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Hope and Worry among Mothers of Children with
an Autism Spectrum Disorder or Down Syndrome

A thesis submitted in partial fulfillment of the requirements for the degree of Master of
Science at Virginia Commonwealth University

by

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Abstract

HOPE AND WORRY AMONG MOTHERS OF CHILDREN WITH
AN AUTISM SPECTRUM DISORDER OR DOWN SYNDROME

By Paula L. Ogston, BA

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Science
at Virginia Commonwealth University

Virginia Commonwealth University, 2010

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The present study used quantitative and qualitative methodology to examine mothers' hope and worry. Participants were recruited via autism and Down syndrome organizations. Two hundred fifty-nine mothers of children with autism spectrum disorders ($n = 199$) and Down syndrome ($n = 60$) responded to the online questionnaire. Most mothers were white ($n = 230$); eighty-seven percent were married and their average age was 39.06 years. Findings support previous research suggesting that hope is a protective factor against psychological distress: mothers with higher hope reported lower dispositional worry. Mothers were asked to describe what they worried about when they woke up at night; a thematic analysis of their responses resulted in identification of a number of self-focused and child and family-focused concerns. Results suggest that maternal level of education as well as child's age, diagnosis and severity of impairment may impact mother's level of hope and worry.

Introduction

Raising any child presents parents with undeniable challenges, but mothers and fathers of children with developmental disabilities—such as autism spectrum disorders (ASD) and Down syndrome—face additional obstacles and stressors. Parents of children with autism experience greater risks to their health and psychosocial adjustment than parents of typically developing children (Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005; Bebko, Konstantareas, & Springer, 1987; Dale, Jahoda, & Knott, 2007; Duarte, Bordin, Yazigi, & Mooney, 2005), and report heightened levels of stress (Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005; Hastings et al., 2005; Weiss, 2002). These parents are at increased risk for depression (Kuhn & Carter, 2006; Olsson & Hwang, 2001) when compared to parents of typically developing children.

Individuals with an autism spectrum disorder display three core characteristics: qualitative impairments in social interaction, deficits in communication, and repetitive and stereotyped patterns of behavior (American Psychiatric Association, 2000). These impairments can range from mild to severe and may manifest through a variety of symptoms. While not required to receive a diagnosis, many individuals on the autism spectrum have cognitive impairments that place them below the cutoff for intellectual disability.

There is no clearly defined prognosis for children with autism. Professionals are currently unable to predict whether a child will show mild, moderate, or severe impairment at adulthood. This uncertainty is stressful for parents. It makes planning for their child's future – as well as their own—more of a challenge (Weiss, 2002). As a result, parents may have unrealistic expectations for their child's outcome as an adult, either overly optimistic or unnecessarily hopeless. Parents of children with autism are at risk for detriments to their own mental health and functioning, including decreased feelings of competence in the parenting role

and lower levels of marital satisfaction (Baker-Ericzén et al., 2005). It is not uncommon for these parents to feel pessimistic when thinking about the long-term prospects for their children, and families with a child with autism describe decreased adaptability in new situations in comparison with families whose child has Down syndrome (Ergüner-Tekinalp & Akkök, 2004; Rodrigue, Morgan, & Geffken, 1990).

Down syndrome is the most common genetic disorder. It is easily diagnosed, at birth or prenatally (Lamb et al., 1997). Impairments in communication and memory are common in individuals with Down syndrome, with relative strengths in receptive language and the social aspects of language and weaknesses in expressive language and grammatical structure (Laws, Byrne, & Buckley, 2000). Social development is generally a strength in individuals with Down syndrome, especially in comparison to the social impairments associated with the autism spectrum disorder (Davis, 2008). Children with Down syndrome frequently experience motor coordination difficulties and neurocognitive deficits. However, they are less likely to display severe problem behavior in comparison with those with other genetic disorders or intellectual disabilities (Davis, 2008).

Parents of children with developmental disabilities report more stress than those of typically developing children. Across developmental disabilities, parents of children diagnosed with autism experience higher levels of stress than parents of children with Down syndrome and intellectual disabilities (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Hastings et al., 2005). There are several explanations for this discrepancy. Individuals on the autism spectrum comprise a heterogeneous group, which creates challenges for parents, professionals, and researchers. Prior to diagnosis, doctors sometimes seem unresponsive to parents' concerns regarding the development of their children (Dale, Jahoda, & Knott, 2007). Children sometimes

receive a different diagnosis depending on the clinician (Dale et al., 2007) and it can take months or years to obtain a stable diagnosis (Goin-Kochel & Myers, 2005). This is very different from a disorder like Down syndrome, which is typically identifiable at birth and can be easily diagnosed through genetics testing. An additional challenge is that the diversity of symptoms displayed by those on the autism spectrum precludes a standardized treatment plan (Dale et al., 2007). Parents of children with autism and other disabilities have the responsibility of utilizing services and obtaining appropriate treatment for their child, yet are sometimes unsure of the exact type and quantity of therapy that would be most beneficial to their child. This uncertainty can result in significant stress and guilt for the parents, as they might worry that they are not advocating effectively for their child (Weiss, 2002).

Parents who experience a high degree of stress or depression may be less able to involve themselves in their child's therapies (Kuhn & Carter, 2006) and may experience greater difficulty advocating for their children to obtain treatment and services. In addition to serving as a barrier in terms of advocacy, parenting stress can have a negative impact on interventions that have already been acquired (Baker-Ericzén et al., 2005; Kuhn & Carter, 2006). This stress or the presence of specific stressors may lessen the effectiveness of intervention strategies in which they are involved with their child (Kuhn & Carter, 2006; Osborne, McHugh, Saunders, & Reed, 2008).

Autism spectrum disorders are pervasive and impact a child's developmental trajectory in a variety of ways, and there is much research that describes how parents and families are impacted by the disorder. However, there are very few studies that have examined either hope or worry in parents of children with ASD's, and no published studies have examined the relationship between hope and worry in this population. Parents of children with autism and

other disabilities must maintain their child's intervention schedules as well as determine a way to finance their child's care (Baker-Ericzén et al., 2005). This requires considerable motivation on the part of the parents, as well as the ability to actually get their child's needs met, both of which comprise the core components of hope (Horton & Wallander, 2001; Snyder et al., 1991). Along those lines, tending to these parenting responsibilities demands a great deal of time and energy, which may contribute to worrisome thought. For parents of children with autism, excessive worry may be an obstacle to responding to their children's core needs. Therefore, it is important to further understand the experience of hope and worry in mothers of children with autism spectrum disorders.

Literature Review

Hope

Hope theory is based on the idea that people are goal-oriented. Defined as the perceptions of both agency and pathways, hope is one's belief in the ability to accomplish future goals. According to the widely accepted theory developed by Snyder (2002), hope is described in terms of cognitive processes, though emotions are recognized as playing an important role (Snyder, 2002). Higher hope is associated with a variety of positive psychosocial and health outcomes, including adaptive coping, and lower levels of depression and anxiety (Snyder, 2000; Snyder, 2002).

Hope rests on the importance and inherent need for goal-setting. Goals are seen as the impetus for actions as well as the object of a person's ambition or effort. Goals must have sufficient value to precipitate their pursuit and should be attainable yet challenging. Goals can be short or long term and may vary in their degree of specificity (Snyder, 2002). Hope theory

recognizes the variety among goal characteristics and does not prescribe greater value to goals that are realistic versus lofty.

A core component of hope is *agency*, or motivation. Agency has a cognitive component and is dependant on the perceived ability to accomplish a goal (Snyder, 2002). The perception of future events influences motivation and serves to regulate behavior and cognitions (Bandura, 1989). Agency incorporates the initiation of action—getting started—as well as the ability to follow through in reaching a desired goal.

The *pathways* component of hope has to do with finding ways of meeting goals. Pathways-thinking is a cognitive process that is based on the generation of one or more possible ways of reaching a desired goal (Snyder, 2002). When faced with a setback en route to achieving goals, an individual may need to come up with alternative pathways. Pathways are most effective when they are concrete, manageable, and appropriate to the goal context (Snyder et al., 2000).

Individuals with high hope possess both high agency—the motivation and belief in the ability to reach goals—and the ability to develop pathways that will help in attaining the goal. Agency and pathways work together in an additive way. Positive changes in an individual’s efficacy in one area will likely be followed by positive changes in the other area (Snyder et al., 2000). Individuals with high hope tend not to avoid or distance themselves from challenges. Instead, they may see that they stand to gain from reaching a goal that was blocked by great obstacles and are likely to learn and benefit from what is experienced during the goal pursuit. On the other hand, those with low hope who encounter obstacles while in pursuit of a goal often engage in negative thinking and are unlikely to learn from the experience (Snyder, 2002). When compared to those with low hope, individuals with high hope are more flexible in coming up

with different ways of reaching a goal, especially in situations where obstacles are present (Snyder, 2002). High hope is also associated with being able to generate a greater number of goals.

