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FACTORS ASSOCIATED WITH QUALITY OF LIFE AMONG MOTHERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

by

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ABSTRACT

FACTORS ASSOCIATED WITH QUALITY OF LIFE AMONG MOTHERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

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The increasing prevalence of Autism Spectrum Disorder (ASD) has levied associated effects upon the quality of life (QOL) of mothers of children with ASD. These mothers are subjected to various influences upon their lives as a result of their role as caregivers to children with ASD. The purpose of this study was to assess the International Classification of Functioning, Disability and Health (ICF) Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors associated with QOL among mothers of children with ASD.

English literate, inhabitants of the United States, mothers over the age of 18, of children with ASD were recruited through Internet sites. Forty-six percent of the respondents were between the ages of 35-44 years, n = 149. The children with ASD had an average age of 11.52 (SD 7.56) years. The web-based survey consisted of researcher-constructed questions for the ICF Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors, with the WHOQOL-BREF assessment. Linear regression and multiple linear regression models were developed to describe the individual and combined effects of the ICF Factors upon the Physical Health, Psychological, Social Relationship, and Environmental QOL domains.

Significant ICF Factors contributing more than 20% of the variance in QOL were identified in the models. Factors associated with a decrease in QOL were found in the

Body Functions and Structures Factors mother comorbid condition of arthritis on Physical Health QOL, the mother comorbid condition diabetes on Environmental QOL, and the Environmental Factor of children receiving physical therapy in the educational setting on Social Relationships QOL. Factors associated with an increase in QOL domains were found in the Body Functions and Structures Factor mother average sleep hours per night on Physical Health and Psychological QOL, the Participation Factor of change in relationship with significant other on Social Relationships QOL, and the Personal Factor household income above $100,000 on Environmental QOL.

Health policy recommendations are made to address QOL among mothers of children with ASD during healthcare visits for their children. Suggestions for the development of technology, support accommodations through community resources, and targeted education of healthcare providers are warranted intervention tactics.

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Thank you all for teaching me “You are never too old to set another goal or to dream a new dream.” (C.S. Lewis)

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CHAPTER I

Various syndromes and diseases have been treated throughout history based on the scientific knowledge available to man at that point in time. Similarly modern science attempts to assess the origin and incidence of present-day disorders based on descriptions provided within ancient texts. Traditionally when physical reasons were found to be the basis of brain-based conditions in children, as with iodine deficiency and cretinism, any stigma associated with this intellectual disability was removed and preventive measures were put into place. However, when no apparent cause could be attributed to a condition at the turn of the nineteenth century, American doctors fell back on the axiom of moral suppositions (Waltz, 2013). As time passed and no hard evidence was found to support a moral connection and outcomes, psychology emerged as a science searching for further explanations.

With the advent of Freudian theories, the typical view became as stated by Bettelheim (1967), "...infants, if totally deserted by humans before they have developed enough to shift for themselves, will die. And if their physical care is enough for survival but they are deserted emotionally, or are pushed beyond their capacity to cope, they will become autistic" (p. 348). Early observations of children with autism and their families ascribed the children's behavior as reactions to threatening experiences and inadequate parenting, described as "extreme emotional isolation" (p. 381). Following along the lines of Bettelheim were three female psychoanalysts, Mahler (1897-1985), Tustin (1913-1994), and Klein (1882-1960), who contributed theories about autism, all blaming a common target: the mother. Autism was eventually identified as a psychosis, treated with psychotherapy. Fromm-Reichmann, a Baltimore analyst in 1948, promoted the idea that autism was the childhood version of schizophrenia, caused by the schizophrenogenic mother (Waltz, 2013). Thus mothers, the caregivers of children with autism, became the central focus of research until it was determined that autism was a neurodevelopmental condition and not the result of bad parenting. The initial stigma placed on mothers as the cause of autism in their children created enormous stress. Associated deleterious strains continue today in the form of daily life challenges with consequential effects upon the mother's quality of life (QOL).

The complexity of Autism Spectrum Disorder (ASD) has resulted in a body of literature that incorporates the prevalence, diagnostic dilemma, etiological propositions, environmental contributions, syndrome diversity, treatment interventions, family influences, and burdens. Due to the increasing prevalence of ASD in the United States today, not only are healthcare and educational system resources being impacted as increasing numbers of families have children with ASD, but also the individual family members are encumbered with managing the care of these children. Each child with an ASD who is atypical in skills, needs, and manifestations requires a wide variation of services with resultant costs. Both the direct and the indirect costs of caring for a child with ASD impinge on all aspects on family life and upon the lives of the individual family members. The lack of a cure for ASD places the impetus upon society to investigate options for management throughout the lifespan, as well as for the alleviation of concomitant adverse effects upon the family, particularly upon mothers of children with ASD.

Background

Surveillance data statistics reveal the overwhelming prevalence of ASD in the United States. For both 2000 and 2002 the prevalence was 1 in 150 (6.7 and 6.6 per 1,000), in 2004 it was 1 in 125 (8.0 per 1,000), and for 2006 prevalence increased to1 in 110 (9.0 per 1,000) children. In 2008, it was 1 in 88 (11.3 per 1,000), and in 2010, it was 1 in 68 (14.7 per 1,000) for 8-year-old children ("Prevalence of autism," 2009; "Prevalence of autism," 2012; "Prevalence of autism," 2014). Further increase is seen in the 2011-2012 estimated prevalence among a wider age group, school-aged children (6-17 years), of 1 in 50 according to the Centers for Disease Control (CDC) (Blumberg et al., 2013). The increases in prevalence have been attributed to increased attention to the developmental disability of ASD, improvements in diagnostic criteria and access to care, a higher prevalence in the surveillance sites, heightened identification in subgroups or a combination of all of these (Baio, 2012; Reber, 2012).

The complex management associated with ASD entangles the resources of both the healthcare and educational systems with a resultant increase in expenditures on all levels. The use of healthcare inpatient, outpatient, and pharmacy services documented in private health insurance claims between 2000 and 2004 for these children, aged 17 years and younger, increased over 20% for individual payers. Additionally there was an increase of over 142%, per 10,000 individuals; this did not consider out of pocket expenses nor the consequences of caregiver burden (Leslie & Martin, 2007).

Families of children with ASD incur the burden of care that encompasses indirect costs such as a loss of earnings or other employment related issues. The 2002-2008 Medical Expenditure Panel Survey was used to compare parental employment and earnings for parents of children with ASD to parents of children with another health limitation and children without health limitation. Family earnings of children with ASD were less than that of the two comparison groups, and mothers in particular earned less than the comparison groups. Mothers of children with ASD were less likely to be employed and worked fewer hours per week than mothers of children without health limitation (Cidav, Marcus, & Mandell, 2012). Parents of children with ASD living in Washington and Oregon, during the period from 2006-2007, completed a survey based upon a Canadian Activities and Participation Limitation survey. The study was designed to assess whether having a child with ASD had an effect on work outside the home, and which family member would be most affected. The majority of respondents felt that the mother's work outside the home was most affected. Mothers of children with ASD tended to change jobs or work hours, decrease the number of hours worked, be unemployed, take a leave of absence, refuse a promotion, be reprimanded at work, or suffer financial problems in order to accommodate the needs of their child with ASD. A higher number of adults in the home, a flexible employment environment including work hours, and interestingly, financial problems were associated with a decrease in the adverse effects on maternal employment. Mothers without financial problems were postulated to have more established careers that would not be adversely affected (Baker & Drapela, 2010).

Mothers of children with ASD perform multiple roles and provide additional care for her child with ASD, and as a result may experience compromised wellbeing. Analysis of existing data from the 2003 National Survey of Children's Health demonstrated a higher child care burden in the families of children with ASD than that of families of children with Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder (ADD/ADHD) (Lee, Harrington, Louie, & Newschaffer, 2008). Since these mothers of children with ASD are continuously responding to their children's needs and to the unpredictable behavioral manifestations accompanying the diagnosis, they experience stress equivalent to the mechanical aspects of providing care, as well as the emotional strain of a long term obligation. Ultimately caregiver challenges include negotiating the home, school, and community environments while simultaneously coping with unpredictable child management problems thus adding to caregiver burden among mothers when compared to fathers (Tehee, Honan, & Hevey, 2009). In-depth semi structured interviews were conducted with seven mothers of children with autistic disorder, aged 6-12 years living in Australia. Their paradox of emotions ranging from acceptance to expectations, frustrations with their personal, educational, and therapy support systems, and acting as their child's therapist, all were sources of stress for the mothers. The multiple roles managed by the mothers in caring for their child had negative effects upon the mother's health (Safe, Joosten, & Molineux, 2012).

There are relationships associated with both the age of a child with ASD and the child's symptoms of ASD that affect the QOL of the mother. Maternal well-being was assessed in data from studies of mothers of toddlers and of adolescents with ASD. Over a third of the mothers in both groups scored above the clinical risk for depression. Emotion-focused coping strategies of the mothers in both groups were associated with higher levels of depression (Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008).

Conceptual Framework

Quality of life is a multidimensional subjective concept that is a target area for investigation in the multidisciplinary field of health services research. The World Health Organization (WHO) defines QOL as " individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment" (WHO, 1997, p. 1). It was the intent of WHO to use information obtained with the *International Classification of Functioning, Disability and Health* (ICF), a system of health and health-related domains, as a complement to purely health-related conditions as provided by the International Classification of Disease (ICD-10) (AMA, 2014; WHO, 2001). By using the two together, information on diagnosis plus information on functioning provides a broader picture of the health of individuals and populations, thereby addressing the WHO definition of QOL. Applying a public health viewpoint, QOL is a primary goal, a key outcome, or a related outcome in each of the four main healthcare strategies for populations: prevention, cure, rehabilitation, and support (Stucki, Cieza, & Melvin, 2007).

Morbidity and mortality data were relied upon in previous research primarily for calculating life expectancy; however, this is no longer sufficient to capture the overall health status of populations, since information about non-fatal health outcomes is becoming more and more relevant secondary to the so-called epidemiological transition– the shift from infectious diseases to increased prevalence of chronic non-communicable diseases. As the WHO began to focus more on the Global Burden of Disease (GBD) it was determined that non-communicable diseases accounted for over half of the GBD, and that collecting information on health state and health outcomes is of primary interest for all countries. The ICF offers insight into all of these factors, which then provides a more comprehensive overview of an individual's health status. The usefulness of ICF goes beyond measuring population health since it becomes possible to identify those environmental factors that have an impact on areas of participation, such as education, transportation, or housing, which may be determinants of health (Ustun, Chatterji, Kostansjek, & Bickenbach, 2003).

Based on the WHO QOL definition, mothers of children with ASD represent a vulnerable population at risk for poor QOL. This characterizes a group that necessitates examination in order to achieve a better understanding of what factors contribute to their stress, what factors could improve their lives, and by extrapolation, their families and society at large (Smith et al., 2010). It is notable that the Institute of Medicine Women's Health Report of 2010 encourages research on social and environmental factors to include the functional aspects of QOL for women (Institute of Medicine & Committee on Women's Health Research, 2010). The NIH strategic plan advises research to include key factors such as women's family care responsibilities, and strategic goals to foster the use of technologies to increase understanding of women's health ("NIH priorities," n.d.). It is the objective of this health services research study to assess QOL among mothers of children with ASD as they represent a targeted subgroup of women whose physical, psychological, social, and environmental factors impact their QOL.

Not only have numerous studies associated a lower QOL among parents of children with ASD (Allik, Larsson, & Smedje, 2006; Lee et al., 2008; Mugno, Ruta, D'Arrigo, & Mazzone, 2007), but mothers of children with ASD were noted to exhibit higher parenting stress and psychological distress compared to mothers of children with developmental delays (Estes et al., 2009). Additionally, these mothers described more depressive symptoms and have a lower sense of well-being (Phetrasuwan & Miles, 2009). An Australian study described that mothers of children with ASD demonstrated more mental health problems, which were inversely related to social support (Sawyer et al., 2010). There are, however, other studies that report positive outcomes from parenting a child with ASD, such as effective coping, positive outlook, less anger, and stronger parent-child relationship, but this is a rarer occurrence (Fleischmann, 2004; Montes & Halterman, 2007; Pottie & Ingram, 2008; Tunali & Power, 2002) These are just a few of the constructs that may affect the QOL of mothers of children with ASD and which, consequently, can be addressed by applying a conceptual framework that portrays the numerous functional characteristics that may influence their multidimensional QOL.

Research on QOL can be performed under the auspices of the ICF instrument, which is a system developed to standardize the assessment of health and health related states through the process of encompassing the body, the individual, and society. This ICF system portrays Functioning and Disability in the first part, which includes two components: Body Functions and Structures, and Activities and Participation. Contextual Factors, the second part, includes two components: Environmental Factors and Personal Factors. The ICF, as a classification system, applies qualifiers using a generic scale to quantify the Body Functions and Structures, Activities and Participation, and

Environmental Factors. The unclassified Personal Factors allow for social and cultural variation promoting international application. An individual's *functioning* is addressed in Body Functions, Activities and Participation, while an individual's *disability* is reflected in impairments, activity limitations, or participation restrictions (WHO, 2001, pp. 3-10, 22). The ICF is recognized internationally as a conceptual model recommended for research and clinical applications (Stucki et al., 2007). This research will use these elements of the ICF conceptual framework, with modification to be further described in Chapter II portraying the interrelationship of functioning that compose the QOL among mothers of children with ASD.

A comparative effectiveness review by the United States Department of Health and Human Services (DHHS) identified cultural contextual factors affecting children with ASD and their families as an area that needs further research in order to provide potential interventions to assist these families (Warren et al., 2011). The contextual factors included in this study and identified in later sections, as relevant to functionality, are ideally classified under the ICF framework. The ICF provides a comprehensive holistic context for interdisciplinary communication, applicable to the complexities associated with ASD and family impact. Such chronic medical conditions require collaboration between numerous healthcare providers at various stages of management, which can be facilitated by using the ICF (Allan, Campbell, Guptill, Stephenson, & Campbell, 2006; Stucki & Grimby, 2004).

Factors that may affect outcomes in the QOL among mothers of children with ASD traverse the more functional aspects of daily life that are embedded in the ICF conceptual framework components of Body Functions and Structures, Activities, and

Participation. The Environmental and Personal Factors comprise the contextual applications as they relate to the culturally purposeful aspects of life. The Personal Factors are generally referred to in the literature as demographic factors. The Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors will be further delineated as the "ICF Model Component Factors" that are associated with QOL among mothers of children with ASD. The rationale of this study encompasses a functional interpretation of QOL that is holistic in nature as it reflects a health state and functioning, rather than disability and impairment (WHO, 2001). Chapter 1 presents the statement of the problem, purpose of the study, significance of the study, research questions, and study variables.

Statement of the Problem

A review of research on health-related QOL of mothers, published between 1997 and 2006, was conducted by Coyle (2009). The qualifying study populations included mothers of children with Asperger syndrome, cerebral palsy, cystic fibrosis, cancer, speech impairment, autism, leukemia, and infants receiving home oxygen therapy and populations of mothers with 17 years of mothering experience, with postpartum depression, welfare receipt, various forms of postnatal care, HIV, and low income. The sample size among the health-related QOL cross-sectional descriptive studies ranged from 20 to 531; there were eight participants in one quasi-experimental study. Results indicate that environmental elements and demands beyond mothering, including caring for a child with a disability, negatively impact health-related QOL. One of the studies used the World Health Quality of Life-BREF (WHOQOL-BREF) assessment in a sample of mothers of children with autism, to be described in Chapter III.

The background literature on QOL for this study identified studies of parents of children with ASD, cerebral palsy, PKU, celiac disease, Down syndrome, and oppositional deviant disorder. These studies examined a limited number of demographic and environmental correlates of health-related QOL. The demographic factors examined in these studies were primarily focused on marital status, employment, income, age, number in family, educational background, caregivers involved, gender and age of child, and occasionally depression screening. A brief overview of these studies follows and it is noteworthy for the international mixture with cultural contextual differences.

Turkish mothers of children with Down syndrome, cerebral palsy, and ASD demonstrated similar levels of depression overall, as measured by the Beck Depression Inventory (BDI). However, depression did decrease with increased educational level and income and increased with increasing maternal age. Likewise QOL of the mothers, as measured by the WHOQOL-BREF, was noted to increase with increasing education and income, and decrease with increasing maternal age. The mothers of children with ASD scored higher on the Social Relationships QOL domain overall, which was a culturally related finding, but lower on the Environmental QOL domain, which was attributed to behavioral problems (Tekinarslan, 2013).

Many studies using the WHOQOL-BREF have depicted a lower caregiver QOL, as in Nigerian caregivers of children with cerebral palsy, when compared to caregivers of normally developing children (Fatudimu, Hamzat, & Akinyinka, 2013). Significantly lower WHOQOL-BREF Social Relationships scores were defined in a Brazilian study among parents of children with celiac disease when compared to a control group (de Lorenzo, Xikota, Wayhs, Nassar, & de Souza Pires, 2012). A Farsi version of the

WHOQOL-BREF, used to determine QOL for caregivers of children with Phenylketonuria (PKU), revealed that employment, depression, and anxiety contributed to a lower caregiver QOL (Mahmoudi-Gharaei, Mostafavi, & Alirezaei, 2011). Generally, analysis of QOL using this instrument has proven it to be capable of assessing QOL for any caregiver of a child with disorders ranging from manageable to severe when compared to controls (Khanna et al., 2011; Lee et al., 2010; Mugno et al., 2007; Webster, Nicholas, Velacott, Cridland, & Fawcett, 2010).

Evaluating the literature for studies of QOL among parents of children with ASD, consideration of a limited number of demographic parental characteristics and minimal characteristics of children is apparent. Parents completing a web-based survey assessing parental stress, family functioning, and physical and mental health found that mothers reported higher caregiving stress as well as lower physical health, while higher family functioning discrepant scores predicted lower mental health. Fathers reported personal and family life stress, while family functioning discrepant scores predicted poorer mental health. The study did not address the child's behavioral problems nor the caregiving time provided (Johnson, Frenn, Feetham, & Simpson, 2011).

Maternal feelings about caring for a child with ASD, using a single ordinal rating question have been shown to predict three of the four WHOQOL-BREF domain scores in a positive relationship. Conversely, mothers reporting having religion had an inverse relationship with two of four QOL domains. The same study showed no relationship between the demographic variables of age, education, employment, and history of chronic disease with QOL, although the factor assessments in some cases were limited to a dichotomous choice (Shu, 2009). Mothers of children with ASD who had higher parenting stress reported lower well-being and higher depressive symptoms (Phetrasuwan & Miles, 2009). Parents of children with Pervasive Developmental Disorder (PDD) had a lower QOL when compared to parents of children with cerebral palsy or mental retardation or a control group. Specifically, mothers of these children reported a lower QOL than fathers (Mugno et al., 2007). Mothers of children with Asperger syndrome and high-functioning autism had lower physical health than a control group and lower physical health than fathers of the same children. Behavioral problems of the child seemed to have contributed to lower health related QOL (Allik et al., 2006).

Attempts to provide interventions for these families have involved offering support groups as a means of intervention; however, following a ten-week support group of a small sample of mothers of children with ASD, no significant differences in the four domain scores of the WHOQOL-BREF were found. This data held true throughout the study when measurements were taken before the intervention of group meetings, following the group meetings, and at one-month follow-up intervals (Shu & Lung, 2005).

Shocking examples of maternal breakdowns have been in the news over the past decade involving attempted suicides, infanticide, and abandonment (Deardorff & Mellor, 2000; Fernandez & Sulek, 2012). The underlying theme through all of these catastrophes has been that these women are emotionally and physically pushed to their limits and burdened by the terrible truth that their child is not going to get better or develop normally. Money, education and even conscientious commitment to the disorder do not protect against the inconceivable strains of caring for chronically ill or disabled children and especially those children with ASD. Although there are widespread support systems available, they are fragmented and oppressive with bureaucracy. Services vary from county to county in each state, and health insurance may cover some equipment and procedures, but not others. As the child with ASD grows, the disability often becomes more pronounced and needs change dramatically. The incidence of children with ASD has increased such that 1 in 50 are now diagnosed (Blumberg et al., 2013). As Robert Ring, chief science officer for the advocacy group Autism Speaks explains, "The new statistics raise significant concerns about access to care, because autism is a lifelong disorder and the need for services only begins at diagnosis" (Falco, 2014, para. 26).

Thus as the WHO elaborated on QOL being individuals' perception of their position in life in the context of the culture and value systems in which they live, is it any wonder these mothers become a shell of their former selves and seek some rest if not release from their lives? For all practical purposes, these women have lost all hope and their QOL continues to spiral downward. Consequently the problem for these women becomes one of seeking a higher level of QOL. The need to know how to help these mothers improve their QOL becomes imperative with the escalating rates of children diagnosed with ASD. Thus the problem statement becomes: With the increasing rate of ASD in the U.S., the QOL of these mothers is decreasing as they become ensnared by the lifelong care these children demand. Research up to this point has reflected a narrow focus on demographic and other characteristics that may influence QOL. Since factors that may affect the QOL of mothers of children with ASD traverse the multidimensional and functional aspects of life, the application of the ICF conceptual model framework justifies an expanded consideration that is built into the design of this research.

The statement of the research problem for this study is: How do the Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors among mothers of children with ASD influence the QOL of the mother?

Purpose of the Study

Mothers tend to be the primary caregivers of children with ASD, with concomitant challenges in activities of daily living (Bromley, Hare, Davison, & Emerson, 2004). The burden of tending to these children falls on the mothers (Tehee et al., 2009). Despite research demonstrating a lower QOL among parents/mothers of children with ASD, little has been done to assess what demographic, or more explicitly, Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors may influence QOL (Allik et al., 2006; Lee et al., 2008; Mugno et al., 2007). Since this relationship has not been fully described, it is the purpose of this research to investigate the Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors associated with QOL in a group of mothers of children with ASD.

Significance of the Study

Maternal QOL impacts the mother herself, her child with ASD and the entire family. Knowledge of the Body Structure and Functions, Activity, Participation, Environmental, and Personal Factors that may affect maternal QOL could lead to modifications in healthcare and educational services with the goal of improving the mother's QOL. Providers can be directed to address treatments and programs to optimize factors associated with improving the mother's QOL. Suggestions for health policy changes, including increased access to care for this vulnerable population, educational services, accessibility regulations, and focused community support programs, that would alleviate the burdens of these mothers, may be determined within this study. Research is needed, and anticipated by those entrenched in the daily challenges that accompany this unique yet complex disorder (Amaral, 2011). This study is not a channeled effort in conflict with "autism pride" and does not deny the neurodiversity in the population of interest, but seeks to further understand the QOL among mothers of children with ASD (Cascio, 2012).

Research conducted by clinicians working with individuals with ASD and their families has contributed to improvements in knowledge base, assessment tools, and intervention practices. This has resulted in benefits to children with ASD and their families (Lord, 2010). A healthcare provider with direct experience in the delivery of services to children with ASD in the public school setting is the principal investigator of this research. Potential contributions in the collaborative areas of healthcare and educational services may be identified to further assist families dealing with the effects of ASD. This includes curriculum integration of the theoretical framework into the fields of medicine, allied health programs, and education for both healthcare providers as well as for mothers and children. The enhanced academic training for healthcare providers may result in a more realistic viewpoint by acknowledging the challenges and benefits that mothers of children with ASD encounter within the educational and therapeutic settings. The resultant ASD shift in focus from disability inabilities to functioning abilities, using the ICF conceptual framework, would allow the identification of factors that could improve the QOL of the mother and of the family of a child with ASD. Thus, provider education directed from a functioning perspective could contribute to further development of best practices intervention programs in the healthcare and educational arenas. Both the mother and the child with ASD spend a great deal of time in the medical and educational settings. In summary, health policy changes, including increased access to services needed by this vulnerable population, accessibility accommodations, and community support programs may result from this study.

Research Questions

Research questions are formulated to identity the targeted objectives of the study. The research questions are as follows:

1. What are the Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors that characterize mothers of children with ASD?
2. What is the QOL, as measured using the WHOQOL-BREF, among mothers of children with ASD?
3. What are the significant relationships between the Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors among mothers of children with ASD, and the QOL of the mothers?
4. What are the predictive Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors among mothers of children with ASD for their QOL?

