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SELF-CARE STRATEGIES AMONG PARENTS WITH A CHILD DIAGNOSED WITH AUTISM SPECTRUM DISORDER

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SELF-CARE STRATEGIES AMONG PARENTS WITH A CHILD
DIAGNOSED WITH AUTISM SPECTRUM DISORDER

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
Shawn Michelle Gorsky

June 2014

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ABSTRACT

The purpose of this study was to explore self-care strategies among parents with a child diagnosed with autism spectrum disorder. The study used a survey design to detect the extent to which respondents used self-care strategies to alleviate high stress levels associated with caring for an ASD child. The study was comprised of twenty eight respondents. The study found that the higher the level of education completed by the parent the greater the likelihood that self-care strategies were utilized. The study also found that the age of the ASD child was a factor in the level of physical self-care being incorporated among parents. Psychological self-care was also found to affect other categories of self-care. Both females and males listed lack of time as the greatest obstacle in implementing self-care. The study recommends that viewing self-care as important and finding small ways to incorporate self-care strategies might well improve other areas of parent well-being.

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I cannot convey enough the appreciation I have for those that have supported me throughout this journey. Without an amazing support system, I would not be where I am now. I am so thankful to my husband, Aaron, who's support and encouragement have kept me moving forward for the past 2 years. His sacrifices and thankless hours of handling all of the things I couldn't manage were never unnoticed. I wouldn't be here without him. I am forever grateful for his love and sweet gestures to motivate me. I am also grateful for my son, Landon, who sacrificed valuable time with me. Though I wasn't always able to be there physically for sports, field trips, and activities, I was always there in spirit. His acceptance and understanding has shown me time and again that he is maturing well beyond his years. I am thankful to Dr. Davis, my thesis advisor, for keeping my anxiety at a tolerable level and for encouraging me despite the hurdles I faced. His immeasurable enthusiasm for my project pushed me that much further to accomplishing my goal. I would also like to acknowledge all of the parents in the UCDD program that participated in this study. Without you this project would not have happened. Lastly, I am grateful to my family and friends, you have been crucial in my success and I'm grateful for each and every one of you. Your thoughts, prayers, and encouragement have provided me with the strength to see past my insecurities. I am blessed beyond words.

DEDICATION

This project is dedicated to God, above all. Without him, I would not have had the strength, courage, and determination to do this. I have no doubt that through him I'll always be exactly where I'm meant to be. I also want to dedicate this project to all of the families affected by Autism Spectrum Disorder. Your strength, sacrifices, and resilience never cease to amaze and inspire me.

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CHAPTER ONE

INTRODUCTION

Chapter one addresses the purpose of the study, which is to explore self-care strategies among parents with a child diagnosed with autism spectrum disorder. This is to gain insight into what self-care needs parents are fulfilling and some which might currently not be in place that could benefit these parents. Also discussed in this chapter is the potential benefit of the project for social work practice.

Problem Statement

According to the Center for Disease Control and Prevention, one out of every eighty-eight American children currently has a diagnosis of autism spectrum disorder (cdc.gov). According to Kaiser Permanente, the reported prevalence of autism spectrum disorders (ASD) has increased dramatically over the last three decades, from an estimate of 0.0004% in the 1980's to nearly 1% today, making autism the second most common developmental disability in the United States, behind mental retardation (http://www.dor.kaiser.org/external/dorexternal/autism/research_projects/index.aspx). Autism is recognized as social and language impairment, typically diagnosed between the ages of eighteen months and three years. Autism spectrum disorders are characterized by moderate to severe impairments in social interactions,

language and cognitive development, and include repetitive behaviors, restricted interests, and emotional distress from environmental changes (American Psychiatric Association [APA], 2000). The child can also exhibit behavioral problems that are difficult to manage and experience social deficits that become increasingly problematic as the child enters the social world (Singh, 1997). These characteristics have been associated with elevated levels of stress among the parents of children with autism (Dyson, 1997).

According to Sharpley et al. (1997), the most significant sources of stress experienced by parents of these children are: (1) permanency of the condition; (2) disapproval for the child's behavior demonstrated by the society and family members; and (3) insufficient professional support. Prior studies have been conducted regarding the experience of parenting a child with ASD and additional stress levels it creates, as opposed to parenting a non-ASD child. However, there have been few studies done regarding the self-care of parents of ASD children and the impact on stress levels that self-care may have.

Purpose of the Study

The purpose of the present study is to examine the self-care being utilized by parents in an attempt to lower the stress associated with having an autistic child. This is being examined in order to understand what tools are effective and currently being utilized, to potentially be recommended to future social service clients. Also, it is important to gain insight into the overall needs

of the families, specifically self-care. There is a lack of research in this area while the diagnosis of ASD continues to increase. Understanding the needs of these families will allow for interventions early on following diagnosis, when stress levels may be at their peak. Specifically, this study addressed the following research questions:

- 1) What areas of self-care are parents applying?
- 2) Is there a relationship between age of the ASD child and use of self-care?

It is hypothesized that parents of children with autism would apply minimal self-care, due to time constraints and fatigue due to stress. It is also hypothesized that as children age, parents will practice more self-care strategies. This might be explained by the reason that older children, with or without special needs, require less attention than younger and more dependent children.

