

POST TO COPE: EXAMINING BLOGS AUTHORED BY PARENTS WITH  
DISABLED CHILDREN

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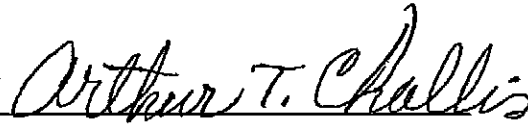
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# Post to Cope: Examining Blogs Authored by Parents with Disabled Children

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## ABSTRACT

In 2006, over 2 million American children were growing up with mental, physical, developmental and sensory disabilities in non-institutionalized settings. The numerous physical, social, and emotional struggles facing these children are obvious and well documented in the media and in academic research. However, one fundamental aspect of living with a disability has been long ignored and under-examined: the role of care giver. Parents of children with disabilities face unique burdens and issues while raising their children and how effectively these parents cope is directly reflected in the well-being of their children, families and communities. This study explores the coping strategies parents of disabled children use to cope by examining the strategies reported on their personal blogs. A generic criticism of parent authored blogs is implemented by applying the Brief COPE Framework (Carver, 1997) to observe parents' tendencies to use specific coping strategies. The results of this study indicate the use of certain problem- and emotion-focused coping strategies when raising a disabled child. Understanding how these parents cope by rhetorically examining a unique medium, extend coping theory to include disability as a coping event, and explore blogging as a unique medium used to cope; most importantly, this study will result in an increased understanding of the unique situation facing parents raising disabled children.

*Keywords:* Coping, Care giving, Blogging

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## Chapter 1: Introduction and Rationale

When blogging her experience of parenting a 10-year-old son with a mood disorder, one blogger explained:

This blog is about my life as a mom, raising a son with a mood disorder. This is a very tough journey and I hope that my words may allow others living with this illness to peek into my world and see that they're not alone. I'm also using this blog as a tool to process my own feelings and let go of some of the pain that I carry inside. If you too have a story to share, please post a comment, I'll be looking to hear from you. (Mama Bear, 2010)

While certainly rare, her experience is shared by parents throughout the United States. According to the *2006 American Community Survey*, conducted by the U.S. Census Bureau, over 2 million non-institutionalized children ages five to 15 years old live with one or more types of disability including sensory, mental, physical, and developmental handicaps.

An individual is considered disabled when he or she has a physical or mental impairment that limits the individual's ability to complete any major life activity (United States Department of Justice, 2011). A disabled child may suffer anything from hearing loss to severe cerebral palsy. Most disabilities require constant care and companionship from a parent. Support groups, doctors, and new technologies offer some help and relief to the parents of these children, but these care givers still deal with deep, unique feelings and emotions about their specific situation. Blogs have quickly become an outlet utilized by care givers to cope with the endless responsibilities of raising a disabled child. Blogger.com, an online community of women writing about all aspects of life, hosts 36,217 blogs; over seven thousand of those blogs are focused on the family. Within the family section of this one hosting site, nearly one hundred women write about the personal struggles of raising a disabled child. Outside of Blogger.com, other hosting

sites, databases, and personal blogs about raising disabled children are easily assessable with a simple Internet search. As parents struggle with the unique stress, confusion, insecurity, and social stigma of raising a disabled child, blogs are quickly becoming a prevalent outlet for these care givers to gain valuable social support, however this outlet has been relatively ignored by scholarship. While research has focused on the unique perspective of the disabled or ill (Frank, 1998; Heilferty, 2009), relatively few studies have explored the experience of siblings, grandparents, extended family, neighbors, friends and parents who intimately experience disability through care giving.

Studies have explored the issues parents of ill children face (Bluebond-Langner, 1996), the cognitive and social strategies care givers use to cope (Lin, Huang, and Hung, 2009), and the effects of care giving (Green, 2004), but no current literature specifically addresses how parents cope through online rhetoric. This study investigates the life experiences of parents with disabled children by qualitatively exploring coping strategies used in parent authored blogs; thus, giving voice to those who “too have a story to share” (Mama Bear, 2010). The results of this analysis hold both theoretical and practical implications. The theoretical expansion of coping research, extension of disability as a coping event, and examination of blogging as a unique medium used to cope, all serve as rationale for this research.

Originally developed by Lazarus and Folkman (1984), the guiding theoretical framework of this study is coping theory. An array of coping theories have been quantitatively developed to include coping styles, coping patterns, and predicates of coping behavior (Carver, Scheier, & Weintraub, 1989), however qualitative application of coping theory is relatively limited. By qualitatively applying the Brief COPE Framework (Carver, 1997) to expand outside of empirical measures, this study will not only extend current theory, but give increase to the depth and

meaning of current findings. Currently, the act and rhetoric of coping is being limited to something measurable, while the very act of coping is inherently humanistic; dependent on the situation and involved actors. Under certain circumstances (e.g. such as parenting a disabled child or dealing with family crisis) coping strategies may be altered or expanded to fit the need of the individual and will subsequently be used in different patterns or for reasons other than those outlined by empirical frameworks. Understanding how individual's tailor behaviors to fulfill particular needs will lead to appreciation of individual communication, meaning, and experience in a plethora of situations while allowing coping theory to be applied beyond numbers and data. For example, the care giver of a child with hearing loss will have a vastly different experience than the care giver of a child with Down Syndrome. While both children will deal with developmental delays, the child with hearing loss, and his or her parent, will be faced with the cultural debate surrounding cochlear implants. The care giver's ability to cope with not only the disability but the very intense social debate will depend on the unique, personal coping strategies employed.

By focusing on the coping strategies used by parents with disabled children, this research serves as a springboard to other qualitative examinations of coping situations. By recognizing how parents utilize blogs to cope, more research could examine the effectiveness of the medium as a therapeutic tool. The successful examination and evaluation of parent authored blogs could also lead to similar examinations in other rhetorical contexts. The coping strategies of unique groups could be more easily explained and human behavior understood. Practically, a deeper understanding of the individual meanings assigned to coping could lead to more effective professional and informal therapy as blogging becomes an alternate outlet used to assist in the coping process.

As a very specific form of rhetoric, coping is unique because it targets how individuals process stress (Carver, Scheier, and Weintraub, 1989). This study will extend the genre of coping to include disability as a coping event, thus making the theory applicable to a greater range of rhetorical situations. The social, emotional, and personal issues surrounding disability can certainly be classified as stressful events that require participants to cope. Disabled individuals and their able-bodied care givers are placed in an environment that requires them to abandon a sense of normality and function with new rules and norms (Lin, Huang, Hung, 2009; Ramsay, 2010). For example, a child's disability may lead to a social stigma that requires care givers to consistently explain their child's physical, mental or emotional issues or justify their decisions concerning schooling, medication or care. Subsequently, some basic social rules may have to be abandoned to accommodate interested parties. As with any traumatic situation, this adaption requires coping. As a field of study, coping, purports to explore how and why individuals and groups assign meaning to life experiences that are outside the normal or usual. Exploring the personal, family and social implications of parenting a disabled child will increase understanding of how parents cope. This serves to extend existing coping literature, as well as influence practical changes in the development and implementation of professional and social support systems.

In addition to strengthening the current literature concerning coping, this research serves two purposes with regards to research about blog use. First, it serves as an extension of the current body of research concerning online interaction. Communication based in online mediums has rapidly increased in popularity and practicality. According to the Pew Internet and American Life Project (2010) 90 - 100% of adults over 18 use email, 80 – 89% use social networking sites, and 10 – 19% use blogs with the primary purposes of connecting with people

(Zickuhr, 2010). The internet is an open form of communication unbound by time or space, which allows users to exchange and disseminate information (Papacharissi, 2002). While the original application of the Internet was to find information, socializing has quickly become one of the most important uses of online mediums (Baym & Lin, 2004). As Internet communication gains reputation, users are quickly becoming major online producers of both professional and personal information. Blogs have been credited with expanding social circles (Papacharissi, 2002), replacing traditional journals (Wei, 2009), giving public meaning to illness (Heilferty, 2009), and increasing writer empowerment (“*Blogging Illness*”, 2008), but few studies have examined parents as blog authors seeking to cope.

Similar to a traditional journal, blogs allow the cathartic release of anxiety. Blogs are highly personal narratives that assist in construction of self-concept (Stefanone & Jang, 2008) and allow the author to vent or explore ideas and feelings that are contrary to popular consensus. However, unlike conventional journals, blogs are a form of public expression. This allows an author to give public meaning to his or her story. In illness blogs, assignment of public meaning to an ailment includes providing context and perspective about the illness and its sufferer, while diminishing the psychosocial effects of the illness (Heilferty, 2009). Similarly, blogs allow a caregiver to put their unique situation in perspective. Through blogging, caregivers give a life to their unique struggle by expressing the fears, joys and trials of caring for a disabled child. This rhetorical release provides a controlled environment in which caregivers can tell their personal story (“*Blogging Illness*”, 2008).

One side effect of blogging is a sense of empowerment (Heilferty, 2009). Blogs allow users to carefully construct a personal story by selecting what information to share. This level of

control may serve as a relief to care givers who have limited control over the health and well-being of their disabled child.

