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Examining the Occupational Engagement of College Students with Asperger's Syndrome: A Mixed Methodology

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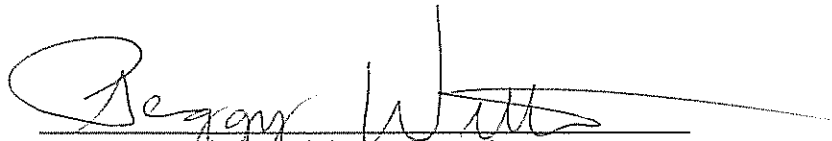
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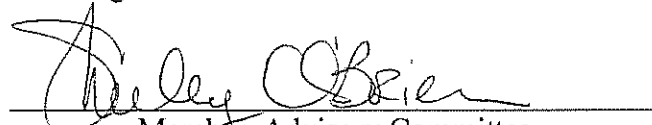
Examining the Occupational Engagement of College Students with Asperger's
Syndrome: A Mixed Methodology


By
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Examining the Occupational Engagement of College Students with Asperger's
Syndrome: A Mixed Methodology

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in partial fulfillment of the requirements
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DEDICATION

This thesis is dedicated to my family and friends in Louisville. It always made the long and sometimes grueling school weeks better knowing I would be spending my weekends with you. Love you all, I'm coming home for good!

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First, I would like to thank the chair of my advisory committee, Dr. Peggy Wittman, for her guidance throughout my time at this university. I would not have written this thesis if not for her relentless persistence and encouragement over the years. I am truly grateful that I found myself sitting in your research class four years ago. I would also like to thank my other committee members, Dr. Shirley O'Brien and Professor Amy Marshall, for their suggestions and enthusiasm. I would like to thank the participants of this study for their time and willingness to participate in the project, as this thesis would not be possible without you. I would like to express thanks to my fellow peers also writing a thesis, as you were always there to listen when I needed a sounding board. Finally, thanks goes out to my friends and family for lifting my spirits over the many weekends I spent at home, especially, Connie, Doug, Daniel, Neil, Stacy, Roo, Andrew, Maria, and Jessica. I love you each more than words can express.

ABSTRACT

The purpose of this convergent parallel mixed methods design was to determine how young adults enrolled in school with Asperger's Syndrome engage in occupations and how this population perceives their quality of life. Quantitatively, assessment data was gathered using Flanagan's Quality of life Scale and the Occupational Behaviors Satisfaction Checklist. Qualitatively, a phenomenological approach was taken utilizing the Lifestyle Performance Model as a guide to administer semi-structured interviews in order to determine occupational engagement experiences of the young adult population with Asperger's Syndrome enrolled in college. Results will be discussed with implications for occupational therapy and future research.

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CHAPTER I

Introduction

Case Vignette

Lucy is 25 years old and lives at home with her mother. She was diagnosed with Asperger's Syndrome later in life as her mother did not suspect problems early on, because her daughter had always excelled academically. Her mother works during the day, therefore Lucy has learned a simple routine of cooking easy meals and taking care of her basic needs. After graduating high school with honors she decided she was going to go to the state university. However, she dropped out after a semester because she was unable to meet the social and organizational demands of college life. Several years later she began attending a small community college where she is now attending classes part time. She has been unable to acquire paid employment and thus is still financially dependent on her mother. Lucy's mother has always been concerned about her lack of social interaction with others and is always telling her coworkers that all she does is watch television or movies revolving around historical events and surfs the internet. Lucy would like to be more social and establish friendships but is just not sure where or how she could begin.

Lucy's scenario is not uncommon for young adults with Asperger's Disorder, especially, since there has been a steady increase in the incidence and prevalence of autism spectrum disorders over the past two decades (CDC, 2010). In analyzing the occupational engagement of those with Asperger's Syndrome research was found which spoke to this population's engagement in areas of special interests. (Mercier, Mottron, & Belleville, 2000; Hilton, Crouch, & Israel, 2008; Klin, Danovitch, Merz, & Volkmar,

2007; Shane & Albert 2008; Jennes-Coussens, Magill-Evans, & Koning, 2006).

However, research was lacking or minimal for this specific population in other areas of occupational engagement. By discovering patterns of occupational engagement clinicians could utilize this information and to enhance health and well being and improve quality of life for these individuals.

Background

The Center for Disease Control and Prevention (CDC, 2010) has estimated that up to 730,000 individuals between the ages of 0 and 21 are living with an Autism Spectrum Disorder (ASD) also referred to as the Pervasive Developmental Disorders (PDD) within the United States. There are various syndromes comprised in the autism continuum and depending on the range and severity of symptoms an individual can either be diagnosed with, Asperger's Disorder (AD), also called Asperger or Asperger's Syndrome, autism, or pervasive developmental disorder-not otherwise specified (PDD-NOS). This researcher preferred to use the term Asperger's Syndrome unless the literature cited specifically used the terminology Asperger's Disorder or AD.

The American Psychiatric Association's (APA) *Diagnostic and Statistical Manual of Mental Disorders, 4th edition, Text revision* (DSM-IV-TR; 2000) and the World Health Organization's (WHO) *International Classification of Functioning, Disability, and Health* (ICF; 2001) use the diagnosis of Pervasive Developmental Disorder which at present are more often referred to as the Autism Spectrum disorders, when referring to any individual who has poor social and communicative abilities varying in degree and intensity, and displays restricted repetitive acts and or a restricted range of interests (Alexander, 2011).

Incidence and prevalence rates are not as well established for Asperger's Disorder. According to the National Institute on Neurological Disorder and Stroke, utilizing the APA's DSM-IV-TR diagnostic criteria for AD, population estimates for the condition are conservatively around 2 out of every 10,000 children, with boys being three to four times more likely to have the condition (2005). However, there is another set of diagnostic criteria often used, the Gillberg diagnostic criteria for Asperger's Syndrome (Gillberg & Gillberg, 1989 & Gillberg, 1991). This set of diagnostic criteria was first published in 1989 by Carina Gillberg and Christopher Gillberg and it was also elaborated on in 1991 by Christopher Gillberg. This set of diagnostic criteria includes characteristics of the syndrome that were close to the original description of AD, some of which the APA's DSM-IV-TR does not recognize as being a criterion for diagnosis. When this set of diagnostic criteria was utilized in a Swedish study, population estimates were much higher. Utilizing the Gillberg criteria for Asperger's Syndrome (Gillberg & Gillberg, 1989, Gillberg, 1991), the results indicated that Asperger's Syndrome was present in at least 36 and possibly up to 71 out of 10,000 children born. Results from the study suggest that Asperger's Disorder is around five times more common than autism (Ehlers & Gillberg, 1993).

For a diagnosis of Asperger's Disorder the disturbance in one's social and communicative abilities as well as one's restricted interests must cause a clinically significant impairment in one of several areas of functioning such as social participation, or occupational engagement (APA, 2000). It is important to note individuals with a diagnosis of Asperger's Disorder do not display significant cognitive or language delays as defined in the criteria for Autism by the APA (2000). The Gillberg diagnostic criteria

for Asperger Syndrome includes speech and language peculiarities, non-verbal communication problems, and motor clumsiness which differs from the APA diagnostic criterion (Gillberg & Gillberg, 1989, Gillberg, 1991).

Currently the DSM-IV-TR, separates Asperger's Disorder from Autistic disorder, which includes high-functioning autism. The DSM-IV-TR does this by emphasizing that the individual with Asperger's Disorder has no significant linguistic or cognitive delay (APA, 2000). This is a cause for controversy amongst researchers in the field (Sanders, 2009). Sanders, conducted research comparing Asperger's Disorder and high-functioning autism from publications dating back to the year 2000. He found that before the DSM criteria were created for the diagnosis that many studies found qualitative differences between Asperger's Disorder and high-functioning autism. Once the DSM-IV distinguished the two he found when the studies used the criteria there were no longer differences (2009). Research by Howlin (2003), also suggests differences between those with high-functioning autism and Asperger's Disorder are minimal, especially once individuals with the condition reach adulthood. Clearly larger scales studies are needed to clarify the differences between these diagnoses. Thus, for the purposes of this master's theses this researcher included literature in both ASDs and Asperger's Disorder.

Problem Statement

Autism Spectrum Disorders are a set of conditions that manifest with the individual throughout one's lifetime affecting his or her social and communicative competence. Currently few studies have focused on the occupational choices and engagement within the young adult population attending college. In researching the occupational engagement choices for this population the researcher found some research

exploring this population's circumscribed interests (Mercier, Mottron, & Belleville, 2000; Hilton, Crouch, & Israel, 2008; Klin, Danovitch, Merz, & Volkmar, 2007; Shane & Albert 2008; Jennes-Coussens, Magill-Evans, & Koning, 2006). Research was lacking or minimal for this specific population in other areas of occupational engagement, including self-care and self-maintenance, societal contribution, as well as occupations centered around maintaining or sustaining relationships with others such as friends, family members, peers and acquaintances. Additional research is needed that explores occupational engagement beyond this population's special interest areas.

Once occupational engagement is better understood within this specific population, clinicians could capitalize on this information and utilize it as a means to provide intervention to enhance social and communicative competence and adaptive behavior in order to promote independence and meaningful relationships. Law, Steinwender and Lenclair, (1998) note that participation in occupation can enhance health and wellbeing. With this population's occupational engagement being centered on circumscribed interests the literature is not clear whether or not this type of occupational engagement produces the benefits of health and well being which are related to a high perceived quality of life.

Statement of Purpose

The purpose of this convergent parallel mixed methods design (Creswell, 2009) is to examine how adults with Asperger's Syndrome enrolled in college engage in occupations, and how this population perceives their quality of life. In this convergent parallel mixed methods design, qualitative and quantitative data were collected in

parallel, analyzed separately, and then merged. Analysis of quantitative data and qualitative data was then compared.

Quantitatively, assessment data was gathered using Flanagan's Quality of life Scale (Flanagan 1978, Burckhardt, Woods, Schultz, & Ziebarth 1989) (see Appendix C) and the Occupational Behaviors Satisfaction Checklist (OBSC) (Wittman & Vaught, 2010) (see Appendix D). The OBSC was developed in 2010 to help develop a way to quantitatively measure occupational choices. The Quality of Life Scale, created by John Flanagan in the 1970s has shown to be a reliable and valid instrument in assessing the quality of life from the perspective of the client across diverse patient groups (Burckhardt & Anderson, 2003; Burckhardt, Anderson, Archenholtz, & Hagg, 2003). Qualitatively, a phenomenological approach was taken utilizing the Lifestyle Performance Model as a guide to administer semi-structured interviews (see Appendix E) in order to determine occupational engagement experiences of the young adult population with Asperger's Syndrome enrolled in school. All three data sets will be used to fulfill the mixed methods approach. Thus, the proposed mixed methods study is designed to explore how this population engages in occupation beyond that of areas of special interests to determine this population's overall engagement in occupation and possible impact on their perceived quality of life.

