

FACTORS ASSOCIATED WITH UNMET RESPITE CARE NEEDS IN FAMILIES OF  
CHILDREN WITH AUTISM SPECTRUM DISORDER

by

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## ABSTRACT

### FACTORS ASSOCIATED WITH UNMET RESPITE CARE NEEDS IN FAMILIES OF CHILDREN WITH AUTISM SPECTRUM DISORDER

by

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**Background.** One in sixty-eight children have Autism Spectrum Disorder (ASD). To optimize outcomes to families through use of respite care, we examined the prevalence of unmet respite care needs and associated factors in families of children with ASD, compared to families of children with special healthcare needs (CSHCN) without ASD.

**Design.** An exploratory secondary analysis of the 2009-2010 National Survey of Children with Special Healthcare Needs (NS-CSHCN) was conducted using a non-experimental, descriptive, correlational design. The NS-CSHCN is a national cross-sectional telephone survey of 40,242 US households. The final sample included parents of children age 2-18 years old with ASD (n=935) and parents of CSHCN without ASD (n=1,583) who reported a need for respite care. Logistic regression was used to examine relationships between context factors that were aligned with the Individual and Family Self-Management Theory and unmet respite care needs.

**Results.** Parents of children with ASD who had unmet respite care needs were predominantly white, well-educated, affluent mothers of male children 12-17 years old with limited functional status. Differences in prevalence of unmet respite care needs were found between parents of children with ASD (14%; n=558) and parents of CSHCN without ASD (2%; n=717). In parents of children with ASD, Child Functional Status, Hours/Week Providing Care, and Family Financial Burden were significant predictors of unmet respite care needs.

**Conclusions.** The prevalence of unmet respite care needs in parents of children with ASD was seven times higher than parents of CSHCN without ASD. Screening all parents of CSHCN for unmet respite care needs is important, recognizing that parents of children with ASD, functional limitations and high caregiving demands are at highest risk for unmet respite care needs. Increased funding for and reimbursement of respite care services is needed to optimize family outcomes.

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I dedicate this work to my loving husband,  
my understanding children,  
my supportive parents,  
and all families of children with special healthcare needs.  
May we all remember how important it is to take a break.

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This dissertation was fueled by love, faith and quad Venti peppermint white mochas from Starbucks. Albeit somewhat unconventional, I am compelled to acknowledge the Broadway musical *Hamilton* as the official soundtrack of my doctoral journey. Watching this powerful story be told (and listening to the soundtrack on repeat while I would *write like I was running out of time*) has truly inspired me to *rise up!* Since starting this journey, I have experienced many *moments when you're in so deep, it seems easier to just swim down. But there's a grace too powerful to name. I stop wasting time on tears and I wrote my way out.*

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*more inside me now. I'm so sorry for not always dedicating every day to you. From now on, I swear that I'll be around for you. I'll do whatever it takes. Thanks for reminding me how important it is for parents to take a break.*

## Chapter 1 Introduction

This purpose of this chapter is to provide a brief introduction to a study exploring the factors associated with unmet respite care needs in families of children with Autism Spectrum Disorder (ASD). Important information about the background of the problem and significance will be described. An overview of the proposed study, including study purpose and research questions, will be presented. Additionally, key concepts and definitions will be defined.

### **Background and Significance**

According to estimates from the Autism and Developmental Disabilities Monitoring (ADDM) Network, about 1 in 68 children has been identified with Autism Spectrum Disorder (Centers for Disease Control and Prevention, 2014). Autism Spectrum Disorder (ASD) is defined as a group of developmental disabilities that can cause significant social, communication and behavioral challenges (Centers for Disease Control and Prevention [CDC], 2015). The increasing prevalence of ASD is a significant public health concern.

While parenting, in general, can be stressful, mothers of children with ASD experience chronic stress comparable to combat soldiers, according to one study (Smith et al., 2010). In addition to typical parenting demands, parents of children of ASD also have added demands related to caring for their child's often unpredictable behavior and emotional challenges. Additionally, parents of children with ASD often experience financial stress and job loss (Lindly, Chavez & Zuckerman, 2016) and are more likely to experience marital stress and have high rates of divorce (Saini et al., 2015), which can further impact their stress levels. Caregivers who are under stress are also more likely to have disrupted relationships and difficulty caring for their child. This increased stress can cause physiological changes, lower the immune response and put caregivers at risk for serious health risks, including depression.

The accumulation of the increased stress can also result in parents abusing or neglecting their children (Cowen & Reed, 2002). Children with special healthcare needs are more likely to be placed in foster care, as a result (Stoltzfus et al., 2014).

### **Respite Care**

Researchers have identified respite care as an important support service for caregivers of children with ASD. According to the Respite Care Association of Wisconsin (2010), respite care is temporary relief for care-givers and families who are caring for people with disabilities or other special needs such as chronic or terminal illnesses; or are at risk of abuse and neglect. Respite care has also been defined as short term care that helps a family take a break from the daily routine and stress of care-giving (Autism and PDD Support Network, 2010).

Articles related to respite care began to be published in the early 1980s and were primarily from social work journals with the focus on respite care to help reduce child abuse (Cohen, 1982; Subramanian, 1985; Cowen & Reed, 2002). While research in the area of respite care is limited in ASD, various caregiver populations have been studied. Specifically, studies have looked at children with chronic illnesses (Campbell, 1996; Odnaha, 1986; Thurgate, 2005), physical disabilities (Cavanagh & Ashman, 1985; Doig, McLennan & Urichuk, 2008; Palisano et al., 2010), cognitive disabilities (Hoare et al., 1998; Preece & Jordan, 2007; Wilkie & Barr, 2008), and developmental disabilities (Chan & Sigafos, 2001; Cowen & Reed, 2002; Mullins, Aniol, Boyd, Page & Chaney, 2002). Respite care has also been studied among caregivers of adults with physical disabilities (Dawson & Liddicoat, 2009) and cognitive disabilities (Mansell & Wilson, 2009). In addition, studies have looked at respite care for caregivers of the elderly (Hong, 2009); persons with dementia (Cohen-Mansfield, Marx, Dakheel, Regier & Thein, 2010; Goodman et al., 2010); persons with mental health

disorders (Doig, McLennan & Urichuk, 2008; Jardim & Pakenham, 2010; Reupert & Maybery, 2009) and patients at the end of life (Barrett et al., 2009; Corkin, Price & Gillespie, 2006).

Respite care has been used to describe services provided in various settings. Respite care can be in-home (Corkin, Price & Gillespie, 2006), community-based (Dawson & Liddicoat, 2009), hospital-based or in a residential facility (Mullins, Aniol, Boyd, Page & Chaney, 2002; Wilkie & Barr, 2008). The providers of respite care can be formal, such as nurses (Barrett et al., 2009) or in-formal (family and friends). Respite care can also occur in varying frequencies and durations (Corkin, Price & Gillespie, 2006; Wilkie & Barr, 2008). Respite care services can be short-term, intermittent, long-term, on-going, or emergency intervention (Corkin, Price & Gillespie, 2006; Wilkie & Barr, 2008). For example, respite care might occur in the form of a short term, intermittent, community-based respite event sponsored by a local church with volunteers providing the care. In contrast, respite care services might also be provided in a hospital-based facility, staffed by trained nurses, for regularly scheduled, long-term stays.

### **Respite Care and Stress**

Numerous researchers have made anecdotal claims that respite care is needed to help reduce stress, typically highlighting this in the implications of their findings. However, very few studies have actually measured this relationship. Whitmore (2016a) conducted an integrative review to better understand the relationship between respite care and stress among parents of children with ASD. After critically evaluating the most current literature in this area, it was clear that studies had significant limitations, making it difficult to compare results across studies and caution is warranted in interpreting the findings. Despite this, results could be grouped into three main categories based on the association between respite care and stress.

While most studies found that respite care was associated with lower stress, several found that respite care was associated with higher stress and one study found no association. Overall, the results of the integrative review provided some evidence that respite care may be associated with a decrease in stress among caregivers of children with ASD. However, additional research is needed to better understand this relationship.

While research on the relationship between respite care and stress among parents of children with ASD is limited, a larger body of evidence can be found in the broader population of children with special healthcare needs (CSHCN). A systematic review by Strunk (2010) found that respite care may be an effective intervention to decrease stress among family caregivers. However, the author concluded that studies are needed to study the impact on parenting stress over time and also need to focus on non-maternal caregivers, such as fathers. A review by Chan and Sigafos (2000) described the characteristics related to the use of respite care among families with children with developmental disabilities. They found that caregiver stress was a significant predictor in the decision to use respite care, indicating that stress levels may be higher, initially, among those who use respite care. Cowen and Reed (2002) found that participation in a county respite care program resulted in significant reductions in parent stress when comparing pre and post intervention data; however, parent stress level remained high, possibly suggesting a need for a more intensive intervention. Harper et al. (2013) found that stress mediated the relationship between respite care use and relationship quality among married parents of children with Autism Spectrum Disorder. McLennan et al. (2011) examined stress before and after participation in a center-based respite program and found that, while stress levels decreased, there was no significant difference between pre and post-test score

among the intervention group. However, qualitative analysis of participants suggested that stress was greatly reduced, at least temporarily.

Other studies have found that respite care, specifically when not meeting the individual needs of the family, can ultimately lead to an increase in caregiver stress (Hoare et al., 1998; Treneman, Corkery, Dowdney & Hammond, 1997). Caregivers in one study expressed feelings of guilt and embarrassment about having to send their children to respite care facilities and therefore, it actually increased their level of stress (Wilkie & Barr, 2008). MacDonald and Callery (2007) found that parents expressed a need for a break but were too worried about the quality of the care to enjoy the time away.

### **Unmet Respite Care Needs**

Despite evidence that respite care is an effective intervention in supporting family caregivers, respite care needs remain largely unmet. Overall, there is limited research examining the prevalence of unmet respite care needs in families of children with ASD. However, several studies have been conducted with the broader population of children with special healthcare needs (CSHCN). Only one study was found that compared the prevalence of unmet respite care needs between families of children with ASD and families of children with other special healthcare needs.

### **ASD Population**

The respite care needs of families of children with ASD are largely unmet. In a study of 143 parents of children with ASD, the greatest single identified service need reported was respite care (Hodgetts, Zwaigenbaum, & Nicholas, 2015). While 57% of parents in the study reported “locating respite care workers able to care for my family” as a need, only 32% of parents stated that need was met. Brown, Ouellette-Kuntz, Hunter, Kelley, and Cobigo (2012)

conducted a cross-sectional survey of 101 Canadian families of school-aged children with ASD. They found that 53.5% rated “respite care for my child” as important and 41.6% rated respite needs as being unmet. Additionally, “difficulty finding respite care” and “respite worker lacking expertise in autism” were themes that emerged in the open-ended responses. In a study of 371 parent-child dyads enrolled in a national autism registry by Farmer et al. (2014), 57.6% had a need for respite care and 70.1% of those with a need reported their needs were unmet. Finally, Lindly, Chavez, and Zuckerman (2016) conducted a secondary analysis of the 2009-2010 NS-CSHCN to examine unmet needs for family health services (including respite care, mental health care, and genetic counseling) among parents of children with developmental disabilities (including those with ASD, developmental delay, and/or intellectual disability). Among the 3,518 respondents, 18.5% had one or more unmet family health service need and respite care was the most common unmet family health service at 11.5%.

### **CSHCN Population**

Respite care needs of families of CSHCN are also largely unmet. Rupp et al. (2005) found that only 7.5% of the 791,954 families who participated in the 2001-2002 National Survey of SSI Children and Families used respite care. However, a total of 28.6% reported a need for respite care. Overall, 73.9% of families with a need for respite care reported their needs were not met (Rupp et al., 2005). Nageswaran (2009) conducted a secondary analysis of the 2001 National Survey of Children with Special Healthcare Needs (NS-CSHCN). Of the 38,831 respondents, 3,178 (8.8%) reported having a need for respite care in the prior 12 months and 24% of those who needed respite care did not receive all the respite care that was needed. Finally, in a study of 21 parents of CSHCN, Aruda, Kelly, and Newinsky (2011) found that 74.9% of parents reported they were unable to get respite care when needed.

## **ASD Compared to Other CSHCN**

Only one study was identified that compared the prevalence of unmet respite care needs of families of children with ASD to families of children with other special healthcare needs. Kogan et al. (2008) conducted a secondary analysis of the 2005-2006 NS-CSHCN and compared three groups: children with ASD (n= 2,088); other children with special health care needs with emotional, developmental, or behavioral (EDB) problems (excluding those with ASD) (n= 9534); and other CSHCN (n= 26,751). They found that parents of children with ASD were nearly six times more likely to have unmet needs for family support services (including respite care), compared to parents of other CSHCN (OR = 5.98; 95% CI [4.55–7.86]). Overall, 19.3% of children with ASD had an unmet need for family support services, compared to only 10.7% of CSHCN with other EDB problems and 1.8% of other CSHCN.

### **Factors Associated with Unmet Respite Care Needs**

Overall, there is limited research examining the factors associated with unmet respite care needs in families of children with ASD. However, while several studies have been conducted with the broader population of CSHCN, no published studies were identified that compared the factors associated with unmet respite care needs between families of children with ASD and families of children with other special healthcare needs.

### **ASD Population**

A variety of factors have been found to be associated with unmet respite care needs in families of children with ASD. Hartley and Schultz (2015) found that mothers had a higher proportion of support needs (including respite care) that are unmet compared to fathers. Child's age, co-occurring behavior problems, presence of intellectual disability, parent education and household income were all related to support needs (Hartley & Schultz, 2015).

Lindly et al. (2016) found that living in the Western US, having a parent with more than a high school education, having an intellectual disability, experiencing functional limitations and having three or more comorbid conditions were positively associated with having any unmet family health service need (including respite care) among families of children with developmental disabilities (including ASD). Compared to families with no unmet need for family health services, families with any unmet need for health services were more likely to spend 11 or more hours per week providing/coordinating care for their child, experience financial problems due to the child's health condition, and have a family member that cut back or stopped working due to the child's health condition (Lindly et al., 2016). Several studies have suggested that family structure and marital status may be factors associated with unmet respite care needs (Dyches, Christensen, Harper, Mandleco, & Roper, 2016; Harper, Dyches, Harper, Roper, & South, 2013). Perceived need for respite care was lowest among Hispanic Spanish speaking parents in a study by Benevides, Carretta, and Mandell (2016). Finally, lower socioeconomic status was found to be associated with reporting a need for respite care by Pickard and Ingersoll (2016).

### **CSHCN Population**

A variety of factors have been found to be associated with unmet respite care needs in families of CSHCN, as well. Nageswaran (2009) found that higher maternal education, lower child functional status, and greater condition instability were associated with greater unmet respite care needs among parents of CSHCN. Benedict (2006) found that having public health insurance, self-care limitations, and being non-Hispanic were associated with greater unmet respite care needs. A study by Gannotti, Kaplan, Handwerker, and Groce (2004) suggested that cultural differences may influence perception of unmet respite care needs; they found that

Euro-American families had a higher prevalence of unmet respite care need compared to Latino families. Medical complexity (Kuo, Cohen, Agrawal, Berry, & Casey, 2011), Geographic differences (Fulda, Johnson, Hahn, & Lykens, 2013), and age (Rupp et al., 2005) have also been cited as potential factors associated with unmet respite care needs in parents of CSHCN.

### **Proposed Study**

With limited research in this area, it is important to further examine the prevalence of unmet respite care needs and associated factors in families of children with ASD, compared to families of children with other special healthcare needs. Little is known about whether having a child with ASD makes parents more likely to have unmet respite care. Since the growing prevalence of ASD has become a public health concern, there is a clear need to examine the prevalence and factors associated with unmet respite care needs in this unique population.

In order to fill this gap in the literature, an exploratory secondary analysis of the 2009/10 National Survey of Children with Special Healthcare Needs (NS-CSHCN) will be conducted. The NS-CSHCN is a national survey sponsored by the Maternal and Child Health Bureau at the Health Resources and Services Administration (HRSA) in partnership with National Center for Health Statistics at the Centers for Disease Control and Prevention (CDC), Child and Adolescent Health Measurement Initiative, and a National Technical Expert Panel. The NS-CSHCN is a cross-sectional telephone survey that assesses overall health and health status of CSHCN, including medical home, adequate health insurance, access to needed services, and adequate care coordination. The survey was conducted at three time periods: 2001, 2005/06, and 2009/10 with sample size ranges between 38,000 and 40,000 total non-institutionalized CSHCN in the US ages 0-17 years.

Several previous researchers utilized data from the NS-CSHCN to examine unmet respite care needs. Since more recent data is available, there is a unique opportunity to re-examine the prevalence of unmet respite care needs and associated factors in a large, nationally representative sample of families of children with ASD. The results of the proposed study can also be compared to the results of previous studies using earlier versions of the NS-CSHCN to determine if needs are better met after the passage of the Life Span Respite Care Act of 2006, which was passed by the US Congress to assist family caregivers to access affordable respite care.

A better understanding of what factors are uniquely associated with unmet respite care needs in families of children with ASD may facilitate targeted program and policy changes to increase access to and improvements of existing respite care services. Additionally, screening tools can be designed to help identify families who are at high risk for having unmet respite care needs. This knowledge would also allow healthcare providers to develop better strategies for matching the needs of families of children with ASD with available resources to promote the use of respite care services. Ultimately, addressing unmet respite care needs may help lower stress levels, decrease fatigue, and improve family self-management among families of children with ASD. Neff (2009) described a need for additional studies because “failure to pay attention to the growing need for respite care could lead to an increase in the disintegration of the family structure and an increase in preventable health care costs for society and children (p. 90)”. This study will contribute to the science in this area and have implications for healthcare professionals working with families of children with ASD, as well as for further research and policy.

## **Purpose and Research Questions**

The purpose of this study is to examine differences in factors associated with unmet respite care needs between families of children with Autism Spectrum Disorder (ASD) and families of Children with Special Health Care Needs (CSHCN) without ASD. The proposed research questions include:

1. What are the differences in the prevalence of unmet respite care needs between families of children with ASD and families of CSHCN without ASD?
2. What are the differences in the prevalence of respite care use between families of children with ASD and families of CSHCN without ASD?
3. What is the relationship between context factors and unmet respite care needs?
  - a. Explore the patterns of context factors between families of children with ASD who have unmet respite care needs and families of CSHCN without ASD who have unmet respite care needs.

## **Conceptual Framework**

The Individual and Family Self-Management Theory (IFSMT) will guide the study. This mid-range theory proposes that self-management is a process by which individuals and families use knowledge and beliefs, self-regulation skills and abilities, and social facilitation to achieve health-related outcomes (Ryan & Sawin, 2009). Self-management takes place in the context of risk and protective factors specific to the condition, physical and social environment, and individual and family. A diagram of the study variables aligned with the IFSMT is provided in Figure 1. Note that, due to limitations in the available measures, respite care use and stress were unable to be measured. The NS-CSHCN did not include any direct measures of stress. While respite care use was measured, the question was only asked of those parents

who responded that they had an unmet respite care need. As a result, there is no variability in the response (e.g. all those who used respite care had an unmet need).

### **Key Concepts and Definitions**

The following section provides a description of key concepts and definition, including: Children with Special Health Care Needs; Autism Spectrum Disorder; Caregiver; Family; Respite Care; Respite Care Use; Unmet Respite Care Needs; and Stress. Definitions of key concepts from the Individual and Family Self-Management Theory (Ryan & Sawin, 2009) are also provided, including: Self-Management; Context Factors; Process Factors; and Outcome Factors.

#### **Children with Special Health Care Needs (CSHCN)**

In accordance with the Maternal and Child Health Bureau (MCHB) definition, CSHCN are “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (The Child & Adolescent Health Measurement Initiative, n.d.).

#### **Autism Spectrum Disorder (ASD)**

Autism Spectrum Disorder is defined as a group of developmental disabilities that can cause significant social, communication and behavioral challenges (Centers for Disease Control and Prevention [CDC], 2015).

#### **Caregiver**

An adaptation of the definition by Drentea (2007) is used to define caregiving. A caregiver is an individual who provides unpaid assistance and support, outside of the norm of

expectations, to someone with a special health care need. This care can include a broad range of assistance related to medical, physical, or emotional needs of the care recipient.

### **Family**

Family is defined using an adaptation of the definition from Mauer and Smith (2013). A family is a self-defined group of individuals who share common characteristics and interact with one another as a system. A family may be related or un-related and may live together or separate.

### **Respite Care**

Respite Care is defined as temporary relief from the responsibilities of caregiving (Whitmore, 2016a). It allows a caregiver to take a break from the daily routine and stress of caregiving (Autism and PDD Social Network, 2010). Respite care can be provided by professionals (formal) and non-professionals (informal) in a variety of settings.

### **Respite Care Use**

A definition of respite care use could not be identified in the current literature. A new definition of respite care use is proposed as a caregiver's intentional use of services that provide for a temporary relief of the responsibilities of caregiving. Respite care use is conceptualized as a self-management behavior, a proximal outcome in the model of the Individual and Family Self-management Theory.

### **Unmet Respite Care Needs**

Unmet Respite Care Needs is defined as an individual's perception of the degree to which their respite care needs are met. This builds off the survey questions in the NS-CSHCN, which defines unmet respite care needs as having a need for respite care, and not receiving all the respite care, that was needed (Bramlett, et al., 2014). Unmet respite care needs is

conceptualized as a knowledge or belief, a process variable in the model of the Individual and Family Self-management Theory.

### **Stress**

Stress is defined as an individual's perception of the degree to which they find their life to be unpredictable, uncontrollable, and overloaded. This builds off the definition by Cohen (1995), who define stress as a process in which demands exceed the adaptive capacity of a person, resulting in psychological and biological changes that may place persons at risk for disease. In this definition, subjectivity is important, recognizing that one's perception is their reality. Stress is conceptualized as a distal, health status outcome in the model of the Individual and Family Self-management Theory.

### **Self-Management (SM)**

Self-management is a process by which individuals and families use knowledge and beliefs, self-regulation skills and abilities, and social facilitation to achieve health-related outcomes (Ryan & Sawin, 2009). Self-management takes place in the context of risk and protective factors specific to the condition, physical and social environment, and individual and family. Proximal outcomes are self-management behaviors and cost of health care services; distal outcomes are health status, quality of life and cost of health.

### **Context Factors**

Risk or protective factors, including: condition specific factors, physical and social environments, and individual and family characteristics (Ryan & Sawin, 2009). Factors in the contextual dimension influence individual and family engagement in the process of SM, as well as directly impact outcomes. Condition specific factors are those physiological, structural, or functional characteristics of the condition, its treatment, or prevention of the condition that

impact the amount, type, and nature of behaviors needed to SM. Environmental factors are physical or social and include factors such as access to health care, transition from one health care provider or setting to another, transportation, neighborhood, work, school, culture, or social capital. Individual/family factors are those characteristics of the individual and family directly.

### **Process Factors**

The process of self-management is influenced by knowledge and beliefs, self-regulation skills and activities, and social facilitation (Ryan & Sawin, 2009). Enhancing the individuals and families SM processes results in more positive outcomes. Persons will be more likely to engage in the recommended health behaviors if they have information about and embrace health beliefs consistent with behavior, if they develop self-regulation abilities to change their health behaviors, and if they experience social facilitation that positively influences and supports them to engage in preventative health behaviors. Knowledge and beliefs impact behavior specific self-efficacy, outcome expectancy, and goal congruence. Self-regulation is the process used to change health behavior and includes activities such as goal setting, self-monitoring and reflective thinking, decision making, planning for and engaging in specific behaviors, self-evaluation and management of physical, emotional and cognitive responses associated with health behavior change. Social facilitation includes the concepts of social influence, social support, and negotiated collaboration between individuals and families and health care professionals.

### **Outcome Factors**

Outcomes in this theory are both proximal and distal (Ryan & Sawin, 2009). The proximal outcome is actual engagement in SM behaviors specific to a condition, risk, or

transition, in addition to managing symptoms, and pharmacological therapies. Cost associated with health care use is a proximal outcome. Distal outcomes are related, in part, to successful achievement of proximal outcomes. These outcomes fall into three primary categories: health status; quality of life or perceived well-being and cost of health—both direct and indirect.

### **Orientation to the Dissertation**

This following chapters in the dissertation include a review of the literature (Chapter 2), three manuscripts (Chapters 3, 4, 5) and a discussion of the implications of the findings (Chapter 6). Chapter 2 is titled *Unmet Respite Care Needs among Families of Children with Autism Spectrum Disorder: A Review* and describes the current state of the science related to unmet respite care needs in families of children with ASD. Chapter 3 is the first manuscript, titled *Respite Care and Stress among Caregivers of Children with Autism Spectrum Disorder: An Integrative Review*, which provides a synthesis of the current science on respite care and stress. While stress was unable to be included as a variable in the study (due to the limitations of the dataset available), it is an important distal outcome variable in the conceptual framework. Chapter 4 is the second manuscript, titled *The Concept of Respite Care*, which provides an analysis of the concept of respite care, including factors associated with unmet respite care needs. The results of the concept analysis provided the author with a framework to create a diagram of the concept of respite care, which illustrates the important need for respite care services to meet the unique needs of the family. Together, Chapters 2 through 4 contribute to understanding the importance of the proposed study. Chapter 5 is a data-based manuscript of the results of the study. Finally, Chapter 6 provides a synthesis of the manuscripts in terms of implications for theory, practice, education, future research and policy.

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## Chapter 2 Unmet Respite Care Needs among Families of Children with Autism Spectrum Disorder: A Review

Despite evidence that respite care is an effective intervention in supporting family caregivers, respite care needs remain largely unmet. Additionally, little is known about what factors are associated with unmet respite care needs. Further, there is limited evidence about the differences in prevalence of unmet respite care needs and associated factors between families of children with Autism Spectrum Disorder (ASD) and families of children with other special healthcare needs. As a result, the purpose of this review of literature is to describe the current state of the science related to unmet respite care needs in parents of children with ASD.

### **Prevalence of Unmet Respite Care Needs**

Overall, there is limited research examining the prevalence of unmet respite care needs in parents of children with ASD. However, several studies have been conducted with the broader population of children with special healthcare needs (CSHCN). Only one study was found that compared the prevalence of unmet respite care needs between families of children with ASD and families of children with other special healthcare needs.