In addition to providing a cathartic release that empowers and gives meaning to the author, blogs also provide a public forum for the personal experience of care giving ("Blogging Illness", 2008). Subsequently, the second purpose of utilizing blogs in this research is to explore social support as a function of blogging. Blogging has been examined as a form of coping because it increases the authors' ability to gain social support (Baker and Moore, 2008; Heilferty, 2009). As with bloggers who write about overcoming illness ("Blogging Illness", 2008), blogs give parent care givers the opportunity to publicly organize, understand, and assign meaning to their situation, while encouraging interactive social support with known and faceless publics. By reaching out to interested audiences, care giving bloggers connect with peers by sharing stories, ideas, and knowledge about disability, their personal situation and their ability to cope. The anonymity of online interaction may lead to increased openness in communication, which allows an author to honestly express his or her feelings and connect with trusted publics (Papacharissi, 2002). Blogs also allow care givers to more fully develop existing relationships. By capitalizing on the interactivity blogging allows, via reader comments, blog authors can maintain discourse with concerned parties and receive important feedback (Stefanone & Jang, 2008). As the care giver of a disabled child, blogging becomes an outlet parents utilize to enhance social support and, subsequently, the ability to cope. Social support is essential to the well-being of care givers and blogging allows authors to openly and interactively gain and maintain support.

By exploring coping strategies commonly used in blogs written by parents of children with disabilities, this study will expand current coping theory to incorporate a qualitative, humanistic perspective. It will extend the idea of coping to disability events, thus allowing

greater explanation of communication phenomenon while also extending the current body of research into online interaction, and it will increase the theoretical and practical implications of online social support through blogging. In addition to expanding research and theory, ultimately, this study will give meaning to the experiences of care givers who daily struggle to cope while raising their disabled child.

The following chapters will outline and discuss significant research concerning coping, blogging, and parenting disabled children, provide a qualitative framework for rhetorical analysis, and conclude with a discussion of results and application.

## **Chapter 2: Literature Review**

The following literature review will discuss three areas of research pertinent to the results and purposes of this study. First, an examination of care giving, with specific focus on care giving for the afflicted, is needed to understand the unique experiences care giving parents face. A discussion of the research surrounding the utilization and popularity of blogs as personal journals and mediums of social support will follow. Understanding how and why afflicted individuals' use blogs will increase the benefits of blogs to authors and readers. Finally, a review of current literature surrounding coping and its potential function in the blogs of care givers will be concluded with research questions.

### **Care Giving For the Afflicted**

An extensive amount of research focuses on family members who see to the needs of loved ones through care giving. More specific research within the genre examines and explains how care givers tend to ill or disabled family members. For example, Kleinman (1988) explains that the chronic disorder, or disability, of a loved one becomes like a sponge that soaks up the personal and social world of the care giver. Essentially, the care giver becomes as much a part of the illness or disability as the afflicted person (Ramsay, 2010). Not surprisingly then, much of the literature concerning care giving of the ill focuses on two major categories: the issues and burdens care givers face and the formal and informal support necessary for care giver well-being.

The issues that care givers experience in tending to a disabled loved one range from physical exhaustion to emotional pain. Leflay (1996) outlines three specific types of burdens faced by care givers: situational burdens, societal burdens, and iatrogenic burdens. Situational burdens include both the objective and subjective physical aspects of living with a disabled individual. The investment of time, energy, and money in seeking medical care, disruption of

household routine, and withdrawal from other important family and social relationships are examples of objective situational burdens. Subjective situational burdens include the mental and physical demands of care giving, social isolation of the care giver, empathic suffering for the afflicted individual and feelings of isolation, depression and guilt. Societal burdens are described as cultural attitudes towards the families of the disabled, cultural attitudes toward the disabled individual and the deficiencies of service systems. Stigmatic cultural attitudes towards the family include perceptions of parental causation, ignorance of family burdens, and shame by association with the disabled individual. Attitudes about the mentally and physically disabled are highly stereotypical; some stereotypes include negative expectancies of recovery, societal indifference and misunderstanding. Finally, iatrogenic burdens are characterized by clinician deficits such as failure to provide information, perpetuation of cultural stigmas and inappropriate or ineffective treatment.

While the objective situational burdens of care giving are perhaps the most visible to outside observers (Bluebond-Langner, 1996), the subjective situational and social burdens are the most examined. Situational burdens are most commonly examined as the personal implications or challenges the care giver must face. In 2009, Phelps, Hodgson, McCammon and Lamson found that parents of autistic children face seven common implications, primary among those being psychological. Psychological implications include the emotional, cognitive and behavioral aspects of having a child diagnosed with autism. Although the negative implications of care giving are obvious, care givers reported both positive and negative aspects. Higher levels of selflessness, more patience and greater compassion for others were all reported as positive implications. Among typical negative implications such as sadness, hopelessness and depression researchers indicated lower self-confidence in care givers as a unique finding (Phelps, Hodgson

& McCammon, 2009). The authors reported that care givers typically attributed lower self-confidence to societal pressures and expectations to be a good parent. In her own auto-ethnography about caring for her mother, who suffered from dementia, Salmon (2006) explained that her personal cost of caring included the physical and mental fatigue of maintaining constant vigilance over her mother while attempting to preserve a sense of normalcy in her professional and social life.

The balance between care giving and personal well-being is tedious. Feelings of frustration, exhaustion, depression, and embarrassment can often lead to care giver guilt. In order to gain a clearer understanding of one aspect of care givers' life experiences, Lin, Huang, and Hung (2009) posited five types of care giver guilt. Care givers frequently blame themselves for causing the illness or disability, for hospitalizing an ill child, or for neglecting healthy family members. Self-blame was also common as care givers felt guilt for being health, whole and participating in social activities without a disabled family member. Care giver guilt often leads to feeling of incompetence in a parent's abilities to raise a disabled child (Lin et al., 2009) as well in the ability to control the situation (Green, 2004).

Care giver well-being is significantly correlated with feeling of control over matters of health and care of a disabled child. In their survey of mothers raising disabled children, Green (2004) found that internality (problem-solving), desire for information, powerful other and chance were all factors of a care givers ability to feel in-control. He explains that parents are totally unprepared for the uncommon life experience of having a disabled child and thus feel that the situation is beyond their ability to manage; however, mothers who approached the situation with high internality, a tendency to focus on problem-solving, were more likely to feel less

distress. A strong belief in chance and an adequate balance between internality and the need for information also increased well-being.

The situational burdens of caring also extend beyond the primary care giver to affect the entire family. Parents often feel the strain of tending to the needs of their disabled children, as well as the priorities of typical siblings, which can lead to familial conflict (Bluebond-Langner, 1996). In their examination of families with school-aged children suffering from attention-deficit hyperactivity disorder (ADHD), Lin et al. (2009) report that misunderstanding between spouses about how a disabled child should be cared for often lead to marital conflict. Other implications for families include uneven distribution of time between disabled and typically developing children, which may lead to jealousy and increased conflict between siblings. More positively, however, stronger familial connections and a greater value of progress were seen as positive familial implications (Phelps et al., 2009). As care givers face the aforementioned situational and social burdens, many feel a lack of formal and social support as leading to increased iatrogenic burden (Leflay, 1996) and a decreased sense of well-being.

Care giver well-being is indicated by factors such as low stress levels, adaptability, high functioning families, marital satisfaction, high self-esteem and healthy child development (Canary, 2008). In order to reach a state of wellness and competence as a care giver, parents need both formal and informal social support (Canary, 2008; Phelps et al., 2009). Formal support is typically provided by clinicians, medical doctors, or government programs. Leflay (1996) indicated that a lack of formal support is a major burden faced by the parents of mentally disabled children. Not only does this lack of support propagate social stigmas surrounding the disabled and their families, it also leads to increased care giver stress because formal services such as schools and respite care, are unavailable or inefficient. For example, one major

complaint of mothers with ADHD children is the lack of professional support systems (Lin et al., 2009) which leaves care givers with a poor understanding of the nature of ADHD, a lack of efficient skills to deal with the disability, and incompetent professional resources. Formal support is usually a primary source of information for care givers, and when that informational system fails, care givers are left with less control over their child's health (Green, 2004).

Similarly, informal support is necessary to care giver well-being. Informal support is the perception of emotional and physical helpfulness from friends and family (Canary, 2008). High levels of informal support are associated with lower parental stress, greater feelings of parental empowerment, and high levels of marital satisfaction (Canary, 2008). Establishing strong social support networks also allow care givers to maintain a sense of personal normalcy (Salmon, 2006). Informal social support may be found by sharing care giving duties with other family members (Lin et al., 2009). In a synthesis of prior research surrounding social support for care givers, Canary (2008) reported that most studies concerning extended family support indicate that relationship qualities and knowledge about the disability contribute to the effectiveness of support from extended family such as grandparents. Mothers of disabled children report greater well-being when they perceive other family members, especially their spouse, as being supportive by sharing child care duties (Lin et al., 2009).