Research Questions

The two primary questions to be answered are; (a) How do young adults enrolled in school with Asperger's Syndrome engage in occupations?; and (b) How do young adults enrolled in school with Asperger's Syndrome perceive their quality of life?

Subquestions:

1. What is the range of occupations this population engages in?
2. Is this population satisfied or dissatisfied with occupational engagement?
3. What occupations do the participants engage in for care of self and personal surroundings?
4. What occupations do the participants engage in for pleasure and enjoyment?
5. What occupations do the participants engage in to contribute to the need fulfillment and welfare of others?
6. What occupations do the participants engage in to sustain relationships with others?
7. Is the environment an influence on the occupational engagement of this population?

Assumptions

I have previous experience interacting with young adults with Asperger's Syndrome. I led a social effectiveness training group with another occupational therapy student and two psychology graduate students, over the course of 6 weeks. Over this period of time, I learned that some individuals with Asperger's Syndrome may have a difficult time appropriately maintaining or initiating social interaction which could limit the quality of the relationships they have with friends or family members. They may also exhibit avoidance of social situations which may impact occupational engagement. I also realized those with Asperger's Syndrome spend excessive amounts of time in their special interest area which may influence other areas of the individual's life. For example, special interests may dominate conversations held with others or limit the range

of activities they participate in for enjoyment. Furthermore, special interest areas could also possibly dominate or reoccur throughout the interview. Participants may be more apt to speak to their passions rather than questions about other areas of occupational engagement which could limit results.

Definition of Terms

- Asperger's Disorder- "The essential features of Asperger's Disorder are severe and sustained impairment in social interaction and the development of restricted, repetitive patterns of behavior, interests." Furthermore, "The disturbance must cause clinically significant impairment in social, occupational, or other important areas of functioning." These individuals do not experience clinically significant delay in language or cognitive development (APA, 2000).
- Autism- The essential features of Autism also known as Autistic Disorder are "Markedly abnormal or impaired development in social interaction and communication and a markedly restricted repertoire of activity and interests." Communication may be delayed or may never develop (APA, 2000).
- Autism Spectrum Disorder-Is a nonspecific diagnosis for a variety of autistic disorders varying in degree and intensity which are characterized by poor social and communicative abilities and restricted repetitive acts. Diagnosis of an autism spectrum disorder commonly includes autism, Asperger's Disorder, and pervasive developmental disorder not otherwise specified. (Alexander, 2011).
- Lifestyle Performance Model-A conceptual framework that identifies a contextual configuration of one's activity patterns in order to optimize one's quality of life through utilization of four occupational domains of self-care and self-

maintenance, societal contribution, intrinsic gratification, and reciprocal interpersonal relatedness (Velde & Fidler, 2002).

- Occupations- “Daily activities that reflect cultural values, provide structure to living, and meaning to individuals; these activities meet human needs for self-care, enjoyment, and participation in society” (Crepeau et al., 2003, p. 1031).
- Occupational Therapy-“The practice of occupational therapy means the therapeutic use of everyday life activities (occupations) with individuals or groups for the purpose of participation in roles and situations in home, school, workplace, community and other settings” (Jacobs & Jacobs, 2009, p. 172).
- Phenomenological research-Is a method of qualitative inquiry which focuses on describing the lived experience of a concept or phenomenon experienced by several individuals (Creswell, 2007).
- Quality of life (QOL)-“Individuals' perceptions 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” (WHO, 1993, p. 153).

CHAPTER II

Review of Related Literature

Introduction

This chapter provides a literature review that was conducted using a variety of resources including books and textbooks, scholarly peer reviewed academic journals, government reports and legal documents, and critically reviewed websites. Databases that were utilized in the search for current literature were: CINAHL with full text, Health Sciences: A SAGE Full Text Collection, OT Search, and the more broad database Academic Search Premiere. Several journals were also searched thoroughly including but not limited to; The American Journal of Occupational Therapy, Journal of Autism and Developmental Disorders, Journal of Intellectual Disability Research, Focus on Autism and other Developmental Disabilities, Journal of Intellectual Disability Research, and the Journal of Vocational Rehabilitation. Other American Occupational Therapy Association publications were searched including the Special Interest Section Quarterly on Developmental Disabilities and OT Practice.

Search terms were related to the research questions to be answered and included; Asperger's Disorder, Autism, Autism Spectrum Disorders, high-functioning autism, quality of life, restricted/circumscribed interests, participation, occupational therapy, and college/post-secondary education. Asperger's Disorder is continuous and lifelong condition, thus literature reviewed includes research conducted with participants ranging from children to adults.

Asperger's Syndrome

In 2000 the CDC established the Autism and Developmental Disabilities Monitoring Network in order to better collect data and determine the incidence of autism spectrum disorders. In 2002 the CDC found that autism spectrum disorders affected an average of one child in every 150 (2007). Surveillance by this network indicated that in California that from 1987-1998 the number of persons receiving services for ASDs increased to 300% (CDC, 2007). Researchers in the field are still not sure why there has been such a boom in the increase in diagnoses, some speculate it could be improved diagnosis and reporting but other causes such as environmental toxins, food allergies, and viruses amongst other things are currently being researched as a possibly cause or link. Currently, there is no consensus regarding the etiology of the autism spectrum disorders. Views to date suggest that there may be multiple factors contributing to the condition including abnormal anatomical neurology, neurochemical imbalances, environmental exposure, and genetics (Miller-Kihaneck & Glennon, 2004).

Both the *Diagnostic and Statistical Manual of Mental Disorders, 4th edition, Text revision* (DSM-IV-TR) (APA, 2000) and the World Health Organization's (WHO) *International Classification of Functioning Disability and Health (ICF)* (2001) consider Asperger's Disorder to be a one of several pervasive developmental disorders with both of their criteria for diagnosis remarkably similar. In chapter one the diagnostic criteria for Asperger disorder as published by the American Psychiatric Association was presented. While the APA's diagnostic criterion is commonly utilized in clinical settings it is important to realize there are other relevant published criteria. The Gillberg diagnostic criteria for Asperger's Syndrome closely resemble that of the original descriptions of the

condition, thus some clinicians prefer utilizing this set of diagnostic criteria (Attwood, 2007). The Gillberg diagnostic criteria have six total criteria (Gillberg & Gillberg, 1989, Gillberg, 1991). The first criteria, social impairment must be present along with four or five of the other criteria for a diagnosis. The other criteria include narrow interests, a compulsive need for adherence to a routine, speech and language problems, non-verbal communication problems, and motor clumsiness. In describing the characteristics of Asperger's Disorder the author will consider both the APA's DSM-IV-TR and the Gillberg diagnostic criteria.

Both the DSM-IV-TR and Gillberg's diagnostic criteria agree that there is a marked social impairment in an individual with Asperger disorder. The social impairment can vary and range in degree and intensity. Commonly one will encounter either a failure or indifference to develop peer relationships, which could be caused by a difficulty in interacting with peers, or a lack of social or emotional reciprocity (Gillberg & Gillberg, 1989, Gillberg, 1991, & APA, 2000). Individuals with the condition may have difficulty interpreting social cues, and may display behavior that is emotionally and socially unacceptable (Gillberg & Gillberg, 1989, Gillberg, 1991).

Restricted and narrow interests are also a diagnostic criteria of individuals with Asperger Disorder (APA, 2000, Gillberg & Gillberg, 1989, & Gillberg, 1991). This could be to the exclusion of other activities (Gillberg & Gillberg, 1989 & Gillberg 1991). Individuals with the disorder also have a need to adhere to a strict routine, (Gillberg & Gillberg, 1989, Gillberg, 1991 & APA, 2000) which can have an impact on everyday life impacting social and occupational areas of engagement.

In the areas of speech and language, Gillberg's criteria and the APA's diagnostic criteria differ. The APA, (2000) believes there is no clinically significant delay in language. According to Gillberg's criteria, he believes that speech and language peculiarities do exist which could manifest in "a delayed speech development, superficially perfect expressive language, formal pedantic language, odd prosody, peculiar voice characteristics, or impairment of comprehension including misinterpretations of literal/implied meanings" (1989, p. 632). Gillberg's criteria also speaks to non-verbal communication problems, and motor clumsiness (1989, 1991).

Currently, neither the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders IV-TR* nor Gillberg's diagnostic criteria include any type of sensory processing challenges in the diagnostic criteria for Asperger's Syndrome. Recent research has contributed literature about the sensory problems that individuals with the disorder may experience. Dunn, Miles, and Orr (2002), conducted a study to gain initial evidence about possible sensory processing patterns that may be present in children and youth with AD through utilization of the Sensory Profile. 42 parents of children with AD completed the profile, as well as 42 parents of children without disabilities in order to complete the group comparison design. A significant difference was found on 22 of the 23 possible statistical comparisons. The children with AD scored lower (displaying the behavior) than that of their peers without disabilities according to the results from the Sensory Profile. Difficulties were found with both hyporesponsiveness and hyperresponsiveness suggesting the children in this study has poor modulation, meaning their responses to stimuli may vary dramatically from one situation to the next.

Further research conducted by Pfeiffer, Kinnealey, Reed, and Herzberg, (2005) revealed that the sensory defensiveness found in children and adolescents with AD is positively correlated with anxiety. A relationship was also found between symptoms of depression and hyposensitivity in the total group and more so in the older group. Depression can develop at a young age within this condition, as early as seven years old. This could be due to child's ability of having the insight that they are different from their peers and mounting frustration and anxiety at attempts of social integration they may experience on a daily basis (Attwood, 2007).

Asperger's Syndrome in Post Secondary Education

As the current population of those diagnosed with Asperger's Disorder is increasing (CDC, 2007 & 2010) an increase has been noticed in the number of students with AD attending college (Smith, 2007). College can be a stressful time of transition for a number of individuals with and without disabilities. College creates an environment where individuals are forced to independently tackle novel sometimes daunting tasks for the first time in their lives. While individuals with AD may have the intellectual ability to handle academic side of college, deficits in social skills and inflexibility in routine could put the college student with Asperger's Syndrome on a collision course to failure. Colleges and universities across the country are beginning to recognize the increasing prevalence and unique needs of individuals with Asperger's Syndrome. Thus, a small number of colleges and universities have began putting support systems in place to help their students with Asperger's Syndrome with social skills and strategies and techniques to help them succeed in a college environment (Wenzel & Rowley, 2010).

Universities have the obligation to abide by the American with Disabilities Act of 1990 (ADA) and Section 504 of the Rehabilitation Act of 1973 to provide appropriate accommodations to students with disabilities when necessary. The Americans with Disabilities Act and Section 504 ensures that public institutions will not discriminate against individuals with disabilities. The ADA defines a disability as any physical or mental impairment which substantially compromises the individual's ability to engage in life events (1990).