Study Variables

The dependent variable of interest is the QOL among mothers of children with ASD. The independent variables comprising the Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors of the mothers of children with ASD can be categorized into the components or constructs of the ICF conceptual model. The independent variables are based upon previous studies with researcher expansion to facilitate the application of the ICF conceptual model in determining the factor influences upon the mother's QOL. The Body Functions and Structures Factors include variables that describe the mother's age, comorbid conditions under current treatment, average number of sleep hours per night, age when her child with ASD was conceived, gestation length, and the presence of problems during pregnancy. The Activities Factors include descriptors of the mother's employment status, employment location, and number of child caregiving hours per day. The Participation Factors reflect: how the mother's relationship with her significant other is affected by having a child with ASD, whether she is associated with an organized religion or spiritual group, areas of life that are negatively or positively affected by having a child with ASD, identification of the source of most emotional support for coping with responsibilities, and identification of the source of significant caregiving for her child with ASD. The Environmental Factors include variables that describe the household environment: number of adults in the household, number of children in the household, and the number of children with ASD. Other Environmental Factors include the age of the father at conception of the child with ASD, age and gender of the child with ASD, age of the child with ASD at diagnosis, the time between when the mother first noticed problems in her child and the ASD diagnosis, and the specific ASD diagnosis. Environmental Factors also include whether the child has healthcare coverage or has military healthcare coverage, comorbid conditions for which her child with ASD is currently receiving treatment, average number of child sleep hours per night, child use of assistive technology, type of therapy received by the child with ASD, and the current classroom setting for her child with ASD. The identification of the source of the most information for the other's needs in raising her child with ASD and the average number of caregiving hours provided by a significant caregiver are Environmental Factors. The Personal Factors of the mother are the basic demographic information variables of education level, race, marital status, income, and whether the mother has healthcare coverage or military healthcare coverage (see Figure 1). This type of alignment of variables, or of informational factors that are relevant in each of the ICF Components, has been proposed for the assessment and rehabilitation of children with cerebral palsy. The framework allows, clients, families, and service providers to collaborate in identifying and achieving goals (McDougall & Wright, 2009).

ICF Model Component	Independent Variable Factor
Body Functions and Structures	Mother Age
	Mother Comorbid Conditions
	Mother Sleep Hours
	Mother Age at Conception
	Gestation Length
	Pregnancy Problems
Activities	Employment
	Employment Location
	Mother Caregiving Hours
Participation	Significant Other Relationship Affected
	Spirituality Association
	Life Areas Affected Negatively
	Life Areas Affected Positively
	Information Source
	Emotional Support
Environmental	Number Adults in Household
	Number Children in Household
	Number Children with ASD
	Father Age at Conception
	Child Age
	Child Gender
	Child Age at Diagnosis
	Time to Diagnosis
	ASD Diagnosis
	Child Healthcare Coverage
	Child Healthcare Coverage Military
	Child Comorbid Conditions
	Child Sleep Hours
	Child Assistive Technology
	Child Therapy Type
	Child Classroom Setting
	Other Caregiver
	Other Caregiver Caregiving Hours
Personal	Mother Education Level
	Mother Race
	Marital Status
	Income Level
	Mother Healthcare Coverage
	Mother Healthcare Coverage Military

Figure 1. International Classification of Functioning, Disability and Health conceptual model component alignment with independent variable factors.

Summary

This chapter has demonstrated the need to assess factors associated with QOL among mothers of children with ASD. Health services research is a viable route for the exploration of the QOL outcome, attending to the burdens experienced by these mothers, while the increase in ASD prevalence declares the urgency of addressing this specific population. The existing literature and numerous international/national organizations affirm the need for research according to the paradigm of the ICF, thereby upholding the application of a functional and holistic perspective.

CHAPTER II

LITERATURE REVIEW

Chapter II presents the theoretical framework and conceptual model for the assessment of QOL among mothers of children with ASD. This is followed by a review of the literature pertaining to QOL as related to the ICF components of Body Function and Structures, Activities, Participation, Environmental, and Personal Factors among mothers of children with ASD. In view of the escalation in ASD literature, an attempt was made to cite those studies having the most pertinent considerations for the present study.

Conceptual Framework

The purpose of a theory is to elucidate the relationships between variables in order to explain the phenomenon undergoing inquiry (Kerlinger, 1979). "Relationships among theory, research, and practice are not simple or linear" (Glanz, Rimer, & Viswanath, 2008, p. 25). Experts in the application of theory to research have illuminated the importance of theory and the resultant appropriate decision-making. The relationships in a model representing a theory are not diagramed merely to depict a simplistic mathematical summation of factors towards an outcome. Rather, theory solidifies the experimental design by designating and organizing the variable associations. A firm theory base allows the delineation of factors as related to the outcome of interest, in this study of QOL, through formal logic by applying critical reasoning to empirical research. This exploratory study uses a conceptual model as the theoretical basis for the assessment of variable relationships in order to answer the research questions and to test the usefulness of the conceptual model in predicting these variable relationships.

The basis of the conceptual framework for this study is a biopsychosocial model that describes the process of functioning and disability (see Figure 2). The ICF, as a classification system, internationally recognized as a conceptual model, posits health domains and health-related domains with constructs depicting functioning (Stucki et al., 2007). Part 1 of the ICF, Functioning and Disability, has two components: Body Functions and Structures, and Activities and Participation. Part 2 of the ICF, Contextual Factors, has two components: Environmental Factors, and Personal Factors. Each component contains domains, within which are classified various categories (WHO, 2001). The umbrella dimensions of functioning and disability (with corresponding problems) include Body Functions and Structures (impairment), Activities (limitation) and Participation (restriction). Interactions of these components with the health condition and Personal and Environmental Factors comprise the model (Cieza & Stucki, 2008, p. 306). The initial publication of the ICF included proposals for its application toward the "development of precise operational definitions of categories for research purposes" and for "establishing links with quality-of-life concepts and the measurement of subjective well-being" (WHO, 2001, p. 251). "Thus the ICF may be seen as a new paradigm for disability and rehabilitation research, but also, more specifically, as a first step towards a general theory of functioning..." (Reinhardt, 2011, p. 272).

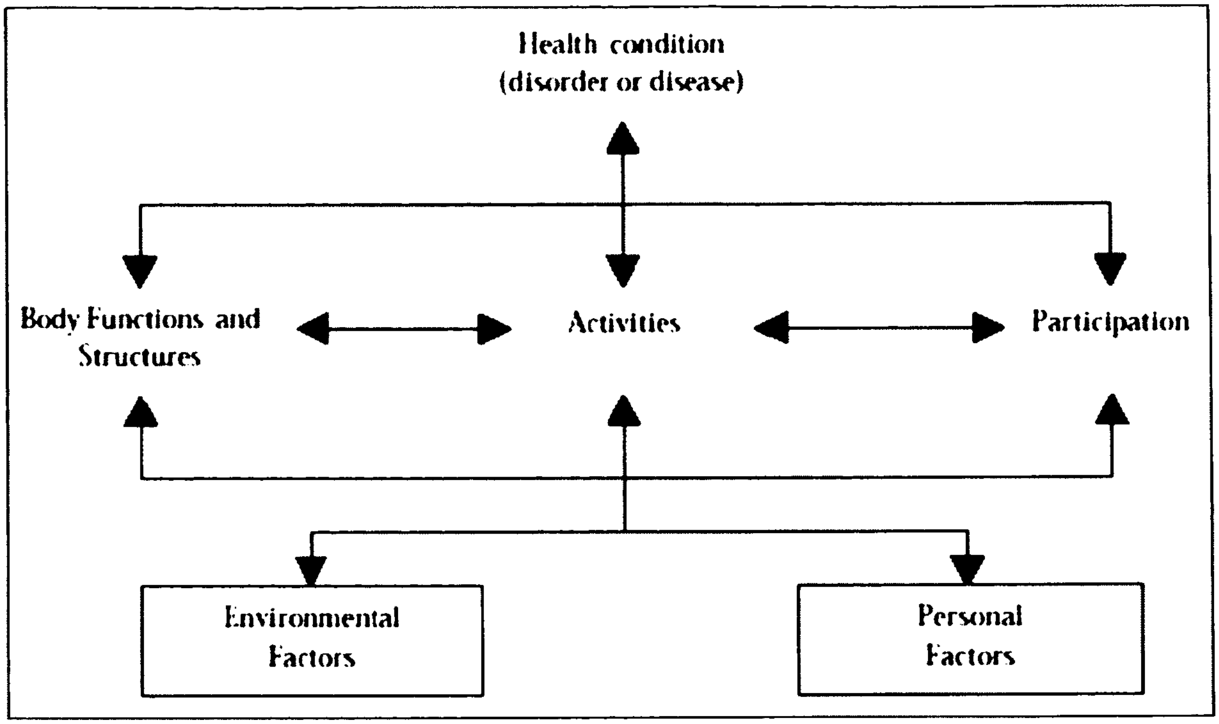

Figure 2. International Classification of Functioning, Disability and Health model of functioning and disability. Reprinted from *International Classification of Functioning, Disability and Health: ICF.* Geneva, Switzerland: World Health Organization, 2001) (World Health Organization, 2001, p. 18). This figure illustrates the basic conceptual framework for the Body Structures and Functions, Activities, Participation, Environmental and Personal Factors addressed in this research.

The ICF has been used as a model to guide clinical thinking, research, and practice for children with cerebral palsy. The ICF was developed to illustrate the interactive relationship between a health condition and contextual factors thereby describing these influences. The bidirectional arrows in the model (see Figure 2) demonstrate the linkage between all components of the model in a nonlinear relationship. For example, consideration of the family as the environment allows a family centered approach that could benefit the parent's health as well. The contextual Environmental and Personal Factors influencing functioning should be considered in the assessments and in the interventions. An additional result of the use of the ICF Factors in this paradigm could be the identification of considerations allowing the child's performance to approximate the child's capacity in different settings or contexts that are critical influences to the child's overall functioning. The individualization of healthcare that is possible using the ICF to direct interventions is ultimately a benefit to the family. Furthermore, the outcome measurements should be multidimensional, and it is therefore recommended that the influence of all ICF component Factors be considered for intervention (Rosenbaum & Stewart, 2004). The modified ICF model was initially proposed for the CanChild Centre for Childhood Disability Research Report "Measuring Outcomes for Children with Special Needs and their Families: Part 2, under the Ontario Ministry of Children and Youth Services. The Centre is based on family centered services within the context of the ICF with its unique functional considerations. This idea was designated the "ICF Framework with Outcome Approaches," thereby demonstrating the integral nature of the ICF model components to the outcome of QOL. The "ICF Framework with Outcome Approaches" constitutes the modified theoretical framework or the conceptual model upon which this research is based. Two of three measures considered for the outcome QOL were assessments for parent and for family QOL in the CanChild Centre program (Rosenbaum, Jaffer, & Russell, 2006) (see Figure 3).

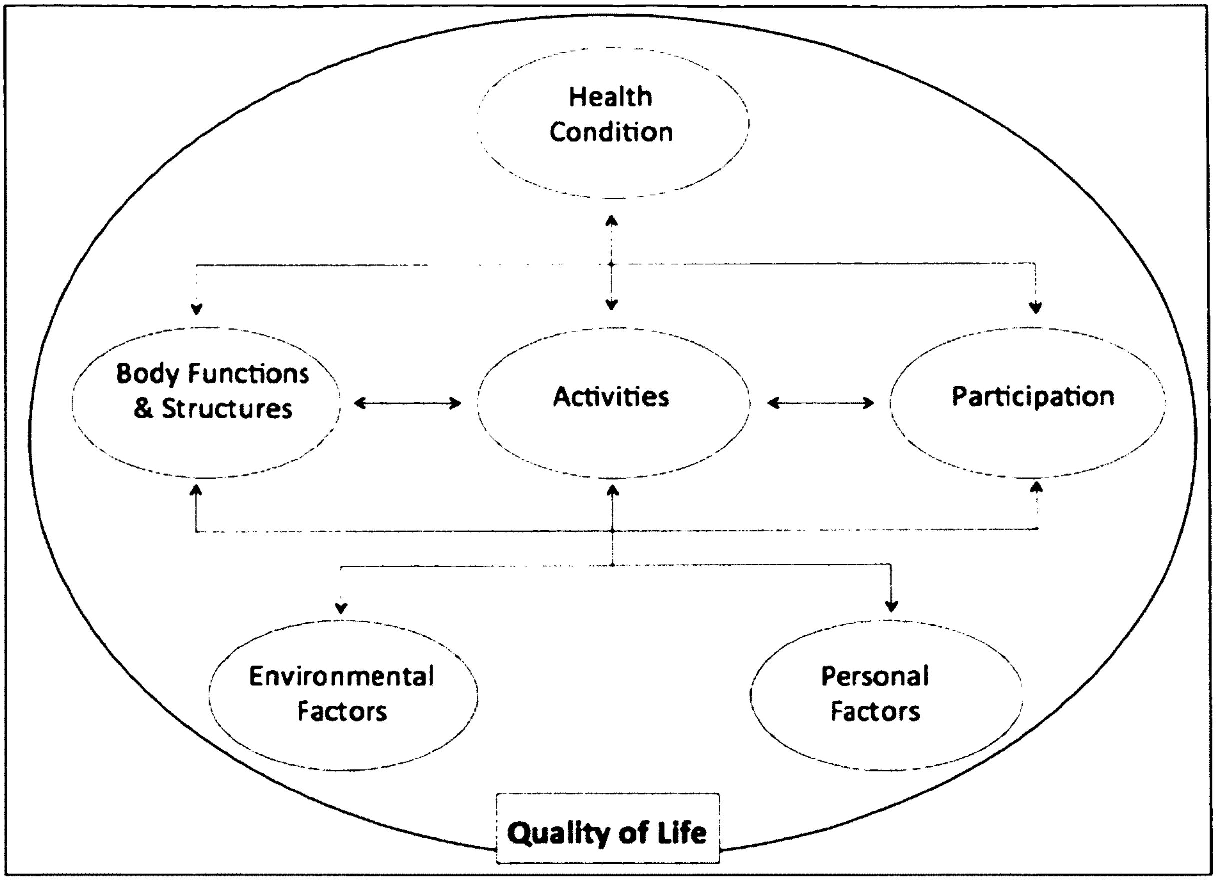

Figure 3. Modified International Classification of Functioning, Disability and Health framework with outcome approaches (Rosenbaum et al., 2006). Figure used with permission (P. Rosenbaum, personal communication, July 29, 2013). This figure depicts the outcome of QOL as it encompasses the ICF framework.

McDougall argues further that a systems perspective overlaps both the concepts of QOL and human development across time, allowing a dynamic interpretation of the functional components in her modification of the ICF model (J. McDougall, personal communication, July 29, 2013). Interactions, relationships, process and outcome, and in particular, QOL, depict the biopsychosocial/holistic model. The systems theory characteristics that are inherent to the ICF are: a holistic perspective, a nonlinear relationship between variables, and the consideration of functioning/disability as a dynamic interaction. This perspective considers interactions and relationships within the environment, and the framework dynamically incorporates function and QOL (McDougall, Wright, & Rosenbaum, 2010). Systems theory, an ecological model, has three levels of environmental influences: the microsystem (family members and work groups), the mesosystem (family, school and work settings), and the exosystem (economics, culture, and politics). The multiple levels of influence allow multiple levels of intervention, an advantage of ecological models (Sallis, Owens, & Fisher, 2008). The modified ICF conceptual model used for this study has its foundation in systems theory.

The ICF has been used to depict health, in contrast to disease, in chronic health conditions such as cerebral palsy. The interactions and nonlinearity of factors related to child functioning, and the constellation of family ecological influences can be incorporated into the ICF framework. Recommendations for enhanced clinical practice and for research based on the inclusivity of the ICF approach continue as different countries apply this concept in different ways (Rosenbaum & Stewart, 2004). In order to describe functioning across health conditions, and to develop a Generic ICF Core Set the ICF checklist data of 125 items from the Body Functions and Structures, Activities and Participation, and Environmental Factors of 1039 patients were regressed with one item of the SF-36. The patients from German rehabilitation centers had at least one of 12 chronic conditions, and the comorbidities were used as control variables (Cieza et al., 2006). The expansiveness of the ICF, the need for generic and condition specific Core Sets, with emphasis on functioning constitute an approach that could impact health services worldwide through research and the development of multivariate models (Stucki & Grimby, 2004).

The validity of the ICF basic conceptual model in terms of exhaustiveness has been accepted. While the objective components of the ICF classify functioning, the same components may focus attention on the subjective concept of QOL. "Since *Quality of Life* can be defined as an individual's perceptions of the domains of *objective well-being*, the ICF with its domains ranging from health to health related and non-health aspects can thus serve as the basis for an operationalization of Quality of Life" (Cieza & Stucki, 2008, p. 311).

ICF Applications

The basic ICF model has been used in a number of studies in clinical practice and in research across disciplines. The treatment approaches for obesity using the ICF model, involves a combination of the model with a medical or social model for a more comprehensive approach (Forhan, 2009). Physical therapy management of low back pain using the ICF can guide the prioritizing of a choice of treatments. The integration of Personal and Environmental Factors into the main components of the ICF allows adjunct educational interventions and work adjustments to optimize treatment (Rundell, Davenport, & Wagner, 2009). A graphical example using the ICF in clinical practice for acquired brain impairment with category level coding trees can create a scheme for the delineation of patient status, clear documentation, and application to research (Tate & Perdices, 2008). The majority of the concepts from three different occupational therapy models can be linked, and analyzed for differences and similarities, with the ICF. The authors suggest that occupational therapists pursue use of the ICF for multidisciplinary and global impact (Stamm, Cieza, Machold, Smolen, & Stucki, 2006).

The ICF has provided a basis for the evaluation of tools designed to assess clinical conditions. The regrouping of the 39-Item Parkinson's Disease Questionnaire was substantiated as an indicator of the main components of the ICF (Nilsson, Westergren, Carlsson, & Hagell, 2011). The Physical Therapist Clinical Reasoning and Reflection Tool, designed for the improvement of professional skills, uses the ICF to shape patient evaluation procedures (Atkinson & Nixon-Cave, 2011). The use of the ICF as a classification system and as an evaluation guide allows the identification of the primary impairment and the primary activity limitation. The process of including Environmental and Personal Factors has facilitated goal setting and treatment regimes for patellar dislocation (Helgeson & Smith, 2008). Stroke rehabilitation requires the collaboration of various disciplines, and the ICF is well suited to this (Allan et al., 2006).

Curriculum design for physical therapist education has been proposed using the ICF to promote a paradigm shift from a disablement medical model to a constituents-of-health approach. The educational plan, professional practice expectations, and practicum experiences were reflected in both the overall curriculum plan and in a specific course application, "Healthcare Management of Persons with Musculoskeletal Health Conditions." The determinations of an individual's disability included Body impairments, Activity limitations, Participation restrictions, and the impact of Environmental Factors upon an individual's functioning (Yoder, 2004).

The literature contains examples of other models that have been constructed by using the ICF framework. This is advantageous when assessing the influence that Environmental Factors have on the functions of persons with disabilities. Outcome measurements for the use of assistive technology reflecting Participation Factors have been used to develop a model justifying accommodation of the environment in the work setting (Schreuer, 2009). An integrated model of physical therapist clinical reasoning was developed for use throughout a rehabilitation cycle while addressing evidence-based practice guidelines (Rundell et al., 2009). The Rehabilitation Problem-Solving Form, based on the ICF, was developed to coordinate patient and clinician viewpoints in decision-making, treatment, and reassessment throughout a rehabilitation program. It has been shown to be successful in analyzing chronic pain. The complicated coding of the ICF is secondary to the benefits of the problem-solving routine (Steiner et al., 2002).

The *International Classification of Functioning, Disability and Health—Children and Youth Version* ICF-CY, developed for policy, practice, and research, covering ages birth through 17 years, includes coding for learning, other developmental activities, and developmental delay (Simeonsson, 2009; WHO, 2007a). The ICF and the ICF-CY have been used in various clinical conditions to create functional profiles in which the Environmental Factors may influence performance. This knowledge in turn guides intervention strategies across disciplines (Leonardi & Martinuzzi, 2009). Parent reports provide information that can be used to establish goals for rehabilitation disciplines. The ICF-CY coding can assess a child's needs, relative to functioning and the environment. The interdisciplinary nature of the rehabilitation field is easily fueled by collaboration guiding intervention using the ICF-CY (McDougall & Wright, 2009).

The WHO, through its ICF-CY, verified specific ASD diagnostic tools that can be used to evaluate the multidimensional functional aspects of life (Castro, Ferreira, Dababnah, & Pinto, 2013; WHO, 2007b). This integration of assessment tools with functional criteria permits the individualization of interventions across disciplines, including rehabilitation and educational programs for children with ASD. Thus, the use of such a classification system for diagnostic outcome can be extrapolated for use in other outcome measures—just as an earlier version of the WHO ICF used in adult populations (WHO, 2001). The ICF-CY, derived from the ICF, and the ICF are currently being merged so that an enhanced consolidated tool will address conditions throughout the lifespan (WHO FIC Advisory Council, 2012).

There are some indications of disapproval of the ICF framework in the literature. One suggestion is that the ICF is not a biopsychosocial model, and should be amended to include another perspective in order to address inequality (Conti-Becker, 2009). Others feel that the ICF does not present functioning as a dynamic process in which an individual interacts with the environment (Masala & Petretto, 2008). Criticism of the ICF for application in certain situations generally results in suggestions for adaptations or additions to the framework. One example, specifically in the field of special education, is the recommendation for a preferred social-relational model over the alleged ICF disability model that may not address empowerment, capability, discrimination, and oppression (Reindal, 2009).

ICF Conceptual Model Justification

The ICF provides an appropriate conceptual model for this investigation. It has been used in studying the activities and participation of adolescents with ASD in Singapore from which the Activities and Participation Rating Scale (52 items from 9 domains of the ICF) was developed. The questions, with prompting, were administered by an interviewer to the parents of 20 adolescents. The initial descriptive data analysis consisted of means and standard deviations for the ordinal 5-point rating questions, so full interpretation of the findings may not be apparent (Poon, 2011).

The ICF has been shown useful as a framework beyond providing an international classification system. The majority of applications of the ICF cover numerous health conditions, assessment tools, intervention tactics, and cultural phenomena while guiding clinical practice and research in the years since its publication. When WHO began to focus on the GBD and found that non-communicable diseases accounted for over half of the GBD (WHO, 2008), the usefulness of the ICF became more apparent. The ICF offered insight into those environmental factors that have an impact on areas of participation, such as education, transportation, or housing, which may be determinants of health as well (Ustun et al., 2003)

Autism Spectrum Disorders

The CDC estimated prevalence of ASD in 2011-2012 for children aged 6-17 years, is 1 in 50. These data were acquired through telephone survey of a nationally representative sample (Blumberg et al., 2013). The trend in prevalence rates can be viewed in CDC network data. Surveillance case definition occurs when a child's evaluation records included the diagnosis of ASD, determined by the Diagnostic and Statistical Manual-IV, Text Revision, for autistic disorder, pervasive developmental disorder–not otherwise specified, including atypical autism, or Asperger syndrome (APA, 2000). The sequence of identifying cases involved a review of records of pediatric clinics, programs for children with developmental disabilities, and public school special education services by trained clinicians who then examined the abstractions in keeping with procedures in the Autism and Developmental Disabilities Monitoring (ADDM)

Network sites. The CDC surveillance data, based on the ADDM Network, for the first surveillance year 2000, was 1 in 150 (6.7 per 1,000) 8-year-old children. The prevalence for 2002 was 1 in 150 (6.6 per 1,000), for 2004, 1 in 125 (8.0 per 1,000), and for 2006 1 in 110 (9.0 per 1,000). The prevalence for 2008 was 1 in 88 (11.3 per 1,000), and 1 in 68 (14.7 per 1,000) in 2010. The increase in prevalence is noted to be a result of the increased attention to the developmental disability of ASD, improvements in access to care, and improved identification in subgroups. The lack of representativeness of the sample sites has contributed to a lack of generalizability for prevalence estimates of ASD in the United States while the ADDM is recognized as the formal data gathering network ("Prevalence of autism," 2014; "Prevalence of autism," 2012). Autism as Title I under the Children's Health Act of 2000 received recognition, funding, and research, thus the ADDM Network was established ("H.R. 4365--106th Congress: Children's Health Act of 2000," 2000).

