PSYCHOLOGICAL CHARACTERISTICS AND ADJUSTMENT IN CAREGIVERS

OF CHILDREN WITH SEVERE NEURODISABILITY WITH

CHRONIC PULMONARY SYMPTOMS

A Dissertation

by

RYAN THOMAS BLUCKER

Submitted to the Office of Graduate Studies of
Texas A&M University
in partial fulfillment of the requirements for the degree of

DOCTOR OF PHILOSOPHY

May 2011

Major Subject: Counseling Psychology

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ABSTRACT

Psychological Characteristics and Adjustment in Caregivers of Children with Severe

Neurodisability with Chronic Pulmunary Symptoms. (May 2011)

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Caregivers of children with chronic illnesses or disabilities face challenges in their various roles as parents and providers of ongoing medical needs that often impact the daily life of the family. Research has shown that many of these caregivers experience emotional distress and psychological maladjustment due to multiple factors associated with being a caregiver. Little research has looked specifically at a unique group of caregivers of children with severe neurodisabilities who require varying degrees of respiratory care including ventilator support. This present study utilized data collected at the Arkansas Center for Respiratory Technology Dependent Children (ACRTDC) outpatient clinic. The data describes the prevalence of caregiver-reported experiences related to general health and psychological adjustment. It was hypothesized that this specific group of caregivers would report relatively high levels of distress related to disability severity and resulting respiratory care management plan. It was further hypothesized that family coping and constructive versus dysfunctional problem-

solving styles would be predictive of general and mental health outcomes. Hierarchical regression analyses were used to test these hypotheses.

Descriptive statistics revealed that the caregivers reported symptoms that were comparable to those of the general population. Neither demographic variables nor respiratory care management scores were predictive of scores associated with somatic complaints, depressive symptoms, anxious symptoms, general health and mental health. Caregivers differed on criterion variables based on differences in one of the coping subscales that measured social support, self-esteem and psychological stability. This relationship was observed on scores of somatization, depression, general health and mental health, but not with anxiety. Social problem-solving scores accounted for significant variance in scores of caregiver distress above that accounted for by family coping. Only negative problem orientation (NPO) accounted for a significant proportion of variance in scores of caregiver health and well-being. This strong relationship was observed on scores of somatization, depression, anxiety and mental health but not general health. Implications of results and directions for future studies are presented.

ACKNOWLEDGEMENTS

This project, from beginning to end, was primarily a result of the tireless effort and commitment of Dr. Robert Warren and Dr. Ann Marie Warren. It began with their desire to better understand and assist the children and the families described in this paper. Their work in obtaining IRB approval, preparing research packets, consenting families and collecting data was in addition to their day to day responsibilities.   I am deeply appreciative to them for graciously allowing me to collaborate in this study that represented the final step of my graduate career. Finally, a special thanks is due to the families that participated in this study. As I researched this population, I developed a tremendous admiration for the level of caregiving provided by these families. It is the hope of all involved in this research project that they would especially be the beneficiaries of our work.

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1. INTRODUCTION

Children, adolescents and young adults can experience neurodisabilities that vary in terms of onset, type, course, severity and impact. Neurodisabilities may occur at or before birth as a result of in utero insult or birth trauma with associated anoxia. The neurologic insult may be acquired later in life such as traumatic injury secondary to motor vehicle accidents or injury caused by perpetrators such as with Shaken Baby Syndrome or any other accident or injury that would cause trauma to the brain and subsequent anatomical damage or anoxia. Neurodisability states are also present in a wide variety of congenital and hereditary disorders. Severe neurodisabilities often result in a wide range of secondary medical and physical outcomes such as the loss of function of vital organs that leave people dependent on medical technology and other people for basic care (Heaton, Noyes, Sloper, & Shah, 2005).

Advances in treatment have resulted in improved survival rates among many people with severe disabilities, chronic illnesses and permanent and life-threatening injuries, often allowing them to live well into adulthood (Kingston, 2007; O'Brien, 2001; Wang & Barnard, 2004; 2008). However, increased survivorship has resulted in growing numbers of children and adults living with long-term severe disabilities, including neurodisabilities (Stanley & Blair, 2000). To meet the reality of caring for these survivors, there has been a significant shift from primarily hospital-based care to family- centered, home-based care (Kirk, 1999; Kirk & Glendinning, 2004; O'Brien,

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This dissertation follows the style of *Rehabilitation Psychology*.

2001; Roberts, 2001; Wang & Barnard, 2004; 2008), with the widely held assumption that returning home to receive care is the best option for the family (Carnevale, Alexander, Davis, Rennick, & Troini, 2006; Sarvey, 2008).

Even when returning home is the best option for the patient and family, this transition is not without significant and stressful effects such as time demands, constant vigilance and provision of medical care, limited availability to work outside the home, family disruption, social isolation, less privacy in the home as nursing care is needed, and irregular and diminished sleep that often leads to physical exhaustion (Heaton, Noyes, Sloper, & Shah, 2005; Kirk, 1998). A subgroup of children dependent on medical technology, representing some of the most challenging consequences for medical staff and family caregivers, concerns children who are dependent on ventilators due to respiratory complications.

According to the United States Congress' Office of Technology Assessment, technology dependent children are characterized as requiring "a medical device to compensate for the loss of vital bodily function and substantial and ongoing nursing care to avert death or further disability" (OTA, 1987, p.3). Prior to the 1980s, care for this specific group of patients was almost exclusively provided in institutions but federal financial assistance allowed for homecare even for such a population with complex medical needs (Sarvey, 2008). Caregiving for such patients requires constant attending to and performing specialized treatments and procedures that were once only carried out by medical staff (Heaton, Noyes, Sloper, & Shah, 2005; Kingston, 2007; Wang &

Barnard, 2004). For these caregivers, it is hard to conceive of life apart from a caregiving role.

As with many caregiver roles, burnout and psychological distress are commonplace, especially when the demands are great and life expectancy is decreased compared to the general population (Raina, O'Donnell, Rosenbaum, Brehaut, Walter, Russell, et al, 2005). In an exclusive study of ventilator-dependent children, Wang and Barnard (2008) identified several themes regarding caregivers experiences. Most salient, some caregivers have expressed that the nature of care is like entering a new world or bringing a new world into their home. At times, the multiple and demanding caregiver roles can feel at odds with "normal" parenting. The demands of caregiving can create stress within the family and be isolating from social support. Kuster and Radz (2006) found that 45% of mothers (n=38) in their study experienced symptoms of depression. Nevertheless, many in this role have indicated the transformative nature of this experience, resulting in personal growth and social empathy (Carnevale, Alexander, Davis, Rennick & Troini, 2006; Wang & Barnard, 2008).

2. CAREGIVER STRESS AND COPING: A REVIEW OF THE LITERATURE

Research in applied settings often has the goal of identifying predictors of certain outcomes or relationships among important variables in order to design measures for prevention and intervention. Previous studies have helped us understand what individual and environmental characteristics may place someone at risk for psychological distress or maladjustment. Early studies focused on the severity of the disease or injury as a predictor of psychological adjustment and led to mixed findings. This likely reflects differences in research models and methods, the complexity of caregiving in the context of disability, and the reality that severity does have some direct and indirect impact. The severity model does not typically account for additional characteristics of children or caregivers and how the social environment further influences outcome. More recently, research has focused on intrapersonal, familial and environmental factors that relate to adjustment and possibilities for intervention, perhaps even more than disease severity and functional status of the child (Kuster & Radz, 2006). Some of the studies more commonly cite several variables correlated with psychological distress and adjustment in caregivers. Caregiver characteristics such as age, years of caregiving, a prior history of psychological distress and coping style along with child characteristics including age and behavior problems appear to have an influence (Ketelaar, Volman, Gorter, & Vermeer, 2008; Wallander & Noojin, 1995). Social functioning and school experience may also have a role (Wallander & Noojin, 1995), Other factors include physical status of the

child and environmental factors such as poor social support, social isolation and family functioning.

2.1 Stress and Coping

The field of psychology has long been involved in trying to understand the human experience of acute and chronic stress, the outcomes of living with stress, what factors place individuals at risk for negative outcomes and which variables are protective and promote resilience. This is an especially important area of study given that stress is an unavoidable and universal experience and there is potential for negative physical, emotional, behavioral and social outcomes of such experiences. Some types of stress are common and expected such as family and work responsibilities. Other types of stresses, such as caring for a child with an illness or disability, are less common.

Stress has been described as a subjective experience that occurs when there is a mismatch between an individual's environment and the available resources that include an individual's appraisal of the situation and coping ability (Lazarus & Folkman, 1984). The work of these authors has helped to identify processes, risk factors and protective factors that are thought to impact psychological adjustment related to stress associated with chronic illness. Appraisal can be understood as a process whereby an individual evaluates the situation and their own abilities to determine to what degree they can influence the outcome. Coping, on the other hand, can be viewed as a response to appraisals and has been described as a process that involves "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). Several coping models have been described in the literature including: problem-focused versus emotion-focused coping (Lazarus & Folkman, 1984); the transactional stress and coping model (Thompson & Gustafson, 1996; Thompson, Gustafson, & Gil, 1995); the disability-stress-coping model (Wallander & Varni, 1992); and the resiliency model of family stress, adjustment and adaptation (McCubbin & McCubbin, 1996).

Coping addresses a person's appraisal of his or her situation and the general strategies, skills and behaviors that facilitate adjustment to a stressful life event or condition. There are a wide range of coping styles that people employ with varying degrees of effectiveness. They often focus on cognition or appraisal, emotion-regulation and problem-solving as ways to deal with stressors. Antonovsky (1993) used the term 'sense of coherence' to describe a particular way of viewing the world that promotes healthy coping. This 'world view' fits with a cognitive model regarding an individual's problem appraisal. As life-limiting or life-threatening illnesses, severe neuro-disabilities often create considerable distress for those in a caregiver role (Wang & Barnard, 2008). It is not surprising that, as more people are surviving neurodisabilities and returning home, provision of care is expanding to include facilitating coping among family members.