### **ASD Population**

The respite care needs of parents of children with ASD are largely unmet. In a study of 143 parents of children with ASD, the greatest single identified service need reported was respite care (Hodgetts, Zwaigenbaum, & Nicholas, 2015). While 57% of parents in the study reported “locating respite care workers able to care for my family” as a need, only 32% of parents stated that need was met. Brown, Ouellette-Kuntz, Hunter, Kelley, and Cobigo (2012) conducted a cross-sectional survey of 101 Canadian families of school-aged children with ASD. They found that 53.5% rated “respite care for my child” as important and 41.6% rated

respite needs as being unmet. Additionally, “difficulty finding respite care” and “respite worker lacking expertise in autism” were themes that emerged in the open-ended responses. In a study of 371 parent-child dyads enrolled in a national autism registry by Farmer et al. (2014), 57.6% had a need for respite care and 70.1% of those with a need reported their needs were unmet. Finally, Lindly, Chavez, and Zuckerman (2016) conducted a secondary analysis of the 2009-2010 NS-CSHCN to examine unmet needs for family health services (including respite care, mental health care, and genetic counseling) among parents of children with developmental disabilities (including those with ASD, developmental delay, and/or intellectual disability). Among the 3,518 respondents, 18.5% had one or more unmet family health service need and respite care was the most common unmet family health service at 11.5%.

### **CSHCN Population**

Respite care needs of parents of CSHCN are also largely unmet. Rupp et al. (2005) found that only 7.5% of the 791,954 families who participated in the 2001-2002 National Survey of SSI Children and Families used respite care. However, a total of 28.6% reported a need for respite care. Overall, 73.9% of families with a need for respite care reported their needs were not met (Rupp et al., 2005). Nageswaran (2009) conducted a secondary analysis of the 2001 National Survey of Children with Special Healthcare Needs (NS-CSHCN). Of the 38,831 respondents, 3,178 (8.8%) reported having a need for respite care in the prior 12 months and 24% of those who needed respite care did not receive all the respite care that was needed. Finally, in a study of 21 parents of CSHCN, Aruda, Kelly, and Newinsky (2011) found that 74.9% of parents reported they were unable to get respite care when needed.

## **ASD Compared to Other CSHCN**

Only one study was identified that compared the prevalence of unmet respite care needs of parents of children with ASD to parents of children with other special healthcare needs. Kogan et al. (2008) conducted a secondary analysis of the 2005-2006 NS-CSHCN and compared three groups: children with ASD (n= 2,088); other children with special health care needs with emotional, developmental, or behavioral (EDB) problems (excluding those with ASD) (n= 9534); and other CSHCN (n= 26,751). They found that parents of children with ASD were nearly six times more likely to have unmet needs for family support services (including respite care), compared to parents of other CSHCN (OR = 5.98; 95% CI [4.55–7.86]). Overall, 19.3% of children with ASD had an unmet need for family support services, compared to only 10.7% of CSHCN with other EDB problems and 1.8% of other CSHCN.

### **Factors Associated with Unmet Respite Care Needs**

Overall, there is limited research examining the factors associated with unmet respite care needs in parents of children with ASD. Several studies have been conducted with the broader population of CSHCN; however, no published studies were identified that compared the factors associated with unmet respite care needs between families of children with ASD and families of children with other special healthcare needs.

### **ASD Population**

A variety of factors have been found to be associated with unmet respite care needs in parents of children with ASD. Hartley and Schultz (2015) conducted a study of 75 married couples with a child with ASD and found that mothers had a higher number of support needs (including respite care) ( $t=3.16, p<.01$ ) and higher proportion of support needs that are unmet compared to fathers ( $t=2.82, p<.05$ ). A total of 57.5% of fathers and 54.8% of mothers

indicated that “respite care for my child” was important and more mothers (15.1%) than fathers (13.7%) indicated that their respite care needs were unmet; however, there was no significant statistical difference. Child’s age, co-occurring behavior problems, presence of intellectual disability, parent education and household income were all related to support needs (Hartley & Schultz, 2015).

Lindly et al. (2016) found that living in the Western US, having a parent with more than a high school education, having an intellectual disability, experiencing functional limitations and having three or more comorbid conditions were positively associated with having any unmet family health service need (including respite care) among families of children with developmental disabilities (including ASD). Compared to families with no unmet need for family health services, families with any unmet need for health services were nearly four times more likely to spend 11 or more hours per week providing/coordinating care for their child (OR = 3.75; 95% CI [2.49–5.63]), nearly six times more likely to experience financial problems due to the child’s health condition (OR = 5.79; 95% CI [4.06–8.25]), and more than three times more likely to have a family member that cut back or stopped working due to the child’s health condition (OR = 3.67; 95% CI [2.53–5.33]) (Lindly et al., 2016).

Single mothers may have unique stressors related to lack of support and increased financial challenges in a single income household. Dyches, Christensen, Harper, Mandleco, and Roper (2016) conducted a study of 122 single mothers of children with ASD and found that more than half (59.8%) accessed respite care and most (71%) were satisfied with this care. However, much of the respite care was provided informally from family members and friends, which could explain why satisfaction was so high.

Harper, Dyches, Harper, Roper, and South (2013) conducted a study of 101 parent dyads of children with ASD and found that 63.6% of the children received some type of respite care. Respite care was provided by grandparents (28%), babysitters (26.7%), community agencies (21.3%), and extended family member (16%). Overall, 88.6% reported being satisfied with their care provider, possibly because the majority of care was provided by family members. There was a significant positive relationship between number of hours of respite care and relationship quality for both husbands ( $\beta = .42, p < .001$ ) and wives ( $\beta = .56, p < .001$ ) (Harper et al., 2013). This study suggests that family structure and marital status may be factors associated with unmet respite care need.

Benevides, Carretta, and Mandell (2016) conducted a secondary analysis of data from the 2005-2006 NS-CSHCN ( $n=2,123$ ) and 2009-2010 NS-CSHCN ( $n=3055$ ) to examine racial and ethnic differences in perceived need for services that children with ASD frequently use. Perceived need for respite care was highest among those who were other race Non-Hispanic (29%), black Non-Hispanic (23.6%), white Non-Hispanic (25.3%) and any race, Hispanic English speaking (22.9%). Perceived need for respite care was lowest among any race, Hispanic Spanish speaking (10.2%). However, these differences were not statistically significant. The researchers suggested that caregivers may not perceive a need because they do not understand the importance of respite care services (Benevides et al., 2016).

Pickard and Ingersoll (2016) conducted a study of 244 parents of children with ASD to examine variation across higher and lower socioeconomic status (SES) groups. Lower SES parents were more likely to report needing respite care (5.95%,  $n=84$ ), compared to higher SES parents (2.31%,  $n=130$ ). Barriers to service use reported included: finances/insurance, information/knowledge, transportation and waitlists (Pickard & Ingersoll, 2016).

## **CSHCN Population**

A variety of factors have been found to be associated with unmet respite care needs in parents of CSHCN, as well. Nageswaran (2009) found that maternal education, child functional status, and condition stability were associated with greater unmet respite care needs among parents of CSHCN. Parents with more than high school education were more likely to have an unmet respite care need compared with those with a high school education or less (OR = 1.6; 95% CI [1.1–2.31]). Compared to parents of children with no functional limitations, parents of children with some functional limitations were more than twice as likely (OR = 2.5; 95% CI [1.3–5.0]), and parents of children with severe functional limitations were more than five times as likely (OR = 5.6; 95% CI [2.9–10.7]), to have unmet respite care needs. When the child's condition was reported as being unstable, parents were more than twice as likely to have unmet respite care needs compared to when the child's condition was reported as stable (OR = 2.3; 95% CI [1.3–3.9]). Parents also described reasons for why their respite care were unmet, including: lack of availability, transportation, cost, health plan problems, time was not convenient and unspecified reasons (Nageswaran, 2009).

Benedict (2006) conducted a secondary analysis of the 1994-1995 Disability Supplement to the US National Health Interview Survey to compare children with functional limitations (n= 3,464) to children without functional limitations (n= 2,323). A total of 11.1 % of children with functional limitations had an unmet need for supportive services (including respite care) compared to only 3.2% of children without functional limitations. When the child's limitation was moderate to severe, they were more than twice as likely to have an unmet need for supportive services, compared to when a child's limitation was mild (OR = 2.27; 95% CI [1.43–3.35]). Children enrolled in public health insurance were more likely to

have an unmet need for supportive services, compared to children who were uninsured (OR = 1.43; 95% CI [.87–2.34]). Children with self-care limitations were nearly six times more likely to have an unmet need for supportive services, compared to those without a self-care limitation (OR = 5.94; 95% CI [4.01–8.80]). Families with at least one member educated beyond 12 years were twice as likely to report unmet needs for supportive services (OR = 2.19; 95% CI [1.33–3.62]). Finally, race and ethnicity were also associated with unmet needs – hispanics were half as likely to have an unmet respite care need, compared to black, non-hispanics (OR = 0.49; 95% CI [0.28–0.86]) (Benedict, 2006).

Gannotti, Kaplan, Handwerker, and Groce (2004) conducted a mixed-methods study of 84 families and 20 providers of children with disabilities to examine cultural differences in perceived unmet needs by Latino and Euro-American parents of children with special health care needs. None of the 42 Latino families indicated an unmet respite care need compared to 15 of the 42 Euro-American families ( $p < .000$ ). Euro-American families cited concerns with the lack of adequately trained and competent respite care providers and the lack of respite and day-care providers willing to provide childcare. However, Latino families actually had to have the concept of respite care services explained to them. The researchers described the cultural value of *familialism*, which is manifested in the close relationships established with the extended family members, as a possible reason why Latino parents could not understand why they would want to leave their child, nor did they feel comfortable leaving their child under the care of someone else. However, researchers cautioned that the fact that Latino families did not identify the need for respite does not mean they do not need these services – they just do not perceive they have a need (Gannotti et al., 2004). This study suggests that cultural differences may influence perception of unmet respite care needs.

Kuo, Cohen, Agrawal, Berry, and Casey (2011) conducted a secondary analysis of the 2005-2006 NS-CSHCN to examine differences between children who are more medically complex and those who are less medically complex. About half of the participants with a need for respite care reported difficulty accessing respite care, regardless of medical complexity.

Fulda, Johnson, Hahn, and Lykens (2013) conducted a secondary analysis of the 2005-2006 NS-CSHCN to examine geographic differences in health indicators for CSHCN. They found that the greatest need for respite care occurred in the south, where 55% of those with a need for respite care reported their needs were unmet. Parents of CSHCN in the South were almost twice as likely as parents of CSHCN in the Midwest to have an unmet need for respite care (OR = 1.71; 95% CI [1.09–2.68]). The researchers discussed that geographic differences may exist due to financial and other program eligibility requirements for health care services or state variation in Medicaid eligibility requirements and coverage.

Rupp et al. (2005) found that unmet respite care needs were greater among parents of children age 13-17 years old (77.8%) and least among parents of children age 0-5% (69.6%) (n= 791,954). The age of the child may be an important factor as needs may possibly increase over time as the child's condition progresses or their physical development makes it difficult to provide for caregiving needs.

### **ASD Compared to CSHCN**

No studies were identified that directly compared factors associated with unmet respite needs in parents of children with ASD to parents of other CSHCN. However, Kogan et al. (2008) found that families of children with ASD have greater financial, employment, and time burdens compared to families of other children with special health care needs. These could potentially be predictive factors of unmet respite care needs in parents of children with ASD.

Additional research is needed to better understand the differences in factors associated with unmet respite care needs between parents of children with ASD and parents of other CSHCN.

### **Importance of the Proposed Study**

With limited research in this area, it is important to further examine the prevalence of unmet respite care needs and associated factors in parents of children with ASD, compared to parents of other CSHCN. Only one study was identified that compared the prevalence of unmet respite care needs in parents of children with ASD to parents of other CSHCN.

Additionally, no studies were found that compared factors associated with unmet respite care needs between parents of children with ASD and parents of other CSHCN. Little is known about whether having a child with ASD makes parents more likely to have unmet respite care needs. Since the growing prevalence of ASD has become a public health concern, there is a clear need to examine the prevalence and factors associated with unmet respite care needs in this unique population.

Several of the studies described previously utilized data from the NS-CSHCN. Since more recent data is available, there is a unique opportunity to re-examine the prevalence of unmet respite care needs and associated factors in a large, nationally representative sample of families of children with ASD. The results of the proposed study can also be compared to the results of previous studies using earlier versions of the NS-CSHCN to determine if needs are better met after the passage of the Life Span Respite Care Act of 2006, which was passed by the US Congress to assist family caregivers to access affordable respite care.

A better understanding of what factors are uniquely associated with unmet respite care needs in families of children with ASD may facilitate targeted program and policy changes to increase access to and improvements of existing respite care services. Additionally, screening

tools can be designed to help identify families who are at high risk for having unmet respite care needs. This knowledge would also allow healthcare providers to develop better strategies for matching the needs of families of children with ASD with available resources to promote the use of respite care services. Ultimately, addressing unmet respite care needs may help lower stress levels, decrease fatigue, and improve family self-management among families of children with ASD. Neff (2009) described a need for additional studies because “failure to pay attention to the growing need for respite care could lead to an increase in the disintegration of the family structure and an increase in preventable health care costs for society and children (p. 90)”. This study will contribute to the science in this area and have implications for healthcare professionals working with families of children with ASD, as well as for further research and policy.

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Chapter 3 Respite care and stress among caregivers of children with Autism Spectrum Disorder: An integrative review

**Abstract**

**Problem.** While parenting, in general, can be stressful, mothers of children with autism spectrum disorder (ASD) experience chronic stress comparable to combat soldiers. Research suggests that respite care may potentially reduce stress among caregivers. However, greater understanding of this relationship is needed. The purpose of this integrative review is to examine the relationship between respite care and stress among caregivers of children with ASD.

**Sample and Eligibility.** A final sample of 11 primary research reports were located using several databases. Articles were included that were: related to the focus of the review, written in English, and published within the last 10 years.

**Results and Conclusion.** While most studies found that respite care was associated with lower stress, several found that respite care was associated with higher stress. One study found no association. A model is presented that contributes to a new understanding of this relationship. Overall, the results of this integrative review provide some evidence that respite care use may be associated with a decrease in stress among caregivers of children with ASD. However, due to the lack of consistency and quality across the studies, these findings must be interpreted with caution.

**Implications.** Healthcare providers must recognize the importance of tailoring respite care services to the unique family needs. Additionally, policy changes and innovative ideas are needed to help improve the quality of respite care and help expand access. Finally, additional

research is necessary to better understand the relationship between respite care and stress among caregivers of children with ASD.

**Key words:** Respite care; Stress; Autism spectrum disorder; Caregivers; Review

## **Background and Significance of the Problem**

While parenting, in general, can be stressful, mothers of children with Autism Spectrum Disorder (ASD) experience chronic stress comparable to that experienced by combat soldiers (Smith et al., 2010). Previous research has shown that stress is more prevalent in caregivers (especially mothers) of children with ASD when compared to caregivers of children with other disorders and typically developing children. In addition to typical parenting demands, caregivers of children with ASD also have added demands related to their child's condition. These additional demands can cause increased stress, which can cause physiological changes, lower the immune response and place caregivers at risk for serious health risks, including depression. Caregivers who are under stress are also more likely to have disrupted relationships and experience difficulty caring for their child. This can impact the child's functioning and can also put the child at a greater risk for abuse or neglect.

Autism Spectrum Disorder (ASD) is a group of developmental disabilities that can cause significant social, communication and behavioral challenges (Centers for Disease Control and Prevention [CDC], 2015). ASD includes several conditions, including: autistic disorder; pervasive developmental disorder not otherwise specified (PDD-NOS); and Asperger's Syndrome. According to estimates from the Autism and Developmental Disabilities Monitoring (ADDM) Network, about 1 in 68 children has been identified with ASD (Centers for Disease Control and Prevention, 2014). The increasing prevalence of ASD is a significant public health concern.

### **Respite Care**

Respite care is an important support service for caregivers. Respite care is simply a break from caregiving that is designed to serve caregivers and families who are caring for

people with disabilities or other special needs such as chronic or terminal illnesses; or are at risk of abuse and neglect (Respite Care Association of Wisconsin, 2016). Respite care has also been defined as planned or emergency care provided to a child with special needs in order to provide temporary relief to family caregivers who are caring for that child (ARCH National Respite Network, 2016).

Studies related to respite care began to be published in the early 1980s primarily in social work journals and focused on respite care to help reduce child abuse (Cohen, 1982; Subramanian, 1985; Cowen & Reed, 2002). While research in the area of respite care for caregivers of children with ASD is limited, a variety of other caregiver populations have been studied, including: children with chronic illnesses (Thurgate, 2005); physical disabilities (Doig, McLennan & Urichuk, 2008; Palisano et al., 2010); cognitive disabilities (Preece & Jordan, 2007; Wilkie & Barr, 2008); and developmental disabilities (Cowen & Reed, 2002; Mullins, Aniol, Boyd, Page & Chaney, 2002).

Respite care can be provided in various settings, including: in-home (Corkin, Price & Gillespie, 2006); community-based (Dawson & Liddicoat, 2009); hospital-based or in a residential facility (Mullins, Aniol, Boyd, Page & Chaney, 2002; Wilkie & Barr, 2008). The providers of respite care can be formal, such as nurses (Barrett et al., 2009) or in-formal (family and friends). Respite care can also occur in varying frequencies and durations (Corkin, Price & Gillespie, 2006; Wilkie & Barr, 2008). Respite care services can be short-term, intermittent, long-term, on-going, or provided as an emergency intervention (Corkin, Price & Gillespie, 2006; Wilkie & Barr, 2008). For example, respite care might occur in the form of a short-term, intermittent, community-based respite event sponsored by a local church with

volunteers providing the care. In contrast, respite care services might also be provided in a hospital-based facility, staffed by trained nurses, for regularly scheduled long-term stays.

Researchers have also identified barriers to respite care use, including: lack of knowledge of available services (Harper, Dyches, Harper, Roper, & south, 2013); limited options and services and lack of trust in respite care providers (Wilkie & Barr, 2008). The results of several qualitative studies suggest that there needs to be a match between the type of respite care service and the unique needs of the family. Timing of services, as well as frequency of services, have influenced parents' perceptions of services as providing what they would consider a true 'break' (Corkin, Price, & Giles, 2006; Wilkie & Barr, 2008). Overall, there is no consistency related to what components are needed to make respite care services adequate from the perspective of the caregivers.

### **Stress Among Caregivers**

Stress is defined as an individual's perception of the degree to which they find their life to be unpredictable, uncontrollable, and overloaded. This is consistent with the definition provided by Cohen, Kamarck, and Mermelstein (1983). In this definition, subjectivity is important, recognizing that one's perception is their reality. The intentional decision was made to not study *caregiver stress* because of the philosophical view that one cannot separate the stress caused from caregiving from other stress in an individual's life. If someone feels stressed, they feel stressed.

Several researchers have examined the impact of respite care use on stress among caregivers. A systematic review by Strunk (2010) found that respite care may be an effective intervention to decrease stress among family caregivers. However, the author concluded that studies are needed to examine the impact on parenting stress over time with a focus on non-

maternal caregivers, such as fathers. A review by Chan and Sigafos (2000) described the characteristics related to the use of respite care among families with children with developmental disabilities. They found that caregiver stress was a significant predictor in the decision to use respite care, indicating that stress levels may be higher, initially, among those who use respite care. Cowen and Reed (2002) found that participation in a county respite care program resulted in significant reductions in parent stress when comparing pre and post intervention data; however, parent stress level remained high, possibly suggesting a need for a more intensive intervention. Harper et al. (2013) found that stress mediated the relationship between respite care use and relationship quality among married parents of children with ASD. McLennan et al. (2012) examined stress before and after participation in a center-based respite program and found that, while stress levels decreased, there was no significant difference between the pre and post-test score among the intervention group. However, qualitative analysis suggested that, at least temporarily, stress was greatly reduced.

Conversely, several researchers have found that respite care, specifically when not meeting the individual needs of the family, can ultimately lead to an increase in caregiver stress (Hoare et al., 1998; Treneman, Corkery, Dowdney & Hammond, 1997). MacDonald and Callery (2007) found that parents expressed a need for a break but were too worried about the quality of the care to enjoy the time away. Caregivers in one study even expressed feelings of guilt and embarrassment about having to send their children to respite care facilities; therefore, it increased their level of stress (Wilkie & Barr, 2008).

### **Relationship between Respite Care and Stress**

Despite the numerous studies previous cited, few researchers have examined the relationship *between respite care and stress* among caregivers of children with ASD.

Numerous researchers have made anecdotal claims that respite care is needed to help reduce stress, typically highlighting this in the implications of their findings. However, very few researchers have actually measured this relationship. Without a more comprehensive understanding of this relationship, it is difficult to claim the effectiveness of respite care on reducing stress. To date, there has been no attempt to synthesize data across these published studies. Such a synthesis is needed to help nurses and other healthcare providers to better support and care for families of children with ASD.

### **Method**

In order to enhance rigor, a systematic approach to the review of the literature was performed based on the integrative review framework by Whitemore and Knafl (2005). They describe integrative reviews as the broadest type of research review methods, as they allow for the simultaneous inclusion of experimental and non-experimental research. Integrative reviews have the potential to build nursing science, informing research, practice, and policy initiatives (Whitemore & Knafl, 2005). This framework involves five stages of review: Problem identification, literature search, data evaluation, data analysis, and data presentation.

#### **Problem Identification**

Whitemore and Knafl (2005) state that a clear problem identification and review purpose are essential to provide focus and boundaries for the integrative review process. Published research from the past decade related to children with ASD suggested that respite care was an important support service that reduced stress among caregivers. However, it was unclear what the similarities are across studies or whether the quality of the studies warrants broad application to practice. Greater understanding of the relationship between respite care and stress may help nurses and other healthcare provider identify more effective ways to

support families of children with ASD. Therefore, the purpose of this integrative review was to answer the following question: What is the relationship between respite care and stress among caregivers of children with ASD?

### **Literature Search**

Primary research reports were located using the following protocol. In January of 2016, a search was conducted using the PubMed, CINAHL, ERIC, and Psych Info databases using the following keywords: (child development disorders, pervasive OR autism OR autism spectrum disorder) AND (stress OR parent stress OR caregiver stress) AND (respite OR respite care). The keywords and databases were identified after an iterative process of searching a variety of databases, reviewing keywords in relevant articles, and based on the recommendation of an experienced health science librarian. This process helped ensure a comprehensive search to identify the maximum number of eligible reports.

Full text articles were included that: related to the focus of the review, were written in the English language, and were published within the last 10 years to consider the most recent information. Articles were excluded that: were non-research, abstracts, or did not relate to the focus of the review. The titles and abstracts were then reviewed and records that did not meet the eligibility criteria were excluded. Studies meeting the inclusion criteria were reviewed and organized into a table, including: author, year, purpose, design/method, sample size and characteristics, location, theoretical framework, measures, analytical/statistical tests, and results (see Table 1). Additionally, a review of article references was conducted to identify additional articles that met the inclusion criteria.

## **Data Evaluation**

During the data evaluation stage, it is important to evaluate the quality of primary sources in a meaningful way (Whittemore & Knafl, 2005). However, evaluating quality is complex and there is no single criterion or instrument recommended for evaluating and interpreting quality in research reviews. In evaluating studies for potential bias, it is important to consider both the level and quality of the evidence (Stillwell, Fineout-Overholt, Melnyk, & Williamson, 2010). In this integrative review, the *Guide to an Overall Critique of a Quantitative Research Report* and the *Guide to an Overall Critique of a Qualitative Research Report*, as described by Polit and Beck (2008) were used, respectively, to analyze the quality of studies. Additionally, appraisal for level of the evidence was based on the hierarchy described by Melnyk and Fineout-Overholt (2011). No report was excluded based on this data evaluation process; however, reports of low rigor contributed less to the analytic process.

## **Data Analysis**

Whittemore and Knafl (2005) describe the goals of the data analysis phase as a thorough and unbiased interpretation of primary sources, along with an innovative synthesis of the evidence. In this review, themes emerged through an iterative process of constantly comparing results from all articles and grouping similar results.

## **Data Presentation**

The final stage of the integrative review framework is to present the results in either a diagrammatic or table form (Whittemore & Knafl, 2005). Ideally, the results should capture the depth and breadth of the topic and contribute to a new understanding of the phenomenon of concern. Implications for practice, research and policy should be emphasized. Additionally, limitations of the review must be explicitly stated.

## **Results**

### **Study Selection**

A total of 26 records were identified through database searches. Figure 2 shows a flow diagram of the search strategy. A final sample of 11 articles was included in this integrative review.

### **Study Quality**

In this integrative review, 10 studies were appraised at level VI (single descriptive or qualitative study). One study (Openden et al., 2006) was a level VII (expert opinion). Results of the quality review suggest that evidence across all studies in this area is less reliable and caution should be taken in applying results to practice. However, the lack of evidence at higher levels in the current literature may indicate that knowledge in this area is in early stages of development.

Overall quality across studies was somewhat limited. Few studies described the conceptual/theoretical framework used to guide the study. Study aims varied greatly, limiting the ability to compare across studies. More rigorous study designs would have enhanced interpretability of the findings, such as: including a comparison group, using a wait-list control or collecting longitudinal data. Sample size varied across studies, ranging from six (Webb, 2013) to 166 (Ogston-Nobile, 2015) total participants. However, most of the samples were non-representative of the population and had limited generalizability. The majority of studies had homogeneous samples that were predominantly Caucasian females who were well-educated, married or partnered, and employed at least part-time with a household income well above the Federal poverty level. Additionally, concepts were not well defined and there was a

lack of reliable measures reported, especially for measuring respite care. Consequently, respite care was inconsistently measured, further limiting the ability to compare across studies.

### **Results of Individual Studies**

Results of individual studies varied, with the strength of relationships also varying across studies. Results were organized and grouped into three main categories based on the association between respite care and stress: lower Stress, high stress, and no relationship.

**Lower Stress.** In several studies, respite care was associated with lower levels of stress. In the only intervention study, parent stress improved after a seven-week summer respite program, as indicated by the scores on several domains of the Parent Stress Index decreasing significantly from Time 1 to 2, including: PSI Child Domain of Acceptability (ESr = .62); PSI Child Domain of Demandingness (ESr = .53); PSI Child Domains of Distractibility (ESr = .49); and Reinforces Parent (ESr = .47); PSI Child Domain Total Score (ESr = .59); PSI Parent Domain Role-Restriction subdomain (ESr = .50); PSI Total Score (ESr = .43); and Life Stress (LS) domain (ESr = .45) (Blank, 2011). However, the intervention also improved child behaviors, which may have also impacted stress. This is a potential confounding variable that was not accounted for in this study; therefore, results should be interpreted with caution.