Occupational Engagement and Asperger's Syndrome

According to the American Psychiatric Association (2000), those diagnosed with Asperger's Disorder display "Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities" (p. 84). This is one of the essential features of the condition which can manifest in restricted patterns of interest, adherence to following a nonfunctional routine or ritual, repetitive or stereotyped motor movements, and or preoccupation with parts of objects. In particular, the preoccupation with restricted interests individuals may display can have a significant impact on social and occupational engagement. Occupational engagement is the participation in occupations, the "Daily activities that reflect one's cultural values, provide structure to living, and meaning to individuals; these activities meet human needs for self-care, enjoyment, and participation in society" (Crepeau et al., 2003, p. 1031). Thus, if one's occupational engagement is centered on circumscribed interests for purposes of enjoyment to the exclusion of other activities, participation in society and self-care activities may be compromised.

There is a large amount of literature that speaks to the occupational engagement of person's with an Autism Spectrum Disorder within the realm of the individual's

restricted interest area, which is often an area of occupation that is engaged in for purposes of enjoyment or pleasure. Mercier, Mottron, and Belleville (2000), explored how restricted interests were perceived by six participants ranging in age from 21 to 52 years old with high-functioning pervasive developmental disorders as well as their relatives, utilizing in-depth semi-structured interviews. The six participants described interests that fell into three main categories which were collections, music (listening or playing), and knowledge and activities pertaining to a very specific area. Results of the study indicate that all family members interviewed, which included parents and siblings, viewed their relative as devoting themselves almost exclusively to their restricted interests.

Klin, Danovitch, Merz, and Volkmar (2007), also report findings indicating a large majority of preschool and elementary aged children with high-functioning autism spend a significant amount of their time around their special interest area as indicated by their parents. The researchers found that 25-75% of the children's time was devoted to their circumscribed interests impacting other areas of activities. This study was also similar to the Mercier, Mottron, and Belleville (2000), study in that special interest areas also included amassing facts and knowledge pertaining to specific areas, which was one of the main categories of interests within the adult population of the study. This study went further to suggest that verbal learning and memorizing are the predominant ways in which this population goes about amassing facts and information (Klin et al., 2007).

Further research examines how children with high-functioning autism differ from their typically developing peers in out of school participation. Hilton, Crouch, and Israel (2008), report that out of school participation among children with high-functioning

autism spectrum disorders ages 6-12 was significantly different than that of their typically developing peers. Utilizing the Children's Assessment of Participation and Enjoyment (CAPE) assessment measure the researchers were able to come to the conclusion that the high-functioning ASD group participated in a narrower range of activities and with fewer participants. Specifically the researchers found that children with high-functioning ASD participated in fewer social and physical activities with less frequency and less number of activities.

Clumsiness and sensory hypersensitivities may impact the individual's desire to participate in occupations which require physical activity. Jennes-Coussens, Magill-Evans and Koning (2006), conducted a quality of life study comparing a group of young men with Asperger's Syndrome and a group of young men without Asperger's Syndrome, utilizing the World Health Organizations Quality of Life Measure, the Perceived Support Network Inventory, and a semi structured interview. The researchers found that the men with Asperger Syndrome reported a lower social and physical quality of life compared to the men in the control group. The researchers found that men with Asperger's Syndrome spent more time in leisure occupations such as watching TV and movies, playing video games, spending time on the internet, and reading than the control group. The control group spent their leisure time in some of the same ways but they also engaged in a variety of sports which those with AD did not.

In a study completed by Shane and Albert (2008), interests similar to that of the Jennes-Coussens, Magill-Evans, and Koning (2006), study the Klin, Danovitch, Merz, and Volkmar (2007), study and the Mercier, Mottron, and Belleville (2000), study were found with children with Autism Spectrum Disorder. In this study the researchers elicited

data from 89 surveys of caregivers or parents with a child with an ASD. The study found that “Heavy participation (defined as 3 or more hours per day) in television and movie viewing accounted for preferences among twice as many children as in play” (p. 1502). The results are not surprising within this population as research by Borremans, Rintala, and McCubbin (2010), found that “Adolescents with AS had lower levels of physical fitness in balance, coordination, flexibility, muscular strength, running speed, and cardio-respiratory endurance, and had higher levels of physical inactivity when compared to age matched peers” (p. 317).

Jennes-Coussens, Magill-Evans and Koning (2006), found that young men with Asperger Syndrome report a lower social quality of life when compared to the control group. Hilton, Crouch and Israel (2008), reported that children with high-functioning ASDs participated in fewer social activities. The American Psychiatric Association (2000) recognizes that individuals with the condition have problems with social aspects of communication which could impact their participation in society, or their overall societal contribution. Velde and Fidler (2002), define societal contribution as “activity patterns concerned with contributing to the need fulfillment and the welfare of others” (p. 14). These activities include work, volunteerism, and education among other things. Literature surrounding these areas indicate that this population may not be satisfied with current levels of occupational engagement (Hurlbutt & Chalmers, 2004).

In the United States, work can be perceived as a way of human life that constitutes a large part of an individual’s identity. For an individual with Asperger’s Syndrome successful employment can be difficult to attain and maintain. Muller, Schuler, Burton, and Yates (2003) suggest that difficulties with social cognition and habit

formation can be hindrances to successful employment. Hurlbutt and Chalmers (2004), interviewed six adults with Asperger Disorder and found that this group experiences frequent unemployment and underemployment and difficulty finding work that correlated with their ability levels. In the study conducted by Jennes-Coussens, Magill-Evans, and Koning (2006) the researchers found that 6 of the 12 participants with Asperger Syndrome were employed, while 1/3 of the participants were neither employed or going to school.

The problems with the social aspect of communication that individuals with the disorder have can also impact the individual's ability to gain or maintain relationships with others. Thus, the occupational engagement one has with friends, family, peers, and acquaintances can be impacted. According to Attwood (2007), during times of emotional distress those with the disorder find that, "The most effective emotional restorative is solitude" (p. 308). In a relationship this could be a problem in that every time there are times of personal distress the person with Asperger's Syndrome wants to go and be alone and may assume that is what the partner needs as well causing rifts in peer, familial and or romantic relationships. Difficulties with managing anxiety can also cause conflict in relationships as the person with Asperger's Disorder may be very controlling with rigid routines. Furthermore, managing conflict successfully can be a weakness of individuals with the disorder further compromising relationships (Attwood, 2007). Research does note several difficulties in sustaining relationships, but is lacking in what occupations individuals with AD and those they have relationships do to sustain those relationships.

In researching the occupational engagement choices for this population the researcher found a significant amount of research exploring this population's

circumscribed interests. Research is lacking for this specific population in other areas of occupational engagement of self-care and societal contribution, as well as occupations centered around maintain or sustaining relationships with others such as friends, family members, peers and acquaintances. Additional research is needed exploring occupational engagement beyond this population's special interest area.

Asperger's Syndrome and Quality of Life

Quality of life can be a subjective phenomena based on an individual view point. The world health organization defines quality of life as an "Individuals' perceptions 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" (WHO, 1993, p.153). Law, Steinwender and Lenclair, (1998) note that participation in occupation can enhance health and wellbeing. With this population's occupational engagement being centered on their circumscribed interests the literature is not clear whether or not this type of occupational engagement produces the benefits of health and well being which are related to a high perceived quality of life.

A study conducted by Limbers, Heffer, and Varni, (2009) sought to examine the feasibility, reliability and validity of the health related quality of life of children with Asperger's Syndrome through utilization of the PedsQL Cognitive Functioning Scale parent proxy-report version. This test was administered to 22 parents of children with Asperger's Disorder ranging in age from 6 to 12 years old. Results indicated that parents of children with Asperger's Disorder report that 50% of the time their child has problems with physical functioning in doing chores around the house. In regards to emotional functioning, 45.5% of the parents report that their child often or almost always is feeling

angry and has difficulty sleeping. In regards to social functioning 63.7% of the parents of children with the disorder reported that t often or almost always other kids do not want to be friends with their child. Other often or almost always responses included difficulty paying attention in class (59.1%), trouble remembering more than one thing at a time (39.4%), and difficulty remembering what people tell their children (36.4%). While this test only sought to determine psychometric properties in utilizing the instrument in children with Asperger's Disorder there was a substantial difference in the results when they were compared with a healthy children sample from a previous PedsQL initial field test. In the healthy sample the highest percentage reported from any parents of almost always or often a problem was 9.3% in being able to pay attention in class, while the other results were all under 7%.

In a sample of young men with Asperger's Syndrome Mercier, Mottron, & Belleville, (2000) found that participants were well aware of the invasive nature of their circumscribed interests but identified that their interests provided them with a sense of well being and a positive way to utilize their time. However, their perceived physical and social quality of life was lower than that of control group of young adult males without Asperger's Disorder. A study that focused more specifically on the social aspect of quality of life, aimed to evaluate the feasibility of using the American Speech-Language-Hearing Association's Quality of Life Scale (Burgess & Turkstra, 2010). The scale was administered to 14 adolescents with high-functioning autism and Asperger's Disorder and 15 of their typically developing peers, as well as mothers of the participants who rated their children's quality of communication life. Results indicated that ratings of the group of individuals with high-functioning autism or Asperger's Disorder were significantly

lower than that of the control group, but were still generally positive. The ratings the individuals with the disorder gave themselves were higher than their parental ratings.

Asperger's Syndrome and Occupational Therapy

The purpose of occupational therapy (OT) is to promote health and wellness in all people through participation and full engagement in occupation (AOTA, 2008).

Occupational therapists focus on enhancing engagement through several areas of occupation including activities of daily living, work, play, education, rest and sleep, leisure, and social participation within a person's living environment. In order to determine the focus and goals for individuals with Autism spectrum disorders the OT must determine specific goals and priorities for participation within the areas of occupation as defined by the domain through evaluation (AOTA, 2010).

In evaluating an individual with an ASD it is important to consider both the individual and the environment. Considerations should also be made due to the variation in the person's day to day occupational performance as well as the intensity or range of symptoms an individual may display (Scott, 2001). The results of the evaluation should then be "implemented to foster occupational engagement and social participation by attending to the transaction among the client, the activity, and the environment" (AOTA, 2010, p. 127).