A comparison of studies published after 1997 reveals findings summarizing the epidemiology of ASD. Certain populations are underrepresented in epidemiological studies, including rural areas, immigrant and ethnic minority origin. The median population age in a review of 37 studies is eight years. The larger the sample size, the lower the prevalence estimate is for ASD. Later studies are shown to be associated with a significantly higher prevalence estimate, with the median range prevalence set at 13 per 10,000 population. The use of different diagnostic criteria can result in a two or threefold increase in the rate of occurrence of ASD. The previously mentioned influences of awareness, diagnosis factors and other referral issues are thought to be confounders that result in inaccurate statistical findings. The age-related component in earlier diagnosis, associated with increased services, might not necessarily indicate an increased incidence. The increasing prevalence, although not directly related to an increased incidence, is attributed to changes in the diagnostic criteria, increased services and awareness (Fombonne, 2005).

The identification of children with ASD in the United States is escalating. There is general agreement that more children are identified as having ASD due to an increased awareness of the disorders among both the health care providers and private sectors. Educators recognize problems associated with social functioning and related activities in the school environment resulting in further identification of characteristics associated with ASD in school-age children. Whether or not there is an actual increase in the incidence of ASD is attributed to the variation in interpretations of incidence and prevalence statistics, the difficulty in comparing different studies, and the inconsistent diagnostic criteria among the several categories of ASD. As more definitive diagnostic criteria are established, there appears to be a general consensus regarding the increase in prevalence of ASD (Fombonne, 2005; Williams, Mellis, & Peat, 2005).

The diagnostic dilemma of ASD has confronted the medical community, the educational system, and parents of children with ASD. A psychiatrist, Dr. Leo Kanner, described autism in 1943, at Johns Hopkins Hospital. The three impairments in autism noted by Kanner were "social difficulties, communication problems, and repetitive and restricted activities" (p. 2). Two years later, a German pediatrician, Hans Asperger, observed symptoms similar to those identified by Dr. Kanner. The term autism, derived from "autos" the Greek word for self, reflects the affective and behavioral syndrome characteristics. In the 1970s the word "spectrum" was applied to describe the characteristics of autism to address the tremendous variation in symptomatology (Hall, 2012).

Autism refers to Autistic Disorder or to the encompassing terms ASD. The disorder is classified as a developmental disability, and has varying manifestations, the most common of which include social interaction dysfunction and repetitive, stereotypical behaviors. Communication deficits are the hallmark and most limiting problem for individuals, families and caregivers of persons with ASD. According to the DSM-IV, applicable at the initiation of this study, ASD included Autistic Disorder, Asperger Syndrome, Pervasive Developmental Disability–Not Otherwise Specified (PDD-NOS), Rett's Syndrome, and Childhood Disintegrative Disorder. The terminology of ASD is synonymous with Pervasive Developmental Disorder (Autism Fact Sheet) (Centers for Disease Control and Prevention). The DSM-IV classification has recently been revised (DSM-V) by the American Psychiatric Association (APA) with a single diagnostic category, Autistic Disorder, with symptoms beginning in early childhood in two areas: social communication and interaction and restricted repetitive behaviors. The single DSM-V diagnostic category now includes the DSM-IV four separate diagnoses of Autistic Disorder, Asperger Syndrome, PDD-NOS, and Childhood Disintegrative Disorder (APA, 2000, 2013).

The wide variation in individual manifestations of ASD has been perplexing for health care providers, educators, and for families of children with ASD. This contributes to disagreement over diagnostic criteria and recognition of the symptoms of ASD. There were as many as fourteen different classification systems of instruments used in assessing the prevalence of ASD in two reviews of the epidemiology of autism. These deviations in guidelines reveal the enormous burden of achieving a correct diagnosis in countries worldwide. The unchartered arena of ASD with subcategories, typical and atypical manifestations further complicates the specificity and clarity of diagnosis. Methodological procedures and population characteristics, such as age ranges, are responsible for discrepancies in the same countries, resulting in differences in findings (Williams et al., 2005).

Data from the 2011 Survey of Pathways to Diagnosis and Services shows that identification of children, aged 6-17 years, with special health care needs and ASD occurs at a median age of five years. Over half of children in this school-age range were diagnosed at age five years and over, less than 20% identified within the first two years of life. Those children identified younger than five years, were diagnosed by generalists (pediatricians, family physicians, and nurse practitioners) and psychologists. Children identified at age five years and over were diagnosed by psychologists and psychiatrists. Nine of ten children with special health care needs and ASD use one or more of eight healthcare services: behavioral intervention or modification services; sensory integration therapy; cognitive based therapy; school-based occupational therapy or other occupational therapy; school-based physical therapy or other physical therapy; school-based social skills training or other social skills training; school-based speech or language therapy or other speech or language therapy; and alternative healthcare or treatment. Younger children, aged 6-11 years, were more likely to use three or more services compared to children aged 12-17 years. Younger children received more occupational and speech or language therapy than older children. Social skills training and speech or language therapy were the most commonly used services by all children. Forty percent of the children used behavioral intervention or modification services. Over 50% of the children used psychotropic medication. In decreasing order of use, other medications used by the children included stimulant, anti-anxiety or mood-stimulating, antidepressant, sleep, antipsychotic, and antiseizure medications (Pringle, Colpe, Blumberg, Avila, & Kogan, 2012).

Children with ASD also experience other health problems and these comorbidities further complicate their lives and increase their need for healthcare services and for caregiving. A literature review of ASD and comorbid conditions found four categories of comorbid conditions (examples in decreasing number of studies): physical conditions (epilepsy, sleep disturbance, gastrointestinal disorders, allergic and autoimmune disease, developmental coordination disorder, deafness, neurological conditions, seizures, obesity, and other medical conditions), comorbid psychopathology (general psychopathology, anxiety, depression, schizophrenia/psychosis, obsessive compulsive disorder, tics and Tourette's, bipolar disorder, and others), challenging behaviors (general, stereotypies, offenders, aggression, self-injurious, disruptive, and selective eating), and intellectual disabilities (associated with genetic conditions) (Matson & Goldin, 2013). Infants and toddlers with ASD were found to have significantly higher psychopathology symptoms than an atypically developing peer group (Konst & Matson, 2014).

The burden of ASD extends beyond financial, health care and educational systems, to more basic QOL considerations. National surveys yield data showing that children with ASD have higher health care utilization and require specialized educational programs (Liptak, Stuart, & Auinger, 2006). Lifetime costs include care throughout life for individuals with ASD, in addition to loss of parental productivity (Ganz, 2007).

The standard of care for children with ASD is embedded in a family centered approach. The development and reinforcement of communication skills, social skills, and behavior require constant implementation throughout the daily life activities in and out of the home of a child with ASD. Best practices from the medical interventions and educational environments should be continued in the home environment (Ruble, Heflinger, Renfrew, & Saunders, 2005). This family centered approach requires the additional parental roles of educator, therapist and advocate (Zeman, Swanke, & Doktor, 2011). A child with ASD may have sensory integration problems that interfere with the performance of activities of daily living and with learning skills in basic developmental sequences. This extends and increases the requirements of care needed from parents and from family members. The families of children with ASD face continuous challenges that can range on a wide continuum. The requirements of providing care to a child with ASD are recognized to elicit stress among family caregivers and a lower QOL. The increased parenting responsibilities can be a burden for the entire family. The adaptation to stress in coping with a child with ASD is related to the family itself and to the community. Sources of support include friends, other families in similar situations, community agencies, special programs, and spiritual support (Twoy, Connolly, & Novak, 2007).

The reaction to the diagnosis of ASD in a child, previously anticipated as being normal, may be emotionally, psychologically, and physically stressful. Singapore parents of children receiving services experienced a delay of about one year between raising their concerns and the diagnosis of ASD. Parents valued information on ASD from professionals, and expressed moderate satisfaction with their collaboration. Parental stress was increased with a higher number of professionals consulted. However, neither collaboration nor number of professionals consulted were significant predictors of parental stress (Moh & Magiati, 2012). An online survey of U.S. parents of children with ASD, predominantly female, showed the presence of posttraumatic stress symptoms associated with the diagnosis of ASD in 20% of the participants. The survey included demographic questions and two established questionnaires (Casey et al., 2012). Telephone interviews were conducted with 50 mothers of children with ASD identified through a large cohort study of nurses' health. These mothers were more likely to have posttraumatic stress syndrome symptoms than mothers of children without ASD (Roberts, Koenen, Lyall, Ascherio, & Weisskopf, 2014). A ten year study of participant data from a national ASD center in Israel for 551 children showed that social impairments and the presence of developmental regression were associated with an earlier age at diagnosis whereas restricted repetitive stereotypical behavior delayed the age of ASD diagnosis. Most of the parents reported socio-emotional development concerns (Mishaal, Ben-Itzchak, & Zachor, 2014).

The culmination of demands associated with continuous care for a child with ASD throughout the day and night hours may result in overload on the family. Historical identification of the caregiving needs has been established in the literature. Caring for the needs of a child with a chronic or long-term disability requires coping with stresses of daily activities through the lifespan. The obligations and the requirements of care extend over years and are associated with chronic strain (Beresford, 1994). Parents who have a child with a disability adjust through phases of understanding the medical condition, accepting the diagnosis, and meeting the needs of the child (Miller, Gordon, Daniele, &

Diller, 1992). Individual, marital, and family burden was increased in caregivers following a diagnosis of ASD within six months. Higher stress was associated with increased individual burden while social support was associated with decreased individual and marital burden. The authors distinguish between general and contextual support warranting further research. The three levels of burden were negatively associated with a negative appraisal of caring. There was a high correlation between individual caregiver and family burden (Stuart & McGrew, 2009). Mother caregivers of children with ASD experience stress as a result not only of the mechanical aspects of providing care, but of the internal reactions inherent to responsibilities throughout the lifespan. These caregiver obligations and challenges include negotiating the social environment and physical obstacles when taking a child with ASD out of the home while the possibility of spontaneous disruptive behavior manifestations may occur. The caregiver burden may affect the functioning of the mother in the multidimensional QOL domains.

Quality of Life

Quality of life, as defined by the Constitution of the WHO, has historical underpinnings in the WHO definition of health "...a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (WHO, 1946). The Institute of Medicine recommends that research on women's QOL in terms of functionality (Institute of Medicine & Committee on Women's Health Research, 2010). Mothers of children with ASD may experience consequences upon their QOL as result of their caretaking role. Australian mothers of children with ASD, the majority male, with a mean age of 11 years reported a higher rate of mental health problems. Multiple regression analysis showed that time pressure was also higher in these mothers. Mothers with higher social support reported fewer mental health problems. Higher maternal depression was associated with less social support and more child behavior problems (Sawyer et al., 2010). Parent feelings of hope and despair toward their child with ASD should be considered when evaluating the well-being of the parent "...as these parents are faced with extraordinary parenting challenges and stressors" (Faso, Neal-Beevers, & Carlson, 2013, p. 295).

Qualitative research methods also reveal the variation in meaning of QOL, which contributes to the constructivist body of knowledge, but also widens the positivist realm of investigatory applications. Qualitative interview studies, generally conducted with small sample sizes, similarly address a limited number of demographic variables. For example, the mother's age, race/ethnicity, marital status, education level, household income, the child's age, age at formal diagnosis, and age at suspected diagnosis comprise the demographic information, in a study of mother's perspectives of ASD on family impact. The study included as participant, an aunt, as one of the eight mothers who participated in semi-structured interviews. Four major themes were identified: emotional impact with three subthemes (stress, worry, and guilt), family relationships impact with two subthemes (other children and spouse), social impact, and financial impact (Nealy, O'Hare, Powers, & Swick, 2012). Such qualitative studies not only elucidate the meaning of QOL, but expound on those Factors that may impact QOL in this vulnerable population.

Family Assets and Burdens

The behavioral and other health problems of children can be related to the QOL of the mother. Mothers of children with oppositional defiant symptoms (ODS) who are younger and of lower education level, have a lower QOL on four domains of the Taiwanese version of the WHOQOL-BREF, compared to children without ODS. The ODS of the children were a significant predictor of the mother's QOL on three domains of the WHOQOL-BREF (Lee et al., 2010). Parents, the majority being mothers, of children with celiac disease have significantly lower WHOQOL-BREF (Brazilian Portuguese version) QOL on the Social Relationships domain when compared to a control group. Lower income was associated with lower WHOQOL-BREF scores on three domains among parents of children with celiac disease while parents in the control group has lower QOL on two domains. Mothers of children with celiac disease with a lower education level had a lower QOL on two domains than mothers of a higher education level (de Lorenzo et al., 2012). The Italian version of he WHOQOL-BREF showed lower QOL domain scores in parents of children with PDD. Fathers had lower Psychological and Social Relationships domain scores, while mothers had lower Physical Health, Psychological and Social Relationships domain scores. A comparison of within PDD group differences found that mothers of children with high-functioning autism/Asperger's syndrome had significantly lower Physical Health and Social Relationships domain scores compared to controls (Mugno et al., 2007).

Families of children with disabilities react to stress with adjustment and adaptation. A ten-year longitudinal study on families of children with ASD found that the majority of parents reported improvement in psychological well-being (Gray, 2002). A literature review of positive functioning in families of children with a disability found the concepts of problem solving, family sense of coherence, positive coping, and positive adaptation. The emotional, cognitive, and behavioral components of the concepts, that may be associated with an individual family member's functioning and investigation of the relationship to QOL and well-being, has not been done (Ylvén, Björck-Åkesson, & Granlund, 2006).

Caregiver Considerations

Parent caregivers of children with Phenylketonuria have a lower QOL, assessed using the WHOQOL-BREF, which was influenced by occupation (or unemployment), depression, and anxiety to cause positive or negative changes in the QOL (Mahmoudi-Gharaei et al., 2011). Caregivers of children with cerebral palsy report a significantly lower QOL than those of normal children (Fatudimu et al., 2013). Mothers of children with ASD, in their caregiving role, are challenged to provide for and nurture a child who may not follow the expected developmental profile--that of moving from dependence toward independence. This added burden of lifelong caring adds considerable stress to QOL.

Parental QOL

A seminal study for this research with parents of children aged 2-18 years, with PDD recruited from a medical university setting, showed significantly lower QOL as measured using the Italian version of the WHOQOL-BREF (see Chapter III) and compared to parents of healthy children or parents of children with cerebral palsy or mental retardation. Demographic information included parental age, gender, education, health status, family status, and child age and gender. Mothers of children with PDD were found to have significantly lower Physical Health domain QOL than fathers. The study did not address parental socioeconomic status, age at diagnosis, comorbidities, nor treatment options of the children (Mugno et al., 2007).

Maternal QOL

Numerous studies reflect a lower QOL while mothering a child with ASD. Mothers of children with ASD have lower physical and mental health than those of children without ASD (Khanna et al., 2011). A structured interview study of 68 biological mothers of children with ASD found conflicting associations between the associated child specific developmental delays and behaviors, formal support, and maternal psychological wellbeing. However, this same study did find that maternal psychological distress was associated with child behavior problems and low levels of informal family support. Further study on the moderating effects of the social situation and the need for post diagnostic support was suggested (Bromley et al., 2004). Mothers of children with PDD who have more education, a higher income, and lower depression report more satisfaction with QOL (Fávero-Nunes & dos Santos, 2010).

The Taiwan version of the WHOQOL-BREF was used to assess the influence that caregiving for a child with ASD has on maternal QOL. Participants in the study, recruited from a volunteer support organization, met the criteria for being the primary caregiver for over 5 years, and being between 25-45 years of age. The demographics were maternal age, education, marital status, employment, religion, history of chronic disease, and their feelings about caring for a child with ASD. The mother's rated feeling (bad, fair, or good) of caregiving was found to be predictive of, and positively associated with, the Physical Health, Psychological, and Social Relationships QOL domains. The authors suggest that more children related factors and other support venues be considered in future research (Shu, 2009). This dissertation study will use the English version of the WHOQOL-BREF while expanding the Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors among mothers of children with ASD.

The choice instrument for the assessment of QOL provides credibility to this study based upon its use in similar research. The WHOQOL-BREF, grounded in the aforementioned conceptual model, presents an appropriate tool for this study (Carr & Higginson, 2001).

Limitations of Previous Research

Previous research on QOL among mothers of children with ASD has addressed associations using a limited number of demographic and comparison variables. These factors are indeed important to the characterization of the sample group, but the integration of an expanded number of Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors in a functional holistic conceptual framework has not been applied.

Summary

This chapter has presented the modified ICF conceptual framework for which the Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors can be related to the QOL among mothers of children with ASD. The QOL among mothers of children with ASD is susceptible to a number of risks among the ICF Factors. The impact of these Factors will be assessed through the methodology of the study presented in the next chapter.

CHAPTER III

RESEARCH DESIGN AND METHODOLOGY

This chapter describes the research design and methodology, sampling procedures, recruitment, data collection, survey instrumentation, and statistical analysis. The purpose of this study was to investigate the relationships among the Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors associated with QOL among mothers of children with ASD, while applying the modified ICF conceptual model (see Figure 3). The study was directed to further delineate the factors contributing to QOL among mothers of children with ASD, in order to identify modifiable interventions that could directly or indirectly enhance the QOL of these mothers. The following research questions were evaluated in a sample of mothers of children with ASD:

1. What are the Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors that characterize mothers of children with ASD?
2. What is the QOL, as measured using the WHOQOL-BREF, among mothers of children with ASD?
3. What are the significant relationships between the Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors among mothers of children with ASD, and the QOL of the mothers?

4. What are the predictive Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors among mothers of children with ASD for their QOL?

Study Participants and Data

A convenience sample of mothers of children with ASD participated in the study. Eligibility criteria, obtained from self-report, required that participants meet the following stipulations and affirm that they: (1) are the mother of a child with an ASD, (2) are at least 18 years of age, and (3) currently reside in the United States. The participants, a virtual community, were self-selected from encountering the recruitment email or recruitment Internet posting information on various websites, including Facebook (see Appendices A and B). The recruitment email requests and postings included a brief description of the study with a direct link to the survey. Informal criteria were used to identify agencies, national organizations, educational affiliations, and websites associated with ASD. National online organizations allowing posting of the research study in order to solicit participants, received a donation to the organization efforts. This recruitment strategy discouraged any inherent bias related to geographic location, income, healthcare, community resources, or other potential influences in the study participants. No incentive for participation was offered, although participants were informed of the importance of their contributions to the research study and to the existing body of knowledge.

Human Subject Protections

Human subject protections approval (No. 12-239) was requested and received through the Institutional Review Board (IRB) of Old Dominion University, Norfolk, Virginia (see Appendix C). Consent for participation was acquired, anonymity of data was ensured, participants were informed that they were free to not answer any questions, and could discontinue the study at any time. This information was addressed at the beginning of the survey so that participants could have full knowledge of the study provisions.

Research Design and Procedure

This study sought to examine the factors that predict QOL among mothers of children with ASD using the modified ICF conceptual model framework. The research design of this investigation was a descriptive cross-sectional study. The descriptive, correlational, and predictive relationships among the Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors and the QOL, acquired through an Internet survey method, in a convenience sample among mothers of children with ASD were statistically analyzed. This inquiry was designed to further the understanding of factors associated with QOL among mothers of children with ASD, and to test the modified ICF conceptual model variable relationships.

Methodology

The methodology for this study was an online survey. Collection of the data, initiated following receipt of IRB approval (see Appendix C), was performed using the internet survey service, *Qualtri*x, the mandated research vehicle through the auspices of Old Dominion University. Recruitment postings included an introduction of the researcher, eligibility criteria, and an explanation of the purpose of the research (see Appendices A & B). The survey was available through the recruitment link accessible via computer access, available at participant convenience. The survey began with a description of the questions and proposed time requirement, assurance of anonymity, an explanation to participants that the survey could be terminated without penalty. Consent for participation was placed at the initiation of the survey.

Advantages for the researcher conducting research through the Internet include the ability to reach a participant pool that would not otherwise be approached, and recruitment of an increased number of potential participants with special interests. The advantages for participants include anonymity, convenience, independence, interest, and ease of completion aspects. For mothers of children with ASD, the target group of respondents for this study, involved in the care of their child and in many other tasks and activities throughout the day and the night, the study methodology and inherent characteristics would constitute an appealing proposition. Further advantages of Internet survey research of lower cost, handling of sensitive issues, decreased time, researcher control, improved data accuracy and efficiency have been shown in a literature analysis of 48 articles drawn from various disciplines. The anonymity in the electronic data collection may also facilitate the respondent's inclusion of personal information (Ahern, 2005).

The method of data collection may influence the response rate, content and nature of self-reported data in health services research, while the context of data collection may contribute bias as well. The anonymity provided in this study's methodology reflects the privacy and impersonality that could improve the respondent's communication of personal information and be less likely to restrict disclosure of information. Survey and researcher legitimacy was presented through the *Qualtrix* interface as well as in the introductory survey information. Cognitive burden and the rate of missing data were reduced using the web-delivered survey method. By minimizing the task requirements, respondent engagement in the survey was optimized. This study methodology is also in keeping with the increased use of a standardized self-reported QOL measure as a patient-reported outcome measure, described in the next section (Robling et al., 2010).

Instrumentation

The survey consisted of 65 mixed-mode (multiple choice, checklist, and fill-in) response questions, presented in three sections. The first two sections included the researcher-constructed questions corresponding the to the ICF framework components (Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors) integrating pertinent factors from the background literature (WHO, 2001). Section I contained researcher-constructed questions about the mother, and Section II contained researcher-constructed questions about her child with ASD. The mothers were instructed to pick the oldest child with ASD on whom to focus survey responses if she had more than one child with ASD. Section III of the survey contained the full QOL assessment tool chosen for this study (WHOQOL-BREF), posted verbatim, described in the next paragraph. The instructions for the Section III questions asked that the mother think about her life in the past two weeks when answering the items. Thus the entire survey represented the modified conceptual model as proposed by Rosenbaum (2006) (see Figure 3), with the items of Sections I and II being the individual independent variables of the ICF components, and Section III representing the dependent variable QOL outcome measure (see Appendix D). The entire survey as posted is presented in Appendix E.

The choice of an instrument as a measuring device for the gathering of data should be a result of inquiry based not upon popularity, but upon reliability and validity standards. A quantitative instrument is better designed to handle both the subjective and multidimensional aspects of the QOL construct. The instrument chosen for assessment of the QOL of mothers of children with ASD was the World Health Organization Quality of Life- BREF (WHOQOL-BREF) (WHO, 1996). Permission to use the WHOQOL-BREF, and verification of the recommended scoring syntax, was received from and confirmed by the Seattle Quality of Life Group, University of Washington (see Appendix F) (G. DeNoble, personal communication, April 10, 2014). The WHOQOL-BREF is an abbreviated (26-item) form of the World Health Organization Quality of Life-100 (WHOQOL-100) ("The development," 1994; WHOQOL Group, 1998). The WHOQOL-100 containing 100 items using a five point rating scale, was developed to assess well-being by addressing health status rather than disease state, as an integrated holistic entity sustainable to cultural diversity. The WHOQOL-100 includes six domains (Physical Health, Psychological, Level of Independence, Social Relations, Environment, and Spirituality/Religion/Personal Beliefs, covering 24 facets, each with four items. Four general items assess the subjective overall QOL and general health. The WHOQOL-100 has internal consistency (0.82-0.95) and test-retest reliability (0.83-0.95) and construct validity (Bonomi, Patrick, Bushnell, & Martin, 2000).

