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Occupations and Quality of Life of Families with Children with ASD: A Survey

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OCCUPATIONS AND QUALITY OF LIFE OF FAMILIES WITH CHILDREN WITH ASD: A SURVEY

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OCCUPATIONS AND QUALITY OF LIFE OF FAMILIES WITH CHILDREN WITH ASD:
A SURVEY

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Master of Science
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DEDICATION

This thesis is dedicated to the families with children with Autism Spectrum Disorders. A limited number of these families shared intimate details of their lives and I am in awe at the wonderful ways that they have adapted and supported their children and the family unit. These families and children are a blessing to our society and my thanks to them to help me to see the world through their eyes even if just for a moment.

ACKNOWLEDGMENTS

I would like to thank my children, Larkin and Maddox, who inspire to become the person that they believe that I am. They help me to see the world in a way that only a child can. Also, I would like to thank my husband, Jason, for his support throughout this academic endeavor. His compassion and love for service has provided guidance in uncertain times. My parents and husband's family have been instrumental through this research project through child care and sharing their distinctive experiences as public educators and parents. Lastly, I would like to thank my advisor, Dr. Peggy Wittman, and other committee members, Dr. Shirley O'Brien and Dr. Dana Howell, who provided academic guidance as I learned the ways of social science research and professional writing. I thank them for sharing their experiences and knowledge in the development of this research project. In all honesty, this research would have not reached completion without their advice and support.

ABSTRACT

In recent literature, it has been suggested that families with children diagnosed with Autism Spectrum Disorders (ASD) have diminished Quality of Life particularly in the areas of social interaction and family outings (Lee et al., 2008). The purpose of this study is to describe quality of life and occupations engaged in along with demographic features of families with children with an ASD. Data was collected utilizing a survey methods, a convenience sample received a questionnaire packet containing: Flanagan Quality of Life Scale, demographic survey and Occupational Checklist. Twenty-two families participated in the study. Descriptive statistics suggested that families with children with an ASD do self-report a diminished Quality of life along with limited occupational engagement.

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CHAPTER I

Introduction

The development of children's occupations cannot be fully understood without insight into what structures their daily habits and routines (Larson & Verma, 1999; Rogoff, 2003). In the context of a family, a child is first provided with opportunities to learn about activities, occupational performance, meaning, and purpose and outcomes (Humphrey, 2002). For service providers, the study of families provides insight into why the involvement of family members is central to best practice that is emerging through research and supported through legislation. The family forms a unique emotional bond between members and its interactions provide special insight into the child's needs, abilities and occupational interests (Humphry & Case-Smith, 2005; Lawlor & Mattingly, 1998). The emotional bond that families hold places them in the situation of helping children to develop fundamental routines and habits that contribute to physical health and well-being.

It is important to remember that families are an open system group of occupational beings with interdependent influences (Humphry & Case-Smith, 2005). The activity of one family member can influence the actions and choices of another member. Interdependent influences of a complex social system such as a family can be strongly influenced by a family member with a special need, especially a child with an Autism Spectrum Disorder (ASD). One of the child's parents may be required to change jobs or stop working outside of the home all together to accommodate the needs of the child with an ASD (Montes & Halterman, 2008). Stressors continue to develop, and stress levels as families try to cope with the diagnosis and wonder how family members and friends will respond to the news and the future of the child and the family (Krausz & Meszaros, 2005; Akshoomoff & Stahmer, 2006). These stressors range from unpredictable behaviors consistent with the diagnosis of an ASD to securing competent care for the child to diminished social activities. The level of stress has been directly linked to change in quality of life scores (Lee, Harrington, Louie & Newschaffer, 2007). A few studies have examined quality of life of families with a child with an ASD. The studies that examined quality of life with families with a child with an ASD used small samples suggested that parents of a child with an ASD report higher levels of stress than those with a child without delays (Baker, Blacher, Crnic & Edlebrook, 2002; Peterson & Mathieson, 2000; Lee, Harrington, Louie & Newschaffer, 2007).

Although limited, some evidence supports the fact that parents of children with severe ASD may experience difficulty engaging in daily family occupations with positive meanings (DeGrace, 2004; Lee et al., 2007). Studies also indicate that families of children with autism reported a higher level of family stress and more family problems than families of children with cognitive disabilities such as Trisomy 21 or other medical conditions (Bouma & Schweitzer, 1990; Donovan, 1988; Holroyd & McArthur, 1976;). Children with an ASD can exhibit a myriad of characteristics including disruptive behaviors and complex ritualistic schedules and the demands for daily life may make it difficult for families to engage in activities outside of the home (Fox, Vaughn, Wyatte, & Dunlap, 2002). Research indicates that difficulty engaging in occupations with positive meaning can lead to diminished quality of life (Lee et. al, 2007).

Quality of Life (QOL) is a measurement of an individuals' well-being that includes the ability to function within society and the community. QOL is increasingly recognized as an important construct to use in the study of developmental disabilities (Lee et al., 2007). Researchers in the field have recently redefined QOL as follows: 1) multidimensional and influenced by personal and environmental actors and in their interactions, 2) has the same basic composition for all people, 3) is both subjective and objective and 4) is enhanced by self-determination, resources, purpose in life and a sense of belonging (Cummins, 2005; IASSID World Congress, 2004; Verdugo et al., 2005). However, an agreement regarding the standards that direct the measurement of QOL has not yet been achieved across disciplines and remains vehement among researchers. The phenomenon related to diminished QOL in families with children with an ASD may be a reflection of the diverse behavior profile of children with an ASD with behaviors ranging from complex rituals to possible self-injurious actions (Lee et al., 2008). In a study conducted by Fox et al. (2002), parents indicated that they refrained from participating in activities outside of the home because their attention was constantly focused on the child with an ASD and because they felt that others did not understand their child's behavior problems.

Autism Spectrum Disorders (ASD) or Pervasive Developmental Disorders is a group of disorders including Autistic Disorder, Asperger's Disorder, Pervasive Developmental Disorder, Not Otherwise Specified, Rett's Disorder and Childhood Disintegrative Disorder. According to the *Diagnostic and Statistical Manual of Mental Disorders,* 4th text revision (APA, 2000), "the disorders on this spectrum typically involves significant and pervasive disruptions in reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior, interest, and activities" (p. 69). The population of families with children with ASD is on the rise. According to the Centers for Disease Control and Prevention (CDC), the prevalence of children with an Autism Spectrum Disorder (ASD) has increased from 4 to 5 in 10,000 children to 2 to 6 per 1,000 children (CDC, 2007). To further note the significance of this increase, the CDC has reported that the numbers of children with an ASD being served by public schools has increased from 22,664 in 1994 to 211,610 in 2006. The CDC indicates that up to 560,000 individuals from birth to the age of 21 are identified as having an ASD.

Statement of the Problem

The number of children with an ASD is increasing; therefore there is a considerable portion of the United States population either diagnosed or affected by familial relations by this disorder. Families with a child with an ASD are continuing to struggle with QOL issues due in part to a lack of valued occupational engagement as a family. Often children with an ASD are referred for occupational therapy services. It is important that occupational therapists are providing high quality services to both the child and the family within the scope of family-centered practice. Currently, many occupational therapists are struggling to meet the occupational engagement needs of these families. The role of the provider is helping the family to expand and enhance occupational participation opportunities with positive meaning and value (Dunst, 2001). If occupational therapy interventions are not guiding and providing these opportunities for the family to engage in occupations that they prefer and value, then the child's development may be hindered (DeGrace, 2004). Along with a possible delay in child development, the family may display signs of diminished QOL.

Purpose of the Study

Since, no published research exists about this topic, the purpose of this study is to describe QOL and occupational choices of families with children with an ASD residing in the home. By understanding the occupational choices and desires of families with children with an ASD, occupational therapists can have greater knowledge from which to develop interventions that are family-centered, evidence-based, and meaningful to the family.

This research project seeks to: 1) describe QOL of families with children with an ASD 2) describe occupations that families with children with ASD engage in, 3) describe occupations not engaged by families with children with an ASD but desired and 4) describe demographics of families with children with an ASD.