2.2 Family Coping

        The ability of a family to demonstrate positive coping and resilience in the face

of a crisis has been shown to lead to better health outcomes and psychological

adjustment. The Resiliency Model of Family Stress, Adjustment, and Adaptation has

been developed by McCubbin and McCubbin (1996). They describe family coping as an

effort by which the whole family or individual members function as a unit to more

effectively handle demands and acquire resources to manage the situation. Family

adaptation results from these efforts as evidenced by a healthy level of balance, harmony

and functioning for the family in crisis (McCubbin & McCubbin, 1996). The model

focuses on not only family types, patterns, processes, and system properties but also

specific family efforts of cognitive, behavioral and social coping strategies in response to

a crisis (McCubbin & McCubbin, 1996). By emphasizing family postcrisis recovery or

adaptation, the Resiliency Model attempts to explain "why some families recover and

are deemed resilient and why others remain vulnerable and some deteriorate under the

same circumstances" (McCubbin & McCubbin, 1996, p. 3).

        The applicability of this model has been examined with a wide range of

populations that include families who are facing issues related to PTSD associated with

war (Jovanovic, Aleksandric, Dunjic, & Todorovic, 2004), head injury (Kosciulek,

1994), and fibromyalgia (Preece & Sandberg, 2005). The model has also been applied to

families caring for children with developmental disabilities (Failla & Jones, 1991),

asthma (Svavarsdottir & Rayens, 2005), childhood cancer (McCubbin, Balling, Possin,

Frierdich, & Bryne, 2002) and cerebral palsy (Lin, 2000; McCubbin, Nevin, Cauble,

Larsen, Comeau, & Patterson, 1982). The above studies on caregivers of children with cerebral palsy illustrates the model well and identifies positive family appraisal, support from concerned others, spiritual support, personal growth and advocacy, and positive social interaction as factors associated with family coping. The use of a family coping model is especially appropriate for family members dealing with conditions that are debilitating to a degree that the person depends upon others for a significant part of their care. Caring for a dependent family member also has an impact on the family as they must adjust to meet this often difficult and time consuming role. Therefore, family coping is considered an essential component of understanding and assisting family caregivers.

2.3 Social Problem Solving

One of the most promising areas of research and practice related to coping with illness has occurred in the study of social problem solving. Social problem solving is conceptualized as a natural approach to solving problems in a real world environment (D'Zurilla & Nezu, 1982). These authors make the important clarification that the "social" terminology does not limit this problem solving strategy to only interpersonal difficulties. In fact, while it does include interpersonal problems, it also relates to personal problems, community and environmental problems and practical problems (D'Zurilla, Nezu, & Maydeu-Olivares, 2004).

First introduced by D'Zurilla & Goldried in 1971, the social problem solving model has undergone several revisions as research and practice has led to further

refinement of the core concepts (D'Zurilla, Nezu, & Maydeu-Olivares, 2002). In general, problem solving can be described as a cognitive-behavioral process that generates multiple feasible solutions to a problem and then uses a strategy to try to select the most effective solution to be implemented (D'Zurilla & Goldfried, 1971). Since the social problem solving model addresses cognition, emotion regulation and behavioral skill sets associated with general coping, it fits well with the family resiliency model that has been described as family "appraisal strategies, coping, supports, problem-solving abilities, and transactions with the community in family post-crisis recovery" (McCubbin & McCubbin, 1996, p. 3).

2.4 Contemporary Social Problem Solving

While early problem solving models consisted of problem orientation and problem solving skills as the two principle constructs (D'Zurilla & Nezu, 1990), subsequent factor analyses have led to a more contemporary model of social problem (Maydeu-Olivares & D'Zurilla, 1995, 1996). This revised model yields five factors. Two of the factors, positive problem orientation (PO) and rational problem solving (RPS), make up the *constructive problem solving style*. Conversely, the *dysfunctional problem solving style* is formed by three components that include negative problem orientation (NO), impulsivity and carelessness (IMP), and avoidance style (AV) (D'Zurilla, Nezu, & Maydeu-Olivares, 2004). This five-factor model is reflected in the *Social Problem Solving Inventory – Revised* (D'Zurilla, Nezu, & Maydeu-Olivares, 2002). According to the *SPSI-R*, higher scores indicate greater representation of the

constructive problem solving (CPS) and dysfunctional problem solving (DPS)

constructs. The *Social Problem Solving Inventory – Revised* is useful in capturing an

individual's overall problem solving style. Beyond the initial support for this five factor

model of social problem solving, more recent factor analytic studies have confirmed this

model of constructive versus dysfunctional problem solving (Berry, Elliott, & Rivera,

2007; Johnson, Elliott, Neilands, Morin, & Chesney, 2006; Rivera, Elliott, Berry,

Oswald, & Grant, 2007).

2.5 Social Problem Solving and Caregiving

Social problem solving has been widely applied to caregivers of people with

physical illnesses. Various studies looking at samples of caregivers have demonstrated a

significant level of distress from their responsibilities that often require a commitment to

availability and care as their primary role (Barg, Pasacreta, Nuamah, Robinson,

Angeletti, & Yasko, 1998; Nezu, Palmatier, & Nezu, 2004). The consequences of

providing care can lead to declines in both physical and emotional health of the

caregiver (Barg, Pasacreta, Nuamah, Robinson, Angeletti, & Yasko, 1998; Vitaliano,

1997). According to Nezu, Palmatier, and Nezu (2004), positive problem solving

orientation and abilities can lead to greater caregiver skills and less emotional distress in

their caregiver role. Additionally, there is evidence that greater relationship satisfaction

has been found among caregivers who utilize a more constructive problem solving style

(Shanmugham, Cano, Elliott, & Davis, 2007).

Barg et al. (1998) found that in caregivers of people with cancer, their experience tended to be characterized by long-term provision of care, roles and responsibilities that required specialized training from medical staff. Isolation from friends and other social support due to stigmatization and high demands, and significant feelings of stress that was often associated with little perceived support, health problems and decreased self-esteem were also noted. In addition to the direct impact on caregivers, there may be an indirect impact on the care recipient if caregivers are unable to provide an optimal level of care (Elliott, Shewchuk, & Richards, 1999).

Research on caregivers of people with developmental disabilities, spinal cord injuries, and traumatic brain injuries in particular, reveal that burnout is an especially noteworthy concern due to the level of caregiver demands and few expectations for improvement (Nezu, Palmatier, & Nezu, 2004). In the case of spinal cord injury, the first year after onset is often characterized by problems with perceived social support that are related to psychological and physical health problems (Shewchuk, Richards, & Elliott, 1998). Fewer studies of caregivers responsible for ventilator-dependent children are available. However, the literature on caregivers of medically fragile children indicate that increased caregiver burdens combined with less hope for positive changes leave this population vulnerable for significant distress (Wang & Barnard, 2008) that could benefit from assessment and intervention related to positive psychological adjustment in the face of their caregiver roles.

2.6 Focus of Study

Collectively, the literature indicates that people in caregiving roles are at risk for experiencing emotional distress and psychological maladjustment. More specifically, primary caregivers of children have been found to experience significant stress reactions. Very few studies have focused on caregivers of children with a combination of such significant disabilities as the population in the present study. The current study attempts to expand the existing body of research by gaining understanding of the experience of this specific group of caregivers. Additionally, the current study aims to test existing theories on coping applied to an understudied population with high caregiving demands. This research project should provide important descriptive information regarding the prevalence of emotional distress and psychological maladjustment in caregivers of children with various neurodisabilities who require specialized care including medical technology. Additionally, results will demonstrate the degree to which family and individual coping will predict emotional distress and psychological maladjustment in caregivers.

2.7 Hypotheses

Hypothesis 1: It is believed that demographic and medical variables will be associated with emotional distress and psychological maladjustment in caregivers. This hypothesis will be measured using the demographics and medical history from questionnaires and medical charts.

Hypothesis 2: As suggested by the literature, it is hypothesized that family coping will mediate the development of symptomatology of psychological distress in caregivers. Family coping will be assessed by the F-COPES and CHIP.

Hypothesis 3: It is hypothesized that constructive problem solving as an individual measure of coping will account for additional significant variance in psychological distress above and beyond the variance associated with family coping. Constructive problem solving will be measured by the Social Problem Solving Inventory – Revised. Psychological distress will be measured by the Patient Health Questionnaire (PHQ) and the SF-12.

Hypothesis 4: It is hypothesized that a dysfunctional problem solving style will predict increased symptomatology of psychological distress. Dysfunctional problem solving will be measured by the Social Problem Solving Inventory – Revised. Psychological distress will be measured by the Patient Health Questionnaire (PHQ) and the SF-12.

3. METHODS

3.1 Participants

The focus of this study is the caregivers of children who are seen in the Arkansas Center for Respiratory Technology Dependent Children (ACRTDC) outpatient clinic. The caregivers are typically parents (either coupled or single), grandparents, older siblings, or an extended family member. The children who attend this clinic include those with over 60 different congenital neurological diagnoses and patients with acquired neurodisabilties such as those resulting from birth trauma and traumatic onset disability (e.g., shaken baby syndrome; traumatic brain injury secondary to motor vehicle accidents; or other accidents resulting in physical brain trauma). All patients followed in the ACRTDC program have chronic pulmonary symptoms requiring daily respiratory care plans. The present patient data base has reached approximately 125 - 150 ventilator-dependent and non-ventilator dependent patients. The present age range of the sample attending the clinic is 3 months to 32 years of age.

Regardless of etiology, these patients tend to have a cluster of similar characteristics that are potential etiological factors that contribute to their pulmonary condition, including seizure disorders, non-ambulatory states, hypotonia, spasticity, hypopneic breathing patterns, ineffective cough, chronic bacterial contamination of the airway, and chronic airway secretions. A small percentage of the patients are verbal and ambulatory to some degree. The respiratory care needs of these children are comprehensive and complex and, in the case of ventilator-dependent children, require

24-hour care due to a combination of symptoms, medication management, continuous

bolus feeds, control of daily seizures, and breathing treatments which may be required

up to four times a day with individual treatment times extending to 45 minutes to 1 hour.