In working with adolescents and young adults with Asperger's Disorder the intervention varies depending on the individual's needs based on the evaluation. For example, OT's may implement environment redesign to optimize occupational performance. Individuals with ASD often report that sensory processing difficulties as a significant barrier to full participation in occupations (Alexander, 2011). Therefore,

occupational therapists can improve sensory modulation by prescribing a sensory diet or sensory activities that are age appropriate. As the individual ages intervention may tend to focus on preparing to successfully transition from high school students into the work force or college students (Scott, 2001). OT's also may work with teachers, family members, and employers in order to implement a stable structured routine, or prepare the person with AD for a change in routine (Alexander, 2011)

Social skills are important for most areas of occupational performance. Those with Asperger's Syndrome may have underlying difficulties in engaging in occupations that require socialization or reciprocity between individuals, therefore understanding and using social skills can be a lifelong challenge for an individual with Asperger's Syndrome. At a young age video modeling utilizing social stories or peer mentoring are often used as a way to model and teach social skills (Ogilvie, 2011). As the individual with the disorder ages, Social Effectiveness Training (SET) or social skills training may be a better option. Social skills training typically includes role play. Once role play is mastered the individual would then practice learned skills with others in real life situations with the therapist providing feedback along the way (Alexander, 2011).

In research conducted by Bundy et al., (2009) the authors set out to determine the effects of a social skills training program based on SET with a group of individuals with Asperger's Syndrome. The participants included 12 individuals with AD ranging in age from 15-46 years with a mean age of 24.33 years. Through utilizing the Burns Depression Checklist and the Burns Anxiety inventory the authors found that the participants reported significantly reducing depression into the mild depression range, and significantly reducing anxiety into the mild anxiety range in just seven group sessions.

Group members were also interviewed about their experiences with the group and upon qualitative analysis the researchers found that the participants enjoyed taking part in the group specifically meeting new people and being in a group setting. Participants enjoyed listening to other group members perspectives.

Similar results were found in a study of a smaller social skills group which included four boys ages 12 to 13 (Teitt, Eastman, O'Donnel, & Deitz, 2010). Intervention included ten one hour sessions over ten weeks. Both parents and facilitators observed and reported improvements in social skills in the participants. All of the participants indicated that they enjoyed coming to the group and were able to identify at least one goal that they had accomplished over the ten weeks of attending the group.

Conclusion

In researching the occupational engagement choices for this population the researcher found some research exploring this population's circumscribed interests (Mercier, Mottron, & Belleville, 2000; Hilton, Crouch, & Israel, 2008; Klin, Danovitch, Merz, & Volkmar, 2007; Shane & Albert 2008; Jennes-Coussens, Magill-Evans, & Koning, 2006). Research was lacking for this specific population in other areas of occupational engagement, including self-care and self-maintenance, societal contribution, as well as occupations centered around maintaining or sustaining relationships with others such as friends, family members, peers and acquaintances. Additional research is needed exploring occupational engagement beyond this population's special interest area.

While some literature exists on the physical and social quality of life for young adults with Asperger's Disorder, no research was found on both males and females attending college perceived quality of life within the United States. This author is

concerned with other areas of quality of life such as material well-being/financial security, relationships with family members, occupational roles, and creativity and personal expression among other areas as covered by Flanagan's Quality of Life Scale. Therefore this researcher set out to answer two primary questions. The two primary questions to be answered are; (a) How do young adults enrolled in school with Asperger's Syndrome engage in occupations?; and (b) How do young adults enrolled in school with Asperger's Syndrome perceive their quality of life?

CHAPTER III

Methodology

Research Design

This study used a convergent parallel mixed methods design. In a convergent parallel mixed methods design quantitative and qualitative data are collected in parallel, analyzed separately, and then merged (Creswell, 2009).

Individuals on the ASD spectrum typically have some type of impairment in social interaction (APA, 2000). Therefore, utilization of only a semi-structured interview may have been a limited source of data because of participant's potential inability to sustain conversation, which lead to the decision of using a mixed methods design. Therefore, quantitative assessment data was gathered first using Flanagan's Quality of Life Scale (Flanagan 1978, Burckhardt, Woods, Schultz, & Ziebarth 1989) and an Occupational Behaviors Satisfaction Checklist (Wittman & Vaught 2010). Qualitatively, the Lifestyle Performance Model was utilized as a guide to administer a semi-structured interview to the participants in order to determine occupational engagement across the four domains of; intrinsic gratification, societal contribution, reciprocal interpersonal relatedness, and self-care/self-maintenance.

The research was approved by Eastern Kentucky University's Institutional Review Board. Please see Appendix B for a copy of the consent form. A consent form was signed by each participant. All necessary precautions were taken to assure confidentiality of all participants including keeping written personal identifying information to a minimum and removing the names of the participants from the actual information obtained. Participants were assigned identification numbers and a list of

study participants including their first and last names with corresponding ID numbers were kept on a password protected computer. All hard copies were kept in a locked filing cabinet separate from the information obtained.

Participants

The participants were selected using purposive sampling methods. Possible participants attended a social effectiveness training (SET) group where the researcher previously volunteered her time during the fall semester. Recruitment occurred through the Eastern Kentucky University Psychology clinic. A volunteer at the psychology clinic was provided a script to use to email participants of previous SET groups that had taken place in the clinic (see Appendix A). If participants choose to participate they were emailed a form with the location of the interview, contact information for the primary investigator and her faculty advisor, and a designated time and date to complete the quantitative assessments and interview that was most convenient to the participant.

The primary investigator emailed the participant the day before his or her scheduled interview. The day of each of the individual interviews and quantitative assessment administration the primary investigator reviewed the consent form with the participant and had the participant sign the consent form. A copy of the consent form was made and given to each participant.

The inclusion criteria for this study was the participant must have a diagnosis of Asperger's Syndrome according to DSM-IV criteria, sufficient communication skills to participate in an interview, be a current student or recent graduate of Eastern Kentucky University, and be 18 years of age or over. The study population included 3 young adults, one Caucasian male and two Caucasian females with Asperger's Syndrome. The

participants ranged in age from 25 to 34. All participants either had or were working on a bachelor's degree and the third was working on her second master's degree. It should be noted that the interviews took place in the summer months from June through August. Participants were asked to take this into consideration when asked about routines which vary during the academic year. Table 1 provides the demographic characteristics of the population as well as the pseudonym given to each of the three participants.

Table 1. Demographics Table

Participant	Pseudonym	Gender	Age	Race
Participant # 1	A.X.	F	29	Caucasian
Participant #2	B.Y.	M	34	Caucasian
Participants #3	C.Z.	F	25	Caucasian

Theoretical Approach

The Lifestyle Performance Model is a framework that provides a format to holistically assess the meanings and roles of an individual's life (Velde & Fidler, 2002). The key construct of the Lifestyle Performance Model is a person's lifestyle. The subconstructs of lifestyle include societal contribution, self-care and self-maintenance, intrinsic gratification and reciprocal interpersonal relatedness. It is important to take into consideration how the environment can support or constrain each of the four subconstructs. When a person's daily living activity configuration is in harmony then a perception of high quality of life will follow. Quality of life is an integral aspect of the model, the single most important focus in living.

Data Collection

Three methods were used to gather data. Data was collected in the Cammack Building at a time and date convenient to the participant. Upon participant arrival the primary investigator and participant reviewed the consent form (see Appendix B). Once the consent form was signed, the two quantitative assessments were administered. The participants were asked to independently fill out Flanagan's Quality of Life Scale and the Occupational Behaviors Satisfaction Checklist. Once assessments were complete a semi structured interview was administered to each participant utilizing the Lifestyle Performance Model as a guide. Open ended interview questions were aimed at gathering information about how young adults enrolled in school with Asperger's Syndrome engage in occupations (see Appendix E). Interviews were recorded via digital recorder and transcribed verbatim. Clarification was needed from two individual interviews. IRB protocol allowed follow up elicited through email from the two participants.

Data Analysis

In a convergent parallel mixed methods design, qualitative and quantitative data are collected in parallel, analyzed separately, and then merged (Creswell, 2009). The quantitative data was analyzed to generate basic descriptive statistics in order to summarize the data. Colaizzi's (1978) phenomenological method was utilized during analysis of participant's transcripts. Typed transcripts were read several times to gain an overall feeling for them. From each of the transcripts significant phrases related directly to the topic of occupational engagement of students with Asperger's Syndrome were identified. Meanings were then formulated from significant statements from the transcribed interviews. Next, formulated meanings were clustered to allow for the

emergence of themes common to all of the participants transcripts. Results from the quantitative and qualitative data were then merged and analyzed. Results were then analyzed in conjunction with the Lifestyle Performance Model to allow the researcher to gain a better understanding of how disability or context affects a person's ability to complete desired occupations across the four subconstructs the Lifestyle Performance Model.

Trustworthiness

According to Creswell (2007), "The naturalistic researcher looks for confirmability rather than objectivity in establishing the value of the data" (p. 204). Therefore, to demonstrate truth value in qualitative research the researcher must use multiple strategies or techniques to ensure validity. Triangulation of the data was established through use of multiple data sets including a quality of life assessment, occupational checklist, and the transcribed interviews for each of the three participants.. An audit trail was established in the form of a journal depicting the schedule and thoughts regarding thesis production which was referred to throughout the research process in order to assure the researcher set aside her own biases and assumptions when interpreting results. All email communication between researcher, her advisor, and participants was saved.

Furthermore, throughout progression of the study the researcher regularly met with her research advisor. Peer debriefing was utilized during these meetings and progression of codes, categories and themes was discussed to get a second opinion in order to increase the validity of the research findings. Once themes were established the

researcher then compared results with subconstructs of Lifestyle Performance Model to elicit another data set further strengthening the data through triangulation.

CHAPTER IV

Results

This study used a convergent parallel mixed methods design. In a convergent parallel mixed methods design, quantitative and qualitative data are collected in parallel, analyzed separately, and then merged (Creswell, 2009). Quantitatively, assessment data was gathered using Flanagan's Quality of life Scale (Flanagan 1978, Burckhardt, Woods, Schultz, & Ziebarth 1989) (see Appendix D) and the Occupational Behaviors Satisfaction Checklist (OBSC) (Wittman & Vaught, 2010) (see Appendix C). The OBSC was developed in 2010 as a means to quantitatively measure occupational choices. The Quality of Life Scale, created by John Flanagan in the 1970s has shown to be a reliable and valid instrument in assessing the quality of life from the perspective of the client across diverse patient groups (Burckhardt & Anderson, 2003; Burckhardt, Anderson, Archenholtz, & Hagg, 2003). Qualitatively, a phenomenological approach was taken utilizing the Lifestyle Performance Model as a guide to administer semi-structured interviews (see Appendix B) in order to determine occupational engagement experiences of the young adult population with Asperger's Syndrome enrolled in school. All three data sets will be used to fulfill the convergent parallel mixed methods approach.

The overall objective of the research was to determine the occupational engagement of students with Asperger's Syndrome and their perceived quality of life thus answering the two grand questions; (a) How do young adults enrolled in school with Asperger's Syndrome engage in occupations?; and (b) How do young adults enrolled in school with Asperger's Syndrome perceive their quality of life? Methods to answer question 'a' were both quantitative and qualitative in nature and included the

Occupational Behaviors Satisfaction Checklist and results from the semi-structured interview (Wittman & Vaught, 2010). In order to answer question ‘b’ quantitative data was collected utilizing the Flanagan Quality of Life Scale.