Because illness is becoming increasingly connected to the care giver and his or her narrative (Ramsay, 2010) social support for care givers has become a cultural experience. When comparing Western and Chinese care givers, Ramsay (2010) explained that Western societies view disability as a tragedy that should be grieved and then overcome with assistance from important social groups. Similarly, Chinese societies view disability as they would a natural disaster, a social phenomenon requiring group efforts to reconstruct lives and futures. Whether

formal or informal, social support gives care givers an outlet for their personal stories (Frank, 1998). Support allows care givers a sense of empowerment (Green, 2004), strengthens care giver emotion (Canary, 2008) and, ultimately, provides more coping opportunities (Phelps et al., 2009).

The stress of care giving is abundantly evident, but the positive aspects of care giving are also reported (Phelps, Hodgson, McCammon & Lamson, 2009). For example, when examining the narratives of family care givers to the mentally ill, Ramsay (2010) reported that care givers found gratification in engaging in a supportive role. Respondents also indicated a heightened sense of self worth and appreciation of others, which led to personal inner growth. Reports of a positive care giving experience may be partly attributed to how individual's cope. Current research places emphasis on the importance of social support to care giver well-being, but few studies address what other coping strategies care givers use to view their role as positive.

Ramsay (2010) briefly describes two coping techniques parents might utilize as cognitive coping strategies and social coping strategies. In a self-report, Salmon (2006) indicates that positive reframing, taking breaks, and creating meaningful shared activities are among her coping strategies. However, a more systematic examination is necessary to understand how care givers actually cope with their unique situation, particularly how parents cope with raising a disabled child.

### **Blogging about Illness**

As online communication becomes increasingly popular, personal blogs have been widely adopted as a medium for individuals to enhance relationships and publish personal information (Stephanone & Jang, 2008). Much like a personal journal, blog narratives allow authors to publicly share their story (Heilferty, 2009). Unlike typical personal blogs, those

authored by the ill have unique characteristics and a specific purpose. Heilferty (2009) explains the defining characteristic of illness blogs as “contents [which] are written to describe or cope with the uncertainty, stress, identity changes and the changes in personal and family identity that come with illness” (p. 1542). The subject matter of illness blogs usually focuses on personal transformations as a result of illness, specifically transformation of the body, emotional state or relationships (“Blogging Illness”, 2008), and include narratives concerning mental or physical disability (Heilferty, 2009). Illness blogs are also used to document the hopes, fears, challenges and successes of the author (Bluebond-Langner, 1996). Much of the research surrounding illness blogs concerns why ill individuals author blogs and how those blogs benefit the authors.

Typically, blogs are utilized as a medium for organizing ideas and processing emotionally charged situations while engaging in cathartic emotional expression (Baker & Moore, 2008). Two inherent features of blogging serve as the primary motivators for ill individuals to author a blog. First, blogs allow users to thoughtfully create messages and project self with full editorial control (Schau & Gilly, 2003; Stephanone & Jang, 2008). Second, blogs allow users to maintain existing relationships and gain social support by interacting with readers (Baker & Moore, 2008). *M/C Journal* (“Blogging Illness”, 2008) reported, “Blogs written about and in the context of personal illness are a perfect example of the inclination to speak the truth of oneself in the confessional mode of modern culture” (p. 3). In an examination of why individuals utilize personal web pages, Schau and Gilly (2003) proposed that users are initially motivated to construct an online self, whether that self mirrors reality or is the perceived ideal. The online self created by blog authors is highly controllable allowing users to present only the personal information or story they want to share, thus controlling how an audience perceives author identity.

In addition to controlling depiction of self, blogs allow the author to control what aspects of their illness story to share (“Blogging Illness”, 2008). Frank (1998) explains that the deeply ill share three types of stories. Stories of restitution are told by newly diagnosed individuals and focus on how that individual is attempting to regain good health. Chaos stories are usually told by those without any hope of restituting good health, and these stories focus on the individual falling more deeply into illness. A quest story describes living with illness and learning from the condition in hopes of educating others. In an effort to connect with audiences, bloggers usually tell these stories accurately and realistically in blog posts (Stephanone & Jang, 2008). Heilferty (2009) reports that narrative expression of illness or disability helps to diminish the psychological side effects of coping. The creation of these narratives online, provide those who create and read them a clearer understanding of the meaning, context, and perspective of illness. Although not anonymous, like other social media outlets, the increased control provided by blogs may lead to more open self-expression (Schau & Gilly, 2003). In their evaluation of the motivations and strategies individuals use when constructing a personal website, Schau and Gilly (2003) report that users use their sites to “enact selves with which they choose to communicate with other web participants” (p. 394). They also reported that users create a likeness of their physical self as well as a digital association with important personal relationships, objects and places by posting specific pictures, using certain language and implementing particular design features (i.e. background pictures, headers, and colors). Bloggers are also able to share feelings and stories without the physical constraints of face-to-face communication, thus online communication may be more useful for those who find conventional communication channels ineffective or unrewarding (Papacharissi, 2002). Blogging allows individuals with low mobility a medium of self-expression that can expand social horizons. Thus, blogging becomes a functional

alternative to traditional methods of expression, such as conversations, photo albums, or letters, which allows users to connect with others in effective communication. Subsequently, the increased control of blogging allows users to more accurately tell their story to successfully connect with audiences and gain social support.

Connection to an audience, known or unknown, is the second motivating factor for ill individuals to author a blog. Usually, bloggers use the informative nature of blogs to enhance existing relationships by writing their story for an audience of friends and family to read (Stephanone & Jang, 2008, 20). Blogs are comparable to an online journal where authors can vent or alleviate stress (Papacharissi, 2002); however, the primary difference between coping through journal writing and blogging is interactivity (Baker & Moore, 2008). Reader feedback, in the form of online comments, helps bloggers interact with their audience and gain vital informational support in an open and transparent interaction. In exploration of the ongoing expression of day-to-day illness experiences, *M/C Journal* ("Blogging Illness", 2008) reported that blogs are the beginning of a shift toward openness and transparency in the discussion of illness and disability. While bloggers can create private, invitation-only blogs, many blogs are public forums open to other bloggers or information seekers. Blog networks are also becoming more common as individuals seek emotional and informational connections online. Specifically for care givers, blogs allow authors a forum to express deep emotion, reach out to peers, and discuss the details of their child's illness and how they, as the care giver, cope with that illness (Heilferty, 2009). As discussed above, much care giving research points to the necessity of social support for care givers. In addition to providing a form of social support, several other benefits of blog use have been examined.

As illness and disability are becoming less socially stigmatized, blogs assist authors in giving public meaning and visibility to illness (“*Blogging Illness*”, 2009). By writing their unique story, authors allow readers to vicariously experience illness, thus increasing reader understanding, empathy, and perspective (Heilferty, 2009). Bloggers also post to strengthen social networks (Baker & Moore, 2008). By connecting with other care givers, the blogs of care givers help to enhance supportive relationships that serve as formal and informal social support (Canary, 2008). Anonymity, openness and interactivity of blogs also allows more therapeutic value than face-to-face interaction (Baker & Moore, 2008) as blog authors fully narrate concerns, difficulties and successes.

Authoring a blog provides several benefits to the afflicted including gaining more social support, giving public meaning to illness, and dealing openly with emotional issues; however, most research focuses specifically on the ill or disabled author rather than the care giver. As Ramsay (2010) explained, illness and disability is becoming increasingly connected to the care giver; thus, in order to expand current research surrounding blogging about illness, this study focuses on examining blogs authored by care givers. Many of the motivations and benefits of blogging will likely be similar to those examined here, but the unique perspective of care givers will result in a greater understanding of how blogs shape their experiences of affliction and coping.

### **Coping**

When faced with an unavoidable stressful situation, such as raising a disabled child, individuals must be able to effectively move past that stress to maintain physical and mental well-being. One widely recognized process used to do so is called coping. Initially developed as a psychological explanation of how individuals recognize, appraise and react to stress (Lazarus

& Folkman, 1984), coping theory has since been implemented in communication scholarship. Coping is defined as “constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Lazarus & Folkman, 1984, p. 141). Coping has been consistently described as a process that is emotion- or problem-focused and based on individual personality traits or social patterns.

Coping is typically viewed as a process. Folkman, Lazarus, Dunkel-Schetter, DeLongis, and Gruen (1986) describe the regulation of stressors as a two-step process: (1) cognitive appraisal and (2) coping. Step one, cognitive appraisal, includes primary and secondary appraisal. In primary appraisal an individual determines his or her personal stake in a potentially stressful situation. Once a stake is recognized, a person engages in secondary appraisal where the options for preventing or altering the stressful situation are evaluated. In the care giving situation, the individual would appraise the harm and benefit with respect to their commitment to and value of their disabled loved one (primary appraisal) and then determine what can be done to deal with the unavoidable situation (secondary appraisal). Step two of Folkman et al.’s (1986) process is the actual act of coping wherein an individual employs a specific strategy to mitigate the effects of the stressor.

In their study of how college students cope with mid-term exams, Folkman and Lazarus (1985) also describe three natural stages to stressful situations by explaining a dynamic, evolving process. In the initial, anticipation, stage an individual prepares for an upcoming encounter. This stage is marked by students’ search for information and social support as they anticipate taking the exam. The second stage, waiting, occurs between exam completion and issuing of score. In this stage and the final stage, outcome, students sought primarily for emotional support as they deal with test results.