In a study of 122 father/mother dyads, the number of hours of respite care was negatively related to parent-reported stresses in both wives ( $b = -.33, p < .001$ ) and husbands ( $b = -.30, p < .001$  for stress) (Harper et al., 2013). Unstandardized betas indicated that for every hour of respite care, daily stress decreased by approximately five units for wives and almost six units for husbands. While these results provide some evidence that the relationship between respite care and stress is similar among fathers and mothers, these findings may be limited as stress was measured by daily hassles rather than by specific parenting stressors.

In another study, researchers found a significant correlation between maternal stress and holiday respite (trips during school breaks) ( $r = 0.217, p = 0.052$ ), and crisis respite ( $r = 0.287, p = .010$ ), as well as a trend towards significance between maternal stress and at-home respite ( $r = 0.201, p = 0.071$ ) and Sunday respite ( $r = 0.209, p = 0.065$ ) (Cavanagh-Husseini, 2015). The vast majority of mothers having experience with respite services reported them as being either most (13.4%) or very effective (22.3%) at relieving stress, while more than one third (38.3%) of the mothers in the study reported having no experience with respite. However, this study measured respite care and stress with unreliable, researcher-developed, single-item questions, limiting the interpretability of these findings.

Ogston-Nobile (2015) found that Responsibility-Related Caregiving explained 5% of the variance in parenting stress [ $\Delta R^2 = .05 (p < .01)$ ], indicating that parenting stress was higher when one parent always managed responsibility-related caregiving. These findings suggest that informal respite care, provided by the spouse, could potentially reduce stress.

In both of the qualitative studies respite was associated with lower stress. In a bounded case study, the main need the family expressed was for respite, which helped decrease the family's stress (Webb, 2013). Minhas et al. (2015) found that mothers frequently described high levels of stress because of the lack of any respite.

**High stress.** Researchers also found that respite care was associated with higher levels of stress. In one study of pre-school parents ( $n = 72$ ), perceived stress was significantly correlated with respite ( $r = .291; p < .05$ ) and respite accounted for 5.4% of the variance in perceived stress ( $r^2 = .054; p < .05$ ) (Shamash, 2012). However, only 11.1% of parents reported participating in respite services, potentially skewing the results. Young et al. (2009) found that use of a greater variety of services (including respite care) was associated with

greater report of parent stress ( $r = .33, p < .01$ ). However, both of these studies were cross-sectional and lacked a control group, making it impossible to make causal inferences.

**No relationship.** In one study of single mothers ( $n = 122$ ), there was not a statistically significant relationship between the amount of respite care and stress ( $b = -.02$ ) (Dyches et al., 2015). However, only 59.8 % of participants in the study indicated receiving any type of respite care. It would have been beneficial to compare this relationship by group (those who received respite care versus those who do not). Additionally, the authors suggested that single mothers, who may be saturated with stress and, therefore, less reactive to specific stressful life events, may not be as impacted by respite care. However, without a comparison group, it is difficult to validate this claim. Alternatively, since participants reported an average of less than one hour a day of respite and most reported that they worked or ran errands during this time, it may not have been an adequate break to alleviate stress.

## **Discussion**

### **Summary of Evidence**

The purpose of this integrative review was to answer the following question: What is the relationship between respite care and stress among caregivers of children with ASD? After critically evaluating the most current literature in this area, it is clear that studies have significant limitations, making it difficult to compare results across studies and caution is warranted in interpreting the findings. Despite this, results could be grouped into three main categories based on the association between respite care and stress. While most researchers found that respite care was associated with lower stress, several found that respite care was associated with higher stress and one found no association. However, none of the study

designs allowed for causal relationships to be inferred. With such inconclusive evidence, it is challenging to answer the question of this review with confidence.

Nevertheless, during the data analysis process of this integrative review, several themes emerged through an iterative process of constantly comparing results from all articles and grouping similar results. The final results of this process are presented in a diagram of the relationship between respite care and stress among caregivers, as shown in Figure 3.

In this model, which flows from left to right, it is recognized that there are increased demands of caregiving. However, the impact those demands have on stress depends on the adequacy of informal respite care. If informal respite care is adequate, stress is low and the need for formal respite care is also low. Alternatively, if informal respite care is inadequate, stress is high and the need for formal respite care is also high. At this point in the model, in either situation a caregiver may receive formal respite care. If formal respite care is adequate, stress levels will be low. If formal respite care is inadequate, stress levels will be high. A more comprehensive description of this model aligned with the results of this review follows.

**Increased Demands of Caregiving.** Across all studies in this review, researchers acknowledged the increased demands of caregiving. This is consistent with other studies of caregivers of children with ASD, as well as studies of caregivers, in general. The question that remains unanswered is what makes these demands stressful for some caregivers and non-stressful for others. This model proposes that the adequacy of informal respite care may be an important factor.

**Adequacy of Informal Respite Care.** Several researchers measured and discussed the importance of informal respite care. Informal respite care was provided by partners, siblings, grandparents and other family members, as well as by friends, neighbors, babysitters, and faith-

based organizations. In several studies, these were the only sources of respite care identified by caregivers. Additionally, when these informal supports were not adequate, an associated increase in stress was found. Therefore, this model proposes that stress is reduced when informal respite care is adequate.

**Need for Formal Respite Care.** In several studies, respite care was associated with higher stress. This model proposes that those individuals who have high stress, as a result of inadequate informal respite care, have a high need for formal respite care. Therefore, individuals who are utilizing respite care services are likely to have a higher level of stress than those who do not have a need for formal respite care. It is not until the formal respite care is adequate that stress levels will decrease. Conversely, those with low stress, as a result of adequate formal respite care, have a low need for formal respite care. Regardless of the need for formal respite care, caregivers may receive respite care. If formal respite care is adequate, stress levels will be low. If formal respite care is inadequate, stress levels will be high.

**Adequacy of Formal Respite Care.** Several researchers described important implications related to the adequacy of formal respite care, highlighting the importance of services being tailored to meet the unique and changing needs of families. In order for formal respite care to be adequate, it first needs to be accessible. There are several potential barriers to accessibility, including: funding/reimbursement for services; the number of programs located in close proximity; the frequency of service availability; the time and duration that services are offered; and the awareness of existing programs. Additionally, studies mentioned the importance of program staff being qualified and capable of providing for their child's needs. Satisfaction with respite care is suggested as a potential measure of the adequacy of respite care.

In summary, this model captures the depth and breadth of the topic and contributes to a new understanding of the relationship between respite care and stress among caregivers of children with ASD (Figure 3). Review of additional literature may add important contributions to further development of this novel model.

### **Limitations**

While attempts to reduce bias and enhance rigor were made, this review was not without limitations. First, this review was conducted by only one person and, therefore, interpretations of the results may be subjective. This review also used a limited number of keywords, in select databases, over a relatively short timeframe. Expanding search terms, databases, and timeframe of publications could potentially broaden the results and create a more comprehensive review, limit bias, and enhance overall rigor. Additionally, only studies that evaluated both respite care *and* stress in caregivers of children with ASD were included. Numerous studies that examined these concepts, independently, were excluded. Further analysis of these studies may result in a deeper understanding of these concepts that could be applied more broadly. Finally, this review was limited to studies focused on caregivers of children with ASD. By expanding the review to include studies of caregivers of children with other disabilities, or to adults with ASD, additional insights may be gained.

### **Conclusions**

Overall, the results of this integrative review provide some evidence that respite care use may be associated with a decrease in stress among caregivers of children with ASD. However, due to the lack of consistency and quality across the studies, these findings must be interpreted with caution. Perhaps the greater finding from this process was that current evidence in the literature has many limitations and significant gaps remain. Fortunately, these

limitations and gaps help provide important implications for the direction of future work in this emerging area of nursing knowledge. Rew (2011) describes reviews as important for not only providing evidence of what is known, but pointing to new questions about what is unknown.

Many questions remain unanswered in the current literature and warrant future investigation. What factors make respite care adequate at reducing stress? How does frequency, duration, and timing of respite care impact this relationship? Do parents with more access to respite experience greater reductions in stress and does frequency, duration, or “dose” of respite care matter? Does respite care provide only a temporary reduction in stress or can effects be sustained over time? Does the quality of respite care impact the association with stress? If so, what is quality respite care? Is satisfaction an important variable that could potentially moderate the relationship between respite care and stress? With so many different types of respite care, how do we consistently measure it? Are there different types of respite care that are better for different families? Can we identify common characteristics to help screen for and refer families to respite care programs that match their needs? Why do some parents use respite care and others not? What additional factors impact access and utilization? How can we help reduce barriers to access? How can we expand opportunities for both informal and formal respite care, especially in rural areas and communities that lack adequate resources or cultural awareness? How is the relationship between respite care and stress the same or different among other non-traditional caregivers or in other cultures? These questions provide important implications for research, practice and policy.

### **Implications for Research**

The many limitations identified in this review provide a wide array of implications for future research in this area. First, since the results of this review found that current literature

does not provide conclusive evidence, additional research in this area is necessary in order to better understand the relationship between respite care and stress among caregivers of children with ASD. However, future studies must be designed using more rigorous methods to help provide a better understanding of causal relationships. A consistent conceptualization of respite care and stress, grounded in theory, is needed. Valid, reliable tools are also needed to better understand and consistently measure these concepts in caregivers of children with ASD. There is a need for longitudinal, interventional, and waitlist control studies. Research is also needed with larger samples and more diverse populations. Recruitment methods are needed that target individuals who are: non-White mothers; fathers; live in rural areas; and have lower incomes and educational levels. Additionally, none of the studies in this review were conducted by nurse scientists. Most were conducted by researchers in the fields of psychology or special education. Nurse researchers are urged to apply their unique perspectives to help expand development in this important area of emerging knowledge.

### **Implications for Practice**

It is important for nurses and other healthcare providers to recognize that every child with ASD is unique and, therefore, interventions to help support families need to be tailored accordingly. Providers need to screen caregivers of children with ASD to assess their stress and satisfaction with respite care, making appropriate referrals to services, as needed. Recognizing that formal respite care may not be available, or culturally appropriate, providers can help caregivers identify informal sources of respite care. Providers can also volunteer with existing respite programs to help expand access to services for caregivers of children with ASD.

Additionally, innovative ideas are desperately needed to help improve the quality of respite care and expand access. Toolkits can be developed to help nonprofit organizations develop respite care programs. Respite provider certifications programs, similar to CPR programs, could be developed to help train staff in existing programs, babysitters, and daycare providers to better care for children with ASD. Online repositories, similar to *Care.com*, could be developed to help caregivers identify local, experienced, and qualified respite providers and programs.

### **Implications for Policy**

There are also significant implications for policy, as a result of these findings. First, research funding needs to be made available to continue to add to the body of knowledge around this emerging topic. Existing and future respite programs need to require formal evaluations of quality and satisfaction. Local, state and federal guidelines should be developed to ensure respite programs are evaluated based on quality and satisfaction and respite care providers are adequately trained to provide for the complex needs of children with ASD. Finally, reimbursement methods, expansion of Medicaid waiver programs, and additional funding opportunities for respite care are also needed to help provide caregivers of children with ASD with a much-needed break from the constant demands of caregiving.

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## Chapter 4 The Concept of Respite Care

### **Abstract**

**Aim.** The aim of this article is to analyze the concept of respite care in the context of caring for a child with special healthcare needs.

**Background.** Respite care has often been identified as an important resource for caregivers of children with special healthcare needs. It can help provide a break from the constant demands of caregiving.

**Design.** A concept analysis was conducted using an evolutionary approach.

**Data source.** The data source for the concept analysis was a review of literature addressing respite care for caregivers of children with special healthcare needs.

**Review methods.** A review of the literature was conducted and a concept model was developed using an evolutionary approach.

**Results.** A theoretical definition of respite care is provided and the defining attributes, related concepts, antecedents, and consequences of respite care are shown in a diagram of the concept of respite care.

**Conclusions.** The conceptual model provides a framework to help nurses better understand the concept of respite care in order to educate caregivers, provide appropriate referrals, serve as providers of respite care, and advocate for policy changes related to the provision of respite care services for caregivers of children with special healthcare needs.

Caring for a child with special health care needs can be exhausting. Caregivers often find themselves overwhelmed, sleep deprived, fatigued, depressed and even hopeless (Kendle & Zoeller, 2007). Respite care has often been identified as an important resource for caregivers of children and youth with special health care needs (CYSHCN). It is important for nurses to understand the concept of respite care in order to educate caregivers, provide appropriate referrals, serve as providers of respite care, and advocate for policy changes related to the provision of respite care services for caregivers of CYSHCN. The purpose of this article is to explore current literature related to the concept of respite care in order to better understand the concept in the context of caregivers of CYSHCN.

### **Nursing Relevance**

According to the National Survey of Children with Special Health Care Needs, conducted by the National Center for Health Statistics, approximately one out of every five households in the United States has a child with a diagnosed special need (Ofstedahl, Benedict & Katcher, 2004). Nurses, regardless of area of specialty, are certain to encounter a caregiver of a CYSHCN. Clarification of concepts, like respite care, is an important step in the process of developing concepts that are useful and meaningful in the discipline of nursing (Rodgers & Knafl, 2000). According to Rodgers and Knafl (2000), when the attributes that comprise the concept are not clear, the ability to communicate and categorize phenomena is severely limited (p. 80). A more effective conceptualization of the concept of respite care is needed to help nurses have a better understanding of the concept as it applies to the practice and science of nursing.

## **The Presence of Respite Care in the Literature**

It is important to have an initial understanding of the definition of the word “respite” and the word “care”, as well as the definition of the combined term “respite care.” According to the Merriam-Webster Online Dictionary (2010), the word “respite” can be a noun—meaning a period of temporary delay—or a verb—meaning an interval of rest or relief. The word “care” also has several meanings. As a noun, the word “care” can mean: suffering of mind; disquieted state of mixed uncertainty, apprehension, and responsibility; a cause for such anxiety; painstaking or watchful attention; maintenance; regard coming from desire or esteem; charge, supervision; or a person or thing that is an object of attention, anxiety, or solicitude. As a verb, the word “care” can mean: to feel trouble or anxiety; to feel interest or concern; to give care; to have a liking, fondness, or taste; to have an inclination; to be concerned about or to the extent of; or wish. Interestingly, the term ‘respite care’ did not result in a definition when the two terms were combined.

However, the term “respite care” has been defined, in combination, by various organizations promoting respite care services. According to the Respite Care Association of Wisconsin (2010), respite care is temporary relief for caregivers and families who are caring for people with disabilities or other special needs such as chronic or terminal illnesses; or are at risk of abuse and neglect. Respite care has also been defined as short-term care that helps a family take a break from the daily routine and stress of caregiving (Autism and PDD Social Network, 2010). According to the Alzheimer’s Association (2010), respite care provides a temporary break from daily caregiving responsibilities. However, while these definitions explain the “respite” component, they do not, specifically, define what the “caring” component involves.

Respite care, as a phenomenon, has been referred to in the literature and has been studied in various forms. Respite care has been studied in the form of short-term versus long-term residential care (Mullins, Aniol, Boyd, Page & Chaney, 2002). Respite care has also been described as a form of palliative care (Corkin, Price, & Gillespie, 2006). The location of respite care can be in home (Corkin, Price, & Gillespie, 2006) or at a respite care facility (Wilkie & Barr, 2008). Respite care has also been described as a one-time intervention versus a regularly scheduled, intermittent service (Corkin, Price, & Gillespie, 2006; Wilkie & Barr, 2008). Respite care has also been described as being a form of emergency care in the time of crisis versus routine care to prevent caregiver burnout (Wilkie & Barr, 2008). In one study, parents suggested a need for respite care provided “home-to-home” — a unique model in which respite care is provided in-home by another family with CYSHCN (Wilkie & Barr, 2008). However, services described lack of consistency in their provision of care that would help to define respite care as a concept. The studies identified all shared the definition of ‘respite’ as giving a break to caregivers; however, none addressed what the caring aspect of the concept of “respite care” involved.

There is evidence in the literature that supports the need for respite care services to provide more than just a break from caregiving (Nageswaran, 2009; Neff, 2009). Even though respite care services may provide the opportunity for parents to be physically separated from their child, they may not be able to mentally stop worrying about their child. Therefore, they are not getting an adequate break, where they are able to relax both physically and mentally. Parents in one study have expressed that the lack of trust and confidence in the provider of respite care served as a major barrier for utilization of existing respite care services (Wilkie & Barr, 2008). Timing of services, as well as frequency of services, have also influenced parents’

perceptions of services as providing an adequate break (Corkin, Price, & Gilespie, 2006; Wilkie & Barr, 2008). However, there is no consensus on what components are needed to make respite care services adequate from the perspective of the caregivers. With such a variety of definitions and inconsistent applications of the concept of respite care, the conceptual meaning of respite care is unclear.

### **Concept Analysis**

An evolutionary approach was selected as the method of concept analysis. This method views concepts as “continually subject to change, and as developing through significance, use, and application” (Rodgers & Knafl, 2000, p. 47). Using an evolutionary approach, the process of concept development is described as a cycle of significance, use, and application that continues through time and within a particular context. The evolutionary approach “espouses a view of reality, and of human beings and related nursing phenomena, as constantly changing, comprised of numerous interrelated and overlapping elements, and interpretable only in regard to a multitude of contextual factors” (Rodgers & Knafl, 2000, p. 77).

### **Procedures for Concept Development**

An evolutionary approach is an inductive method that involves a nonlinear series of overlapping phases to help clarify concepts (Rodgers & Knafl, 2000). These phases include identifying: the concept of interest, sample for data collection, surrogate terms; related concepts; references; antecedents, attributes of the concept; consequences of the concept; and a model case.

**Identifying the concept of interest.** The identified concept of interest is respite care. A concept by definition is a cluster of attributes (Rodgers & Knafl, 2000). It is not the word (expression) that is of primary interest, but the idea (concept) that is expressed using the

identified word (Rodgers & Knafl, 2000, p. 79). The author wishes to explore the concept of respite care specifically related to caregivers of CYSHCN. While respite care is also provided to other populations, such as caregivers of older adults and patients with terminal illness, respite care for caregivers of CYSHCN has unique attributes. Caregivers of CYSHCN are often in a dual role both as a caregiver and the parent of the child. Additionally, the caregiving needs are chronic and often change dramatically over time as the child develops and the caregiver ages.

**Identify a sample for data collection.** For the purposes of this article, data collection occurred in the form of a literature search. In order to better understand the concept of respite care, the database CINAHL Plus (via EBSCOhost) and Medline (Pubmed) were searched using the keyword “respite care” in the abstract and/or title. Articles were not limited to the United States as the author wanted to gain a global perspective. Limits were also not set for publication year, as it is important to have a historical perspective of the concept of respite care.

Initially, the Pubmed search resulted in 769 articles written from 1980 to 2010. This number was reduced to 138 after a limit was set to include only those articles relating to children. The CINAHL Plus search resulted in 268 articles written from 1986 to 2010. This number was reduced to 68 after the limit was set to include only those articles relating to children. Next, the author compared results from both the databases to eliminate duplicate articles. The author also scanned the titles and abstracts of all articles and eliminated those that did not reflect relevance to respite care for caregivers of CYSHCN. For example, one article discussed respite care for children caring for their parents (Richardson, Jinks, & Roberts, 2009). Ultimately, there were 34 unique articles that were used for analysis that related

specifically to respite care for caregivers of CYSHCN. Since it was a limited number, there was no need to randomize selection of articles for analysis, as is commonly done when using an evolutionary approach.

Articles were organized by publication year and were read in chronological order. A spreadsheet was created to help the author keep organized notes about each article as they related to the different aspects of concept analysis. After reading all of the articles, frequently cited works were examined and further literature, such as seminal work, was obtained.

**Identify surrogate terms.** Surrogate terms are “means of expressing the concept other than the word or expression selected by the researcher to focus the study” (Rodgers & Knafl, 2000, p. 92). The results of the data analysis identified the following terms being used to describe respite care: breaks (MacDonald & Callery, 2007), time-out (Doig, McLennan & Urichuk, 2008; Kendle & Zoeller, 2007), support services (MacDonald & Callery, 2007) and emergency relief (Cohen, 1982; Cowen & Reed, 2002).

**Identify related concepts.** Identifying related concepts is important as a means of expressing concepts that bear some relationship to the concept of interest but do not seem to share the same set of attributes (Rodgers & Knafl, 2000). The following related concepts were identified in the literature: caregiver burden (MacDonald & Callery, 2007; Thurgate, 2005), caregiver burnout (MacDonald & Callery, 2007), caregiver/parent stress (Cowen, 1982; Cowen & Reed, 2002; Hoare, Harris, Jackson, and Kerley, 1998; MacDonald & Callery, 2007; Mullins, Aniol, Boyd, Page & Chaney, 2002; Wilkie & Barr, 2008), coping (Cohen, 1982; Doig, McLennan & Urichuk, 2008), and support (Cohen, 1982; Floyd & Gallagher, 1997).

**Identifying references.** References in the literature include actual situations to which the concept has been applied. The focus of this analysis involves exploring the contextual

aspects of the concept to begin to gain understanding of the situations in which the concept is used, the use of the concept in those varying situations, and its use by people with potentially diverse perspectives (Rodgers & Knafl, 2000). The focus of this article is related to the population of care-givers of CYSHCN; however, it is important to explore other situations in which respite care is applied, as well. Identifying a contextual basis of the concept refers to the situational, temporal, and sociocultural and disciplinary contexts for application of the concept (Rodgers & Knafl, 2000).

Articles related to respite care began to be published in the early 1980s and were primarily from social work journals with the focus on respite care to help reduce child abuse (Cohen, 1982; Cowen & Reed, 2002; Subramanian, 1985). Over time the concept has changed from being a crisis intervention to a support service for caregivers to help reduce caregiver stress (Hoare, Harris, Jackson, & Kerley, 1998).

Various caregiver populations have been studied, including children with chronic illnesses (Campbell, 1996; Odnaha, 1986; Thurgate, 2005), physical disabilities (Cavanagh & Ashman, 1985; Doig, McLennan & Urichuk, 2008; Palisano et al., 2010), cognitive disabilities (Hoarse et al., 1998; Preece & Jordan, 2007; Wilkie & Barr, 2008), and developmental disabilities (Chan & Sigafos, 2001; Cowen & Reed, 2002; Mullins, Aniol, Boyd, Page & Chaney, 2002). Respite care has also been studied among caregivers of adults with physical (Dawson & Liddicoat, 2009) and cognitive disabilities (Mansell & Wilson, 2009). In addition, researchers have examined respite care for caregivers of the elderly (Hong, 2009); persons with dementia (Cohen-Mansfield, Marx, Dakheel, Regier & Thein, 2010; Goodman et al., 2010); persons with mental health disorders (Doig, McLennan & Urichuk, 2008; Jardim & Pakenham,

2010; Reupert & Maybery, 2009) and patients at the end of life (Barrett et al., 2009; Corkin, Price, & Gillespie, 2006).

Respite care has been used to describe services provided in various settings. Respite care can be: in-home (Corkin, Price & Gillespie, 2006), community-based (Dawson & Liddicoat, 2009), hospital-based or in a residential facility (Mullins, Aniol, Boyd, Page & Chaney, 2002; Wilkie & Barr, 2008). The providers of respite care can be formal, such as nurses (Barrett et al., 2009) or informal (family and friends). Respite care can also occur in varying frequencies and durations (Corkin, Price, & Gillespie, 2006; Wilkie & Barr, 2008). Respite care services can be: short-term; intermittent; long-term; on-going; or emergency intervention (Corkin, Price, & Gillespie, 2006; Wilkie & Barr, 2008). For example, respite care might occur in the form of a short term, intermittent, community-based respite event sponsored by a local church with volunteers providing the care. In contrast, respite care services might also be provided in a hospital-based facility, staffed by trained nurses, for regularly scheduled, long-term stays.

**Identifying antecedents.** Identifying the antecedents helps to build understanding of what happens before respite care occurs. Generally speaking, in order to be able to utilize respite care services, you would need to be a caregiver of a CYSHCN. The literature also supports a need for the caregiver to recognize a need for respite care services, as well as an acceptance of the use of respite care services (Wilkie & Barr, 2008). While caregiver stress may need to be in place before respite care could occur, it seems that respite care should be utilized before stress occurs in order to prevent caregiver stress.

**Identifying attributes of the concepts.** According to Rodgers and Knafl (2000), identifying the attributes of the concept represents the primary accomplishment of concept

analysis and constitutes a *real* definition, as opposed to a nominal or dictionary definition. An important question to ask is “What are the characteristics of respite care?” or “What is this ‘thing’ the writer is discussing?” (Rodgers & Knafl, 2000, p. 91).

Respite care is commonly referred to as a break for caregivers. However, the literature supports a need for respite care to be more than just the physical separation of a caregiver from their child (Mansell & Wilson, 2009; Neufeld, Query & Drummon, 2001; Wilkie & Barr, 2008). In order for respite care services to be an adequate break for a caregiver, there must be care that is safe and of high quality and by someone they trust (Barrett et al., 2009; MacDonald & Callery, 2007; Mansell & Wilson, 2009; Wilkie & Barr, 2008). Respite care services need to be: accessible; affordable; in a location that is convenient; provided at the right time; in the right duration; and in the right frequency (Damiani, Rosenbaum, Swinton, & Russell, 2004; MacDonald & Callery, 2007; Mansell, & Wilson, 2009; Wilkie & Barr, 2008). It also needs to be the right type of respite care for the family (Joyce & Singer, 1983; MacDonald & Callery, 2007; Mansell & Wilson, 2009; Wilkie & Barr, 2008).

If the needs of the family are not considered, the caregiver does not experience an adequate break and respite care has not been provided. In a study by Mansell and Wilson (2009), the majority of caregivers reported that their respite needs were not being met. MacDonald and Callery (2007) also found that respite needs evolve over time as children develop, parents grow older and their family circumstances change. There is a clear need for individual family needs to be considered.

**Identifying consequences of the concept.** Consequences refer to what happens after respite care occurs or as a result of respite care. The literature supports that respite care use can result in a reduction of the level of stress in the caregiver. Cowen and Reed (2002) found

significant decreases in total stress scores ( $t = 3.27$ ,  $df = 86$ ,  $p = 0.0016$ ) among parents following provision of respite care. Mullins et al. (2002) found that psychological distress among caregivers was significantly lower at discharge and 6 month follow-up after respite care use.