Individualized respiratory care in the clinic intends to attain a degree of stability

to prevent acute medical crises, and reduction or elimination of emergency room visits

and hospitalizations. This entails anticipatory care for acute respiratory events at home

as well as initial and ongoing caregiver education and support. Patients are scheduled to

be seen in routine clinic visits every 3-6 months.

3.2 Procedures

IRB approval was obtained through Arkansas Children's Hospital (Little Rock,

Arkansas). Potential caregiver participants for the study were identified from the

ACRTDC patient database. In some instances caregivers were contacted prior to the

anticipated study date either by telephone or letter. Other caregivers were presented

with the opportunity to participate in the study at the time of their child's regularly

scheduled clinic visit. Participants were self- identified as a primary caregiver of a

patient followed in the ACRTDC program. Inclusion criteria required caregivers to be at

least 18 years of age and to be able to read and write in English. The clinician and

primary investigator initially estimated approximately 125-150 families in the clinic

would meet inclusion criteria. A total of 62 families were presented with details of the

study and given the opportunity to participate. All 62 families consented to participate.

These families were given a study packet that contained all research questionnaires

including demographic information and measures of family coping, social problem

solving, and subjective general and mental health. Medical information was obtained

from the child's medical record. The completion of the measures took approximately 45

minutes.

3.3 Demographics Measures

Demographic and medical information was gathered from the patients' charts

and reviewed during the initial interview. For purposes of this study, demographic

information included age, ethnicity, and gender of both the patient and caregiver.

Additionally, the number of years the participant was in the caregiving role was

recorded.

Respiratory Management Plan - Acuity Score Assessment

Medical information about the severity of the condition was limited to the child's

Respiratory Management Score (RMS). The RMS was developed by the primary

clinician at the ACRTDC. This scale was developed to obtain an indicator of the acuity

of a child's pulmonary condition with implications for clinical management. The total

"Acuity score" from the RMS is rated on a scale of 1 to 4:

> 1   Daily respiratory care plan includes aerosol medications including
>
> bronchodilators, steroid, and mucolytics. Antibiotics are used as needed for
>
> exacerbations of respiratory infections. Care plan includes one or more
>
> respiratory therapy devices, such as the ThAIRpy Vest or Emerson In-
>
> Exsufflator. If patient has a hypopneic breathing pattern defined as a resting

tidal volume of less than 7 ml/kg, then hyperinflation technique will be used

to deliver aerosol medication using an Ambu bag.

2   Daily respiratory care plan as above plus presence of a

tracheostomy tube which has been required because of upper airway

dysfunction.

3   Daily respiratory care plan as above with the requirement of night

time mechanical ventilatory support for chronic hypoventilation. Night time

mechanical ventilatory support may utilize both an invasive interface –

tracheostomy tube – or a non-invasive interface – nasal or face mask.

4   Daily respiratory care plan as above with the requirement of

continuous mechanical ventilatory support 24 hours a day utilizing a

tracheostomy tube as an invasive interface.

It is important to note that this scale was developed by the medical provider and

based on clinical judgment rather than standardized instrument development procedures.

Therefore, it does not necessarily reflect how other medical professionals categorize

medical disability severity or respiratory management plans. Rather, it reflects how this

specific clinic has identified the progressive nature of the chronic lung disease in a

manner that informs clinical case management. In fact, enrollment requirement into the

Arkansas Center for Respiratory Technology Dependent Children (ACRTDC) requires

the patient to demonstrate a need for a respiratory therapy device such as the ThAIRpy

Vest or Emerson In-Exsufflator. The clinician suggested that disease progression is

variable in terms of time and would probably correlate with primary diagnosis, success

in controlling airway secretions, severity of seizure activity, and other possible parameters. The use of this instrument is especially informative for this specific clinic population.

3.4 Measures of Coping

Family Crisis Oriented Personal Scales (F-COPES; McCubbin, Olson, & Larsen, 1987). The F-COPES is a 30-item self-report measure that was developed to assess coping and resiliency among family caregivers of children with chronic illnesses or disabilities. Responses range from 1 (Strongly Disagree) to 5 (Strongly Agree) and measure five factors. These factors include 1) acquiring social support, 2) reframing, 3) seeking spiritual support, 4) mobilizing to acquire and accept help, 5) passive appraisal. The estimated range of Cronbach's Alpha for the F-COPES is .77-.86 (.63-.83 for the subscales). Demonstrated test-retest reliability is .81 (.61-.95 for the subscales). The F-COPES has been used to assess family caregivers of children with a wide range of chronic illnesses and disabilities including cerebral palsy.

Coping Health Inventory for Parents (CHIP; McCubbin, McCubbin, Nevin, & Cauble, 1981; McCubbin, McCubbin, Patterson, Cauble, Wilson, & Warwick, 1983). The *CHIP* is a 45-item self-report measure of coping patterns in caregivers of chronically ill children. The three factor structure includes 1) maintaining family integration, cooperation and an optimistic definition of the situation, 2) maintaining social support, self-esteem and psychological stability, and 3) understanding the medical situation through communication with other parents and consultation with the medical

staff. Originally studied with children with cystic fibrosis, the CHIP has been used as a measure of coping related to various other chronic illnesses or disabilities such as cerebral palsy, developmental disabilities, diabetes, HIV, congenital heart disease and liver transplant. The CHIP has demonstrated that social support is correlated with depression and subjective health perception among caregivers of children with cancer (Fotiadou, Barlow, Powell, & Langton, 2008).

   Social Problem Solving Inventory – Revised: Short Form (SPSI-R:SF). The SPSI-R (D'Zurilla, Nezue, & Maydeu-Olivares, 2002) is a measure of a respondent's orientation toward solving problems in routine and stressful situations, and of the styles in which they typically try to solve problems. The SPSI-R has been used to measure problem-solving abilities and adjustment of people with diabetes (Hill-Briggs, 2003), adherence to HIV medications (Johnson, Elliott, Neilands, Morin, & Chesney, 2006), low vision (Dreer, Elliott, Shewchuk, Berry, & Rivera, 2005), of persons with spinal cord injuries (Elliott, 1999), and their family caregivers (Elliott, Shewchuk, & Richards, 2001). Nezu and his colleagues have used the SPSI-R to study how problem solving orientation and problem solving skills relate to psychological adjustment in women diagnosed with breast cancer. The Short Form of the SPSI-R asks subjects to respond to 25 items with responses ranging from 0 (Not at all true of me) to 4 (Extremely true of me). This instrument was normed on 1,928 subjects ages 13 and older and requires a 4th grade reading level. The SPSI-R is comprised of 5 scales. Constructive Problem Solving includes 1) Positive Problem Orientation – includes appraising problems as challenges, believing that problems are solvable, addressing problems rather than

avoiding them, believing that successfully solving problems requires time and effort, and believing in one's own ability to solve problems successfully, and 2) Rational Problem Solving – rational and systematic approach to solving problems. Dysfunctional Problem Solving includes 3) Negative Problem Orientation – includes viewing problems as threats, believing that problems are unsolvable, experiencing frustration and having little tolerance when experiencing problems, and doubting one's ability to successfully solve problems, 4) Impulsivity/Carelessness Style (ICS) – impulsive or careless approach to responding to problems, and 5) Avoidant Style (AS) – avoidance of problems, dependency on others to solve one's problems, and procrastination. Higher scores on each scale indicates greater use of that particular problem solving style.

3.5 Measures of Outcome Variables

Patient Health Questionnaire (PHQ; Spitzer, Kroenke, & Williams, 1999). The PHQ is the patient self-report version of the Primary Care Evaluation of Mental Disorders (PRIME-MD) which is used as a broad measure of mental health. The PRIME-MD contains items that reflect DSM-IV diagnoses including Somatoform Disorder, Major Depressive Disorder, Panic Disorder, and Other Anxiety Disorder. Since the PHQ is a screening measure, scores alone are not sufficient to make mental health diagnoses. Rather, this instrument identifies likely syndromes that require additional follow-up by a clinician in order to rule out other possible diagnoses or alternative reasons for the presentation of symptoms and to confirm a diagnosis. In addition to the four major mental health syndromes, the PHQ also elicits current

psychosocial concerns and identifies potential concerns regarding eating disorders, alcohol or drug abuse and interpersonal violence.

A validation study indicated good sensitivity and specificity of the PHQ, revealing its clinical utility. The vast majority of subsequent studies have only used the depression module although a few studies have used the additional modules as well. The PHQ demonstrates equivalent diagnostic accuracy compared to the physician administered PRIME-MD. In the validation study, 3000 participants completed the PHQ followed by interviews of 585 participants with mental health professionals. Results demonstrated agreement between diagnoses made by the PHQ and by the mental health professionals, with an overall sensitivity of 75% and specificity of 90%. In addition to being widely used in research, the PHQ is a valuable diagnostic screening tool that can be efficiently used in the primary care and outpatient setting for both patients and caregivers.

Short Form-12 Version 2, Health Survey (SF-12v2; Ware, Kosinski, & Keller, 1996). The SF-12v2 is a 12-item, self-report measure that gives an indication of the degree to which physical or mental health issues interfere with daily functioning across various domains. This self-report questionnaire measures eight concepts including physical functioning, role limitations due to physical health problems, bodily pain, general health, vitality, social functioning, role limitations from emotional problems, and psychological distress. General Health and Mental Health composite scores are obtained. The SF-12v2 shows very good psychometric properties and is a widely used outcome measure for mental health problems in the clinical and research setting.

General Health is one of the four subscales that makes up the Physical Health scale.

Respondents rate their overall health on a five-point scale (excellent, very good, good,

fair, and poor). Higher scores indicate better general health. Mental Health is assessed

on a six-point scale (e.g., all of the time, most of the time, a good bit of the time, some of

the time, a little of the time, and none of the time). Higher scores on this scale

correspond with better overall mental health.