A quantitative survey was administered in order to target specific self-care items being utilized by parents of an ASD child. Through the use of a survey, parents were able to clearly identify which areas of care are currently being implemented. In addition to this, each parent was provided potentially new ideas for care as a result of reading the survey. Exposure to opportunities for coping strategies and a clear list of possibilities that may have been already implemented, but not considered as self-care by the parent previously, would allow for encouragement and adaption of new interventions.

This approach ensures that participants are given the opportunity to identify currently utilized means of care that may have not been identified or recalled during an interview. Daily rituals consistent with coping may not have been considered if not offered as a survey question. This is important due to it allowing the researcher to explore various areas of personal care, rather than focusing on a few items at deeper length than necessary for the purpose of this study.

Finally, there is a need to understand what forms of care are not being identified, along with areas of deficiencies that could be integrated into social work services with the parents of a child with ASD. Peer group sessions, psycho-educational group topics, and individual therapy sessions could potentially introduce parents to stress reducing behaviors and interventions.

Significance of the Project for Social Work

As the number of diagnoses of ASD continues to rise every year, it is important to identify how to assist parents with reducing their stress levels. An ASD diagnosis can be not only an emotional, psychological, and spiritual burden, but a financial one as well. By encouraging the implementation of tools and interventions that are readily available and economical, needs and well-being of parents can be met through research-supported information. Clinicians will be better prepared to assist the parents of ASD children.

Following an assessment determining stress levels of these parents, recommendations for self-care interventions can be introduced. Self-care

goals can be measured and recorded to allow for self-reflection at a later time. Clinicians providing support groups and individual therapy sessions can incorporate this research into their theoretical approach to assist clients in lowering their stress levels. Therefore, it is important to gain insight into the self-care of parents of a child diagnosed with autism spectrum disorder.

Definition of Terms

Parents of Children with Autism: A person who has at least one child with a diagnosis of autism spectrum disorder and the child lives in the home.

Autism: The presence of a diagnosis made by a medical professional, with the child meeting the criteria based on the *Diagnostic and Statistical Manual of Mental Disorders* (American Psychiatric Association, 2000).

Self-Care: Pertains to the decisions and actions that a person takes to enhance health, prevent disease, limit illness, and restore health.

CHAPTER TWO

LITERATURE REVIEW

Introduction

This chapter will provide an overview of research on families with autistic spectrum disorder children. The effects on parents and siblings, specifically the stressors and coping strategies, will be discussed. The research of self-care as a whole is explored, as there is currently very little research specific to parents of ASD children. The purpose of this section is to gain insight from the literature and explore the numerous stressors families face when a child is diagnosed with ASD.

Background

In 1943, Leo Kanner coined the term “autism” to describe a group of children who displayed similar behavioral characteristics related to difficulties with social communication and social interaction (Kanner, 1943). Early theory-driven (rather than data-based) psychoanalytic treatments for these children were developed based on a parental causation theory (Koegel, Koegel, & Brookman, 2003, p. 341). Children were removed from their homes and sent to live permanently in institutions. Not only were parents told that they were the cause of the child’s disorder, but that it would be best if they had no involvement with the child in the future. The accepted belief among the medical community was that autistic children were actually schizophrenic

(Kanner, 1943). However, data failed to support this etiological perspective. In fact, systematic studies have demonstrated that parents of children with autism do not differ from those who have children without psychiatric disorders (Koegel et al., 2003, p. 342). Because of the little success in improving the condition of autism with non-data-based, theory-driven interventions, beginning in the early 1960's researchers began to focus on behavioral intervention techniques that were empirically supported (Lovaas, Koegel, Simmons, & Long, 1973).

There are currently three criteria for a diagnosis of autism spectrum disorder, according to the *Diagnostic and Statistical Manual of Mental Disorders* (APA, 2000, p. 75). The first is qualitative impairment in social interaction, including an inability to use nonverbal behaviors to guide interactions, impairment in the use of eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction. This also includes a failure to develop peer relationships, a lack of social and emotional reciprocity, and lack of seeking to share interests. The second criteria include communication impairments, manifested as the lack of spoken language, inability to initiate conversation, and repetitive use of words. The third criteria include the display of repetitive and stereotyped patterns of behavior, interests, and activities. These can include a preoccupation with parts of objects (APA, 2000).

Theory Guiding Conceptualization

The guiding theory in working with families with an autistic child is family systems theory. Bowen's family systems theory is a theory of human behavior that views the family as an emotional unit and uses systems thinking to describe the complex interactions in the unit (www.thebowencenter.org).

According to this theory, behavior symptoms are tied to the entire family system and a shift in one part of the family unit affects the other parts of the family unit (O'Gorman, 2012). Within the family system, each member takes on a role that guides the unit as a whole. As stressors intercept the unit, family members may begin to see their role change and create an imbalance that other members must adjust to and rebalance the unit. As one member of the family begins to drain the emotional levels of other family members, they may begin to pull away, isolating the child, creating disequilibrium among the unit. But because the family is an emotional unit, it is interconnected and interdependent and will utilize other outside systems in which they are a part of, in order to maintain the balance necessary to achieve equilibrium.

The various dynamics within the family to consider include the family as a whole, parents, ASD siblings, and non-ASD siblings. Parental anxiety and stress, financial burden, isolation among non-ASD children, and impairment of the child are all factors within the study. Families with a child diagnosed as having ASD are exposed to stressors from internal sources within the family

and from external sources when advocating for health and social services and educational services for the child (Twyo, Connolly, & Novak, 2007, p. 252).