In addition to reduction of caregiver stress, the family can have other positive benefits as a result of respite care use. In one study, parents associated use of respite care with a sense of “renewal and confidence in their ability to continue caring for their child” (Wilkie & Barr, 2008, p. 32). Joyce, Singer & Isralowitz (1983) found that respite care helped improved parents’ perceptions of quality of life. Respite care services have also been described as providing an opportunity for increased social interaction and skills development for the child (Neufeld, Query & Drummon, 2001). Siblings can also have positive benefits from respite care, such as getting more individual attention from their parents (Wilkie & Barr, 2008). Respite care may even improve marital relationships and decrease divorce rates among parents of CYSHCN (Kendle & Zoeller, 2007). Finally, children being cared for can be at reduced risk for abuse if caregivers use respite care services (Cohen, 1982; Cowen & Reed, 2002; Subramanian, 1985).

However, other studies have found that respite care, specifically when not meeting the individual needs of the family, can ultimately lead to an increase in caregiver stress (Hoare et al., 1998; Treneman, Corkery, Dowdney & Hammond, 1997). MacDonald and Callery (2007) found that parents expressed a need for a break but were too worried about the quality of the care to enjoy the time away. Caregivers in one study even expressed feelings of guilt and embarrassment about having to send their children to respite care facilities and, therefore, it increased their level of stress (Wilkie & Barr, 2008).

## Results

The results of the concept analysis provided the author with a framework to create a diagram of the concept of respite care. A comprehensive definition of the concept of respite care was also formulated. A model case is offered to help better demonstrate the components of the evolutionary approach found in the diagram.

**Diagram of the concept of respite care.** As a final outcome of the concept analysis process, a diagram of the concept of respite care was constructed (Figure 4). This diagram attempts to provide a visual depiction based upon the author's interpretation of the findings of the concept analysis from an evolutionary approach.

The antecedents in the diagram include the need to be a caregiver of a child with special healthcare needs, as well as, the need to be both aware of the need and accepting of the use of respite care services. This will result in utilization of respite care services. If the caregiver is either not aware of the need for respite care services and/or not accepting of the use of respite care services, this will result in non-utilization of respite care services.

The attributes of respite care are depicted in the puzzle pieces that are matched together and lie on a puzzle board. These attributes include: trust in provider, type of services, timing, safety, location, cost, frequency, duration, and the unique family needs. Family needs are placed as the center puzzle piece as that is the core attribute.

The puzzle board represents the changing family needs. It is important for all the "pieces" of respite care to fit with the changing family needs. This will help to decrease caregiver stress and has the potential to improve family quality of life. If the "pieces" do not fit with the changing family needs, it will not be an adequate break for the caregiver and this

will result in nonutilization of respite care services. This has the potential to increase caregiver stress and decrease family quality of life.

**Definition of the concept of respite care.** Mansell and Wilson (2009) suggested that a definition of respite care needs to be developed that reflects what caregivers and their offspring want when they seek respite care. After a thorough concept analysis, the following definition of the concept of respite care was formulated: respite care provides caregivers temporary relief from their responsibilities of caregiving. The type of respite service, location, safety, duration, timing, frequency, and trust in provider must match with the changing family needs in order for caregivers to have an adequate break and receive the potential benefits of reduced stress and improved family quality of life.

**Identify a model case.** Rodgers emphasizes the importance of identifying real-life model cases as a means to enhance the degree of clarification offered as a result of analysis by providing an everyday example that includes the attributes of the concept (Rodgers & Knafl, 2000). A real-life model case could not be identified in the literature. However, the author has had vast experience working with families of CYSHCN who have utilized respite care services. One particular family was identified that does not regularly utilize respite care services. The family is a middle-class Caucasian couple with a 10 year-old daughter diagnosed with a rare congenital abnormality. As a result, the child is significantly developmentally delayed, nonverbal, wheelchair bound, is reliant on enteral nutritional support, has constant seizures, and a vast array of medication management issues. It is difficult for the parents to physical transport their daughter to respite events that are far away, especially during the winter months. They also have difficulty trusting the typical high school students who volunteer at the community-based respite events to care for their child's complex medical

needs. The few times that they have tried to use the respite events the mother reported spending the whole day worrying about her child and waiting for a call that something had gone wrong. This increased her stress level and did not provide her with an adequate break, mentally or emotionally. The mother has expressed that she hesitates to use respite events, and other types of respite care services, because of the lack of trust of providers being able to provide safe, quality care for their child's complex medical needs.

This model case reflects the diagram of the concept of respite developed by the author. Though the caregivers in this example recognized the need for and accepted the use of respite care services, the specific attributes of respite care did not fit within their individual family needs. Specifically, the caregiver did not trust the provider of the respite care services. The caregiver also did not feel that the quality of care and safety of care were adequate for the complex needs of their child. This led to nonutilization of respite care services and now has the potential to increase caregiver stress and decrease family quality of life.

### **Discussion**

This concept analysis has provided a more comprehensive understanding of the concept of respite care. Gaps remain in the literature related to how to best assess for the need of respite care services and provide respite care services that meet the changing needs of families. However, the concept analysis lays a solid foundation and gives direction to future inquiry. Specifically, future research is needed to better understand the meaning of respite care among caregivers of CYSHCN and design and implement effective respite care services that can meet changing family needs. Additionally, programs and policies are needed to help improve access to respite care services that are able to meet the changing family needs.

## Conclusion

The purpose of this article was to explore current literature related to the concept of respite care in order to better understand the concept in the context of caregivers of CYSHCN. The relevance for nursing science was discussed. Rodgers' evolutionary approach was utilized to critically analyze the concept of respite care in the context of caregivers of CYSHCN. Successfully completing the concept analysis resulted in a more comprehensive understanding of the concept of respite care for caregivers of CYSHCN, recognizing that the concept is continuously subject to the context and application. According to Rodgers and Knafel (2000), the results do not reveal precisely what the concept *is* or *is not*. Instead, consistent with the idea of a cycle of continuing development, the results serve as a heuristic by providing the clarity necessary to create a foundation for further inquiry and development. Having this understanding will provide a better conceptual foundation for further study related to the concept of respite care for CYSHCN and may have application to a variety of other populations, as well.

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Chapter 5 Factors associated with unmet respite care needs in families of children with Autism  
Spectrum Disorder

**Three Key Points**

**Question:** What is the prevalence of and factors associated with unmet respite care needs in families of children with Autism Spectrum Disorder (ASD)?

**Findings:** In this secondary analysis of 40,242 parents, the prevalence of unmet respite care needs in parents of children with ASD was seven times the prevalence in parents of children with special healthcare needs without ASD. Child Functional Status, Hours Providing Care and Family Financial Burden were significantly associated with unmet respite care needs.

**Meaning:** Respite care needs are largely unmet with parents of children with ASD, functional limitations and high caregiving demands being highest risk.

**Abstract**

**Importance and Objective.** The growing prevalence of children with Autism Spectrum Disorder (ASD) is a public health concern. To optimize outcomes to families through use of respite care, it is important to examine the prevalence of unmet respite care needs and associated factors in families of children with ASD, compared to families of children with special healthcare needs (CSHCN) without ASD.

**Design.** An exploratory secondary analysis of the 2009-2010 National Survey of Children with Special Healthcare Needs (NS-CSHCN) was conducted using a non-experimental, descriptive, correlational design.

**Setting.** The NS-CSHCN is a national cross-sectional telephone survey of US households.

**Participants.** The total sample included 40,242 parents of CSHCN. The final analytical sample included parents of children age 2 to 18 years old with ASD (n=935) and parents of CSHCN without ASD (n=1,583) that reported a need for respite care.

**Main Outcome and Measures.** Logistic regression was used to examine relationships between context factors, aligned with the Individual and Family Self-Management Theory, and unmet respite care needs.

**Results.** Parents of children with ASD who had unmet respite care needs were predominantly white, well-educated, affluent mothers of male children between 12 and 17 years old with limited functional status. Differences in prevalence of unmet respite care needs were found between parents of children with ASD (14%; n=558) and parents of CSHCN without ASD (2%; n=717). In the sub-group of parents of children with ASD, Child Functional Status, Hours per Week Providing Care, and Family Financial Burden were significant predictors of unmet respite care needs.

**Conclusions and Relevance.** The prevalence of unmet respite care needs in parents of children with ASD was seven times the prevalence in parents of CSHCN without ASD. It is important for healthcare providers to screen all parents of CSHCN for unmet respite care needs, recognizing that parents of children with ASD, functional limitations and high caregiving demands are at highest risk. Policy changes are needed to increase funding for and reimbursement of respite care services. Additional research is needed to further examine the long-term benefits of respite care on families, communities, and the health care system.

## **Background and Significance**

According to estimates from the Centers for Disease Control and Prevention (2014), about 1 in 68 children has been identified with Autism Spectrum Disorder (ASD). The increasing prevalence of this group of developmental disabilities that can cause significant social, communication and behavioral challenges is a significant public health concern (Centers for Disease Control and Prevention [CDC], 2015). While parenting, in general, can be stressful, mothers of children with ASD experience chronic stress comparable to combat soldiers (Smith et al., 2010). In addition to typical parenting demands, parents of children with ASD also have added demands related to caring for their child's often unpredictable behavior and emotional challenges. Additionally, parents of children with ASD often experience financial stress and job loss (Lindly, Chavez & Zuckerman, 2016) and are more likely to experience marital stress and have high rates of divorce (Saini et al., 2015), which can further impact their stress levels. Caregivers who are under stress are also more likely to have disrupted relationships and difficulty caring for their child. This increased stress can cause physiological changes, lower the immune response and put caregivers at risk for serious health risks, including depression. The accumulation of the increased stress can also contribute to abuse or neglect (Cowen & Reed, 2002), making children with special healthcare needs more likely to be placed in foster care, as a result (Stoltzfus et al., 2014).

### **Unmet Respite Care Needs**

Respite care has been defined as short term care that helps a family take a break from the daily routine and stress of care-giving (Autism and PDD Support Network, 2010). Several researchers have found that respite care use is associated with lower stress in parents of children with ASD (Blank, 2011; Harper et al., 2013; Cavanagh-Husseini, 2015; Ogston-

Nobile, 2015; Webb, 2013; & Minhas et al., 2015). Yet, there is evidence that respite care needs in families of children with ASD are largely unmet (Hodgetts, Zwaigenbaum, & Nicholas, 2015; Brown, Ouellette-Kuntz, Hunter, Kelley, & Cobigo, 2012; Farmer et al., 2014; Lindly, Chavez, & Zuckerman, 2016). Farmer et al. (2014), found that 70.1% of the 371 parents enrolled in a national autism registry with a need for respite care reported their needs were unmet. In a study of 143 parents of children with ASD, the greatest single identified service need reported was respite care, yet only 32% of parents stated that need was met (Hodgetts, Zwaigenbaum, & Nicholas, 2015).

A variety of factors have been found to be associated with unmet respite care needs in parents of children with ASD. Lindly et al. (2016) found that parent education, functional limitations of the child, time spent providing/coordinating care for the child, and experiencing financial problems or work issues due to the child's health condition were all associated with unmet respite care needs. Other factors identified include: relationship to the child (Hartley & Schultz, 2015); child's age, co-occurring behavior problems, presence of intellectual disability, household income (Hartley & Schultz, 2015); family structure and marital status (Dyches, Christensen, Harper, Mandleco, & Roper, 2016; Harper, Dyches, Harper, Roper, & South, 2013); race/ethnicity (Benevides, Carretta, & Mandell, 2016); and socioeconomic status (Pickard & Ingersoll, 2016).

The broader population of CSHCN without ASD may serve as an important comparison group to examine the unique differences in unmet respite care needs and associated factors in families of children with ASD. Researchers have found that respite care needs of families of CSHCN, broadly defined, are also largely unmet (Rupp et al., 2005; Nageswaran, 2009; and Aruda, Kelly, & Newinsky, 2011). However, only one study was found that

compared the prevalence of unmet respite care needs between families of children with ASD and families of CSHCN without ASD. Kogan et al. (2008) found that parents of children with ASD were nearly six times more likely to have unmet needs for family support services (including respite care), compared to parents of CSHCN without ASD (OR = 5.98; 95% CI [4.55–7.86]). While several studies have examined factors associated with unmet respite care needs in the broader population of CSHCN (Nageswaran, 2009; Benedict, 2006; Gannotti, Kaplan, Handwerker, & Groce, 2004; Kuo, Cohen, Agrawal, Berry, & Casey, 2011; Fulda, Johnson, Hahn, & Lykens, 2013; and Rupp et al., 2005), no published studies were identified that compared families of children with ASD to families of CSHCN without ASD.

To optimize outcomes to families through use of respite care, it is important to further examine the prevalence of unmet respite care needs and associated factors in families of children with ASD, compared to families of CSHCN without ASD, because it is unknown whether having a child with ASD makes families more likely to have unmet respite care needs. Since the growing prevalence of ASD has become a public health concern, there is a clear need to examine the prevalence and factors associated with unmet respite care needs in this unique population to inform practice, research and policy. Therefore, in a nationally representative sample comparing families of CSHCN with and without ASD, this study examined differences in the prevalence of unmet respite care needs and use and, secondarily, explored differences in factors associated with unmet respite care needs. The Individual and Family Self-Management Theory (IFSMT) (Ryan & Sawin, 2009) guided the study.

## **Methods**

### **Study Design**

An exploratory secondary analysis of the 2009-2010 National Survey of Children with Special Healthcare Needs (NS-CSHCN) was conducted using a non-experimental, descriptive, correlational design. Since data from the NS-CSHCN is publicly available and de-identified, the exploratory secondary analysis was granted exempt status by the University of Wisconsin – Milwaukee Institutional Review Board (IRB).

### **Setting**

The 2009-2010 NS-CSHCN is a national cross-sectional telephone survey sponsored by the Maternal and Child Health Bureau that assesses overall health and health status of CSHCN. Telephone numbers of potentially eligible participants living across the United States were randomly called to find households with children under 18 years old.

### **Participants**

Participants were included in the larger 2009-2010 NS-CSHCN study if they met the following eligibility criteria: Parents or guardians (over 18 years of age); Lived in the same US household as a child with special health care needs (under 18 years of age); Knowledgeable about the health and health care of the child with special health care needs; Had a landline or cellphone (if they did not have a landline or were unlikely to answer it); and Spoke one of the following languages: English, Spanish, Mandarin, Cantonese, Vietnamese, or Korean. A total of 372,698 children were screened for special health care needs, resulting in a total of 40,242 interviews completed with caregivers of CSHCN (Bramlett et al., 2014).

Participants were included in the final analytical sample of the secondary analysis if they: Responded “YES” (1) or “NO” (0) to question K2Q35A (“Has a doctor or other health

care provider ever told you that [your child] had autism, Asperger's disorder, pervasive developmental disorder, or other autism spectrum disorder"); Child was 24 months of age or older (those with children under 24 months were not asked question K2Q35A); Responded "YES" (1) to question C4Q06\_1 ("[During the past 12 months], was there any time when you or other family members needed respite care?"); Responded "NO" (1) to question C4Q06\_1A ("Did you or your family receive all the respite care that was needed?")

### **Variables and Measures**

The variables included in this study were guided by the conceptual framework and data available from the NS-CSHCN. The NS-CSHCN was administered at one point in time, immediately following verbal consent to participate in the study. Figure 5 shows the concepts and associated measures from the 2009-2010 NS-CSHCN aligned with the IFSMT.

For a detailed description of each study measure and the associated response options, see Table 2. Unmet Respite Care Needs were measured by survey question C4Q06\_1A, which asked, "Did you or your family receive all the respite care that was needed?" Participants were only asked this question if they responded "YES" to survey question C4Q06\_1, which asked, "During the past 12 months, was there any time when you or other family members needed any [respite care] because of [your child's] health?"

### **Study Size**

Sample size was determined, *a priori*, based on a calculation described by Peduzzi et al. (1996). It was determined that a minimum of  $n=360$  total participants would be required, based on the following calculation:  $N=10(19) / (.5)$ . Figure 6 is a flow diagram showing how the total sample size was limited based on eligibility criteria.

## Statistical Methods

**Data Management.** Data were imported into *SPSS Statistics 23* for management and analysis and then stored in a password protected computer to protect the confidentiality of the individual results.

**Data cleaning.** Errors from data entry were limited due to the use of a computer-assisted telephone interview (CATI) technology system that helped to correct respondent error and identify and correct data-entry error by interviewers with automated warning screen messages (Bramlett et al., 2014). However, even with many built in CATI checks, it was still necessary to clean the data to verify accuracy. This was done by verifying the valid number of cases in the data file and evaluating frequency distributions of all variables to look for outliers or suspicious data. Invalid values, where they occurred, were deleted and blank values were checked to see whether they were allowable (e.g., due to skip patterns in the questionnaire) or could be easily corrected based on related questions (Bramlett et al., 2014). Records having missing responses for unknown reasons were left missing. Since the participants recorded their responses anonymously, there was no ability to cross-check individual responses for accuracy.

**Missing data.** A statistician was consulted to help make decisions about missing data. It was determined that the amount of missing data for all variables of interest was minimal (<.05% on average) and, given the large sample size, could be ignored. As a result, appropriate filters were applied in SPSS to limit the analysis to only those records with valid responses.

**Data analysis.** A  $p$  value of less than .05 was considered to be statistically significant. First, three variables (Unmet Respite Care Needs, Insurance Status, Child Functional Status) were recoded to provide more meaningful interpretation of results. Next, descriptive statistics were used to describe and summarize sample characteristics and study variables. Since all

variables were categorical, chi-square analysis was used to examine associations between variables and identify significant differences between sub-groups. All assumptions of chi-square analysis, as described by Field (2009) were examined and met. Several chi-square analyses were conducted to compare all variables between those with and without unmet respite care needs in the total population and between the two subgroups – Parents of children with ASD versus Parents of CSHCN without ASD. Table 3 shows the variables that were removed from further analysis for having no significant association with the dependent variable (unmet respite care need). Logistic regression was used to examine the relationships between context factors and unmet respite care needs. All assumptions of logistic regression, as described by Fields (2009) were examined and met. First, univariate analyses were conducted to examine the relationship between each context factor and unmet respite care needs. All variables were found to have a significant relationship to the dependent variable (unmet respite care needs). Next, all predictor variables were examined for multicollinearity using the variance inflation factor (VIF) test. Several variables were removed from further analysis because of high collinearity and concerns that variables were measuring the same construct (Table 4). Impact on family work life was a composite measure of the variables Family members stopped working and Cut down hours working that was available in the dataset. The composite variable was selected as a global measure of the impact on family work life in the multivariate analysis. Finally, multi-variate analysis was conducted with all remaining variables. Control variables were included in Block 1 and predictor variables were included in Block 2, based on the multivariable models found in Table 5.

## Results

### Characteristics of the Sample

Characteristics of the sample can be found in Table 6. Parents of children with ASD who had a need for respite care (n=935) were predominantly white, well-educated, affluent mothers of male children between 6 and 11 years old with limited child functional status. Two-thirds of families of children with ASD provided health care at home for their child, with nearly half spending 11 or more hours per week providing care. A quarter of the children with ASD lived in a mother-only household. Almost two-thirds of parents of children with ASD reported that the child's condition caused financial problems. Three-quarters of the sample reported that a family member cut back hours or stopped working because of their child's health conditions.

Parents of CSHCN without ASD who had a need for respite care (n=1,583) were predominantly white, well-educated, affluent mothers of male children between 12 and 17 years old with limited child functional status. Two-thirds of families of CSHCN without ASD provided health care at home for their child, with almost a third spending 11 or more hours per week providing care. More than a quarter of the CSHCN without ASD lived in a mother-only household. More than a third of parents of CSHCN without ASD reported that the child's condition caused financial problems and a family member cut back hours or stopped working in about half of the sample.

When comparing subgroups, there was a statistically significant difference in all characteristics of the sample except for the caregiving needs of the child. In both subgroups, family members provided care at home for in two-thirds of the sample.

## **Unmet Respite Care Needs and Use**

**Prevalence of unmet respite care needs.** In the total sample (n=38,934), 7% (n=2,518) of respondents indicated having a need for respite care during the past 12 months. When comparing subgroups, 23% (n=935) of parents of children with ASD and 5% (n=1,583) of parents of CSHCN without ASD indicated having a need for respite care during the past 12 months. Respondents who indicated a need for respite care were asked if they received all the respite care that was needed. While only 3% (n=1,275) of the total sample (n=38,934) had an unmet respite care need, 14% (n=558) of parents of children with ASD and 2% (n=717) of parents of CSHCN without ASD had an unmet respite care need. Among parents who expressed a need for respite care, there was a significant difference in unmet respite care need between parents of children with ASD (60%; n=558) and parents of CSHCN without ASD (45%; n=717) ( $p < .001$ ).

Respondents who indicated having an unmet respite care need were asked, “Why did you or your family not get *all* the respite care that was needed?”. In the total sample, the most frequently reported response was “other” (30%), followed by “not available in area/transportation problems” (22%), “cost was too much” (19%), “not convenient times/could not get appointment” (12%) and did not know where to go for treatment (11%). Responses in the sub-groups did not vary significantly from the total sample.

## **Prevalence of Respite Care Use**

A total of 69% (n=879) of respondents in the total sample who indicated having an unmet need for respite care did not receive any respite care in the past 12 months. There was a significant difference in respite care use between groups; 63% (n=353) of parents of children

with ASD who had an unmet respite care need did not receive any respite care in the previous 12 months compared to 72% (n=518) of parents of CSHCN without ASD ( $p < .01$ ).

### **Factors Associated with Unmet Respite Care Needs**

Tables 7-9 provide a summary of the univariate analysis results that identify factors associated with unmet respite care needs among parents with a need for respite care. Among participants who reported a need for respite care, parents of children with ASD were almost twice as likely to have unmet respite care needs, compared to parents of CSHCN without ASD. Parents of children with ASD were more likely to have unmet respite care needs when: the family experienced financial problems due to their child's health care needs; family members cut back hours or stopped working; the highest level of parent education was more than high school; the child had private insurance; their child's condition always affects their ability to do things other children their age can do; and they spent 5-10 hours per week providing care for their child. Parents of CSHCN without ASD were more likely to have unmet respite care needs when: the family experienced financial problems due to their child's health care needs; family members cut back hours or stopped working; the highest level of parent education was more than high school; the child was 12-17 years old; their child's condition always affects their ability to do things other children their age can do; their child's needs change all the time; and family members provided any health care at home for the child.

A summary of the multivariate analysis results can be found in Tables 7-9, as well. Parents of children with ASD were almost one and a half times more likely to have unmet respite care needs, compared to parents of CSHCN without ASD. In the sub-group of parents of children with ASD, Child Functional Status, Hours per Week Providing Care, and Family Financial Burden were all significant predictors of unmet respite care needs. Impact on Family

Work Life was not a significant predictor of unmet respite care needs in parents of children with ASD. In the sub-group of parents of CSHCN without ASD, Child Functional Status, Impact on Family Work Life, and Family Financial Burden were all significant predictors of unmet respite care needs. Condition Stability and Hours per Week Providing Care were not significant. In the total sample, Child Condition, Child Functional Status, Hours per Week Providing Care, Family Financial Burden and Impact on Family Work Life were all significant predictors of unmet respite care needs. Condition Stability was not a significant predictor of unmet respite care needs.

### **Discussion**

The main finding of this study is that the prevalence of unmet respite care needs in parents of children with ASD was seven times the prevalence of unmet needs in parents of CSHCN without ASD. This is consistent with the secondary analysis of the 2005-2006 NS-CSHCN by Kogan et al. (2008) which found that parents of children with ASD were nearly six times more likely to have unmet needs for family support services (including respite care), compared to parents of other CSHCN ( $OR = 5.98$ ; 95%  $CI [4.55-7.86]$ ). Sixty percent of parents of children with ASD with a need for respite care did not get all the respite care that was needed. This is consistent with previous studies with small sample sizes that found unmet respite care needs ranging from 41.6% (Brown et al., 2012) to 70.1% (Farmer et al., 2014). However, it is important to also recognize that parents of CSHCN without ASD had a prevalence of unmet respite care needs (48%) that was almost double the prevalence (24%) found by Nageswaran (2009) in a secondary analysis of the 2001 NS-CSHCN. The overall prevalence of unmet respite care needs in the United States has grown significantly despite the passage of The Life Span Respite Care Act of 2006 by the US Congress that was intended to

assist family caregivers to access affordable respite care (Administration for Community Living, n.d.). In both groups, nearly three-quarters of parents with unmet respite care needs did not get any respite care in the previous 12 months.

When parents were asked why they did not get all the respite care that was needed, “other” was the most frequently reported reason in both groups. Unfortunately, the publicly available NS-CSHCN dataset did not contain the narrative responses that would have provided additional explanation. As a result, further research is warranted to better understand the “other” reasons for unmet respite care needs. Previous research has found that possible reasons for unmet needs include: cost, restrictive eligibility criteria, waiting lists, limited or no respite options, accessibility, inadequate supply of trained providers or appropriate programs, lack of information, lack of trust of providers, and guilt (National Respite Coalition, 2010). Verifying the degree to which “other” responses relate to these reasons or newly emerging reasons may be important for driving future research and policy.

Cost was a frequently reported reason for having unmet respite care needs. This is consistent with previous research by Nageswaren (2009). This is especially important to recognize, given that 58% (n=538) of parents of children with ASD with a need for respite care reported their child’s condition caused financial problems. Parents of children with ASD may have added healthcare-related costs compared to parents of CSHCN without ASD, specifically related to behavioral therapy services that are costly and frequently not covered adequately by insurance (Buescher et al., 2014).

Three-quarters of parents of children with ASD reported that one or more family members cut back or stopped working because of the child’s health condition, consistent with the findings from the study by Lindly et al. (2016). This could be due to the lack of respite

care, childcare, and educational services that are capable of caring for the often challenging behavioral problems. Frequent parental absences from work due to a child's behavioral outburst at school may jeopardize a parent's employment. However, the impact on family work was not a significant predictor of unmet respite care needs in the multivariate analysis of the subgroup of parents of children with ASD. This is an interesting finding that requires further investigation to determine if cutting back or stopping work may serve as a protective factor for parents of children with ASD. One hypothesis is that cutting back on work may allow a parent to have more time to care for their child without the added work-related stress. Additionally, the relationship between family work impact, financial problems and the cost barrier may be cyclical, meaning the lack of respite care access or adequate childcare services may limit a parent's ability to work, thereby creating a financial burden that itself limits a family's ability to afford respite care. Additional research is warranted to better understand these relationships.