The current study utilizes a widely accepted cognitive model of hope that does not place particular emphasis on the role of emotion. Rather, emotions are viewed as a consequence of factors related to hope. For example, whether or not individuals reach their goals—as well as how easy or enjoyable they feel the path to be—will impact subsequent feelings (Snyder, 2002). Hope is associated with one's overall experience of emotions, and while emotions may vary across situations, they are reflective of one's dispositional hope (Snyder, 1995). Hope theory describes this relationship as more unidirectional rather than bidirectional, where hope impacts emotions.

The groundwork for an individual's hope—or goal-directed thinking—is laid over the course of development (Ong & van Dulmen, 2007). Beginning in childhood, individuals begin to develop a cognitive framework for the motivation and energy with which they pursue their goals (Snyder, 2002). The same is true for pathways thinking: the ability—and perception of one's ability—to generate ways of reaching goals is shaped from a young age. Research has shown that adults with high versus low hope are more apt to have had close bonds to their parents during childhood and are more likely to develop strong attachments as adults (Shorey, Snyder, Yang, & Lewin, 2003; Snyder, Cheavens, & Sympson, 1997). A greater understanding of how hope develops is important, due to the implications that agentic and pathways thinking both have for functioning across the lifespan.

Goal-directed thought follows a sequence, where individuals approach goals using pathways and agentic thinking (Snyder, 2002). This progression occurs alongside trait-like emotions and moods, which set a tone for how a given goal will be approached. This emotional

valence is built upon the experience and perceptions of one's prior goal-related efforts. Before deciding on a goal, one assesses whether or not its potential outcome is valuable enough to pursue. Individuals frequently continue to reassess the goal's potential outcome value throughout the goal pursuit process, to ensure that the effort being put forth is still warranted. Subsequent emotions regarding the effort that has been invested, as well as the outcome of the present pursuit, may affect perception of the value of obtaining the goal. As a person begins working towards a goal, feelings that are experienced can affect hope-related thoughts (Snyder, 2002). Similarly, whether or not a goal-pursuit is perceived as going well will influence subsequent behaviors and emotions.

Those with high hope tend to enjoy pursuing their goals and typically remain focused when doing so. This is in contrast to those with low hope, who tend to be unsure of themselves and are easily distracted from tasks by negative self-talk (Snyder, 2002). Those with low hope are easily deterred by obstacles and have difficulty thinking of alternative pathways. Being confronted with a barrier may affect hopeful thinking, given that obstacles are interpreted differently depending on one's preexisting hope. A goal pursuit can be successful or unsuccessful, and the emotions that occur during goal pursuit will be incorporated to one's hope related thinking on both a specific and general level (Snyder, 2002).

While hope is related to optimism and self-efficacy, these constructs do not share complete overlap (Magaletta & Oliver, 1999). Optimism theory focuses on general outcome expectancies, in which people attempt to reach desirable goals and stay away from negative goals or outcomes (Scheier & Carver, 1985). Conceptually, optimism is similar to hope's agency component. Self-efficacy is defined as the beliefs about one's capability to achieve a given task (Bandura, 1977). Self-efficacy is described in relation to a specific situation (e.g.,

mathematics, basketball), while hope is stable over time and across contexts and applies to both general and specific goals. Hope, optimism, and high self-efficacy are all indicative of a positive outlook on life, contributing towards overall adjustment (Horton & Wallander, 2001; Magaletta & Oliver, 1999). These constructs are correlated but are distinct constructs (Snyder, 2002).

There is a concept of “false hope” that has been addressed within the literature. False hope is associated with unrealistic expectations for either a goal itself or for the pathway developed to reach the goal (Kwon, 2002). An individual may respond to standardized measures of hope (e.g., The Hope Scale; Snyder et al., 1991) with perceptions or expectations that are not based on reality (Kwon, 2002). For example, a person might show unrealistically high hopes about winning the lottery or becoming a rock star. False hope may rely on illusions regarding past and future events. An individual may interpret past ineffective behavior as being effective and thus repeat the behavior in an attempt to reach a goal. As described in Kwon (2000), Breznitz (1983) found that this might relate to the tendency of those with false hope to deny the existence of obstacles, which leaves them unprepared for challenges they encounter en route to a goal. Individuals with false hope expect to reach their goals, but often have neither the agency nor the pathways to bring their goals to fruition. In contrast, genuine hope is rooted in reality. That is, genuine hope is associated with the use of viable pathways and the pursuit of realistic goals.

Hope in parents of children with disabilities. Mothers of children with disabilities and chronic illnesses typically show higher levels of psychological distress than the general population. Nonetheless, there is variability, as some parents experience high distress and others experience very little. This suggests that having a child with special needs does not fully explain parents’ distress and dispositional factors likely play a role. A growing literature has examined

hope as a correlate of the psychological functioning of parents of children with special needs, and hope research has been conducted with parents of children with a range of disabilities and chronic illnesses. A recent study (Lloyd & Hastings, 2009) conducted with mothers of children with intellectual disability, including autism and Down syndrome, found hope to be a resilience factor for their psychological wellbeing. In another study, hope was found to be a protective factor against psychological distress in mothers of children with diabetes and that mothers with higher hope had lower levels of anxiety (Mednick et al., 2007). While autism and diabetes are very different disorders, they are both lifelong illnesses with no known cure. Therefore, these findings may inform similar research done with parents of children with autism.

A study conducted with parents of children with cerebral palsy, spina bifida, and type I diabetes examined the relationships among hope, distress, and social support (Horton & Wallander, 2001). A significant interaction was found between disability-related stress and hope. When stress was low, there were no differences in distress between the low and high-hope groups. However, mothers with high levels of both hope and disability-related stress reported lower levels of distress than mothers who had low hope and high disability-related stress. Hope and social support were both found to account for a significant and unique amount of the variance in maternal distress. In addition, the relationship between severity of disability and either maternal distress or hope was not significant (Horton & Wallander, 2001).

Given that individuals with ASD's sometimes display disruptive behavior, research conducted with parents of children with externalizing disorder—who also display challenging behavior but lack the social deficits characteristic of those with autism—may inform the autism literature. A study conducted with parents of children with externalizing disorders examined the relationship between hope and self-esteem, familial functioning, stress and coping (Kashdan et

al., 2002). For mothers, there was a positive relationship between hope and self-esteem, as well as hope, social adjustment, marital adjustment and family adjustment. Additionally, mothers' level of hope was positively correlated with family adjustment, as measured by the Family Environment Scale.

Worry

Worry is a cognitive process defined as “a chain of thoughts and images, negatively affect-laden and relatively uncontrollable; it represents a recurrent attempt to engage in mental problem-solving on an issue whose outcome is uncertain but contains the possibility of one or more negative outcomes; consequently, worry relates closely to the fear process.” (Borkovec, Robinson, Pruzinsky, & DePree, 1983). The most salient characteristic of worry is that it is an internal verbal-linguistic process. When people worry, their engagement in cognition heightens and their experience of imagery lessens (Davey & Tallis, 1994). More simply, worry involves negative thoughts.

Worry is generally described in relation to future-related anxiety or fear, as opposed to concern regarding past events (Borkovec et al., 1983; Davey & Tallis, 1994; Dugas et al., 2005). Most worries concern issues pertaining to oneself (Metzger, Miller, Cohen, & Sofka, 1990) and nearly everyone – even those who are well adjusted—engages in worry from time to time. Fortunately, worry can have potential adaptive benefits at non-pathological levels (Davey & Tallis, 1994). Engaging in moderate levels of worry may aid in problem solving (Borkovec et al., 1983) and has been found to be associated with preparation for action, decision-making, and adaptive levels of motivation (Floyd, Garfield, & LaSota, 2005). Those who engage in excessive worry sometimes view this as a form of adaptive coping (Francis & Dugas, 2004). However,

when excessive, worry becomes pathological and is more likely to be associated with feelings of anxiety (Davey & Tallis, 1994).

Researchers have conceptualized worry as a way to disengage from stressful experiences, leading to emotional avoidance (Fresco, Frankel, Mennin, Turk, & Heimberg, 2002). This may prevent individuals from developing adaptive coping mechanisms. Borkovec et al., (1983) suggest that worrying typically means that an individual is thinking about things in a superficial way, which serves as a distraction from more distressing topics. Worrying may also prevent people from thinking about stressful topics in a concrete and realistic way.

Worry creates a negative association regarding the topic of concern, and these feelings tend to be drawn out for an extended period (Girodo & Stein, 1978). Furthermore, worrying may influence how we interpret new situations and may decrease the odds that new experiences will have an influence or change one's perspectives. Excessive worry may serve as a way to avoid thinking about the reality of a stressful situation. This prevents the optimal processing of information to be gleaned from one's experiences (Borkovec, 1994; Fresco et al., 2002). The negative outcomes that are associated with worry may happen in part because of the time and energy spent worrying, which increases the chance that past or future events will be remembered or viewed in a distorted way. In situations where the worrisome topic is very stressful, worry may serve as a defense mechanism against the possible experience of trauma (Metzger et al., 1990).