CHAPTER II

Literature Review

This chapter reviews several key areas addressing the research literature with regard to understanding the life of a family with a child with an Autism Spectrum Disorder (ASD). In order to provide context for the proposed research, this literature review will focus on five areas. The first section reviews family occupations, the Person, Environment and Occupation (PEO) Model in respect to families, followed by defining family systems and dynamics, the impact of having a child with ASD on family occupations, and Autism Spectrum Disorders. Lastly, a summary addresses the importance of research to aid the field of occupational therapy in providing services to families with children on the Autism Spectrum.

Family Occupations

Family members, individually or together, engage in a part of variety of different activities that are part of home management, care-giving, employed work, education, play and leisure domains and that help them feel connected to each other (AOTA, 2008). Family occupations occur when daily activities and special events are shared by the family members. Societies first anticipate that families provide children with a cultural foundation for their development as occupational beings. Families share and pass on a cultural model; a habitual framework for thinking about events, for determining the occupations the family will engage the temporal context of engagement (Dunst, Trivette, Humphries, Raab & Roper, 2001; Gallimore, Weinsner, Kaufman & Bernheimer, 1989; Gallimore & Lopez, 2002). By providing the child with a cultural foundation, the child is introduced to behaviors and occupations that are consistent with the culture in which they reside (Humphrey & Case-Smith, 2005).

Occupations are activities which provide meaning and understanding to the environment and context for an individual and the place in which they connect with others. Routine family occupations and special occasions form the basis for repeated interpersonal experiences that provide family members with a sense of belonging. The importance of family occupations is reflected by the fact that families create special activities for the purpose of spending time together (Schultz-Krohn, 2004).

Family Rituals

Fiese et al. (2002) suggested that family rituals are a form of symbolic communication that helps to express the family identity, provides family members with a sense of belonging and promotes continuity of meaning across generations. It is important to note the difference between routines and rituals within the family dynamic. Routines are patterned behaviors with outcomes from measurable goals thus providing structure and organization to the environment; whereas, rituals are occupations that the family has projected meaning onto (Schuck & Bucy, 1997; Segal, 2004). Family celebrations fall on the spectrum of family rituals also, occasions such as specific holidays are indicative of cultural reflections. For example, a family that celebrates Hanukkah is marker of a religious preference (Segal, 2004). The value of family rituals has been studied in relation to well-being and overall health. Family rituals can serve as a protective mechanism for anxiety in children with asthma (Markson & Friese, 2000).

Other forms of family interaction patterning are family traditions, which are imposed by the family and unique to each family. Family traditions are activities such as birthdays, anniversaries, and vacations. Although family traditions are developed by the family themselves they are often influences by the practices of earlier family generations and built upon to meet the present family's needs (Segal, 1999). Patterned interactions are the daily routines of the family such as mealtimes, bedtime routines and morning routines (Segal, 2004).

Family identity is the subjective sense of its own continuity across time including present situation and the development of family character (Gillis, 1996). Family identity is a continuous process while its members add and subject occupations to further define the family's character. The family identity is further shaped by the stories that the family values relating past experiences (possibly generational) and future aspirations (Gillis, 1996). Occasionally, the actual experiences and the family stories have various discrepancies such that stories from distant experiences tend to be idealized (Daly, 1996; Gillis, 1996). It is through these stories that family members assume assigned roles which become dramatized with time and serve as symbols for the family. Gillis (1996) suggests that these idealized versions and symbols permit family connections to the past and promote shared aspirations for the future. Schuck & Bucy (1997) add from their research that the stories detail family rituals that hold value and meaning to the family. In summary, family rituals are the mechanism for construction and affirmation of family identity because of the symbolic and affective components.

One aspect of family identity is the inclusion of exclusion of individuals from the family unit. This notion of inclusion can be linked with invitations to culturally-based family rituals such as weddings (Oswald, 2002; Richlin-Klonsky & Bengtson, 1996). Often, the individuals that a considered included as part of the family identity are often referred to in the aforementioned family stories or identified as integral piece in the familial legacy (Gillis, 1996; Richlin-Klonsky & Bengtson, 1996).

Ochs, Taylor, Rudolf, & Smith (1992) studied the communication and interactions between family members during evening mealtime. They found that the evening meal is the time when children are socialized according to the family's values on gender roles, conflict resolution and turn-taking. Mealtime rituals often reflect the family's internal power relationships, preconceived notions concerning gender roles, and expectations of individuals.

Rituals are mechanisms by which families teach the conceptualization of family identity, socialization and the instilling of pride and value of one's heritage and connectivity to a sense of belonging as a part of larger group. Family rituals have been studied in relation to well-being and overall health which is suggested to be a predicator of QOL (Gillis, 1996; Schuck & Bucy, 1997).

Family Routines

As mentioned previously according to the occupational science literature, rituals are chaining of occupations with meaning while routines are established patterns of performance with goals and purpose to provide organization and structure to the family unit (Segal, 2004). According to Boyce et al. (1983), routines are "repetitive behaviors that involve two or more family members and which occur with predictable regularity in the ongoing life of the family (p. 194). The completion of a routine is not an absolute but the family member(s) completing the routine attributes meaning to the tasks. Schultz-Krohn (2004) employed the example of evening meal preparation. While one mother may find the routine satisfying by providing nutrition and expression of her love to her family, another mother may find the routine boring and unproductive. Furthermore, engagement in routines serves "to buffer the impact of stressful experiences impinging on the family and to protect its members against ill health by fostering a sense of stability" (Boyce et. al, 1983, p. 201). In addition, routines have been identified as a critical component for promoting healthy lifestyles for both the individual family members and the family unit (Schultz-Krohn, 2004). From an occupational therapy perspective, health refers to the capability to optimally function within a specific environment (Schultz-Krohn, 2004). For a family, healthy behaviors must promote growth of the individual and increase the strength and integrity of the family as a system (Schultz-Krohn, 2004). This growth allows for optimal functioning of the family within social and cultural environment of a given community. Family routines allow for predictability which in some individuals can be linked to a decrease in stress due to the lack of external factors and changes in environment (Schultz-Krohn, 2004).

Person, Environment, Occupation Model

Person, Environment, Occupation (PEO) Model supports an occupation-based approach to occupational therapy service delivery. PEO model was first published in 1996 by Mary Law et al., as a transactive approach to occupational performance utilizing the theoretical foundations from the Canadian Guidelines for Occupational Therapy, environmental-behavioral theory and the work of Csikszentmikhalyi & Csikszentmikhalyi (1988) on the theory of optimal experience. The PEO Model centers equally on facilitating change in the person, occupation, and/or the environment to promote optimal occupational performance. The PEO model summarizes the concepts of person, environment, and occupation as follows: Person: a unique being who, across time and space, engages various roles significant to him or her; Environment: cultural, socioeconomic, institutional, physical and social factors external to the person that affect his or her experiences; and Occupation: groups of self-directed, functional tasks and activities in which a person participates over the life span (Law et al., 1996).

The PEO model suggests that occupational performance is the result of the dynamic, transactive relationship involving the person, environment, and occupation (Figure 1). Across the life span and in different environments, the three major components--person, environment, and occupation—interact continually to determine occupational performance. Increased congruence, or fit, among these factors represents more optimal occupational performance (Law et al., 1996). See Figure 1: A PEO Model of Occupational Performance, areas of occupational congruence are shaded.

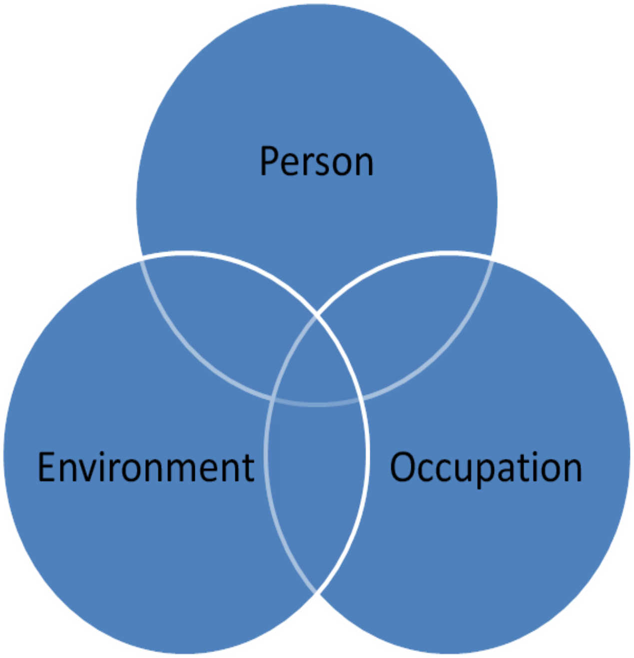

Figure 1: A PEO Model of Occupational Performance

The PEO model is used as an analytic tool to identify factors in the person, environment, and occupation that facilitate or hinder the performance of occupations chosen by the person. Occupational therapy intervention can then focus on facilitating change in any of these three dimensions to improve occupational performance (Law et al., 1996).