As a process, coping is a dynamic encounter and thus should not be examined as a static, unitary event. Primary and secondary appraisal lead to coping which, if unsuccessful, will lead to reappraisal, and in each step different levels of anticipation and waiting will result in the selection of coping strategies which may or may not result in a satisfactory outcome. The selection of a specific coping strategy cannot be judged as good or bad but rather as individually effective or ineffective dependent on the resulting relationship between individual and stressor (Pearlin & Schooler, 1978). To reach a positive outcome, individuals employ strategies dependent on individual personality characteristics, situational contexts, and the type of stressor encountered.

In their seminal study of social and situational coping, Pearlin and Schooler (1978) identified common resources and responses individuals use when coping in four role areas: marriage, parenting, occupation, and personal finances. Resources refer to innate personality characteristics, specifically individual self-concept, self-denigration, and mastery. Coping responses are the actual behaviors and cognitions individuals use to cope with life-problems. When faced with occupational or financial concerns, Pearlin and Schooler reported that an individual's coping resources were most important in mediating the problem. Conversely, when faced with marriage or parenting stressors, an individual's utilization of multiple coping responses resulted in more positive outcomes. Thus, relatively impersonal issues, like professional and financial strain, may be most effectively resolved with manipulation of goals and values while maintaining personal distance from the problem, while highly emotional problems, such as marriage and parenting, are best handled by multiple coping responses that show high commitment and engagement.

Coping has been examined as both an individual personality trait and as a function of the situation. Coping as a trait refers to the way individuals prefer to cope regardless of situation (Carver et al., 1989). Historically, coping is examined as highly individualized in highly individual situations; however, Pearlin and Schooler (1978) explain that since many of the impinging forces that cause individual stress are social in origin, coping should be examined as a function of situation. When considering the situation or context surrounding coping, factors such as novelty, predictability, ambiguity and timing all influence how individuals respond to stressors (Lazarus & Folkman, 1984). Many difficult situations, like parenting a disabled child, are not exceptional situations experienced by uniquely incomparable people, but are persistent burdens consistently experienced by many people. Thus, examining coping with a situational approach also allows an examination of common strategies and types of coping.

The two most recognized types of coping are problem-focused coping and emotion-focused coping (Carver et al., 1989). Problem-focused coping is aimed at problem solving or actually doing something about the sources of stress (Folkman et al., 1986). This type of coping is usually active and is used when an individual appraises high stakes in an encounter along with a high probability of resolving the issue. Emotion-focused coping is aimed at reducing or managing emotional distress (Carver et al., 1989). Individuals usually utilize emotion-focused coping when a stressful situation must be accepted or endured rather than resolved (Folkman et al., 1986). For example, stress at work is associated with higher levels of problem-focused coping as most related issues can be solved, while health related issues are associated with emotion-based coping because an illness must be emotionally reconciled (Folkman & Lazarus, 1980). Just as in other health-related situations, parents of disabled children faced with the task of care giving will likely use more emotion-focused strategies because they perceive the situation

as needing to be accepted rather than changed. It is important to note, however, that most stressful situations are managed with both types of coping. In their study of 1,332 coping episodes in a middle-aged sample, Folkman and Lazarus (1980), found that less than 2% of individuals used only one type of coping.

While most research focuses on coping with daily stressors, two studies exemplify coping with illness (Carver, Pozo, Harris, Noriega, Scheier, Robinson, Ketcham, Moffat, & Clark, 1993; Lutgendorf, Antoni, Ironson, Starr, Costello, Zuckerman, Klimas, Fletcher, & Schneiderman, 1998). When examining what coping strategies are most effective in group therapy sessions for HIV-positive men in dealing with illness, Lutgendorf et al. (1998) found that high levels of active coping and acceptance resulted in decreased stress. These results indicate that acceptance of an illness is the outcome of a series of adjustments throughout the course of the disease. Initially, patients must accept the diagnosis of illness and as the illness progresses acceptance of each specific issue or symptom of the illness becomes necessary. Similarly, women with early stage breast cancer reported less distress pre-surgery, post-surgery and six months after treatment when utilizing acceptance as a primary coping strategy (Carver et al., 1993). Given the nature of coping with illness, strategies used to actively problem-solve may not be effective because an illness is unavoidable and must be accepted; thus, an ill individual cannot begin to actively cope with a challenge until it has been accepted.

As applied to human communication, coping theory is a valuable tool in understanding the unique perspectives of individuals under stress. While the purpose of this study is not to explain the process of blogging to cope, a difference of strategies may inherently rise out of the extended examination. Based on the literature presented here concerning care giving for the afflicted, blogging about illness, and coping the following research questions are proposed:

RQ 1: What coping strategies are evident in the blogs authored by parents of children with disabilities?

RQ 2: Are the primary coping strategies evident in those blogs effective for parents of children with disabilities?

### **Chapter 3: Method**

In response to the research questions posited by this study and to fulfill the call for more subjective examination of coping (Folkman & Lazarus, 1980), a generic analysis was chosen as the method of analysis. The results of this analysis will be a direct observation of the strategies parents employ when coping with the burdens of raising a disabled child.

#### **Sample Texts**

To collect sample texts for analysis, a cluster method was used. Cluster samples are most valuable when obtaining a random sample is impractical (Frey, Botan, Friedman, & Kreps, 1991). When examining online content, knowing the entire population is difficult, thus cluster sampling is commonly utilized to provide the most random selection of personal online texts (e.g. Stephanone & Jang, 2008; Papacharissi, 2002; and Schau & Gilly, 2003). Initially, three blogging databases, [bloom-parentingkidswithdisabilities.blogspot.com](http://bloom-parentingkidswithdisabilities.blogspot.com), [parentingacomplexchild.blogspot.com](http://parentingacomplexchild.blogspot.com), and [blogher.com](http://blogher.com) were utilized to gather sample blogs. These databases were selected because they fulfilled three criteria. First, each database is easily accessible through an online search and is frequently updated with new content. Second, the databases were well linked with individual bloggers and other informational resources for parents, indicating that the databases, and the blogs they include, are popular resources for both blog writers and blog readers. Finally, these databases were selected because they focused on the writings of individuals dealing with a wide range of disabilities. For example, some databases like [autism-hub.com](http://autism-hub.com) contain blogs specific to parents of autistic children, but the database [bloom-parentingkidswithdisabilities.blogspot.com](http://bloom-parentingkidswithdisabilities.blogspot.com) contain the blogs of parents with autistic children, ADHD children, and bipolar children, among other disabilities. The examination of a

wide variety of care giver experiences is fundamental to understanding how care givers as a group cope rather than in the specific context of a single disability.

The first five blogs listed on each database's link list were selected for analysis. From this initial sample, only blogs with one author were selected. This limitation was imposed so focus could be given to care givers rather than advocates or therapy groups. A cursory examination of each blogger's profile was done to confirm that the purpose of the blog was to document experience raising a special needs child. This resulted in 10 blogs selected for analysis. Within each blog, the first 10 posts were examined resulting in 100 units of text. A complete list of the blogs can be found in Appendix A. Each blog was authored by the mother of a disabled child. While each blogger's style is unique, all of the authors indicated the need to share their experience raising a disabled child in the 'about' or 'profile' section of the blog. Five of the blogs were written by mothers with autistic children. The remaining five blogs were authored by mothers of children with cerebral palsy, a severe but unnamed seizure disorder, the neurological and physical results of a childhood stroke, and a mood disorder.

The selection of these sample texts fulfills Lazarus and Folkman's (1985) three criteria for adequately examining coping strategies. First, coping must be examined as a function of context. Second, the actual coping behavior must be examined as opposed to what the person usually does or would do. Finally, coping must be examined as part of a process. Criteria one is fulfilled by the examination of the specific context of blogs. Folkman and Lazarus (1985) suggest that examination of coping needs to be extended to more significant settings. While illness has been examined, care giving is an equally unique, significant context ready for examination. The second criterion is fulfilled by the observative nature of generic analysis. Most current research utilizes self-report, but Folkman and Lazarus (1980) call for more direct

evaluation. They suggest that observation of coping strategies may be more reliable because memory problems and retrospective falsification may affect the given results of self-report methods. The third criterion is fulfilled by an examination of multiple posts on each blogs, thus seeing an evolution of coping strategies within the narratives. The Brief COPE measure, posited by Carver (1997), was utilized as the framework of analysis.