Worry typically involves thoughts, as opposed to images, that lack specific details. This abstract quality may interfere with processing regarding the worrisome topic. Abstract images are more difficult to generate than abstract thoughts, which may also help to explain why worry involves more thoughts and less imagery (Borkovec, Ray, & Stöber, 1998; Stöber, 1998). The

abstract nature of worry may contribute to a reduction in fearful images that are necessary for more complete emotional processing. Similarly, problem solving that lacks concreteness yields the production of abstract–versus concrete–solutions or consequences that are unlikely to be effective. It is likely that the reduced concreteness associated with worrisome thoughts contributes to the maintenance of worry in the long term (Stöber, 1998).

Engagement in excessive worry is a core feature of anxiety and generalized anxiety disorder (GAD). Worry is most problematic and more likely to meet diagnostic requirements when it is excessive and perceived as being both uncontrollable and problematic (Ruscio, 2002). Not surprisingly–given the link between anxiety and depression – worry is also correlated with depression, as discussed in Borkovec (1994). High levels of worry are also found in individuals with simple phobias, panic disorders, social phobia, simple phobia, and obsessive-compulsive disorder (Davey, 1994). These findings speak to the relationship between excessive psychopathology and worry.

In an early study of worry, it was found that the amount of time one spends worrying each day is associated with a variety of fears and negative outcomes, including anxiety and depression (Borkovec et al., 1983). Fears that were social in nature were especially relevant (Borkovec et al., 1983). Worriers reported significantly more difficulty with worry cessation than non-worriers. When completing an attention task, worriers also had a greater incidence of intrusive worrisome thought (Borkovec et al., 1983). There is also some evidence that the fear of failure and evaluation are hallmark features of worry (Borkovec et al., 1983; Metzger et al., 1990).

Worry in parents of children with disabilities. Beginning in the 1980's, the scope of worry research—which had been narrowly focused on test anxiety—began to broaden.

Researchers began to explore the relationship of worry to a variety of health and psychological outcomes. A study of mothers of survivors of childhood cancer examined mothers' worries regarding cancer-specific issues, their child's psychosocial adjustment, and their perceptions of their child's worry (Zebrack, Chesler, Orbuch, & Parry, 2002). Mothers' worry about their child's cancer was related to worry about their child's psychosocial adjustment. Mothers who were not married/partnered reported more child-related worry, and mothers' worry was best predicted by perceptions about the content and frequency of their child's worry, even after controlling for a range of mother and child characteristics. Neither child demographic variables nor medical status were related to maternal worry (Zebrack et al., 2002).

In a study of mothers' worry regarding the health of their hospitalized infants who had been hospitalized in the NICU, it was found that mothers frequently worried about their child's present and future health problems (Docherty, Shandor Miles, & Holditch-Davis, 2002). In line with other research, child's diagnosis did not predict mother's level of worry. However, in contrast to other studies that have not found a relationship between education level and measure's of adjustment (Mednick et al., 2007), mother's education level was significantly related to level of worry, where mothers who were more educated reported less worry (Docherty et al., 2002).

Researchers have also begun to examine a different kind of worry experienced by parents of children with special needs: worries related specifically to their child's future. A study done with parents of children with a range of intellectual, physical, and learning disabilities utilized both quantitative and qualitative analyses in their assessment of parents' future related worries (Heiman, 2002). Many parents expressed concern about their child's future financial and physical independence (55%), and their child's education and future employment (50%). Nearly

a third expressed concern for child's future (30%) – both in terms of financial and emotional support – once both parents were unable to care for the child. Despite having these various concerns for their child's future, the majority of parents were not presently doing anything to address these future related concerns (70%).

Study Purpose

There is a paucity of research that has examined either hope or worry in parents of children with an ASD or Down syndrome, and to date there have been no published empirical studies that have examined these two constructs together. Hope and worry in parents of children with an ASD and Down syndrome warrant increased attention. It is important to further explore both child and parent variables that may serve as risk or protective factors for parents, in terms of their experience of hope and worry.

Research has found hope to be a stable dispositional trait; therefore, we did not expect to find significant differences between hope in mothers of children with an ASD and Down syndrome (Snyder, 2002). Hope is made up of one's motivation to get things done, as well as the ability to come up with ways to accomplish these goals. It makes sense that greater hope would be associated with lesser worry. Individuals who are successful in reaching their goals are likely to experience less worry than individuals who approach goals with low confidence and have a history of failure. Those who engage in excessive worry are distracted from focusing their energy and thoughts on pertinent issues and often have difficulty blocking intrusive negative thoughts. The relationship between hope and worry may have important implications for parents' adjustment.

Parents' perceptions of their child's disability, as well as their own characteristics, seem to better predict adjustment, more so than objective—or subjective—measures of diagnosis or

degree of impairment. The present study examined both parent and child characteristics in relation to parents' hope and worry and utilized both quantitative and qualitative methods to explore these issues. These findings will further inform our understanding of the experience of raising a child with an autism spectrum disorder or Down syndrome.

Hypotheses

- 1.) Mothers of children with autism spectrum disorders will report greater worry than mothers of children with Down syndrome.
- 2.) Mothers with higher hope will report lower dispositional worry.
- 3.) Mothers of older children and children with more severe impairment will report greater maternal (future) worry.
- 4.) Hope will not differ between mothers of children with autism spectrum disorders and those with children with Down syndrome.
- 5.) Mothers of children with more severe impairment will report lower hope.
- 6.) Mothers' level of education will be positively correlated with hope.
- 7.) Mothers also responded to an open-ended question that asked, "When you wake up in the middle of the night, what is it that you worry about?" Using a qualitative analysis technique, these responses were explored for emerging themes.

Methods

Participants

Two hundred fifty-nine mothers of children with autism spectrum disorders ($n = 199$) and Down syndrome ($n = 60$) participated in this study. Mothers reported their child's diagnosis on the autism spectrum, including autism ($n = 130$), Asperger's syndrome ($n = 32$), and PDD-NOS ($n = 37$). Using SPSS, child's diagnosis was dummy coded to allow for the use of this categorical variable in multiple regression analyses. Demographic characteristics of the mothers and children are presented in Table 1 and Table 2. The sample was primarily white (89%) and middle to upper income; 54.1% reported a family income of more than \$70,000. The average education was 15.7 years, where 16 years is a bachelor's degree, and 87% of respondents were married or had a domestic partner.

Procedure

Participants were recruited via advertisements placed in newsletters and on websites of organizations associated with autism spectrum disorders and Down syndrome. The advertisement provided a link to an online questionnaire, titled "My Child's Therapies" (Mackintosh, 2007). The website provided a description of the study as well as informed consent information, followed by the measures. Submission of the completed questionnaire constituted consent. No identifying information was collected to assure participants' anonymity and confidentiality of responses. Participants received no payment or other benefits. This online survey was developed using the Inquisite program, and data were collected between July of 2006 and February of 2007. This study was approved by the university's Institutional Review Board.

Table 1

Mother Demographics by Diagnosis

	AUT	AS	PDD-NOS	DS	Total/Avg
Age - Years (SD)	38.85 (7.59)	39.5 (8.49)	36.42 (5.76)	40.92 (7.66)	39.06 (7.57)
Marital Status - <i>n</i>					
Married/Domestic Partner	107	28	32	57	224
Divorced/Separated	14	2	3	2	21
Single/Widowed	8	2	2	1	13
Race - <i>n</i>					
Black, not Latino	6	0	0	0	6
Hispanic/Latino	3	1	1	3	8
Native American	0	0	1	0	1
Asian, Pacific Islanders	4	0	0	2	6
White, not Latino	115	29	33	53	230
Biracial or Multiracial	1	2	1	1	5
Other	1	0	1	1	3
Education ^a - Mean (SD)	15.42 (2.46)	16.55 (2.72)	15.46 (2.60)	16.18 (2.6)	15.74 (2.58)
Family Income - <i>n</i>					
< \$10,000	3	0	0	0	3
\$10,000 - \$29,999	16	2	4	0	22
\$30,000 - \$49,999	20	11	8	6	45
\$50,000 - \$69,999	20	4	5	9	38
\$70,000 - \$89,999	22	5	9	8	44
\$90,000 - \$109,999	12	5	4	12	33

\$110,000 - \$129,999	10	2	2	8	22
> \$130,000	20	3	5	13	41

^ahigh school diploma = 12 years; completed college = 16 years

note:

Autism (AUT)

Aspergers Syndrome (AS)

Pervasive Developmental Disorder - Not otherwise specified (PDD-NOS)

Down syndrome (DS)

Table 2

Child Demographics by Diagnosis

	AUT	AS	PDD-NOS	DS	Total/Avg
Sex (<i>n</i>)					
Male	111	29	32	29	201
Female	19	3	5	31	58
Age - Years (<i>SD</i>)	8.38 (4.36)	10.99 (4.6)	8.17 (4.01)	8.50 (5.66)	8.70 (4.73)

note:

Autism (AUT)

Aspergers Syndrome (AS)

Pervasive Developmental Disorder - Not otherwise specified (PDD-NOS)

Down syndrome (DS)

Measures

Child and parent information. Mothers provided information pertaining to their child's demographics: sex, age, time elapsed since diagnosis received, race, primary diagnosis, additional diagnosis. Parent demographics included sex, age, race, family income, years of education, marital status, and relationship to the child. These questions are included in the Appendices A and B.