The number of hours per week providing or coordinating healthcare was a significant predictor of unmet respite care needs in the total sample and in the sub-group of parents of children with ASD; however, it was not a significant predictor of unmet respite care needs in the subgroup of parents of CSHCN without ASD. This is an interesting finding given that children with ASD typically do not have intensive health care needs at home (e.g., changing bandages, care of feeding or breathing equipment and giving medication and therapies). However, parents of children with ASD often spend significant time coordinating the intensive behavioral therapy needs of their children (Autism Speaks, n.d.). Further research should examine the impact of care coordination and medical homes in improving respite care needs in families of children with ASD. Another explanation could be that the top category in the

survey item was “11 or more hours”, allowing for great variability in caregiving that exceeds this. Unmet respite care needs could be much greater for a caregiver providing care 40 hours a week, compared to a caregiver providing care 11 hours a week. No published studies were found that examined the relationship between hours providing care and unmet respite care needs. Further research is warranted to better understand the impact of caregiving demands on unmet respite care needs.

The caregiving needs of the child may be heavily influenced by the child’s functional status. Child functional status was a significant predictor of unmet respite care needs in the total sample, as well as in both subgroups. This is consistent with previous research in both the ASD population (Lindly et al., 2016) and the broader CSHCN population (Nageswaran, 2009; Benedict, 2006). However, there was a significant difference in child functional status between groups, with 66% of parents of children with ASD reporting that their child’s condition always affects their ability to do things other children their age do, compared to only 36% of parents of children without ASD. However, even when parents of children without ASD reported their child’s condition “sometimes” affects their ability to do things other children their age can do, they were more than one and a half times more likely to have unmet respite care needs. These findings suggest that even a minor limitation in child functional status can result in unmet respite care needs in parents of children without ASD. Child functional status may be an important indicator to help identify families at risk for unmet respite care needs. Respite care services should also be examined to determine if they are able to provide adequate support for children with significant functional limitations.

Age and parental education were both significant predictors of unmet respite care needs in the bivariate analysis. Parents of older children had greater unmet needs, possibly due to

decreased supportive services available to older children or the increased caregiving needs as children develop physically with age (Havlicek, Bilaver & Marissa, 2016). Providers should continuously assess for unmet respite care needs, since these needs may change over time as children and families develop. Parents with a higher level of education were also more likely to have unmet respite care needs, which is consistent with findings from Nageswaren (2009). Parents with a higher level of education may be more knowledgeable about services and, therefore, more likely to be dissatisfied with barriers to access and quality issues. Additionally, parents with a higher level of education may be more likely to have higher paying careers with high demands, which could make managing their child's condition more challenging or result in a greater financial burden if they have to cut back or quit a higher paying job.

### **Limitations**

While attempts to reduce bias and enhance rigor were made, this study is not without limitations. First, in a secondary analysis, measures are limited by the data collected and restricted to the sampling method and size determined by the original study investigators. The non-experimental design limits the ability to make causal inferences and increases the risk for bias. Most of the questions in this survey were single-item, categorical variables with unknown validity and reliability. For example, the survey item used to categorize subgroups does not account for other potential coexisting conditions. There may also be concerns about the validity of the data due to the nature of self-report and the wide variation in one's accuracy of recall. Generalizability of findings is limited by use of a convenience sample of parents and guardians of children with ASD and other special healthcare needs. The selected recruitment method and telephone survey increase the potential for self-selection bias and potentially limits the diversity and generalizability of the sample. This study was limited to the United States,

and therefore not generalizable to populations living in other countries. The study does not account for other potential context, process or outcome factors that may be associated with study variables, such as informal respite care provided by children being in school, daycare, babysitters, spousal support or respite care offered by friends or family. Finally, this study does not answer all the questions to fully explain this complex phenomenon. Since individuals are unique and families are complex, there likely are other confounding variables that were not examined in this study.

### **Conclusion**

To the best of our knowledge, this is the first study to specifically examine the factors associated with unmet respite care needs in families of children with ASD at the population level. Additionally, no published studies were identified that compared the factors associated with unmet respite care needs between families of children with ASD and families of children with other special healthcare needs. As a result, this study contributes to the science in this area and has important implications for healthcare professionals working with families of children with ASD, as well as for further research and policy.

With the high rates of unmet respite care needs, it is important for healthcare providers to screen all parents of CSHCN for unmet respite care needs, recognizing that parents of children with ASD, functional limitations and high caregiving demands are at highest risk. Valid, reliable screening tools need to be developed that can be easily incorporated into the clinical workflow and documented in the electronic health record for ongoing monitoring. Reimbursement for screening should be explored to help incentivize providers.

Once unmet respite care needs are identified, providers need to provide appropriate information and referrals to parents. This requires providers to be knowledgeable about

existing resources and limitations in access and quality of the available respite care services. Social workers and state respite coalitions may serve as a great resource for providers and parents. In situations where respite care services are unavailable or not adequate to meet the needs of the family, providers should consider the important role of informal respite care services that may be more readily available and culturally appropriate.

Additional research is needed to further examine the reasons for unmet respite care needs and better understand the causal relationships between other context, process, and outcome factors that were not measured in this study. Further investigation of the impact on work, financial burden and cost is especially warranted. Studies of opportunity costs, cost-shifting, and long-term benefits of respite care on families, communities, and the health care system are needed. Research in more diverse populations is needed to examine potential disparities in unmet respite care needs. Additionally, a valid and reliable measure of respite care should also be developed that includes a clear definition of respite care, accounting for both formal and informal respite care. When more recent national data is available, this study should be replicated to examine differences in unmet respite care needs related to the passage of the Patient Protection and Affordable Care Act (ACA), which promoted care coordination and the medical home model. Further, as healthcare reform continues to evolve with changing political agendas, it will be important to examine the impact on the respite care needs of families of children with ASD. Additional funding for research is needed to continue to add to the body of knowledge around this emerging topic in this expanding population.

Finally, policy changes are needed to increase funding for and reimbursement of respite care services. Medicaid waiver programs should be considered that promote cost-shifting to provide better coverage of preventive respite care services. Policies that help support parents

of CSHCN to remain in the workforce, are also needed. Ultimately, addressing the unmet respite care needs of families may improve parent and family outcomes, enhance family economic security, and yield a high return on investment for healthcare and societal costs.

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## Chapter 6 Implications

The purpose of Chapter 6 is to provide a synthesis of the manuscripts and discuss the broad implications for theory, practice, education, policy and research in order to better address the unmet respite care needs in parents of children with ASD.

### **Synthesis of the Manuscripts**

Together, the manuscripts included in this dissertation help provide a deeper understanding of the concept of respite care, the potential benefit of respite care to family caregivers and factors associated with unmet respite care needs. The manuscript titled *The Concept of Respite Care* (Whitmore, 2016a) helps provide a better understanding of respite care, suggesting the need for a consistent conceptualization. The puzzle board diagram (Figure 4) presented in this manuscript suggests that caregivers need to be both aware of the need for and accept the use of respite care. It is interesting that, in the dissertation study presented in Chapter 5, the overall need for respite care was not significant, even though unmet needs were high among those in need. One explanation of this could be that survey respondents lacked a clear understanding of respite care or that they did not accept the use of respite care for personal or cultural reasons. Parents may feel guilty about taking a break or view respite care use as an admission that they cannot manage their own child. The puzzle board diagram (Figure 4) also recognizes that for respite care to be effective at decreasing stress, it needs to fit the unique needs of the family. Many of these “puzzle pieces” aligned with stated barriers identified in the dissertation study presented in Chapter 5 (e.g. cost, location, access). However, the concept analysis in Chapter 4 does not address the critical role of informal respite care.

The manuscript presented in Chapter 3, titled *Respite care and stress among parents of children with Autism Spectrum Disorder: An integrative review* (Whitmore, 2016b), builds upon the knowledge of respite care from the concept analysis by recognizing the important role of informal respite care serving as a first line of defense for many who have unmet respite care needs. The diagram of Respite Care and Stress presented in Chapter 3 (Figure 3) suggests that if informal respite care is not adequate, parents will have a high need for formal respite care services. Both Chapter 3 and Chapter 4 emphasize that, if respite care does not meet the needs of family, stress may increase. This might explain why some studies have found that respite care use is associated with increased stress. Chapter 3 was the first known attempt to synthesize the knowledge in this area. While results were inconclusive, it provided important implications, especially the need to explore factors associated with satisfaction (e.g. unmet needs) as potentially influencing the relationship between respite care use and stress. Several studies compared stress levels of caregivers using respite care to those who did not use respite; however, this does not recognize that parents who use respite care may have higher baseline stress levels. Parents who do not use respite care may have lower stress levels, perhaps due to adequate informal respite care. Satisfaction with respite care (or perceived unmet needs) may be an important factor that can be measured in order to begin to better understand these relationships.

Finally, the manuscript presented in Chapter 5, titled *Factors associated with unmet needs in parents of children with Autism Spectrum Disorder*, validates findings from the review presented in Chapter 2 that respite care needs are largely unmet and greater in parents of children with ASD and contributes to the science by identifying risk factors for unmet respite care needs that can be used to develop screening tools. While the available dataset used

in this secondary analysis did not include any items that allowed for measurement of stress as an outcome, understanding the factors associated with unmet needs provided an important first step in understanding the larger conceptual model presented in Chapter 1 (Figure 1). A limitation in the study was that unmet respite needs was measured by a single item dichotomous variable that asked parents “did you *get* all the respite care that was needed”. It did not ask about the quality, but just the quantity, of respite care. We know from the concept analysis in Chapter 4 that quality of respite care is important to consider. This study also does not account for the differences in formal and informal respite care that are important to consider based on the model proposed in Chapter 3. However, these limitations contribute to numerous implications for theory, practice, education, policy and future research.

### **Implications for Theory**

This dissertation was the first study to examine the concept of unmet respite care needs in parents of children with ASD using the IFSMT. The IFSMT may serve as an ideal framework for this work, as it accounts for the variability that each individual and family experiences when trying to manage a chronic condition. The IFSMT also recognizes that the individual cannot be separated from the family context or environment (Ryan & Sawin, 2009).

However, a more effective conceptualization of concepts is needed to help nurses have a better understanding of the concepts as they apply to the practice and science of nursing. The lack of consistency and conceptual clarity in concepts is inherent in the currently literature and pervasive throughout this dissertation, as well. “Respite Care” was typically referred to in a manner consistent with the definition presented in the concept analysis in Chapter 4 – “Respite care provides caregivers temporary relief from their responsibilities of caregiving.” However, a new conceptualization of “respite care use” is presented that has not been found in the current

literature. Conceptualizing respite care use as a self-management behavior allows nurses to interact with the patient and help influence this behavior. According to Donaldson and Crowley (1978), “The goal of nursing science is the foster self-caring behavior that leads to individual health and well-being” (p. 211). Through this conceptualization, the decision to use respite care is similar to the decision to take a medication or attend a therapy session. Additionally, the terms “unmet needs”, “adequate respite care”, “satisfaction with services” and “quality respite care” were often used, interchangeably. Even the term “respite care” was not clearly defined throughout the literature. As a result, study participants may have different meanings attached to the term, resulting in wide variability in their responses about respite care use and perceived unmet respite care needs. There needs to be a clear, consistent conceptualization of concepts and valid, reliable measures in order to advance research in this area.

The results of the secondary analysis presented in Chapter 5 suggested a potential cyclical relationship between several factors. This has potential to extend the IFSMT model to include feedback loops, further illustrating the complex dynamic relationships that shape the experience of caregivers of children with ASD. Respite care use, unmet needs, financial stress and impact on family work could be considered context factors, as well as outcome factors. For example, stress may be an important context factor that predicts respite care use (parents who have high stress levels need respite), while at the same time also being an outcome factor (respite care use, if it adequately meets the family needs, may reduce stress). Additionally, perceived unmet need (e.g. satisfaction) could serve as a moderator between respite care use and outcomes factors, such as stress. For example, if a parent’s use of respite care is a bad

experience, this could result in respite care use being associated with increased stress, as suggested in the SOS and concept analysis.

This potential to build upon the existing theory may help provide a better description of the ‘grand narrative’ for this population. This will allow for the provision of multiple opportunities for interventions targeted to address context, process, and outcome variables that shape the unique experiences of families of children with ASD. This work needs to be continuous and ongoing and seek to explore the many “truths” that shape the experience of caregivers of children with ASD. New theories, frameworks, and clearer definitions of concepts will only begin to provide nurses and other healthcare providers with a better understanding of how to best support family caregivers.

### **Implications for Practice**

Nurses and other healthcare professionals play a critical role in addressing the unmet respite care needs of parents of children with ASD. Given the high prevalence of unmet respite care needs and the growing population of children with ASD, it is imperative that screening for unmet respite care needs becomes integrated into clinical practice. This screening should occur in all settings, not just in pediatric specialty clinics, and consideration should be given to universal screening in all practice settings for early detection and referral. However, the results of the secondary analysis in Chapter 5 suggest that having a child with ASD, functional limitations, and increased caregiving demands, should be included as risk factors as screening tools are developed and validated.

Providers are encouraged to reframe the conversations about respite care when talking with parents to help reduce the potential stigma and guilt associated with respite care use. Parents should be reminded of the sayings, “you can’t pour from an empty cup” and “you need

to put on your own oxygen mask before assisting others” to emphasize the potential benefits of respite care to the child, marital relationships and the family, as a whole. Exploring the meaning of respite care in parents may help parents avoid viewing respite care use as a ‘selfish’ act to take time for themselves or feel like as “failing” as a parent if they admit they need a break. Recognizing that the term “respite care” can, for some, have a negative association, respite care providers are encouraged to be creative in how they name and market respite care services. For example, a parent may be more likely to enroll their child in a “fun filled teen night” than to register for a “respite event”. By normalizing opportunities for respite care, parents may be more likely to participate.

Once respite care needs are identified, nurses and other healthcare providers need to provide appropriate referrals to respite care services that will meet the unique needs of the family, as illustrated by the puzzle board diagram in Figure 4. However, providers often lack the knowledge, experience, and resources to best support these families. Providers should think of respite care use for caregivers of children with ASD in the same way that they think of inhaled medication for children with asthma. It is a vital intervention that requires engagement in a self-management behavior in order to properly manage a chronic condition. The role of the provider is to help promote this self-management behavior. Nurses have been taught the importance of triple checking the “Five Rights” whenever they administer a medication to ensure that the right *person* is given the right *medication*, at the right *time*, in the right *dose*, in the right *route*. Similarly, nurses should triple check the “Five Rights” of respite care whenever they encounter a family of a child with ASD. The right *family* needs the right *type* of respite care, at the right *time*, in the right *dose*, in the right *location*. Providers might also consider creating “Autism Action Plans” similar to “Asthma Action Plans” that help parents

self-monitor their own need for respite care (National Institute of Health, n.d.). Referring to the diagram presented in Figure 3, informal respite care may be analogous to the “controller inhaler” that is taken regularly, while formal respite care programs may serve more as “rescue inhalers” when parents recognize symptoms of increased stress and need to take a break.

However, while respite care should be considered as important as a prescribed medication (and covered by insurance equally), it is important to avoid being too prescriptive. Respite care use should be a shared decision that allows parents to feel in control versus needing to be “saved” by respite care. We don’t want to wait until parents need respite as a life preserver, but instead encourage respite care as a preventative support service for family self-management.

Providers may lack awareness of respite care resources. Professional organizations, such as the National Respite Association, State Respite Coalitions, and local chapters of the Autism Society, serve as great partners to help educate providers and provide up-to-date information about respite care services. Recognizing that formal respite care may not be available, or culturally appropriate, providers can help caregivers identify informal sources of respite care, as described in Chapter 3 and Chapter 4. Providers can also volunteer with existing programs to help expand access to respite care services and increase the availability of adequately trained respite care providers that parents can trust to provide for the complex needs of the child with ASD.

Innovative ideas are needed to improve the quality of respite care and expand access. Online repositories similar to *Care.com* (n.d.) could be expanded to help caregivers identify local, experienced, and qualified respite providers and programs. Finally, the development of

an easy to use app could be developed to help parents and providers easily identify respite care services that meet their needs.

### **Implications for Education**

Current and future nurses and other healthcare professionals need to be educated on the importance of respite care and the impact of having a child with ASD on families. Innovative service learning experiences, such as Project REACH (Respite Events Allowing Caregivers Hope) (Whitmore, 2010) and the “Time Out” Program (Kendle & Zoeller, 2007) that utilize nursing students to provide respite care for families should be modeled in university settings across the country. Toolkits can be developed to help schools, churches and other community-based organizations develop and evaluate their own respite care programs, similar to that presented by Whitmore (2011). Respite care certification programs, similar to CPR programs or the American Red Cross Babysitter’s Training (American Red Cross, n.d.), could be developed to help train staff in existing programs, babysitters, teachers, and daycare providers to better care for children with ASD. Informal respite care providers, such as community health workers, could be trained to provide more cultural appropriate services, as well. One example of a successful training program is the Lifespan Caring Network Training (Respite Care Association of Wisconsin, n.d.), which has trained more than 500 people to be respite care providers.

Finally, parents also need training on how to be good recipients of respite care and disclose important information to the providers that will help them provide the highest quality of care to their child. Parents could be given binders with templates to complete to provide information about their child or an app could be developed that parents could easily keep

updated with their child's healthcare needs and tips and tricks on how to deal with behavior problems.

### **Implications for Policy**

Reimbursement methods, expansion of Medicaid waiver programs and additional funding opportunities for respite care are critically needed to expand access to respite care programs. Eskow, Pineles and Summers (2011) found that parents receiving services through the Autism waiver in one state reported higher family quality of life. However, it is also important to recognize that the quality of respite care services may be more important than the quantity of respite care services received, as illustrated by Figure 4 from Chapter 4. As a result, local, state, and federal guidelines should be developed to ensure that respite programs are evaluated based on quality and satisfaction (similar to The Joint Commission accreditation process) and ensure providers of respite care are adequately trained to provide for the complex needs of children with ASD. Similarly, an accreditation process for daycare facilities could be developed to create "Autism Friendly Daycares" that require annual training for staff and quality measures. This accreditation could be linked with licensing to increase compliance and create a more sustainable model to expand childcare options for parents of children with ASD.

Community level policies to help create a more inclusive environment for parents of children with ASD are also needed. Similar to "Dementia friendly communities" (Dementia Friendly America, n.d.), communities could become "Autism Friendly Communities". One town in South Carolina has been promoting their town as an "Autism Friendly Vacation Destination" where they aim to create a judgement-free zone and a place where the community understands autism and caters to the needs of individuals on the spectrum (TheAutismSite.com, n.d.). This model could be expanded to encourage daycares, churches,

schools and businesses to be more aware of the challenges families of children with ASD face and provide support and services that are more inclusive of their unique needs. For example, movie theaters can regularly offer sensory-friendly films for children with ASD.

Healthcare policies are needed to create reimbursement incentives for screening for respite care in clinical settings. Additionally, healthcare systems should consider ways to leverage the electronic health record to help with screening, tracking of referrals and documentation of respite care use and outcomes. Expansion of care coordination and medical home models may also be warranted as possible methods to better identify and coordinate respite care needs. Finally research funding needs to be made available to continue to add to the body of knowledge around this emerging topic.

### **Implications for Future Research**

The IFSMF provides an excellent framework for sustained research in this area. Much remains to be explored related to the context, process and outcomes factors that help families optimize management of their child's condition. Furthermore, how respite care affects proximal and distal outcomes such as stress, family quality of life, health status, and cost also need further exploration. Research is needed to explore whether more access to respite care results in greater reductions in stress (i.e. does frequency, duration, or "dose" of respite care matter). Research is also needed to examine the relationships between satisfaction and the quality of respite care. There is a need to better understand how to tailor respite care services to the unique needs of families to optimize outcomes. Barriers to access need to be explored, as well as opportunities to expand both informal and formal respite care, especially in rural areas and communities that lack adequate resources. Finally, we need to better understand

factors associated with unmet respite care needs among other non-traditional caregivers and in other cultures.

Additional qualitative research is needed to better understand the meaning of respite care and what ‘other’ factors are associated with unmet needs. Since funding for respite care varies by states, and sometimes county, it is important to consider research that examines differences in unmet respite care needs by geographic location. Furthermore, future research must examine family outcomes using appropriate family measures and associated analytic methods. Additionally, health services research is needed to examine the cost shifting related to changes in respite care utilization and to measure the return on investment for preventative respite programs in reducing healthcare, workforce and societal costs.

Future studies should consider using more rigorous designs and methods to improve the field’s understanding of causal relationships. However, while there is a need for longitudinal, intervention and experimental studies, it may be difficult and possibly unethical to randomly assign families to respite care and a control group due to the limited programs and potential benefits of this service to families. As a result, waitlist controls may be a possible alternative design. There is also a need to use more objective measures, such as confirmed diagnosis, actual time spent using respite care, and biomarkers for stress.

There is a unique opportunity to compare the results of this dissertation to newer data and examine the impact of health reform. The NS-CSHCN was combined in 2016 with the National Survey of Children’s Health (NSCH) (Health Resources & Services Administration, n.d.), which may also allow for the examination of additional outcome factors that were not included in the NS-CSHCN, implementation. The questions asked in the NSCH may include

additional factors that were unable to be assessed in the current study. The linking of these two surveys may be an avenue for expanding research in area.

Finally, limited research in this area has been led by nurse scientists. Most studies were conducted by researchers in the fields of psychology or special education. Nurse researchers are urged to apply nursing's unique perspectives to expand development in this important area of emerging knowledge.

### **Conclusion**

The prevalence of unmet respite care needs in parents of children with ASD was seven times higher than parents of CSHCN without ASD. Screening all parents of CSHCN for unmet respite care needs is important, recognizing that parents of children with ASD, functional limitations and high caregiving demands are at highest risk for unmet respite care needs. The new knowledge gained from understanding the factors associated with unmet respite care needs in families of children with ASD informs future research, policy and practice changes to optimize family outcomes through respite care. Respite care that meets the context and needs of families has the potential to lower stress levels, decrease fatigue, and improve family self-management.

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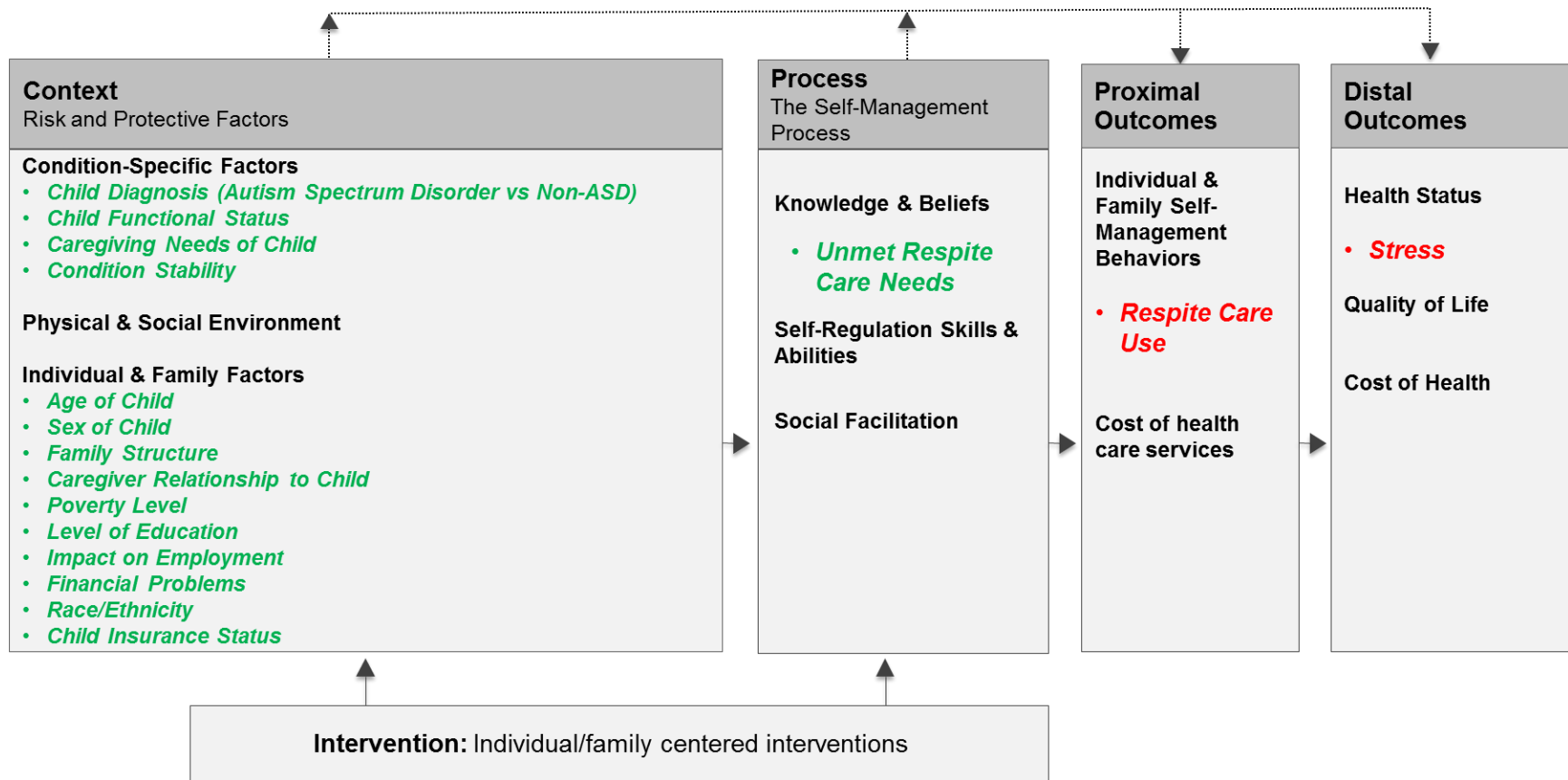
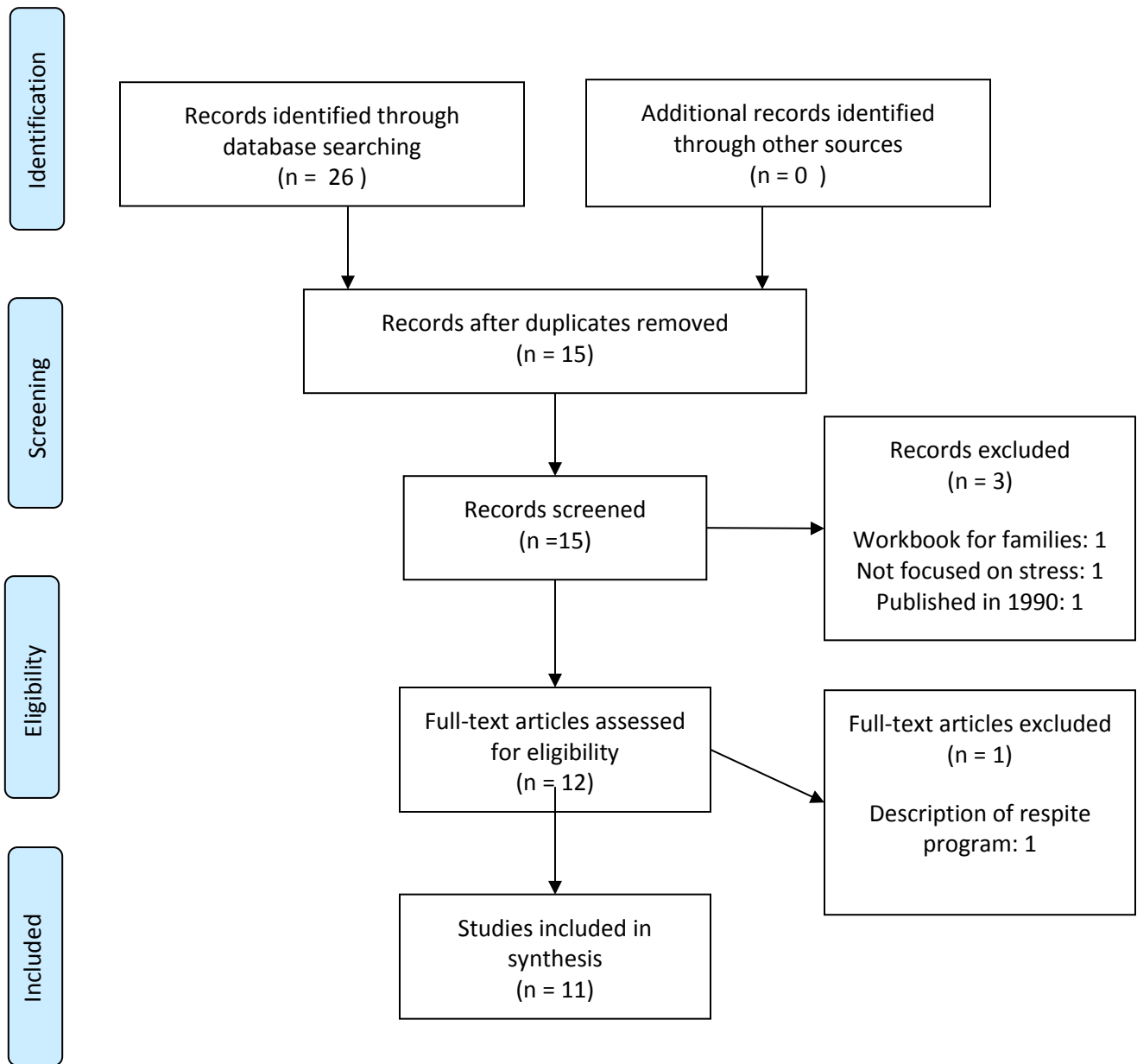