The PEO model is often beneficial for the occupational therapist in the identification and addressing a child’s and family’s ability to engage in meaningful occupations. It’s foundation in occupational performance allows the PEO model to focus on identifying the skills needed to perform life tasks rather than on sequential skill acquisition (Law et al., 1996).

Family Systems/Dynamics

The family systems perspective holds that individuals are best understood within the context of relationships and through assessing the interactions within the entire family (Bitter & Corey, 2001). Indications are often viewed as an expression of a dysfunction within a family; these dysfunctional patterns are often thought to be passed across several generations. It is revolutionary to conclude that the identified client's problem might be an indicator of how the system functions not just a sign of an individual's maladjustment, past experiences, and psychosocial development. This perspective is based on the assumptions a client's undesirable behaviors may 1) serve a function or purpose for the family; 2) be a function of the family's inability to operate productively, especially during developmental transitions; or 3) be a symptom of dysfunctional repetitive occupational patterns that are passed through generations (Bitter & Corey, 2001).

The central theme agreed upon by most family system therapy practitioners, regardless of theoretical perspective, is that the client is interconnected to the environment and that change in one part of the environment in any context reverberates throughout the other parts. Due to the nature of family system operating as an open system, the treatment approach should include not only the client but also the client's family to develop best practice to better understand the family as an interactional unit (Bitter & Corey, 2001).

Occupations in Family Systems

In recent years, it has been observed that the family is a major factor in the health and well-being of a child with ASD. It has been a long held theory that familial balance is an important contributor to the health and well-being of all family members. Family members have to coordinate what and when they engage in occupations to share in family routines, traditions, and special events (Humphry & Case-Smith, 2005). Families are complex social systems in which the family is a dynamic system in which its members, as parts of the system, engage in occupations together to fulfill the functions of the family. As with any system, interdependent influences exist among the various parts; meaning the activity of one person can influence another family member or the entire family unit. Interdependent influences can affect familial routines and habits such as mealtimes, leisure activities, and social outings.

Key Concepts of a Family System Model (Humphrey & Case-Smith, 2005 p. 119)

1. A family system is composed of individuals who are interdependent and have reciprocal influences on each other's occupations.
2. Within the family, subsystems are defined with their own patterns of interaction and shared occupations.
3. A family must be understood as a whole, and it is more than the sum of its parts
4. The family system works to sustain predictable patterns in family occupations and to be part of a larger community.
5. Change and evolution are inherent in a family.
6. A family, as an open system, is influenced by its environment.

Source: Humphrey, R. & Case-Smith, J. (2005). Working with families. In, J. Case-Smith (Ed.) *Occupational therapy for children* (5th ed.) (pp. 117-159). St. Louis, MS: Elsevier Mosby.

Family system models have been heavily researched in recent years. Adlerian family therapy is a family systems model developed with the basic assumption of that both parents and children often become locked in repetitive, negative interactions based on mistaken goals that motivate all parties involved. Further, these negative interactional patterns are a reflection of the autocratic/permissive dialectic that has permeated much of our social heritage. In most cases, therefore, the problems of any one family are common to all others in the community. Although much of Adlerian family therapy is conducted in private sessions, Adlerians also use an educational model to counsel families in public in an open forum at schools, community agencies and specially designed family education centers.

Adlerians believe human beings are essentially social, purposeful, subjective and interpretive in their approach to live. Without the social, physical, and emotional nurturing provided in the family, no infant would survive. Within the family, children quickly become agents, defining and redefining the family constellation or system; striving for growth, significance, and meaning; and acting in line with their subjective and sometimes mistaken interpretations of life.

According to Adlerian family theory, in line with the characteristics, parents should be the natural leaders of the family. They are suited for such roles based on experience and social mandate from the previous generations. Often, however, children especially in Western culture have increased influence on the development and interactions of the family than the parents. The family is viewed as a whole functioning unit and neither the children nor the parents are viewed as the identified client (Sperry, 1986). Like a number of other systems theory approaches, Adlerian family therapy assumes that each family member must learn that self-change must precede any attempt to change other family members.

Adler often noted that the family system or constellation consisted of the parents, children and even extended family members however birth order is very important in the hierarchy of the children. Adler identified five birth positions: oldest, second of only two, middle, youngest, and only. These five birth positions offered the vantage points from which children view the world. It is not the position that has value, however, but rather the meaning and interpretation the child gives to the position. Family life-style assessment examines relationship patterns, family myths, values, roles and climate. Family stories can be interpreted like early recollections. Adlerian family therapy is special in that the focus is on individual and family strengths along with weaknesses. A detailed investigation of family interactions during a typical day is important to guide therapy along with a level of functioning for activities of daily living (Sperry, 1986).

A small amount of research has been conducted on the use of the Adlerian family therapy approach with the family with a child with an ASD (Berner & Spiel, 1958; Harrison, Damon, Czesak, & Tomlin, 1982; Hartshorne & Herr, 1983). However, Huber & Zivalich (2004) found that "from an Adlerian perspective, an operant paradigm can be used to encourage socially interested behavior: Namely empathic and cooperative skills can be honed so a child with autism can be made to feel more at home with others" (p. 352).

Not all members share in all activities that contribute to family functions; at times, certain family members form a special interactive relationship, or subsystem, to engage in shared activities. Subsystems include: adult-child, an adult caring for an infant therefore engaging in co-occupations or sibling subsystems such as siblings engaging in a sport together.

These subsystems are developed by families to help in organization. Organization of the family leads to predictable patterns of daily and weekly and sometimes yearly occupations. These predictable patterns can range from bedtimes routines to weekend outings or family traditions. It is advantageous for the family to develop predictable patterns as they aid in organization and effectiveness of the family unit. Studies show that families report more meaning and commitment to their routines and special experienced better health of family members and stronger interpersonal relationships (Fiese & Tomcho, 2001; Markson & Fiese, 2000).

Impact of having a Child with an ASD on Family Occupations

The family system is subject to the interdependent influences of a child with ASD. Living with a child with disabilities can bring opportunities and challenges to families. The ways that having a child with disabilities can influence how family members organize their time, engage in activities and interact with one another. The child may require special and related services through school or out-patient settings that can interfere with the daily routines and the predictable patterns of the family unit (Humphry & Case-Smith, 2005). Each family member’s role is altered as a result of the additional duties required for the child with ASD (Humphry & Case-Smith, 2005). When considering the family of a child with ASD, typical family occupations such as social outings, home maintenance, and eating meals together become altered due to the increased care necessary for the child with ASD (Baker-Ericzen, Brookman-Frazee & Stahmer, 2005; Burrows, Adams, & Spiers, 2008). The additional services that children with ASD receive often impact the entire family unit due to open systems approach and therefore can impede occupational performance and quality of life.