The State Hope Scale (Snyder et al., 1996). This scale assesses an individual's level of hope and reflects the agency and pathways components that comprise Hope Theory (Snyder et al., 1991; Snyder, 2002). State hope as measured by the State Hope Scale (Appendix F) has been found to significantly correlate with dispositional hope, which is measured by the trait version of the scale (Snyder et al., 1996). This scale consists of 6 items, with 3 items that assess agency and 3 that assess pathways. Responses were provided on an 8-point Likert scale ranging from 1 (definitely false) to 8 (definitely true). A sample item from the agency subscale is "At this time, I am meeting the goals that I have set for myself." A sample from the pathways subscale is "There are lots of ways around any problem that I am facing now." The State Hope Scale shows significant convergent validity with several expected measures, including State Self-Esteem, State Positive Affect, and State Negative Affect. This scale shows high internal consistency. Cronbach alphas ranged from .82 to .95 on a standardization sample that was measured daily for 30 days (Snyder et al., 1996). Internal consistency for this sample was $\alpha = .91$.

The Penn State Worry Questionnaire (PSWQ; Meyer, Miller, Metzger, & Borkovec, 1990). This questionnaire (Appendix D) is a measure of trait worry and consists of 16 items, where responses are provided on a 3-point Likert scale ranging from 1 (not at all typical) to 3 (very typical;). Two sample items are: "If I do not have enough time to do everything, I do not

worry about it,” and, “Once I start worrying, I can’t stop.” The PSWQ shows high internal consistency in both normative and clinical samples. Cronbach’s Alpha’s have been found ranging from .86 to .95 (Davey & Tallis, 1994) and in this sample, $\alpha = .94$.

The Maternal Worry Scale for Children with Chronic Illness (DeVet & Ireys, 1998). This scale (Appendix E) measures worry experienced by mothers of children with chronic illness. It was modified to refer to “disability” instead of “illness” or “health condition.” One item was removed due to its redundancy (e.g., “I worry that my child will: need medications or will need stronger medications). In addition, two items were added and several were modified to better capture the experience of mothers’ worries about children with developmental disabilities, yielding a total of 13 items for this modified version. Responses were provided on a 4-point Likert scale, ranging from 1 (not at all) to 4 (most of the time). Two sample items are: “I worry that my child won’t be able to handle things in the future when she/he is on her/his own,” and, “I worry that my child will be vulnerable to abuse due to the disability.” Due to the fact that the measure focuses primarily on future related concerns, it will be referred to as Maternal (Future) Worry. Cronbach’s alpha was .94, and test-retest reliability was reported at .84 in the standardization sample (DeVet & Ireys, 1998). In this sample, $\alpha = .90$.

Autism Treatment Evaluation Checklist (ATEC; Rimland & Edelson, 1999). The ATEC (Appendix G) was originally developed to evaluate the effectiveness of treatments for children with autism and as a way of tracking progress over time. However, the ATEC is also appropriate for assessing degree of impairment. The ATEC measures four areas: Speech, Sociability, Sensory/Cognitive Awareness, and Health/Physical Behavior. Response options were Likert scales with 3 or 4 levels. A sample items from the Speech subscale is, “My child knows own name;” from the Sociability subscale, “My child ignores other people;” from the

Sensory/Cognitive subscale, “My child is aware of danger;” and from the Health/Behavior subscale, “My child soils pants/diapers.” ATEC norms have not been published. However, the Autism Research Institute’s website (http://www.autism.com/ari/atec/atec_report.htm) provides psychometrics on the measure. Cronbach’s alpha for the individual subscales reported by the authors are: Speech ($\alpha = .92$), Sociability ($\alpha = .84$), Sensory/Cognitive ($\alpha = .88$), Health/Physical behavior ($\alpha = .82$). For the overall scale, internal consistency is $\alpha = .94$. For the present sample, internal consistency for the overall scale is $\alpha = .95$.

Data Analysis Plan

Before beginning analysis, data were cleaned and twenty cases were removed due to incomplete data. The data were checked for normality, skewness, and kurtosis; all standardized measures were within normal ranges. Data were checked for univariate outliers using box plots and standardized values. One case’s standardized ATEC score (3.56, $p < .001$) was well outside of the normal range and was removed. When checked for multivariate outliers using Mahalanobis distance, two cases were found to surpass the critical chi-square value and were also removed from the analyses. The assumption of linearity was confirmed through a visual check of the data’s scatterplot. Overall, 23 cases were removed from the dataset. Due to the fact that many of these 23 participants did not provide basic demographic information or did not fill out the scales that assessed the constructs of interest, it is difficult to assess whether or not they differed in some way from participants whose data were included in the analyses.

Results

Means and standard deviations for the State Hope Scale, PSWQ, Maternal (Future) Worry and ATEC are presented in Table 3. The bivariate correlations among study variables are presented in Table 4.

Table 3

Descriptive Data for Measures

Measures	<i>M</i>	<i>SD</i>	Actual Range	Potential Range
Autism Treatment Evaluation Checklist ^a	54.08	27.06	1-127	0-180
Penn State Worry Questionnaire ^b	33.96	7.95	18-48	16-48
Maternal (Future) Worry ^b	31.96	8.19	13-52	13-52
State Hope Scale ^b	32.78	9.03	6-48	6-48

^aNote. A high numerical score indicates greater impairment.

^bNote. A high numerical score indicates a high level of the construct.

Table 4

Bivariate Correlations among Study Variables

Variable	1	2	3	4	5	6	7	8	9
(1) Child's Age	-	-.17**	.18**	.14*	0.08	.63***	.05	-.05	.17**
(2) Autism Treatment Evaluation Checklist	-	-	.43***	-.29***	-0.30***	-.29***	-.44***	.25***	.34***
(3) Parent Rating of Impairment	-	-	-	-0.03	0.05	-.11	-0.19**	-.02	.27***
(4) Family Income	-	-	-	-	.49***	.36***	.25***	-.06	-.05
(5) Mother's Education (years)	-	-	-	-	-	.34***	.32***	-.16	-.01
(6) Mother's Age	-	-	-	-	-	-	.13*	-.13	.12
(7) State Hope Scale	-	-	-	-	-	-	-	-0.45***	-.40***
(8) Penn State Worry	-	-	-	-	-	-	-	-	.37***
(9) Maternal (Future) Worry	-	-	-	-	-	-	-	-	-

* $p < 0.05$. ** $p < 0.01$. *** $p < .001$.

Dispositional worry, diagnosis, impairment and hope. A hierarchical linear regression (Table 5) was used to predict dispositional worry (Penn State Worry Scale). The independent variables were entered in 3 steps: (i) diagnosis, (ii) impairment (ATEC), and (iii) hope (Hope Scale). Diagnosis alone did not predict worry, $R^2 = .03$ ($p = .07$). When impairment was added, $\Delta R^2 = .04$ ($p = .001$), and with the addition of hope, $\Delta R^2 = .15$ ($p < .001$). Mothers with lower hope and whose children had greater impairment had higher worry. Results of an ANOVA indicate that the overall model predicted dispositional worry, $F(5, 253) = 13.78$, $p < .001$. The R^2 for the full model was .21.

Mother's dispositional worry (PSWQ) did not significantly differ across the different diagnoses ($p = .068$). However, there was a trend wherein mothers of children with autism, Asperger's syndrome and PDD-NOS reported more dispositional worry than mothers of children with Down syndrome (Figure 1).

Maternal (future) worry, diagnosis, impairment and child's age. A hierarchical linear regression was performed with maternal (future) worry as the dependent variable (Table 6). The independent variables were entered in 3 steps: (i) diagnosis, (ii) child's impairment (ATEC), (iii) child's age. Results show that for diagnosis, $R^2 = .03$ ($p = .031$). When impairment was added, $\Delta R^2 = .09$ ($p < .001$) and when child's age was added, $\Delta R^2 = .05$ ($p < .001$). Worry was higher for mothers of older children and those whose children were more severely impaired. Results of an ANOVA indicate that the overall model predicted future related worry, $F(5, 253) = 10.64$, $p < .001$. The R^2 for the full model was .17.