Utilizing an eco-map, a diagram depicting the systems the family unit is a part of, parents can identify sources of support to potentially offset the strain resulting from constant care of an ASD child. The eco-map is a popular tool meshed within family systems theory. Visually presenting the available systems of support to parents who are overwhelmed and possibly functioning as a closed system might allow for reconnections and an expansion of their system to alleviate some of their burden.

Parental Issues

In a 2010 study by Dabrowska and Pisula, parenting stress of pre-school aged children with autism, Down syndrome, and typically developing children was examined. One hundred and sixty-two parents were given Hoyroyd's Questionnaire of Resources and Stress for Families with Chronically Ill or Handicapped Members and Endler and Parker's Coping Inventory for Stressful Situations. Their findings included higher stress levels for parents of autistic children, especially among mothers. This was not found in either of the other two categories of parents (Dabrowska & Pisula, 2010).

In prior studies, it was found that mothers experienced higher stress levels associated with their child's low degree of self-sufficiency, behavioral problems and physical development than did fathers (Moes, Koegel, Schreibman, & Loos, 1992). Fathers were found to have greater stress in

relation to their child's communication problems and in some studies, reported higher levels of stress from the child's behavior (Dabrowska & Pisula, 2010, p. 267).

While there appears to be a lack of consistent reporting in prior studies, they all carry the main theme that parenting a child with ASD is extremely stressful. Marital quality has varied in previous studies. Hartley *et al.* (2010) found a rate of divorce among parents of children with an autism spectrum disorder that was nearly twice that of control parents (Norlin & Broberg, 2013, p. 553).

However, Baker *et al.* (2005) found that parents of children with an intellectual disability and control parents showed no difference in marital adjustment (Norlin & Broberg, 2013, p. 553). What remains to be evident is how individual well-being of each parent carries over into marital quality and adjustment.

Sibling Issues

Many of the children with ASD have siblings. While there are many programs and interventions for children with autism and their parents, there is minimal research on the effects on siblings of autistic children. Of the 839 studies reported within the past four years in the *Journal of Autism and Developmental Disorders*, only four were devoted to siblings, and their primary focus was on genetic risk rather than life experience (Cain, 2012).

Previous research conducted has shown a gap in information regarding the effects of ASD on siblings. Studies such as *Emotional and behavioral adjustment in typically developing siblings of children with Autism Spectrum Disorder* found few effects in children over the age of four, both as reported by parents and teachers (Dempsey, 2011, p. 106). This study failed to assess for current interventions being utilized by siblings that could skew the results.

Other elements that limited the study were the lack of demographic information on participation, the voluntary participation of parents that could misrepresent the actual ability to generalize about the population, and that the study did not have a control sample of children without siblings with ASD.

Another study explored the effects of Applied Behavior Analysis (ABA) among families with ASD children with siblings. This study found that ABA did not have either a positive or detrimental effect on siblings during and following treatment (Cebula, 2011, p. 847). However, this study was conducted with siblings that were teenagers at the time of the study. Teenagers are typically not home and engaged with the family unit, specifically with the ASD sibling, therefore the views and responses may not have been accurate in describing the experience of younger siblings.

Self-Care

The stress on families with an ASD child is quite considerable. It is essential for caregivers to find appropriate and valuable self-care interventions to alleviate its effects on the family system and increase its resiliency.

According to Merluzzi et al., self-care practices can include maintaining one's health and well-being, actively seeking support, and maintaining some activity apart from the caregiving situation (Merluzzi, Philip, Vachon, & Heitzmann, 2011, p. 22). In a 2002 study completed on coping strategies by families with and without children with ASD, parents with ASD children scored higher on the strategies of distancing and escape (Sivberg, 2002, p. 406). It is important to note that while both of these behaviors can be viewed as self-care, for example, taking time alone or spending time as a couple away from the children, they can lead to negative behaviors such as avoiding the ASD child or not addressing the needs of the child.

A 2006 study on coping of parents of an ASD child found that using social support within the family's social network, including close friends and the extended family ranked high among parents (Troy et al., 2007). Found to be highly useful among parents was seeking out other parents of ASD kids. Ninety-three percent of the parents surveyed stated that they sought the advice of other families in similar circumstances (Troy et al., 2007, p. 258).

A recent study on maternal fatigue and maladaptive coping of mothers of ASD preschoolers examined the effects of stress on mothers. The study found that fatigue, rather than maladaptive coping, was found to be an important construct in understanding the pathways between child behavior difficulties and maternal stress (Seymour, Wood, Giallo, & Jellett, 2013, p. 1553). However, limitations of this study included a very small sample size,

the majority of the women were married and were employed. These factors would all have a great influence on results.

Summary

This chapter included a review of the literature on families with autistic spectrum disorder children. The effects on parents and siblings, specifically the stressors and coping strategies, were discussed. The research of self-care as a whole was explored. The purpose of this section was to gain insight from the literature and explore the numerous effects families face when a child is diagnosed with ASD.

CHAPTER THREE

METHODS

Introduction

Chapter three will review the purpose of this study, which is self-care strategies among parents with a child diagnosed with autism spectrum disorder. It will provide information on the participants and the selection process, and include a review of the methodology for gathering and recording data. Also discussed in this section is the instrument utilized.