Evidence suggests that having a child with special needs is connected with child-caring stress as well as less time for parents to meet personal and relationship needs (Bouma & Schweitzer, 1990; Kalssen et al., 2004; Escobar et al., 2005; Seltzer et al., 2004). Compared to parents of typically developing children, parents of children with an ASD report greater family burden and are at an increased risk of experiencing physical and psychological distress (Bouma & Schweitzer, 1999; Seltzer et al., 2004). In addition, it has been reported that the level of emotional stress in parents is positively associated with the level of challenging behavior in the child and is negatively associated with the child's ability to communicate functionally (Allik et al., 2006; Baker et al., 2002; Bromley et al., 2002; Klassen et al., 2004). Financial challenges may also occur, as having a child with an ASD is linked with higher rates in loss of employment and medical costs than families without a child with an ASD (Hecimovic & Gregory, 2005). There is evidence that socioeconomic status, as assessed by using a modified Hollingshed four-factor index, is weakly associated with family stress and that there is greater family stress when the child with ASD is an older adolescent or young adult (aged 15-21.9) compared to a younger adolescent (aged 10-14.9) (Donovan, 1988). Evidence regarding effects on siblings is assorted in that there are findings both for and against an increase in their risk for externalizing and internalizing adjustment problems and decreased level of social competence (Kaminsky & Dewey, 2002).

Although acceptance of a child's disability may be a major stress, as the disability persists it has been demonstrated that families begin to see the lifestyle that have resulted from the medical disability as being ordinary. This phenomenon is called normalization and viewed as a positive adaptation of parenting a child with special needs (Deatrick, Knafl, & Walsh, 1988; Cronin, 2004). Normalization is a construct that reflects an internalization of the specialized habits and routines associated with the disorder to such a degree that they are integrated into ordinary family occupations (Knafl & Deatrick, 2002). Walker, Van Slyke, & Newbrough (1992) found that due to the effects of normalization that families with children with chronic illness report similar stress levels as families with non-disabled children on surveys and Likert-type stress measures. Distinctions have been made been disabilities of either medical or behavioral nature. Families of children with behavioral disorders tend to report higher levels of stress. Minimal research exists studying the correlation between normalization and behavioral disorders in children such as ASD (Cronin, 2004).

Much research has been conducted on the child with an ASD; however a limited amount of the literature focuses on the family of the child with ASD (O'Mullan Wayne & Krishnagiri, 2005; Baker-Ericzen, Brookman-Frazee & Stahmer, 2005; Tomanik, Harris & Hawkins, 2004; Burrows, Adams, & Spiers, 2009). New evidence is emerging for healthcare professionals to provide family-centered care (Mahoney & Bella, 1998; Mahoney, Sullivan, & Dennebaum, 1990). Family-centered service is a philosophy of service provision that highlights the principal role of families in making decisions concerning the care of their child (Law, Missiuna, Pollack, & Stewart, 2005). By utilizing a family-centered model of care, the healthcare practitioner is better able to serve and meet the unique needs of the family (Humphrey & Case-Smith, 2005). In order to practice effective family-centered care the practitioner needs to have an understanding of the occupations of the family. However, there is a small body of research that emphasizes the importance of the daily occupations of the family of a child with ASD.

DeGrace (2004) found that families with children with severe autism may experience difficulty in engaging in daily occupations that hold positive meaning and the family relies on strict routines and habits that revolve around the child with ASD to organize their occupational performance. DeGrace (2004) found that the family's life revolves around autism; "For the families, autism is an entity of its own. It 'autism' controls their daily lives" (pg 3). Families can feel that they lose their identity as a family and become defined by their child's diagnosis (DeGrace, 2004).

With the control and the daily effects that parenting a child with an ASD brings, marriages are at a higher risk of separation (Hartley et al., 2010). The extent of this risk is highly speculated by the media, with divorce rates of 80% or higher in some cases (Doherty, 2008). Hartley et al. (2010) studied the relative risk and timing of divorce in families with children with an ASD as the first published empirical study. The researchers compared the occurrence and timing of divorce among parents or an adolescent with an ASD with a closely matched sample of parents of adolescents and adults without a disability drawn from a nationally representative sample. Parents of children with an ASD had a higher rate of divorce than the comparison group (23.5% vs. 13.8%). The rate of divorce remained high throughout childhood, adolescence and early adulthood for parents of children with an ASD, while it decreased following the son's or daughter's childhood in the comparison group (Hartley et al., 2010).

In addition to the stress on marriages, siblings are often a forgotten piece in the study of ASD's. Siblings of children with ASD experience a lifelong connection with their sibling with ASD, however this group of individuals is understudied (Smith & Edler, 2010). Clinical and preliminary research suggests that they may have a variety of adjustment and coping difficulties, as well as weakened intimate relationships with their sibling with ASD (Smith & Elder, 2010; Kaminsky & Dewey, 2001; Rivers & Stoneman, 2003; Orsmond & Seltzer, 2007). Orsmond, Kou & Seltzer (2009) conducted the only longitudinal study found to study the impact of growing up with a sibling with ASD and factors that impact future care-giving relationships.

The work of McHale, Sloan, & Simeonsson (1986) indicated the need for further research when the results of their study suggested that siblings of a child with ASD experience higher levels of stress compared to siblings of other disabilities and typically developing (TD) siblings. Rodrigue, Geffken & Morgan (1993) in their study lower competency scores in siblings with ASD and their psychological adjustment (depression scores) affected by sibling age, family size and marital status of parents.

It's important to note that added stress in families with children with ASD may be the result of many varying factors; the research supports positive results within these environments (Lobato & Kao, 2002). In older TD siblings, were found to help manage and teach their younger siblings, resulting in fewer behavior problems of the TD sibling (Ross & Cuskelly, 2006). Stalker & Conners (2004) and Benderix & Siverberg (2007) found that siblings of a child with ASD often exhibit higher levels of empathy and patience. Higher concept and social competence levels were found in siblings with a child with high functioning autism than siblings in comparison groups (Verte, Roeyers, & Buysse, 2003).

Bayat's (2007) survey methodology study suggests that: families with a child with ASD develop stronger relationships among family members by organizing family resources; families gain the ability to gain understanding of their difficulties; finding greater levels of compassion, and ascertaining spiritual beliefs or developing new belief systems. Themes of the parent and family were for the most part negative experiences related to financial burden, altercations with providers and payers in the healthcare system, concerns of the future care of their child, meeting daily goals/events and worries over putting the parent(s)'s career on hold. The major findings of this study were the multifactorial influences affecting family's coping and parenting styles.

Studies have evolved from descriptive designs correlating gender, birth order, and age of siblings with ASD and other disability types to exploratory designs investigating personality types. Factors contributing to the interactive nature of sibling relationships are dependent on coping styles, family resources, and sibling perspectives. Investigations on sibling adjustments have found a combination of fixed (family size, socioeconomic status, and age of siblings) or modifiable (depression, conduct and self-concept) variables that have biological, psychological, sociologic and ecological influences on the sibling; thus it is crucially significant to consider both the positive and negative valence of each environmental context for an accurate evaluation of sibling health and as their role as possible future caregivers (NIH, 2009).

Quality of Life Measures

Quality of Life (QOL) and family functioning are interconnected entities with stressful events in one area directly affecting the other as a result of the open system of the family. Many measures have been developed over the years to assess quality of life with a health-related focus. The Flanagan Quality of Life Scale (QOLS) was originally developed by psychologist John Flanagan in the 1970's to measure quality of life. Since its origination, the QOLS has been adapted to assess quality of life in individuals with chronic illness (Burckhardt, 2003). The original QOLS was developed with 15 questions representing five conceptual domains of QOL: physical and material well-being; relations with other people; social, community and civic activities; personal development and fulfillment; and recreation (Burckhardt et al., 2003). The QOLS was developed over a random sampling of 3000 American adult individuals through an interview technique, followed by presenting the survey instrument to 3000 people aged 30, 50 and 70 years of age (Burckhardt et al., 2003). After reassessment of the need for an instrument to survey QOL with individuals with chronic conditions, the QOLS expanded to include a 16th prompt to assess satisfaction levels in independence (Burkhardt & Anderson, 2003).

Flanagan did not report psychometric data during the development of the QOLS therefore the original psychometrics are estimated. Estimates from the first study of 240 American clients with chronic conditions indicated that the 15 item QOLS satisfaction scale as one scale containing all 15 items were internally consistent ($\alpha = .82$ to $.92$) and had high test-retest reliability over three weeks in stable chronic condition population groups ($r= .78$ to $r=.84$) (Burckhardt et al., 2003). Researchers have reported similar reliability in the various translations (Burckhardt & Anderson, 2003; Burckhardt et al., 2003).