3.6 Data Management

Once participants provided informed consent and completed the research

measures, they were given a unique participant number that was to be used to identify

them for the purposes of data collection and analysis. These completed research

questionnaires were maintained in the study chart assigned to the participant. An excel

spreadsheet was created to manage the demographic variables as well as data from the

questionnaires. The spreadsheet was password protected and only the key personnel

were to have access to this file. All data in this file was de-identified to maintain

confidentiality. IRB approval was obtained through Arkansas Children's Hospital for

copies of the de-identified data to be shared with Tim Elliott, Ph. D., at Texas A&M

University and the chair of this dissertation research. Agreement was reached between

the two institutions that Dr. Tim Elliott and Ryan Blucker, M. S. were to be responsible

for managing and analyzing the data that would be used for this dissertation. IRB

approval was obtained by Texas A&M University before any of the de-identified data

was sent to Texas A&M University where the data analysis took place.

3.7 Statistical Analysis

The existing research on psychological distress and adjustment among caregivers in various populations has shown a relationship between various aspects of the caregiver experience and outcomes of physical health and psychological adjustment. Many studies have demonstrated that the use of specific problem solving appraisal and skills and family coping strategies are predictive of outcomes of physical health and psychological adjustment among caregivers. This specific model of distress and coping has yet to be tested specifically among caregivers of children with severe neurodisabilities and pulmonary symptoms, arguable one of the most demanding and stressful caregiver experiences.

Since previous research provides a theoretical basis for the relationship among demographic, medical, coping and physical and mental health outcome variables, hierarchical regression analysis was selected as the most appropriate method for analyzing these same variables among this research sample, especially given the small sample size. Hierarchical regression analysis is a procedure whereby a series of regression analyses is used to demonstrate proportions of variance accounted for by each of the variables that have been selected based on relationships demonstrated in previous research and endorsed by the clinician involved in the study. (Hoyt, Imel & Chan, 2008).

First, the prevalence and severity of somatic complaints, depressive symptoms, and anxiety symptoms were estimated among this caregiver population using the DSM-IV based scoring criteria from the PHQ. Prevalence and severity of functional

impairment was measured using the SF-12. Second, correlational analyses examined the relationships among variables that were to be used in the regression model. Finally, specific demographic, family coping, problem-solving and health outcomes variables that demonstrated significant correlations were selected and examined with hierarchical regression in order to test the stress and coping model for caregivers of this specific medical population.

The first block was comprised of two variables years of caregiving and the respiratory care management score. The second block was limited to the "Maintaining Social Support, Self Esteem and Psychological Stability" subscale of the *Coping Health Inventory for Parents* (CHIP) as it was the only subscale on any of the family coping measures that demonstrated a significant association with the health outcome variables. The third block included the "Negative Problem Orientation" and "Positive Problem Orientation" subscales from the *Social Problem Solving Inventory* (SPSI-R) as they have shown a stronger relationship than the Dysfunctional and Constructive Problem Solving scales. It was expected that the variables in each block would account for unique variance related to health outcome scores.

4. RESULTS

4.1 Demographic Information

Of the 62 participants who were consented and given research questionnaires, 56 returned completed, or mostly completed, packets demonstrating a 90% completion rate. This number represents approximately one-third of the population of interest at this particular clinic. Due to a few incomplete questionnaires, there was a range of 54 to 56 participants with complete data that were analyzed for each outcome variable. Demographic information was provided for patient age, patient gender, parent age, parent gender, parent race, and the number of years the parent has been a caregiver. Additionally, a Respiratory Care Management Score (RCMS) was given for each patient.

Table 1 displays the descriptive statistics for the demographic variables. Patients ranged in age from 4 to 30 with a mean age of 13.43. 57% of the patients were male (n=35). Parents ranged in age from 24 to 60 with a mean age of 43.04. Consistent with previous studies showing that the majority of identified caregivers of children with disabilities are mothers or other female relatives, only one male caregiver participated in this study. Therefore, no analyses of outcomes by gender was possible. The number of years that parents have provided caregiving ranged from 2 to 26 with a mean of 12.23 years. Information regarding race is available for 59 caregivers. 79.7% (n=47) of caregivers self-identified as Caucasian and 20.3% (n=12) of caregivers as African American. Respiratory Care Management Scores, a reflection of both physical status

and care required, were available for 58 patients, and scores ranged from 1 (aerosol medications and at least one respiratory therapy device, but no mechanical ventilation) to 4 (requirement of mechanical ventilator support 24 hours per day utilizing tracheostomy). 29.3% (n=17) received a score of 1; 10.3% (n=6) received a score of 2; 36.2% (n=21) received a score of 3; and 24.1% (n=14) received a score of 4.

Prevalence rates for each of the three diagnostic categories (somatoform, depression, other anxiety) were calculated using recommended guidelines for interpretation of the PHQ. Total scores for each syndrome were used as continuous variables in order to perform regression analyses. 56 caregivers completed the Depression module. Participants were asked to respond to a series of nine questions regarding how much they had been bothered by depressive symptoms during the past two weeks. Possible responses included "Not at all", "Several days", "More than half the days", and "Nearly every day." PHQ scoring guidelines suggest that a respondent must endorse 5 or more items (including at least one of the first two items) with a rating of at least "More than half the days." The possible range of scores was from 0 to 27. The range of scores for this sample of caregivers was from 0 to 25 (mean = 3.75).

According to this screening criteria, 3 (5.36%) of the caregivers' responses met criteria for Major Depressive Syndrome. It is important to note that a diagnosis of Major Depressive Disorder cannot be assumed based on these scores. Rather, the responses indicate a need for additional assessment and require that other conditions be ruled out before making a definitive diagnosis. In addition, the following recommended alternative scoring was used to further classify caregivers according to the severity of

their depressive symptoms: None (0-4), Mild (5-9), Moderate (10-14), Moderately Severe (15-19), Severe (20-27).

There were 54 caregivers who completed the Other Anxiety Syndrome module of the PHQ. Participants responded to 7 questions regarding how much they had been bothered by symptoms of anxiety during the prior four weeks. Possible responses included "Not at all", "Several days", and "More than half the days." PHQ scoring guidelines suggest that a respondent must endorse the first item and at least 3 additional items with a rating of "More than half the days." The possible range of scores was from 0 to 14 points. Scores among this population of caregivers ranged from 0 to 14 (mean = 2.91). According to the PHQ scoring recommendations, 3 (5.5%) of the respondents met criteria for the Other Anxiety Syndrome which, in a clinical context, would warrant follow-up and additional information in order to rule out contributing factors and make a definitive diagnosis.

There were 56 caregivers who completed the Somatoform Syndrome module of the PHQ. Participants responded to 13 questions regarding how much they had been bothered by somatic symptoms during the previous four weeks. Possible responses included "Not bothered at all", "Bothered a little", and "Bothered a lot." PHQ scoring guidelines suggest that a respondent must endorse at least 3 items with a rating of at least "Bothered a lot." The possible range of scores was from 0 to 26 points. Among this population of caregivers, scores ranged from 0 to 14 (mean = 4.61). 5 (8.93%) of the respondents were identified as meeting symptom criteria for Somatoform Disorder though diagnostic rule out considerations are appropriate.

There were 56 caregivers who completed the SF-12v2, resulting in valid scores

for General Health (GH) and Mental Health (MH). According to 1998 General U. S.

population means and standard deviations, based on 0 – 100 scoring, (Ware, Kosinski,

Turner-Bowker, & Gandek, 2002), the mean and standard deviation for General Health

are 72.20 and 23.19, respectively. The mean and standard deviation for Mental Health

are 70.18 and 20.51, respectively. The current study revealed a similar pattern with a

mean and standard deviation of 70.54 and 25.63 for General Health and a mean and

standard deviation of 75.00 and 15.81 for Mental Health. Based on caregivers'

responses, 10.71% (n=6) scored more than one standard deviation above the mean on the

General Health scale. Responses also demonstrated that 5.36% (n=3) of caregivers

scored more than one standard deviation above the mean on the Mental Health scale.

4.2 Preliminary Analyses

Table 2 depicts the original model for examining the variables of interest. Due to

variability in the number of completed research questionnaires, each analysis is

calculated according to available data, accounting for differences in degrees of freedom

across analyses. It is important to consider this variability when interpreting results

since this discrepancy likely leads to slight fluctuations in strength of correlations and,

therefore, the percentage of accounting of variance in the model. However, the change

in sample size is not believed to impact the overall fit of the model being tested.

Prior to running regression analyses, distributions for each variable were

examined to take into account skewness and kurtosis. The Depression and Anxiety

modules of the PHQ were shown to demonstrate abnormal distributions. Therefore, a square root transformation was performed in order to obtain scores that were more normally distributed. These transformed Depression and Anxiety scores were used in all correlation and regression analyses. All other variables of interest were determined to be normally distributed.

Table 3 displays Pearson correlations that were computed to examine the expected associations among demographic variables, respiratory care rating, self-report coping and problem-solving variables, and health outcome variables. A p value $< .05$ was selected to examine significance values. No significant associations were found between demographic variables and health outcome variables. Additionally, no significant relationship was observed between respiratory care management score and health outcome variables. Table 3 provides means, standard deviations, and correlation matrix of demographic variables, F-COPES, CHIP, SPS, PHQ and SF-12. An *a priori* model was used to test the initial hypotheses about the expected relationships. Table 4 displays correlations among coping, social problem-solving and health outcomes while Table 5 presents correlations of those variables identified in the adjusted model.

No significant correlations were found between the Respiratory Care Management Scores and the health outcome variables. Due to the low sample size and corresponding low n in each of the four RCMS categories, power for detecting significance was low. In order to provide additional significance testing, analysis of variance was utilized. The original lower two levels of the RCMS were combined to produce a new Level 1 and the original upper two levels 2 were combined to form a new

Level 2. These new levels were analyzed to determine if they could account for significant variance in scores associated with the criterion variables. Results confirmed the original correlation analysis suggesting that scores on the criterion variables did not significant differ according to the RCMS. Table 7 displays the ANOVA summary of these data.

The five subscales of the F-COPES and the three subscales of the CHIP were examined for strength of relationship with the health outcome variables. Among the F-COPES subscales, no significant relationships with the health outcome variables were observed, contrary to expectations based on demonstrated relationships in previous research. The coping scales of the CHIP were also expected to show a strong correlation with health outcome variables; however, only the Social Support, Self-esteem, and Psychological Stability subscale demonstrated a significant relationship. Though no other family coping subscale was correlated, the Social Support, Self-esteem, and Psychological Stability subscale was very strongly correlated with four of the five health outcome variables being examined.