Qualitative analysis was conducted through using Colaizzi’s (1978) phenomenological method. Typed transcripts were read several times to gain an overall feeling for them. From each of the transcripts significant phrases related directly to the topic of occupational engagement of students with Asperger’s Syndrome were identified. Further analysis was done with the data obtained from the follow up interviews via email. Meanings were then formulated from significant statements from the transcribed interviews. Next, formulated meanings were clustered to allow for the emergence of themes common to all of the participants transcripts. A total of 20 meanings were derived from significant statements from the interview. Examples include; success with light meal preparation, established morning routine for care of self, unsuccessful attempts at conflict resolution, and distant relationships with family members. From these clustered meanings three themes emerged; (a) I wish it were different, (b) reliance on selected others, and (c) sticking to the routine. Themes are in order that they emerged during data analysis. They are listed alphabetically since no one theme is more significant than the other.

Identified Themes

I Wish it Were Different

There were several areas within the participants lives in which they wished things were different. When asked if there were any areas B.Y. would like to change in his life he stated, “I wish I could have people over more often, I mean just have more people

involved in my daily life.” When asked about why he has a problem with this he stated, “I like to reach out to people. Sometimes it’s a little hard for me to read if they are reaching back like the way I am.” C.Z. stated, “I wish I could be more social.” When asked about her participation in CRU a Christian group on campus she stated, “I’m probably more of an observer in CRU. I’m trying to become more of an active participant.” She also felt that when socializing with others that most people were not patient enough with her. When asked about maintaining friendships A.X. stated, “It’s harder because I am not a social person in so many words. Like, when I think to do something I don’t think um let’s go do things with people.”

Attaining and sustaining employment was a problem area for the participants. B.Y. identified several instances in which conflict arose in the work place but felt he could not say anything about it. He stated, “You don’t want to say anything, you don’t want to complain because if you have a job you want to keep the job even if you hate the job.” He said, “So I just basically had to put up with all the slings and arrows.” At C.Z.’s volunteer job at the hospital when she has people complain she is not sure how to deal with it and will just apologize about it until her supervisor comes. She has expressed frustration in not being able to get a job and said, “I also have trouble with interviews, I have trouble thinking and talking at the same time and thinking of answers in a short amount of time.” A.X. mentioned that she has, “always done well in terms with the work itself but it has always been the social aspect that got me fired.” She also talked about how she doesn’t see the point in looking for a job anymore, she said, “I mean I don’t see the point in trying to fight to get a job and spend five times longer looking as anyone else and then to just be fired most likely within a month.”

The participants expressed a desire for certain relationships or interactions with people to be different. While B.Y. did have someone he considered to be his best friend he stated that she is, “Someone I talk to when I can, she is in Idaho, with her husband and two kids not so we are not always as communicative as I’d like.” C.Z. stated, “I have some acquaintances but no one I am really close to.” She also stated that relationships she does have with others, “Are not the best, it’s hard for me to be open with people.”

Dating is a particular problem area for B.Y. he stated, “I would like to date other people, I would like to do that very much. It’s just sometimes a little hard for me to establish a connection with a person that could even lead to dating.” C.Z. said that her dating relationships don’t last very long. When asked why she said, “Probably because I am not open. I am not exactly sure but it’s probably because I don’t talk enough or open with them.” A.X. expressed concerns over past relationships now before even considering dating anyone she said, “I have to learn he is trustworthy first.”

The participants also expressed that they had distant relationships with family members. When asked about her relationship with her parents A.X. stated, “Um, its good considering how I grew up, it’s not awesome by any stretch of the imagination, but it’s good enough.” She also rarely sees her brothers she stated, “I call them on their birthdays and not too much more, I see them when I go up there but that is not very often.” B.Y. and C.Z. also had distant relationships with their siblings. C.Z. stated, “I used to be very close to my brother. My brother seemed to have changed his personality sometime when he was in high school.” B.Y. talked about his sister and expressed, “I wish it was better,” in referring to his relationship with her. He stated, “I don’t talk to her very much. I will

leave her voicemails on her cell phone and I never here back. I want there to be something a little more concrete because I worry about her.”

A.D and M.S both also had distant relationships with one or both of their parents. C.Z. is still attempting to try to engage in activities with her parents she said, “I try to get them to play family games. I try to encourage them to play at least once a month as a family because we don’t do much as a family. Usually my mom is on the computer and my dad is watching TV.” When asked about how she would describe her relationships with them she said, “We are not that close anymore. They seem to be more critical of me now and I don’t share things with them.” In referring to his mother B.Y. stated that, “I appreciate that she takes care of me in terms of the financial things and things like that, but I think it should also come with a little bit more degree of independence.” B.Y. also referred to his father, “I have not spoken to my father at all since about 1997. I thought about it a little bit.”

Concerning the realm of physical fitness and health the participants expressed the desire to change some habits. A.X. spoke about physical therapy exercises she has been prescribed she stated, “I am supposed to do them everyday it hasn’t happened recently but hopefully it will start back up again.” She would also, “Love to have more endurance when it comes to exercise.” When it comes to exercise C.Z. also expressed a similar desire she stated, “I get worn out easily and rather sit than do exercise. I usually have the motivation but not the energy to make myself exercise.” When asked about exercising B.Y. stated, “I would like to do it more but the other problem is whatever exercise I do is going to affect my blood sugar.”

Reliance on Selected Others

There were several areas of their life where the participants relied on others. One of the areas was financial management. The participants were dependent on outside sources in order to get their bills paid. In order to purchase the groceries to make meals the participants were relying on outside financial sources. B.Y. lives by himself in a house that his mother pays for. His mother gives him, “A set budget of about three hundred dollars for groceries per month.” A.X. relies on food stamps to get her groceries. C.Z.’s parents will give her a list and money to go grocery shopping. Besides groceries participants were also relying on an outside source for the roof over their head as well as other expenses. A.X. stated she pays for her rent and utilities with “disability money,” she also stated, “My medical expenses are paid for by Medicare and Medicaid.” B.Y. stated, “I don’t have to worry about the finances too much because my mom covers most of it, groceries, the utilities, stuff like that. She still supports me while I am working my way through college as long as I keep going to my classes she’ll pay the bills.” When asked about purchasing items she wanted C.Z. stated, “If it was something I thought was important I would use my credit card.” She then explained her dad would help her pay it off if she had no birthday or Christmas money.

Throughout their college careers the participants relied on academic advisors, professors, or their accommodations from the ADA in order to get them through the school year. A.X. identified her accommodations as, “Time and a half, and clarity with feedback, along with a fragrance free policy.” C.Z. identified her accommodations as, “Mostly just getting extra time on tests, uhm once I had a note taker and, and make sure that I am meeting with professors for concerns and stuff.” B.Y. had not used

accommodations but stated, “So far I haven’t had any challenges I know I am kind or sort of on file with them.” All three participants identified a specific person that had supported them throughout their educational endeavors. When A.X. was asked what was helpful about professors that supported her she said, “Well they were willing to listen and give me constructive feedback and um essentially were on my side.”

As a means for social outlet the participants relied on groups they were involved in order to be able to interact with others and work on social skills. A.X. stated, “I rarely do unscheduled stuff with them it is more you know regular scheduled things where I interact with people. That is probably the reason why I am so involved with church and do so many church activities because I know that if I didn’t do those I would not see those people because that is just the way I am.” In referring to her CRU meetings C.Z. stated the following, “I’m trying to make it a goal to contribute in bible study, say prayers out loud in prayer team. Trying to be more social at functions.”

Sticking to the Routine

The participants all recognized and spoke to completion of a daily routine to maintain adequate hygiene. A.X. feels her grooming is, “Adequate to maintain health” but realized, “I know I have to do the grooming thing more often.” B.Y. stated, I usually shower two to three times a week usually once a day or every other day or so. I want to get back to doing that more.” When asked about their morning routine responses were not extensive. A.X. made the following statement about what is included in her routine, “I wake up and put in some anti allergy eye drops and I go get some food, assuming that takes ten minutes then I go and wash my hands and put in my contacts, and then I just do whatever.” When asked about what is included in her routine C.Z. said, “Take a shower,

and get dressed, then eat breakfast. I usually brush my teeth after I eat.” However, B.Y.’s routine was more extensive due to his diabetes.

The participants did mention dressing as part of their routine, but felt they had a different style in terms of dressing than other people. A.X. stated, “I am anti-fashion. I could care less.” C.Z. stated, “I don’t consider much about what I wear.” She also thinks that people dress more nicely than she does. B.Y. felt that his clothing, “tends to be more neutral than everybody else.”

Cooking was not something that was part of the daily routine as two of the participants mentioned they cooked about once a week and the other prepared sandwiches or prepackaged foods instead of a meal. C.Z. stated that, “I try to cook once a week for my family.” A.X. also cooks, “Once a week at most.” She stated, “I essentially have like pre packaged stuff but stuff that is easy to cook.” Consumption of meals and a regimented diet is part of a routine for B.Y. who said, “I have the same thing I had for breakfast everyday. Two waffles and two pieces of bacon. Lunch always varies a little but it’s usually a sandwich with a bag of chips and water. Dinner is usually consistently the same thing again because of the dietary things.”

As for maintaining the household in which they live the participants tried to keep things clean but only a few chores were completed on a regular basis. C.Z. does laundry on a regular basis but when asked about other chores she stated, “keep my room clean, not too much.” As for A.X. she takes care of emptying the trash and doing dishes once a week. She said, “Every once in a while I’ll clean and it looks like God helped me to put it simply. When I do it right which is about the only I do it.” She mentioned that this only happens about four times per year. A.X. stated. In talking about his housekeeping

routines B.Y. stated, “I am better at it when it is cleaned up initially. I take care of what I need to do in terms of the laundry and the other general housekeeping things as much as I need to. As long as I think it’s organized I am ok with it.”

The participants also mentioned consistency in their routines. C.Z. stated, “It stays pretty consistent.” B.Y. stated, “As long as I can keep things consistent that keeps me pretty happy.” He also stated later in the interview, “As long as I’m in my routine and I know what to do and I have the time to do it I’m fine.” The participants also spoke to how school impacts their routine. B.Y. talked about how over the summer his sleeping habits varied, he stated, “I blame summer because I have more freedom of my time. I am sure during the fall I will be back to my regular routines again.” A.X. also spoke about school interfering with the pursuit of her interests, she stated, “School work takes up more of my time and some of it isn’t exactly enjoyable.” C.Z. talked about how her home environment can distract her from completing her schoolwork she stated, “I try to stay on campus as long as possible to work on homework because I can’t really do it at home.