Study Design

The purpose of this study was to explore self-care strategies among parents with a child diagnosed with autism spectrum disorder. The object was for the respondents to tell the researcher, through a survey, whether they are utilizing any means of self-care to alleviate the high stress levels associated with caring for an ASD child.

A survey was chosen for this study due to its ability to scale each parent's usage of interventions. It was also chosen as a means of presenting additional sources of interventions, to potentially increase self-care use among parents through exposure to the survey items. Additionally, children participating in the service center where the survey was administered are typically brought in by only one parent. As a way of capturing both parents' responses, a survey was deemed the more appropriate instrument, as one

parent can provide the survey to the other parent to complete and mail in to the UCDD center.

The limitations of this method are that because the parents are scaling their usage of interventions, they may over report or under report certain behaviors. Another limitation of this method is that parents were not able to explain their answers or expand upon responses they wished to clarify.

Sampling

The type of sampling used for this study was purposive. This study is interested in the experiences and behaviors of those individuals who have children diagnosed with ASD. Participants were located through the University Center for Developmental Disabilities, located on the campus of California State University, San Bernardino. Attempts were made by the researcher to include both mothers and fathers, to include various ethnicities, and to include various socioeconomic status.

Data Collection and Instruments

Data was collected using the quantitative method of surveys with participants. The researcher utilized a modified version of the survey *Transforming the Pain: A Workbook on Vicarious Traumatization*, by Saakvitne, Pearlman and Staff of TSI/CAAP (Norton, 1996), which is included as Appendix A. Demographic information was collected within this survey, including the age the child was diagnosed with autism spectrum disorder,

gender of the child, the child's current age, if there are other children in the home and their ages, the parent's relationship status, the parent's age and gender, and the parent's highest level of education. Scaling questions from the following five categories were provided: physical, psychological, emotional, spiritual, and the workplace. Also included in the survey was an open-ended question, allowing the participants to describe any obstacles that they face in implementing self-care. The independent variables of this study are the ages and gender of the participants, and the dependent variable is the self-care strategies used by the parents.

Procedures

The researcher visited the UCDD center to administer the surveys four separate times. Surveys were administered by the researcher to 33 parents who have a child enrolled in the UCDD program, which provides classes and services to families with ASD children. Participants in the study were given the researcher's credentials, the purpose of the study was explained, and then they were asked if they would be willing to participate. Parents had the option to complete and return the survey while at the UCDD center, or to mail them in to the center at their earliest convenience.

Many children are brought to the center by one parent only. To include parents not visiting the center, surveys were available be sent home with visiting parents in a self-addressed, stamped envelope to be completed,

sealed, and mailed back to the UCDD center. The researcher was prepared to revisit the center to collect any mailed surveys if necessary.

Protection of Human Subjects

The purpose of the study was explained to the subjects and they were asked to sign an Informed Consent Form, a copy is included as Appendix B. Surveys were anonymous. All survey forms collected were stored in a locked box in the researcher's home. Once the study is concluded, the surveys will be destroyed. All participants were asked if they had any questions or concerns upon completion of the survey form.

Data Analysis

The researcher entered all quantitative data from surveys collected into the SPSS system for analyzing. Descriptive statistics were used to summarize all demographic data collected. Relationships among self-care strategies were examined in correlation to the age of the ASD child and self-care being practiced among parents. A frequency distribution presented the univariate data analysis.

Summary

Chapter three addressed the purpose of this study in exploring the self-care being implemented by parents of children with autism spectrum disorder, provided information on the participants and the selection process,

and included a review of the methodology for gathering and recording data.

Also discussed in this section was the instrument utilized.

CHAPTER FOUR

RESULTS

Introduction

Chapter four will review the results of this study, which is to examine self-care strategies among parents with a child diagnosed with autism spectrum disorder. This was an exploratory study, which sought to find if there was any relationship between the self-care of parents and the age of the ASD child, and the levels of self-care being utilized by parents. Univariate data analysis was completed in order to obtain the study's results.

Presentation of the Findings

A total number of 33 participants attempted to complete the survey, but 5 participants were excluded from the study due to either not completing the survey in its entirety or incorrectly completing the survey. Excluding these participants from analyses resulted in 28 parents who completed the survey. Of the participants demographic information collected, 67.9% of females and 32.1% of males completed the survey. This will be demonstrated in Table 1.

Table 1. Gender Frequency Count and Percentages

	Gender of Parents	
	N	Percent
Female	19	67.9
Male	9	32.1
Total	28	100.0

Of the participants surveyed, the minimum age of parents was 23 years old. The maximum age of parents was 44 years old. This resulted in a mean age of $M = 35.9286$. The standard deviation for this was 5.03270. This will be demonstrated in Table 2.

Table 2. Age Range of Parents

Parents Age Range	
Minimum	23
Maximum	44
Mean	35.93
SD	5.03

Frequencies were run on the highest level of education completed by parents surveyed. The majority of parents completed at least some college ($N = 8$). Of the respondents, 21.4% completed Graduate Degrees, 14.3% completed Undergraduate Degrees, 7.1% completed an Associates Degree, 3.6% completed a Certificate/Credential Program, 28.6% completed some

college courses, 21.4% completed high school, and 3.6% did not complete high school. This is demonstrated in Table 3 below.