### **Brief COPE Framework**

Originally developed by Carver, Sheier, and Weintraub (1989), the COPE Framework was a culmination of current coping measures. The scale consisted of 60 measures used to determine common coping strategies across stressful contexts and specific instances. Because the original scale was so extensive and arduous for participants, Carver (1997) reconstructed the scale, combing and redefining some measures into 14 scales. Although several coping frameworks, such as Lazarus and Folkman's Ways of Coping, have been widely applied in research, the Brief COPE measure addresses three specific issues found in other frameworks (Carver et al., 1989). First, the Brief COPE combines scales for both emotion- and problem-focused coping. Other measures seem to focus predominantly on problem-focused coping. Second, the Brief COPE measure seeks to reduce ambiguity by clearly focusing measures on the act that is being done. Each individual Brief COPE scale is focused in such a way that the measure could be applied retrospectively, concurrently, or dispositionally which allows more dynamic application (Carver, 1997). Third, and possibly most vital, the Brief COPE was developed both theoretically and empirically. Carver et al. (1989) explains that most scales are developed empirically and purported this scale as a combination of the empirical and theoretical in order to measure a wider range of coping strategies. For example, the strategies of denial, positive reframing and acceptance were developed empirically, through factor analysis, with the

underlying dimensions of those strategies only being described statistically. Conversely, the development of theoretically based strategies, such as active coping and planning, is based on rational interpretation of the functionality of those strategies.

The Brief COPE framework has been used in several health-related studies and as a measure for online coping communication. Lutegendorf et al. (1998) applied the finding of previous Brief COPE research to introduce the elements of positive reframing and acceptance in group therapy session for HIV-positive men and found that patients who implemented the strategies felt less disease related stress. Here the effectiveness of COPE strategies were measured with self-reports. The framework was also applied to explore the function of optimism in women diagnosed with breast-cancer (Carver et al., 1993). Several coping strategies suggested in the measure - acceptance, use of humor, and positive reframing - were found to have beneficial effects on patients, while denial and behavioral disengagement were found to have harmful effects. As typical, the strategies of the Brief COPE were measured by self-report. As an extension of the framework to online coping, Baker and Moore (2008) used the Brief COPE to analyze the intentions of new MySpace bloggers. They utilized an online self-administered self-report survey, and found that the most significant coping strategies used by bloggers are venting and self-blame. Use of planning and positive reframing were also prevalent strategies as blog posting became more frequent. While generally employed empirically, the Brief COPE was intended to examine a wide range of naturally occurring coping settings (Carver, 1997). Thus, the following 14 strategies as defined by Carver (1997) in the Brief COPE Framework will be applied to the sample texts.

The first strategy reflects personal action by the care giver. *Active Coping* is the process of taking active steps to try to remove or circumvent the stressor or to ameliorate its effects. For

example, statements similar to “I’ve been concentrating my efforts on doing something about the situation I’m in” or “I’ve been taking action to try to make the situation better” are evidence of active coping. The next three strategies indicate a change of care giver cognition concerning the stressor. *Planning* is thinking about how to cope with a stressor. Comments like “I’ve been trying to come up with a strategy about what to do” or “I’ve been thinking hard about what steps to take” are evidence of Planning. *Positive Reframing* is thoughts aimed at managing emotional distress rather than dealing directly with the stressor. Statements of Positive Reframing may include “I’ve been trying to see it in a different light, to make it seem more positive” or “I’ve been looking for the something good in what is happening. *Acceptance* is acknowledging the reality of the stressful situation. Comments like “I’ve been accepting the reality of the fact that it has happened” and “I’ve been learning to live with it” indicate Acceptance. While these three categories are closely related to Active Coping they do not signify any action on the part of the care giver but instead reflect intrapersonal thought.

Strategy five, *Humor* is the use of jokes or comedy to explain the situation. Individual’s employing humor may make statements like “I’ve been making jokes about it” or “I’ve been making fun of the situation.” Statements of humor should be found in the content of the message and not merely stylistic uses of sarcasms or wit.

Similarly strategy six, *Religion*, is not statements of belief but statements indicating the tendency to turn to religion in times of stress. Comments such as “I’ve been trying to find comfort in my religion or spiritual beliefs” or “I’ve been praying or meditating” indicate the use of religion as a coping strategy.

The use of support as a coping strategy is defined as two distinct strategies. *Using Emotional Support* is getting moral support, sympathy, or understanding from another party.

“I’ve been getting emotional support from others” or “I’ve been getting comfort and understanding from someone” are both examples of emotional support. Statements of emotional support focus on finding relief for distressed feelings not on gaining information. *Using Instrumental Support* is seeking advice assistance, or information from another party. These statements are exemplified by the passing of information from another party to the care giver. Statements of Using Instrumental Support include “I’ve been trying to get advice or help from other people about what to do” or “I’ve been getting help and advice from other people.”

The strategy of *Self-Distraction* is focusing more explicitly on doing things to take one’s mind off the stressor. Statements of Self-Distraction include “I’ve been turning to work or other activities to take my mind off things” or “I’ve been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping or shopping.” These comments do not indicate denial of the stressor but an avoidance of focus on the stressor.

Conversely, *Denial* is refusal to acknowledge the existence of the stressor. For example, “I’ve been saying to myself ‘this isn’t real’” or “I’ve been refusing to believe that it has happened” are both examples of denial coping.

*Venting* is the tendency to focus on whatever distress or upset one is experiencing and to ventilate those feelings. Statements of ventilation include, “I’ve been saying things to let my unpleasant feelings escape” or “I’ve been expressing my negative feelings”.

Turning to a substance for emotional release is categorized as *Substance*. “I’ve been using alcohol or other drugs to make myself feel better” and “I’ve been using alcohol or other drugs to help get me through it” are both examples of substance.

*Behavioral Disengagement* is reducing or giving up one’s effort to deal with the stressor. Statements like “I’ve been giving up trying to deal with it” or “I’ve been giving up the attempt to

cope” both exemplify Behavioral Disengagement. Again, this strategy does not reflect denial of the stressor, rather a discontinuance of previous coping strategies.

The final strategy, *Self-Blame* is attribution to self for causing the stressful situation to occur. For example, “I’ve been criticizing myself” and “I’ve been blaming myself for things that happened” both indicate Self-Blame.

### **Generic Criticism**

Generic Criticism was selected as the method of analysis for this study because it “is based on the idea that observable, explicable, and predictable rhetorical commonalities occur in groups of discourses as well as in groups of people” (Benoit, 2009). Edwin Black (as cited in Benoit, p. 79) suggested that there are a limited number of rhetorical situations with a limited number of responses resulting in similar rhetorical situations with share common features (Harrell & Linkugel, 1978). By observing and describing these commonalities, generic critics will be better able to understand rhetorical practices, help practitioners produce similar types of discourse, and apply analysis to other, unexamined genres (Benoit, 2009).

In this study, generic analysis was applied both inductively and deductively. While generic criticism is typically viewed as a deductive process, Benoit (2009) distinguishes between the two by describing the deductive approach as application and the inductive approach as description. In order to conduct a deductive analysis, texts must already be conceptualized as a genre. Conversely, the inductive approach applies a generalization to specific texts in order to develop a genre. As blogs authored by care givers have not been conceptualized as a genre, an inductive approach, was used to distinguish blogs as a genre by observing and explaining similarities among the texts. Simultaneously, a deductive approach was used to observe coping

strategies by applying the guiding framework of the Brief COPE. Exemplars of each observed strategy were recorded and used to address posited research questions.

This study applies the Brief COPE Framework to parent authored blogs in three steps: (1) identifying the defining characteristics, (2) carefully scrutinizing examples to identify similarities, and (3) explaining the observed similarities. Identification of the defining characteristics involves recognition of the situation, purpose, medium and kind of rhetor in the rhetorical situation. The generic situation of this study is parent reaction to raising a disabled child. The purpose of the rhetoric includes sharing personal narrative, gaining social support and coping with the burdens of care giving through the specific medium of a blog. The kind of rhetor in this situation is the parent blog author coping with raising a disabled child. These defining characteristics provide the basis for what artifacts, blogs, were selected for analysis, thus defining the genre of blogs.

Step two in the inductive analysis, scrutiny of the texts, was conducted by statements analysis. McLeod and Tichenor (2003) explain that units of analysis are “the objects that are the focus of the explanation” (p. 94). In analysis these units can range from single words to entire stories. In this study, the unit of analysis is a statement. Complete sentences, containing a subject and predicate, were considered statements. Sample texts were examined until thematic saturation was accomplished.

Step three, the explanation of observed similarities was completed in reporting the results of the examination. Generic criticism seeks to describe the actual practice of discourse (Benoit, 2009). Blogs authored by parents raising children with disabilities share similar characteristics which define them as a specific genre. Likewise, the motivations of those parents, to cope with

their burdens, are likely similar and the pursuance of those goals can be described by generic criticism (Harrell & Linkugel, 1978).

### **Chapter 4: Results**

Examination of the sample texts revealed that parent authors do utilize several of the strategies found in the Brief COPE framework, thus satisfying the research questions proposed by this study. The first research question asked what coping strategies are evident in the blogs of parents with disabled children. While twelve of the fourteen strategies suggested in the framework were evident in the text, two strategies, denial and behavioral disengagement, were absent. A discussion on the absence of these strategies and the fulfillment of the second research question posited by this study will be included in the discussion, what follows is an illustration of each coping strategies found in the sample texts.

#### **Active Coping**

Defined as the process of taking active steps to try to remove or circumvent the stressor or to ameliorate its effects, active coping was the most prominent strategy found in the text. When directly acting to alleviate the stress surrounding their parental responsibilities, many blog authors reported specific personal behaviors and specific activities used to cope. Bloggers often attempted to change personal behavior in order to cope. For example, Katy from *Bird on the Street* (2007, May 30) told of her encounter with a stranger interested in her son's medical

condition by saying, “I explained Charlie’s issues, and the woman didn’t run screaming from the building or anything.” This indicates an active attempt at alleviating the stress of staring eyes and questions that arise when taking her disabled son to the store by verbally acknowledging the stressor and explaining the circumstances.