Convergent and discriminant construct validity of the QOLS in chronic illness groups was first confirmed by the high correlations between QOLS total score and the Life Satisfaction Index-Z (LSI-Z) ($r= 0.67$ to 0.75) and its low to moderate correlations with the physical health status subscale ($r=0.25$ to 0.48) from the Duke-UNC Health Profile and a disease impact measure, the Arthritis Impact Measurement Scale (AIMS) ($r=0.28$ to 0.44) (Wood, Wylie, & Shaefor, 1969; Parkerson, Gelhbach, Wagner, James, Clapp, & Mulhbaier, 1981; Meenan, Gertman, & Mason, 1980). Thus, the QOLS is a reliable and valid instrument for measuring the domains of quality of life important to individuals across the lifespan and cultures.

Autism Spectrum Disorders

Pervasive Developmental Disorders are often referred to as Autism Spectrum Disorders. This group of disorders includes Autistic Disorder, Asperger's Disorder, Pervasive Developmental Disorder, Not Otherwise Specified and two rare disorders Rett's Disorder and Childhood Disintegrative Disorder. These conditions have similar symptoms; however they differ in terms of on-set of symptoms, severity of symptoms and exact nature of symptoms. According to the *Diagnostic and Statistical Manual of Mental Disorders,* 4th text revision (APA, 2000), "the disorders on this spectrum typically involves significant and pervasive disruptions in reciprocal social interaction skills, communication skills, or the presence of stereotyped behavior, interest, and activities" (p. 69).

The number and type of symptoms differ drastically and range from mild to severe. Symptoms fall into a range of categories, including problems with social interactions, repetitive stereotypical movements, somatosensory interruption, atypical movement patterns, mood disturbances and problems with attention and safety (Mayes & Calhoun, 1999). Dysfunction in perceptual and sensory processing as well as in communication and neurological functioning results in various functional behavior limitations (Watling, Deitz, Kanny, & McLaughlin, 1999).

Often ASD is typically diagnosed in early childhood or adolescence. Children with an ASD may display a variety of delays early on; however, parents may find it difficult recognizing or understanding these delays. Early detection and intervention appears to be pivotal in addressing the child's needs (Bailey, Nelson, Hebbeler, & Spiker, 2007); however, one source of stress for parents appears to be receiving the correct diagnosis, and then other stressors include decisions concerning the best treatment, or combination of treatments and interventions.

The Centers for Disease Control and Prevention (2010) estimated the prevalence of ASD at approximately 1 in 110 children. The CDC reported that the number of children with an Autism Spectrum Disorder being served by public schools has increased from 22,664 in 1994 to 211,610 in 2006 (CDC, retrieved 01/30/2010). It is also suspected that up to 560,000 individuals from birth to the age of 21 are identified as having an Autism Spectrum Disorder. In 2006, the CDC concluded that one percent of 8 year old children were diagnosed with an ASD. This is a 57 percent increase from the rate of 1 in 150 children found in 2002 using the same research methods. Males were four times as likely to be affected as girls, with 1 in 70 boys receiving a diagnosis. Although functional capacity of individuals with ASD varies, the life expectancy is not impacted; therefore the special needs of a child with ASD are likely to extend beyond the years of their parents and within the span of siblings (Smith & Elder, 2010).

Summary

As evidenced in the literature review, children with ASD can often require extensive additional health services. The family unit due to its open systems nature is affected in various ways due to the needs of the child. Several factors have been proposed to account to for the diminished quality of life of parents of children with an ASD, including the uncertainty surrounding ASD diagnosis and the long-term prognosis of an individual with an ASD, the stressful nature of associated symptoms and related behavior problems, and the lack of public understanding of and tolerance of the behaviors of children with an ASD (Gray & Holden, 1992). As a result of these factors, families with children with ASD report compromised quality of life, higher levels of family stress and more family problems than families of children with cognitive disabilities such as Down 's syndrome (Donovan 1988; Holroyd & McArthur, 1976). With increasing numbers of children diagnosed with ASD, service providers and educators should be aware of the possible lack of familial harmony. Understanding how families with children with ASD describe their quality of life and occupational engagement, can provide occupational therapists and other service providers with constructive information to support the family to engage in valued occupations to increase quality of life. Therefore, this research project seeks to describe the family's quality of life and describe preferred occupations using the Person, Environment, Occupation Model (PEO) to define occupational performance.

CHAPTER III

Methods

Overview of Design

A survey design was utilized to describe quality of life of families with children with ASD, occupations that these families participate in currently and desire to engage in the future, and demographics of the research population. A packet was mailed to families that included: a cover letter, 2 consent forms, Flanagan Quality of Life Scale (QOLS), Occupational Checklist, demographic survey and self-addressed stamped envelope to elicit information relevant to the study objectives. As results were received the consent letter was filed and the remaining surveys were coded numerically. The gender of the individual completing the packet was recorded on the demographic survey alongside the numerical code. The data was analyzed using descriptive statistics through Microsoft EXCEL. The study was approved by the Institutional Review Board at Eastern Kentucky University on October 27, 2010.

Descriptive statistics and univariate analysis were used to analyze the data. This research project seeks to: 1) describe quality of life of families with children with an ASD 2) describe occupations that families with children with ASD engage in, 3) describe occupations not engaged by families with children with an ASD but desired and 4) describe demographics of families with children with an ASD.

Participants

The participants for this study were accessed through a convenience sample of families who volunteered to take part in the study and through personal relationship to the researcher and through snowball sampling in which they knew of other families willing to participate. Participants were recruited at seven locations through distribution of flyers with the researcher's contact information. The population for this study was 20-30 families with children with ASD. Although children were not directly involved in the research, the family must have had at least one child ranging in age from 3 to 18 years, living in the household and diagnosed with an ASD. Diagnoses were self-reported by parents. The population targeted was central and eastern Kentucky.

Measures

Flanagan Quality of Life Scale is a self administered mail survey concerning the quality of life of individuals. The form of the QOLS administered in this research has 16 items rather than 15 found in the original Flanagan version in order to address independence. Item #16 "Independence, doing for yourself" was added after a qualitative study indicated that the instrument had content validity in chronic illness groups but the form required an item that reflected the importance to these people of remaining independent (Burckhardt, 1989).

The Occupational Checklist was developed by Vaught and Wittman (2010) to develop a simple method of gaining information about leisure activities of possible interest. The Occupational Checklist serves as a tool to assess the preferences, knowledge and frequency of various leisure activities. Furthermore, the Checklist provides the families with the opportunity to think about others leisure occupations that the family is not currently engaged in but would like more information about.

A Demographic survey was created to describe the participants in the study. The survey elicits information concerning sociodemographic status through annual income and education of the parents, paid employment, size of the family, ages of family members, and ethnicity of family members.

Data Collection

Families who volunteer to participate were mailed a package containing a cover letter, two consent forms, Flanagan Quality of Life Scale, occupational checklist, demographic survey and a self addressed stamped envelope. One parent completed the surveys about the family. The primary researcher's information was located on the distributed flyer. Once a family contacted the researcher, the family received a packet in the mail which contained the previously listed data collection materials. Families were asked to return the completed study materials and signed consent form in the envelope provided addressed to EKU's Occupational Therapy Department to the attention of the primary research. One copy of the consent form served as the family's copy to keep and offered contact information if the participants had any further questions throughout the survey process. Mailed surveys were sent to participants beginning on October 28, 2010 through December 2, 2010. Mailed surveys require standard follow-up procedures (email, phone call or personal communication) to ensure maximum response rates. Standard follow-up methods for survey research were utilized (Fowler, 2002; Forsyth & Kviz, 2006). Six weeks post initial mailing attempt, accrual ceased, no additional surveys were processed and data was entered in a Microsoft EXCEL program.

Data Analysis

Descriptive statistics were used to analyze survey data. Descriptive analyses included the assessment of frequency and percentage data for sociodemographic variables. Univariate analysis was utilized to describe the distribution, central tendency, and dispersion of data collected from QOLS, Occupational Checklist, and demographic survey. QOLS is scored by summing the items to make a total score. Participants are encouraged to complete every item even if they are not currently engaged in that particular occupation. Missing data was treated by entering the mean score for the missing item per QOLS instructions. Data was divided into higher and lower income subsets and analyzed to further describe distribution, central tendency and dispersion.