Figure 1. The Individual and Family Self-Management Theory (IFSMT) Applied to Families of Children with Special Healthcare Needs. Adapted from Ryan, P. A., & Sawin, K. J. (2014). Individual and Family Self-Management Theory [Revised Figure]. Retrieved from <http://www4.uwm.edu/nursing/about/centers-institutes/self-management/theory.cfm>



*Figure 2.* Flow Diagram of Search Strategy for Respite Care and Stress Review of Literature. Adapted from Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement.* PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097.

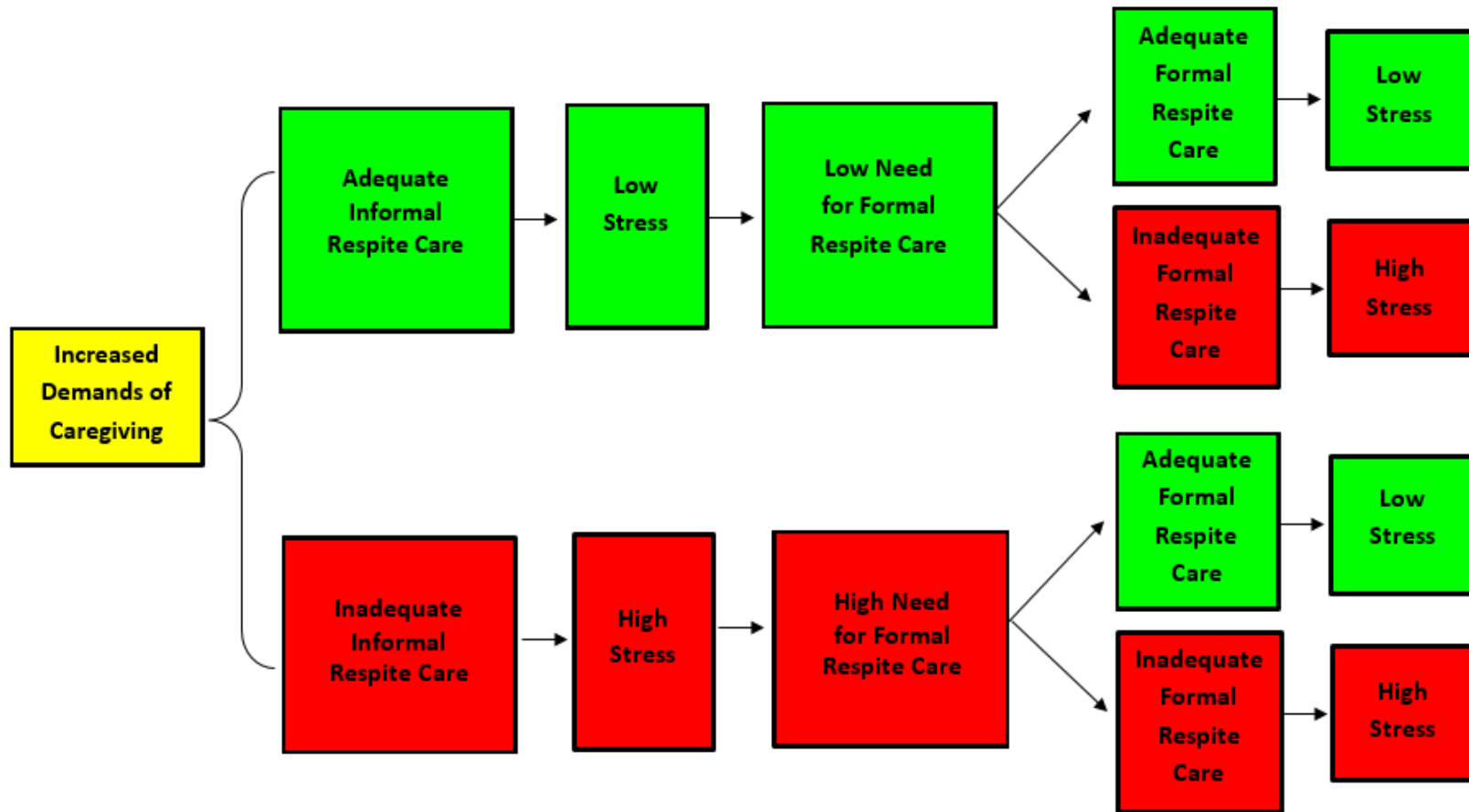


Figure 3. Diagram of Respite Care and Stress.

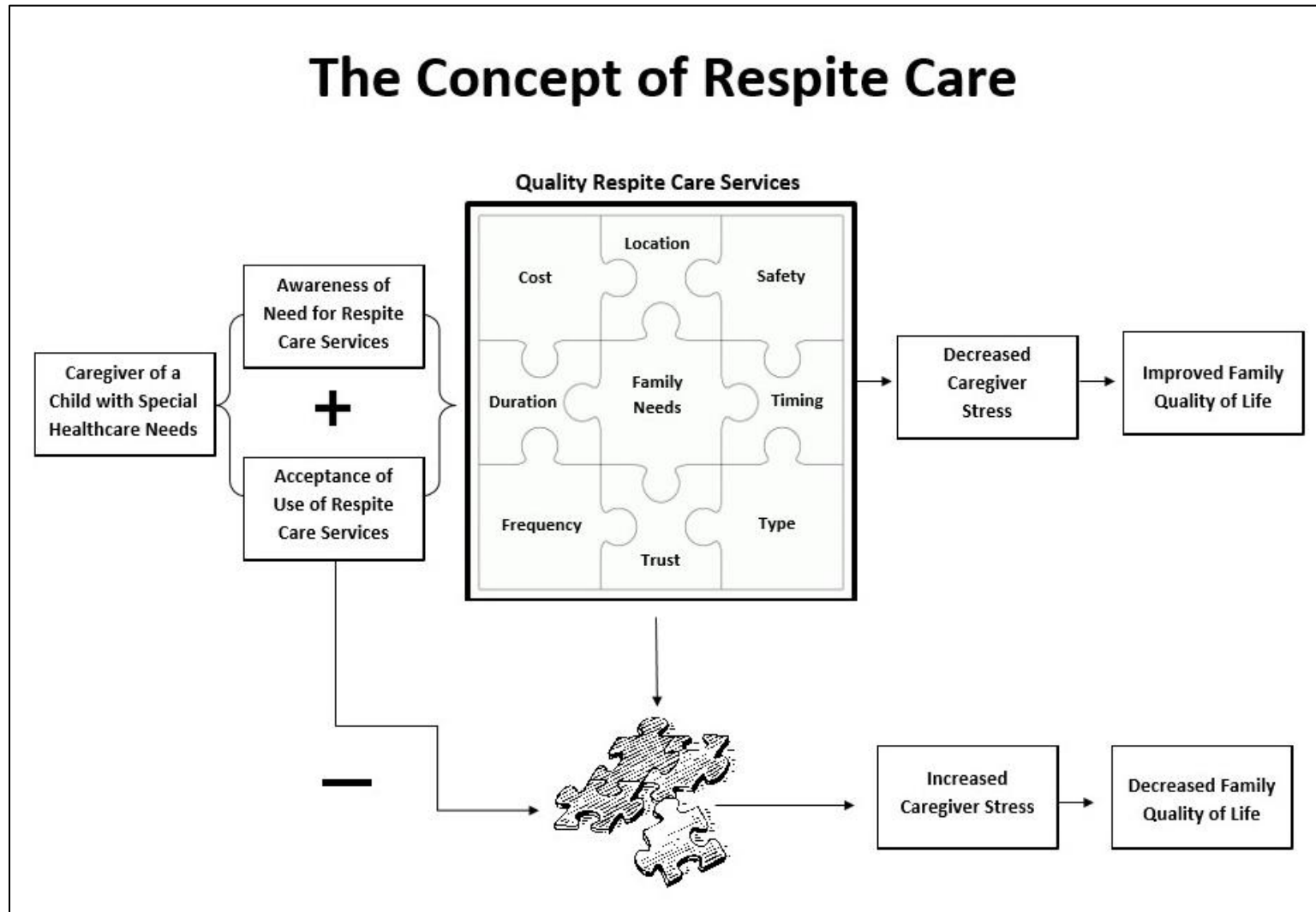


Figure 4. Diagram of the Concept of Respite Care for Caregivers of Children with Special Healthcare Needs.

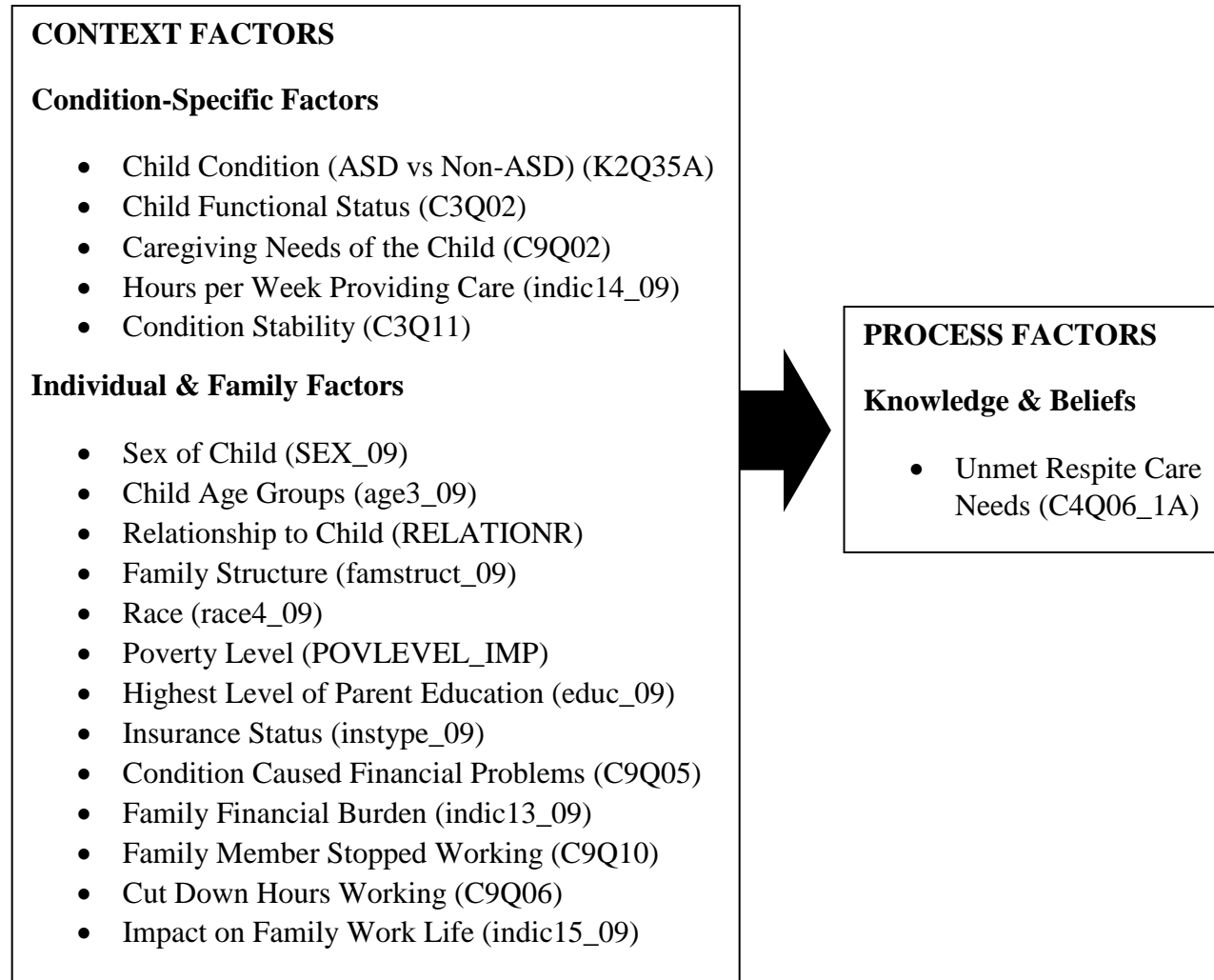


Figure 5. Measurement Model

## Sample Size Flow Diagram

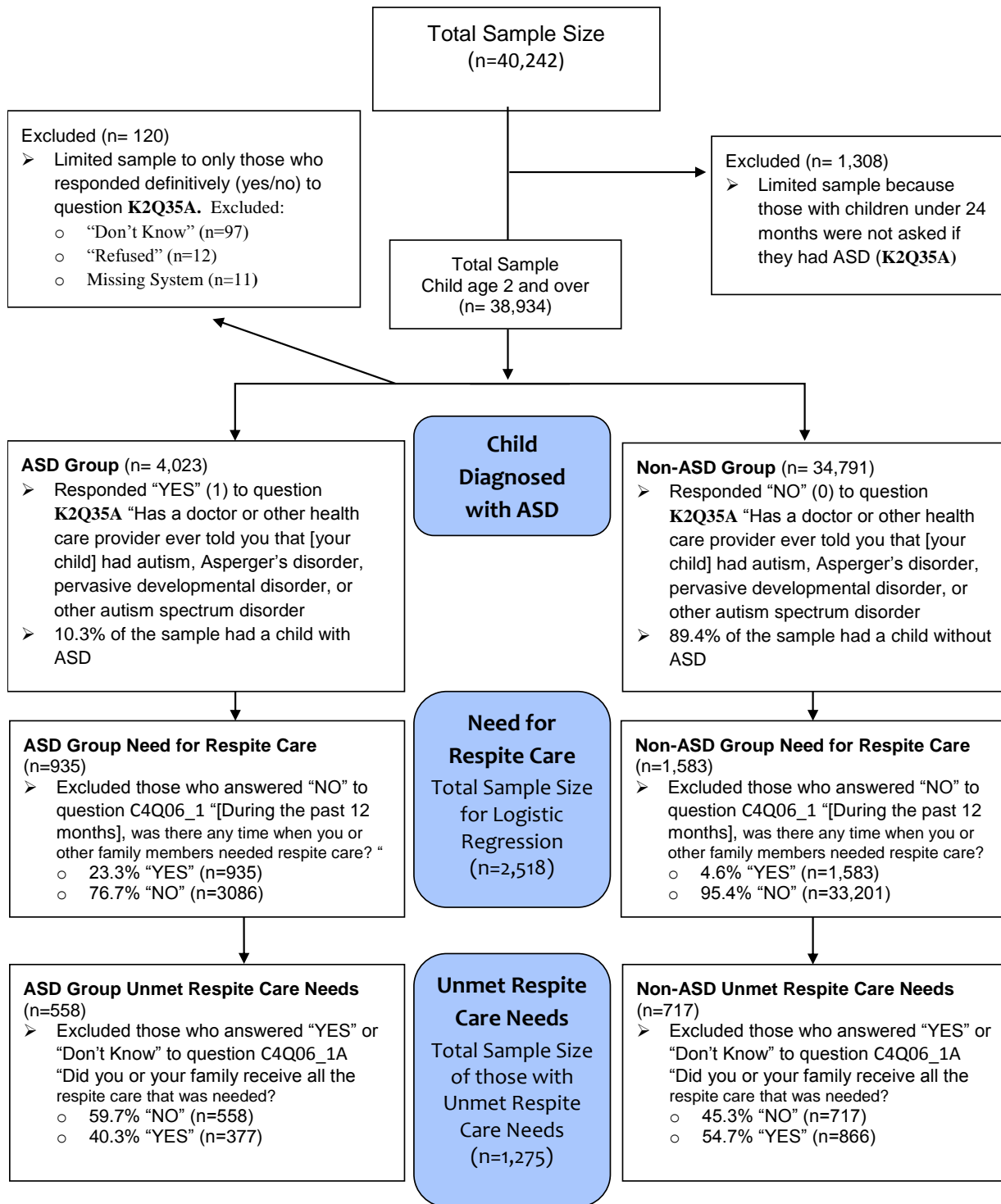


Figure 6. Sample Size Flow Diagram

Table 1

*Evidence table*

Author(s), year	Objective/Purpose/Aim	Design, theoretical framework, level of evidence*	Sample location, sample size (n), major sample characteristics	Respite and stress measures	Analysis/Statistical tests	Major findings/Conclusions
Blank, 2011	<ul style="list-style-type: none"> <li>To better understand the predictive factors that influenced positive response to a respite program for children with an SED.</li> </ul>	<ul style="list-style-type: none"> <li>Longitudinal, descriptive, observational study</li> <li>Fite, Greening, and Stoppelbein (2008) transactional model</li> <li>Level VI</li> </ul>	<ul style="list-style-type: none"> <li>United States</li> <li>n= 33 children with serious emotional disturbance (SED) [includes ASD]. (contacted 35)</li> <li>Children: males (69.7%), 5 to 16 years (Mean Age = 11.10); Diverse sample (39.4% African-American, 33.3% Hispanic, 21.2% Caucasian); participating in the Family Services of Westchester (FSW) respite summer camp program (therapeutic recreational/ respite program.)</li> </ul>	<ul style="list-style-type: none"> <li>Parenting Stress Index (PSI) administered at beginning and end of 7 week summer camp</li> </ul>	<ul style="list-style-type: none"> <li>Descriptive</li> <li>Correlations</li> <li>Paired sample t-tests</li> <li>Pearson Product-Moment Correlation Coefficients</li> </ul>	<ul style="list-style-type: none"> <li>Significant difference (and large effect size) in scores from Time 1 to 2 on: PSI Child Domain of Acceptability (AC) (ESr = .62); PSI Child Domain of Demandingness (DE) (ESr = .53); PSI Child Domains of Distractibility (DIS) (ESr = .49); and Reinforces Parent (RP) (ESr = .47); PSI Child Domain (CD) Total Score (ESr = .59); PSI Parent Domain (PD) Role-Restriction (RR) subdomain (ESr = .50); PSI Total Score (PD &amp; CD) (ESr = .43); Life Stress (LS) domain (ESr = .45)</li> <li>No significant relationships between any of the four social skills domains on the Camper Weekly Adjustment Scale and PSI domains from Time 1 to Time 2.</li> <li>Overall, camp helped reduce parent stress, but also improved child behavior, which could have also reduced parent stress (cyclical).</li> </ul>
Cavanagh-Husseini, 2015	<ul style="list-style-type: none"> <li>To examine, through a maternal caregiver survey, which services positively impact the ability of mothers of children diagnosed with</li> </ul>	<ul style="list-style-type: none"> <li>Descriptive, observational study</li> <li>None stated</li> <li>Level VI</li> </ul>	<ul style="list-style-type: none"> <li>United States</li> <li>n = 115 (359 surveys mailed)</li> <li>Mothers who utilized a variety of programs through Eden II/Genesis Program.</li> <li>Worked outside of home average of 19.67 (0-55 hours, SD = 7.599).</li> </ul>	<p>Researcher Developed Survey including:</p> <ul style="list-style-type: none"> <li>Background Information</li> <li>Characteristics of the Child</li> <li>Current Level of Stress Experienced by the Mother (5 point likert scale)</li> </ul>	<ul style="list-style-type: none"> <li>Descriptive</li> <li>Coorelations</li> </ul>	<ul style="list-style-type: none"> <li>Maternal stress ranged from 42-99 on a scale of 21 to 105 (SD =12.353)</li> <li>66% experienced feelings of frustration or anger more toward their child with ASD than with other children</li> <li>75% caring for their child with ASD takes more time and energy than they have to give</li> <li>Significant correlation between maternal stress and holiday (trips during school breaks) respite (<math>r = 0.217</math>, <math>p = 0.052</math>), and crisis respite (<math>r = 0.287</math>, <math>p = .010</math>).</li> <li>Trend towards significance between</li> </ul>

ASD to deal with the stressors associated with the diagnosis.