The WHOQOL-BREF assesses four domains (merged from the original six) of the WHOQOL-100: Physical Health, Psychological, Social Relationships, and Environmental, taking one item from each of the 24 facets of the WHOQOL-100. Two additional items, reduced from the original four in the WHOQOL-100, assess overall

QOL and general health. These two individual items were not used in the statistical analysis for this research study. The WHOQOL-BREF correlates at 0.89 or higher with the WHOQOL-100 domain scores. The WHOQOL-BREF has good discriminant and content validity, internal consistency and test-retest reliability (Frank-Stromberg & Olsen, 2004). Excellent construct validity has been noted. Less than adequate content validity of the Taiwan version of the WHOQOL-BREF was shown in a study of undergraduate students and community adults when using rating and sorting quantitative methods (Grace, Chia-Huei, & Cheng-Ta, 2008). Field trials of the WHOQOL-BREF among sick and well respondents in 23 countries, including the United States, show it to be a sound and valid assessment of QOL. It has shown acceptable validity in three of four domains, with Cronbach's alpha in Physical Health 0.82, Psychological 0.81, and Environmental 0.80 and marginal validity in Social Relationships 0.68. It was predicted that all four domains would show a strong and significant association with overall QOL and general health, so construct validity was partially assessed by correlating the domain scores with the two general facet items (Skevington, Lotfy, & O'Connell, 2004).

A research review of 17 studies published from 1997 to 2006 measuring mothers' physical and emotional health identifies the WHOQOL-BREF as one of five measures of health related QOL. Two of the 17 studies have a sample of mothers of children with ASD, and one of those two studies used the WHOQOL-BREF (Allik et al., 2006; Coyle, 2009; Shu & Lung, 2005). The WHOQOL-BREF correlates well with child functional measures among caregivers of children with cerebral palsy receiving physical therapy for motor disabilities in Nigerian hospitals when compared to caregivers of normally developing children. This provides information regarding QOL for caregivers of children with functional limitations; when improvements were shown in child functional status, improvements were seen in QOL (Fatudimu et al., 2013).

The individual items of the WHOQOL-BREF have been found to be relevant in cross-cultural research as studied in 14 countries using 12 languages. Differences in item ratings were seen by women and by young adults, although income and education were addressed (Saxena, Carlson, Billington, & Orley, 2001). The WHOQOL-BREF has also been used to assess QOL in parents of children with autism (Mugno et al., 2007; Shu, 2009).

The ICF has also been proposed as a framework for the evaluation of interdisciplinary assessment tools. A comparison of how five different QOL indices correspond to function and extend to global feelings of well-being was conducted. The 26 items of the WHOQOL-BREF items were individually mapped to the ICF codes by 15 trained raters. Seven items (27%) of the WHOQOL-BREF were associated with predominant function codes by 70% of raters. Five items corresponded to satisfaction with function, five items with the environment (more items than other indices), four items with satisfaction with environment, while four items were not associated with function. Six items of the WHOQOL-BREF were found to be QOL or health-related items (Mayo, Moriello, Asano, Spuy, & Finch, 2011).

Although the Personal Factors are not classified in the original ICF system, some studies have used the component for the mapping of Personal Factors. This allows for individualization in consideration of relevant factors for specific and diverse populations. The further mutability of the modified conceptual ICF framework for a target population is demonstrated in the purposeful and practical application of the model components for which it was designed, and is therefore appropriate in this study of QOL among mothers of children with ASD.

Operational Definitions

The operational definition for each variable, assigned as the response to the individual or group of survey items, located and grouped within the modified ICF conceptual model components is presented in Appendix D. The alignment of the ICF components with the corresponding independent variable designation was previously shown in Figure 1. The actual survey items, with respective individual item response categories, are presented in Appendix E, the survey questionnaire as it appeared to the study participants.

Statistical Analysis Plan

The statistical analysis plan is presented in the following sections according to each research question. This orderly presentation introduces the building of statistical models to ultimately describe those factors associated with QOL among mothers of children with ASD.

Research Question 1. What Are the Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors That Characterize Mothers of Children With ASD?

Univariate descriptive analysis of the study participants was conducted. The distribution of each categorical factor, the majority of the independent variables, was described in frequency of occurrence and in relative frequency, i.e., the percentage of respondents. The distribution of the five continuous factors (gestation length, mother caregiving hours, child age, child age at diagnosis, and other caregiving hours) was assessed visually and tested for normality. Where values were approximately normally distributed, they were described using the mean, standard deviation, median, interquartile range (IQR), and the minimum and maximum values for the continuous variables.

The response options to the five categorical multiple response survey items became individual variables for the analysis. Each of the responses for these five items was analyzed as a separate variable since the mothers could choose more than a single response for the survey items. The survey items and respective response choices were: Please check any health problems for which you currently receive treatment (anxiety, arthritis, cancer, depression, dermatological problems, diabetes, high blood pressure, gastrointestinal problems, musculoskeletal problems, neurological problems, pain, other medical condition, and other mental health problem); What areas of your life are **negatively** affected by caring for your child with ASD (no areas are negatively affected, family relationships, other relationships, physical health, mental health, sports/recreational activities, social activities, spirituality)?; What areas of your life are **positively** affected by caring for your child with ASD (no areas are negatively affected, family relationships, other relationships, physical health, mental health, sports/recreational activities, social activities, spirituality)?; Please check any health problems for which your child with ASD is currently receiving treatment (anxiety, behavioral problems, depression, feeding problems, gastrointestinal problems, musculoskeletal problems, seizures, sensory integration problems, toe walking, other medical condition, other mental health problem); and, What therapy services does your child with ASD currently receive (no therapy service, occupational therapy educational setting, occupational therapy medical setting or clinic, physical therapy educational setting, physical therapy medical setting or clinic, speech therapy educational setting, speech therapy medical setting or clinic).

There were five categorical items that allowed an option for a fill in response: race, ASD diagnosis, child classroom type, information source, and emotional support. The fill-in responses were coded as "other."

Research Question 2. What is the QOL, as Measured Using the WHOQOL-BREF, Among Mothers of Children With ASD?

The distributions of the WHOQOL-BREF scores for the four domains (Physical Health, Psychological, Social Relationships and Environmental) were assessed visually and tested for normality. Where values were approximately normally distributed, they were described using the mean, standard deviation, and the minimum and maximum values for each domain. The scoring for the WHOQOL-BREF followed established guidelines for the instrument, as published by the WHO Group in Seattle, Washington, USA and by the WHO Group in the WHOQOL-BREF manual ("Syntax file," 1997; WHO, 1998). The syntax used for the computation of the WHOQOL-BREF scores is presented in Appendix G. Follow-up confirmation was received from the WHOQOL Team regarding the scoring syntax recommendations (S. Chatterji, personal communication, April 14, 2014; S. M. Skevington, personal communication, April 14, 2014). Missing values on the WHOQOL-BREF were coded as missing and were not calculated. Neither imputation nor the rates of missing values have been shown to affect accuracy in the WHOQOL-BREF Taiwan version assessment (Lin, 2006). Published studies using the WHOQOL-BREF often show variation in score reporting and uncertainty regarding specific scoring syntax used for the calculation of the scores. It is helpful to clearly identify the scoring syntax used in order to reinforce interpretive conclusions. An example of this detailed inclusion is found when applying the WHOQOL-BREF in new populations (Colbourn, Masache, & Skordis-Worrall, 2012).

Research Question 3. What Are the Significant Relationships Between the Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors Among Mothers of Children with ASD, and the QOL of the Mothers?

Regression analysis was used to determine the relationship between each of the categorical and continuous independent variables and the dependent WHOQOL-BREF domain scores. A total of 81 variables were individually regressed with each of the four QOL domains. There were six survey items: mother age, mother comorbid condition with 13 options, mother sleep hours, mother age at conception, gestation length, and pregnancy problems in the Body Functions and Structures Factors that were regressed with each of the four QOL domains (Physical Health, Psychological, Social Relationships, and Environment). There were three survey items: employment, employment location, and mother caregiving hours in the Activities Factors that were regressed with each of the four QOL domains. There were six survey items: significant other relationship affected, spirituality association, life areas affected negatively with eight options, life areas affected positively with eight options, information source, and emotional support in the Participation Factors that were regressed with each of the four QOL domains. There were 18 survey items: number of adults in household, number of children in household, number of children with ASD, father age at conception, child age, child gender, child age at diagnosis, time to diagnosis, ASD diagnosis, child healthcare coverage, child healthcare coverage military, child comorbid conditions with 11 options, child sleep hours, child assistive technology, child therapy type with seven options, child classroom setting, other caregiver, and other caregiver hours in the Environmental Factors that were regressed with each of the four QOL domains. There were six survey items: mother education, mother race, marital status, mother income level, mother healthcare coverage, and mother healthcare coverage military in the Personal Factors that were regressed with each of the four QOL domains. This resulted in a total of 324 individual linear regressions, i.e., 81 for each of the four QOL domains.

The strength and direction of the relationship in the best-fitting linear regression lines were determined. Dummy variables were created for each categorical variable as needed. Assuming the distribution of the QOL domains were approximately normal, a simple linear regression model was fit against each independent variable. Significance of the model indicated that the independent variable was significantly related to the QOL domain. Coefficients were interpreted appropriately to describe the relationship between each independent variable, or significant factor and the QOL domain. The level of significance was set at 0.05.

Research Question 4. What Are the Predictive Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors Among Mothers of Children With ASD for Their QOL?

This study is based upon the modified ICF conceptual model (Rosenbaum & Stewart, 2004). The advantages of applying a regression statistical analysis to the study data is based upon existing literature and upon clinical judgment seeking practical applications for the findings. "...regression modeling enables a better understanding of the relative contribution of individual ICF categories in relation to others" (Cieza et al., 2006, p. 12).

Assuming the distribution of the QOL for each of the four WHOQOL-BREF domains was approximately normal, a backward stepwise regression model was fit against the significant factor-related variables from the results of Research Question 3, for each of the five ICF components. A sixth backward stepwise regression model was fit against the "All Significant ICF Component Factors," the combined significant factors from all five ICF components for each of the four WHOQOL-BREF domains. The additional sixth regressions were done to develop models for each of the four QOL domains using the "All Significant ICF Component Factors." These models demonstrated the significant Body Functions and Structures, Activities, Participation, Environmental, Personal, and the All Significant ICF Component Factors regression results, again with each of the four QOL domains. A total of 24 multiple linear regression models were developed to answer Research Question 4. Stepwise multiple regression analysis was used to determine the relationship between each of the continuous and categorical independent variables that were found to be individually significant, grouped, and then summed. This procedure was implemented according to the Body Functions and Structures, Activities, Participation, Environmental, Personal, and All Significant ICF Components Factors, and the dependent variables for each of the four WHOQOL-BREF domains. Dummy variables were created for each interval categorical factor variable.

A stepwise regression can start with all potential variables in a model and proceed backward (removing one variable at a time). At each step, calculations are performed for each variable currently in the model while simultaneously calculating the t-statistic for its estimated coefficient. It is squared and reported as an "F-to-remove" statistic. For each variable not in the model, it computes the t-statistic that its coefficient would have if it were the next variable added, squares it, and reports this as its "F-to-enter" statistic. At the next step, the program automatically enters the variable with the highest F-to-enter statistic, or removes the variable with the lowest F-to-remove statistic, in accordance with specified control parameters. So the key relation is: F = t-squared. A stepwise regression was performed that began with all of the variables, and a model was fit against each factor-related variable (Daniel & Cross, 2013).

Stepwise multiple regression to determine the effect of a number of independent variables on the dependent variable gave the equation that best described the data, the overall variance explained by the model, the statistical significance of the model, which independent variables were statistically significant contributors to the model, and the unique contribution (strength and direction) of each significant independent variable. The assumptions that underlie the application of stepwise multiple regression were: a parametric test, a roughly normal distribution of the dependent variable, a linear relationship between the dependent variable and the independent variables, homogeneity of variance (for each value of the independent variable, the variance of distribution of the dependent variable is equal), and the absence of colinearity (strongly inter-correlated independent variables). Finally a model was fit for each QOL domain using only significant variables within each factor, and then for all factors combined, to describe how the Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors influenced each QOL domain (Physical Health, Psychological, Social

Relationships, and Environmental), and also how the combination of All Significant ICF Component Factors predicted each QOL domain. The final six factor models were fit using the backward elimination approach for each of the four QOL domains. Coefficients were interpreted appropriately to describe the relationship between each significant factor and the QOL domain. The level of significance was set at 0.05.

Power and Sample Size Estimate

To achieve answers to Research Question 3, assuming no adjustment for confounding, the linear regression test of $\rho=0$ ($\alpha= 0.050$ two sided) for each normally distributed QOL domain would have 90% power to detect ρ of -0.250 when the sample size is 160. This test would have 80% power for a sample size of 120. The correlation between mother caregiving hours and QOL domain = ρ was based on the correlations found specifically between Physical Health and Environmental QOL domains. The Pearson correlation coefficients were -0.253 and -0.261 respectively (nQuery Advisor 7.0). The correlation analysis for the power and sample size estimate was conducted on the WHOQOL-BREF scores as computed using the Seattle WHOQOL Group syntax ("Syntax file," 1997).

Summary

Chapter III justified the research design and methodology for the assessment of factors associated with QOL among mothers of children with ASD. The statistical analysis plan coordinated the modified ICF conceptual model with a depiction of the relationships between the independent and dependent variables. Thus the need for this study as a quantitative investigation in health services research has been bolstered with a solid framework and rationale.

CHAPTER IV

RESULTS AND DISCUSSION

The results of the statistical analysis of the study data are presented in this chapter. Findings are organized according to the Research Questions. The descriptive characteristics of the Body Structures and Functions, Activities, Participation, Environmental, and Personal Factors answer Research Question 1. This is followed by an illustration of the QOL domain scores among mothers of children with ASD, the results of Research Question 2. The significant relationships of the individual Body Structures and Functions, Activities, Participation, Environmental, and Personal Factors among mothers of children with ASD, with the QOL of the mothers comprise the answers to Research Question 3. Finally, the models developed to demonstrate how the ICF Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors influence and predict the QOL of the mother, Research Question 4 solutions, conclude the chapter. The dependent variable, QOL, is presented in the four WHOQOL-BREF domains of Physical Health, Psychological, Social Relationships, and Environmental.

Study Participants and Data

Study recruitment via Internet postings and email promoted the acquisition of a nationally representative sample group of respondents. This method disallowed any sample selection that would result in bias while controlling for distinguishing and differentiating characteristics of the healthcare and educational services in the United States.

The survey was available online for approximately six months. Data were obtained with the mandated Old Dominion University *Qualtrix* Internet research survey service. The researcher and author of this study did not have direct access to *Qualtrix*. The survey data was received in exported Excel and SPSS file formats. The study data set was managed in SPSS (21.0) and Excel formats as well as follow-up in SAS v9.1 (Cary, NC). Management of the data included cleaning with the exclusion of incomplete surveys. Descriptive analysis was completed in SPSS. Missing item responses were not assigned a default value, and were coded as system missing. This dataset, exported to Excel, including any further data management to facilitate the inferential analysis was initially conducted in SAS.

The data were cleaned for inclusion in the analysis. A total of 197 individuals accessed the survey website. The first three qualifying items, required verification that the respondent was the mother of a child with ASD, 18 years of age or older, and a current resident of the United States. The survey began with 39 items, researcher-constructed questions in the first two sections addressing the Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors among mothers of children with ASD. The final 26 items were those of the WHOQOL-BREF instrument assessing four domains of QOL (see Appendix E). Thirty respondents either did not qualify to be included in the study (having a negative response to any of the three qualifying questions) or they did not complete the survey by not answering the final 26 WHOQOL-BREF items, resulting in an absence of the dependent variable QOL scores. This left a study sample size, n=167, of qualifying respondents. The data were additionally assessed for accuracy of response entry and missing values, which resulted in a removal of an additional eighteen questionnaires leaving a sample size of n=149, which exceeded the sample size of 120 required for 80% power. The actual response rate was not calculated due to the inability to assess the number of potential respondents who visited but did not enter the posted survey site (Rhodes, Bowie, & Hergenrather, 2003). Finally, an evaluation of the errors for each variable within the domains was determined to have a normal distribution within the respondent population, which is desirable in any analytical procedure.

The data entries for the independent variables of the first 39 survey items were straightforward. The single response, multiple response, and continuous variable item responses were coded as entered by the respondent, with adjustments as described in the previous chapter. The scoring of the WHOQOL-BREF followed recommended procedures for the reverse coding of three items, and the calculation of domain and transformed domain scores. Missing item responses were coded as system missing according to the WHOQOL-BREF scoring procedures and SPSS syntax ("Syntax file," 1997; WHO, 1998) (see Appendix G).

Research Question 1. What Are the Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors That Characterize Mothers of Children With ASD?

The Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors that characterize mothers of children with ASD are the independent variables. These are described in corresponding univariate frequencies for the categorical variables in Table 1, and for the continuous variables in Table 2.

Table 1

Categorical Independent Variable Descriptive Statistics, n = 149

ICF MODEL COMPONENT Independent Variable Factor	n	% of respondents
BODY FUNCTIONS AND SRUCTURES		
Mother Age		
18-24 years	1	0.7
25-34 years	27	18.1
35-44 years	70	47.0
45-54 years	43	28.9
55 years and older	8	5.4
Mother Comorbid Conditions		
Anxiety	47	44.8
Arthritis	17	16.2
Cancer	4	3.8
Depression	51	48.6
Dermatological Problems	11	10.5
Diabetes	11	10.5
High Blood Pressure	23	21.9
Gastrointestinal Problems	23	21.9
Musculoskeletal Problems	13	12.4
Neurological Problems	11	10.5
Pain	29	27.6
Other Medical Condition	45	42.9
Other Mental Health Problem	12	11.4
Mother Sleep Hours		
Less than 4 hours	5	3.4
4-5 hours	21	14.1
5-6 hours	66	44.3
7-8 hours	53	35.6
More than 8 hours	4	2.7
Mother Age at Conception		
Under the age of 18	2	1.4
18-24 years	33	22.8
25-34 years	89	61.4
35-44 years	19	13.1
45-54 years	2	1.4
Pregnancy Problems		
No	90	62.5
Yes	54	37.5
ACTIVITES		
Employment		
Unemployed	62	42.2
Part-time	34	23.1
Full-time	51	34.7

Table 1. *Categorical Independent Variable Descriptive Statistics, n = 149* (continued)

ICF MODEL COMPONENT		
Independent Variable Factor	n	% of respondents
Employment Location		
Home	36	24.5
Other than home	111	75.5
PARTICIPATION		
Significant Other Relationship Affected		
No change	54	36.5
Negative Change	72	48.6
Positive Change	22	14.9
Spirituality Association		
No	66	44.3
Yes	83	55.7
Life Areas Affected Negatively		
No areas	8	5.4
Family Relationships	88	59.1
Other Relationships	79	53.0
Physical Health	55	36.9
Mental Health	94	63.1
Sports/Recreational	58	38.9
Social Activities	127	85.2
Spirituality	32	21.5
Life Areas Affected Positively		
No areas	25	17.4
Family Relationships	79	54.9
Other Relationships	54	37.5
Physical Health	13	9.0
Mental Health	9	6.2
Sports/Recreational	11	7.6
Social Activities	17	11.8
Spirituality	63	43.8
Information Source		
Health Care Provider	35	23.6
Spouse	1	0.7
Health Care Provider	35	23.6
Spouse	1	0.7
Other family	2	1.4
Friend	1	0.7
Teacher	2	1.4
Therapist	20	13.5
Support Group	15	10.1
Internet	30	20.3
Other	42	28.4

Table 1. *Categorical Independent Variable Descriptive Statistics, n = 149* (continued)

ICF MODEL COMPONENT Independent Variable Factor	n	% of respondents
Emotional Support		
No one	33	22.3
Family	60	40.5
Friends	19	12.8
Support Groups	14	9.5
Church, religious organization	4	2.7
Internet	2	1.4
Other	16	10.8
ENVIRONMENTAL		
Number Adults in Household		
1	22	14.8
2	104	69.8
3	15	10.1
4	7	4.7
5 or more	1	0.7
Number Children in Household		
1	42	29.4
2	61	42.7
3	26	18.2
4	9	6.3
5 or more	5	3.5
Number Children with ASD		
1	119	79.9
2	25	16.8
3 or more	5	3.4
Father Age at Conception		
18-24 years	19	13.1
25-34 years	84	57.9
35-44 years	33	22.8
45-54 years	8	5.5
55 years and older	1	0.7
Child Gender		
Male	116	77.9
Female	33	22.1
Time to Diagnosis		
<6 months	28	18.9
1 year	40	27.0
2 years	30	20.3
3 years	13	8.8
4 years	8	5.4
5 years or more	29	19.6

Table 1. *Categorical Independent Variable Descriptive Statistics, n = 149* (continued)

ICF MODEL COMPONENT Independent Variable Factor	n	% of respondents
ASD Diagnosis		
Do not know	2	1.4
Autism Disorder	58	39.5
Asperger Syndrome	42	28.6
PDD-NOS	36	24.5
Other	9	6.1
Child Healthcare Coverage		
No	3	2.0
Yes	144	98.0
Child Healthcare Coverage Military		
No	130	87.2
Yes	19	12.8
Child Comorbid Condition		
Anxiety	72	55.4
Behavioral Problems	84	64.6
Depression	26	20.0
Feeding Problems	16	12.3
Gastrointestinal Problems	37	28.5
Musculoskeletal Problems	5	3.8
Seizures	9	6.9
Sensory Integration Dysfunction	57	43.8
Toe walking	12	9.2
Other Medical Condition	37	28.5
Other Mental Health Problem	33	25.4
Child Sleep Hours		
<4 hours	1	0.7
4-5 hours	4	2.7
5-6 hours	26	17.4
7-8 hours	72	48.3
>8 hours	46	30.9
Child Assistive Technology		
No	130	87.8
Yes	18	12.2
Child Therapy Type		
No Therapy Services	42	30.4
OT, Educational Setting	54	39.1
OT, Medical Setting	32	23.2
PT, Educational Setting	16	11.6
PT, Medical Setting	6	4.3
SP, Educational Setting	67	48.6
SP, Medical Setting	31	22.5

Table 1. *Categorical Independent Variable Descriptive Statistics, n = 149* (continued)

ICF MODEL COMPONENT Independent Variable Factor	n	% of respondents
Child Classroom Setting		
Does not attend	9	6.0
Regular	44	29.5
Inclusion	24	16.1
Self-contained	30	20.1
Home	17	11.4
Other	25	16.8
Other Caregiver		
No one	29	19.6
Spouse	95	64.2
Sibling	7	4.7
Parents or Spouse's parents	9	6.1
Other Relative	8	5.4
PERSONAL		
Education		
< High School	1	0.7
High School diploma/GED	55	36.9
Some college	46	30.9
Bachelor's degree	33	22.1
Graduate School	14	9.4
Race		
White	133	89.3
Hispanic or Latino	5	3.4
African American	7	4.7
Other	4	2.7
Marital Status		
Single	24	16.1
Living with a Partner	6	4.0
Married	116	77.9
Widowed	3	2.0
Income		
< $35,000	35	24.0
$35,000 - $49,999	18	12.3
$50,000 - $74,999	31	21.2
$75,000 - $99,999	30	20.5
$100,000 or more	32	21.9
Mother Healthcare		
No	20	13.5
Yes	128	86.5
Mother Healthcare Military		
No	129	86.6
Yes	20	13.4

Table 2

Continuous Independent Variable Descriptive Statistics

ICF MODEL COMPONENT Independent Variable Factor	n	Mean (SD)	Median	IQR	Min-Max
BODY FUNCTIONS AND STRUCTURES					
Gestation Length (weeks)	142	37.96 (2.69)	38.5	37-40	25-42
ACTIVITIES					
Mother Caregiving Hours	141	11.30 (7.2)	10.0	5-17	0-24
ENVIRONMENTAL					
Child Age (years)	147	11.52 (7.56)	10.0	6-15	2-45
Child Age Diagnosis	145	5.03 (3.83)	4.0	2-7	1-21
Other Caregiver Hours	124	4.63 (4.91)	3.0	2-5	0-24

The constellation of the independent variables into the ICF conceptual framework was as follows: The six Body Functions and Structures Factors included mother age, mother comorbid conditions, mother sleep hours, mother age at conception, gestation length, and pregnancy problems. The Activities Factors included employment, employment location, and mother caregiving hours. Participation Factors included significant other relationship affected, spirituality association, life areas affected negatively, life areas affected positively, information source, and emotional support. Environmental Factors included the number of adults in household, number of children in household, number of children with ASD, father age at conception, child age, child gender, child age at diagnosis, time to diagnosis, ASD diagnosis, child healthcare coverage, child healthcare coverage military, child comorbid conditions, child sleep hours, child assistive technology, child therapy type, child classroom setting, other caregiver, and other caregiver hours. The Personal Factors included education, race, marital status, income, mother healthcare coverage, and mother healthcare coverage military. These results are the respondent Factors that describe the study sample group according to the ICF components.