Table 3. Education Frequencies and Percentages

Highest Level of Education Completed		
	N	Percent
Graduate Degree	6	21.4
Undergraduate Degree	4	14.3
Associates Degree	2	7.1
Certificate/Credential	1	3.6
Some College	8	28.6
High School Diploma	6	21.4
Did not complete High School	1	3.6
Total	28	100.0

Frequencies were also run on the participants' relationship status (N = 23). Of the respondents, 82.1% stated that they were married, 7.1% were single, 3.6% were separated, and 7.1% reported being partnered. This is demonstrated in Table 4 below.

Table 4. Relationship Frequencies and Percentages

Relationship Status		
	N	Percent
Married	23	82.1
Single	2	7.1
Separated	1	3.6
Partnered	2	7.1
Total	28	100.0

An Anova test was run to examine the levels of education among parents and the categories of self-care; which were physical self-care, psychological self-care, emotional self-care, spiritual self-care, and workplace self-care (n = 26). There was a significant correlation between the level of education and amount of self-care being implemented. The higher the level of education among parents, the more self-care being utilized. This is demonstrated in Table 5 below.

Table 5. Self-Care among Education Levels

ANOVA Test between Level of Education and Self-Care						
		Sum of Squares	df	Mean Square	F	Sig.
Physical Self-Care	Between Groups	488.470	6	81.412	2.095	.097
	Within Groups	816.208	21	38.867		
	Total	1304.679	27			
Psychological Self-Care	Between Groups	228.256	6	38.043	2.573	.050
	Within Groups	310.458	21	14.784		
	Total	538.714	27			
Emotional Self-Care	Between Groups	157.595	6	26.266	4.711	.003
	Within Groups	117.083	21	5.575		
	Total	274.679	27			
Spiritual Self-Care	Between Groups	430.565	6	71.761	1.795	.149
	Within Groups	839.542	21	39.978		
	Total	1270.107	27			
Workplace Self-Care	Between Groups	99.798	6	16.633	.863	.538
	Within Groups	404.917	21	19.282		
	Total	504.714	27			

An Independent Sample T Test was run to examine the correlation between the current age of the ASD child and level of self-care among parents. A significant correlation was found between the ASD child's current

age and the amount of physical self-care being utilized by parents. It was found that the older the ASD child, the more physical self-care being conducted by parents. There was also a significant finding in the correlation between psychological self-care and all other categories of self-care. The more psychological self-care being implemented, the more of the other categories of self-care were also being implemented. This is demonstrated in Table 6 below.

Table 6. Correlations with Autism Spectrum Disorders Child's Age/Categories

		Correlation with Child's Age and Categories					
		Child's Current Age	Physical Self- Care	Psych Self-Care	Emotional Self- Care	Spiritual Self- Care	Workplace Self-Care
Child's Current Age	Pearson Correlation	1	.399	.195	.107	.156	.239
	Sig. (2-tailed)		.035	.321	.587	.428	.220
	N	28	28	28	28	28	28
Physical Self- Care	Pearson Correlation		1				
	Sig. (2-tailed)	.035		.000	.000	.001	.007
	N	28	28	28	28	28	28
Psych Self- Care	Pearson Correlation	.195		1			
	Sig. (2-tailed)	.321	.000		.000	.000	.022
	N	28	28	28	28	28	28
Emotional Self- Care	Pearson Correlation	.107			1		.284
	Sig. (2-tailed)	.587	.000	.000		.000	.143
	N	28	28	28	28	28	28
Spiritual Self- Care	Pearson Correlation	.156				1	.333
	Sig. (2-tailed)	.428	.001	.000	.000		.083
	N	28	28	28	28	28	28
Workplace Self- Care	Pearson Correlation	.239			.284	.333	1
	Sig. (2-tailed)	.220	.007	.022	.143	.083	
	N	28	28	28	28	28	28

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

A frequency test was run to examine the obstacles that females and males face in implementing self-care (N = 10). Both females and males listed

lack of time as their largest obstacle (60.7%). Of the respondents, 50% of females surveyed did not respond to the question. Of the respondents, 75% of the males surveyed did not respond to the question. This is demonstrated in Table 7 below.

Table 7. Largest Obstacle to Self-Care

Obstacles to Self-Care				
	Frequency	Percent	Valid Percent	Cumulative Percent
Lack of Time	17	60.7	60.7	60.7
Money	3	10.7	10.7	71.4
Willing babysitters	1	3.6	3.6	75.0
Health reasons	1	3.6	3.6	78.6
Lack of close friends	1	3.6	3.6	82.2
Not enough sleep	3	10.7	10.7	92.9
Imbalanced schedule	1	3.6	3.6	96.4
Work stress	1	3.6	3.6	100
Total	28	100	100	

Summary

Univariate analysis was conducted in order to obtain statistical results. Frequency distribution, Anova testing, and an Independent Sample T Test were run to examine the correlations between variables. Data analysis results indicated strong correlations between the current age of the ASD child and level of physical self-care implemented, implementation of psychological

self-care and the increase of other categories of self-care, and the higher the education level of the parent, the more self-care being implemented. Lack of time was the greatest obstacle to self-care among both female and male respondents.

CHAPTER FIVE

DISCUSSION

Introduction

Chapter five will discuss the significant findings and implications of this study, which is to examine the self-care strategies of parents with a child diagnosed with Autism Spectrum Disorder. The limitations of the study will be discussed. Future recommendations for social work practice, policy and research will also be examined.