Although the participants did not explicitly state their routines involved their areas of special interest two of the participants were able to put an amount of time as to how much they spent in these areas each day. C.Z. stated, “I like reading a lot, listening to music, playing the piano.” These activities would typically take up to three to four hours of her day. A.X. also said she likes, “Reading, watching TV, and going to church.” When asked about online gaming she said, “Oh yeah that is fun too believe me, I guess that is sort of a given that I don’t mention.” She spent more time dedicated to her interests anywhere from 5 to 11 hours per day. B.Y. also stated that he, “Liked playing games either board or computer.” He talked about how his free time also went to books, movies,

games, and spending time on the internet especially playing World of War Craft, and collecting.

The Occupational Behaviors Satisfaction Checklist

To further determine the occupational engagement of students with Asperger's Syndrome the Occupational Behaviors Satisfaction Checklist was utilized as a method of data collection. The OBSC was developed in 2010 to help develop a way to quantitatively measure occupational choices (Wittman & Vaught, 2010). The OBSC lists a total of 28 activity choices. Participants are then asked if they like to do the activity, how often they do the activity, and how satisfied they are with doing the activity. At least 2 of the 3 participants marked that they liked doing 16 out of the total of 28 activities either individually or with others.

In regards to how often participants completed activities there were four identified activities that all three participants engaged in, in at least once per week which were; internet, (Facebook, etc.) music, (singing, listening, playing, etc.) reading, and watching television. Participants also identified these activities as liking to do them by themselves or with others. There were two activities that all the participants marked as liking to do with others which were board games and card games and community outings. These two activities were completed less often either at least once a month or once per year.

There were four more activities that all three participants engaged in at least once a week or once a month which were; cooking, shopping, playing video/computer games, and attending religious activities. One may also want to note the activities that the participants marked as never doing. There were a total of five of these activities which were; horseback riding, martial arts, model cars, sewing, and water sports.

Participants were asked to mark their satisfaction level with the activities with how satisfied they were at the time including the activities they may not participate in. Regarding the four activities all three participants identified as participating in at least one time per week 2 of the 3 participants were satisfied, mostly pleased, or delighted with three of the four activities. Television was the exclusion with one participant having mixed levels of satisfaction with that particular activity. For the activities the participants marked as never doing there were mixed levels of satisfaction. For example with the activity of golf responses selected were satisfied, mixed, and terrible. This range of satisfaction was evident in the other four activities the participants marked as never participating in (horseback riding, martial arts, sewing, model cars, and water sports).

Flanagan's Quality of Life Scale

As mentioned earlier, the Flanagan Quality of Life Scale was utilized in order to collect data regarding the participant's perceived quality of life (Flanagan 1978, Burckhardt, Woods, Schultz, & Ziebarth 1989). The Quality of Life Scale, created by John Flanagan in the 1970s has shown to be a reliable and valid instrument in assessing the quality of life from the perspective of the client across diverse patient groups (Burckhardt & Anderson, 2003; Burckhardt, Anderson, Archenholtz, & Hagg, 2003).

All three of the participants completed the survey. In the QOLS survey participants are asked to rate each item and circle the corresponding number which describes how satisfied she or he is at the time taking the survey. Items are ranked one through seven, with seven being delighted and one being terrible. The mean total score of the three participants was 76.3 out of a total possible score of 112. The median score was

73 and the range 72-84. Table 2 identifies the participant's individual and mean scores per item for the QOLS.

Table 2. Individual and Mean Scores by QOLS Item

ITEM NUMBER (BRIEF DESCRIPTION)	Participant 1	Participant 2	Participant 3	Mean Score
1. Material Comforts home, food, conveniences	4	5	6	5
2. Health-being physically fit	3	4	3	3.3
3. Relationships with parents, siblings	4	5	1	3.3
4. Having and rearing children	6	5	4	5
5. Close relationship with spouse or significant other	3	5	5	4.3
6. Close friends	5	5	5	5
7. Helping and encouraging others, giving advice, volunteering	6	6	6	6
8. Participation in organizations and public affairs	5	5	5	5
9. Learning-attending school	5	6	7	6
10. Understanding yourself-knowing your assets and limitations	6	5	5	5.3
11. Work-job or home	1	5	5	3.7
12. Expressing yourself creatively	4	6	2	4
13. Socializing-meeting other people, doing things	4	5	2	3.7
14. Reading, listening to music, observing entertainment	6	7	7	6.7
15. Participating in active recreation	4	5	4	4.3

Table 2 (Continued)

ITEM NUMBER (BRIEF DESCRIPTION)	Participant 1	Participant 2	Participant 3	Mean Score
16. Independence, doing for yourself	7	5	5	5.7

Sources: Burckhardt, C. S., Woods, S.L, Schultz, A. A., Ziebarth, D. M. (1989). Quality of life of adults with chronic illness: A psychometric study. *Research in Nursing Health, 12*, 347-354.

Flanagan, J. C., (1978). A research approach to improving our quality of life. *American Psychologist, 33*, 138-147.

The two lowest mean scores per item were health, being physically fit and vigorous and relationships with parents, siblings, and other relatives. Both of these items were in between a mean of 3 (indicating mostly dissatisfied) and 4 (mixed feelings of satisfaction and dissatisfaction). There were also two other items in between a mean of 3 and 4; work and socializing. The highest mean scores per item were reading, listening to music, or observing entertainment with a score of 6.67. The next two highest mean scores with a score of 6 were learning which includes school and helping and encouraging others which includes volunteering.

Resulting Relationship with Lifestyle Performance Model

In order to further triangulate the data, results from the semi-structured interview, OBSC, and QOLS were then analyzed in combination with the Lifestyle Performance Model to allow the researcher to gain a better understanding of how disability or context

affects a person's ability to complete desired occupations across the four subconstructs the Lifestyle Performance Model. The subconstructs of lifestyle include societal contribution, self-care and self-maintenance, intrinsic gratification and reciprocal interpersonal relatedness. It is important to take into consideration how the environment can support or constrain each of the four subconstructs. In this section results will be presented within the four domains of the Lifestyle Performance Model. Domains are presented in no particular order, thus no one domain is more important than the next.

Societal Contribution

Societal contribution can encompass occupations of paid work, volunteerism, education, or other areas in which a service may be provided to another. Velde and Fidler, define societal contribution as "Activities contributing to the need fulfillment and welfare of others" (p. 35, 2002). As the interview took place over the summer months the participants were either taking classes or enrolled to take classes in the fall. There were mixed experiences regarding volunteerism and employment. There are several QOLS scores that inform this domain. The activity of helping and encouraging others including volunteerism was a mean score of 6 indicating the participants are mostly pleased. In the area of learning and attending school the mean score was 5.3. Finally in the area of work the mean score was 3.7.

The participants identified barriers as well as supports to education and satisfactory levels of academic achievement. Identified supports to education included ADA accommodations and supportive teachers and or mentors. A.X. identified her accommodations as, "Time and a half, and clarity with feedback, along with a fragrance free policy." C.Z. also had used accommodations for extra time on tests, and meeting

with teachers for clarification. All three participants identified a specific person that had supported them throughout their educational endeavors. Furthermore, students reported achieving satisfactory levels of academic achievement. C.Z. stated that she, “Made straight A’s the past two semesters.” A.X. also reported having over a 3.9 GPA, and B.Y. reported that he was, “An A, B, sometimes C student.”

Barriers to education identified by the participants were conflicts with specific teachers. A.X. stated, “My first semester here was absolutely awful because my professor took every opportunity she could to put me down and embarrass me in front of others.” C.Z. spoke about a time when she had asked a teacher a question to clarify something she said, “He didn’t understand why I had the question, basically called me dumb.” She ended up withdrawing from the class. B.Y. also spoke about a conflict he had with a teacher and stated, “She never liked me after that.”

The participants spoke to having difficulty attaining and maintaining employment. C.Z. believes that the job interview may be a deterring factor to being hired for a job. She stated, “I also have trouble with interviews, I have trouble thinking and talking at the same time and thinking of answers in a short amount of time.” A.X. mentioned that she has, “always done well in terms with the work itself but it has always been the social aspect that got me fired.” She also talked about how she doesn’t see the point in looking for a job anymore, she said, “I mean I don’t see the point in trying to fight to get a job and spend five times longer looking as anyone else and then to just be fired most likely within a month.” While B.Y. did maintain a job for several years he was dissatisfied with the job and felt he was being pressured to leave. He said, “I picked up on a pattern of harassment that had been happening over the past year trying to slowly pressure me out.”

Conflicts also arose in the work place that were difficult for the participants to handle or which lead to their firing. A.X. described two instances were conflict with co-workers which led to her being fired. B.Y. also described conflict with management which eventually led to his firing. B.Y. stated “Conflict has always been tough for me, because when an argument starts, I usually feel very strongly that I am in the right otherwise there would be no disagreement. Getting me to back down is hard enough, but usually if I feel I cannot make headway, I'll either become obstinate and won't back down or, if I feel I must, I'll just surrender and let them win, just saying that they are right, I am wrong and I am done debating the issue.” C.Z. also has trouble with conflict resolution in her volunteer role, she said, “I have some people complain, and uhm about their situation just trying to..uh apologize about until my supervisor comes.” In regards to conflict resolution she said, “Trying to come up with solutions to conflicts is probably the hardest for me.”

All of the participants were engaged in volunteerism or giving back in some way. B.Y. felt that by responding to people on message boards by “being there for support of giving a message of support” that were having difficulties was his way of giving back. C.Z. and A.X.’s volunteer roles revolved around their participation in religious affiliated groups. C.Z. had also taken on other volunteer roles such as working in a library, for the red cross, and a local hospital.

Reciprocal Interpersonal Relatedness

Reciprocal interpersonal relatedness differs from societal contribution in that the interplay between two or more people determines the actions and outcomes of an activity. Velde and Fidler, define reciprocal interpersonal relatedness as, “Activities pursued in

order to develop and sustain relationships with others and that involve reciprocity” (p. 36, 2002). Occupations in this domain would typically include interactions with peers, family members, friends, and acquaintances. The mean score in the QOLS for relationships with parents and siblings was 3.3. A score of 3 represents mostly dissatisfied. The mean score for close relationship with spouse or significant other was a 4.3 indicating mixed feelings of satisfaction. However, the mean score for close friends was 5 indicating satisfaction.

The participants described difficulty in establishing close relationships with family members and peers. Relationships with siblings were described as distant. Concerning relationships with his older sister B.Y. stated “I wish it was better. I don’t talk to her very much. I will leave her voicemails on her cell phone and I never hear back.” A.X. also rarely speaks to her siblings, she stated, “I call them on their birthdays and not too much more, I see them when I go up there but that is not very often.” C.Z. also speaks about having a distant relationship with her older brother she remarked, “We used to be very close when we were younger. Now it’s distant I guess. It’s probably since he was in high school and he is 22 now.”