In addition to altering personal behavior, the theme of active coping included specific activities done with or for the child. Jen from *Living life with a side of autism* (2010, May 27) indicates active coping when explaining her decision to allow her daughter a normal school field trip. She wrote, “I was told I could just bring Katie separately, but decided, to keep things as normal for her as possible, I would throw caution to the wind and allow her to go.” This statement shows an active initiative to remove the stress of unique treatment for herself and her disabled daughter by allowing Katie to go to school as usual with her typical classmates.

Similarly, Mama Bear of *My Son has 2 Brains: A Mood Disorder Blog* explained:

When our son would go into a rage, we tried giving him outlets to exert his anger, like punching a beanbag, but our son sadly said that I can’t do that since I need to destroy something to feel better inside. (2010, February 22)

Both of these examples indicate the use of a specific behavior or activity, allowing her daughter to attend the field trip and providing a physical outlet for rage, employed to actively cope with the stress or effects of the child’s disability.

Other examples of active coping include dealing with the financial burdens of treatment, “If our insurance fails to pay, we’ll do so with a smile because we know our son needs it till he’s at least six months” (Katy, 2007, October 30b), and physically altering the environment to fit the needs of a disabled child:

We put every last bit of our resources into this house, but it was worth it: Leelo now has the space and more of the resources he needs, his sisters have their own separate space it they need it, and our house is enticing enough that our friends and their children want to visit – and can stay over. (Shannon Des Roches Rosa, 2003, May 20)

Reports of active coping included altering personal behavior, facilitating activities or behaviors with or for the child, and dealing with the more material stressors of the disability.

### **Acceptance**

Acknowledging the reality of the stressful situation was another prominent theme in the text. While acceptance was usually focused on the larger situation of raising a disabled child rather than handling specific events or side effects, acceptance was explained both positively and negatively.

Themes of positive acceptance include utterances like “So, I guess Adam, who is autistic in a non autistic family, really does belong” (Estée Klar, 2008, December 15). Similarly, Kiralea Powell (2006, January 4) accepts her situation by writing, “This blog is all about Jordan and how I learn to cope with 3 children each with different needs. My life would not be the same without these challenges in life!” These two examples both indicate the author has acknowledged the reality of their situation but is doing so in with a positive perspective.

Blog authors also indicated acceptance of the situation with a more negative tone. Statements like, “we are tired, lonely, and wish for better. . . but we do what we have to do” (Claire, 2008, December 30b) and “There is no way to properly feel this, think about his. We just

do our best” (Elizabeth, 2008, July 21) illustrate that the reality of the situation has been accepted, but with a greater focus on negative aspects such as loneliness, struggle and pain.

### **Using Instrumental Support**

Unlike the use of emotional support, using instrumental support is the seeking of advice, assistance, or information from another party. These statements were typically found in question form. For example, after a particularly tough day Love That Max (2008, November 7) simply asked, “What works for you?” Other statements seeking instrumental support asked for specific information. Shannon Des Roches Rosa wrote:

Now, no one is more grateful than I that he is talking, doing so spontaneously, and giving great eye contact with these requests, but do I really, really have to play that frigging video all day long? It’s perseveration, right? Guidance! Please! (2003, July 16)

Whether asking a simple question or seeking specific information, all statements of instrumental support were petitions of more information or advice from an outside party.

### **Venting**

Venting is defined as the tendency to focus on whatever distress or upset one is experiencing and to ventilate those feelings. This theme was evident in several different contexts within these blogs. Several bloggers indicated their blog as an ideal medium to vent. Claire (2008, December 29) explained, “This blog is partly for me . . . to have the opportunity to rant somewhere other than in my head.” Utterances like these show a tendency, or at least the need, to vent feelings.

Venting was also directly expressed as feelings of distress over a child’s behavior, personal stress or social reaction to the child. Statements ventilating about their child’s behavior were most commonly in reaction to a specific situation. Concerning her daughter’s inability to

converse, Jen (2010, May 28) wrote, "I hate this part the most. Probably even more than the behavior issues. I want to be able to share with my daughter. . . hear about her day. . . hear about friends. . . anything." Mama Bear (2010, March 5b) also vented about her sons abusive behavior, "Emotionally I feel abused, I'm trying not to cry, I feel very sad for my other children who heard me screaming in pain." By ventilating the emotional and physical distress caused by their child's behavior, these mothers are able to cope.

Statements of ventilation were also made about the personal stress and social stigma associated with a child's disability. Jen (2010, June 14) described how raising her daughter affects her personally, "Really, it's not like I am blaming my husband it probably sounds that way, but life happens and just b/c it isn't happening to benefit me doesn't mean I can place all the blame on someone else." While attempting to positively reframe her situation, this statement indicates the tendency to alleviate stress by expressing her feelings. Likewise, Claire (2008, December 31) ventilates her feelings about how society reacts to her daughter when she wrote, "My daughter does not exist. . . nor do the hundreds of others living at home, cared for by parents, fighting neurological weirdness that makes their kids too hard to look at or handle in public places." Obviously distressed by the social stigmas assigned to her disabled daughter, this blogger, like the others, focuses on her own upset feelings and copes by venting.

### **Positive Reframing**

The theme of positive reframing includes thoughts aimed at managing emotional distress rather than dealing directly with the stressor. Blog authors usually reframed either their child's behavior or their situation. Comments focused on reframing the child's behavior usually focused on seeing a more positive future. For example, after her autistic son hides instead of interacting with his grandparents K.C.'s Mommy (2006, October 28) wrote, "I know in my heart one day

when my Dad comes to visit he is going to run out of his hiding spot and smile and sit with my Dad. He's so close to coming out!!" Reframing a child's behavior assist the blogger in managing the present emotional distress by mentally justifying the behavior or thinking about its positive aspects and outcomes.

Managing emotional distress by mentally creating a brighter future rather also extends to positively reframing the situation. For example, Katy (2007, November 11) reported, "As for what the future holds, who knows, but we try to stay hopeful." While looking for a brighter future, bloggers also reframe the situation by comparing it to another, direr, circumstance. For example, Kiralea Powell (drew comparisons between her experience and that of a fellow blogger:

Her dedication to Billy Ray and information provided helps you realize at times like myself, there are people out in the world who have too deal with a lot more, raising a child like Billy Ray.

Whether reframing a child's behavior or the situation, authors utilized this strategy to emotionally cope with stress by mentally creating a more positive experience.

### **Using Emotional Support**

Using emotional support was defined as getting moral support, sympathy, or understanding from another party. Rather than direct petitions for emotional support, these themes were most commonly an acknowledgment of support given to the blogger. For example, Kiralea Powell (2006, February 13) wrote, "Thanks to everyones kind words of support and encouragement. It uplifts ones spirits when you know you have people 100% behind you." This statement indicates that Emotional Support, while not necessarily actively sought, was given through supportive comments on the blog.

The emotional support provided by other blogs and blog authors was also a common acknowledgement of understanding. “I want to take this opportunity to thank all of my fellow Autism Hub bloggers, writers, friends, and an online community that threads us all together” (Estée Klare, 2008, December 16). Similarly, Claire of *Life with a Severely Disabled Child* (2008, December 31) wrote, “It was, frankly, a relief to read about someone experiencing the same thing as those of us with severely disabled kids.” By thanking their readers for support and other blog authors for sharing similar stories, these bloggers indicate their use of emotional support to cope.

### **Planning**

Planning is defined as thinking about how to cope with a stressor. Typically, this theme included explanations of how parents intended to actively cope with the stress of raising their child. For example, K.C.’s Mommy of *Autism Schmatism* (2006, October 8) explained, “I am hoping cooking in the kitchen will be some sort of break through for K.C. something we can do as a family and have fun.” Here, the author is planning on how to actively deal with the stress of including her autistic child in typical family activities but has yet to implement her strategy.

Similarly, Love That Max (2008, November 5) wrote, “While I like having Max around normally-developing kids, I also think it would be good for him to be with kids more like himself. I need to get going on that.” While the author has not actually taken her son to participate in a playgroup with other disabled children, she is planning to participate in that specific coping behavior.

### **Religion**

The use of religion includes statements indicating the tendency to turn to religion in times of stress. These statements include references to a supreme being and to religious practices.

Elizabeth of *a moon, worn as if it had been a shell* (2008, August 4) refers to a supreme being when explaining that “A hodgepodge belief in a Creator and a sense of humor” are how she copes. Similarly, Katy uses religion to explain why her son is disabled when she wrote, “He is just the way God intended for his purposes-not anyone else’s” (2007, November 28). These statements indicate a reliance on a religious belief in a supreme being to cope with the difficulties of raising a disabled child.