Discussion

This study explored the self-care strategies among parents with a child diagnosed with Autism Spectrum Disorder. Connections between the age of the ASD child and amount of self-care were examined. Also, various categories of self-care were evaluated to identify which categories were being utilized as opposed to others, or in conjunction with others.

Through this study it was found that higher levels of education completed by the parent resulted in more self-care being incorporated. A possible meaning for this could be parents with higher education having greater insight into caring for their own needs while managing school, work, and family life. Self-care is stressed among numerous college disciplines and may have already been implemented prior to having an ASD child. For psychology students in particular, APA ethics state that self-care is an

important piece of professional education. According to Barnett, Johnston, and Hillard (2006),

Self-care is not an indulgence. It is an essential component of prevention of distress, burnout, and impairment. It should not be considered as something 'extra' or 'nice to do if you have the time' but as an essential part of our professional identities. (p. 263)

Colleges frequently offer workshops, events, and clubs promoting exercise, healthy relationships, eating well, proper sleep habits, and better time management. Flyers can be seen throughout buildings promoting overall wellness among students. Counseling services are promoted, including group therapy to encourage self-care during stressful times.

Another possible meaning could be due to parents with higher levels of education generally being older and more financially stable. Not having the stressors of possibly working multiple jobs, low paying wages, and not being able to afford services for their child might allow for more time to incorporate self-care. A study conducted in 1998 by Patricia Katz on people with arthritis found that persons with over thirteen years of education were significantly more likely to perform specific self-care activities, use relaxation methods, and use stress control methods (Katz, 1998, p. 1057).

Both females and males listed lack of time as the greatest obstacle in implementing self-care. Caring for an ASD child is a full-time, demanding job that leaves little time for attention to themselves. The routines and rigid structure

that many ASD children require can make it difficult to incorporate time away. According to a study by Tway and Connelly, families with children with ASD had restricted level of contacts with the community because family, friends, teachers, and the community did not understand the behavioral characteristics of children with ASD (Tway et al., 2007, p. 253). These children demand full attention and stealing a few moments to read a book or meditate may not always be an option. Trying to write in a journal or watch a favorite movie at the end of the day might seem like more work than its work after struggling all day with a child to accomplish daily tasks. In a 2009 study on mothers with an ASD child, it was found that mothers reported stress related to not having time for their own activities and needs and difficulty in giving themselves permission for such needs (Phetrasuwan & Miles, 2009, p. 162).

The age of the ASD child was a factor in the level of physical self-care being incorporated. This might be due to young children needing constant monitoring and parents not being able to take time to do physical self-care tasks alone. Many physical self-care items require time away from the child, which might not be possible when the child is young and babysitters are hard to find. Two of the survey respondents stated that they had no one that was able to care for their autistic children. Finding willing people who are able to understand the routines, behaviors and requirements of caring for an ASD child is difficult. While they might initially want to offer a helping hand, the fear of the unknown and the challenging reality of it might cause them to refrain.

But as ASD children age, they might be in school during the day or able to manage independently for longer periods of time, allowing the parents some independent time.

This would be important to consider when working with parents. As they struggle to incorporate self-care into their daily life, it might be important to focus on other areas of self-care rather than physical until the child is older. Starting with tools such as journaling, meditating, or reaching out to friends for support might be easier to manage than exercise or day trips away from the child. Another option might be to help parents find creative ways to incorporate their children into physical activities, allowing the child to be near but still allowing the parent to nurture their own needs.

Psychological self-care was found to affect other categories of self-care. This might be explained by the initial attitude towards self-care. Viewing self-care as important and finding small ways to incorporate time for self could cause other areas to increase as well. Psychological self-care might lead to encouragement, insight and beliefs that overall mental health is important.

If parents view taking time for themselves as unimportant, they are not likely to make any effort to incorporate it. As one survey respondent stated, their biggest obstacle to implementing self-care was “My busy schedule, not a lot of time to be selfish”. If the mental attitude towards self-care is that it is selfish to care for one’s self, none of the categories of self-care are going to be

implemented. Encouraging parents to see their own health as valuable is a step in changing their attitude about how they perceive self-care.

When working with parents, a possible implication of this study might therefore be the importance of focusing initially on psychological self-care. Encouraging daily practices of journaling or saying no to extra responsibilities sometimes might begin the process of incorporating self-care, leading to all categories of self-care being utilized eventually.

Limitations

A significant limitation to this study was the small sample size. The parent groups surveyed were comprised of multiple diagnoses, not just autism spectrum disorder. Had the study examined all special needs, this would have allowed for a larger population to be surveyed and all parents attending UCDD to be included. Self-care is important for parents of all special needs children, and would be a valuable study to conduct.

While the diagnosis of autism spectrum disorder has been noted to be more challenging for many parents, special needs children of many diagnoses are very time demanding and parents would benefit from education and encouragement in ways to incorporate self-care into their daily lives. Little research was found on parental self-care of any special needs circumstances. Though the diagnoses may differ in how their child is unique, parents are experiencing many of the same struggles and obstacles.

Through surveying all the parents in UCDD parent groups, it could have allowed for comparing self-care among various diagnoses. This would be helpful information in order to examine why parents are completing some self-care categories, but not others. Correlations between diagnoses and self-care categories could open doors to further research regarding factors that influence self-care among various diagnoses.