Caregivers' scores on the CHIPSES subscale (mean = 28.70; *SD* = 8.85) were comparable to mean scores observed in previous research regarding caregivers who have children with a chronic illness including specific populations, such as cerebral palsy, that are similar to the present research population (McCubbin & McCubbin, 1996). Correlations revealed that greater use of coping efforts involving developing social relationships, engaging in activities that promote individual identity and self-worth, and behaviors to manage psychological tensions and pressures was correlated with less

somatic concerns ($r = -.364$, $p < .006$) and depressive symptoms ($r = -.344$, $p < .009$).

Additionally, these coping efforts were associated with greater reports of general health

($r = .36$, $p < .01$) and mental health ($r = .36$, $p < .01$).

The five subscales of the Social Problem Solving Inventory – Short Form (SPSI)

demonstrated varying degrees of associations with the health measures. Dysfunctional

Problem Solving Style (mean = 9.16; $SD = 6.39$) was shown to have stronger

relationships with health measures than the Constructive Problem Solving Style (mean =

30.46; $SD = 7.35$). Specifically, Negative Problem Orientation (NPO; mean = 4.52; SD

= 3.12) had the strongest associations with health measures including somatic symptoms

($r = .56$, $p < .01$), depression ($r = .53$, $p < .01$), anxiety ($r = .49$, $p < .01$), general health

($r = -.31$, $p < .02$), and mental health ($r = -.45$, $p < .01$). Avoidance Style (AS; mean =

1.88; $SD = 2.52$) also showed significant correlations with depression ($r = .37$, $p < .01$)

and mental health ($r = -.39$, $p < .01$) but no strong relationships with the other health

measures. The Impulsive Careless Style (ICS; mean = 2.77; $SD = 2.91$) demonstrated a

strong association only with depression ($r = .37$, $p < .01$). Among the subscales that

make up the Constructive Problem Solving Style, Positive Problem Orientation (mean =

15.43; $SD = 3.37$) was significantly related to mental health ($r = .34$, $p < .02$) but no

other health measures. Rational Problem Solving style did not show any significant

relationships among the health measures.

The correlations discussed above revealed the appropriateness the inclusion and

exclusion of variables in the original model. Based on these correlations, only 1)

number of years caregiving and 2) the respiratory care management score were included

in Block One of the model. In Block Two, only the Social Support, Self-esteem, and Psychological Stability subscale of the CHIP was included. No subscales of the F-COPES were included in the model. Finally, correlations resulted in the inclusion of Negative Problem Orientation and Positive Problem Orientation in Block Three.

4.3 Caregiver Somatic Complaints

Hierarchical regression examined the revised model regarding the percentage of variance accounted for by each of the blocks as they were entered in sequential order. The first set of regression equations tested the relationship between demographic, coping and social problem solving variables with reports of somatic symptoms. Years Caregiving and Respiratory Care Management Score (RCMS) were entered as the first block. Block 1 did not account for any variance in caregivers' self-report scores of somatic symptoms, F_{inc} (2, 53) = .11, R^2_{inc} = .00, *ns*. After controlling for years of caregiving and the respiratory care management score, CHIPSES augmented the equation in the second step, F_{inc} (1, 52) = 8.01, R^2_{inc} = .13. Block 2 accounted for 13% of the variance in somatic complaints. Lower scores in social support, self-esteem, and psychological stability, (β= -.37, t = -2.83) were associated with higher somatization scores ($p < .01$). The block of problem orientation – NPO and PPO – revealed additional variance accounted for in the final step, F_{inc} (2, 50) = 10.29, R^2_{inc} = .25. This block accounted for 25% of the variance in somatic complaints. Higher scores in Negative Problem Orientation (β = .53, t = 4.53) were associated with higher somatization scores ($p < .01$).

4.4 Caregiver Depression

The second set of regression equations examined the relationship between demographic, coping and social problem solving variables with depression. Years Caregiving and Respiratory Care Management Score (RCMS) did not account for significant variance in scores of depressive symptoms in the first step, F_{inc} (2, 53) = .05, R^2_{inc} = .00, *ns*. CHIPSES scores were associated with depression at the next step, F_{inc} (1, 52) = 6.92, R^2_{inc} = .18. Block 2 accounted for 18% of the variance in depression scores. Lower scores in social support, self-esteem, and psychological stability, (β= -.34, *t* = - 2.63) were associated with higher depression scores (*p* < .05). Block 3, problem orientation, revealed the strongest relationship with depressive symptoms, F_{inc} (2, 50) = 8.63, R^2_{inc} = .23. This block accounted for 23% of variance in depression scores. Higher scores in Negative Problem Orientation (β = .50, *t* = 4.16) were associated with higher depression scores (p < .01).

4.5 Caregiver Anxiety

The third set of regression equations examined the relationship among demographic, coping and social problem solving variables with anxiety. In the first step, Years Caregiving and Respiratory Care Management Score (RCMS) did not reveal a significant relationship with symptoms of anxiety, F_{inc} (2, 51) = .22, R^2_{inc} = .01, *ns*. In Block 2, CHIPSES scores were also unrelated to scores of anxiety, F_{inc} (1, 50) = .81, R^2_{inc} = .02, *ns*. In the final step, the block for problem orientation demonstrated a significant relationship with scores of anxiety, F_{inc} (2, 48) = 7.21, R^2_{inc} = .23. Block 3

accounted for 23% of the variance with anxiety scores. Higher scores in Negative

Problem Orientation ($\beta = .48$, $t = 3.65$) were associated with higher depression scores (p

$< .01$).

4.6 Caregiver Physical and Mental Health

The regression model revealed a similar pattern of relationships among variables

regarding quality of life, including general health and mental health (as measured by the

SF-12). Similar to the relationship with other health outcomes, Years Caregiving and

Respiratory Care Management Score (RCMS) did not account for any variance in

relation to general health, F_{inc} (2, 53) = .06, R^2_{inc} = .00, ns. At the next step, CHIPSES

demonstrated a strong relationship with general health scores, F_{inc} (1, 52) = 7.70, R^2_{inc} =

.13. This block accounted for 13% of the variance in general health scores. Higher

scores in social support, self-esteem, and psychological stability, (β= .36, $t = 2.77$) were

associated with higher scores in general health ($p < .01$). At the final step, problem

orientation accounted for minimal additional variance, F_{inc} (2, 50) = 2.24, R^2_{inc} = .07, ns.

In the final set of regression equations, Years Caregiving and Respiratory Care

Management Score (RCMS) demonstrated an insignificant relationship with mental

health in the first step, F_{inc} (2, 53) = .04, R^2_{inc} = .00, ns. The next step showed a strong

relationship between CHIPSES scores and mental health, F_{inc} (1, 52) = 7.45, R^2_{inc} = .13.

This block accounted for 13% of the variance in scores of mental health. Higher scores

in social support, self-esteem, and psychological stability, (β= .36, $t = 2.73$) were

associated with higher mental health ($p < .01$). The final step revealed a strong

association between problem orientation and scores of mental health, F_{inc} (2, 50) = 6.26,

R^2_{inc} = .18.   This block accounted for 18% of the variance in scores of mental health.

Higher scores in Negative Problem Orientation (β = -.35, t = -2.81) were associated with

lower scores of mental health ($p < .01$).

4.7 Summary of Findings

Table 4 summarizes the results of the adjusted regression equations. On the

variables of somatic complaints, depressive symptoms, anxious symptoms, general

health and mental health, caregivers did not differ according to demographic variables

such as child and caregiver age, caregiver ethnicity, number of years in the role of

caregiver, and the physician-determined respiratory care management plan of each child.

As expected, caregivers differed on criterion variables based on differences in coping.

However, the CHIPSES subscale measuring social support, self-esteem and

psychological stability was the only specific measure that was significantly associated

with caregiver health and well-being. This relationship was observed on scores of

somatization, depression, general health and mental health, but not with anxiety. No

other subscale on the F-COPES or CHIP was highly correlated with these measures.

Finally, social problem-solving scores demonstrated a significant relationship with

scores of caregiver health and well-being. Only negative problem orientation (NPO)

accounted for a significant proportion of variance in scores of caregiver health and well-

being. This strong relationship was observed on scores of somatization, depression,

anxiety and mental health but not general health.

5. DISCUSSION AND CONCLUSIONS

The purpose of this study was to describe this unique sample of caregivers in terms of their experiences of distress, general health and mental health and to test a model examining the relationships among demographic variables, coping, problem-solving and the measures of general and mental health. Surprisingly, this study found that the prevalence of these caregivers that possibly meet criteria for a major depressive disorder (5.4%) are even lower than the national prevalence rate for major depressive disorder (6.7%) for all adults in the United States as reported by the National Institute of Mental Health (2010). It was assumed that the caregivers in this sample would report levels of distress comparable to that reported in other caregiver samples (e.g., Singer, 2006; Vitaliano, Schultz, Kiecolt-Glaser, & Grant, 1997; Vitaliano, Zhang & Scanlan, 2003). Not only were the indications of a major depressive disorder lower than expected, a significant proportion of caregivers endorsed minimal scores of "0" or "1" associated with depression (n=29; 52%), and a small percentage of those who endorsed significant symptoms. While the PHQ scores for anxiety symptoms in this study represent "other anxiety syndrome" rather than a specific diagnosis, a comparison with the original study of 3000 primary care patients reveals that this sample endorsed minimal symptoms. In the original study, the prevalence of "other anxiety syndrome" was shown to be 3 to 10% (Spitzer, Kroenke & Williams, 1999). Only 5.5% of this sample reached the criteria for the syndrome. Additionally, a high proportion of caregivers endorsed no symptoms and received a score of "0" associated with anxiety

(n=24; 43%). Caregivers responded with more variability regarding somatic complaints, with fewer scores of "0".

Several possibilities exist for the current findings. First, caregivers' scores might simply reflect the true experience of this sample. It is possible that these scores reflect a response style based on an idealistic view of their coping and adjustment to their role. In the present study, caregivers knew the responses could be viewed by the attending physician in the clinic. It is possible that this methodological feature prompted caregivers to give more cautious, and possibly "socially appropriate" responses. These results raise important issues to consider regarding how to interpret unexpected response styles to the self-report measures used in this study.