Mothers' level of maternal (future) worry differed depending on child's diagnosis (Figure 2), $F(3, 255) = 3.01$, $p = .031$. Post hoc tests using Tukey's HSD showed that mothers of children with autism reported greater future related worry than mothers of children with

Table 5

Hierarchical Regression Analysis for Variables Predicting Dispositional Worry

Predictor	B	SEB	β	β in final model	R^2	ΔR^2
Step 1: Diagnosis					0.03	0.03
AUT	34.61	0.69	-	-	-	-
AS	0.49	1.56	0.02	0.06	-	-
PDD-NOS	-0.05	1.47	0.00	0.04	-	-
DS	-3.03	1.23	-.16*	0.00	-	-
Step 2: ATEC	0.07	0.02	.23*	0.06	0.07	0.04*
Step 3: Hope	-0.37	0.05	-.43***	-.43***	0.21	0.15***

* $p < 0.05$. ** $p < 0.01$. *** $p < .001$.

note:

Autism (AUT)

Aspergers Syndrome (AS)

Pervasive Developmental Disorder - Not otherwise specified (PDD-NOS)

Down syndrome (DS)

Mothers' Dispositional Worry

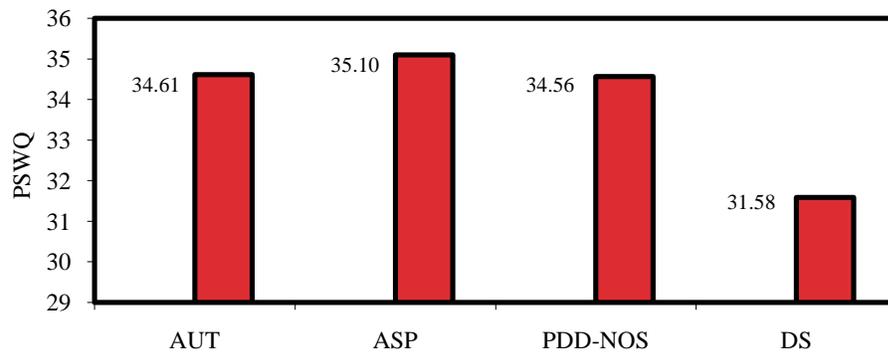


Figure 1

Mothers' Dispositional Worry by Child's Diagnosis

note:

Autism (AUT)

Aspergers Syndrome (AS)

Pervasive Developmental Disorder - Not otherwise specified (PDD-NOS)

Down syndrome (DS)

Table 6

Hierarchical Regression Analysis for Variables Predicting Maternal (Future) Worry

Predictor	B	SEB	β	β in final model	R^2	ΔR^2
Step 1: Diagnosis					0.03	0.03*
AUT	33.06	0.71		-	-	-
AS	0.25	1.60	0.01	0.01	-	-
PDD-NOS	-2.49	1.51	-0.11	-0.04	-	-
DS	-3.35	1.26	-.17**	0.04	-	-
Step 2: ATEC	0.10	0.02	.35***	.40***	0.12	.09***
Step 3: Child's Age	0.41	0.10	.23***	.23***	0.17	.05***

* $p < 0.05$. ** $p < 0.01$. *** $p < .001$.

note:

Autism (AUT)

Aspergers Syndrome (AS)

Pervasive Developmental Disorder - Not otherwise specified (PDD-NOS)

Down syndrome (DS)

Mothers' Maternal (Future) Worry

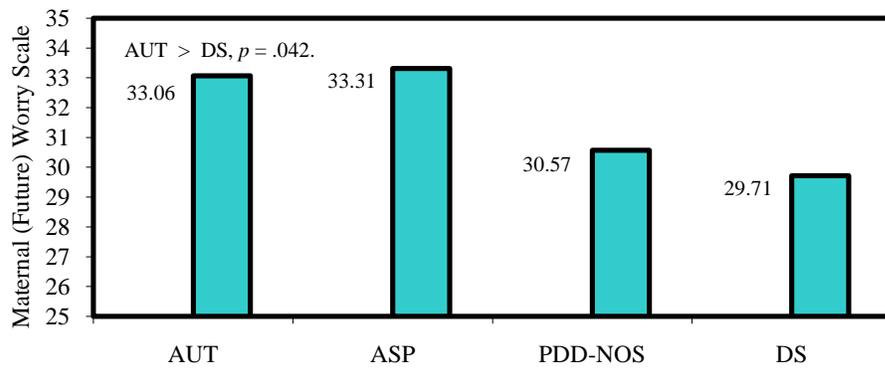


Figure 2

Mothers' Maternal (future) Worry by Child's Diagnosis

note:

Autism (AUT)

Aspergers Syndrome (AS)

Pervasive Developmental Disorder - Not otherwise specified (PDD-NOS)

Down syndrome (DS)

Down syndrome, $p = .042$. No significant differences were found in planned contrasts of the remaining diagnostic categories.

Hope, diagnosis, impairment and maternal education. A hierarchical linear regression was performed to predict hope (Hope Scale; Table 7). The independent variables were entered in 3 steps: (i) diagnosis, (ii) child's impairment (ATEC), (iii) Mother's Education (years). For diagnosis, $R^2 = .08$ ($p < .001$). When child impairment was entered, $\Delta R^2 = .11$ ($p < .001$), and when mother's education was added to the model, $\Delta R^2 = .04$ ($p < .001$). The F change was significant at each block, $p < .001$. Mother's hope was lower for those with less education and when child's impairment was more severe. Results of an ANOVA indicate that the overall model is a significant predictor of hope, $F(5, 252) = 15.16$, $p < .001$; the model's total $R^2 = .23$.

Contrary to the hypothesis, mother's level of hope varied by diagnosis (Figure 3), $F(3, 255) = 7.07$, $p < .001$. Post hoc tests using Tukey's HSD revealed that mothers of children with autism reported lower hope than mothers of children with Down syndrome, $p < .001$. No significant differences were found in comparisons of the remaining diagnostic categories.

Thematic Analysis

Parents responded to an open-ended question, "When you wake up in the middle of the night, what is it that you worry about?" The primary and secondary coder conducted a thematic analysis of mothers' responses, using an analytic induction procedure. Both coders reviewed the transcripts and attained agreement on tentative themes. Then, the primary coder assigned responses to designated themes, allowing responses to contain more than one theme. The secondary coder examined the primary coder's classification of mothers'

Table 7

Hierarchical Regression Analysis for Variables Predicting Hope

Predictor	B	SEB	β	β in final model	R^2	ΔR^2
Step 1: Diagnosis					0.08	.08***
AUT	30.76	0.76	-	-	-	-
AS	2.82	1.73	0.10	0.03	-	-
PDD-NOS	2.03	1.62	0.08	0.03	-	-
DS	6.27	1.35	.30***	0.10	-	-
Step 2: ATEC	-0.13	0.02	-0.38***	-0.31***	0.19	.11***
Step 3: Education	0.76	0.20	.22***	.22***	0.23	.04***

* $p < 0.05$. ** $p < 0.01$. *** $p < .001$.

note:

Autism (AUT)

Aspergers Syndrome (AS)

Pervasive Developmental Disorder - Not otherwise specified (PDD-NOS)

Down syndrome (DS)

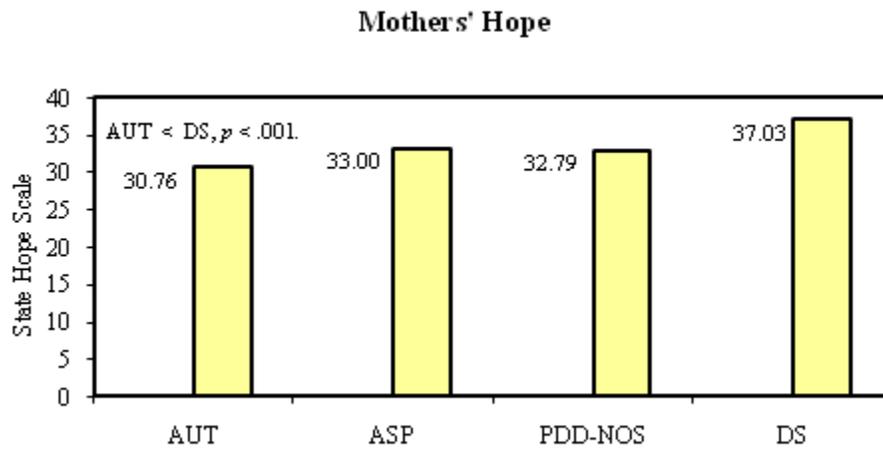


Figure 3

Mothers' Hope by Child's Diagnosis

note:

Autism (AUT)

Aspergers Syndrome (AS)

Pervasive Developmental Disorder - Not otherwise specified (PDD-NOS)

Down syndrome (DS)

responses; this process was repeated in an iterative fashion. New themes emerged during this coding, which were discussed and incorporated into the coding scheme. Responses could be assigned to more than one theme. Full agreement between coders on themes and assignment of responses was reached. Both coders were blind to child's diagnosis.