Body Functions and Structures Factors. The Body Functions and Structures Factors addressed the descriptors of the physical status of the mother and her pregnancy history variables: mother age, mother comorbid conditions, mother sleep hours, mother age at conception, pregnancy problems, and gestation length. Almost half (47%, n = 70) of the respondents were between the ages of 35-44 years in a steep sloped normal distribution. Eighteen percent (n = 27) were between the ages of 25-34 years, and 29% (n = 43) were between the ages of 45-54 years. Viewing the broader upper age range, 76% (n = 113) of the mothers were between the ages of 35 and 54 years. There was a high occurrence in three of the mother comorbid condition responses. Forty-nine percent (n = 51) of the mothers reported that they were currently receiving treatment for depression, 45% (n = 47) were currently receiving treatment for anxiety, and 43% (n = 45) for another medical condition. Twenty-eight percent (n = 29) were receiving treatment for pain; 22% (n = 23) for high blood pressure, 22% (n = 23) for gastrointestinal problems, and 16% (n = 17) for arthritis. Thirty-eight percent (n= 57) of mothers reported that they slept 7 or more hours per night, while 44% (n = 66) reported sleeping 5-6 hours per night. The majority of mothers, 61% (n = 89) were between the ages of 25-34 years when they became pregnant with their child with ASD. More of the mothers denied experiencing pregnancy problems (63%, n = 90) than those who reported problems (see Table 1). The mean gestation length was 38 weeks (SD 2.7) (see Table 2).

Activities Factors. The Activities Factors include the mother's employment, employment location, and her caregiving hours. Most mothers (42%, n = 62) were unemployed at the time of the study, compared to full-time and part-time employed mothers. Of those mothers who worked full-time (35%, n = 51) and part-time (23%, n = 34), 76% (n = 111) worked in a location other than the home (see Table 1). The average number of mother caregiving hours was 11.3 hours (SD 7.2) per day (see Table 2).

Participation Factors. The Participation Factors depict social involvement and relationships. Under this ICF component several survey items dealt with inquiring about how having a child with ASD affected the mothers' lives. The variables were: significant other relationship affected, spirituality association, life areas affected negatively, life areas affected positively, information source, and emotional support. Forty-nine percent (n = 72) reported experiencing a negative change in the relationship with their significant other, while 56% (n = 83) belonged to an organized religion or spiritual group and 44% (n = 66) did not. Eighty-five percent (n = 127) experienced negative effects in the life areas of social activities, mental health (63%, n = 94), family relationships (59%, n = 88), other relationships (53%, n = 79), sports/recreational (39%, n = 58), and physical health (37%, n = 55). Only 5% (n = 8) denied that any life areas were negatively affected. Conversely, 55% (n = 79) reported positive effects in life areas divided between family relationships, 44% (n = 63), spirituality, and other relationships, 38% (n = 54). Positive effects on any life areas were denied by 17% (n = 25) of the mothers. The majority of information for the mothers' needs in raising a child with ASD was reported as received about equally from health care providers (24%, n = 35) and from the Internet (20%, n = 30). Another information source provided most of the information to mothers in raising their child with ASD for 29% (n = 42). Family, as the source of the most emotional support for coping, was reported by 40% (n = 60). No one provided emotional support for 22% (n = 33) of the mothers (see Table 1).

Environmental Factors. The Environmental Factors describe the home environment, characterized by the assemblage of the household, and the individuals and events in the life of the mother. These variables were: number of adults in household, number of children in household, number of children with ASD, father age at conception, child age, child age at diagnosis, time to diagnosis, ASD diagnosis, child healthcare coverage, child healthcare coverage military, child comorbid conditions, child sleep hours, child assistive technology, child therapy type, child classroom type, other caregiver, and other caregiver hours. Seventy percent (n = 104) of the mothers reported having two adults in the household. There was one child per household in 29% (n = 42) of the cases, and 43% (n = 61) of the households had 2 children. Those households with one child diagnosed with ASD comprised 80% (n = 119) of the respondents whereas 16% (n = 25) had two children diagnosed with ASD, and 3% (n = 5) had 3 or more children diagnosed with ASD. Fifty-eight percent (n = 84) of fathers were aged 25-34 years at the time of conception of the child with ASD (see Table 1).

The average age of the child with ASD age was 11.5 years (SD 7.6). Seventy-eight percent (n = 116) of the children with ASD were male. The average age of the child at diagnosis was 5 years (SD 3.8). Forty-six percent (n = 68) of the children were diagnosed by one year after the mother first noticed problems. Nineteen percent (n = 28) of those children with ASD were diagnosed under 6 months, another 20% (n = 30) after two years, and another 20% (n = 29) after five years of the mother first noticing problems. The most common specific diagnoses of children, in decreasing order were Autism Disorder (40%, n = 58), Asperger Syndrome (29%, n = 42), and PDD-NOS (25%, n = 36). Only 1% (n = 2) of the mothers did not know their child's diagnosis. The majority (98%, n = 144) of children had healthcare coverage and most (87%, n = 130) were non-military covered (see Tables 1 and 2).

Mothers reported that their child with ASD had a number of comorbid conditions. Over half reported behavioral problems (65%, n = 84) and anxiety (55%, n = 72), followed by sensory integration dysfunction (44%, n = 57). Two other conditions, gastrointestinal problems and other medical condition were reported by 29% (n = 37). Seventy-nine percent (n = 118) of the children sleep more than 7 hours per night. Twelve percent (n = 18) of the children with ASD use assistive technology. Speech (49%, n = 67) and occupational therapy (39%, n = 54) in an educational setting were the most common therapy services received by the children, while fewer than 12% (n = 16) of the children received physical therapy in an educational setting. Speech (23%, n = 31) and occupational therapy (23%, n = 32) in a medical setting were the next most frequent therapies received by the children. Thirty percent (n = 42) of the children received no therapy services in either the educational or in the medical setting. Thirty percent (n = 44) attended school in a regular classroom, 20% (n = 30) in a self-contained setting, and 16% (n = 24) in an inclusion classroom. The spouse was cited as providing significant caregiving by nearly 65% (n = 95), while 20% of the mothers (n = 29) had no one to report as providing significant caregiving for their child with ASD. The average number of caregiving hours provided by another person was 4.6 (SD 4.9) hours per day (see Tables 1 and 2).

Personal Factors. The Personal Factors included general demographics and questions on health care coverage of the mother. These variables were: education, race, marital status, income, mother healthcare coverage, and mother healthcare coverage military. Regarding education, 62% (n = 93) of the mothers had some college or more. The majority of mothers were white (89%, 133) and married (78%, 116). A household income of less than $35,000 occurred 24% (n = 35) of the time. The majority of mothers had nonmilitary health care coverage (87%, n = 128) (see Table 1).

Research Question 2. What Is the QOL, as Measured Using the WHOQOL-BREF, Among Mothers of Children With ASD?

Each of the four domains of the WHOQOL-BREF measures a different aspect of health related QOL and the reporting of separate scores is justified (Sijtsma, Emons, Bouwmeester, Nyklícek, & Roorda, 2008). This is congruent with the definition of QOL as a multidimensional concept, previously described.

The WHOQOL-BREF domain scores were obtained first using the syntax of the SEAQOL Group as posted under the University of Washington website ("Syntax file," 1997), and then (for this study score report) according to the WHO scoring manual (WHO, 1998). The application of the SEAQOL Group syntax led to the observation of 12 missing values among the four domain scores for the 149 respondents (G. De Leo, personal communication, April 10, 2014), constituting 2% of the data. These 12 items were distributed as three scores in the Physical Health domain, three scores in the Psychological domain, two scores in the Social Relationships domain, and four scores in the Environmental domain. Further investigation of the scoring syntax was pursued by email contacts to the WHO and to published researchers using the WHOQOL-BREF. It was then recommended that the WHO scoring manual syntax be applied and that the transformed scores be used when making comparisons between the different domain scores, as there is different number of items in each of the WHOQOL-BREF domains (S. Chatterji, personal communication, April 14, 2014; S. M. Skevington, personal communication, April 14 and 21, 2014). The WHOQOL-BREF consists of seven survey items in the Physical Health domain, six survey items in the Psychological Domain, three survey items comprise the Social Relationships domain, and five survey items in the Environmental domain (see Appendix D). The scoring syntax, used for this research study report, recommended by the WHO and Skevington is found in Appendix G (WHO, 1998). Correlation analysis using a paired t-test between the WHOQOL-BREF domain scores obtained with the SEAQOL Group and those obtained with the WHO scoring manual yielded a perfect relationship of 1.000.

The WHOQOL-BREF domain and transformed domain scores, with mean and standard deviation results, are presented in Table 3. The highest QOL transformed domain mean (SD) score was found in the Physical Health domain, 60.61(19.00), closely followed by the Environmental domain mean score of 59.78 (17.37). The Psychological domain mean score of 54.64 (17.24) was next in decreasing order, with the lowest mean score found in the Social Relationships domain, 49.75 (22.13). The spread of the scores within each domain was at the broadest 0-100 in the Social Relationships domain, with an approximately 14% decrease in the narrower Environmental domain range for the WHOQOL-BREF transformed domain scores.

Table 3

Dependent Variable WHOQOL-BREF Domain and Transformed Scores, n = 149

WHOQOL-BREF Domain	Mean (SD)	Min-Max
Domain score		
Physical Health	13.70(3.04)	4.00-19.43
Psychological	12.74(2.76)	4.00-19.33
Social Relationships	11.96(3.54)	4.00-20.00
Environmental	13.57(2.78)	5.71-19.50
Transformed domain score		
Physical Health	60.61(19.00)	0-96.43
Psychological	54.64(17.24)	0-95.83
Social Relationships	49.75(22.13)	0-100.00
Environmental	59.78(17.37)	10.71-96.88

The WHOQOL-BREF Physical Health domain, the highest transformed mean domain score, addresses physical pain limitations, need for medical treatment, energy for everyday life, ability to get around, satisfaction with sleep, ability to perform activities of daily living, and satisfaction with work capacity. The Environmental domain, the second highest mean transformed domain score, focuses on feelings of safety during daily life, how healthy one's physical environment is, and whether one has enough money for needs, information for daily life, and opportunity for leisure activities. The Psychological domain, the third highest mean transformed domain score, inquires about life enjoyment and meaningfulness, concentration ability, acceptance of body appearance, satisfaction with abilities, and occurrence of negative feelings. The Social Relationships domain, the lowest transformed mean domain score, reflects satisfaction with personal relationships, sex life, and support from friends.

Research Question 3. What Are the Significant Relationships Between the Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors Among Mothers of Children With ASD, and the QOL of the Mothers?

Individual linear regressions were analyzed between the individual independent variables of the study and the four WHOQOL-BREF dependent variable measures. The regression analyses of the Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors with the WHOQOL-BREF Physical Health, Psychological, Social Relationships, and Environmental (non-transformed) domain scores were performed using the WHO scoring manual syntax (see Appendix G). There were 81 independent variables representing the ICF Model Component Factors elicited from the first 39 (researcher-constructed) items in the survey in Sections I and II (see Appendices D and E). Thirty-four of the items were single response categorical or fill-in continuous variables. Five of the 39 items were in a multiple response format allowing a respondent to choose a maximum of all the options, or a category representing none of the choices, if applicable. This multiple response format considerably increased the number of independent variables in the study and acquired additional information, while not increasing the length of the survey from the respondent's perspective. The errors were normally distributed, thus allowing the conduct of regression analysis. These variables were aligned with the Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors of the ICF Model Components. The dependent variable QOL, assessed using the WHOQOL-BREF four domains of Physical Health, Psychological, Social Relationships, and Environmental demonstrated in the four separate measures, maintained the multidimensional perspective of the concept of QOL.

The conduct of 324 individual linear regressions yielded 78 significant individual linear regression relationships. There were 23 significant predictors for Physical Health QOL, 19 significant predictors for Psychological QOL, 15 significant predictors of Social Relationships QOL, and 21 significant predictors of Environmental QOL. These are the individual independent variable significant predictors of the four WHOQOL-BREF domains. The actual significance level of the ICF Component individual linear regressions associated with the WHOQOL-BREF domains are presented in Table 4.

Table 4

ICF Model Component Factor and QOL Domain Regression Level of Statistical Significance (p values)

ICF Model Component Factor	WHOQOL-BREF Domain			
	Physical Health	Psychological	Social Relationships	Environmental
	BODY FUNCTIONS AND STRUCTURES			
Mother Age			.0412	
Mother Comorbid Condition				
Anxiety	.0057			
Arthritis	.0000	.0292		.0193
Depression	.0009	.0015		
Diabetes	.0055	.0147		.0001
Hypertension	.0092	.0169		
Musculoskeletal	.0075			
Neurological	.0096	.0263		
Pain	.0000			
Other Medical	.0077			
Other Mental Health	.0496		.0341	
Mother Sleep Hours	.0001	.0067	.0079	.0265
Gestation Length	.0393			
Pregnancy Problems	.0014	.0520	.0105	.0026

Table 4. *ICF Model Component Factor and QOL Domain Regression Level of Statistical Significance (p values)* (continued)

ICF Model Component Factor	WHOQOL-BREF Domain			
	Physical Health	Psychological	Social Relationships	Environmental
ACTIVITES				
Employment	.0117			
Mother Care Hours	.0031			.0008
PARTICIPATION				
Significant Other Relationship Affected		.0050	.0000	.0000
Life Areas Affected Negatively				
None		.0101	.0001	.0125
Family	.0499	.0012	.0012	.0018
Other Than Family		.0129	.0029	.0211
Physical Health	.0000	.0000	.0001	.0000
Mental Health		.0025	.0016	
Sports	.0520	.0345		
Social			.0063	
Spirituality	.0309	.0059	.0101	
Life Areas Affected Positively				
Other Than Family		.0158	.0388	
Physical Health		.0255		
ENVIRONMENT				
Number Children		.0246	.0388	.0505
Child Gender	.0012			.0178
Child HC Military				.0107
Child Comorbid Condition				
Toe Walking				.0463
Child Sleep Hours	.0024	.0476		.0037
Assistive Technology	.0099		.0111	.0016
Child Therapy				
PT Educational			.0439	
SP Educational				.0215

Table 4. *ICF Model Component Factor and QOL Domain Regression Level of Statistical Significance (p values)* (continued)

ICF Model Component Factor	QOL Domain			
	Physical Health	Psychological	Social Relationships	Environmental
	PERSONAL			
Education	.0246			.0009
Income				.0000
Mother Healthcare				.0006
Mother Healthcare Military				.0044

Research Question 4. What Are the Predictive Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors Among Mothers of Children With ASD for Their QOL?

Stepwise multiple regression analysis was performed to determine the significant Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors, and for All Significant ICF Component Factors, that were predictive of QOL among this sample of mothers of children with ASD. The ICF Component Factors that were individually significant with a QOL domain (see Table 4) were then assessed as contributors (according to the respective ICF Component, and then combined for the All Significant ICF Component Factors) for the overall multiple linear regression models, with backwards elimination, to answer Research Question 4. This procedure was performed for each of the four WHOQOL-BREF (non-transformed) domain scores for Physical Health, Psychological, Social Relationships, and Environmental, using the WHO scoring manual syntax (see Appendix G) (WHO, 1998), in order to maintain the multidimensional aspects of QOL. Backwards elimination removed variables in order to obtain the most parsimonious model for each of the four QOL domains. The significant multiple linear regression models for the QOL domains, as measured by the WHOQOL-BREF, for each of the ICF components (Body Functions and Structures, Activities, Participation, Environmental, and Personal) and for All Significant ICF Components were developed. For each of the four WHOQOL-BREF domains, six multiple regression analyses were applied to formulate models predicting QOL.

Physical Health QOL. The multiple linear regression results for each of the ICF Components (Body Functions and Structures, Activities, Participation, Environmental, and Personal) and for All Significant ICF Components determining the WHOQOL-BREF Physical Health are presented in Table 5. The interpretation of Table 5, and for similar tables, is clarified here. The model regression equation Constant, or the y-intercept, is the value of y when all other contributor or independent (ICF Component Factors) variables are zero. The unique interpretation of the table results is explained with the baseline description for a referent mother. Additional statistical analyses detailed results are provided for each study model stipulating that for each unit change in the independent variable, when adjusting for all other factors, the dependent variable domain QOL is predicted to change, on average, by the number of points listed as β, the parameter estimate, the unadjusted β. A negative value of β indicates a predicted lowering of the domain QOL by the presence of the independent variable, while a positive β is associated with an improvement in domain QOL. Confidence intervals that contain zero denote those independent variables that were not found to be significant contributors to the model, adjusting for all other ICF Component Factors. Error is an assumed additional consideration in all model equations. The percentage variance associated with each variable upon the domain QOL was calculated as the ratio of the unadjusted β to the model Constant. A positive variance indicates a contributed improvement in domain QOL, while a negative variance indicates a lowering of the domain QOL for each Factor (independent variable) in each regression model.

Table 5

ICF Model Component Factor Predictors of WHOQOL-BREF Physical Health QOL

Factor	β	*p*	95% CI	% Variance
BODY FUNCTIONS AND STRUCTURES, p = .000				
Constant*	12.486	.000	[9.999, 14.972]	
Mother Comorbid:				
Arthritis	-3.155	.000	[-4.580, -1.730]	-25.3
Other Medical	-1.339	.006	[-2.293, -0.385]	-10.7
Mother Sleep 4-5 Hours	1.610	.232	[-1.040, 4.261]	12.9
Mother Sleep 5-6 Hours	1.543	.224	[-0.956, 4.043]	12.4
Mother Sleep 7-8 Hours	2.937	.024	[0.384, 5.491]	23.5
Mother Sleep >8 Hours	0.755	.678	[-2.830, 4.340]	6.0

*Baseline: Mother without comorbid conditions of arthritis and other medical problem, who sleeps less than 4 hours on average per night.

Factor	β	*p*	95% CI	% Variance
ACTIVITIES, p = .003				
Constant	14.868	.000	[13.937, 15.799]	
Mother Caregiving Hours	-0.106	.003	[-0.175, -0.036]	-0.7
PARTICIPATION, p = .000				
Constant*	14.662	.000	[14.096, 15.227]	
Life Areas Affected Negatively:				
Physical Health	-2.613	.000	[-3.543, -1.683]	-17.8

*Baseline: Mother without life area affected negatively of physical health.

Table 5. *ICF Model Component Factor Predictors of WHOQOL-BREF Physical Health QOL* (continued)

Factor	β	*p*	95% CI	% Variance
ENVIRONMENTAL, p = .001				
Constant*	12.208	.000	[11.195, 13.220]	
Child Gender	1.913	.001	[0.765, 3.060]	15.7
*Baseline: Mother has a female child with ASD.				
ALL SIGNIFICANT ICF COMPONENTS, p = .000				
Constant*	16.000	.000	[10.733, 21.267]	
Employment Part time	0.405	.487	[-0.744, 1.553]	2.5
Employment Full time	1.310	.012	[0.292, 2.327]	8.2
Life Area Affected Negatively:				
Physical Health	-2.511	.000	[-3.451, -1.571]	-15.7
Spirituality	-1.026	.068	[-2.127, 0.075]	-6.4
Mother Education:				
High school or GED	-2.437	.369	[-7.783, 2.908]	-15.2
Some college	-1.448	.594	[-6.811, 3.915]	-9.1
Bachelor's Degree	-1.373	.617	[-6.794, 4.049]	-8.6
Graduate school	-0.487	.861	[-5.983, 5.009]	-3.0

*Baseline: Mother is without the physical health life area affected negatively, unemployed, with less than a high school degree or GED.

The multiple linear regression results for Physical Health QOL reveal the development of five significant models. The first model for Body Functions and Structures has a Constant of 12.486 for a baseline. The baseline data are reported for a mother who does not have the comorbid conditions of arthritis or another medical condition, and who sleeps less than 4 hours, adjusting for all other Body Functions and Structures Factors. If mothers report the comorbid condition arthritis, Physical Health QOL is predicted to be lower by 25.3%, and lower by 10.7% for another comorbid medical condition. Physical Health QOL is predicted to increase by 23.5% for mothers getting 7-8 hours of sleep. The variables of mother sleep hours of 4-5, 5-6, and > 8 hours of sleep were not significant contributors in this model.

The Activities Factors model for Physical Health QOL has a constant of 14.868. For every additional hour of caregiving reported by mothers, Physical Health QOL is predicted to be lower by 0.7%.

The Participation Factors model has the constant of 14.662, the baseline data for a mother who does not report that the life area of physical health is negatively affected by having a child with ASD, adjusting for all other Participation Factors. If a mother reports that the life area of physical health has been negatively affected, Physical Health QOL is predicted to be lower by 17.8%.

The Environmental Factors model has a constant of 12.208, the baseline data for a mother whose child with ASD is female, adjusting for all other Environmental Factors. A mother with a male child with ASD is predicted to have a 15.7 % higher Physical Health QOL.

There were no significant Personal Factors predicting Physical Health QOL, so a model for this ICF Factor was not developed. The traditional demographic factors of education, race, marital status, income and healthcare coverage were not found to be individually predictive of Physical Health QOL, although the individual linear regression of mother education level was significant in predicting Physical Health QOL

The All Significant ICF Component Factors model has a constant of 16.00, the baseline data for a mother who does not report the physical health life area as being affected negatively by having a child with ASD, and who is unemployed with less than a high school degree, adjusting for other All Significant ICF Component Factors. If a mother reports that the life area of physical health is negatively affected by having a child with ASD, her Physical Health QOL is predicted to be lower by 15.7%. Full-time employment would predict an increase in Physical Health QOL by 8.2%. The individual regression of mother employment status was not found to be a significant predictor of Physical Health QOL. Although mother education level was significant in the individual regression with Physical Health QOL, all education levels above the referent, with less than a high school degree, were not significant contributors to Physical Health QOL in this model.

Psychological QOL. The multiple linear regression results for each of the ICF Components (Body Functions and Structures, Activities, Participation, Environmental, and Personal) and for all significant ICF Factors determining Psychological QOL, as measured by the WHOQOL-BREF, are presented in Table 6. Three significant models were developed for Body Functions and Structures, Participation, and for All Significant ICF Components.

Table 6

ICF Model Component Factor Predictors of WHOQOL-BREF Psychological QOL

Factor	β	*p*	95% CI	% Variance
BODY FUNCTIONS AND STRUCTURES, p = .000				
Constant*	9.882	.000	[7.567, 12.198]	
Mother Comorbid:				
Depression	-1.373	.003	[-2.263, -0.483]	-13.9
Mother Sleep 4-5 Hours	3.258	.013	[0.712, 5.805]	33.0
Mother Sleep 5-6 Hours	3.032	.013	[0.658, 5.406]	30.7

Table 6. *ICF Model Component Factor Predictors of WHOQOL-BREF Psychological QOL* (continued)

Factor	β	*p*	95% CI	% Variance
Mother Sleep 7-8 Hours	4.093	.001	[1.697, 6.490]	41.4
Mother Sleep >8 Hours	2.637	.131	[-0.796, 6.071]	26.7
*Baseline: Mother without comorbid condition depression, who sleeps less than 4 hours per night.				
PARTICIPATION, p < .0001				
Constant*	13.222	.000	[12.613, 13.830]	
Life Areas Affected Negatively:				
Physical Health	-2.222	.000	[-3.064, -1.380]	-16.8
Life Areas Affected Positively:				
Other Relationships	0.940	.030	[0.095, 1.785]	7.1
*Baseline: Mothers without physical health life area affected negatively and without other relationships life area affected positively.				
ALL SIGNIFICANT ICF COMPONENTS, p < .0001				
Constant*	12.577	.000	[11.771, 13.383]	
Mother Comorbid:				
Diabetes	-1.819	.021	[-3.364, -0.275]	-14.5
Life Area Affected Negatively:				
Physical Health	-2.147	.000	[-2.972, -1.322]	-17.1
Life Areas Affected Positively:				
Other Relationships	0.849	.049	[0.004, 1.694]	6.8
Number Children in Household:				
2	1.362	.005	[0.429, 2.295]	10.8
3	0.693	.251	[-0.495, 1.881]	5.5
4	1.401	.122	[-0.377, 3.178]	11.1
5 or more	0.616	.590	[-1.641, 2.873]	4.9
*Baseline: Mothers without comorbid condition diabetes, without physical health life area affected negatively and without other relationships life area affected positively, and having one child in the household.				