The researcher was not able to obtain a large population of men to survey. While UCDD does have a larger number of male parents attending their groups than most agencies, there was still a gap between female and male respondents. Based on this, there were no significant findings between female and male self-care being conducted. There might also be a gap in the amount of daily care being provided by divorced or single men who are the primary caregivers. They might have responded differently had they been the sole provider and caregiver. Had there been a larger number of men in the survey, comparisons of self-care categories could have been made in order to determine which gender integrated which categories more.

Another limitation to the study was that the majority of the respondents were married. Had there been more of a variance among relationship status, this might have led to significant findings among single parents or divorced parents who are the only or main caregiver for the child. A study conducted on one hundred and forty-eight single mothers of developmentally disabled children found that the mothers who did not have the support of a partner

experienced greater depression and lower psychological wellbeing (Gottlieb, 1997). Having a two parent household allows for parents to spend individual time away from the child and participate in activities that can rejuvenate their mood. Parents might also be allowed to vent and process more easily and frequently if there are two parents in the household. Shifting responsibilities and daily duties is only possible if there is another adult to delegate to. Had the study included variance in relationships, other factors could have been included; such as whether or not they are the primary caregiver, sole income source, and whether or not they receive any social support from family or friends in caring for the ASD child.

Had there been a greater variance in time spans from diagnosis until attending UCDD for services, other correlations might have been made. Newly diagnosed children not receiving all of their available services yet might lead to a greater deficiency in parental time for self-care. Exploring the variance between levels of self-care, based on time since diagnosis might have allowed for new discoveries.

Another limitation was the small variance in ages of the ASD children. Of the child's current ages, the youngest child reported was four years old. The oldest child reported was fifteen years old. Had there been greater range in children's ages, this could have allowed for findings between age groups. This could have also allowed for correlating levels of self-care among parents

with newly diagnosed, younger children and ASD children about to become adults.

Recommendations for Social Work Practice, Policy and Research

This study provided insight into the self-care practices of parents with a child diagnosed with Autism Spectrum Disorder. It was a small-scale study, but nonetheless showed the correlations between psychological self-care and other categories of self-care. Social workers should incorporate this finding into assisting families with ASD children. Encouraging therapy, journaling, and other psychological self-care means could increase other areas of self-care.

Encouraging parents to release their guilt feelings towards taking time for themselves and to nurture their spirit is important in working with ASD families. Taking time away to spend with non-ASD children who might be feeling ignored or stressed from the challenges of living with an ASD sibling, or spending time with other parents who can relate to their situation and concerns can release tension and frustration the parents are facing. Processing with parents the issues, disappointments and realities of future expectations can help transition a difficult situation into a positive outlook. ASD children are all unique and have gifts that need to be treasured by those around them. The less stress the parents carry, the greater the outlook towards circumstances will be.

Incorporating the topic of self-care into parent groups, mental health visits, online resources, and other environments parents are found is important in order to share with parents the effects self-care can have on stress levels and other aspects of life. Openly sharing the stressors of having an ASD child and ways in which to cope with it are beneficial. Parents might not have considered their own needs and the importance of incorporating time for themselves into their day. Educating them on the many ways in which to make their overall mental health a priority is crucial to overcoming the anxiety and stress of balancing life with an ASD child.

Research needs to continue regarding self-care of parents, in order to address multiple factors; including the mental and physical effects of self-care on parents, the effects of self-care on the parent/ASD child dynamic, and how to increase awareness of the importance of self-care. Being an evidenced-based practice field, social work will begin to incorporate the self-care discussion more as evidence continues to show that it is important and relevant to increasing overall wellbeing of the people we are serving.

It would also be beneficial to conduct further research on the UCDD parents who participated in this study, at a later time. After participating in this survey and being exposed to self-care strategies they might not have considered, followed by a parent group session discussing the importance of self-care and time to put into practice what they've discussed, it would be

valuable to re-survey the same parents to see if their self-care scores have changed.

Within the weekly parent group sessions at UCDD, if a “check in” of each parent’s prior week’s self-care practices was incorporated, it might encourage the behaviors of the parents. Knowing that it is a weekly discussion and they are going to be presenting what they had done, or not done, might increase awareness and interest in being prepared to share something. By incorporating it into the weekly group sessions, it becomes a natural part of the discussion and remains at the forefront of the parents’ minds. Things that are not practiced often become forgotten or are easily set aside.

Focusing research on the factors that determine whether or not a parent is motivated to implement self-care is also important. Examining if parents view self-care as beneficial, despite whether or not they are actually performing any self-care, can assist social workers in working with parents. Determining if the focus of encouraging parents should be on educating them on importance, advising them of possible self-care examples, or motivating them to make priority something they are already aware of as important, are all unique approaches to take.

Conclusions

Self-care is an important element in everyone’s daily life. Taking time to maintain a healthy balance in life is a key factor in overall health. For parents with an ASD child, this is even more important. Finding time to fill emotional,

psychological, spiritual, physical, and workplace needs should be a priority in parents' lives. Each category is unique and important in the parent as a whole. Drawing attention to what gives them pleasure in life and how they find peace of mind is crucial to showing parents that taking time for themselves will have positive benefits. As parents, being at their overall best determines the success of the relationship with their child.