A similar pattern was seen concerning the participants relationships with their parents. C.Z. remarked, “We don’t do much as a family.” In referring to the relationships with her parents she stated, “We are not that close anymore. They seem to be more critical of me now and I don’t share things with them.” B.Y. said, “I have not spoken to my father at all since about 1997. I thought about it a little bit.” A.X. stated, “I talk to my parents at times if you know I might bring up something that I want advice on, but not that often.” A.X.’s parents live many miles away this she does not see them that often, but when she does see them she says she can only handle them in “short bursts.”

Concerning maintaining relationships with friends the participants found it difficult, C.Z. did not have someone she considered to be a best friend and A.X. and A.D had a best friend figure but the friend lived states away and conversations were rare and over the phone or via email. When J.H was asked about maintaining friendships she answered, “Ones that are my age it is more difficult. Plus it is also I just hate stupidity. And most people are stupid when they are young.” A. D. made the following statement about the person he considered his best friend, “Is someone I talk to when I can, she is in Idaho, with her husband and two kids now so we are not always as communicative as I’d like.” C.Z. stated, “I have some acquaintances but no one I am really close to.”

Sustaining romantic relationships was also another area of difficulty for the participants. C.Z. was asked about her prior dating experiences, she responded that “It doesn’t last too long, the longest was a month. She wasn’t exactly sure why her relationships did not last but talked about “not being open” or talking enough as a problem. B.Y. stated that, “It’s just sometimes a little hard for me to establish a connection with a person that could even lead to dating.” J.H also reported relationships that did not last long.

Self-Care and Self-Maintenance

The self-care and self-maintenance domain comprises activities that a person does in order to care for his or her self and meet personal needs. This domain also encompasses functional activities of daily living such as food preparation, housekeeping, and financial management among other things. The mean score for material comforts including home, food, conveniences and financial security on the QOLS for the participants was 5 indicating satisfaction.

The participants all recognized completion of a daily routine to maintain adequate hygiene. A.X. feels her grooming is, “Adequate to maintain health” but realized, “I know I have to do the grooming thing more often.” B.Y. stated, I usually shower two to three times a week usually once a day or every other day or so. I want to get back to doing that more.” The participants also mentioned consistency in their routines. C.Z. stated, “It stays pretty consistent.” B.Y. stated, “As long as I can keep things consistent that keeps me pretty happy.”

The participants felt that they had a different style in terms of dressing than other people. A.X. stated, “I am anti-fashion. I could care less.” C.Z. stated, “I don’t consider much about what I wear.” She also thinks that people dress more nicely than she does. B.Y. felt that his clothing, “tends to be more neutral than everybody else.”

The participants had success with light to minimal meal preparation. C.Z. stated that, “I try to cook once a week for my family. I have an easier time cooking deserts or one dish dinners.” A.X. also cooks, “Once a week at most.” She stated, “I essentially have like pre packaged stuff but stuff that is easy to cook.” B.Y. considers his diet “pretty regimented” due to his diabetes. He said, “I have the same thing I had for breakfast everyday; Two waffles and two pieces of bacon. Lunch always varies a little but it’s usually a sandwich with a bag of chips and water. Dinner is usually consistently the same thing again because of the dietary things.”

In order to purchase the groceries to make the food the participants were relying on outside financial sources. B.Y.’s mother gives him, “A set budget of about three hundred dollars for groceries per month.” A.X. relies on food stamps to get her groceries. C.Z.’s parents will give her a list and money to go grocery shopping. Besides groceries

participants were also relying on an outside source for the roof over their head as well as other expenses. A.X. stated she pays for her rent and utilities with “disability money,” she also stated, “My medical expenses are paid for by Medicare and Medicaid.” B.Y. stated, “I don’t have to worry about the finances too much because my mom covers most of it, groceries, the utilities, stuff like that. She still supports me while I am working my way through college as long as I keep going to my classes she’ll pay the bills.” When asked about purchasing items she wanted C.Z. stated, “If it was something I thought was important I would use my credit card.” She then explained her dad would help her pay it off if she had no birthday or Christmas money.

As for maintaining the household in which they live the participants tried to keep things clean. A.X. stated, “My only rules are it can be a total mess but it can’t promote bugs and it can’t promote odors.” She mentioned that she only thoroughly cleans about four times per year. When speaking to what others may think about B.Y.’s housekeeping style he said, “My mom may consider it messy but I knew where everything was, strange as that may sound I refer to it as my order, my way of doing things.” C.Z. stated, “I try to keep things clean when I am motivated too.”

Intrinsic Gratification

The domain of intrinsic gratification includes the occupations that one does just for fun and enjoyment. Results from the Occupational Behaviors Satisfaction Checklist indicated that the participants liked and were satisfied with the occupations of reading, music, internet, and watching television. On the QOLS on the item concerning reading, listening to music, or observing entertainment on the participants had a mean score of 6.7

indicating satisfaction in this area. Results from the interviews further corroborated the quantitative data.

C.Z. stated, “I like reading a lot, listening to music, playing the piano.” These activities would typically take up to three to four hours of her day. A.X. also said she likes, “Reading, watching TV, and going to church.” When asked about online gaming she said, “Oh yeah that is fun too believe me, I guess that is sort of a given that I don’t mention.” She spent more time dedicated to her interests anywhere from 5 to 11 hours per day. B.Y. also stated that he, “Liked playing games either board or computer.” He talked about how his free time also went to books, movies, games, and spending time on the internet especially playing World of War Craft, and collecting.

The participants also had activities they did for fun with other people as part of a group that revolved around their interests. A.X. is participating in a bible study and C.Z. is involved in CRU a Christian group on campus. Although C.Z. is involved in CRU she said, “I am probably more of an observer in CRU. I am trying to become a more active participant.” B.Y. mentioned that he is going to try to go to Lexington once a week “to do a gaming night.”

Impact of the Environment

The environment can support or constrain each of the four domains of the Lifestyle Performance Model. Each of the participants had different living arrangements. J.H lived in an apartment by herself, C.Z. lived in a house with her parents, and B.Y. lived in a house by himself. C.Z. stated, “I live out toward the country and my free time activities are mostly at home.” A.X. had lived with roommates prior to living by herself but identified that it did not work out because her roommates were ‘psychotic.’

The participants spoke to the time of year, particularly when school was in session as having an impact on their occupational participation and routines. B.Y. talked about how over the summer his sleeping habits varied, he stated, “I blame summer because I have more freedom of my time. I am sure during the fall I will be back to my regular routines again.” A.X. also spoke about school interfering with the pursuit of her interests, she stated, “School work takes up more of my time and some of it isn’t exactly enjoyable.” C.Z. talked about her home environment can distract her from completing her schoolwork she stated, “I try to stay on campus as long as possible to work on homework because I can’t really do it at home.”

Alternative ways of interaction were sought out by the participants. All of the participants reported involvement in the virtual context. For example, all of the participants enjoyed participating in online activities including Facebook, online games, or message boards. One of the participants even felt a sense of reciprocal interpersonal relatedness when speaking to others on message boards. Specifically, B.Y. said, “Spending time on message boards and sometimes being there for support or giving a message of support could be volunteerism or maybe it’s just being nice, I don’t know.”

Conclusion

The four data sets described above answered the two grand questions; (a) How do young adults enrolled in school with Asperger’s Syndrome engage in occupations?; and (b) How do young adults enrolled in school with Asperger’s Syndrome perceive their quality of life? In the next chapter both quantitative and qualitative results will be discussed.

CHAPTER V

Discussion

The overall objective of the research was to determine the occupational engagement of students with Asperger's Syndrome and their perceived quality of life thus answering the two grand questions; (a) How do young adults enrolled in school with Asperger's Syndrome engage in occupations?; and (b) How do young adults enrolled in school with Asperger's Syndrome perceive their quality of life? Methods to answer question 'a' were both quantitative and qualitative in nature and included the Occupational Behaviors Satisfaction Checklist and results from the semi-structured interview.

Themes

The resulting themes that emerged from data analysis of the semi structured interviews were; (a) I wish it were different, (b) reliance on selected others, and (c) sticking to the routine. These themes will be discussed in order as they were presented in chapter four to answer the question how young adults enrolled in school with Asperger's Syndrome engage in occupation.

I Wish it Were Different

Results of this study suggested that there were several areas of the participants' lives in which they wished things were different. These areas included, employment, dating and socializing, relationships with family members and friends, and physical fitness. Employment seemed to be a central concern for the participants. At the time of the study none of the participants were employed. A study by Renty and Roeyers, (2006) found that out of the 58 participants with ASD only half were employed, with some of

the participants in a mainstream job while others were in sheltered or supported employment. Further research by Muller, Schuler, Burton, and Yates, (2003) also speaks to the concerns of those with ASD have in attaining and sustaining employment. These researchers completed interviews with 18 adults with ASDs about their work experiences. One of the emerging themes from the study was obstacles to successful employment which included, “mastering the job application process, acclimating to new job routines, communication, and navigating social interactions with supervisors and co-workers” (p. 167). Results from this study affirm the perceived difficulty in communication and social interaction theme also recognized in the Muller et al., study (2003). For example, B.Y. identified several instances in which conflict arose in the work place but felt he could not say anything about it. A.X. mentioned that she has, “always done well in terms with the work itself but it has always been the social aspect that got me fired.”

Wanting to be more social with others was a major concern for the participants of this study. Being able to effectively communicate and socialize with others may have an impact as to closeness and development of relationships that one has with others. Two of the participants had people they considered best friends but lived in other states and friendships were maintained through occasional phone calls or emails. C.Z. stated, “I have some acquaintances but no one I am really close to.” Difficulty with friendships is explored in research by Baron-Cohen and Wheelwright, (2003) who found that individuals with high-functioning autism as a group scored significantly lower on the Friendship Questionnaire compared with the control group from the general population. This research indicated that while individuals with high-functioning autism may have friends, “compared with people in the normal population, their relationships are less

close, less empathetic, less supportive, and less important to the individual” (p. 513). Furthermore, the authors found that the participants were less interested in people and less likely to enjoy interaction with others (Baron-Cohen & Wheelwright, 2003).

Physical fitness was another identified area that the participants wished was different. This will be discussed in the quality of life section as it was ranked as one of the lowest areas on the Flanagan Quality of Life Scale (Flanagan 1978, Burckhardt, Woods, Schultz, & Ziebarth, 1989).

Reliance on Selected Others

There were several areas of their life where the participants relied on others. Living arrangements varied with the participants of this study. However, all of the participants relied on outside sources in order to get their bills paid for their specific living arrangements. Research by Renty and Roeyers, (2006) found that more than three quarters of the 58 participants with high-functioning ASD out of Belgium were living with professional supports or with their parents. Participants in this study were also asked about perceived informal support. When asked about who they counted on for support it was identified that 77.5% counted on their mother, 43.1% their father, 68.9% their siblings, 75.9% their friends, 15.4% other family members, and 8.6% their partner.