CHAPTER IV

Results

Packets were mailed to 35 families with children with an ASD, 24 packets were returned to the researcher with 22 responses analyzed for this study. Two of the responses were not considered for the research since in one case the packet was incomplete and in the other case the packet was incomplete and the consent form was returned unsigned. Of the 22 responses selected for data analysis the majority of the packets were completed by the mother (77.2%) as opposed to completion by the father (22.7%).

Demographic Survey

A demographic survey was used to determine the characteristics of the sample participants. The survey asked a series of questions pertaining to family characteristics such as age, income, highest level of education, gender of the child with an ASD, ethnicity and family size. 100% of the participants reported ethnicity as Caucasian. The number of male children with an ASD were 16 (72.7%) versus 6 (27.2%) female children. The ratio of male to female children in this study is 8:3. The age of the child with an ASD ranged from 4-18 years, with a median age of 6 years and a mean of 8.4 years the most frequently occurring age was 4 years with 6 families reporting a child 4 years of age. Ages of the parents were separated by gender and analyzed. Ages of male parents ranged from 26-53 years, with central tendencies of median of 33 years and mean of 36.1 years while most occurring age was 30 years. Ages of Female parents ranged from 24-49 years, mean of 33.7 years, median of 32 years and mode of 28 years. See Table 1: Dispersion of Family Member Ages in Years for analysis.

Table 1: Dispersion of Family Member Ages in Years

Family Member	Mean	Median	Mode	Range
Father	36.1	33	30	26-53
Mother	33.7	32	28	14-49
Child with an ASD	8.4	6	4	4-18

Estimated annual income of the sample was quite dispersed. Annual income ranged from $35,000-$150,000 dollars. Central tendencies scores were a median of $70,000 and mean of $72,363. Most frequently occurring annual income was $80,000. Due to the large range of annual incomes reported incomes were separated into low and high income brackets with comparison analysis of the two. This analysis will be discussed later in the results.

Family size ranged from 3-6 family members. Median family size was 3.5 family members. Mean family size was 3.6 family members. The most frequently occurring family size was 3 family members. See Figure 2: Family Size.

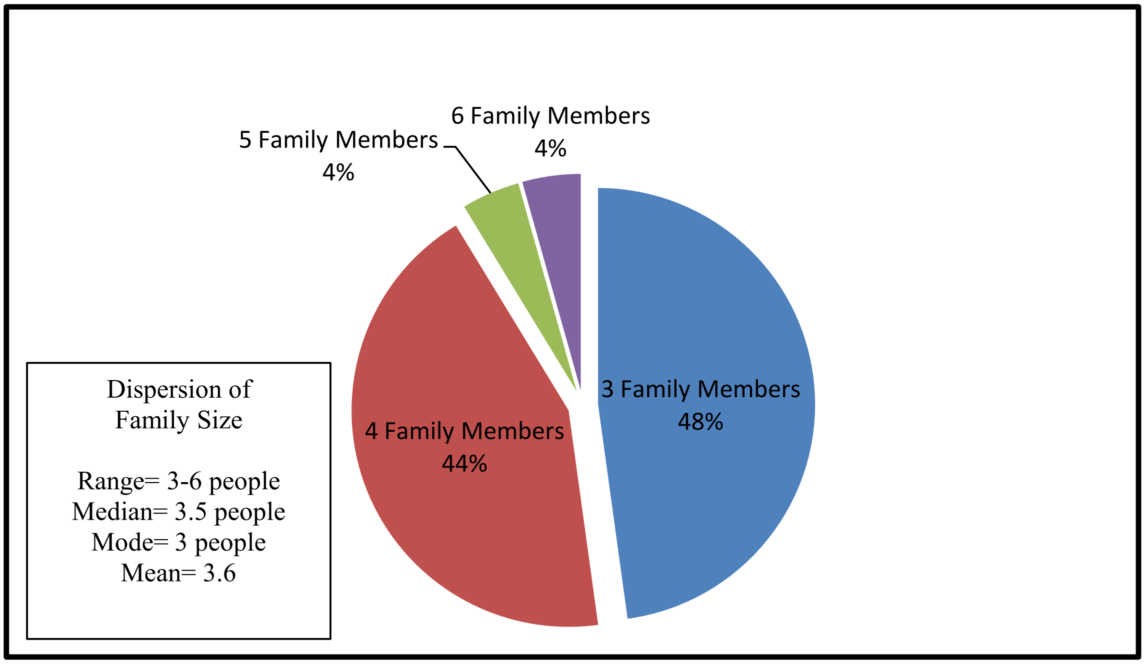

Figure 2: Family Size

All participants had a high school diploma. The average highest level of education for male parents of children with an ASD was a high school diploma (63.6%). The average highest level of education for female parents of a child with an ASD was a high school diploma or Master's degree (27.2%). See Figure 3: Highest Level of Education among Parents with a Child with an ASD.

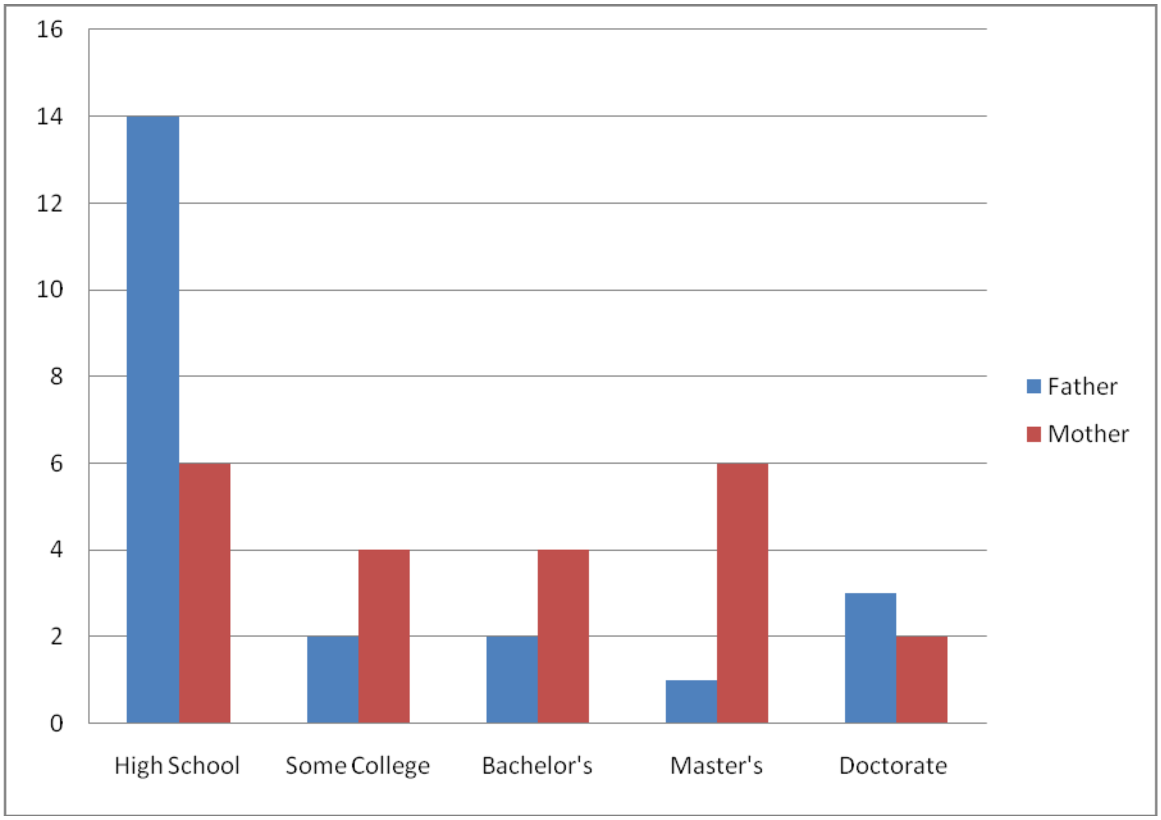

Figure 3: Highest Level of Education among Parents with a Child with an ASD

Flanagan Quality of Life Scale

To describe the quality of life of families with children with an ASD, the Flanagan Quality of Life Scale was utilized due to its content validity in chronic illness groups. Twenty-two families completed and returned the packet of surveys. The mean score was 73, median score of 68, and range 44-104. No mode score was attained. Table 2: Mean Scores by QOLS Item identifies the mean score of each item within the QOLS.