- 78.3% mothers of male children,
  - 79.1% married or living with their significant other
  - 20.9% child never exhibited aggressive behavior
  - need for physical assistance to accomplish daily living skill - 24.3% as often (n = 28) or always 32% (n = 15)
  - 35.7% of the mothers reported that their child physically hurt them or another family member rarely
- does not explicitly ask about "stress")
  - Support for Mothers (yes/no with number of hours/week for informal and formal support services)
  - Perceived Effective Supports.
  - Open-ended questions asking 1.) Other services 2.) Most/Least Effective Services
- maternal stress and at-home Respite ( $r = 0.201$ ,  $p = 0.071$ ) and Sunday respite ( $r = 0.209$ ,  $p = 0.065$ ).
- The vast majority of mothers having experience with respite services reported them as being either most or very effective at relieving stress [The effectiveness of at-home respite services in relieving stress, more than a third, 35.7%, of the mothers responding in the positive with 22.3% reporting the service was very effective in reducing stress (n = 25), and 13.4% reported this service most effective in relieving stress (n = 15). More than a third, 38.3%, of the mothers reported having no experience with this service (n = 44).]
  - When asked about not having enough formal supports causing a negative impact on caring for their child with ASD, 11.5% responded that this is always or almost always a factor (n = 13).
  - Regarding the lack of support from family members, 19.3% responded that it always or almost always has a negative impact (n = 22).
  - 24.3% spouse/partner never shared in childcare responsibilities equally (n = 28); 25.2% never received support from extended family members with childcare; 56.5% responded they never receive support from friends with childcare.
  - Support from the community with childcare was reported as never for 63.5%.
  - 87.8% responded that they never receive support from religious affiliation with childcare
  - More than 75% reported never or rarely receiving informal supports in the form of childcare from friends, local parent support groups, religious affiliations
  - 35.7% reported never paying someone privately to help care for their child
  - 42.2% reported receiving at-home respite

Dyches, Christensen, Harper, Mandelco & Roper, 2015

The purpose of the current study was twofold:

- to investigate the perceptions of single mothers of children with ASD regarding their daily stress (as measured by daily hassles and caregiver burden), daily uplifts, depression, and respite care, and
- to examine the relationship between respite

- Descriptive, observational study
- Family adaptation (McCubbin and Patterson, 1983)
- Level VI

- United States
- n=122 (n=169 returned) non-cohabiting single mothers of children diagnosed by a medical professional as having ASD or classified by the child's school as having autism
- Average age 36.66 (SD = 6.96)
- never married (23.8 %)
- divorced, widowed, or separated (76.2 %)
- 71.3 % non-Hispanic white
- 53.3 % lived in

- Caregiver Burden Instrument, an adaptation from Robinson (1983) [.92 current study (range a .86-.88)]
- Hassles and Uplifts Scale (HUS; Lazarus and Folkman 1984) [a = .96 for hassles, and a = .95 for uplifts]
- Respite Care Questionnaire (developed by Harper et. al 2013) [Types and hours/week; satisfaction with

- Descriptive
- Corelations
- Confirmatory Factor Analysis
- Structural Equation Modeling
- Sobel test for mediation

(mean of 2.88 hours per week (0-20; SD= 4.472)

- 44.5% received Saturday respite services;
- 37.3% received summer day camp
- 19.1% overnight respite services (0-12 with a mean of 0.304 nights per year (SD = 1.352)
- 5.5% crisis respite services (mean of 0.04/week (0-3; SD = 0.335)
- Open ended questions 1. Private pay, therapeutic and recreational programs were also utilized 2. After-school services listed 21 times, in-home respite (11 times), other respite (10 times), summer camp (19 times), Overnight respite (15 times), center-based respite (24 times), weekend respite (38 times); comments regarding waiting for services and the difficulties with obtaining services; misc. comments related to need for respite to meet needs (timing, duration, lack of trained staff, etc..)
- 59.8 % accessed some form of respite care
- Received by multiple sources (41 %), grandparents (24.7 %), community agencies (13.7 %), and extended family (11 %)
- 71% were satisfied with this care
- Most mothers (77 %) were at risk for clinical depression.
- Average of 6.98 h of respite care per week (SD = 10.70)
- During respite mothers: did work (32.9 %), ran errands (20.65), took naps, went to dinner with friends, did housework.
- Mean hassles frequency score (average number of times items indicated as stressful) was 33.14 (SD = 10.76), suggesting slightly over 60 % of the 54 listed items were annoyances or bothers.
- Respite care was positively related to daily uplifts, and uplifts mediated the relationship between respite care and depression. not a statistically significant relationship between the amount of respite care and stress (b = -

	care and depression with stress and uplifts as mediators.		western United States	respite care and how they spend time when child receives respite care]		.02); positive relationship between the amount of respite care and daily uplifts (b = .15, p<.05); thus as respite care increased, daily uplifts increased
			<ul style="list-style-type: none"> <li>all graduated HS and 43.4 % had Bachelor's degree</li> <li>49.2 % earned less than \$25K and 79 % earned \$50,000 or less</li> <li>42% received no child support income</li> <li>17.2 % had more than 1 child with ASD</li> <li>2.14 (SD = 1.09) average total children</li> <li>84.5 % reported medical diagnosis of ASD and 15.5 % were categorized by schools' educational teams as having autism.</li> <li>59.8 % accessed some form of respite care (most from multiple providers)</li> </ul>	<ul style="list-style-type: none"> <li>Latent variable stress created using three indicators: the intensity scores and frequency scores from the Daily Hassles subscale of the HUS and the amount of caregiver burden from the Caregiver Burden Instrument</li> <li>Latent variable called uplifts created with two indicators: the intensity scores and frequency scores from the Daily Uplifts subscale of the HUS</li> </ul>		<ul style="list-style-type: none"> <li>Bootstrap results showed the size of the indirect effect (-.11, SE = .048, 95 % CI [-.312 to -.183] p = .24) was nonsignificant, suggesting stress did not mediate the relationship between respite care and depression.</li> <li>The size of the indirect effect (-.23, SE = .04, 95 % CI [-.425 to -.012], p&lt;.01) was significant, meaning uplifts significantly mediated the relationship between respite care and depression (b = .15, p&lt;.05 between respite care and uplifts); stress levels did not decrease, but uplifts were likely to significantly increase (b = .15, p&lt;.05) with respite care</li> </ul>
Harper, Dyches, Harper, Roper & South, 2013	The purpose of this study was twofold: <ul style="list-style-type: none"> <li>to examine the relationship between respite care and quality of marriage for couples with a child with ASD, with wife and husband stress as</li> </ul>	<ul style="list-style-type: none"> <li>Descriptive, observational study</li> <li>None stated</li> <li>Level VI</li> </ul>	<ul style="list-style-type: none"> <li>United States</li> <li>101 mother/father heterosexual dyads</li> <li>average age of husbands 39.21 years (SD = 6.89); average age of wives 38.01 years (SD = 7.04)</li> <li>average length of marriage 11.89 years (SD = 3.12)</li> </ul>	<ul style="list-style-type: none"> <li>Latent variables regarding stresses and uplifts were created from the Hassles and Uplifts Scale (HUS; Lazarus and Folkman 1984)</li> <li>Respite care [hours and minutes received</li> </ul>	<ul style="list-style-type: none"> <li>Descriptive</li> <li>Coorelations</li> <li>t-tests</li> <li>Confirmatory Factor Analysis</li> <li>Structural Equation Modeling</li> <li>Sobel test for mediation</li> <li>Actor Partner Independence</li> </ul>	<ul style="list-style-type: none"> <li>63.6 % received some type of respite care</li> <li>Respite provided by: 28.0 % grandparents, 26.7 % babysitter, 21.3 % community agency, 16.0 % extended family, and 8.0 % combination</li> <li>88.6 % reported being satisfied</li> <li>Number of hours of respite care was positively correlated to parent-reported uplifts and negatively related to parent-reported stresses [wives (b = .20, p&lt;.01 for uplifts; b = -.33, p&lt;.001 for stress &amp; husbands (b = .37, p&lt;.001 for uplifts; b = -</li> </ul>

- potential mediating variables, and
- (b) to examine maternal and paternal daily uplifts as potential mediating variables.

- average number of children 3.09 (SD = 1.65)
- husbands worked average of 41.27 h (SD = 12.17) and only 4 % were unemployed
- mothers worked average of 12.17 h per week (SD = .70) and 71.3 % were unemployed
- household income of \$55,353 (SD = \$18,649)
- 97 % of the couples were both biological parents
- Most were white (husbands 82.2 %, wives 86.1 %); Hispanic or Latino (husbands 8.9 %, wives 6.9 %), African American (husbands 5 %, wives 4 %)
- Well educated (43.5 % of husbands and 43.9 % of wives holding bachelor's degrees, 12.5 % of husbands and 8.8 % of wives holding master's degrees, 5.1 % of husbands and 4.1 % of wives holding doctorate/professional degrees)

1.) from M-F in a typical week and 2.) on typical weekend days 3.) SUM Total Hours]

Model (APIM; Kenny et al. 2006) was used to estimate the effects of the independent variable (amount of respite care) on the dependent variables (husband and wife relational quality).

- .30,  $p < .001$  for stress)]
- Unstandardized betas indicate that for every hour of respite care, daily stress decreased by approximately 5 units for wives and almost 6 units for husbands. \*just one additional hour of respite care per week was related to an increase of 6–7 points in marital quality.
  - Findings that mothers and fathers reported similar stress levels may be related to the fact that stress was measured by daily hassles rather than by specific parenting stressors.

Minhas, Vajaratkar, Divan, Hamdani, Leadbitter, Taylor, . . . Rahman, 2015	<ul style="list-style-type: none"> <li>To explore existing parental beliefs and care practices for children with ASD in the two largest countries of South Asia, India and Pakistan</li> </ul>	<ul style="list-style-type: none"> <li>Descriptive, observational study &amp; Synthesis involving systematic triangulation. Combined two different methods: In Pakistan, primary data were collected through in-depth interviews of parents, while in India a narrative review of existing studies was conducted.</li> <li>None stated</li> <li>Level VI</li> </ul>	<ul style="list-style-type: none"> <li>118 children (42 females, 76 males); age ranged from 1 to 33 years (<math>x = 8.23</math>; <math>SD = 3.54</math>)</li> <li>Pakistan and India</li> <li>PAKISTAN <math>n=15</math> parents (11 mothers, 4 fathers)</li> <li>INDIA: 5 relevant qualitative studies</li> <li>PAKISTAN: new referrals to the Centre where their children had been diagnosed with childhood autism by a specialist using the ICD-10 diagnostic criteria</li> <li>Children were mostly male (<math>n=12</math>); diverse education and geographic location (rural and urban)</li> <li>INDIA: 2003-2013 Literature search - Studies were included if parental and community beliefs and practices related to ASD were the focus of at least one aspect of analysis.</li> </ul>	<ul style="list-style-type: none"> <li>PAKISTAN: "Topic guides" created and piloted. Did not specify questions included.</li> <li>INDIA: Studies were included if parental and community beliefs and practices related to ASD were the focus of at least one aspect of analysis.</li> </ul>	<ul style="list-style-type: none"> <li>PAKISTAN: thematic analysis based on the framework analysis approach (Ritchie &amp; Spencer, 1994)</li> <li>INDIA: literature was also analyzed thematically.</li> <li>Data synthesis involved a systematic triangulation process by which findings from the qualitative study in Rawalpindi and the studies from India identified in the review were combined to obtain an in-depth understanding of the care-giving beliefs, perceptions, and practices of parents.</li> </ul>	<ul style="list-style-type: none"> <li>Triangulation of the primary and secondary data identified four domains of care: (1) primary carer/s for the child, (2) problems in caring for a child at home, (3) availability of care outside the home, and (4) attitude of the community to ASD.</li> <li>State-provided respite or remedial care was almost non-existent in both rural and urban areas.</li> <li>Burden of care is almost entirely on the mother, leading to high levels of stress.</li> <li>Mothers frequently described high levels of stress because of the constant attention required by the child, and the lack of any respite.</li> <li>Only the very educated had information about ASD, and most rural parents ascribed their child's condition to the 'will of God' and 'a test by God'.</li> <li>Did not find any major differences in the findings between the two countries.</li> </ul>
Ogston-Nobile, 2015	<ul style="list-style-type: none"> <li>To investigate the associations among parents' management of</li> </ul>	<ul style="list-style-type: none"> <li>Descriptive, Observational Study</li> </ul>	<ul style="list-style-type: none"> <li>United States</li> <li><math>n= 166</math> (369 interested, 247</li> </ul>	<ul style="list-style-type: none"> <li>Questionnaire on Resources and Stress – Short Form</li> </ul>	<ul style="list-style-type: none"> <li>Descriptive</li> <li>Correlations</li> <li>independent</li> </ul>	<ul style="list-style-type: none"> <li>Fathers managed less Responsibility-Related Caregiving than mothers [fathers (<math>M = 50.7</math>, <math>SD = 21.3</math>) and mothers (<math>M = 99.2</math>, <math>SD = 16.2</math>); <math>t(163) = 16.49</math>, <math>p &lt; .001</math>]</li> </ul>

	and satisfaction with the division of family work, parenting stress, parents' relationship adjustment, and family functioning in fathers and mothers of children with an ASD	<ul style="list-style-type: none"> <li>• Informed by Family Systems Theory</li> <li>• Level VI</li> </ul>	<ul style="list-style-type: none"> <li>enrolled, 207 completed survey</li> <li>• Fathers (n = 62) and mothers (n = 104) of school-age children with an ASD</li> <li>• parents (mean 41.4 y) were white (95%) and well-educated (98% had at least some college), married average 13 years</li> <li>• fathers (85.5%) worked full-time</li> <li>• mothers (41.3%) were employed full-time</li> <li>• ~30% both worked full time</li> <li>• high household income (79% &gt; \$50k; 58% &gt; \$80k)</li> <li>• child (82% boys, mean 8.8 y.)</li> <li>• 56.6% reported a comorbid condition</li> </ul>	<ul style="list-style-type: none"> <li>(Abbreviated) (QRS-SFA) [Friedrich, Greenberg, &amp; Crnic, 1983] Cronbach's alpha = .88</li> <li>• Responsibility-Related Caregiving Management Scale (created based on the Parental Responsibility Scale (PRS; McBride &amp; Mills, 1993) <math>\alpha</math> = .98</li> <li>• Responsibility-Related Caregiving Satisfaction Scale (created for this study) Cronbach's alpha = .97.</li> </ul>	<ul style="list-style-type: none"> <li>sample t-tests</li> <li>• one-way between-groups ANOVA</li> <li>• Post-hoc comparisons using the Tukey HSD test</li> <li>• hierarchical linear regression</li> </ul>	<ul style="list-style-type: none"> <li>• Significant model predicted Parenting Stress (QRS-SFA) [F (6, 155) = 14.67 (p &lt; .001) R2 = .36], where child level of functioning accounted for 30% of the variance [ATEC, R2 = .30 (p &lt; .001)]; RRC-MNG explained an additional 5% of the variance in parenting stress [<math>\Delta</math>R2 = .05 (p &lt; .01)], indicating that Parenting stress was higher when a child's functioning was lower and when one parent always managed Responsibility-Related Caregiving, regardless of whether it was the responding parent or their partner.</li> <li>• "parents and families are better off when the family work is shared."</li> </ul>
Openden, Symon, Koegel & Koegel, 2006	<ul style="list-style-type: none"> <li>• This article delineates the steps for identifying potential respite providers through the development of a babysitter list of university undergraduates who show interest in babysitting children with</li> </ul>	<ul style="list-style-type: none"> <li>• n/a</li> <li>• None stated</li> <li>• Level VI</li> </ul>	<ul style="list-style-type: none"> <li>• United States</li> <li>• Unknown</li> <li>• Unknown</li> </ul>	n/a	n/a	<ul style="list-style-type: none"> <li>• Over the 10 years we have conducted this project, hundreds of lists have been distributed to families.</li> <li>• Based on the positive feedback received from families and respite providers, the following impressions have been formed: The respite list reduced family stress by providing a single source with many options of babysitters and allowed them to devote time to other demands and other aspects of their lives</li> </ul>

Preece & Jordan, 2007	<p>autism.</p> <ul style="list-style-type: none"> <li>This current study sought to obtain as close to a whole (geographically defined) population of families with children with ASD as possible, identifying why some families accessed short breaks services and others did not.</li> </ul>	<ul style="list-style-type: none"> <li>Descriptive, observational study</li> <li>None stated</li> <li>Level VI</li> </ul>	<ul style="list-style-type: none"> <li>United Kingdom</li> <li>n=155 (60.5% response rate)</li> <li>Postal survey sent to all families with children with ASD appearing on one rural English county's register of disabled children</li> <li>Sample not well described</li> <li>From rural area, with little urbanisation, and a low minority ethnic community population.</li> </ul>	<ul style="list-style-type: none"> <li>Robinson and Stalker's Ten Point Dependence Scale (1990) = stress?</li> <li>Respite use (Did not describe how measured but included survey in appendix and simply asked "Do any of the following people help to look after your child?")</li> </ul>	<ul style="list-style-type: none"> <li>Descriptive</li> <li>Chi-squared analysis</li> </ul>	<ul style="list-style-type: none"> <li>non-users had on average 2.0 sources of informal social support, compared with 1.8 sources available to users of short breaks and X2 analysis identified that this difference was not significant (P-value = .70)</li> <li>Provided by: spouse/partner (80%), grandparents (39%), other children (36%), friends (15.5%) or neighbours (4.5%)</li> <li>43% of families that did not access short breaks expressed a current need for them</li> <li>Over 40% of non-users who wished to access short breaks did not have a social worker</li> <li>Children of users of short breaks were reported as being, on average, dependent in 8.2 of the areas measured on the Ten Point Dependence Scale, compared to 6.9 areas for the children of non-users. This was shown by X2 analysis to be significant (P-value = .05)</li> </ul>
Shamash, 2012	<ul style="list-style-type: none"> <li>To investigate the possible relationships between parent stress, parent self-efficacy, belief in intervention, parent knowledge of autism, perception of child progress and parent satisfaction with intervention in families of children with ASD</li> </ul>	<ul style="list-style-type: none"> <li>Descriptive, Observational Study</li> <li>None stated</li> <li>Level VI</li> </ul>	<ul style="list-style-type: none"> <li>United States</li> <li>n= 72 parents of preschool aged (2-5y) children/78 received (~270 sent invite)</li> <li>Parents: 88.9% female, 40-44 age range (38.9%), 84.7% white, 94.4% married, 45.8% master's degree.</li> <li>Children: 80.6% male</li> </ul>	<ul style="list-style-type: none"> <li>Family Stress and Coping Interview (FSCI) (Nachsen et al., 2003) a = .91</li> <li>Perceived Stress Scale (PSS) (Cohen et al., 1983) a= .87</li> <li>Youth Services Survey for Families (YSSF) by Riley, Stromberg and Clark (2005) a=.94</li> <li>respite care (yes/no)</li> </ul>	<ul style="list-style-type: none"> <li>Descriptive</li> <li>Correlations</li> <li>hierarchical regression analyses</li> </ul>	<ul style="list-style-type: none"> <li>Only 11.1% of parents reported participating in respite services</li> <li>Perceived stress: (M 29.02/56 SD 8.06) 6.9% high, 51.4% notable, 40.3 moderate, 1.4% low</li> <li>Disability Stress: (M 27.07/51, SD 11.15) 20.8% high, 43.1% notable, 26.4% moderate, 9.7% low</li> <li>parent self-efficacy, belief in the efficacy of intervention being used, program satisfaction with access to services and appropriateness of services as well as not participating in a live support group and not using respite services were the best set of predictors for perceived stress.</li> <li>PROGRAM SATISFACTION (not specific to respite): Cultural Sensitivity M 20.23/25, SD 3.41; Access M 11.84/15, SD 2.24</li> <li>Perceived stress was significantly correlated with: Access (r = -.240; p &lt;.05), Respite (r = .291; p&lt;.05).</li> </ul>

Webb, 2013

- 1.) To understand the unique role of organized religion as a support system to families who have children with ASD.
  - 2.) To find out to what degree clergy were aware of the issues that surround families in coping with ASD, and how Christian churches responded to families who have children with a diagnosis of Autism Spectrum Disorder (ASD).
  - Descriptive, observational study, using a mixed methods approach (a bounded case study of one family coupled with a phone survey of churches)
  - Family ecology theory
  - Level VI
  - United States
- CASE STUDY:
- n=6
  - 1 mother, 3 siblings, and two church staff.
- SURVEY:
- n= 125 Churches (sampled 300 total; response rate of 41.7%.)
- CASE STUDY:
- Middle class Caucasian family from an affluent church in a mid-size metropolitan area in the south.
  - Child is 15 and has severe behavior issues.
  - Parents married with 4 total children. (Interviewed mother, siblings (17 & 8 yo brothers, 13 yo sister), and two church staff (special needs coordinator and
- Interview Guide (didn't specifically ask about respite or stress)
  - Central question of the case study was, "What types of support does a typical church provide to the family when one of its members has been diagnosed with ASD, and what is the impact of this support on the family?"
  - Questionnaire for churches (included types of programs offered for children with ASD)
- Qualitative data from interviews: content analysis using constant comparative techniques
  - Survey: non-parametric tests, descriptive and Chi-Square tests
- Disability Stress was sign. correlated with Access ( $r = -.279$ ;  $p < .05$ ).
  - Respite accounted for 5.4% of the variance in Perceived Stress ( $r^2 = .054$ ;  $p < .05$ )
  - The most important finding was that parent self-efficacy was the most significant predictor of both general perceived stress and stress related to child disability.
- CASE STUDY:
- The main need this family expressed was the need for respite, which helped decrease the family's stress.
  - The key to recovering as much normal life as possible was respite.
  - In addition to the Sunday morning respite at church, she discussed three other sources of respite: the monthly program run by the county rec center, her parents, and sitters who spend time with Jacob during the summer and afterschool during the school year.
  - Trisha's foremost source of respite was her financial ability to pay for sitters since she and her husband had increased their monthly income.
  - All of these sources of respite combined to buffer her stress—she felt less tied down, less nervousness, and had more pleasant interactions with Jacob when she was with him.
- SURVEY:
- Churches from the wealthiest zip codes ( $\chi^2 (6, N = 125) = 13.13, p = .03$ ), with the largest congregations ( $\chi^2 (3, N = 125) = 37.28, p = .00$ ), and with more than five full-time staff ( $\chi^2 (4, N = 125) = 27.52, p = .00$ .) were more likely to have a program for children with autism.
  - Only 4.8% of churches surveyed reported offering Formal Respite and 19.2% offered Informal respite (didn't define formal vs informal)

- Christian education director.)
- SURVEY:**
- Young, Ruble & McGrew, 2009
- To better understand the correlations between financing and outcomes of services among children with ASD, a community based survey was developed and administered that allowed for a preliminary examination of the associations between several interdependent variables: (a) out-of-pocket expenditures, (b) variety of services used, (c) access to services, (d) child and family outcomes of services, and (e) satisfaction with the financier of services. The differences between these variables were
  - Descriptive, Observational Study
  - None stated
  - Level VI
  - United States
  - n=113 parents/caregivers of children (ages 2.5–21) with ASD
  - Children: M 9.9 years (SD = 4.4 years)
  - education (35.4% college graduate and 24.8% Graduate/Professionals)
  - income levels (33.6% \$50-100K; 15% >\$100K annual) were somewhat higher than typical for the state
  - 93.8% Caucasian children
  - 79.7% married
  - 43-item questionnaire regarding services received in the prior 6 months
  - Targeted nine specific services—inpatient care, medication management, counseling or training, individual therapy, in-home behavior therapy, speech and language therapy, occupational therapy, case management, respite care
  - Items from the questionnaire were used to construct the five variables evaluated against type of insurance: (a) out-of-pocket expenditures, (b) variety of services used, (c) access to services, (d) child and family outcomes of services, and (e) satisfaction with the financier of services.
  - Parent stress was measured by responses to the question, “On a scale of 1–10, how would you rate your level of stress caused by issues having to do with your child who has an autism spectrum disorder?” (1 “No
  - Descriptive
  - Correlations
  - Mann–Whitney U-test
  - t-tests
  - Chi-square tests
  - only 29.3% of Private insured and 33.3% of public insured reported using respite in past 6 months (no sign diff between groups  $X^2=.146$   $p=.703$ )
  - Parents reported a mean stress rating of 7.04 (10 = very much) (SD = 2.16) “caused by issues having to do with your child who has an ASD.”
  - A Mann–Whitney U-test revealed no significant difference in self-reported stress of parents with privately (Mdn = 7.00, n = 82) and publicly (Mdn = 7.50, n = 22) insured children,  $U = 800.0$ ,  $z = -.083$ ,  $p = .41$
  - mean access to care rating of 2.44 (SD = 1.0) was calculated out of a possible of 5
  - Use of a greater variety of services was associated with lower ratings of access to care ( $r = -.19$ ,  $p < .05$ ) and greater report of parent stress ( $r = .33$ ,  $p < .01$ )
  - the association of increased parent stress with both a need for a greater variety of services and poorer access to those services is likely producing an artifactual correlation between service use and access to care
  - After controlling for parent stress, the negative correlation between access to care and variety of

evaluated by  
type of  
insurance  
(public vs.  
private).

problem”, 10 “Big  
problem”).

services was reduced to  
insignificance ( $r = -.093$ ,  $p = .336$ )

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#### Levels of evidence

Level 1 - Systematic review & meta-analysis of randomized controlled trials; clinical guidelines based on systematic reviews or meta-analyses

Level 2 - One or more randomized controlled trials

Level 3 - Controlled trial (no randomization)

Level 4 - Case-Control or cohort study

Level 5 - Systematic review of descriptive & qualitative studies

Level 6 - Single descriptive or qualitative study

Level 7 - Expert opinion

Source: Melnyk, B.M. and Fineout-Overholt, E. (2011). Evidence-based practice in nursing and healthcare: A guide to best practice.

Philadelphia: Lippincott, Williams & Wilkins.

\*Level of evidence based on Melnyk and Fineout-Overholt (2011).

Table 2

*Study Measures and Response Options*

Concept	Measure	Description	Coding
<b>CONTEXT FACTORS</b>			
Condition-Specific Factors	Child Diagnosis (ASD vs Non-ASD) (K2Q35A)	K2Q35A (READ IF NECESSARY: Has a doctor or other health care provider <i>ever</i> told you that [S.C.] had...) Autism, Asperger's Disorder, pervasive developmental disorder, or other autism spectrum disorder?	0=NO 1=YES 6=DON'T KNOW 7=REFUSED
Condition-Specific Factors	Child Functional Status (C3Q02)  Recoded Functional Status (FunctionREC)	C3Q02 [During the past 12 months/Since [his/her] birth], how often have [S.C.]'s (medical, behavioral, or other health conditions / emotional, developmental, or behavioral problems) affected [his/her] ability to do things other children [his/her] age do? Would you say:	1=NEVER 2=SOMETIMES 3=USUALLY 4=ALWAYS 6=DON'T KNOW 7=REFUSED  1=SOMETIMES 2=USUALLY 3=ALWAYS 4=NEVER
Condition-Specific Factors	Caregiving Needs of the Child (C9Q02)	C9Q02 Many families provide health care at home such as changing bandages, care of feeding or breathing equipment, and giving medication and therapies. Do you or other family members provide health care at home for [S.C.]? <b>READ IF NECESSARY:</b> Please base your answer on the last several weeks. <b>READ IF NECESSARY:</b> Only include care related to the child's condition.	0=NO 1=YES 6=DON'T KNOW 7=REFUSED

Condition-Specific Factors	Hours per Week Providing Care (indic14_09)	INDICATOR #14: Hours per Week Providing Care: CSHCN whose families spend 11 or more hours per week providing and/or coordinating health care for child	1=Less than1 hour 2=1-4 hours per week 3=5-10 hours per week 4=11 or more hours per week 99=DK/REF
Condition-Specific Factors	Condition Stability (C3Q11)	C3Q11 Which of the following statements best describes [S.C.]’s health care needs? [S.C.]’s health care needs change all the time, [S.C.]’s health care needs change only once in a while, or [S.C.]’s health care needs are usually stable?	1=CHILD’S HEALTH CARE NEEDS CHANGE ALL THE TIME 2=CHILD’S HEALTH CARE NEEDS CHANGE ONLY ONCE IN A WHILE 3=CHILD’S HEALTH CARE NEEDS ARE USUALLY STABLE 4=NONE OF THE ABOVE 6=DON’T KNOW 7=REFUSED
Individual & Family Factors	Sex of Child (SEX_09)	Sex of child	1=Male 2=Female 99=DK/RF
Individual & Family Factors	Family Structure (famstruct_09)	Family structure of the CSHCN population	1= CSHCN in 2 parent household 2=CSHCN in 2 parent stepfamily household 3=CSHCN in mother only household 4=CSHCN in other family structure household
Individual & Family Factors	Poverty Level (POVLEVEL_IMP)	Derived. Poverty level of this household based on DHHS guidelines - Imputed	1=AA –At or below 50% poverty level 2=A – Above 50% to at or below 100% poverty level 3=B – Above 100% to at or below 133% poverty level 4=C-Above 133% to at or below 150% poverty level 5=D – Above 150% to at or below 185%

			poverty level 6=E – Above 185% to at or below 200% poverty level 7=F – Above 200% to at or below 300% poverty level 8=G –Above 300% to at or below 400% poverty level 9=H – Above 400% poverty level
Individual & Family Factors	Race (race4_09)	Race/ethnicity categories - 4 categories based on imputed screener file data	1=Hispanic 2=White, non-Hisp 3=Black, non-Hisp 4 = Other, non-Hisp
Individual & Family Factors	Age Groups (age3_09)	How many children of different ages are in the CSHCN population?	1=0-5 yrs old 2=6-11 yrs old 3=12-17 yrs old
Individual & Family Factors	Relationship to Child (RELATIONR)	DERIVED. Respondent's relation to selected child	1=Mother (Biological, Step, Foster, Adoptive) 2=Father (Biological, Step, Foster, Adoptive) 3=Other Relative or Guardian 6=Don't Know 7=Refused
Individual & Family Factors	Highest Level of Parent Education (educ_09)	What is the highest education level attained by any parent in the household?	1=Less than high school 2=High school grad 3=More than high school
Individual & Family Factors	Insurance Status (instype_09)	Type of Insurance Coverage	1=Private only 2=Public only 3=Both Public and Private 4=Uninsured 99=Missing or comprehensive other insurance
	Insurance Recorded (INSrecorded)		RECODED: 1=Public only 2=Both Public and Private 3=Uninsured

4=Private only

Individual and Family Factors	Condition caused financial problems (C9Q05)	Have [S.C.]'s health conditions caused financial problems for your family?	0=No 1=Yes 6=Don't Know 7=Refused
Individual and Family Factors	Family Financial Burden (indic13_09)	INDICATOR #13: Family Financial Burden: CSHCN whose families experienced financial problems due to child's health needs	0=No financial problems due to child's health 1=Yes, financial problems 99=DK/REF or MISSING
Individual and Family Factors	Family Member Stopped Working (C9Q10)	Have you or other family members stopped working because of [S.C.]'s health conditions?	0=No 1=Yes 6=Don't Know 7=Refused
Individual and Family Factors	Cut down Hours Working (C9Q06)	[Not including the family members who stopped working,] Have you or other family members cut down on the hours you work because of [S.C.]'s health conditions?	0=No 1=Yes 6=Don't Know 7=Refused
Individual and Family Factors	Impact on Family Work Life (indic15_09)	INDICATOR #15: Impact on Family Work Life: CSHCN whose family members cut back and/or stopped working because of child's health needs	0=Employment not affected 1=Family member cut back hours or stopped working or both

**PROCESS FACTORS**

Knowledge & Beliefs	Unmet Respite Care Need (C4Q06_1A)	Did you or your family receive <i>all</i> the respite care that was needed?	0=No 1=Yes 6=DK 7=RF
	Reverse Coded to: Unmetneed		Reverse Coded: 0=YES (Needs met) 1=NO (Unmet needs)

Table 3

*Variables with No Association with Unmet Respite Care Needs*

Sample	Variable Removed from Further Analysis
CSHCN with ASD subgroup	Caregiving needs of child
	Condition stability
	Age groups
	Sex of child
	Family structure
	Poverty level
	Race
CSHCN without ASD subgroup	Relationship to child
	Insurance status
	Sex of child
	Family structure
	Poverty level
	Race
Total Sample	Sex of child
	Family structure
	Poverty level
	Race

*Note.*  $p > .05$  for all variables.