The results demonstrate differential support of the research hypotheses. No support was found for Hypothesis 1 concerning the relationship of demographic variables to caregiver adjustment. As burnout among caregivers has been noted in the literature, it was hypothesized that both years of caregiving and the RCMS would be associated with worse scores related to psychological adjustment and subjective well-being. Based on expected associations by the clinical researcher and qualitative research describing the experiences of caregivers of children with severe neurodisabilities who depend on medical technology and complex, home-based medical care protocols, it was expected that the severity of disability and level of respiratory care plans (as reflected in the RCMS) would account for a significant proportion of variance associated with the health outcome scores. It was also expected that the individuals who had been caregivers for a longer period of time would report more distress than caregivers who

had spent less time as caregivers. The contribution of these primary variables was not

confirmed among this sample of caregivers. None of the other demographic variables

were significantly predictive of the criterion variables.

Hypothesis 2, concerning the relationship of caregiver coping to adjustment,

received limited support. None of the five dimensions that comprise the F-COPES

measure demonstrated significant associations with measures of psychological

adjustment, general health and well-being. Additionally, only one of the three

dimensions of the CHIP measure accounted for a significant proportion of variance.

However, the CHIPSES scale, representing social support, self-esteem, and

psychological stability, exhibited a consistent and strong relationship with the outcome

variables of interest. Correlations revealed that greater use of coping efforts involving

developing social relationships, engaging in activities that promote individual identity

and self-worth, and behaviors to manage psychological tensions and pressures was

correlated with less somatic concerns and depressive symptoms. Additionally, these

coping efforts were associated with greater reports of general health and mental health.

Though the limited support among the majority of family coping dimensions was

unexpected, the presence of the strong support for the inclusion of CHIPSES in the

model was consistent with related studies that used the CHIPSES scale to demonstrate

social support as a predictor of distress in caregivers of children with chronic illness or

disabilities (Dunst, Tivette, & Hamby, 1994; Horton & Wallander, 2001; Fotiadou,

Barlow, Powell, & Langton, 2008). It is believed that social support is central in

appraisal and coping (Lazarus & Folkman, 1984) and provides "emotional,

psychological, physical informational, instrumental and material aid and assistance that directly or indirectly influences the behaviour of the recipient of these various kinds of resources" (Dunst , Tivette, & Hamby, 1994, p.152).

Two findings raise the implications for future studies with caregivers in similar scenarios. First, how do we account for such limited support of family coping variables that have demonstrated significant and meaningful results in other studies? As will be discussed later, these results may be accounted for by a combination of the specific measures being used and the unique population being studied. Second, why was there a different strength of relationship between CHIPSES and two of the FCOPES scales that tap into the dimension of social support? At the very least, we can conclude that the concept of social support has multiple dimensions that appear to vary in their relative importance to caregivers' health and well-being. This creates interpretive problems when talking about the importance of caregiver support as if it were a unitary dimension. To enhance our understanding of caregivers, researchers must consider specific aspects of support that are important for unique populations. Qualitative research may help define the experiences of this specific population. Further, factor analysis and studies of factorial invariance (Lin, 2000) may reveal if measures vary significantly among different populations. We must strike a balance between the desire to compare diverse populations, even among caregivers of children with chronic illness or disability, and the recognition that some populations of children and their caregivers are so unique that using the same measures across diverse populations may produce invalid scores that make desired comparisons across samples tenuous.

Results demonstrated that responses among this population varied according to styles in family coping, especially related to social support. It is important to note that, even though social support was associated with lower rates of endorsement of psychological maladjustment and increased rates of general health and subjective well-being, a substantial number of caregivers reported that social support was not an option for them. This finding may reflect the difficult reality of caregiving in this population as a relatively high proportion of caregivers may be isolated (Kirk, 1999; Wang & Barnard, 2004).

Isolation from support systems can limit caregiver access to experiences, relationships, and other factors often associated with better psychological adjustment and health outcomes. Most of the longitudinal research of caregivers of children with chronic illness and disability has focused on the first year or two after onset, limiting our understanding of long-term adjustment. However, other research indicates that social support is most likely to be present in the acute phase or onset of an illness or disability but that support erodes over time (Pinelli, 2000; Quittner, Glueckauf, & Jackson, 1990; Whitlatch, Feinberg, & Sebesta, 1997). Research with adults has provided more evidence. For example, in a review of 117 studies examining caregivers of stroke survivors, the author found little evidence for a direct relationship between caregiver distress and duration of caregiving (Gaugler, 2010). Similarly, Goode (1998) found that primary stressors associated with caregiving did not directly affect changes in physical and mental health outcomes over time; however, he did find that psychosocial variables including appraisals, coping responses, and social support accounted for caregiver

outcomes. This leads to an important question about how to provide and facilitate increased access to support among caregivers, especially when caring for children with severe disabilities that require substantial care defined by the number of hours dedicated to the caregiving role and the level of specialty medical care necessary.

Hypotheses 3 (Constructive Problem Solving) and 4 (Dysfunctional Problem Solving) were initially examined to determine the contribution of social problem solving style to the model. While analyses revealed relationships among these variables and the outcome variables, further examination revealed that negative orientation was most strongly predictive of criterion variables. These results support findings from previous studies that revealed negative orientation is the most significant SPS dimension associated with psychological maladjustment and poor health (Elliott & Shewchuk, 2003; Elliott, Shewchuk, & Richards, 2001; Grant, Elliott, Weaver, Glandon, Raper, & Giger, 2006; Rivera, Elliott, Berry, Grant, & Oswald, 2007). Although the constructive and dysfunctional problem-solving style variables continue to be a meaningful way to organize dimensions of problem solving styles, they appear less meaningful for this particular sample of caregivers. We may conclude that the singular dimension of negative problem orientation is most important to consider for this sample regarding psychological maladjustment and poor general health and subjective well-being.

One significant limitation of this study, and others like it, is the tendency to utilize small sample sizes. Many other studies were limited by a low sample size which, in turn, reflects difficulties commonly encountered in studying people who live with low-incidence disabilities (e.g., Reddon, McDonald, & Kysela, 1992; Svavarsdottir &

McCubbin, 1996). Unfortunately, the low number adversely impacts the number of variables that can be considered, the type of analyses that may be used (i.e., correlational versus Structural Equational Modeling), and the overall generalizability of the findings. To be fair, these numbers might also reflect the difficulty studying relatively small populations that are geographically sparse. These conditions make multisite studies almost essential to obtain sample sizes sufficient for adequate power to overcome the limitations mentioned above. Future research related to caregivers of children would be greatly enhanced by adopting multisite approaches to increase sample sizes, increase geographic representation, and facilitate consistency in the study design, instrumentation and analyses. This model would likely have the added benefit of promoting communication among researchers and clinical professionals that could enhance clinical practice. Despite the limitations regarding quantitative studies with this population, several qualitative studies have made a substantial contribution to our understanding the experiences of these caregivers.

Several areas for future research are essential to address. First, social support is one of the most commonly examined variables in the literature on caregiver distress. There is considerable evidence to show that social support is associated with the caregiver experience and health outcomes. However, it is evident that social support is not always clearly or consistently defined, making it difficult to make comparisons across studies, unless they utilize the same measures. We need better ways to examine social support across varying caregiving scenarios that take into account and differentiate between availability of support, barriers to receiving support when it is

available, responsiveness help-seeking behavior regarding support, types of support, subjective helpfulness of support, objective impact, and satisfaction. Using simple and generic terms such as support do not adequately reflect the diversity and complexity of caregivers' experiences.

A second area of caregiver research that appears especially problematic relates to the examination of disease or disability severity as a meaningful variable for analysis. Examining the association between caregiver distress and disability severity is difficult for several reasons. The problematic nature is due to mixed findings across studies that make conclusions and generalizations difficult. There are several possible reasons that should be considered. Different levels of severity of disease or disability could result in qualitatively different experiences in the children and caregivers, each of which is rated as distressing by caregivers. Second, it is also likely that severity level is inconsistently defined making comparisons less meaningful. However, some measure of disability will continue to be important in order to rule out medical variables. A more promising approach by researchers has been to focus on functional abilities and specific areas of impairment of the care recipient. For example, Msall (2005) proposed the use of two contemporary models that describe a comprehensive view of disability. First, the International Classification of Functioning (World Health Organization, 2001) uses the following components to describe health and well-being: 1) body structures, 2) body functions, 3) activities, and 4) participation. A more recent model of functioning, the Developmental Kaleidoscope Model of Children's Health (National Research Council and Institute of Medicine, 2004) encompasses biology and behavior, the physical and

social environment, and policy and services. As Elliott and Warren (2007) point out, these models acknowledge "the limited explanatory power of any given medical diagnosis in the prediction of any significant index of adjustment" (p. 21). The use of one of these models in research might represent a more appropriate variable, or collection of variables, to examine than a diagnosis or severity level since they can be more objectively measured. Even more, as Msall (2005) suggested, these models are appropriate because of the holistic view of disability that looks beyond dysfunction and identifies specific areas of functioning that can be addressed by appropriate interventions at the individual, family or community level.

Alternatively, qualitative analysis might offer plausible insights into the unique stressors encountered by caregivers of children with severe disabilities. For example, some researchers have determined that it is important to study the reality of specific populations of caregivers' by eliciting themes that represent their experiences, challenges and needed services (O'Brien, 2001; O'Brien & Wegner, 2002; Resch, Mireles, Benz, Grenwelge, Peterson, & Zhang, 2010; Wang & Barnard, 2008). Resch et al, for example, utilized focused groups to identify four major themes including 1) obtaining access to information and services, 2) financial barriers to services, 3) school and community inclusion, and 4) family support. Qualitative research on technology-dependent children has shown a range of challenges and needs that vary, at least partly, according to the level of functioning of the child (O'Brien, 2001; O'Brien & Wegner, 2002; Wang & Barnard, 2008). For those caregivers who have relatively higher functioning children (i.e., ambulatory, communicative) that attend school, behavior

problems and school difficulties are often cited as the most distressing aspects of caring for their children (Ketelaar, Volman, Gorter, & Vermeer, 2008; Wallander & Noojin, 1995). For those caregivers of children with more impaired functioning, levels of distress and psychological maladjustment could include frequent medical complications, high levels of medical care and the threat of loss of life (Rolland, 1994). The fact that all of these caregivers of children with differing diagnoses and levels of functioning could report similar levels of distress suggests that disability and functioning are unlikely to serve as consistent predictors of caregiver distress.