Table 2: Mean Scores by QOLS Item

ITEM # (BRIEF DESCRIPTION)	MEAN SCORE
1. Material Comforts home, food, conveniences	5.0
2. Health-being physically fit and vigorous	3.5
3. Relationships with parents, siblings	4.7
4. Having and Rearing Children	5.7
5. Close Relationships with spouse	5.6
6. Close Friends	4.3
7. Helping and encouraging others, volunteering	4.0
8. Participating in organizations and public affairs	3.5
9. Learning-attending school, improving knowledge	4.6
10. Understanding yourself	5.3
11. Work-job or in home	4.5
12. Expressing yourself creatively	4.2
13. Socializing-meeting other people	3.9
14. Reading, listening to music, or observing entertainment	4.1
15. Participating in active recreation	4.0
16. Independence, doing for yourself	5.4

Occupational Checklist

The occupational checklist data was tallied and a percentage assigned to each occupation concerning enjoyment, knowledge and frequency of participation. See Table 3: Occupational Checklist. According to the Occupational Checklist the top six most enjoyable occupations were 1) Internet (100%); 2) Playing video/computer games or

Facebook (95%); 3) Watching Television (95%); 4) Attending religious activities (91%); 5) Dining or going out for a meal (91%); and 6) Music (91%). Least enjoyable occupations are: 1) Gymnastics (77%); 2) Collecting items (73%); 3) Dancing (73%); 4) Acting/Drama (73%); 5) Writing (64%) and 6) Water Sports (60%).

Table 3: Occupational Checklist (adapted by Vaught & Wittman, 2010)

Occupation	Do you like to do this activity?			How much do you know about this activity?			How often do you do this activity?			
	Yes	No	I Don't Know	A lot	A little	Nothing	At least once a week	Once a month	Once a year	Never
Acting/Drama	4 (18%)	16 (73%)	2 (9%)	2(9%)	10 (45%)	10 (45%)	0	0	10 (45%)	10 (45%)
Board Games	14 (64%)	8(36%)	0	7(32%)	10(45%)	5(23%)	2(9%)	6(27%)	7(32%)	7(32%)
Card Games	7(32%)	15(68%)	0	7(32%)	10(45%)	5(23%)	2(9%)	2(9%)	10(45%)	8(36%)
Collecting Things (stamps, dolls, cars…)	6(27%)	16(73%)	0	3(14%)	14(64%)	5(23%)	0	7(32%)	1(5%)	14(64%)
Cooking	18(82%)	4(18%)	0	16(73%)	6(27%)	0	19(86%)	3(14%)	0	0
Dancing	6(27%)	16(73%)	0	0	17(77%)	5(23%)	0	1(5%)	6(27%)	15(68%)
Fishing/Hunting	12(55%)	10(45%)	0	8(36%)	10(45%)	4(18%)	1(5%)	6(27%)	7(32%)	8(36%)
Gardening/Yard Work	17(77%)	5(23%)	0	6(27%)	15(68%)	1(5%)	10(45%)	9(41%)	3(14%)	0
Golf	9(41%)	10(45%)	3(14%)	4(18%)	10(45%)	8(36%)	2(9%)	3(14%)	6(27%)	11(50%)
Gymnastics	2(9%)	17(77%)	3(14%)	3(14%)	7(32%)	12(55%)	0	1(5%)	0	21(95%)
Horseback Riding	16(73%)	5(23%)	1(5%)	4(18%)	15(68%)	3(14%)	4(18%)	3(14%)	7(32%)	8(36%)
Internet	22(100%)	0	0	15(68%)	7(32%)	0	17(77%)	5(23%)	0	0
Martial Arts	1(5%)	8(36%)	13(60%)	0	3(14%)	19(86%)	0	1(5%)	1(5%)	20(91%)
Model Cars	0	9(41%)	13(60%)	0	3(14%)	19(86%)	0	0	0	22(100%)
Music	20(91%)	2(9%)	0	6(27%)	16(73%)	0	16(73%)	6(27%)	0	0
Painting/Coloring/Drawing	14(64%)	8(36%)	0	6(27%)	16(73%)	0	2(9%)	7(32%)	6(27%)	6(27%)
Photography	12(55%)	5(23%)	5(23%)	2(9%)	19(86%)	1(5%)	4(18%)	5(23%)	3(14%)	10(45%)
Play Musical Instrument	11(50%)	9(41%)	2(9%)	2(9%)	12(55%)	8(36%)	4(18%)	1(5%)	7(32%)	10(45%)
Playing Sports (basketball, soccer, football, etc.)	10(45%)	8(36%)	4(18%)	6(27%)	15(68%)	1(5%)	5(23%)	5(23%)	3(14%)	9(41%)
Doing Puzzles (crossword, etc.)	13(60%)	9(41%)	0	11(50%)	11(50%)	0	3(14%)	10(45%)	2(9%)	7(32%)
Reading	13(60%)	9(41%)	0	12(55%)	10(45%)	0	8(36%)	8(36%)	7(32%)	5(23%)
Sewing/Needlework	12(55%)	10(45%)	0	3(14%)	16(73%)	3(14%)	0	4(18%)	10(45%)	8(36%)
Shopping	19(86%)	3(14%)	0	19(88%)	3(14%)	0	11(50%)	11(50%)	0	0
Singing	13(60%)	9(41%)	0	5(23%)	14(64%)	3(14%)	6(27%)	3(14%)	7(32%)	6(27%)
Skateboarding/Rollerblading	3(14%)	11(50%)	8(36%)	0	13(60%)	9(41%)	0	2(9%)	2(9%)	18(82%)
Swimming	19(86%)	3(14%)	0	9(41%)	12(55%)	2(9%)	4(18%)	7(32%)	8(36%)	3(14%)
Playing Video/Computer Games/Facebook, etc.	21(95%)	1(5%)	0	15(68%)	7(32%)	0	19(86%)	3(14%)	0	0
Volunteering	19(86%)	2(9%)	1(5%)	7(32%)	14(64%)	1(5%)	2(9%)	13(60%)	3(14%)	4(18%)
Watching Television	21(95%)	1(5%)	0	17(77%)	5(23%)	0	20(91%)	2(9%)	0	0
Water Sports (surfing, water skiing)	5(23%)	13(60%)	4(18%)	0	12(55%)	10(45%)	0	0	4(18%)	18(82%)
Writing (poems, stories, journal…)	8(36%)	14(64%)	0	2(9%)	13(60%)	7(32%)	0	8(36%)	2(9%)	11(50%)
Dining (going out for a meal)	20(91%)	2(9%)	0	14(64%)	8(36%)	0	3(14%)	16(73%)	3(14%)	0
Attending religious activities	20(91%)	2(9%)	0	12(55%)	7(32%)	3(14%)	7(32%)	7(32%)	4(18%)	4(18%)
Community outings (attending a concert, movie, etc.)	19(86%)	3(14%)	0	13(60%)	9(41%)	0	0	3(14%)	16(73%)	3(14%)

Due to the large dispersion of the approximate annual income reported by participants, data was sorted into high and low annual income, to determine if any variations exist between socio-economic status and QoL of the families with children with an ASD. High incomes (n=11) range from \$80,000-\$150,000 annually. Low incomes (n=11) range from \$35,000-\$60,000 annually. A significant difference of \$20,000 between high-end of the low income bracket and the low-end of the high income bracket was noted and provoked further investigation and analysis. Central tendencies, QOL scores and education status were analyzed to determine variances. Those families with higher incomes (>\$80,000) had a mean QOL score of 76.1 while lower incomes (<\$60,000) had a mean QOL score of 69.1. This is only a slightly higher score for higher incomes. In relation to highest level of education comparing mothers and fathers of children with an ASD, it appears that education level is inconclusive for predicting QOL scores while education beyond high school seems to increase QOL scores for mothers. See Figure 4: Parental Education Level and Quality of Life Scores.