Likewise, the use of religion may be indicated by a reference to religious practices. This is exemplified by the reliance of prayer in *Mama Bear*. The author explained the influence of religion in her decision to medicate her son when she pens, “I honestly believe every parent takes this step with great caution and much prayer.” As an evident coping strategy, the tendency to turn to religion focused on either a reference to a supreme being or a reference to a religious practice.

### **Self-Distraction**

The strategy of self-distraction is defined as focusing more explicitly on doing things to take one’s mind off the stressor. Some authors indicate their blog as the means of their escape from daily stress, Kiralea Powell of *Jordans Life with Autism* (2006, January 15) wrote:

The last two weeks I have been feeling somewhat uptight, teary and it seemed my blog site was my only escape from reality, though everything I write is fair dinkom, was to get on my blog site and just type away.

Other bloggers describe other activities or hobbies, which allow them to focus on something other than their child’s disability. Love That Max (2008, November 7) listed “other stuff that keeps me sane: playing hide-an-go-seek with the kids. . .; reading. . .; going out for coffee and carrot cake with Dave;. . . actually calling friends instead of e-mailing” among other activities.

An important distinction of self-distractive behavior is the ability of the author to focus on something else while still recognizing the need to cope with the stressor. Unlike behavioral disengagement, this category does not indicate giving up on coping with the stressful situation; rather it indicates directing attention and effort elsewhere for a short time.

### **Substance**

In the Brief COPE framework, the theme of substance refers to turning to a substance for emotional release. For example, Kiralea Powell (2006, January 15) explained, “Well 5 days ago I started on my Prozac again, and feeling again somewhat normalised. While Prozac doesn’t work for some, it sure works for me.” Jen (2010, June 11) also described turning to a substance for emotional release, “In my quest to hold onto my sanity, I have been trying to find a good anti-depression and anxiety medicine.” Within these texts, substance themes refer specifically to the use of prescribed medication to cope with depression, anxiety, and stress.

### **Self-Blame**

The final category evident in the text was self-blame. When utilizing this strategy, bloggers coped through attribution to self for causing the stressful situation to occur. This theme was evident in bloggers’ explanations of why they had not taken active steps to cope with their child’s disability and its resultant stress. Love That Max uses Self-Blame twice when describing her son’s treatment. She wrote, “This leaves me feeling guilty, and I keep meaning to make plans with kids in Max’s class (he’s at a school for the disabled)” (2008, November 5). Later she describes her guilt at not learning about a new medical device:

On the Good Mom scale, I’d usually give myself an 8. But sometimes, I slip way down.

Take the fact that Max got a communication device in August, a Dynavox and Dave and I have still not really figured out how to use it. (2008, November 11)

Statements of self-blame found in the texts did not indicate attribution to self for the actual cause of the disability; rather authors attributed ongoing or increased stress as a result of the disability to their inaction.

### **Humor**

The strategy of humor was not abundantly employed; however, when bloggers did indicate their use of jokes or comedy to explain the situation it was to describe themselves as seeking humor. For example, Elizabeth described “An ability to see the absurd in just about anything truly horrifying is really what keeps me going and I figure it’s a blessing from the Creator” as her primary tactic to maintain stability (2008, August 4).

### **Additional Categories**

Although grounded theory was not the intent or method of this study, two additional categories arose naturally from analysis: (1) advocating and (2) providing instrumental support. As evidenced in the text, these two categories are definitionally distinct and mutually exclusivity from the existing Brief COPE categories, and may provide more specific insight into how the parents of disabled children cope.

**Advocating.** The category of advocating includes promotion of causes and awareness for and about the stressful situation. For example, Kiralea Powell (2006, February 18) advocated for the general support of disabled individuals:

Yes I am so excited. . . I want to be heard, listened to and fight for our sons and everyone elses children who are served a life sentence called. . . AUTISM. I want justice and it will prevail one way or another because funding is so inadequate within this area and the frustrations we as parents have to endure raising our children.

Here, advocating takes the form of a promotion of awareness for the situation facing disabled children and their families. Another example from *Estée Klar the Joy of Autism* focuses on a specific cause, “The Autism Acceptance Project is also on Facebook. Make sure to check us out there. If you haven’t already, sign up for our TAAProject newsletter at [www.taaproject.com](http://www.taaproject.com)” (Estée Klar, 2008, December 16). By promoting the Autism Acceptance Project cause, this blogger is advocating for the support of her child and her family.

**Providing instrumental support.** Contrary to the aforementioned category of Using Instrumental Support, which seeks for support, this category is defined as *providing* advice, assistance, or information to another party. The distinction between seeking support and providing support was obvious in the texts. An example of providing support is Mama Bear writing (2010, February 22b), “I figured I would make note of it in case another mom is looking for information they can relate to.” Here, the blogger is recording information and advice for other parents in a similar situation. Similarly, Kiralea Powell (2006, January 9) provided links to more traditional information in her post, “Here is some blog pages so far for people to read if you have not so far red any of them.” Many bloggers exhibited signs of wanting to reach out and help other parents with disabled children find important information or receive assistance.

## Chapter 5: Discussion

The purpose of this study was to gain a deeper understanding of how parents cope with the ongoing burdens and issues of raising a disabled child through generic analysis of parent-authored blogs. The 2006 American Community Survey reported over 2 million children ages five to 15 years with one or more types of sensory, mental, physical or developmental handicap are living outside of an institution, which means parents, siblings, grandparents, relatives or friends are coping with meeting the physical, mental, medical, and social needs of these children. Most current research surrounding the ability of caregivers to cope is empirically focused on care giving for the ill. Alternatively, by qualitatively extending coping theory, through the use of a recognized framework in the Brief COPE, to the online rhetoric of primary caregivers, this study observes what coping techniques are commonly used by parent care givers and how those techniques are used to explain parents' experience.

This discussion will address how blogs can be used in rhetorical analysis and it will explore qualitative examination of coping. The second research question of this study, examined the effectiveness of the primary coping strategies evident in the blogs. Although frequencies were not reported in this study, the strategies most commonly reported by parents were: active coping, acceptance, using instrumental support, venting, positive reframing and using emotional support.

The most prevalent, and likely the most effective strategy, is *active coping*. While raising a disabled child is undoubtedly an unchangeable situation that should elicit emotion-focused coping approaches, active coping focuses on altering the situation in a problem-focused manner (Lazarus & Folkman, 1984). Parents indicated active coping as the primary strategy to deal with specific problems related to their child's disability. Typically parents wrote about directly

confronting an issue and actually changing the environment surrounding that issue to ensure it would not occur again. This approach proved effective in handling the daily situational, societal and iatrogenic burdens facing parents as they reported feeling satisfied with the results of their actions.

Another prominent problem-focused strategy was *using instrumental support*. Parents typically solicited instrumental support from informal sources and directed queries to other parents in similar circumstances. Research has explained the necessity of social support for caregiver wellbeing. Using their blogs to gain information and support allowed parents to reach a wide audience, including friends, family, professionals and, most commonly, other parents. By reaching these audiences, parents were able to gather information which would otherwise be unavailable.

While two problem-focused strategies were obvious and supported the efficiency of this approach, a greater number of emotion-focused strategies were observed. The primary strategy focused on dissipating emotional distress as *acceptance*. Statements of acceptance indicated that parents recognized the reality of their situation, which allowed them to utilize other, more active, strategies. Although acceptance is a personally active strategy, as parents mentally reconciled their thoughts, emotions and expectations about their child's handicap, it does not involve physically doing something to alleviate their stress; rather, acceptance leads to the use of active coping and instrumental support as physical remedies to burdens. Carver et al. (1989) describes acceptance as a positive strategy when circumstances must be endured because it allows them to become engaged in coping. Acceptance may also be an obvious coping strategy because raising a disabled child is not a situation that can be changed or altered but must be accepted, thus parents

would cope by accepting their child's circumstance and each symptom or burden that develops as a result.

Emotion-focused coping was also indicated by the use of *positive reframing*. Utilizing this strategy allowed parents to cope by subscribing more positive characteristics to their child's condition or behavior. This strategy was typically applied in a wishful context where parents explained their hopes for the future and focused on how their child's condition may improve. As an emotion-focused technique, reframing the situation more positively likely assisted parents in resolving the cognitive dissonance that occurred when considering their disabled child through their expectations of a typical child with typical behaviors and development.

While the strategy of *venting* has been viewed as a negative indication of emotional well-being (Carver et al., 1989), parents often ventilated complaints about specific situations or events, like a disengaged doctor or a child's tantrum, rather than complaining about their terrible circumstances or the personal burdens of their child. In this context, venting served a useful function as blogs are usually a forum whereon individuals can freely express emotion. Although venting is typically perceived as a negative strategy, its use may actually allow parents to healthily verbalize negative feelings and move on.

The final most common strategy was *using emotional support*. Like the use of instrumental support, this category supported research that suggests social support as vital to caregiver wellbeing. Interestingly, statements of social support were not found in the form of query or plea, but in explanations of gratitude for support already received. This could indicate that parents utilize their blogs as mediums to connect with supportive others with whom they have an existing offline relationship.