Table 4

*Variables with High Collinearity*

Sample	Variable Removed from Analysis	High Collinearity With	VIF
CSHCN with ASD subgroup	Condition caused financial problems	Family Financial burden	1.202
CSHCN without ASD subgroup	Caregiving needs of the child	Hours per week providing care	1.360
	Condition caused financial problems	Family financial burden	1.258
Total sample	Caregiving needs of the child	Hours per week providing care Family	1.356
	Condition caused financial problems	financial burden	1.304

Table 5

*Multivariable Models*

Sample	Block 1 Control Variables	Block 2 Predictor Variables
CSHCN with ASD subgroup	Relationship to child	Child functional status
	Highest level of parent education	Hours per week providing care
	Insurance status	Family financial burden Impact on family work life
CSHCN without ASD subgroup	Age groups	Child functional status
	Highest level of parent education	Hours per week providing care
		Condition stability
		Family financial burden Impact on family work life
Total sample	Age groups	Child condition
	Relationship to child	Child functional status
	Highest level of parent education	Hours per week providing care
	Insurance status	Condition stability
		Family financial burden Impact on family work life

*Note.* Dependent Variable = Unmet Respite Care Needs

Table 6

*Demographic Characteristics of Parents with a Need for Respite Care*

Variable	Parents of Children with ASD (N=935)		Parents of CSHCN without ASD (N=1583)		<i>p</i>
	<i>n</i>	%	<i>n</i>	%	
Sex of child					<.001
Male	731	78	900	57	
Female	203	22	680	43	
Age groups					.046
0 – 5 years	118	13	257	16	
6 – 11 years	409	44	654	41	
12 – 17 years	408	44	672	43	
Race					<.001
Hispanic	88	9	222	14	
White, non-Hispanic	660	71	976	62	
Black, non-Hispanic	75	8	212	13	
Other, non-Hispanic	112	12	173	11	
Poverty level					<.001
≤50%	43	5	157	10	
>50%	123	13	236	15	
>100%	78	8	144	9	
>133%	44	5	76	5	
>150%	65	7	141	9	
>185%	32	3	59	4	
>200%	169	18	291	18	
>300%	122	13	198	13	
>400%	259	28	281	18	
Family structure					<.001
2 parent household	552	60	726	46	
2 parent stepfamily household	66	7	131	8	
Mother only household	214	23	435	28	
Other family structure	89	10	274	18	
Relationship to child					<.001
Mother	730	78	1171	74	
Father	130	14	203	13	
Other	74	8	206	13	
Highest level of parent education					<.001
Less than high school	35	4	100	6	
High school graduate	97	10	254	16	
More than high school	803	86	1229	78	
Insurance status					<.001
Private only	291	32	408	27	
Public only	358	39	797	52	
Both private and public	249	27	288	19	
Uninsured	18	2	46	3	
Child functional status*					<.001
Never	10	1	218	14	
Sometimes	147	16	565	36	
Usually	161	17	234	15	
Always	614	66	564	36	

Table 6 (Continued)

Caregiving needs of child					.712
No care provided at home	313	34	552	35	
Family members provide care	619	66	1024	65	
Hours per week providing care					<.001
< 1 hour per week	72	8	262	17	
1 – 4 hours per week	255	28	552	36	
5 – 10 hours per week	171	19	227	15	
≥ 11 hours per week	412	45	475	31	
Condition stability					<.001
Needs change all the time	194	21	230	15	
Needs change only once in awhile	370	40	587	37	
Needs are usually stable	364	39	754	48	
Condition caused financial problems					<.001
No	390	42	962	61	
Yes	538	58	612	39	
Family financial burden					<.001
No	390	42	962	61	
Yes	538	58	612	39	
Family member stopped working					<.001
No	466	50	1080	68	
Yes	461	49	490	31	
Cut down working hours					<.001
No	481	51	1037	66	
Yes	448	48	535	34	
Impact on family work life					<.001
No	255	28	804	51	
Yes	671	73	765	49	
Unmet respite care needs					<.001
Needs met	377	40	866	55	
Unmet needs	558	60	717	45	

*Note.* The *p*-value is reported from the chi-square or Fisher's exact test, as appropriate, to compare the results between Parents of Children with ASD and Parents of CSHCN without ASD. The total of percentages may not equal 100 because of rounding. \*Child Functional Status: "During the past 12 months, how often have [your child's condition] affected [his/her] ability to do things other children [his/her] age do?"

Table 7

*Factors Associated with Unmet Respite Care Needs in Parents of Children with ASD*

	Parents of Children with ASD	
	Unadjusted Odds Ratio (95% CI)	Adjusted Odds Ratio (95% CI)
Relationship to child		
Mother	<b>1.655 (1.137-2.407) †</b>	<b>1.732 (1.141-2.631) †</b>
Father	1 (reference)	1 (reference)
Highest level of parent education		
Less than high school	1 (reference)	1 (reference)
High school graduate	0.881 (0.397-1.954)	0.884 (0.332-2.351)
More than high school	<b>2.438 (1.213-4.900) †</b>	<b>1.819 (0.756-4.380) †</b>
Insurance status		
Public only	1 (reference)	1 (reference)
Private only	<b>2.103 (1.516-2.916) †</b>	<b>1.956 (1.314-2.910) †</b>
Both private and public	0.742 (0.536-1.026)	<b>0.592 (0.406-0.863) †</b>
Child functional status*		
Never	2.638 (0.656-10.598)	2.841 (0.608-13.285)
Sometimes	1 (reference)	1 (reference)
Usually	1.363 (0.870-2.134)	1.205 (0.714-2.032)
Always	<b>2.010 (1.398-2.891) †</b>	<b>1.893 (1.224-2.930) †</b>
Hours per week providing care		
< 1 hour per week	1 (reference)	1 (reference)
1 – 4 hours per week	1.277 (0.756-2.156)	1.675 (0.913-3.073)
5 – 10 hours per week	<b>2.226 (1.266-3.915) †</b>	<b>2.595 (1.340-5.024) †</b>
≥ 11 hours per week	1.497 (0.906-2.474)	1.843 (0.990-3.431)
Family financial burden		
No	1 (reference)	1 (reference)
Yes	<b>2.330 (1.780-3.049) †</b>	<b>1.975 (1.422-2.742) †</b>
Impact on family work life		
No	1 (reference)	1 (reference)
Yes	<b>1.730 (1.293-2.315) †</b>	1.187 (0.821-1.715)

*Note.* Acceptable multivariate model fit (Hosmer-Lemeshow  $\chi^2$  (8) = 6.207,  $p$  = .624). † $p$ <0.05

\*Child Functional Status: “During the past 12 months, how often have [your child’s condition] affected [his/her] ability to do things other children [his/her] age do?”

Table 8

*Factors Associated with Unmet Respite Care Needs in Parents of CSHCN without ASD*

	Parents of CSHCN without ASD	
	Unadjusted Odds Ratio (95% CI)	Adjusted Odds Ratio (95% CI)
Age groups		
0 – 5 years	1 (reference)	1 (reference)
6 – 11 years	<b>1.410 (1.048-1.896) †</b>	1.379 (0.999-1.903)
12 – 17 years	<b>1.607 (1.196-2.158) †</b>	<b>1.596 (1.157-2.202) †</b>
Highest level of parent education		
Less than high school	1 (reference)	1 (reference)
High school graduate	1.322 (0.811-2.155)	1.258 (0.734-2.156)
More than high school	<b>1.840 (1.195-2.833) †</b>	<b>1.686 (1.044-2.724) †</b>
Child functional status*		
Never	1 (reference)	1 (reference)
Sometimes	<b>2.026 (1.45-2.862) †</b>	<b>1.594 (1.094-2.323) †</b>
Usually	<b>3.295 (2.216-4.899) †</b>	<b>2.429 (1.576-3.745) †</b>
Always	<b>3.142 (2.227-4.433) †</b>	<b>2.078 (1.397-3.091) †</b>
Hours per week providing care		
< 1 hour per week	1 (reference)	1 (reference)
1 – 4 hours per week	<b>1.955 (1.434-2.665) †</b>	1.420 (1.021-1.974)
5 – 10 hours per week	<b>2.101 (1.453-3.037) †</b>	1.250 (0.835-1.872)
≥ 11 hours per week	<b>2.204 (1.605-3.027) †</b>	1.015 (0.697-1.479)
Condition stability		
Needs change all the time	<b>1.590 (1.182-2.139) †</b>	0.984 (0.703-1.377)
Needs change only once in awhile	<b>1.280 (1.030-1.591) †</b>	1.020 (0.803-1.295)
Needs are usually stable	1 (reference)	1 (reference)
Family financial burden		
No	1 (reference)	1 (reference)
Yes	<b>2.619 (2.127-3.226) †</b>	<b>2.119 (1.670-2.688) †</b>
Impact on family work life		
No	1 (reference)	1 (reference)
Yes	<b>2.090 (1.707-2.558) †</b>	<b>1.533 (1.204-1.953) †</b>

*Note.* Acceptable multivariate model fit (Hosmer-Lemeshow  $\chi^2$  (8) = 11.132,  $p = .194$ ). † $p < 0.05$

\*Child Functional Status: “During the past 12 months, how often have [your child’s condition] affected [his/her] ability to do things other children [his/her] age do?”

Table 9

*Factors Associated with Unmet Respite Care Needs in the Total Sample*

Context Factors	Total Sample	
	Unadjusted Odds Ratio (95% CI)	Adjusted Odds Ratio (95% CI)
Age groups		
0 – 5 years	1 (reference)	1 (reference)
6 – 11 years	<b>1.313 (1.037-1.664) †</b>	1.245 (0.941-1.646)
12 – 17 years	<b>1.459 (1.152-1.849) †</b>	<b>1.540 (1.164-2.038) †</b>
Relationship to child		
Mother	<b>1.373 (1.086-1.735) †</b>	<b>1.484 (1.143-1.926) †</b>
Father	1 (reference)	1 (reference)
Highest level of parent education		
Less than high school	1 (reference)	1 (reference)
High school graduate	1.187 (0.783-1.799)	1.052 (0.613-1.807)
More than high school	<b>2.143 (1.487-3.089) †</b>	<b>1.650 (1.013-2.687) †</b>
Insurance status		
Private only	<b>1.524 (1.267-1.833) †</b>	<b>1.382 (1.103-1.733) †</b>
Public only	1 (reference)	1 (reference)
Both private and public	0.918 (0.747-1.127)	<b>0.636 (0.498-0.812) †</b>
Child condition		
Child with ASD	<b>1.788 (1.517-2.106) †</b>	<b>1.271 (1.037-1.556) †</b>
CSHCN without ASD	1 (reference)	1 (reference)
Child functional status*		
Never	1 (reference)	1 (reference)
Sometimes	<b>1.920 (1.388-2.657) †</b>	1.405 (0.950-2.078)
Usually	<b>3.030 (2.135-4.300) †</b>	<b>2.010 (1.310-3.083) †</b>
Always	<b>3.623 (2.654-4.946) †</b>	<b>2.285 (1.529-3.416) †</b>
Hours per week providing care		
< 1 hour per week	1 (reference)	1 (reference)
1 – 4 hours per week	<b>1.826 (1.403-2.376) †</b>	<b>1.684 (1.229-2.308) †</b>
5 – 10 hours per week	<b>2.480 (1.838-3.347) †</b>	<b>1.765 (1.228-2.537) †</b>
≥ 11 hours per week	<b>2.208 (1.702-2.865) †</b>	1.372 (0.971-1.937)
Condition stability		
Needs change all the time	<b>1.544 (1.232-1.936) †</b>	1.015 (0.767-1.345)
Needs change only once in awhile	1.163 (0.978-1.382)	0.848 (0.689-1.044)
Needs are usually stable	1 (reference)	1 (reference)
Family financial burden		
No	1 (reference)	1 (reference)
Yes	<b>2.683 (2.281-3.155) †</b>	<b>2.054 (1.674-2.520) †</b>
Impact on family work life		
No	1 (reference)	1 (reference)
Yes	<b>2.150 (1.829-2.528) †</b>	<b>1.437 (1.160-1.781) †</b>

*Note.* Acceptable multivariate model fit (Hosmer-Lemeshow  $\chi^2$  (8) = 7.798,  $p$  = .453). † $p$  < 0.05

\*Child Functional Status: “During the past 12 months, how often have [your child’s condition] affected [his/her] ability to do things other children [his/her] age do?”

## CURRICULUM VITAE

Kim Whitmore

Place of birth: Marshfield, WI

### Education

Honors Bachelor of Science, Marquette University, May 2003  
Major: Exercise Science Minor: Psychology and Coaching

Master of Science in Nursing, Marquette University, May 2007

Dissertation Title: Factors Associated with Unmet Respite Care Needs in Families of Children with Autism Spectrum Disorder.

### Publications

Whitmore, K. (2016). Respite care and stress among caregivers of children with Autism Spectrum Disorder: An integrative review. *Journal of Pediatric Nursing*, 31(6), 630-652. doi:10.1016/j.pedn.2016.07.009

Whitmore, K. (2016). The concept of respite care. *Nursing Forum*. doi:10.1111/nuf.12179 [Epub ahead of print].

Hartlep, N.D., Ecker, M.M., Miller, D.D. & Whitmore, K.E. (2013). Asian Pacific American college freshman: Attitudes toward the abolishment of affirmative action in college admissions. *Critical Questions in Education*, 4, 1-20.

Whitmore, K. (2011). Asthma and poverty: Implications for school nurses. *Western Journal of Nursing Research*, 33, 1102. doi: 10.1177/0193945911413671 [abstract].

Whitmore, K. (2010). Respite care – A service learning experience. *Journal of Pediatric Nursing*, 25, e23 [abstract].

### Presentations

Simons, H., Whitmore, K. & Cruz, E. (2015, November). *Health Equity Check-In: A community-led evaluation strategy for promoting health equity*. Podium presentation at the American Public Health Association Annual Meeting, Chicago, IL.

Whitmore, K. & Snethen, J. (2014, March). *Parental perceptions of respite care services for families of children with special healthcare needs*. Poster presentation at the Midwest Nursing Research Society Regional Conference, St. Louis, MO.

Whitmore, K. & Snethen, J. (2013, June). *Parental perception of respite care services for families of children with special healthcare needs*. Paper presentation at the 11th International Family Nursing Conference, Minneapolis, MN.

Sawin, K., Ridosh, M. & Whitmore, K. (2013, June). *Divergent factors related to QOL in family members of young adults with spina bifida*. Paper presentation at the 11th International Family Nursing Conference, Minneapolis, MN [Presented by Ridosh, M].

Whitmore, K. & Sawin, K. (2013, March). *Factors related to health competence in young adults during transition to adulthood*. Poster presentation at the Midwest Nursing Research Society Regional Conference, Chicago, IL.

Sawin, K. J., Whitmore, K., Waring, W., Conner, R. C., Orr, M., Rauen, K., Bartelt, T. & Miranda, H. (2012, September). *The impact of mobility, self-efficacy, family factors, and perceived competence on self-management behaviors in young adults with spina bifida*. Paper presentation at the Council on the Advancement of Nursing Science State of the Science Conference, Washington, DC [Presented by Sawin, K.].

Sawin, K. J., Whitmore, K., Waring, W., Conner, R. C., Orr, M., Rauen, K., Bartelt, T. & Miranda, H. (2012, August). *Factors associated with self-management in transition-age young adults with a neurological condition*. Paper presentation at the Sigma Theta Tau International Research Congress, Brisbane, Australia [Presented by Sawin, K.].

Whitmore, K. & Sawin, K. (2012, May). *Transition to adult healthcare: Factors related to the perception of health competency in young adults with spina bifida*. Poster presentation at the Building Bridges Conference, Milwaukee, WI.

Whitmore, K. & Sawin, K. (2012, March). *Transition to adult healthcare: Factors related to the perception of health competency in young adults with spina bifida*. Paper presentation at the Second World Congress on Spina Bifida Research and Care, Las Vegas, NV.

Whitmore, K. & Snethen, J. (2012, February). *Through the eyes of parents: Respite care for children with special healthcare needs*. Podium presentation at the Interdisciplinary Pediatric Behavioral Health Research Conference, Milwaukee, WI.

Whitmore, K. & Snethen, J. (2011, November). *Through the eyes of parents: Respite care for children with special healthcare needs*. Poster presentation at the Pediatric Nursing Conference, Brookfield, WI.

Holmes, L., Whitmore, K. & Partain, M. (2011, July). *The health status and needs of Milwaukee's homeless*. Poster presentation at the Marquette University College of Nursing Conference, Milwaukee, WI.

Whitmore, K. (2011, May). *Understanding the respite care experience through the eyes of parents of children with special health care needs*. Podium presentation at the Building Bridges Conference, Milwaukee, WI.

Whitmore, K. (2011, May). *Barriers to asthma management among families living in poverty*. Poster presentation at the Building Bridges Conference, Milwaukee, WI.

Whitmore, K. (2011, April). *Understanding the respite care experience through the eyes of parents of children with special health care needs*. Podium presentation at the National Society of Pediatric Nurses Conference, Las Vegas, NV.

Whitmore, K. (2011, April). *The ABC's of respite care*. Invited keynote speaker at the Sigma Theta Tau International (STTI) Phi Beta Chapter Induction Ceremony, Mequon, WI.

Whitmore, K. (2011, March). *Asthma and poverty: Implications for school nurses*. Poster presentation at the Midwest Nursing Research Society Regional Conference, Columbus, OH.

Whitmore, K. (2011, February). *Respite care – A model interdisciplinary project to support families of children with special health care needs*. Poster presentation at the 4th Annual Interdisciplinary Pediatric Behavioral Health Research Conference, Wauwatosa, WI.

Whitmore, K. (2010, November). *Asthma and poverty – Implications for school nurses*. Poster presentation at the Pediatric Nursing Conference, Brookfield, WI.

Whitmore, K. (2010, October). *Respite care for caregivers of CYSHCN*. Invited guest lecturer for graduate nursing specialty course at UW-Milwaukee, Milwaukee, WI.

Whitmore, K. (2010, September). *Respite care – A service learning experience*. Poster presentation at the Sigma Theta Tau International Honor Society of Nursing Leadership Summit, Indianapolis, IN.

Whitmore, K. (2010, April). *Respite care – A service learning experience*. Poster session presented at the National Society of Pediatric Nurses Conference, Orlando, FL.

## Professional Memberships

- International Family Nursing Association
- Midwest Nursing Research Society
- National League for Nursing
- Sigma Theta Tau International
- American Public Health Association
- Wisconsin Public Health Association
- Society of Pediatric Nurses
- National League for Nursing
- American Nurses Association
- Institute of Medicine of Chicago
- Health & Medicine Policy Research Group

## Teaching Experience

### Loyola University Chicago, Marcella Niehoff School of Nursing

#### a. Courses Taught

- CMAN 417 *Advanced Practicum: Health System Management* (Summer 2016, Fall 2016, Spring 2017)
- CMAN 434 *Health Program Planning and Evaluation* Online (Spring 2016, Spring 2017)
- CMAN 435 *Health Policy and Healthcare Delivery* Online (Fall 2015, Fall 2016)
- CMAN 533 *Fiscal Management in Healthcare Organizations* Online (Spring 2017)
- CMAN 468 *Advanced Concepts in Health Systems Management* Online (Fall 2016)
- CMAN 375 *Community Health Nursing* Online (Fall 2013, Summer 2014, Fall 2014, Spring 2015, Summer 2015)
- CMAN 375L *Community Health Nursing Clinical* Online (Fall 2013, Fall 2014, Spring 2015)
- GNUR 207 *Individual, Family, Community, and Health* Online (Fall 2013, Spring 2014, Summer 2015)

#### b. Non-Classroom Teaching

- Program Director for the Graduate Health Systems Management Program (2016 to present)
- Co-advisor for Graduate Nursing Student Association (GNSA) (2016-present)

### Marquette University College of Nursing

#### a. Courses Taught

- NURS 179 *Nursing of Communities Practicum* (Summer 2009, 2010, 2011, 2013)
- NURS 172 *Family Centered Care of Children Practicum* (Summer 2008)
- Worked with Dr. Maureen O'Brien, Pediatric Options Coordinator, to develop a respite experience and associated coursework for undergraduate nursing students (2006-2008)
- Graduate Course Seminar: *Entrepreneurship in Nursing Practice* (March 2007)
- Nursing Faculty Seminar: *Using Endnote for Nursing Research* (February 2005)

University of Wisconsin – Milwaukee College of Nursing

a. Courses Taught

- NURS 440 *Nursing Specialty Elective: Children and Youth with Special Healthcare Needs* (Spring 2008)
- NURS 331 *Foundations of Clinical Practice I* (Spring 2008-Spring 2009)

Concordia University Wisconsin Department of Nursing

a. Courses Taught

- NURS 320 *Pediatric Nursing* (Spring 2010-Spring 2012)
- NURS 321 *Pediatric Nursing Practicum* (Spring 2008-Spring 2012)
- NURS 340 *Community Wellness* (Fall 2008-Spring 2012)
- NURS 341 *Community Wellness Practicum* (Fall 2008- Spring 2011)
- NURS 452 *Global Education - Belize* (Fall 2008-Spring 2012)
- EDU 178 *Health Education in the Classroom* (Spring 2010 – Spring 2011) – Co-taught

Awards/Honors

- Nominated for Fellowship in the Institute of Medicine of Chicago (IOMC) (2016)
- University of Wisconsin-Milwaukee Graduate Student Excellence Fellowship Award (2016-2017)
- Nominated by the University of Wisconsin-Milwaukee College of Nursing for the Distinguished Graduate Student Fellowship (2016)
- Fellow in the University of Illinois at Chicago, School of Public Health MidAmerica Regional Public Health Leadership Institute (MARPHLI) (2013-2014)
- Fellow in the National Association of City and County Health Officials (NACCHO) Survive and Thrive Program for New Health Officials (2012-2013)
- Nominated for the American Association of Colleges of Nursing (AACN) Novice Faculty Excellence in Clinical Teaching Award (2011, 2012)
- Midwest Nursing Research Society (MNRS) Doctoral Student Poster Award (2011)
- Ranked in the “Top 25 Most Effective Teachers” at Concordia University Wisconsin based on student course evaluations (2010)
- Nominated for the National League for Nursing Johnson and Johnson Faculty Leadership and Mentoring program (2010)
- Milwaukee District Nurses’ Association (MDNA) Student Scholarship Recipient (2010)
- UW-Milwaukee Chancellor’s Award (2009-2011)
- June Price Spirit Award (2009)
- Sigma Theta Tau International Graduate Student of the Year Award (2007)
- Aurora Star Recipient for Excellent Patient Care (2006)
- Graduated Cum Laude from Marquette University (2003)
- Marquette University Honors Program (1999-2003)
- Marquette University Ignatius Scholarship for Academic Excellence (1999-2003)

## University Service

- Loyola University Chicago Undergraduate Health Systems Management Committee Member (2016 – Present)
- Loyola University Chicago Marcella Niehoff School of Nursing Masters and DNP Committee (MDC) Member (2015 – Present)
- UW-Milwaukee Doctoral Nursing Student Organization (DNSO) Member (2009-Present); Secretary/Treasurer (2010-2011); President (2011-2012)
- Concordia University Wisconsin Student Nurse Association (SNA) Advisor (2010-2012)
- Concordia University Wisconsin Institutional Review Board (IRB) Member (2010-2012)
- Elected doctoral student representative for UW-Milwaukee's Graduate Program Committee (GPC) (2009-2011)
- Elected student representative for Marquette University's Graduate Program & Curriculum Committee (GPCC) (2004-2005)