” (one week workshop). Archie Hinchcliff, Amman, Jordan. October 2 – 8, 1997.

➤ **Languages:**

- Arabic: Mother language
- English: Fluent