The Body Functions and Structures Factors model equation for Psychological QOL has a Constant of 9.882, the baseline data for a mother who does not have comorbid depression and who sleeps less than four hours per night, adjusting for all other Body Functions and Structures Factors. For a mother who reports comorbid depression, Psychological QOL is predicted to be lower by 13.9%. Psychological QOL is predicted to increase by 33%, 30.7%, and by 41.4% for a mother sleeping 4-5, 5-6, and 7-8 hours respectively. The category for mothers getting > 8 hours of sleep was not a significant contributor in this model.

There were no significant Activities Factors predicting Psychological QOL. A model for this ICF Factor was not developed.

The Participation Factors model has a Constant of 13.222, the baseline data for a mother without physical health life area affected negatively and without other relationship life area affected positively, adjusting for all other Participation Factors. Mothers who report that the life area of physical health is affected negatively by having a child with ASD would have a 16.8% lower Psychological QOL. Mothers who report that the life area of other relationships is affected positively would have a 7.1% increase in Psychological QOL.

The two individually significant Environmental Factors, the number of children in the household and child sleep hours, were not significant contributors to Psychological QOL. When combined, a regression model was not developed.

There were no significant Personal Factors predicting Psychological QOL, so a model for this ICF Factor was not developed. The traditional demographic factors of education, race, marital status, income and healthcare coverage were not found to be significant contributors to Psychological QOL.

The All Significant ICF Components model has a Constant of 12.577, the baseline data for a mother without comorbid diabetes, without the physical health life area affected negatively, without the other relationship life area affected positively, and having one child in the household, adjusting for other All Significant ICF Component Factors. The presence of comorbid diabetes would lower Psychological QOL by 14.5%. Reporting a negative affect in the life area physical health would lower Psychological QOL by 17.1%. A mother who reports that the life area of other relationships is positively affected would have a predicted increase in Psychological QOL of 6.8%. A second child in the household would contribute to an increase in Psychological QOL by 10.8%. Additional children in the household were not found to be significant contributors to the model for All Significant ICF Components.

Social Relationships QOL. The multiple linear regression results for each of the ICF Components (Body Functions and Structures, Activities, Participation, Environmental, and Personal) and for All Significant ICF Components determining Psychological QOL, as measured by the WHOQOL-BREF, are presented in Table 7. Three significant models were developed for Participation, Environmental, and for All Significant ICF Components.

Table 7

ICF Model Component Factor Predictors of WHOQOL-BREF Social Relationships QOL

Factor	β	*p*	95% CI	% Variance
		PARTICIPATION, p = .000		
Constant	10.061	.000	[9.253, 10.868]	
Significant Other Relationship:				
No Change	3.150	.000	[2.021, 4.279]	31.3
Positive Change	2.828	.000	[1.301, 4.355]	28.1
Life Area Affected Positively:				
Other Relationships	0.938	.086	[-0.135, 2.010]	9.3

*Baseline: Mothers who report a negative change in relationship with significant other and without other relationships life area affected positively. Life area affected positively for other relationships is not a significant contributor.

		ENVIRONMENTAL, p = .003		
Constant*	11.122	.000	[10.108, 12.136]	
Number of Children in Household:				
2	1.699	.011	[0.400, 2.997]	15.3
3	1.698	.043	[0.055, 3.342]	15.3
4	2.447	.055	[-0.056, 4.951]	22.0
5 or more	2.212	.168	[-0.947, 5.370]	19.9
Assistive Technology	-1.989	.022	[-3.691, -0.288]	-17.9
Therapy Type:				
PT School setting	-3.061	.037	[-5.941, -0.181]	-27.5

*Baseline: Mother has one child in the household, and her child with ASD does not use assistive technology or receive physical therapy services in the school setting.

		ALL SIGNIFICANT ICF COMPONENTS, p = .000		
Constant*	9.253	.000	[8.246, 10.260]	
Significant Other Relationship:				
No change	3.183	.000	[2.068, 4.297]	34.4
Positive change	2.747	.000	[1.232, 4.263]	29.7
Number of Children in Household:				
2	1.634	.008	[0.437, 2.831]	17.7
3	1.522	.049	[0.009, 3.034]	16.4

Table 7. *ICF Model Component Factor Predictors of WHOQOL-BREF Social Relationships QOL* (continued)

Factor	β	*p*	95% CI	% Variance
Number of Children in Household:				
4	1.964	.087	[-0.286, 4.214]	21.2
5 or more	2.807	.058	[-0.099, 5.713]	30.3

*Baseline: Mothers who report a negative change in the relationship with her significant other and who have one child in the household.

The Body Functions and Structures model was not a significant predictor of Social Relationships QOL. Although mother age, mother comorbid condition of other mental health problem, mother sleep hours, and pregnancy problems were individually significant in the prediction of Social Relationships QOL, a model was not developed for the these factors.

There were no significant individual Activities Factors predicting Social Relationships QOL. A model for this ICF Factor was not developed.

The Participation Factors model has a Constant of 10.061, the baseline data for a mother whose significant other relationship was reported as negatively changed as a result of having a child with ASD, and who did not report the life area for other relationships affected positively, adjusting for other Participation Factors. Reporting no change in one's significant other relationship was associated with a 31.3% improvement in Social Relationships QOL, while reporting a positive change was associated with a 28.1% increase in Social Relationships QOL. The life area positively affected for other relationships was not a significant contributor in this model.

The Environmental Factors model has a Constant of 11.122, the baseline data for a mother with one child in the household, and her child with ASD does not use assistive technology or receive physical therapy services in the school setting, adjusting for other Environmental Factors. Having two or three children in the household is associated with an increase in Social Relationships QOL by 15.3%. The child's use of assistive technology and the receipt of physical therapy services in the school setting are associated with a decrease in Social Relationships QOL by 17.9% and 27.5% respectively.

There were no individual significant Personal Factors predicting Social Relationships QOL. A model for Personal Factors was not developed.

The All Significant ICF Components model has a Constant of 9.253, baseline data for a mother reporting a negative change in the relationship with her significant other and who has one child in the household, adjusting for other All Significant ICF Component Factors. Reporting no change or a positive change in one's significant other relationship was associated with a 34.4% and a 29.7% increase respectively in Social Relationships QOL. An increase in Social Relationships QOL was associated with having two or three children in the household, and the increases were 17.7% and 16.4%.

Environmental QOL. The multiple linear regression results for each of the ICF Components (Body Functions and Structures, Activities, Participation, Environmental, and Personal) and for All Significant ICF Components determining Psychological QOL, as measured by the WHOQOL-BREF, are presented in Table 8. Six significant models were developed for each of the ICF Component Factors and for All Significant ICF Component Factors combined.

Table 8

ICF Model Component Factor Predictors of WHOQOL-BREF Environmental QOL

Factor	β	*p*	95% CI	% Variance
BODY FUNCTIONS AND STRUCTURES, p = .000				
Constant*	13.802	.000	[13.355, 14.249]	
Mother Comorbid:				
Diabetes	-3.211	.000	[-4.856, -1.566]	-23.3
*Baseline: Mothers without comorbid condition diabetes.				
ACTIVITIES, p = .001				
Constant*	14.716	.000	[13.882, 15.551]	
Mother Caregiving Hours	-0.107	.001	[-0.169, -0.045]	-0.7
PARTICIPATION, p = .000				
Constant*	13.303	.000	[12.591, 14.015]	
Significant Other Relationship:				
No change	1.766	.000	[0.849, 2.683]	13.3
Positive change	1.671	.006	[0.489, 2.853]	12.6
Life Areas Affected Negatively:				
Physical Health	-1.692	.000	[-2.562, -0.822]	12.7
*Baseline: Mothers who reported no change or a negative change in relationship with significant other and did not report life area affected negatively of physical health.				
ENVIRONMENTAL, p = 002				
Constant*	13.612	.000	[13.096, 14.128]	
Child Health Care Coverage				
Military	1.734	.009	[0.431, 3.037]	12.7
Therapy Type:				
SP in school setting	-1.287	.019	[-2.358, -0.216]	-9.5
*Baseline: Mother whose child with ASD does not have healthcare coverage military and does not receive speech therapy in the school setting.				

Table 8. *ICF Model Component Factor Predictors of WHOQOL-BREF Environmental QOL* (continued)

Factor	β	*p*	95% CI	% Variance
PERSONAL, p < .000				
Constant*	11.706	.000	[10.887, 12.526]	
Income $35,000-49,999	1.932	.010	[0.467, 3.396]	16.5
Income $50,000-74,999	2.217	.001	[0.984, 3.450]	18.9
Income $75,000-99,999	1.993	.002	[0.748, 3.238]	17.0
Income >$100,000	2.692	.000	[1.471, 3.914]	23.0
Mother Healthcare Coverage				
Military	1.378	.029	[0.142, 2.615]	11.8
*Baseline: Mother whose income is less than $35,000 and who do not have healthcare coverage military.				
ALL SIGNIFICANT ICF COMPONENTS, p = .000				
Constant*	12.040	.000	[11.171, 12.908]	
Mother Comorbid:				
Diabetes	-2.631	.000	[-3.999, -1.264]	21.9
Significant Other Relationship:				
No change	1.645	.000	[0.815, 2.474]	13.7
Positive change	1.614	.003	[0.555, 2.674]	13.4
Life Areas Negatively Affected:				
Physical Health	-1.485	.000	[-2.270, -0.701]	-12.3
Income $35,000-49,999	1.448	.024	[0.189, 2.706]	12.0
Income $50,000-74,999	1.797	.001	[0.734, 2.859]	14.9
Income $75,000-99,999	1.545	.005	[0.479, 2.611]	12.8
Income >$100,000	2.673	.000	[1.635, 3.710]	22.2
*Baseline: Mother without comorbid condition diabetes, who reported no change in the relationship with her significant other, without life area affected negatively of physical health, and who have an income less than $35,000.				

The single significant Body Functions and Structures Factor in the multiple linear regression model for Environmental QOL is the mother comorbid condition diabetes. The Constant of 13.802 is the baseline data for a mother without the comorbid condition of diabetes. A mother with diabetes would have a lower Environmental QOL by 23.3%, adjusting for other Body Functions and Structures Factors.

The model for the Activities Factors predicting Environmental QOL has a Constant of 14.716. The single significant Activities Factor is mother hours of caregiving. For each additional hour of caregiving, Environmental QOL would decrease by 0.7%, on average, adjusting for other Activities Factors.

The Participation Factors model has a Constant of 13.303, the baseline data for a mother reporting a negative change in her relationship with her significant other and who does not report physical health as a negatively affected life area. Reporting no change in the significant other relationship would increase Environmental QOL by 13.3%, and reporting a positive change would increase Environmental QOL by 12.6%, adjusting for other Participation Factors. Mothers who reported a life area being affected negatively of physical health showed a 12.7% lower Environmental QOL.

The Environmental model has a Constant of 13.612, the baseline data for a mother whose child with ASD does not have military healthcare coverage and does not receive speech therapy services in the educational setting. A mother who has a child with military healthcare coverage would have a 12.7% higher Environmental QOL. Less than 13% of the mothers reported that their child with ASD had military healthcare coverage (see Table 1). Mothers of children with ASD who receive speech therapy services in the educational setting report a 9.5% lower Environmental QOL. The ICF Environmental Factors are regressed with the WHOQOL-BREF Environmental domain for this model.

The Personal Factors model has a Constant of 11.706, the baseline data for a mother whose household income is less than $35,000 and who does not have military healthcare coverage. Household incomes of $35,000-49,999, $50,000-74,999, $75,000-99,999, and $100,000 or more, are associated with an increase in Environmental QOL by 16.5%, 18.9%, 17,0%, and 23.0% respectively, adjusting for all other Personal Factors. A mother with military health care coverage would have an 11.8% higher Environmental QOL.

The All Significant ICF Components Factors model has a Constant of 12.040, the baseline data for a mother without comorbid diabetes, who reports a negative change in her relationship with her significant other, without the life area of physical health negatively changed, and who has an income under $35,000. All eight of the independent variables in the All Significant Components model were significant contributors to Environmental QOL, adjusting for all other All Significant ICF Component Factors. A mother with comorbid diabetes would be predicted to have a 21.9% lower Environmental QOL. Reporting a change in relationship with her significant other of no change or of a positive change would be associated with an increase in Environmental QOL by 13.7% and 13.4% respectively. A mother who reports a negative change in the physical health life area would have a lower Environmental QOL by 12.3%. Gradually increasing Environmental QOL contributions were found in the income levels of $35,000-49,999, $50,000-74,999, $75,000-99,999, and above $100,000 of 12.0%, 14.9%, 12.8%, and 22.2% respectively.

Summary

This chapter presented the results of the statistical analysis of data gathered in an Internet survey among mothers of children with ASD, according to the modified ICF conceptual framework. Regression models were developed to represent the contributions of the Body Functions and Structures, Activities, Participation, Environmental, Personal, and All Significant ICF Component Factors in predicting the Physical Health, Psychological, Social Relationships, and Environmental QOL domains. The next chapter discusses the implications of this research to effect change in QOL among mothers of children with ASD.

CHAPTER V

SUMMARY AND CONCLUSIONS

Chapter V presents the summary, discussion, and conclusions based on the results of the statistical analysis of the data. These comments provide the interpretation of the findings as pertinent to practice, for health policy, and future research. The sample of respondents for this study portrays a nationally representative sample acquired through Internet solicitation. The sample size met the statistical power requirements and thereby provides inferences that contribute to existing knowledge regarding QOL among mothers of children with ASD. Discussion of each of the research questions follows.

Research Question 1. What Are the Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors That Characterize Mothers of Children With ASD?

The study sample respondents of mothers of children with ASD was described according to the Body Functions and Structures, Activities, Participation, Environmental, and Personal ICF Component Factors. These were the responses to the first 39 researcher-constructed questions of the survey, identifying and comprising the independent variables, with descriptive statistics presented in Tables 1 and 2.

Body Functions and Structures Factors. The Body Functions and Structures Factors of the mothers of children with ASD included the variables of mother age, mother comorbid conditions, mother sleep hours, age at conception, gestation length, and pregnancy problems. The group of respondents, the majority who were under the age of 44, with nearly half of those between the ages of 35-44 years and more than a third over the age of 44 years, approximates a normal distribution. It was anticipated that the respondents would be of a younger age, interested in engaging the web-based survey. The findings demonstrate that the methodology of recruitment and data collection yielded a representative age sample.

The highest occurrence of comorbid conditions, for which mothers reported receiving current treatment, were those of depression, anxiety, and other medical condition, followed by pain, high blood pressure, gastrointestinal problems, and arthritis. This is consistent with other studies, for example an increased rate of depression associated with the stress experienced by mothers as primary caregivers of children with ASD contributed to a lower well-being (Faso et al., 2013; Seymour, Wood, Giallo, & Jellett, 2013; Sijtsma et al., 2008). A large web-based survey found that child specific problems associated with ASD occurred with increased maternal depression and lower QOL in the mother (Zablotsky, Anderson, & Law, 2013).

These mothers had no unusual findings for the age at which they became pregnant with their child with ASD, although over a third reported pregnancy problems, and most pregnancies were full term. This study did not accommodate for either adopted or foster children with ASD; QOL of non-birth mothers of children with ASD was not evaluated. Over a third of mothers reported getting an average of seven or more hours of sleep per night while maintaining their caregiving responsibilities.

Activities Factors. The three Activities Factors assessed in this study included employment, employment location, and mother caregiving hours. Just over a third of the mothers worked full-time, and over two-fifths were unemployed. Similarly, having a child with ASD has been shown to be associated with lower earnings, less likelihood of being employed, and fewer hours of employment per week (Phetrasuwan & Miles, 2009). The reported number of caregiving hours per day reported by these mothers could have been influenced by their employment status and other caregiver involvement. Furthermore, mothers of children without ASD could provide similar caregiving hours, as U.S. mothers might perceive their caregiving role as their total responsibility to their child throughout a 24-hour day. This survey question did not have a secondary source of caregiving data as in a study using a diary of daily activities among Australian mothers of children with ASD that showed an average of 5.6 - 6.8 caregiving hours per day, with more caregiving time received by younger children (Sawyer et al., 2010).

Participation Factors. The Participation Factors included significant other relationship affected, spirituality association, life areas affected negatively, life areas affected positively, emotional support, and other caregiver. Nearly half of these mothers reported a negative change in their relationship with their significant other as a result of having a child with ASD. Relationships can be adversely affected by the stresses associated with having a child with ASD. About 10% more of the mothers belonged to an organized religion or spiritual group than those who did not. The majority of mothers reported a negative change in life areas including social activities, mental health, and in family and other relationships, in descending order of occurrences. All but 5% of the mothers reported negative changes in at least one of the life areas, while conversely 17% denied positive changes in at least one of the life areas. Comparable numbers of mothers reported that family relationships were negatively affected, and slightly fewer reported that family relationships were positively affected. Perhaps the additional family responsibilities of having a child with ASD brought solidification into the lives of over

55% of mothers who reported a positive change in family relationships. This appears to be harmonious with the response that over 40% of mothers reported the family as the source of most emotional support, and for nearly 65%, the spouse provided significant caregiving. In a similar fashion, approximately a fifth of the mothers had no one to provide emotional support or to act as the other caregiver. These findings are consistent with research showing that higher levels of informal social support from family, friends, and partner have been associated with lower levels of stress and depression among mothers of children with ASD (Ekas, Lickenbrock, & Whitman, 2010).

Environmental Factors. The Environmental Factors reveal the predominance of households with expected family characteristics of two adults, two children, one with ASD, and fathers of a similar age as mothers at the time of conception. The average child age at ASD diagnosis occurred close to the time that mothers noticed problems, given reasonable timeframes for appointments, testing, and data gathering from sources like educational facilities. This may be attributed to the increased awareness in both the medical and educational community efforts in identifying children with ASD in the U.S. The diagnostic categories provided in the survey questionnaire were based on the DSM-IV, and provide more information than the single diagnostic category in the DSM-V. Indian mothers who noticed early indicators of autism in their child experienced a delay of approximately 6 years for diagnosis (Kishore, 2011). About 10% more of the children in this study had healthcare coverage than the mothers, with similar numbers of mothers and children having military coverage. The availability of healthcare coverage in this U.S. study sample could also have affected the prompt diagnosis, as well as cultural appreciation for maternal concerns resulting in attention from healthcare providers.

The three highest frequencies in the child comorbid conditions undergoing current treatment included one that is managed by the healthcare system, anxiety, one that is predominantly addressed in educational programs, sensory integration dysfunction, and one that could receive services in both arenas, behavioral problems. Although the majority of children were described as sleeping well, there was no data collected on whether those children were receiving any treatments for night sleep. Only 12% of the children with ASD used assistive technology, however this is highly indicative of the available educational system resources and to some extent to healthcare services. Both speech and occupational therapy in the educational or in the medical setting were the most popular therapies received by the children while almost a third of the children received no therapy services. The classroom environment, or educational setting, for the children was well distributed from least to most restrictive.

A comparable number of mothers received the most information about raising her child from the healthcare provider and from the Internet. Mothers reported receiving more information from the other category, and this was not further delineated in the survey item. Another caregiver, in most cases the spouse, provided less than five hours per day of caregiving, on average. Time of day was not specified and this could reflect the time between when a child returns home from school until bedtime, or even the time after the mother returns home from work until bedtime. Information on use of before or after school programs was not elicited in this survey.

Personal Factors. The Personal Factors reveal that, in the predominantly white, married, working out of home, nonmilitary healthcare covered sample respondent group, almost three-fifths were living in a household with income under $75,000. Almost seventenths of the mothers reported having some college education. Almost a quarter had a Bachelor's degree and almost another tenth graduate school. This is likely consistent with Internet users in general, and mothers who are caregivers for a child with special problems, seeking online information and support.

Research Question 2. What Is the QOL Among Mothers of Children With ASD?

The WHOQOL-BREF scores, ranked from highest to lowest scores, were the 1Physical Health, Environmental, Psychological, and Social Relationships domain scores (see Table 3). The Physical Health domain survey items address pain, current medical treatment, energy, mobility, sleep, activities of daily living, and work capacity. Specifically, the Physical Health domain reflects pain as a comorbid condition, medical treatment, sleep, and other feelings about functional capacities that are primarily found under the Body Functions and Structures component of the ICF. The Environmental domain items inquire about the mother's feeling of safety, health, financial situation, information for daily life, leisure, living conditions, healthcare, and transportation. In this study the Environmental domain reflects items that would be reflective of the Personal Factors of income, and information source, which is among the Environmental Factors. Leisure is somewhat reflected among the Participation Factors. The Psychological domain items address enjoyable and meaningful life, concentration ability, appearance and ability acceptance, and negative feelings. In this study, the Psychological domain items refer primarily to feelings about oneself as well as comorbid conditions such as anxiety and depression that are found among the Body Functions and Structures Factors. There are only three WHOQOL-BREF items for Social Relationships, addressing satisfaction with personal relationships, sex life, and support from friends.

The issues addressed in this domain reflect a lower QOL in this group of mothers, as two of the questions are similar to the Participation Factors of life areas affected negatively, life areas affected positively, and emotional support. The Social Relationships domain addresses personal relationships, sex life, and support from friends. Two of these items are similar to items among the Participation and Environmental Factors.

The WHOQOL-BREF was developed for international applications and as such provides profiles that characterize particular cultural groups or subgroups. Indian parents of children with ASD show WHOQOL-BREF domain scores, from highest to lowest, in the Social Relationships, Environmental, Psychological, these first three domains having similar scores, and the lowest in the Physical Health domain. All four of the domain scores were significantly lower than the scores of parents of children with physical disabilities, or those of parents of healthy children (Perumal, Veeraraghavan, & Lekhra, 2014).

Research Question 3. What Are the Significant Relationships Between the Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors Among Mothers of Children With ASD, and the QOL of the Mothers?

The frequency of occurrence of significant individual linear regression relationships between the ICF Component Factors and the four WHOQOL-BREF domains yields observations of patterns that are independent of the number of factors within an ICF Component (see Table 4). The number of significant individual Body Functions and Structures Factors linear regressions is found, in decreasing order, in the Physical Health domain, followed by the Psychological domain, and an equal number in the Social Relationships and Environmental domains. The number of significant individual Activities Factors linear regressions is found in the Physical Health domain followed by the Environmental domain. The number of significant individual Participation Factors linear regressions is found, in decreasing order, in the Psychological QOL domain, followed by the Social Relationships domain, then the Environmental domain, and the Physical Health domain. The number of significant individual Environmental Factors linear regressions is found, in decreasing order, in the Environmental domain, followed by the Physical Health domain, then the Social Relationships domain, and lastly the Psychological domain. The researcher constructed survey items did not intentionally represent coordination between the ICF Component Factors and the WHOQOL-BREF domains. Rather the survey items were designed to identify factors associated with QOL among mothers of children with ASD based upon the existing literature, clinical experience, and judgment from a healthcare provider's perspective. It appears that the researcher-constructed survey items, constituting the ICF Component Factors, do reflect the functional holistic perspective of the modified ICF conceptual model, while demonstrating the mutability of the ICF framework for both research and clinical application.

Observations of the frequency that an ICF Component Factor significantly affects a QOL domain should be mentioned in discussion. The Body Functions and Structures Factors that were significantly associated with three or four of the QOL domains include the mother comorbid conditions of arthritis, diabetes, mother sleep hours and pregnancy problems. The Participation Factors that were significantly associated with three or four of the QOL domains include significant other relationship, and life areas affected negatively of none, family relationships, other relationships, physical health, mental health, and spirituality participation. The Environmental Factors that were significantly associated with three or four of the QOL domains included the number of children in the household, child sleep hours, and assistive technology.

Research Question 4. What Are the Predictive Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors Among Mothers of Children With ASD for Their QOL?