An additional explanation for mixed findings regarding the impact of severity on caregivers relates to the idea that subjective distress is continually redefined. For example, the experience of most chronic health conditions is not static. Rather, patients and caregivers go through periods of effective management with few crises and other times of deterioration and complications that impact a child's health and functioning and require increased levels of care. This becomes clear if we consider two examples.

In one example, we can imagine three families caring for children with varying degrees of disability, functioning and levels of care required. Especially in the early stages of diagnosis, following a significant injury, or during subsequent times of crisis, each of these families is likely to experience significant distress and endorse similar levels of distress on research measures even though an objective observer would rate these experiences differentially. A second example would consider a family's experience of the progression of a child's illness or disability that is deteriorating. If a caregiver were to rate levels of distress throughout the deterioration of the child's

condition, it is possible that at each point, there would be significant levels of distress with little variability. These examples illuminate the problem of how distress can continually be redefined so that the current level of distress is always high and, what was once considered a high level of distress is now only moderate. Other important factors relate to the dynamic model of coping and adjustment in the context of disability.

Wallander and Varni's (1998) "disability-stress-coping model" has demonstrated specific risk factors are important in understanding caregiver distress, including 1) disease/disability parameters, 2) functional dependence, and 3) disease and non-disease related psychosocial stressors. In the present study, the RCMS as a single score tapped into the first two categories but without appropriate specificity as described above in the models of functional abilities. Another limitation was that the study failed to examine specific disability-related stressors which could account for additional variance in the model. Within the disability-stress-coping model, stress related to illness and disability, environmental factors and coping are assumed to be the most significant factors associated with psychological adjustment or maladjustment in the families of chronically ill children (Wallander & Varni, 1998; Wallander & Varni, 1992). These stressors could be identified by the use of focus groups as described in Resch et al (2010).

In other words, researchers have the goal of examining levels of distress from an objective point of reference that allows for comparisons while caregivers who complete questionnaires have no point of reference except their own experience which includes dynamic psychological characteristics. This can make comparisons difficult and less meaningful if we rely on ratings of subjective experiences. Research that relies more on

objective measures of child and parent functioning, caregiving responsibilities and outcome measures will help address this problem.

Finally, in addition to coping, stress processing variables such as cognitive appraisals are shown to be essential in psychological adjustment of caregivers (Sloper, 2000; Thompson, Gustafson, & Gil, 1995; Wallander & Varni, 1992). Variables such as objective medical and disability parameters, financial concerns, family conflict can certainly serve as specific stressors within the disability-stress-coping model but caregivers exhibit a range of appraisals about those situations that influence that actual experience of distress. Cognitive appraisals can influence the perception, experience and rating of symptoms and impairment (Elliott & Warren, 2007).

As an example of disability parameters, how do appraisals differ depending on whether a child's condition is life-threatening or not, or is chronic and stable versus chronic and deteriorating? Life expectancy seems to be an important variable related to appraisal. For a child with asthma who experiences relatively little impairment in day-to-day functioning, a caregiver's appraisal might be defined as the belief or expectation that the child is able to participate in normal social and school activities, with certain restrictions and precautions to be considered. Appraisals related to a child with mild cerebral palsy could mean that caregivers expect the child to receive appropriate accommodations and services in the school setting in order to obtain an education, maintain social relationships and engage in activities despite significant limitations regarding physical activity, transportation and access. Parents would also expect to effectively manage occasional health crises, see their child function independently in

many contexts, enjoy meaningful relationships and have an integral role within the family.

These examples can be contrasted with the appraisals and expectations of caregivers of children with severe and life-threatening disabilities that require 24-hour care due to dependence on medical technology and lack of self-care skills. Many of these children are not able to breathe without assistance, communicate or have meaningful social interaction, ambulate, or attend school. Caregivers are therefore required to provide specialized medical care in the home, often with the assistance of home-healthcare workers; are isolated from family, peers and the community; and are constantly vigilant due to recurring crises that require immediate medical attention. Many of these caregivers also live with the expectation of a lower life expectancy for their child. For such a population of caregivers, it is not difficult to imagine how appraisals and expectations would be distinct from the other two examples. For some caregivers, expectations may simply be defined in life-and-death terms, living from crisis to crisis. These examples illustrate how we often are talking about different contexts even though we use identical terms to describe them. The literature on outcomes associated with cognitive appraisals and stress processing would be greatly enhanced if researchers clearly defined these terms for specific populations.

With all of these potential disability-related stressors, we are reminded that disability always occurs within a temporal context (Elliott & Mullins, 2004). In other words, medical crises occur, functional abilities change, financial burdens mount, social support fades over time, family dynamics change and children and caregivers age.

Additionally, the impact on stressors can lead to psychological maladjustment which impacts important activities such as caregivers' cognitive appraisals, use of active coping and seeking and requesting appropriate services. It is recommended that future research with this particular population seeks to identify the temporal context that will inform the inclusion of specific variables to study and the appropriate timing of measurement and intervention (Elliott & Warren, 2007).

Although caregiving across populations and contexts certainly shares several common experiences and challenges, it is essential to utilize qualitative methods to help identify how specific populations differ, especially in the early stages of studying a particular group of caregivers. As mentioned previously, lack of understanding about unique populations likely leads to inaccurate assumptions and the use of instruments that produce invalid results because the measurement items do not accurately or completely represent the most important variables.

It is recommended that caregiving experiences be continually examined to learn what would be most helpful to them (O'Brien, 2001; O'Brien & Wegner, 2002; Wang & Barnard, 2008). While interesting research questions and types of analyses abound, the importance of research for improving clinical practice and the caregiving experience should not be overlooked. This would include involvement of caregivers as experts who provide valuable information and direction in addition to a review of the literature, especially when studying a population that has unique characteristics such as the current study. Another suggestion would be to discuss results and conclusions of the study with clinicians and caregivers as collaboration of these multiple and equally valid

perspectives could enhance understanding and advancement for future research and practice.

One of the specific limitations of this study was the lack of specific demographic variables that could have contributed to additional variance in the scores on health and well-being. Future studies would do well to include information on marital status and family composition as family serves as both a potential source of stress and perhaps the most significant source of social support. Family structure can directly impact the most available and useful source of support. For example, in the current study we do not know how marital status impacts the responses of caregivers on measures of family coping and social problem solving. It is possible that social problem solving style, as a personal approach to coping, is more important for caregivers who do not have a strong support network within the family. It would also be important to consider how family conflict may influence the use of coping styles. Additionally, financial concerns and sleep difficulties have been identified in other studies as a significant source of distress in family caregivers. It seems likely that caregivers of children with severe disabilities that require the ongoing use of medical technology, skilled nursing assistance and routine clinic visits and hospitalizations would be especially at risk for financial strain and inconsistent sleep.

No preliminary research on a specific population will completely answer questions of interest or describe a population of interest. Rather, we think of a body of research or a series of studies that is continually refined to answer more specific questions and respond to limitations of the previous studies. Such is the case with the

findings of this study. No empirical study of caregivers of individuals with severe neurodisability and pulmonary disorders was found in the extant, peer-reviewed literature. Consequently, the present study may be among the first to examine caregiver adjustment in this clinical area. The results of the present study may advance our current understanding of health, coping and quality of life among caregivers in this particular scenario. Finding from this research has equal value for the limitations and questions that it identified to address in subsequent studies.

Finally, the researchers involved in this study have an interest in these results informing and enhancing clinical practice. One contribution of such a study is the identification of the utility of particular measures within a clinical context. Utility would include how efficient the measures are to administer, complete, score and interpret. Studies such as this one will hopefully reveal how meaningful the results are in regards to identifying caregivers who are in crisis or at risk for adjustment problems. Future studies are needed to address this question and further define this unique caregiver experience and identify which constructs and specific questions are most helpful. With an effective questionnaire available for clinicians, caregivers in distress can more appropriately be identified and referred to providers for such issues as depression, anxiety, somatic complaints, financial assistance, family conflict, child behavior problems and school and academic concerns.

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APPENDIX A

LIST OF ABBREVIATIONS FOR TABLES

Demographics

PAGE = patient age
PGEN = patient gender
CAGE = caregiver age
CETH = caregiver ethnicity
YCG = years caregiving
RCMS = respiratory care management score

Coping

CHIP = Coping Health Inventory for Parents
    CHIPCO = Family Integration, Cooperation and an Optimistic Definition of the
    Situation
    CHIPSES = Maintaining Social Support, Self-Esteem and Psychological Stability
    CHIPMCC = Understanding the Health Care Situation Through Communication with
                         Other Parents and Consultation with the Health Care Team

FCOPES = Family Crisis Oriented Personal Evaluation Scales
    FCASS = Acquiring Social Support
    FCREF = Reframing
    FCSSS = Seeking Spiritual Support
    FCMF = Mobilizing Family to Acquire and Accept Help
    FCPA = Passive Appraisal

Social Problem-Solving

CPSS = Constructive problem solving style
    PPO = Positive problem orientation
    RPS = Rational problem solving
DPSS = Dysfunction problem solving style
    NPO = Negative problem orientation
    ICS = Impulsivity/carelessness style
    AS = Avoidant style

Health Outcomes

PHQ = Patient Health Questionnaire
    PHQSOM = PHQ Somatization
    PHQDEP = PHQ Depression
    PHQANX = PHQ Anxiety
SF-12 = Short Form-12 Version 2, Health Survey
    GH = General Health
    MH = Mental Health