Themes emerged under two central domains: children and family focused worries (Table 8); self focused worries (Table 9). These central domains each held a number of themes. Table 8 and Table 9 provide examples of mother's responses for each theme and Table 10 shows how many mothers described worries fitting each theme. The number of statements in each theme did not differ by diagnosis (series of chi square tests, $p > .05$).

Children and family focused worries.

School related worries. Mothers described worries regarding their children's academic potential or if they would be able to learn. Respondents also expressed concern as to whether their child's needs were being met by the school.

Child's capacity to be self-sufficient in the future. The respondents wondered what their children's job prospects would be and to what degree their children would be self-sufficient as they grew older.

Well-being and adjustment. Mothers indicated concerns regarding their children's social adjustment. They questioned whether or not their child would ever have real friends or romantic relationships. Some respondents wondered whether their child would have a happy life.

Health, safety and death. Some mothers described general concerns as to whether their child was safe or still in bed. Others were more specific and mentioned medical issues and safety concerns, such as worrying about a house fire or that their child would get outside and get hit by a car.

Table 8

Illustrative Quotes by Theme: Children and Family Focused Worries

Response to question: *When you wake up in the middle of the night, what is it that you worry about?*

Illustrative Quotes

Themes: *Children and Family Focused Worries*

School related worries School, school, and school. I work at my school. It is a small private school and the director is

in ill health. If something happens to her I need to have a back-up plan and there are few educational situations that are a good match.

I worry about my child day at school, are they going to be safe, is the teachers going to do their job of teaching.

What are we going to do about kindergarten, the schools aren't equipped to help my child.

Child's capacity to be self sufficient I worry about whether or not he'll be able to hold down a decent job, and be able to at least partially support himself.

What her job prospects will be.

Whether have any kind of a job (I assume she'll never completely be self-supporting).

Wellbeing & Adjustment I worry about whether or not he'll have deep meaningful relationships outside of those with family members.

Social stuff...That my son won't have real friends, that he won't even realize when he's being teased or picked on.

If things are not going well for my kids or how I am going to take action to help them through the difficult times.

Health, Safety & Death That my daughter with Down syndrome isn't breathing

That he'll get abused because he's so vulnerable, that professionals won't take these concerns seriously and he'll get hurt.

The fear that there may be a fire and I can't get my kids out of the house.

Table 9

Illustrative Quotes by Theme: Self Focused Worries

Response to question: *When you wake up in the middle of the night, what is it that you worry about?*

Illustrative Quotes	
<i>Themes: Self Focused Worries</i>	
Work responsibilities & stressors	<p>Work, deadlines, not enough time to get everything done.</p> <p>Not completing a work project the correct way.</p> <p>Usually work-related or volunteer-related tasks I need to get done.</p>
Financial concerns	<p>If we will have enough money to make it through the next few months.</p> <p>Usually it is the financial strain of my son's disability.</p> <p>Money; my job ended two years ago and our insurance will end in July. Will I have to go back to work to be able to afford insurance?</p>
Daily Hassles	<p>What I have to do the next day and prioritizing the list.</p> <p>The things I need to do. Did I do this paperwork. I will call my voice mail at work to remind myself of things so I don't forget.</p> <p>Sometimes it is about getting things accomplished that I need to do and how to best compensate for my forgetting things so much.</p>
What happens to child when parents die?	<p>I've had a lot of friends die young of cancer recently. Could that happen to me, leaving my son without a mother.</p> <p>That I will live basically in a prison having to care for her until I die and what will happen to her when I do?</p> <p>If I were to die how would my son survive if his father were able to obtain custody.</p>
Wellbeing & adjustment	<p>Relationships, when will I ever be non-tired, how can I make it through life.</p> <p>Most of them (worries) involve my relationships with other people and how they need to be handled.</p> <p>Worrying about if my kids are happy, am I doing everything possible to help them. Guilt thinking I haven't done enough.</p>

Health, safety &
death of self or
partner

My husband's health

Our life, dying, you name it!

Money, health, husband, son.

Tries not to worry

I'm getting better about letting go of the things I can't control. I try had to redirect my thoughts if they stray into useless thinking patterns.

I do not tend to worry about things because worrying does nothing but make things

health worse. If I cannot do anything about a problem, then I go to someone that I think can.

Spiritual or
Religious Support

I used to worry about my child's future a lot but now, I put my faith and trust in God and that has really helped a lot.

I try not to worry. My faith tells me not to. God will provide and has provided in many ways.

Sleep issues

How much sleep I can get - I am tired all the time, and can't seem to get enough sleep to feel energetic during the day.

Not getting enough sleep and then not having enough patience to deal with my daughter and life, work and other situations.

Table 10

Representation of Mothers' Worries Across Themes

<i>Response to question: When you wake up in the middle of the night, what is it that you worry about?</i>	Total
	<i>n (%)</i>
<i>Themes: Children and Family Focused Worries</i>	
School related worries	14 (5.4)
Child's capacity to be self sufficient	5 (1.9)
Wellbeing and adjustment	20 (7.7)
Health, safety and death	42 (16.2)
<i>Themes: Self Focused Worries</i>	
Work responsibilities and stressors	18 (6.9)
Financial concerns	38 (14.7)
Daily hassles	63 (24.3)
What happens to child when parents die	17 (6.6)
Wellbeing and adjustment	33 (12.7)
Health, safety and death of self or partner	12 (4.6)
Tries not to worry	3 (1.2)
Spiritual or religious support	7 (2.7)
Sleep issues	32 (12.4)
Did not respond to question (blank)	34 (13.1)

Self focused worries.

Work responsibilities and stressors. Mothers expressed frustration in how to balance work and everything else that needed to be taken care of. Others mentioned having too much work to do and not being able to attend to all of their work-related responsibilities.

Financial concerns. Respondents described general financial concerns, as well as more specific worries regarding the ability to pay for their children's treatments. Some mothers mentioned wanting to change their careers in order to make more money for their family.

Daily Hassles. Some mothers wrote that they worried about "everything." Others mentioned worrying about tasks for the next day, general daily problems, chores, and taking care of their children's appointments.

What will happen to child when parents die. Mothers worried about what would happen to their children when they died. Some mothers expressed concern that no one would be able to care for their child as well as they were able. Others worried that their child would be institutionalized when they died.

Well-being and adjustment. Some mothers mentioned general concerns regarding their relationships or marriage. Others worried about their own ambitions and goals, and whether they were doing the best they could for their child.

Health, safety and death of self or partner. Some mothers briefly described concerns for their own health or their partner's health or mentioned general worries about death and dying. Others mentioned having a lack of energy, which was of concern to them.

Tries not to worry. Mothers described trying not to worry about the things they were unable to control. Some of these responses were also faith related.

Spiritual/religious. Mothers mentioned faith in relation to letting go of their worries. Some respondents indicated that prayer was used as a way of finding answers to handle the things they needed to do. Others mentioned going to a spiritual leader as a way of processing their concerns.

Sleep issues. Respondents described a variety of sleep-related concerns. The prevalence of this theme is very likely related to the terminology used in the question. Some wrote that they worried about getting back to sleep. Mothers worried that they would not be able to get back to sleep and that this would affect their ability to function the next day.

Discussion

Findings from the current study lend support to previous research suggesting that hope is a protective factor against psychological distress. Hope rests on the perceived ability to set and find ways of meeting goals, and individuals with high levels of hope tend to report higher levels of happiness and confidence (Snyder, 2002). In this case, hope was found to protect against high levels of worry. It seems that thinking that you are able to meet your goals is associated with worrying less about your goals. In line with the second hypothesis, mothers with higher hope reported lower dispositional worry. The direction of effect cannot be assumed in this correlational finding; alternatively, individuals who do not spend their time worrying may hold higher hope. Either way, we can assume that mothers fare better when they have higher hope and engage in less worry. Mothers who feel better able to plan for and meet their goals – a tenet of high hope—may spend less time worrying in general.

It is important to consider the possible outcomes of engaging in high levels of worry for mothers of children with disabilities. Excessive worry sometimes interferes with thinking about stressful topics in a meaningful way (Fresco et al., 2002), which may impede planning for goals and overcoming challenges. While these mothers have a great deal to worry about, engaging in too much worry or worrying too intensely may make it more difficult for mothers to take care of their own needs. This may deter them from engaging in activities that will foster their own wellbeing.

Mothers of children with less severe impairment had higher hope, which supports hypothesis five. Having a child who was higher functioning was associated with perceptions of being better able to set and meet goals. Mothers of children with more severe impairment may be overwhelmed by the demands of raising their child with disabilities to the point that it

negatively affects their level of hope. Having a child with a more severe disability likely means more time spent on doctors' appointments, obtaining treatment or services, and dealing with challenges in educational planning. The sheer amount of energy and time that is required to meet all of these demands may very well affect mother's perceptions of their ability to meet their goals.