The significant individual linear regression ICF Component Factors were combined and assessed as contributors in the development of multiple linear regression models for each of the four WHOQOL-BREF domains according to each ICF Component, and for All Significant ICF Components (see Tables 4 - 8). This was done in order to detect the predictor risk factors that would have an influence on each of the four QOL domains among these mothers of children with ASD. The magnitude of influence was an additional computation to provide further information regarding the ICF Component Factor contribution to QOL. Those factors associated with greater influence or magnitude of contribution warrant attention and intervention. The following discussion emphasizes those factors associated with the most influence on QOL.

The Body Functions and Structures Factor that predicted the greatest decrease in Physical Health QOL was the mother comorbid condition of arthritis, while mothers sleeping seven to eight hours per day was associated with the greatest increase in Physical Health QOL. Children often develop problems as a result of or in conjunction with their mother's health status. An increase in brain-reactive antibodies that may be associated with autoimmunity has recently been documented in mothers of children with ASD (Brimberg, Sadiq, Gregersen, & Diamond, 2013). Mothers who reported the life area of physical health as being negatively affected by having a child with ASD had lower Physical Health QOL in the models developed with the Participation Factors and in the model with All Significant ICF Factors. This could reflect the overriding influence that feelings about one's physical health have an extending effect upon the mother's actual Physical Health QOL.

The Body Functions and Structures Factor that predicted a decrease in Psychological QOL was the mother comorbid condition of depression, while mothers sleeping four to eight hours per day was associated with the greatest increases in Psychological QOL. Mothers who reported the life area affected negatively of health had lower Psychological QOL in the models developed with the Participation Factors and in the model with All Significant ICF Component Factors. The second All Significant ICF Component Factor that predicted a decrease in Psychological QOL was the mother comorbid condition of diabetes.

The Participation Factor that predicted the greatest increase in Social Relationships QOL was in mothers who reported that their relationship with their significant other either was not changed, or was positively changed. This Factor influence was found in both the Participation Factor model and in the All Significant ICF Component Factors models for Social Relationships QOL. The Environmental Factors that predicted decreases in Social Relationships QOL were physical therapy services in the educational setting and, to a lesser degree, among children who used assistive technology, although both of these factors occurred in a small percentage of the sample. Nigerian mothers of children with cerebral palsy receiving physical therapy services had a lower QOL as measured using the WHOQOL-BREF compared to caregivers of normally developing children. Functional status improvement in the children was associated with improvement in caregiver QOL. The functional limitations of the child combined with the chronic nature of the burden may be associated with lower QOL (Fatudimu et al., 2013). Caution in the interpretation of the appearance of a Factor's influence on QOL is advised. The presence of a significant contribution to the variance in QOL may reflect multiple sources of impact beyond the Factor construct. For example, the individual characteristics of children with ASD who receive physical therapy services, and the associated contextual factors, could reflect sources of variation in the mother's QOL.

The Body Functions and Structures Factor that predicted a decrease in Environmental QOL was the mother comorbid condition of diabetes in the Body Functions and Structures model and in the All Significant ICF Components model. The Participation Factors of the significant other relationship and life areas affected negatively of physical health had similar influences in the Participation Factors model and in the All Significant ICF Component Factors model. The Environmental Factors had lower degrees of influence on Environmental QOL. The Personal Factors of household income above $100,000 predicted a higher Environmental QOL in the Personal Factors model and in the All Significant ICF Component Factors model.

The ICF Component Factors associated with the most influence, more than 20%, on the variance in QOL among mothers of children with ASD identified in the previously mentioned models, is summarized here. The greatest effect on lowering Physical Health QOL was predicted by the Body Functions and Structures Factor mother comorbid condition arthritis. The greatest increase in Physical Health QOL was predicted by an average of seven to eight hours of sleep in mothers, another Body Functions and Structures Factor. The greatest increase in Psychological QOL was predicted among mothers who reported sleeping an average of four to eight hours of sleep per night. The Participation Factor predicting the greatest increase in Social Relationships QOL was in mothers who reported either no change or a positive change in their relationship with their significant other. Mothers whose children with ASD received physical therapy in the educational setting, an Environmental Factor, were predicted to have the biggest effect on lowering in Social Relationships QOL. The mother comorbid condition diabetes, a Body Functions and Structures Factor, predicted the most lowering of Environmental QOL; the Personal Factor, household income above $100,000, predicted the greatest increase. These factors of influence comprise both modifiable and non-modifiable risk factors, but more importantly help to identify those mothers who might experience a lower QOL. For example, mothers with arthritis might have a lower Physical Health QOL, while mothers with diabetes might experience a lower Psychological QOL. Mothers whose children with ASD receive physical therapy in the educational setting might have a lower Social Relationships QOL. Those mothers who report a negative change in their relationship with their significant other might present as a vulnerable group for lower Social Relationships QOL.

Comments from Mothers

Respondents were given an opportunity to provide comments after completion of the survey. The data will be analyzed separately from this study. However, several remarks encompassed the needs and stresses of the mothers. One mother described her daily journey:

> In all things I consider ASD. It is a daily part of life for our entire family now. Some days I would like to forget about it, if only for a little while. But it is constant. It never goes away.

Regarding caregiving, another mother expressed: "How many hours do I care for my ASD child on average? Whenever he needs me. If he has a problem at school, I need to be there. It depends on the day, so there is no average." The future concerns many mothers as one expressed "It is fear for my son's future that causes the anxiety."

The diminishment in social life and activities is reflected in these statements: "Raising a child is overwhelming and causes a great deal of isolation." The escalation of stressful feelings is inherent in this mother's plea: "I think I may go mad. Life is very hard and isolating and there's a lot of sadness trying to set up life and be positive and just persevere and be hopeful and live in the moment."

Two mothers reported specific frustration with healthcare providers:

> Unless you live with autism on a daily basis, you will not be able to understand what family members go through each day. I am amazed at the lack of education and understanding, even in the medical field, regarding autism.

The need for mental health care is a plea from a mother who states: "The impact my child and myself endure from the stigma and denial of mental health among estranged family members and local community agencies who appear lacking reality common sense is a disgrace."

Issues that arise when dealing with healthcare coverage are major barriers to these mothers.

> A major stressor is having to constantly fight for medical coverage for necessary therapies, finding providers that will accept our insurance or have available appointments/slots to take in patients, and dealing with state medical agencies ... which continue to impede and cause difficulties in acquiring proper care for my child...it's all making me feel physically ill.

Mothers report problems with their child's educational services. "I find that teachers are not teaching her because they feel she is unteachable. The stress is overwhelming!" Mothers are sensitive to influences that their children are subjected to: "There is such a social stigma of ASD, especially in the school systems." There are additional burdens that accompany school attendance: "I have good days and bad. My mood has been negative recently because we have been fighting with my son's school over his IEP."

Several mothers acknowledged spirituality as an avenue of support. "My faith gives me strength!" These types of resources often traverse the domains of QOL:

> We have enjoyed a great deal of support from our new church. ... I see the next few years as being very critical for my son's future as well as my own. With continued support I believe that he will achieve a normal adult life and I will be able to overcome many of my emotional problems and improve physically so that I can take up my life again.

And from another mother "Having a (now adult child) with Autism Spectrum Disorder has been a blessing in my life. He has been an awesome teacher to me!"

Limitations of the Study

The limitations of this study are related to the sample, respondent bias, research design, and methodology. The convenience sample was nonrandom, and therefore generalizations are applied to the sample of respondents. The data is cross-sectional; causality is not implied. Web-based research protocols have associated limitations such as bias, inherent in survey research. Respondents are self selected and are influenced by confounding variables. The disadvantages of web-based survey research include as sources of error: response bias, veracity, representativeness, and a lack of response rate (Wright, 2005). Further bias in the form of confounding factors may be a result of daily life activities of both the mother and the child. Extraneous factors occurring in the environment of the respondent, Internet access, the mother's personal situation, time, health, etc., are considerations. The complex role of caregiver may cause mothers of children with ASD to over or underestimate their QOL. In addition, situational factors in the life of the child may have affected the survey responses. Both current and persistent factors in the lives of these mothers and in the lives of their children could contribute to bias. Systematic differences interposing error are further research limitations.

Participant recruitment for the present study via hyperlinked web-based survey methodology may be criticized as not being representative of the general population, although the potential advantages of Internet research outweigh such threats. This Internet survey recruited subjects via social media, posted as a research study on various Internet sites.

This study did not collect information on medication status of either the mothers or of their children. Medication for a comorbid condition, or for sleep, could have an effect on the domains of QOL. Historical medical information was not collected to assess effects of previous acute or chronic medical conditions and treatment. There was no validation of medical conditions in the respondents or their children.

This study did not include any formal medical substantiation of the diagnosis of Autism Spectrum Disorders by records review or contact with medical or educational systems, and therefore relied on the mothers' self report. Severity of ASD symptoms was not quantified in this study. Behavioral problems beyond the presence or absence were not addressed in this study.

Strengths of the Study

This study presents an example of original research in a population of mothers of children with ASD who might not be accessed via other cumbersome and time-consuming methodologies. The extensive data collection with respect to the number of independent variables that resulted from the researcher-constructed survey items facilitated the acquisition of a large amount of information through a single short web-based survey session. The creation of the researcher-constructed items of the survey allowed the researcher the opportunity and advantage to determine the data rather than use preexisting data to determine the study. Furthermore, the deciphering of the significant factors associated with QOL among mothers of children with ASD was not only in the identification of the specific factors but in the constellation of the relationships between the ICF Component Factors of the conceptual model and the multidimensional QOL domains assessed using the WHOQOL-BREF. This was solidified by the research design, the methodology, and statistical analysis.

Despite the lack of etiological progress in the understanding of ASD, research is needed, and anticipated by those entrenched in the daily challenges that accompany this unique yet complex disorder. The survey design was appropriate for this vulnerable population. The methodology allowed mothers who are involved in the obligations of raising a child with ASD to conveniently participate in the study.

Researchers have applied the ICF and the ICF-CY to analyze the gap between capacity and performance in complicated clinical conditions. "ICF functional profiles might be used...in identifying environmental factors that may act as barriers or facilitators to...recovery, well-being and inclusion in society" (Leonardi & Martinuzzi, 2009, p. S86). The ICF theoretical framework for this study establishes the rationale for the research design and findings as coherent contributions to the existing body of knowledge. The validation for the use of the ICF framework is in its inherent conceptualization of the contextual factors that affect an individual's health situation (Skevington & McCrate, 2012)

Future Research

Studies that address the assessment of QOL as an outcome make adjustments and modifications in the procedures associated with the methodology in following research protocols. Knowledge of adjustments made in the handling of data is vital to the interpretation of results. This investigation yielded QOL data collected utilizing the WHOQOL-BREF instrument as an assessment tool. This study utilized an intact established measure of generic QOL, thus promoting appreciation of the multidimensional aspects of QOL. However there is a discrepancy in the syntax recommended for the scoring of the WHOQOL-BREF. The Seattle Group associated with the WHO currently posts the SPSS scoring syntax, freely available on the Internet. As this study was conducted within the confines of the U.S., it is logical to use the scoring syntax version published by the U.S. research site. This study identified that application of the SEAQOL Group scoring syntax results in domain scores that are different than scores computed using the WHOQOL User Manual ("Syntax file," 1997; WHO, 1998). Further research is recommended to assess the syntax properties of the two WHO recommended sources.

The ICF applications have been established in the literature. Quality of life has been proposed to expand the framework of the ICF and superimpose human development for a more holistic view (McDougall et al., 2010). A longitudinal study is suggested using the current study protocol to further assess the QOL of mothers of children with ASD through life years. Since ASD affect an individual throughout life, the years of chronic caregiving may in turn affect the QOL of the mothers. Other factors to consider include the transition of the child to adult life and the aging of the mother.

Health Policy Recommendations

This study has shown that the identification of factors associated with QOL among mothers of children with ASD has warranted implications for health policy. Research conducted by clinicians working with individuals with ASD and their families has contributed to improvements in knowledge base, assessment tools, and intervention practices. This has resulted in benefits to children with ASD and to their families (Lord, 2010). A health care provider with direct experience in the delivery of services to children with ASD in the public school setting is the author of this research study.

Potential contributions in the collaborative areas of healthcare and educational services are identified to further assist families dealing with the effects of ASD.

Female caregivers of children with ASD have lower health related QOL scores as compared to U.S. population norms (Khanna et al., 2011). Maternal QOL impacts the mother, her child with ASD, and the family. Mothers that are currently receiving healthcare treatment for comorbid conditions may have a lower QOL. Since these mothers often accompany their children to primary care doctor visits, it is suggested that a resource file, in a variety of formats, with a listing of community and other resources be made available to mothers. Mothers can be given an opportunity during the many child healthcare provider visits to address their own concerns that may be related to their Physical Health, Psychological, Social Relationships, or Environmental QOL. The applications targeted to the Physical Health of the mother would be aligned as the Body Functions & Structures resources. The Activities resources could be a list of certain options such as spas, parks, recreation areas, and supervised physical activity locations, with particular emphasis on those resources that offer specialized childcare services or scheduling preferences. The Participation resources could include family friendly sites such as restaurants and movie theatres, churches, etc. The Environmental resources could include support groups in both online and actual community level opportunities. The support resources could also include local educational institutions for the variety of healthcare providers. The Personal resources might be those of local employment agencies that specialize in addressing the needs of mothers. Work locations, flexible hours and onsite childcare that would allow children with special needs to attend would be assets for employers to develop.

In addition to the above resource information, mothers can be provided with technological support in the form of a QOL app assessment that could be engaged at their convenience. Informational guidance could include aspects from the multidimensional QOL domain areas with an integrated plan for self-assessment and QOL improvement. The app design is to coordinate the ICF Component Factors with the Physical Health, Psychological, Social Relationships, and Environmental QOL domains reinforcing a holistic approach.

Resources for mothers of autistic children could be expanded via support accommodations through existing community resources such as the public schools. These institutions have gymnasiums and physical facilities that can be used for child care during the day and after school hours. Extension of the availability of these programs, including nutritional supports, could be targeted to include children with ASD, on days including weekends and non-school attendance days. The staffing of such programs, coordinated with area public health clinics and healthcare provider training institutions would ensure high quality services.

Communication and collaboration ventures should be developed between the healthcare providers and the educational systems. As mothers may experience deleterious effects upon their QOL, such as this study showed in a lower Social Relationships QOL when their child receives physical therapy services in an educational setting, an emphasis on sensitivity, mediation, and resolution of conflict management techniques (as mentioned in the Comments from Mothers) that intervene between the healthcare and educational systems would be beneficial. The separate nature of the entities should not limit joint efforts in serving mothers and children with ASD. The healthcare and the educational systems could provide coordinated supports to improve QOL for mothers of children with ASD.

Targeting healthcare provider education regarding the QOL of mothers of children with ASD and would enhance intervention through community cooperation and policy changes. Program modification would optimize factors that are associated with improving QOL by the identification of risk factors forthcoming from this research. Curricula that train physicians, nurses, therapists, and other healthcare providers could be expanded and offered through participation in community social events and healthcare clinics that serve children with ASD while promoting an awareness of the needs of the mothers. This would benefit both the provider as well as the recipient population.

An outgrowth of the latest revision of the DSM – V, with a single diagnostic category, is a need for the gathering of further information on the functioning of the child with ASD. This entails assessment information that addresses the various aspects of functioning, with special attention to factors associated with QOL of the mothers. Incorporating the ICF framework over the lifespan would be facilitated by use of electronic medical records and easily translates the information for the documentation of progress over time.

Summary

This chapter has concluded with the interpretation of the results of this study with the identification of factors associated with QOL among mothers of children with ASD. Based upon the modified ICF conceptual framework, health policy changes are recommended to improve QOL among mothers of children with ASD. The inherent flexibility of the ICF framework allows consideration of individual characteristics of both mothers and of their children with ASD. Hence the value of the recommendations rests upon the healthcare and educational systems to attend to the ICF constellation of Body Functions and Structures, Activities, Participation, Environmental, and Personal Factors associated with QOL among mothers of children with ASD.

There is an appreciable amount of stress on mother caregivers of children with ASD. The diagnostic criteria and interventions are nebulous, and the scientific community may not have the answers to allay the fears and anxieties of a mother of a child with ASD. This study has attempted to elucidate those factors that are associated with QOL among mothers of children with ASD. The complexity of ASD, the randomness and unpredictability of the needs of mothers and of their children emphasize the necessity for research of this nature.

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APPENDIX A

RECRUITMENT EMAIL

I am recruiting participants to complete a web questionnaire for my doctoral dissertation entitled "Factors Associated with Quality Among Life of Mothers of Children with Autism Spectrum Disorders." I am seeking English literate mothers (over the age of 18), residing in the United States, who have children with Autism Spectrum Disorders.

Participation in this research offers no benefit but could serve to enhance the quality of life of mothers who have children with Autism Spectrum Disorders. The following link will take you to the survey that consists of approximately 60 questions and could be completed in less than 30 minutes:

https://odu.qualtrics.com/SE/?SID=SV_eldq9Sl9UxYydA9

I would appreciate your assistance in identifying potential participants via the posting of this announcement on your website, or by email from you. If there are any questions regarding the study (IRB Approval No. 12-239), please contact me, Marian Marconyak, at 757-635-5006 or mmarc001@odu.edu. My dissertation director is Dr. Gianluca De Leo, who can be reached at 757-683-6733 or gdeleo@odu.edu.

Thank you for your assistance in this research.

Respectfully,

Marian Marconyak MA, PT
Doctoral Candidate
Old Dominion University
Program in Health Services Research

Gianluca De Leo PhD, MBA
Associate Professor
Medical Laboratory & Radiation Sciences
Old Dominion University
College of Health Sciences – Annex
1015 West 47th
Norfolk, VA 23529

APPENDIX B

RECRUITMENT INTERNET POSTING

Invitation to Mothers of Children with Autism Spectrum Disorder (ASD)

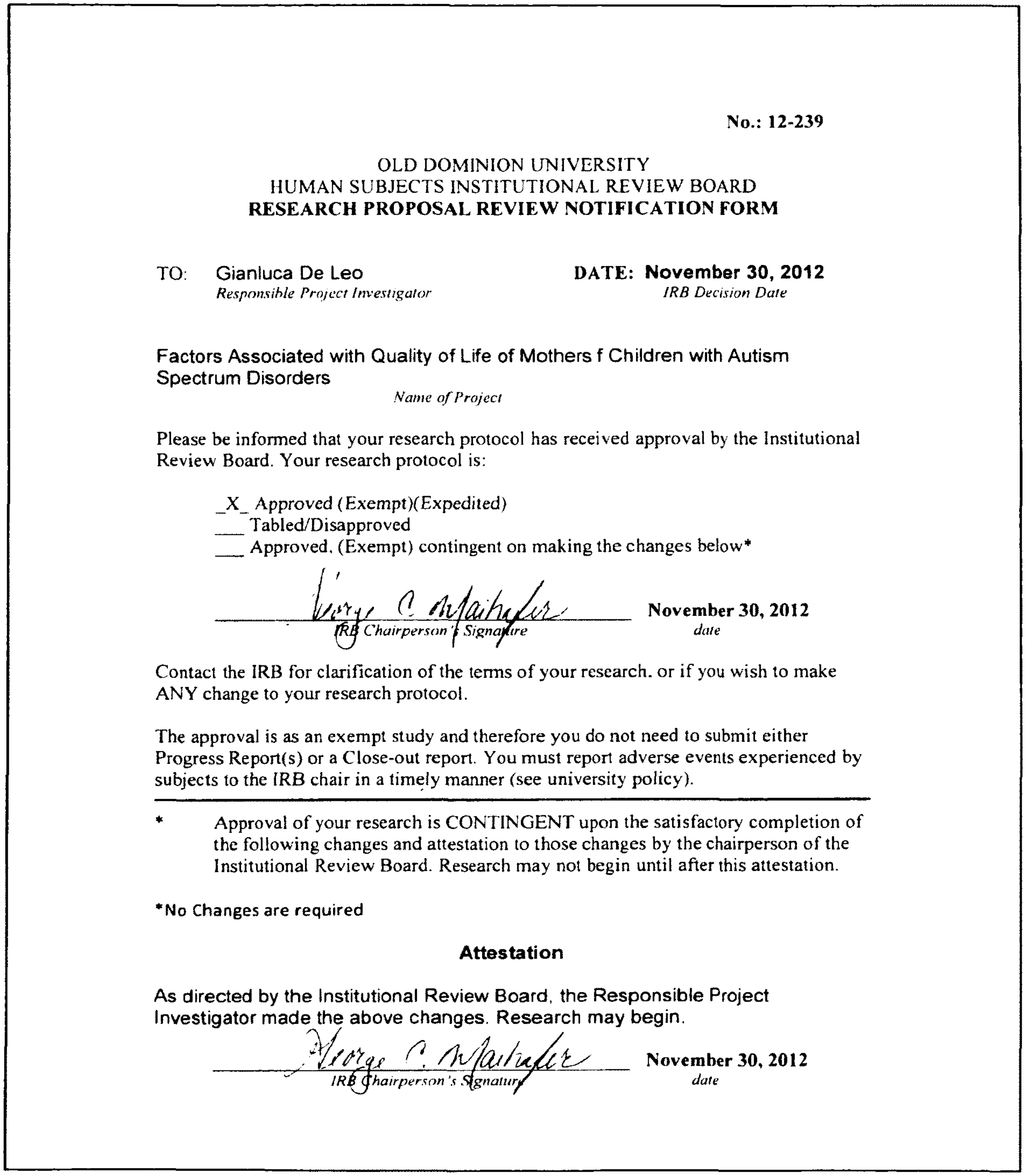
I am a doctoral student recruiting participants for my dissertation, a web questionnaire entitled "Factors Associated with Quality of Life Among Mothers of Children with Autism Spectrum Disorders." I am seeking English literate mothers over the age of 18, who reside in the United States, and have children with ASD. Participation in this research offers no direct benefit but could serve to enhance the quality of life of other mothers who have children with ASD. The following link goes directly to the survey of approximately 60 questions and can be completed in less than 30 minutes:

https://odu.qualtrics.com/SE/?SID=SV_eldq9SI9UxYydA9

Please contact me with any questions by email mmarc001@odu.edu

APPENDIX C

INSTITUTIONAL REVIEW BOARD LETTER OF APPROVAL



No.: 12-239

OLD DOMINION UNIVERSITY
HUMAN SUBJECTS INSTITUTIONAL REVIEW BOARD
RESEARCH PROPOSAL REVIEW NOTIFICATION FORM

TO: Gianluca De Leo
Responsible Project Investigator

DATE: November 30, 2012
IRB Decision Date

Factors Associated with Quality of Life of Mothers f Children with Autism Spectrum Disorders
Name of Project

Please be informed that your research protocol has received approval by the Institutional Review Board. Your research protocol is:

_X_ Approved (Exempt)(Expedited)
___ Tabled/Disapproved
___ Approved, (Exempt) contingent on making the changes below*

George C. Maihafer
IRB Chairperson's Signature

November 30, 2012
date

Contact the IRB for clarification of the terms of your research, or if you wish to make ANY change to your research protocol.

The approval is as an exempt study and therefore you do not need to submit either Progress Report(s) or a Close-out report. You must report adverse events experienced by subjects to the IRB chair in a timely manner (see university policy).

---

* Approval of your research is CONTINGENT upon the satisfactory completion of the following changes and attestation to those changes by the chairperson of the Institutional Review Board. Research may not begin until after this attestation.

*No Changes are required

Attestation

As directed by the Institutional Review Board, the Responsible Project Investigator made the above changes. Research may begin.