Table 1
Descriptive Statistics

Variable	n	% of Sample	Range	Mean	SD
Patient Gender					
Male	33	58.93			
Female	23	41.07			
Patient Age			4 – 30	13.43	6.10
Parent Gender					
Male	1	1.79			
Female	55	98.21			
Parent Age			24 – 60	43.18	9.03
Parent Ethnicity					
Caucasian	44	78.57			
African-American	12	21.43			
Years Caregiving			3 – 26	12.36	5.50
Respiratory Care Management Score			1 – 4	2.61	1.14

Table 2

Original Regression Model with All Variables Under Consideration

Variables	PHQSOM	PHQDEP	PHQANX	SF12G	SF12MH

Block 1: Demographics
Patient Age
Patient Gender
Parent Age
Parent Gender
Parent Ethnicity
Years of Caregiving
Respiratory Care Management Score

Block 2: Family Coping
FCOPES
  Acquiring Social Support
  Reframing
  Seeking Spiritual Support
  Mobilizing Family to Acquire and Accept Support
  Passive Appraisal
CHIP
  Integration, Cooperation, and Optimism
  Social Support, Self-esteem, and Stability
  Understanding the Health Care Situation

Block 3: Social Problem Solving
Constructive Problem Solving Style
  Positive Problem Orientation
  Rational Problem Solving
Dysfunctional Problem Solving Style
  Negative Problem Orientation
  Avoidance Style
  Impulsivity and Carelessness

Table 3

Correlations of Demographics with Coping, Problem Solving and Health Outcomes

	1. PAGE	2. PGEN	3. CAGE	4. CETH	5. YCG	6. RCMS
1. PAGE	1.00					
2. PGEN	- .15	1.00				
3. CAGE	.52**	- .03	1.00			
4. CETH	- .11	.16	- .04	1.00		
5. YCG	- .14	- .03	.47**	- .14	1.00	
6. RCMS	.29*	- .18	- .01	- .01	.30*	1.00
7. CHIPCO	- .02	.02	- .02	- .06	- .00	.05
8. CHIPSES	.03	- .06	- .25	.14	.05	.09
9. CHIPMCC	- .22	.18	- .26	.13	- .23	.11
10. FCASS	- .27*	- .13	- .36**	.16	- .28*	.09
11. FCREF	.07	- .14	- .01	- .05	.05	- .09
12. FCSSS	- .12	- .08	- .12	.10	- .12	- .06
13. FCMF	- .23	- .08	- .20	.13	- .26	- .17
14. FCPA	- .31	.14	- .05	.36**	- .29*	- .12
15. CPSS	.10	- .02	- .10	- .10	.10	- .14
16. DPSS	- .02	- .16	.02	- .07	- .08	- .09
17. PPO	.09	.01	.07	- .09	.08	- .23
18. NPO	- .10	- .15	- .03	- .10	- .07	.01
19. ICS	.02	- .20	.18	.01	- .06	- .28*
20. RPS	.06	- .03	- .24	- .19	.04	- .02
21. AS	- .03	.01	- .12	- .06	- .04	.07
22. SOM	.06	- .17	.10	- .12	.05	- .03
23. DEP	.02	- .18	.02	- .22	- .04	- .03
24. ANX	- .00	- .19	- .06	- .06	- .06	- .08
25. GH	- .07	.17	- .20	.12	- .04	.01
26. MH	- .00	.23	.08	.24	.02	.04
Mean	13.43		43.18		12.36	2.61
SD	6.10		9.03		5.50	1.14

* p < .05, ** p < .01

Table 4

Correlation of Original Coping and Problem Solving Variables with Health Outcome Variables

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
1. CPCO	1.00																			
2. CPSES	.64**	1.00																		
3. CPMCC	.61**	.46**	1.00																	
4. FCASS	.37**	.38**	.53**	1.00																
5. FCREF	.51**	.29*	.09	.12	1.00															
6. FCSSS	.30*	.25	.41**	.37**	.02	1.00														
7. FCMF	.22	.19	.48**	.56**	.11	.49**	1.00													
8. FCPA	-.11	-.13	.06	.11	.11	.17	.09	1.00												
9. CPSS	.28*	.34*	.14	.07	.57**	-.11	.23	-.28*	1.00											
10. DPSS	-.01	-.16	.02	.11	.01	.03	.04	.38**	-.17	1.00										
11. PPO	.08	.31*	-.03	.04	.53**	-.16	.22	-.24	.87**	-.21	1.00									
12. NPO	-.05	-.23	.11	.12	-.13	.20	.06	.36**	-.23	.80**	-.29*	1.00								
13. ICS	-.03	-.08	-.16	-.02	.11	-.13	.09	.24	-.03	.70**	.08	.27*	1.00							
14. RPS	.11	.22	.15	.02	.40**	.02	.15	-.33*	.91**	-.28*	.60**	-.26	-.27*	1.00						
15. AS	.07	-.03	.09	.17	.05	-.03	-.08	.25	-.11	.75**	-.26	.47**	.28	-.06	1.00					
16. SOM	-.10	-.36**	-.18	-.15	.01	-.01	-.14	.21	-.08	.38**	-.11	.56**	.01	.09	.24	1.00				
17. DEP	-.21	-.34**	-.17	-.08	-.01	-.04	.03	.21	-.05	.58**	-.18	.53**	.37**	.03	.53**	.59**	1.00			
18. ANX	-.10	-.13	.02	.14	-.16	.08	.09	.18	-.18	.43**	-.15	.49**	.17	-.12	.25	.43**	.61**	1.00		
19. GH	.09	.36**	.02	.12	.03	-.01	.04	-.05	.22	-.20	.26*	-.31*	-.07	.04	-.03	-.61**	-.46**	-.20	1.00	
20. MH	.25	.36**	.19	.03	.25	-.05	.05	-.12	.25	-.45**	.34**	-.45**	-.17	.13	-.39**	-.33*	-.59**	-.64**	.14	1.00
Mean	44.20	28.70	16.41	28.18	33.21	14.40	14.36	6.40	30.46	9.16	15.43	4.52	2.77	15.59	1.88	4.61	1.62	1.22	70.54	75.00
SD	9.34	8.85	4.95	7.57	5.39	4.42	3.41	2.97	7.35	6.39	3.37	3.12	2.91	3.79	2.52	3.03	1.08	1.21	25.63	15.81

*p < .05, **p < .01

Table 5
Correlation Matrix for Identified Variables in Adjusted Model

	YCG	RCMS	CPSES	PPO	NPO	SOM	DEP	ANX	GH	MH	MEAN	SD
YCG	1.00										12.36	5.50
RCMS	.27	1.00									2.61	1.14
CHIPSES	.05	.09	1.00								28.70	8.85
PPO	.08	- .23	.31	1.00							15.43	3.37
NPO	- .07	.01	- .23	-.29*	1.00						4.52	3.12
PHQSOM	.05	- .03	- .36**	- .13	.56**	1.00					4.61	3.03
PHQDEP	- .04	- .03	- .34**	- .12	.53**	.59**	1.00				1.62	1.08
PHQANX	- .06	- .08	- .13	- .15	.49**	.43**	.61**	1.00			1.22	1.21
SF12GH	- .04	.01	.36**	.26*	- .31**	- .61**	- .46**	- .20	1.00		70.54	25.63
SF12MH	.02	.04	.36**	.34**	- .45**	- .33*	- .59**	- .64**	.14	1.00	75.00	15.81

$* p < .05, ** p < .01$

Table 6
Regression of Health Outcome Variables on Predictor Variables Related to Hypotheses

	*df*s	R^2	ΔR^2	ΔF^2	β
PHQ SOMATOFORM					
Block 1: Demographics	2	- .03	.00	.18	
Years Caregiving					.06
RCMS					- .05
Block 2: Family Coping	1	.09	.13	8.01	
CHIP SES					- .37**
Block 3: Social Problem Solving	2	.33	.25	10.30	
Positive Problem Orientation					.10
Negative Problem Orientation					.53**
PHQ DEPRESSION					
Block 1: Demographics	2	- .04	.00	.05	
Years Caregiving					- .03
RCMS					- .02
Block 2: Family Coping	1	.07	.18	6.92*	
CHIP SES					- .34*
Block 3: Social Problem Solving	2	.28	.23	8.63**	
Positive Problem Orientation					.12
Negative Problem Orientation					.00**
PHQ ANXIETY					
Block 1: Demographics	2	- .03	.01	.22	
Years Caregiving					- .04
RCMS					- .07
Block 2: Family Coping	1	- .03	.02	.81	
CHIP SES					- .13
Block 3: Social Problem Solving	2	.17	.23	7.21**	
Positive Problem Orientation					- .02
Negative Problem Orientation					.48**
SF-12 GENERAL HEALTH					
Block 1: Demographics	2	- .04	.00	.06	
Years Caregiving					- .05
RCMS					.02
Block 2: Family Coping	1	.08	.13	7.70**	
CHIP SES					.36**
Block 3: Social Problem Solving	2	.12	.07	2.23	
Positive Problem Orientation					.13
Negative Problem Orientation					- .22
SF-12 MENTAL HEALTH					
Block 1: Demographics	2	- .04	.00	.04	
Years Caregiving					.01
RCMS					.04
Block 2: Family Coping	1	.08	.13	7.45**	
CHIP SES					.36**
Block 3: Social Problem Solving	2	.23	.18	6.26**	
Positive Problem Orientation					.19
Negative Problem Orientation					- .35**

Table 7

ANOVA Table of 2 Levels of Respiratory Care Management Score and Criterion Variables

Criterion Variable X Level of RCMS		Sum of Squares	*df*s	Mean Square	F	Sig.
PHQDEP	Between Groups	.288	1	.288	.245	.623
	Within Groups	63.241	54	1.174		
	Total	63.709	55			
PHQANX	Between Groups	1.629	1	1.629	1.119	.295
	Within Groups	75.665	52	1.455		
	Total	77.294	53			
PHQSOM	Between Groups	4.005	1	4.005	.431	.514
	Within Groups	501.352	54	9.284		
	Total	505.357	55			
SF12GH	Between Groups	781.071	1	781.071	1.193	.280
	Within Groups	35352.857	54	654.683		
	Total	36133.929	55			
SF12MH	Between Groups	47.619	1	47.619	.188	.667
	Within Groups	13702.381	54	253.748		
	Total	13750.000	55			

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