Mothers' level of education was positively associated with hope, where mothers who had more education reported higher levels of hope. This lends support to hypothesis six. Education was also positively correlated with family income ($r = .49, p < .001$). Mothers with greater financial resources might more easily access treatment and educational services for their child. Beyond that, mothers with higher socioeconomic status—as indicated by higher education and income—may also have access to greater resources in their communities that may contribute to their higher levels of hope. This in turn may contribute to a greater sense of the ability to set and meet goals. It is important to consider that individuals with higher hope may also be more apt to set and achieve goals (Snyder et al., 1991), such as those related to higher education.

Mothers of children with Down syndrome had higher hope than those whose children had autism (Figure 3), which was contrary to the expectation described in hypothesis four. This is likely a corollary to our finding that worry was higher for the autism group. Mothers who frequently worry have lower hope; parents who have higher hope worry less often and with less intensity. Hope is generally thought of as a stable construct, not much affected by situational factors. However, hope has not been examined extensively in parents of children with disabilities, and having a child with a disability is more than an everyday situational factor. Hope is influenced by stress and uncertainty, both of which are common in the lives of parents with disabilities—but are more common in mothers of children with autism when compared to

mothers of children with Down syndrome (Myers, Mackintosh, & Goin-Kochel, 2009). Down syndrome is very different from the autism spectrum disorders. Unlike an ASD, it is easily diagnose and its developmental progression is much more predictable.

Children's level of impairment was significantly associated with dispositional worry, which had not been hypothesized. Mothers of children with more severe impairment reported more worry. It may be the case that mothers whose children are more impaired simply have more to worry about, especially at higher levels of impairment. The PSWQ taps into one's ability to dismiss worrisome thoughts and being overwhelmed by worries. For a mother of a child who is severely impaired, it is likely overwhelming to manage the child's treatment schedule, appointments, educational planning, and behavioral challenges (Baker-Ericzén et al., 2005) while at the same time managing the things that mothers typically have to attend to. Dismissing worrisome thoughts might be a luxury these mothers cannot afford.

Children's level of impairment was also significantly associated with maternal (future) worry, which was an expected finding described in hypothesis three. Mothers of children who were lower functioning worried more about issues related to their child's health, disability, and future. This relationship can be explained in thinking about the additional demands, stressors, and concerns that mothers of children with more severe impairment experience. It was found that mothers of older children reported greater maternal (future) worry, which also provided support for hypothesis three. As children grow older, their mothers worry more about future-related issues pertaining to their child's disability and development. The Maternal Chronic Worry scale taps into life stage issues that emerge as children grow up and transition to young adulthood (e.g., being able to marry, live independently and hold a job). These issues are more salient for mothers of older as compared with younger children.

Mothers of children with autism reported more maternal (future) worry in comparison with mothers of children with Down syndrome (Figure 2), lending support for hypothesis one. This may be due to the greater ambiguity that exists regarding prognosis for children with autism. We can consider this finding in relation to the fact that, with young children with autism, there is no reliable way of predicting their developmental outcome. Families quickly learn that some children on the autism spectrum make large gains while others do not, and so parents have a realistic worry as to whether their child will gain skills or not. It is likely that the trajectory of improvement depends to a large extent on the treatments and therapies that are provided to the child—though even this is not for certain (Francis, 2005)—and so selecting those treatments becomes a big responsibility (Lord, Cook, Leventhal, & Amaral, 2000). Realistically, these families have a lot to worry about.

Mothers were asked to describe what they worried about when they woke up at night, and a thematic analysis of their responses resulted in identification of a number of concerns experienced by mothers of children with an autism spectrum disorder or Down syndrome. For many mothers, daily hassles—experienced by all parents but perhaps heightened for mothers of children with autism—came to mind. Mothers described a wide range of issues that they worried about, some of which were unrelated to their child with disabilities. Many mothers voiced worries about their own well-being and happiness and wondered whether they would be able to meet their own goals while attending to all of their other responsibilities. Mothers' responses ranged from one word, that they worried about “everything,” to several paragraphs.

This question was posed at the end of a rather lengthy online questionnaire; the focus of the survey was on their child, though mothers provided information about themselves, as well. In responding to this particular question, one mother wrote that she worried about current

bothersome situations and that “most of them are not related to my disabled child. Most of them involve my relationships with other people.” Some mothers worried about their own ambitions and whether their own goals would ever be met. Mothers described worrying about work-related tasks and whether or not they would have the time to accomplish everything they needed to do. Some mothers wrote that they worried about “forgetting things, not getting things done.”

While mothers wrote about self-focused worries, their children and family were also central to their concerns. Mothers worried about whether their child was safe or would stay safe; they worried that their child would get sick or die. Some worried about whether their child would ever be able to live independently or hold down a job. One mother wondered whether he would ever be able “to lead a normal life.” These worries are clearly different than those of mothers whose children are healthy and typically developing.

A review of mothers’ responses gave a glimpse of their experience as a mother of a child with a disability. However, it is also clear that their lives have additional dimensions. Participants in this study hold many roles: as mothers, wives, workers, and women. They have to clean their house, feed the dog, service the car, and remember to take out the garbage just as most other women do. For those who are employed outside the home, they also have to attend to all of their work related responsibilities. These mothers worry a great deal about their children and family, but they also worry about their own wellbeing and happiness. Our findings serve to remind us that that these mothers are people in their own right, with hopes and dreams and problems of their own; they are more than simply mothers of children with special needs.

Limitations and Directions for Future Research

The sample of respondents who participated in this study over-represented well educated, middle to high socioeconomic status families. Eighty-seven percent of mothers were married or had a partner, higher than the married-parent rate in the United States. In 2002, about 30% of children in the U.S. were not living in a two-parent household (Fields, 2003). There is speculation—but no empirical support—that divorce rates are higher among parents who have a child with disabilities. The over-representation of high SES participants may be the result of both recruitment and methodology related issues. Participants were recruited through autism and Down syndrome organizations, which limited the sample to families who were at least somewhat involved in an organization related to their child's disability. In addition, respondents had to have internet access in order to participate. Single or lower-income mothers may have higher levels of worry or lower levels of hope than those who participated in this study, though this cannot be said with certainty. An additional limitation was that children's diagnosis and assessment of degree of impairment were obtained through mothers' self-report and that mothers were the sole reporter of all of the data that was collected. The latter may have contributed to some of the correlational findings.

The study of fathers' experiences associated with parenting a child with an autism spectrum disorder or Down syndrome is an important topic of exploration. Therefore, future research ought to examine hope and worry in fathers, as there may be unique perspectives in their experiences of parenting a child with disabilities. Unfortunately, the small number of fathers who participated in this study ($n = 25$) did not allow for their use as a comparison group and their data were excluded from analyses. Given that mothers are typically the ones who

participate in research and tend to their child's needs, the fathers who participated in this study may not have been representative of fathers of children with disabilities.

Attention to mothers' psychological wellbeing is important in its own right, as well as with regard to how it influences their children. The presence of pathology or illness in one family member can affect functioning in the other, and future research needs to examine the bi-directional relationship between parents' psychological wellbeing and the developmental progress and wellbeing of their children with these disabilities. A further question is whether parents' hope and worry serve as either a risk or protective factor in the delivery of interventions or in their children's responsiveness to interventions.

This study informs our understanding of the experience of mothers who have a child with an autism spectrum disorder or Down syndrome. Results suggest that maternal level of education as well as child's diagnosis and severity of impairment may be risk factors for mother's level of hope and worry. There is the potential for these findings to be incorporated into intervention programs focused on hope and worry in mothers of children with an autism spectrum disorder or Down syndrome, with the goal of improving their wellbeing and adjustment.

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Appendix A

Informed Consent

My Child's Therapies

Are you the parent or caregiver of a child with an autism spectrum disorder, Down syndrome, or cerebral palsy? Your child may be of any age between 18 months old and 21 years old. If so, please consider participating in our study of what it is like for parents to choose and provide therapies and interventions for their children with disabilities.

We are very much interested in parents' experiences of choosing which treatments are best for their children, and what parents are expecting from those treatments. This information will help us to (a) better understand the struggles parents face in trying to decide what is best for their child, and (b) assess which therapies are being used, what you expected from those therapies, and the results you have actually seen. We hope that you will assist us by participating in this research.

Below is a list of information we would like for you to read before completing the questionnaire. If you have questions about any of these items, please feel free to contact me, Virginia Mackintosh (doctoral student in the Department of Psychology at Virginia Commonwealth University), through e-mail at mackintoshvh@vcu.edu or Dr. Barbara Myers (associate professor in the Department of Psychology at Virginia Commonwealth University) at bmyers@vcu.edu or by phone at (804) 828-6752.