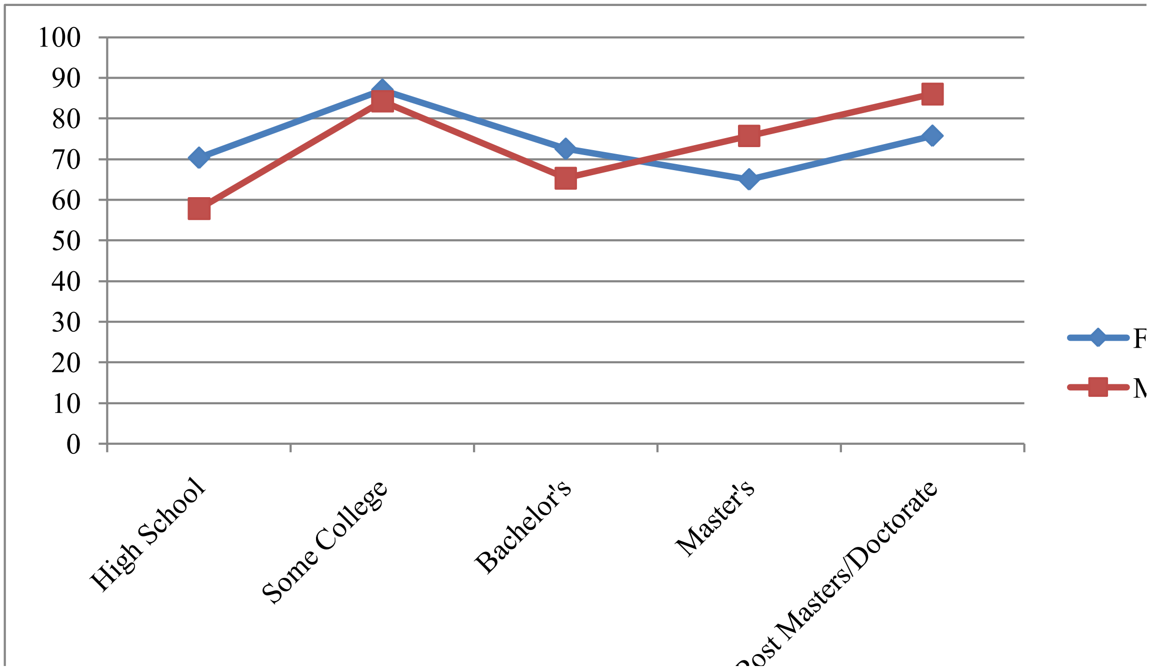

Figure 4: Parental Education Level and Quality of Life Scores

CHAPTER V

Discussion

The results indicate that families in this study are most likely to be young adults with a father aged 36 years and a mother aged 33 years with one child with an ASD approximately 6 years of age. These families have varying levels of education with most fathers holding a high school degree and most mothers with a post bachelor's degree. Average annual income for these families was $72,000. However, it should be noted that income ranged from $35,000-$150,000 annually. Families with children with an ASD self-reported that they enjoy activities that are individualized rather than group activities such as internet browsing, social networks and video games and watching television. The families in the study noted that the following activities were least enjoyed: gymnastics, collecting items and dancing.

Family Occupations

A limited number of the available occupations from the Occupational Checklist were identified as engaged in at least once a week by more than 50% of the participants. This data could indicate that the families have a narrow selection of occupations that are completed routinely. The data suggests that 86% of families engage in cooking at least once during a week that appears to indicate that cooking is an established routine in these households. According to Schultz-Krohn (2004) routines have been identified as a critical component for the promotion of healthy lifestyles. This suggests that families are attempting to engage in the family occupation of dining together during an evening meal which has been evidenced as one of the most critical opportunities to introduce a child to the family's beliefs in social and communication domains (Ochs, Taylor, Rudolf & Smith, 1992).

Financial challenges are also a factor in QOL scores, as having a child with a developmental disability is associated with higher rates in work loss and medical costs as compared to unaffected families (Hecimovic & Gregory, 2005). Evidence exists that socioeconomic status, as assessed by a modified Hollingshead four-factor, is weakly associated with family stress and that there is greater family stress when the child with an ASD is an older adolescent or young adult (15-21.9 years) compared to a younger adult (aged 10-14.9 years) (Donovan, 1988). Family stress such as work loss and high medical costs translate to financial worries. Those families in this study with annual income greater than $60,000 dollars did not display an increased QOL score when compared to those families with lower annual incomes. Therefore, according to the results of this study, annual income is not an indicator in increased QOL scores with families with children with an ASD. With that said, since income is not an indicator of QOL scores in this study, it can be interpreted than the behaviors associated with ASD can be the primary contributing factor in lack of occupational engagement. However, it is imperative to note the locale of the participants.

Person, Environment, Occupation Model

The PEO Model supports occupation-based approach to occupational therapy service delivery. PEO centers equally on facilitating change in the person, occupation and/or environment to promote optimal occupational performance (Law et al., 1996). Increased congruence of person, environment and occupation represents optimal occupational performance which can be linked as a predictor of QOL scores. Families that participated in this study appear to have a limited variety of occupational interests with the families only identifying 6 out of the 34 listed occupations on the Occupational Checklist as frequently participated meaning that greater than 50% of families engage in that occupation at least once a week. This would suggest a lack of congruence among occupation, person and environment. Research has identified several attributes of an ASD that impedes social interaction either through behavior or sensory outbursts (Doherty, 2008). The lack of congruence between the three main components of PEO would suggest a decrease in occupational performance which was also reflected in QOLS scores for the families with an average score of 73.

In a study completed by Lee et al., 2007, parents of children with an ASD were significantly less likely to attend religious services, more likely to miss school and less likely to participate in organized activities. The results of this study suggest that in those areas of concern were occupations desired but not frequently engaged in by the family. This further implies a disconnection between person, environment, and occupation if the family wishes to participate in certain occupations but is unable to do so for undisclosed reasons.

Family Systems/Dynamics

The family size data indicates that most of the families in this study had only one child. Many factors can be attributed to the small family size from the young age of the parents, factors and stress associated with having a child with an ASD or simply a personal choice to have only one child. With financial considerations, singleton children typically have a heightened interest and ability to provide and pay for extra services and therapies (Orsmond, Kuo, Seltzer, 2009).

Implications for Clinical Practice

From the results of this study it is suggested that service providers encourage families to participate and develop more family routines to incorporate active occupations into their daily life to possibly improve QOL. As practitioners we should incorporate the importance of healthy occupational functioning into intervention sessions as education/family support or offer opportunities to explore other occupational ventures.

Furthermore, this research reveals that many of these families spent a large percentage of their time using computers or some variety of technology. In therapy, particularly school-based practice, it would be beneficial to utilize the family's interest of technology such as computer based programming or the iPad in therapy to meet treatment goals and promote school success.

The importance of family identity has a wealth of research; however its importance has not been presented in published research with regards to families with children with disabilities. A qualitative study into the family stories that families with children with an ASD utilize as part of their family identity would be valuable to service clinicians providing interventions for the family to further understand the mechanism for the construction and affirmation of family identity.

Limitations

This research study was limited by a multitude of factors including small convenience sample, literacy levels of participants, and threats to internal validity. It would be beneficial to expound upon this research with a larger, randomized population to achieve a clearer picture of occupational engagement and quality of life. In addition, to this enlarged quantitative research, a qualitative component to describe the quality of life in families with children with an ASD would be essential to the development of a panoramic view into the daily lives and value system of these families. The instruments used in this study although suitable for a small study would need to be more exhaustive if included in a broad-based study. Furthermore, the Occupational Checklist could have included other occupations that are more prevalent to the region. The participants were given the opportunity to list any other occupations that the family enjoys but many participants chose not to complete that section of the survey. The Occupational Checklist included a variety of occupations ranging across the lifespan however some items were not culturally relevant such as “constructing model cars” or “martial arts” in which only one family responding in enjoying either of those activities. Although, those activities remain quite popular in the United States it appears that other occupations could have been listed such as “spending time with family and friends”, “tending to animals or crops” or “riding ATV’s, 4-wheelers or motorcycles”.

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