The prevalence of these six strategies alludes to their effectiveness. Because blogs are a real-time report of the strategies parents actually employ, this analysis suggests the combination of both problem-focused and emotion-focused coping as effective when raising a disabled child. Emotion-focused strategies seemed to provide the cognitive stability parents needed to use problem-focused strategies. Although Lazarus and Folkman (1984) suggested a separation of the two types, it is evident that in combination both types function effectively. While observation of the result of specific coping acts was beyond the scope of this study, the reoccurrence of the prevalent strategies, within and across blogs, is evidence that parents find these tactics effective and useful.

The absence of two strategies, denial and behavioral disengagement, also speaks to which coping strategies parents find effective. Carver et al. (1989) describe both denial and behavioral disengagement as ineffective coping strategies. For parents raising a disabled child that is certainly true. A child's disability is not a situation that can be ignored or denied, thus these two strategies would not result in alleviation of stress. Denying the existence of the disability or its resulting burdens would only harm the caregiver, the disabled child, and other family members ultimately resulting in more stress and inevitable acceptance. Similarly, behavioral disengagement from the stressor, condition or resulting burden, would likely lead to increased stress rather than wellbeing. The nonexistence of these two strategies anywhere in the texts may indicate that parents who use blogging as a medium to cope have already accepted the implications of raising a disabled child and have thus abandoned the use of these two, ineffective strategies.

The observation of two strategies not proposed in the framework is also an interesting insight into the unique experience of coping with raising a disabled child. The prevalence of

*advocating* suggests that parents cope by supporting causes and raising awareness for their child and others with a disability. Because coping measures are typically applied to everyday contexts (i.e. test taking, natural disasters, marriage) this may be absent from scales; however, the inclusion of this strategy would likely assist in the description of how individuals cope with more unique circumstances, like disability. This strategy also suggests the active nature of coping with the emotional stress of raising a disabled child. While many of the emotion-focused strategies observed in the texts suggest an internal process, this strategy is a form of coping that allows parents to feel like they are actively making a difference in their child's life.

The second unique strategy which naturally developed in the texts, was that of *giving instrumental support*. Unlike using instrumental support, this strategy showed parents as actively offering advice and information to outside parties. This strategy is another example of how caregivers seek and utilize social support. The tendency to give support suggests that parents cope by reaching out to others in order to form helpful relationships.

As open and expressive forums, blogs provide parents the opportunity to honestly record how they experience raising their disabled child rather than the typical self-report of how parents usually cope; subsequently, that rhetoric provides a text that reflects a report of actual coping strategies. The observations of this study show that parents typically cope by using both problem-focused and emotion-focused strategies typically found in other stressful situation, but also use the unique strategies of advocating and giving instrumental support. The strategies discussed here are effective by mere presence and ineffective by absence.

These results also serve to extend coping theory beyond the typical empirical examination that utilizes survey response after natural disasters, college exams, or everyday stressful interactions. Coping is a highly unique experience with highly unique stressors.

Individuals dealing with a natural disaster will not utilize the same strategies as a parent raising a child with autism. Likewise, the motivation behind using a particular strategy is highly dependent on the circumstance, which is better captured through examination of individual rhetoric than response to survey questions. Qualitative application of coping theory, like this study, will provide theoretical insight into how and why individuals cope in their specific situation, thus providing practical solutions to the burdens people face.

In addition to a better understanding of coping, this study provides a unique perspective of blogs. Blogs provide a unique medium wherein individuals can share personal narratives. The openness of blogs provides authors a medium to express honest inner feelings. Strategies like positive reframing, venting, using instrumental support, and using emotional support all suggest expression of feelings that may be threatened in face-to-face interaction. For example, Lutendorf et al. (1998) found that in a group therapy setting, individuals most commonly utilized the strategies of positive reframing and acceptance, which are both considered positive strategies, but this study suggested that in online interaction, individuals are likely to use both socially acceptable strategies (i.e. reframing, acceptance, active coping) and less accepted strategies like venting and substance use. Ramsay (2010) explains that how individuals deal with disabilities is highly dependent on the environment and perhaps, the open, transparent, and anonymous culture of online interaction will allow caregivers to cultivate a positive culture surrounding their role, the meaning associated with it, and cope more positively. The unique culture of blogging provides a more accurate examination of rhetoric, uninhibited by typical communication constraints.

Blogs also provide authors' access to an expansive audience. In the context of raising a disabled individual, blogs give parent bloggers access to necessary social support. Two of the

most prevalent strategies suggest that parents are utilizing instrumental and emotional support. In addition to explicit statements of support, the interactive nature of blogs provides a unique social network. Parents often asked for advice or information, which was likely answered through the comment function of blogs. The interconnectivity between blogs also provides authors with social support. As evidenced by the collection of the sample texts for this study, blogs focused on similar topics are typically linked. Databases and websites publishing blogs are becoming more easily accessible as bloggers appear to develop networks.

These unique characteristics, and other indicated in academic literature, suggest the analysis of blogs as a rhetorical genre. Harrell and Linkugel's (1978) suggestion that the classification of particular texts depends on the observation of a group which "shares some important characteristic which differentiates it from all other entities" should be applied to the rhetoric of blogs (p. 262). As blogging becomes increasingly popular in the private and public sectors, the rhetoric found within these texts will become culturally and historically relevant. Not only do blogs give individuals, such as parents with disabled children, an additional opportunity for free expression, blogs have become the engines for political, cultural, and society change. Subsequently, the introduction of blogs a genre for analysis is necessary to adequately understand the communication of an era.

### **Limitations and Future Research**

This study proposed to examine the coping strategies used by parents of disabled children by applying the Brief COPE framework to parent authored blogs through generic analysis. Although empirical researchers might be tempted to dismiss the merits of these finding because the sample of texts is not generalizable, the purpose of this study was merely to explore the themes present in this kind of discourse. Future studies can examine the frequencies in which

these themes emerge, but for now, this study illuminates the presence of some very important coping themes. Additionally, qualitative research provides the possibility of transference rather than generalizability. This means that the themes carry the potential to be relevant in related context although qualitative researchers do not make conclusive claims about the level of application.

Similarly, the issue of objectivity may be raised given the personal nature of the sample texts. While the narratives of these parents is certainly emotionally charged, every precaution was taken to ensure the framework was applied objectively and observation done without bias. Observation was completed without prejudgment of specific strategies as good or bad because of the appreciation of coping as a highly personal phenomenon based on personal needs, contexts, beliefs, and abilities. Certainly some strategies could be viewed as more positive, however the purpose was not judgment of strategy use but rather understanding of how parents cope. For example, the strategy of venting – which is usually explained as a negative technique– was reported as a very prevalent category. As the main focus of this research, increased understanding of the coping strategies employed by parents was accomplished by objectively applying the Brief COPE framework without bias for particular strategies.

Regardless of these potential limitations, the results of this study serve as a catalyst for future research in two key areas: practical coping theory and the use of blogs in rhetorical analysis. As Folkman and Lazarus (1985) suggested, coping theory must be extended with more qualitative methods. The results of this study illustrate how empirical measures can be used to more fully capture the experience of coping in any context. Coping is a personally unique phenomenon and additional qualitative examination would serve to extend our understanding of how individuals and groups facing similar stressors cope. A direct extension of this study may

include a comparison of actual strategies reported on blogs and the strategies parents think they are using through subject interview.

Additionally, this study exemplifies how blogs should be treated as source for generic analysis. Specific types of blogs, authored by specific demographics like caregivers, are rich with the record of how individuals actually behave and communicate. Studies examining the motivations behind blogging could move beyond survey methods to evaluate motivation and purpose found in author rhetoric. Clearly, one study will not establish blogs as a rhetorical genre, but these texts have the potential to become a unique genre utilized to examine how individuals communicate.

### **Conclusion**

Evident in parent authored blogs are the common strategies used to cope with raising a disabled child. These strategies include both problem- and emotion-focused strategies that are effective given the situational, societal and iatrogenic burdens facing parents. Not only does this study achieve its purpose of extending coping research to include care giving as a coping event, it serves as a response to calls for qualitative examination of coping. Likewise, this study exemplifies how the rhetoric posted by blog users could be used as a valuable text for generic criticism. However, the most important contribution of this study is its examination of how parents experience raising their disabled child. Care giving is an important aspect to the functioning of relationships, families, and communities, and by examining how parents cope with caring for their disabled children we can more fully understand and appreciate the life experiences and communication of care givers.

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**Appendix A**

Posts from the following blogs and date ranges were selected as texts of analysis:

Autism Schmatism! (September 28, 2006 – October 28, 2006)

Jordans life with Autism (January 4, 2006 – February 18, 2006)

a moon, worn as if it had been a shell (July 2, 2008 – August 5, 2008)

Estée Klar the Joy of Autism (October 9, 2008 – December 19, 2008)

life with a severely disabled child (December 29, 2008 – January 10, 2009)

Love That Max (October 28, 2008 – November 13, 2008)

Living Life with a side of autism (May 27, 2010 – June 17, 2010)

Bird on the Street (October 30, 2007 – November 17, 2007)

My Son Has 2 Brains: A Mood Disorder Blog (February 19, 2010 – March 5, 2010)

Squidalicious: The adventures of Leelo and his potty-mouthed mom (May 20, 2003 – July 24, 2003)