- By completing and submitting this questionnaire, you are agreeing to participate in a research study. All responses to questionnaire items will be completed using the internet.
- It may take you anywhere from 40 to 60 minutes to complete the questionnaire. You may stop and save your progress at any point and return at a later time to complete it. Your progress is saved only to the computer you are working at, so you will need to use that same computer to finish the survey.
- All responses that you give will be completely anonymous. We do not ask for any contact or otherwise identifiable information, and we will not have any way to link your answers back to you. All information will be stored using identification numbers. We will not have your name or e-mail address and have no means of obtaining them. The only individuals who will have access to the data are Dr. Myers and myself.
- Results from this study will be presented collectively and may be published in journals, presented at professional conferences, and used for educational purposes. Participants will not be compensated as a result of any presentation or publication of the results.
- A possible risk is that you may feel uncomfortable about revealing information about your child and family.

- A potential benefit of participation is that you will have the opportunity to share your experiences in raising a child with a disability.
- Your choice to participate is strictly voluntary. You may choose (a) not to answer a certain question or questions and (b) not to submit your answers once you have completed the questionnaire.
- Please feel free to print out a copy of these informed consent items to keep for your records. Simply click the "print" icon in the toolbox menu of your browser.
- If you have any questions about this study, please feel free to contact Virginia Mackintosh at mackintoshvh@vcu.edu or Dr. Barbara Myers by e-mail at bmyers@vcu.edu, by phone at (804) 828-6752, or by mail at Department of Psychology, 808 West Franklin Street, Virginia Commonwealth University, Richmond, VA 23284-2018. If you have any specific concerns about your participation rights, you may also contact the Office of Research Subject Protection, 800 E. Leigh Street, PO Box 980568, Richmond, VA 23298, by phone at (804) 827-1735, or by e-mail at orsp@vcu.edu.

Thank you for your time and participation. Your cooperation is greatly appreciated!

Please Click the Arrow Button Below to Begin!

Appendix B

Child Demographics

Sex of your child

Male Female

Age --

Years:

Months:

How do you describe your Child's Race?

- Black, not Latino
- Hispanic/Latino
- American Indian
- Asian, Pacific Islanders
- White, not Latino
- Biracial or Multiracial
- Other

What is your child's primary diagnosis?

- Autism
- Asperger Syndrome
- Pervasive Developmental Disorder-NOS
- Cerebral Palsy
- Down Syndrome
- No clear diagnosis yet
- Other

Appendix C

Parent Demographics

Your Age: _____

Your Sex

Male Female

How do you describe your race?

- Black, not Latino
- Hispanic/Latino
- American Indian
- Asian, Pacific Islanders
- White, not Latino
- Biracial or Multiracial
- Other

Your marital status

- Single
- Married
- Widowed
- Domestic Partner
- Divorced
- Separated

How many years has the mother of the disabled child had (for example: High School diploma = 12 years; completed college = 16 years)?

Family Income

- Less than \$10,000
- Between \$10,000 & \$29,999
- Between \$30,000 & \$49,999
- Between \$50,000 & \$69,999
- Between \$70,000 & \$89,999
- Between \$90,000 & \$109,999
- Between \$110,000 & \$129,999
- Above \$130,000

Your relation to the child:

- Mother
- Father
- Step-mother
- Step-father
- Grandmother

- Grandfather
- Sibling
- Foster Parent
- Other

Appendix D

Penn State Worry Questionnaire

Responses are provided on a 3-point Likert Scale:

1 - Not at all typical of me

2 - Somewhat typical of me

3 - Very typical of me

1. If I don't have enough time to do everything, I don't worry about it
2. My worries overwhelm me
3. I don't tend to worry about things
4. Many situations make me worry
5. I know I shouldn't worry about things, but I just can't help it
6. When I am under pressure, I worry a lot
7. I am always worrying about something
8. I find it easy to dismiss worrisome thoughts
9. As soon as I finish one task I start to worry about everything else I can do
10. I never worry about anything
11. When there is nothing more I can do about a concern, I don't worry about it anymore
12. I've been a worrier all my life
13. I notice that I have been worrying about things
14. Once I start worrying, I can't stop
15. I worry all the time
16. I worry about projects until they are all done

Appendix E

The Maternal Worry Scale for Children with Chronic Illness

Responses are provided on a 4-point Likert Scale:

4 – Most of the time

3 – Often

2 – Sometimes

1 – Not At All

I worry that my child...

1. will look different from other teenagers or adults because of his/her disability
2. will have a harder time finding a boyfriend or girlfriend because of the disability
3. won't get married because of her/his disability
4. will have poor physical health as he/she gets older
5. won't be able to do things he or she wants to do because of the disability
6. will have a hard time getting around or going places compared to other teens or adults
7. will always have to take medications
8. will have future side effects from his/her medications
9. won't be able to handle things in the future when she/he is on her/his own
10. will be vulnerable to abuse due to the disability
11. won't be able to make friends
12. will not be able to care for him/herself after I'm gone
13. won't ever be self-supporting as an adult

Appendix F

The State Hope Scale

Responses are provided on an 8-point Likert Scale:

1 – Definitely False

2 – Mostly False

3 – Somewhat False

4 – Slightly False

5 – Slightly True

6 – Somewhat True

7 – Mostly True

8 – Definitely True

1. If I should find myself in a jam, I could think of many ways to get out of it.
2. At the present time, I am energetically pursuing my goals.
3. There are lots of ways around any problem that I am facing now.
4. Right now I see myself as being pretty successful.
5. I can think of many ways to reach my current goals.
6. At this time, I am meeting the goals that I have set for myself.

Appendix G

Autism Treatment Evaluation Checklist

I. Speech/Language/Communication

Response Options re: child

Not true

Somewhat true

Very true

1. Knows own name
2. Responds to 'No' or 'Stop'
3. Can follow some commands
4. Can use one word at a time
5. Can use 2 words at a time
6. Can use 3 words at a time
7. Knows 10 or more words
8. Can use sentences with 4 or more words
9. Explains what he/she wants
10. Asks meaningful questions
11. Speech tends to be meaningful/relevant
12. Often uses several successive sentences
13. Carries on fairly good conversation
14. Has normal ability to communicate for his/her age

II. Sociability

Response Options re: child

Not descriptive

Somewhat descriptive

Very descriptive

1. Seems to be in a shell - you cannot reach him/her
2. Ignores other people
3. Pays little or no attention when addressed
4. Uncooperative and resistant
5. No eye contact
6. Prefers to be left alone
7. Shows no affection
8. Fails to greet parents
9. Avoids contact with others
10. Does not imitate
11. Dislikes being held/cuddled
12. Does not share or show
13. Does not wave 'bye bye'
14. Disagreeable/not compliant
15. Temper tantrums
16. Lacks friends/companions
17. Rarely smiles
18. Insensitive to other's feelings
19. Indifferent to being liked
20. Indifferent if parent(s) leave

III. Sensory/Cognitive Awareness

Response Options re: child

Not descriptive

Somewhat descriptive

Very descriptive

1. Responds to own name
2. Responds to praise
3. Looks at people and animals
4. Looks at pictures (and T.V.)
5. Does drawing, coloring, art
6. Plays with toys appropriately
7. Appropriate facial expression
8. Understands stories on T.V.
9. Understands explanations
10. Aware of environment
11. Aware of danger
12. Shows imagination
13. Initiates activities
14. Dresses self
15. Curious, interested
16. Venturesome - explores
17. "Tuned in" - Not spacey

18. Looks where others are looking

IV. Health/Physical/Behavior

Response Options re: child

Not a Problem

Minor Problem

Moderate Problem

Serious Problem

1. Bed-wetting
2. Wets pants/diapers
3. Soils pants/diapers
4. Diarrhea
5. Constipation
6. Sleep problems
7. Eats too much/too little
8. Extremely limited diet
9. Hyperactive
10. Lethargic
11. Hits or injures self
12. Hits or injures others
13. Destructive
14. Sound-sensitive
15. Anxious/fearful
16. Unhappy/crying

17. Seizures
18. Obsessive speech
19. Rigid routines
20. Shouts or screams
21. Demands sameness
22. Often agitated
23. Not sensitive to pain
24. “Hooked” or fixated on certain objects/topics
25. Repetitive movements

Vita

Paula L. Ogston was born in Lansing, Michigan on April 1, 1981. She graduated with honors from Michigan State University in East Lansing, Michigan, where she received a BA in Psychology and a BA in Studio Art. While completing her graduate work at Virginia Commonwealth University, Ms. Ogston taught an undergraduate service-learning class that focused on child development; her students had the opportunity to volunteer at schools in the Richmond area. She also served as a teaching assistant for an undergraduate service-learning class focused on the juvenile courts system in Virginia and gave students the chance to tutor students in the Department of Correctional Education schools. Her current assistantship is in the Department of Special Education and Disability Policy, where she is a research assistant and behavioral consultant to preschool teachers in the Richmond area. Ms. Ogston lives in Richmond, Virginia.