This study has shown that while self-care may be important to parents, there are obstacles that may prevent them from making self-care a priority. Changing parents' daily habits to include time for themselves might be a challenge. However, ASD children have advocates within their parents, extended family members, and social support system. Parents need these same advocates to encourage them to spend time caring for themselves. Removing the guilt feelings that parents might encounter while taking time to participate in something that they enjoy is important to increasing behaviors. As social workers, it is our job to promote wellness among our clients, including parents of autism spectrum disorder children. Providing them with the support and encouragement to make their overall wellbeing as important as their child's wellbeing can ensure that ASD children are being cared for by well-balanced parents who are able to take on the challenges ahead.

APPENDIX A
SURVEY

Self-Care Strategies Among Parents with a Child Diagnosed with Autism Spectrum Disorder

Survey questions to be administered to mothers and fathers individually

1. At what age was your child diagnosed with Autism Spectrum Disorder? _____
2. What is the child's gender? Male/ Female
3. What is the child's current age? _____
4. Do you have other children? Yes/ No
5. If so, what are their ages? _____
6. What is your relationship status? Married/ Single/ Divorced/ Separated/ Widowed/ Partnered
7. What is your age? _____
8. What is your gender? Male/ Female
9. What is the highest level of education you completed? _____

For the following self-care assessment, using the scale below, rate the following areas in terms of frequency:

- 5 = Frequently
- 4 = Occasionally
- 3 = Rarely
- 2 = Never
- 1 = It never occurred to me

Physical Self-Care

- ___ Eat regularly (e.g. breakfast, lunch and dinner)
- ___ Eat healthy
- ___ Exercise
- ___ Get medical care when needed
- ___ Take time off when needed
- ___ Get massages
- ___ Dance, swim, walk, run, play sports or do some other physical activity
- ___ Get enough sleep
- ___ Take vacations
- ___ Take day trips or mini-vacations
- ___ Gardening or yard maintenance
- ___ Other:

Psychological Self-Care

- ___ Have your own therapist visits
- ___ Write in a journal
- ___ Read literature unrelated to autism
- ___ Decrease areas of stress in your life
- ___ Spend quality time with significant other without children present
- ___ Say "no" to extra responsibilities sometimes
- ___ Strive for balance among work, family, play and rest
- ___ Other:

Emotional Self-Care

- Stay in contact with important people in your life
- Re-read favorite books, re-view favorite movies
- Allow yourself to cry
- Find things that make you laugh
- Attend a support group
- Other:

Spiritual Self-Care

- Make time for reflection
- Spend time in nature
- Find a spiritual connection or community
- Be open to not knowing
- Cherish your optimism and hope
- Meditate
- Pray
- Sing
- Read inspirational literature
- Other:

Workplace or Professional Self-Care

- Take a break during the workday (e.g. lunch)
- Make quiet time to complete tasks
- Balance your workload so that no one part of the day is “too much”
- Set limits with clients and colleagues
- Other:

10. What obstacles do you face with self-care implementation? _____

Source: Modified from Saakvitne, K. W. & Pearlman, A. (1996). *Transforming the pain: A workbook on vicarious traumatization*. Traumatic Stress Institute/Center for Adult and Adolescent Psychotherapy.

APPENDIX B
INFORMED CONSENT

INFORMED CONSENT

The study in which you are being asked to participate is designed to examine the self-care strategies among parents with a child diagnosed with autism spectrum disorder. This study is being conducted by Shawn Gorsky, under the supervision of Dr. Thomas Davis, Associate Professor of Social Work, California State University, San Bernardino. This study has been approved by the School of Social Work Subcommittee of the Institutional Review Board, California State University, San Bernardino.

If you choose to participate in this study, you will be asked to complete a brief survey, which should take about 10 minutes to complete. All of your responses will be kept confidential, and your name will not be connected with your responses in any way. Once the study is complete, all surveys will be destroyed.

Your participation in this study is completely voluntary. You are free to not answer any of the survey questions, and are also free to withdraw from the study at any time without penalty. Participation or non-participation in this study will not affect the services you receive from the University Center for Developmental Disabilities (UCDD). There are no foreseen risks with participating in this study. Participation in this study will contribute to social work research, educate others about self-care strategies being implemented by parents of autistic spectrum disorder children, and create insight into possible interventions in working with parents of autism spectrum disorder children. The results of this study can be obtained after the completion of this study after December, 2014. The results will be available at the Pfau Library, located on the California State University, San Bernardino campus.

If you have any questions, please contact Dr. Thomas Davis, Professor of Social Work at (909) 537-3839, or tomdavis@csusb.edu.

By placing a check mark in the space below, I acknowledge that I have been informed of, and that I understand, the nature and purpose of this study, and that I freely consent to participate.

Place a check mark here _____

Today's date _____

APPENDIX C
DEBRIEFING STATEMENT

DEBRIEFING STATEMENT

The study you have just completed was designed by Shawn Gorsky to examine the self-care strategies among parents of a child diagnosed with autism spectrum disorder. In this study, you were asked to participate in a survey, lasting approximately ten minutes.

Thank you for your participation in this study. If you have any questions about this study, please feel free to contact Dr. Thomas Davis, Associate Professor of Social Work, at (909) 537-3839, or tomdavis@csusb.edu. If you would like to obtain a copy of the study, please refer to the California State University, San Bernardino, John M. Pfau Library after December, 2014.

If you find that the study topic has caused some emotional discomfort that you had not anticipated, or for any reason would like to speak to someone further regarding the study topic, please contact either the San Bernardino County Crisis Center at (909) 421-9233, or Dr. Thomas Davis, Associate Professor of Social Work, at (909) 537-3839.

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