George C. Maihafer
IRB Chairperson's Signature

November 30, 2012
date

APPENDIX D

MODIFIED INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH CONCEPTUAL MODEL COMPONENTS AND CORRESPONDING OPERATIONAL VARIABLE DEFINITIONS

ICF Model Component	**Independent Variable Factor**	**Variable Definition Survey Question**
Body Functions and Structures	- Mother Age - Mother Comorbid Conditions: - Mother Sleep Hours - Mother Age at Conception - Gestation Length - Pregnancy Problems	- What is your age? - Please check any health problems for which you currently receive treatment. Check all that apply: Anxiety, Arthritis, Cancer, Depression, Dermatological problems, Diabetes, High blood pressure, Gastrointestinal problems, Musculoskeletal problems, Neurological problems, Pain, Other medical condition, Other mental health problem. - On average, how many hours a night do you sleep? - How old were you when you became pregnant with your child with ASD? - How many weeks pregnant were you when you delivered your child with ASD? -Did you have any problems during the pregnancy with your child with ASD?
Activities	- Employment - Employment Location - Mother Caregiving Hours	- What is your employment status? - Is your home your location of employment? - On average, how many hours per day do you spend in caregiving for your child with ASD?
Participation	- Significant Other Relationship Affected - Spirituality Association - Life Areas Affected Negatively	- How has having a child with ASD affected your relationship with your significant other? - Do you belong to an organized religion or spiritual group? - What areas of your life are **negatively** affected by caring for your child with ASD? Check all that apply: No areas, Family relationships, Other relationships, Physical health, Mental health, Sports/recreational activities, Social activities, Spirituality.

	- Life Areas Affected Positively	- What areas of your life are **positively** affected by caring for your child with ASD? Check all that apply: No areas, Family relationships, Other relationships, Physical health, Mental health, Sports/recreational activities, Social activities, Spirituality.
	- Information Source	- Who provides the majority of information for your needs in raising your child with ASD? Healthcare provider, Spouse, Other family member, Friend, Teacher, Therapist, (Occupational, Physical, or Speech), Support Group, Internet, Other.
	- Emotional Support	- Who provides the most emotional support for coping with your responsibilities as a mother of a child with ASD? No one, Family, Friends, Support Groups, Church or religious organization, Internet, Other.
Environmental	- Number of Adults in Household	- How many adults (including yourself), age 18 and older, live in your household?
	- Number of Children in Household	- How many children, under the age of 18, live in your household?
	- Number of Children with ASD	- How many children in your family have a diagnosis of ASD?
	- Father Age at Conception	- What was the age of the father of your child with ASD when you became pregnant?
	- Child Age	- What is the current age of your child with ASD?
	- Child Gender	- What is the gender of your child with ASD?
	- Child Age at Diagnosis	- At what age was your child diagnosed with ASD?
	- Time to Diagnosis	- How long was it between when you noticed that your child had problems and when your child was diagnosed with ASD?
	- ASD Diagnosis	- What is the specific ASD diagnosis that your child has?
	- Child Healthcare Coverage	- Does your child with ASD have health care coverage?
	- Child Healthcare Coverage Military	- Does your child with ASD receive military benefits?
	- Child Comorbid Conditions	- Please check any health problems for which your child with ASD is currently receiving treatment: Anxiety, Behavioral problems, Depression, Feeding problems, Gastrointestinal

		problems, Musculoskeletal problems, Seizures, Sensory integration dysfunction, Toe-walking, Other medical condition, Other mental health problem.
	- Child Sleep Hours	- On average, how many hours a night does your child with ASD sleep?
	- Child Assistive Technology	- Does your child with ASD use any assistive technology?
	- Child Therapy Type	- What therapy services does your child with ASD currently receive? Check all that apply: No therapy services, OT educational, OT medical, PT educational, PT medical, SP educational, SP medical.
	- Child Classroom Setting	- What type of classroom best describes the educational setting of your child who has ASD? Does not attend school, Regular, Inclusion, Self-contained, Home school, Other.
	- Other Caregiver	- What other person provides significant caregiving for your child with ASD? No one, Spouse, Sibling, Your parents of spouse's parents, Other relative.
	- Other Caregiver Caregiving Hours	-On average, how many hours per day does this person spend in caregiving for your child with ASD?
Personal	- Mother Education Level	- What is your level of education?
	- Mother Race	- What is your race?
	- Marital Status	- What is your current marital status?
	- Mother Income Level	- What is your annual household income?
	- Mother Healthcare Coverage	- Do you yourself have healthcare coverage?
	- Mother Healthcare Coverage Military	- Do your receive military healthcare benefits?
	Dependent Variable	**WHOQOL-BREF Survey Question**
QOL	- Overall QOL	- How would you rate your quality of life?
QOL	- General Health	- How satisfied are you with your health?
QOL	- Physical Health Domain	- To what extent do you feel that physical pain prevents you from doing what you need to do? - How much do you need any medical treatment to function in your daily life? - Do you have enough energy for everyday life?

		- How well are you able to get around? - How satisfied are you with your sleep? - How satisfied are you with your ability to perform your daily living activities? - How satisfied are you with your capacity for work?
QOL	- Psychological Domain	- How much do you enjoy life? - To what extent do you feel your life to be meaningful? - How well are you able to concentrate? - Are you able to accept your bodily appearance? - How satisfied are you with your abilities? - How often do you have negative feelings, such as blue mood, despair, anxiety, depression?
QOL	- Social Relationships Domain	- How satisfied are you with your personal relationships? - How satisfied are you with your sex life? - How satisfied are you with the support you get from your friends?
QOL	- Environmental Domain	- How safe do you feel in your daily life? - How healthy is your physical environment? - Have you enough money to meet your needs? - How available to you is the information that you need in your day-to-day life? - To what extent do you have the opportunity for leisure activities - How satisfied are you with the conditions of your living place? - How satisfied are you with your access to health services? - How satisfied are you with your mode of transportation?

APPENDIX E

RESEARCH SUBJECT CONSENT AND SURVEY QUESTIONNAIRE

(Posted on Qualtrix)

Factors Associated with Quality of Life Among Mothers of Children with Autism Spectrum Disorders

This survey will take approximately 30 minutes to complete. There are three sections. You will be asked questions about yourself, your quality of life, your child with Autism Spectrum Disorder (ASD), and your household.

Your name and any identifying information will not be requested. Thus all answers will be anonymous. No record of web or email address will be collected.

You do not have to participate in this study. If you choose to participate you may exit the study anytime without penalty. You may also choose to not answer particular questions without penalty. Pick one answer for each question unless otherwise indicated.

By clicking the arrow on the bottom right, you are indicating that you freely consent to participate.

If you have any questions, please contact the PhD Student/Student Investigator Marian Marconyak MA, PT, at (757) 635-5006 or by email mmarc001@odu.edu or the Responsible Project Investigator, Dr. Gianluca De Leo, PhD, MBA, Associate Professor, College of Health Sciences, Old Dominion University at (757) 683-6733, or by email gdeleo@odu.edu

Press the arrow on the bottom right to start the survey.

Are you the mother of a child/children with Autism Spectrum Disorders?

○ No
○ Yes

Are you 18 years of age or older?

○ No
○ Yes

Do you currently reside in the United States?

○ No
○ Yes

Section I. This section asks questions about you.

What is your age?

○ 18-24 years
○ 25-34 years
○ 35-44 years
○ 45-54 years
○ 55 years and older

What is your level of education?

○ Less than a high school diploma
○ High school diploma or GED
○ Some college
○ Bachelors degree
○ Graduate school

What is your race?

○ White
○ Hispanic or Latino
○ African American
○ American Indian
○ Asian
○ Pacific Islander
○ Other ________________

What is your current marital status?

○ Single
○ Living with a Partner
○ Married
○ Widowed

What is your employment status?

○ Unemployed
○ Part-time
○ Full-time

Is your home your location of employment?

○ No
○ Yes

How many adults (including yourself), age 18 or older, live in your household?

○ 1
○ 2
○ 3
○ 4
○ 5 or more

How many children, under the age of 18, live in your household?

○ 1
○ 2
○ 3
○ 4
○ 5 or more

How many children in your family have a diagnosis of ASD?

○ 1
○ 2
○ 3 or more

What is your annual household income?

○ Less than $35,000
○ $35,000-$49,999
○ $50,000-$74,999
○ $75,000-$99,999
○ $100,000 or more

Do you yourself have health care coverage?

○ No
○ Yes

Do you receive military health care benefits?

○ No
○ Yes

Please check any health problems for which you currently receive treatment. (Check all that apply.)

☐ Anxiety
☐ Arthritis
☐ Cancer
☐ Depression
☐ Dermatological problems
☐ Diabetes
☐ High blood pressure
☐ Gastrointestinal problems
☐ Musculoskeletal problems
☐ Neurological problems
☐ Pain
☐ Other medical condition
☐ Other mental health problem

On average, how many hours a night do you sleep?

○ Less than 4 hours
○ 4-5 hours
○ 5-6 hours
○ 7-8 hours
More than 8 hours

How has having a child with ASD affected your relationship with your significant other?

○ No change
○ Negative change
○ Positive change

Do you belong to an organized religion or spiritual group?

○ No
○ Yes

What areas of your life are **negatively** affected by caring for your child with ASD? (Check all that apply.)

☐ No areas are negatively affected
☐ Family relationships
☐ Other relationships
☐ Physical health
☐ Mental health
☐ Sports/recreational activities
☐ Social activities
☐ Spirituality

What areas of your life are **positively** affected by caring for your child with ASD? (Check all that apply.)

☐ No areas are positively affected
☐ Family relationships
☐ Other relationships
☐ Physical health
☐ Mental health
☐ Sports/recreational activities
☐ Social activities
☐ Spirituality

Section II. This section asks questions about your child who has ASD. If you have more than one child with ASD, please choose the oldest child for the following questions.

How old were you when you became pregnant with your child with ASD?

○ Under the age of 18
○ 18-24 years
○ 25-34 years
○ 35-44 years
○ 45-54 years
○ 55 years and older

What was the age of the father of your child with ASD when you became pregnant?

○ Under the age of 18
○ 18-24 years
○ 25-34 years
○ 35-44 years
○ 45-54 years
○ 55 years and older

What is the current age of your child with ASD?

______Years

What is the gender of your child with ASD?

○ Male
○ Female

How many weeks pregnant were you when you delivered your child with ASD?

______Weeks

Did you have any problems during the pregnancy with your child with ASD?

○ No
○ Yes

At what age was your child first diagnosed with ASD?

______Years

How long was it between when you first noticed that your child had problems and when your child was diagnosed with ASD?

○ Less than 6 months
○ 1 year
○ 2 years
○ 3 years
○ 4 years
○ 5 years or more

What is the specific ASD diagnosis that your child has?

○ Do not know
○ Autistic Disorder
○ Asperger Syndrome
○ PDD-NOS (Pervasive Developmental Disorder - Not Otherwise Specified)
○ Rett's Syndrome
○ Childhood Disintegrative Disorder
○ Other ________________

Does your child with ASD have health care coverage?

○ No
○ Yes

Does your child with ASD receive military health care benefits?

○ No
○ Yes

Please check any health problems for which your child with ASD is currently receiving treatment.

☐ Anxiety
☐ Behavioral problems
☐ Depression
☐ Feeding problems
☐ Gastrointestinal problems
☐ Musculoskeletal problems
☐ Seizures
☐ Sensory Integration Dysfunction
☐ Toe walking
☐ Other medical condition
☐ Other mental health problem

On average, how many hours a night does your child with ASD sleep?

○ Less than 4 hours
○ 4-5 hours
○ 5-6 hours
○ 7-8 hours
○ More than 8 hours

Does your child with ASD use any assistive technology to communicate?

○ No
○ Yes

On average, how many hours per day do you spend in caregiving for your child with ASD?

______Hours

What therapy services does your child with ASD currently receive? (Check all that apply.)

☐ No therapy service
☐ Occupational therapy, educational setting
☐ Occupational therapy, medical setting or clinic
☐ Physical therapy, education setting
☐ Physical therapy, medical setting or clinic
☐ Speech therapy, educational setting
☐ Speech therapy, medical setting or clinic

In what type of classroom best describes the educational setting of your child who has ASD?

○ My child does not attend school
○ Regular classroom
○ Inclusion classroom
○ Self-contained classroom
○ Home school
○ Other _______________

Who provides the majority of information for your needs in raising your child with ASD?

○ Health Care Provider (doctor, nurse)
○ Spouse
○ Other family member
○ Friend
○ Teacher
○ Therapist (Occupational, Physical, or Speech)
○ Support group
○ Internet
○ Other _______________

Who provides the most emotional support for coping with your responsibilities as a mother of a child with ASD?

○ No one
○ Family
○ Friends
○ Support groups
○ Church, religious organization
○ Internet
○ Other _______________

What other person provides significant caregiving for your child with ASD?

○ No one
○ Spouse
○ Sibling
○ Your parents or your spouse's parents
○ Other relative

On average, how many hours per day does this person spend in caregiving for your child with ASD?

_____Hours

Section III. This questionnaire (WHOQOL-BREF) asks how you feel about your quality of life, health, or other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response. Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last two weeks.

Please read each question, assess your feeling, and choose the best answer.

How would you rate your quality of life?

○ Very poor
○ Poor
○ Neither poor nor good
○ Good
○ Very good

How satisfied are you with your health?

○ Very Dissatisfied
○ Dissatisfied
○ Neither satisfied nor dissatisfied
○ Satisfied
○ Very Satisfied

The following questions ask about how much you have experienced certain things in the last two weeks.

To what extent do you feel that physical pain prevents you from doing what you need to do?

○ Not at all
○ A little
○ A moderate amount
○ Very much
○ An extreme amount

How much do you need any medical treatment to function in your daily life?

- ○ Not at all
- ○ A little
- ○ A moderate amount
- ○ Very much
- ○ An extreme amount

How much do you enjoy life?

- ○ Not at all
- ○ A little
- ○ A moderate amount
- ○ Very much
- ○ An extreme amount

To what extent do you feel your life to be meaningful?

- ○ Not at all
- ○ A little
- ○ A moderate amount
- ○ Very much
- ○ An extreme amount

How well are you able to concentrate?

- ○ Not at all
- ○ Slightly
- ○ A moderate amount
- ○ Very much
- ○ Extremely

How safe do you feel in your daily life?

- ○ Not at all
- ○ Slightly
- ○ A moderate amount
- ○ Very much
- ○ Extremely

How healthy is your physical environment?

○ Not at all
○ Slightly
○ A moderate amount
○ Very much
○ Extremely

The following questions ask about how completely you experience or were able to do certain things in the last two weeks.

Do you have enough energy for everyday life?

○ Not at all
○ A little
○ Moderately
○ Mostly
○ Completely

Are you able to accept your bodily appearance?

○ Not at all
○ A little
○ Moderately
○ Mostly
○ Completely

Have you enough money to meet your needs?

○ Not at all
○ A little
○ Moderately
○ Mostly
○ Completely

How available to you is the information that you need in your day-to-day life?

○ Not at all
○ A little
○ Moderately
○ Mostly
○ Completely

To what extent do you have the opportunity for leisure activities?

○ Not at all
○ A little
○ Moderately
○ Mostly
○ Completely

How well are you able to get around?

○ Very poor
○ Poor
○ Neither poor nor well
○ Well
○ Very well

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over the last two weeks.

How satisfied are you with your sleep?

○ Very Dissatisfied
○ Dissatisfied
○ Neither satisfied nor dissatisfied
○ Satisfied
○ Very Satisfied

How satisfied are you with your ability to perform your daily living activities?

○ Very Dissatisfied
○ Dissatisfied
○ Neither satisfied nor dissatisfied
○ Satisfied
○ Very Satisfied

How satisfied are you with your capacity for work?

○ Very Dissatisfied
○ Dissatisfied
○ Neither satisfied nor dissatisfied
○ Satisfied
○ Very Satisfied

How satisfied are you with your abilities?

○ Very Dissatisfied
○ Dissatisfied
○ Neither satisfied nor dissatisfied
○ Satisfied
○ Very Satisfied

How satisfied are you with your personal relationships?

○ Very Dissatisfied
○ Dissatisfied
○ Neither satisfied nor dissatisfied
○ Satisfied
○ Very Satisfied

How satisfied are you with your sex life?

○ Very Dissatisfied
○ Dissatisfied
○ Neither satisfied nor dissatisfied
○ Satisfied
○ Very Satisfied

How satisfied are you with the support you get from your friends?

○ Very Dissatisfied
○ Dissatisfied
○ Neither satisfied nor dissatisfied
○ Satisfied
○ Very Satisfied

How satisfied are you with the conditions of your living place?

○ Very Dissatisfied
○ Dissatisfied
○ Neither satisfied nor dissatisfied
○ Satisfied
○ Very Satisfied

How satisfied are you with your access to health services?

○ Very Dissatisfied
○ Dissatisfied
○ Neither satisfied nor dissatisfied
○ Satisfied
○ Very Satisfied

How satisfied are you with your mode of transportation?

○ Very Dissatisfied
○ Dissatisfied
○ Neither satisfied nor dissatisfied
○ Satisfied
○ Very Satisfied

The following question refers to how often you have felt or experienced certain things in the last two weeks.

How often do you have negative feelings, such as blue mood, despair, anxiety, depression?

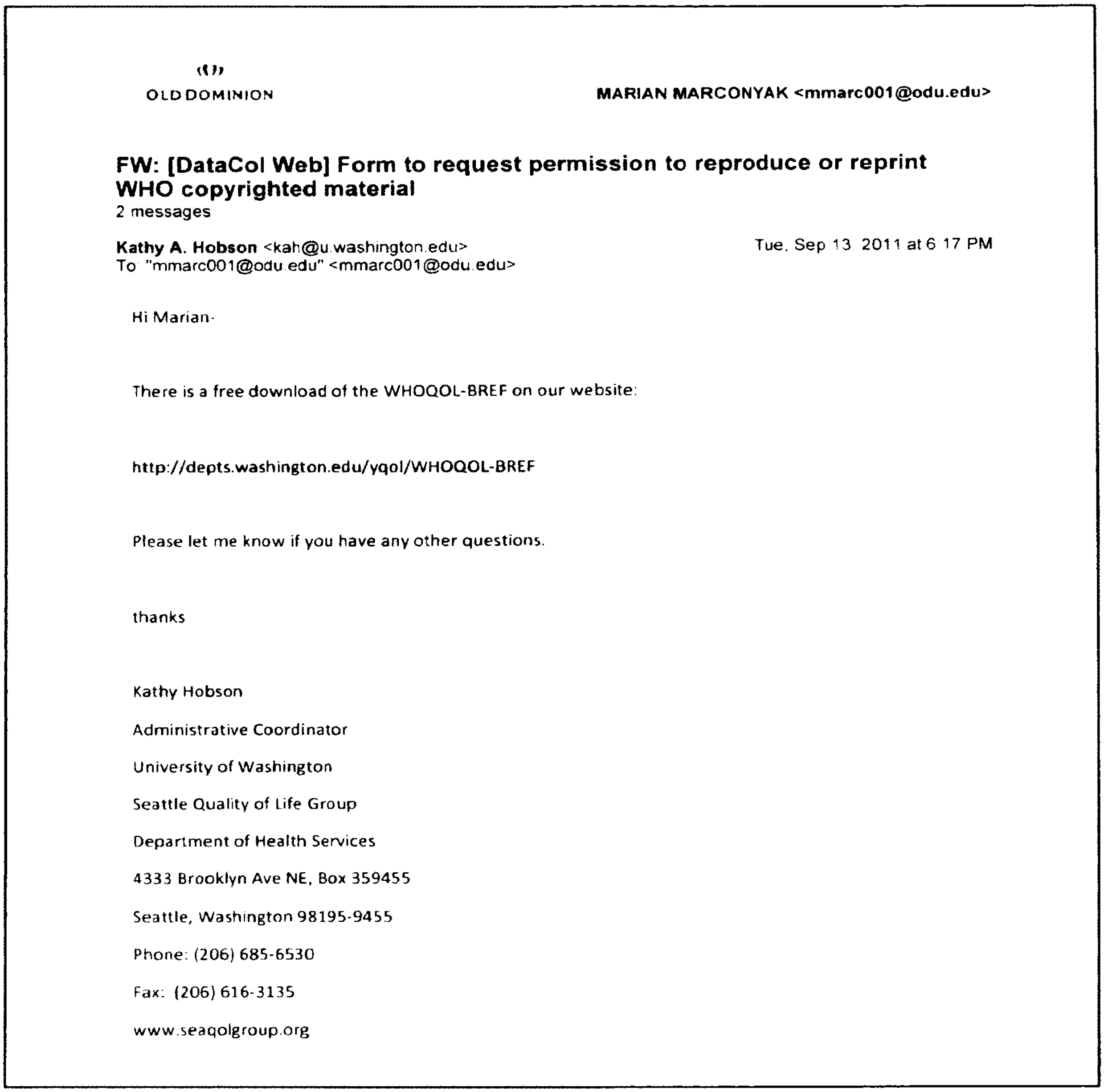
○ Never
○ Seldom
○ Quite often
○ Very often
○ Always

Do you have any comments that you would like to add?

____

APPENDIX F

PERMISSION TO USE WHOQOL-BREF



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MARIAN MARCONYAK <mmarc001@odu.edu>

FW: [DataCol Web] Form to request permission to reproduce or reprint WHO copyrighted material

2 messages

Kathy A. Hobson <kah@u.washington.edu>
To: "mmarc001@odu.edu" <mmarc001@odu.edu>

Tue, Sep 13, 2011 at 6:17 PM

Hi Marian-

There is a free download of the WHOQOL-BREF on our website:

http://depts.washington.edu/yqol/WHOQOL-BREF

Please let me know if you have any other questions.

thanks

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APPENDIX G

WHOQOL-BREF SPSS Syntax*

1. Check that all 26 items have a range of 1-5.

```
RECODE Q1 Q2 Q3 Q4 Q5 Q6 Q7 Q8 Q9 Q10 Q11 Q12 Q13 Q14 Q15 Q16 Q17 Q18
Q19 Q20 Q21 Q22 Q23 Q24 Q25 Q26
(1=1) (2=2) (3=3) (4=4) (5=5) (ELSE=SYSMIS).
```

(This recodes all data outside the range 1-5 to system missing.)

2. Reverse the three negatively phrased items.

```
RECODE Q3 Q4 Q26 (1=5) (2=4) (3=3) (4=2) (5=1).
```

(This transforms negatively framed questions to positively framed questions.)

3. Compute domain scores.

```
COMPUTE PHYSICAL=MEAN.6(Q3,Q4,Q10,Q15,Q16,Q17,Q18)*4.
COMPUTE PSYCHOLOGICAL=MEAN.5(Q5,Q6,Q7,Q11,Q19,Q26)*4.
COMPUTE SOCIAL RELATIONSHIPS=MEAN.2(Q20,Q21,Q22)*4.
COMPUTE ENVIRONMENTAL=MEAN.6(Q8,Q9,Q12,Q13,Q14,Q23,Q24,Q25)*4.
```

(These equations calculate the domain scores. All scores are multiplied by 4 so as to be directly comparable with scores derived from the WHOQOL-100. The '.6' in 'mean.6' specifies that 6 items must be endorsed for the domain score to be calculated.)

4. Transform scores to a 0-100 scale.

```
COMPUTE TRNASFORMED PHYSICAL=(PHYS-4)*(100/16).
COMPUTE TRANSFORMED PSYCHOLOGICAL=(PSYCH-4)*(100/16).
COMPUTE TRANSFORMED SOCIAL RELATIONSHIPS=(SOCIAL-4)*(100/16).
COMPUTE TRANSFORMED ENVIRONMENTAL=(ENVIR-4)*(100/16).
```

5. Delete cases with >20% missing data

```
COUNT TOTAL=Q1 TO Q26 (1 THRU 5).
```

(This command creates a new column 'total'. 'Total' contains a count of the WHOQOL-BREF items with the values 1-5 that have been endorsed by each subject. The 'Q1 TO Q26' means that consecutive columns from 'Q1', the first item, to 'Q26', the last item, are included in the count. It therefore assumes that data is entered in the order given in the assessment.)

```
SELECT IF (TOTAL>=21). EXECUTE.
```

(This second command selects only those cases where 'total', the total number of items completed, is greater than or equal to 80%. It deletes the remaining cases from the dataset.)

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* WHOQOL User Manual

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EDUCATION:

1972	Bachelor of Arts. Psychology, Chatham College, Pittsburgh, PA
1974	Master of Arts. Health, Physical, and Recreation Education, University of Pittsburgh, Pittsburgh, PA
1976	Master of Arts. Physical Therapy, Stanford University, Stanford, CA

LICENSURE:

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2004, 2010	OT/PT Handbook Development Committee. Handbook for Occupational & Physical Therapy Services in the Public Schools of Virginia. Commonwealth of Virginia, Department of Education, Richmond, VA

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