One of the challenging areas identified with the participants was social participation. Therefore, it could be extremely difficult for a student with Asperger’s Syndrome to adapt to the social demands of college life. One of the ways the participants coped with the stressors of college was seeking out an individual or mentor to go to when they were confused or stressed. Other authors also recommend establishing a mentor or liaison or person to go to when stressed (Jekel & Loo, 2002). Furthermore, two of the

participants relied on classroom accommodations in order to meet the demands of their school work. Under the American with Disabilities Act (Public Law 110-335) institutions of higher education must provide classroom supports to those with disabilities which would include individuals with Asperger's Syndrome. However, these individuals must identify their disability and be able to negotiate their own accommodations (Stodden & Mruzek, 2010). Negotiating the institutional structures to seek necessary accommodations is a challenge for this population.

As a means for social outlet the participants relied on groups that they were involved with in order to be able to interact with others and work on social skills. J. H. revealed that if she was not involved in church groups she would not have opportunities to regularly interact with others. Harpur, Lawlor, and Fitzgerald, (2004) encourages those with AD to seek out clubs or societies in order to meet students outside of one's academic classes. The authors feel that campus clubs are suited to individuals with AD in that they are based on promoting understanding of one subject area and provide a venue for like minded people.

Sticking to the Routine

The participants frequently mentioned the idea of adhering to a consistent routine throughout their daily lives. This is not surprising as one of the diagnostic criteria for diagnosis is the need to adhere to a strict routine (Gillberg & Gillberg, 1989, Gillberg, 1991, APA, 2000). Hygiene, dressing, and cleaning, and cooking were all identified aspects of the participant's daily routines. However, some of the common activities of daily living were still neglected or impoverished in some of the participants.

Harpur, Lawlor, and Fitzgerald, (2004) discuss the domestic responsibilities that adolescents and adults must manage when attending college. Concerning hygiene they feel that many individuals with AD may not realize the impact that bad hygiene may have on their social lives. Two of the participants in this study had fallen out of the routine of showering daily. Harpur et al., warns that those falling out of their hygiene schedule over time, may be an indicator of depression (2004).

All or most of the areas of occupation, as defined by the AOTA Practice Framework, comprise these participants' daily routines (2008). However, it seems as though the participants struggle with instrumental activities of daily living (IADLs) that comprise their routines. Sensory sensitivities in this population may hinder or have an impact on successful completion of a daily routine.

Recent research has contributed literature about the sensory problems that individuals with the disorder may experience. Dunn, Miles, and Orr (2002), conducted a study to gain initial evidence about possible sensory processing patterns that may be present in children and youth with AD through utilization of the Sensory Profile and found that the children with AD scored lower (displaying the behavior) than that of their peers without disabilities. Difficulties were found with both hyporesponsiveness and hyperresponsiveness suggesting the children in this study has poor modulation, meaning their responses to stimuli may vary dramatically from one situation to the next.

IADLs such as home management, financial management, health management, meal preparation and cleanup, shopping, and care of others present a wide range of sensory experiences. Therefore, due to the hyporesponsiveness or hyperresponsiveness a young adult with Asperger's Syndrome may exhibit it has the potential to impede with

the development of a more established daily routine that one may expect a young adult to possess. Furthermore, these sensitivities could be restricting other areas of occupational exploration which could lead to higher levels of occupational competence. This may be why these individuals are finding themselves falling back into the same consistent, repetitive routine they find so calming and comforting.

It is also important to consider that although the participants were enrolled in college their ages did range from 25-34. Societal expectations and cultural norms in the United States would suggest that this is an age where individuals should have the skills necessary to successfully live independently. Although the participants performed IADLs they remained simple, perhaps not to the level of typically developing adults in this age range.

Occupational Behaviors

Administration of the Occupational Behaviors Satisfaction Checklist (Wittman & Vaught, 2010) was a quantitative measure to answer how young adults enrolled in school engage in occupation. In regards to how often participants completed activities there were four identified activities that all three participants engaged in, in at least once per week which were; Internet, (Facebook, etc.) music, (singing, listening, playing, etc.) reading, and watching television. These activities were similar to other studies examining the circumscribed interests of adolescents with Asperger's Syndrome. Results were most similar to the Jennes-Coussens, Magill-Evans and Koning, (2006) study which found that men with Asperger's Syndrome spent more time in leisure occupations such as watching TV and movies, playing video games, spending time on the internet, and reading than the control group. Mercier, Mottron, and Belleville, (2000) also explored restricted interests

within the adult population. Results yielded similar findings to this study in that the participants described interests that fell into three main categories which were collections, music, (listening or playing) and knowledge and activities pertaining to a very specific area.

Quality of Life

In order to answer question ‘b’ quantitative data was collected utilizing the Flanagan Quality of Life Scale. One of the lowest mean scores per item was health, being physically fit and vigorous. This result is similar to the findings of the Jeannes-Coussens et al., study (2006). The 12 participants with Asperger’s Syndrome also reported lower levels of satisfaction with physical health. Clumsiness and sensory hypersensitivities associated with the disorder could have an impact the individuals desire to participate in occupations which require physical activity thus having a resulting consequence on the individuals perceived level of physical fitness or health. Research by Borremans, Rintala, and McCubbin, (2010) found that “Adolescents with AS had lower levels of physical fitness in balance, coordination, flexibility, muscular strength, running speed, and cardio-respiratory endurance, and had higher levels of physical inactivity when compared to age matched peers” (p. 317).

Environment

According to Law, (2002) “Experience in a wide variety of settings is essential for the development of participation patterns and interactions with others encountered in daily life” (p. 644). With the limited occupational behaviors described by the participants, they may have limited participation experiences in a wide variety of settings. Therefore, coming into the specific sociocultural environment of a college campus, fitting in may be

difficult. Typical ways that college student's relieve stress would include spending time with friends and family including social activities. Due to the limitations in communication and socialization a student with Asperger's Syndrome may not have the same levels of social support or close circle of friends to turn to in difficult times. Furthermore, rigidity in routine can be hard to accommodate in a college environment. Especially, when for many college students the overall mentality is to "go with the flow."

As individuals with Asperger's Syndrome may not see themselves fitting in within the culture of the college campus they may look for alternative or safer means of social interaction. For example, all of the participants enjoyed participating in online activities including Facebook, online games, or message boards. Through participating in online activities the participants are still gaining social interaction just not face to face interaction. One of the participants even felt a sense of reciprocal interpersonal relatedness when speaking to others on message boards. However, these activities can still be socially isolating as the participants described doing these activities alone for extended periods of time. Furthermore, the activities are sedentary in nature, thus the individuals would not get the health benefits that more active occupations can provide.

Implications for Occupational Therapy

Children with Asperger's Syndrome are supported in the school systems under the Individual with Disabilities Education Act of 2004. Once this population reaches the age of post secondary education they can receive classroom accommodations through the American with Disabilities Act 1990. As young adults transition out of the school systems and into post secondary opportunities to socialize with other peers, gain or sustain employment, and engage within the community may seem out of reach for some

of these individuals as evidenced by the results of this research study. Furthermore, research by Law, Steinwender, and Leclair, (1998) indicates that there is a positive relationship with daily activity, social activity, and life satisfaction, establishing the relationship between occupation and life satisfaction. It was also found that removal of an occupation from daily routines can increase an individuals stress, cause physiological changes, and thus overall decrease an individuals overall health status and well being. With this population's limited occupational engagement and social repertoire, they could be put at risk to be socially isolated or marginalized, which could cause or add to existing psychological problems of stress, anxiety, and depression.

As occupational therapists we can foster occupational engagement for this population to support healthy and productive lives through community engagement. Establishment of community based centers for this population is ideal. Crabtree (2011) in affiliation with Towson University in Maryland established a Center for Adults with Autism. This center provides young adults on the spectrum an opportunity to be able to interact with their peers within the college campus. The program is self sustaining due to student volunteers and professionals on campus who plan age appropriate activities for the group in order to promote social and community integration within this population.

Results from this research could frame activities that could be utilized within community based centers. Activities could include; working on improving levels of physical fitness, strategies for successful employment, vocational exploration or volunteer experience, establishing independent behaviors, social skills, and establishing healthy relationships with friends and family, and leisure exploration among other areas. Garcia-Villamisar and Dattilo, (2010) studied the effect of a 12 month long leisure

programs on 37 adults with an ASD. Findings from the study indicated that participation in recreational activities can have a positive impact on stress and quality of life of adults with an ASD. Utilization of these activities within a community based center would provide an outlet for this population to experience occupational engagement outside of their restricted interest area in a familiar and safe environment. Through the power of occupation outcomes of life satisfaction and a sense of competence essential for psychological, social, and emotional well being would result (Law, 2002).

Other students within this population may want to explore options of post secondary education. Occupational therapists have a defined role in the school systems with adolescents with Asperger's Syndrome who have an Individualized Education Program. However, more of these young adults are pursuing post secondary education, yet still need some level of support within the university system in order to be successful. As these students are being admitted to universities it is important to consider resulting implications and ways universities can support this population. Therefore, occupational therapists could take on an emerging role in post secondary education providing consultation to administrators or the office of students with disabilities in the university setting on ways to support this population in their academic endeavors.

Beyond college there is a demand to meet the vocational support needs of individuals with ASD. Muller, Schuler, Burton, and Yates, (2003) interviewed 18 individuals with ASD about their experiences in the work place. The researchers found that there was a need for vocational rehabilitation counselors to provide individualized supports and found the recipients of vocational rehabilitation services were overall

dissatisfied. Therefore, this population may need more extensive support in employment that vocational rehabilitation services may not be able to provide.

Occupational therapists could provide intervention to those under supported employment services. OT's have advanced skill in activity analysis and can recognize deficits or impairments which may impede occupational performance in the work environments. OT's could help those with ASD with the job search process including the follow up process, provide extra job training assistance, negotiate social interactions with fellow employees, or even provide education on ASD to the individuals within the place of employment.

Implications for Future Research

Two quantitative assessment tools were utilized in this research, the Flanagan Quality of Life Scale (Flanagan 1978, Burckhardt, Woods, Schultz, & Ziebarth 1989) and the Occupational Behaviors Satisfaction Checklist (Wittman & Vaught, 2010). Now that data has been obtained through these two quantitative assessments on young adults with Asperger's Syndrome in college it would be beneficial to begin data collection on neurotypical young adults in college in order to compare the two populations. This should be done in order to determine if young adults with Asperger's Syndrome in college have quantitative difference in occupational choices and quality of life compared with neurotypical young adults in college.

Furthermore, there is a need for those with high-functioning autism and Asperger's Syndrome to contribute to research which pertains to them. However due to social and communicative impairments such contributions may be limited. Both the DSM-IV-TR and Gillberg's diagnostic criteria agree that there is a marked social

impairment in an individual with Asperger's Syndrome. The social impairment can vary and range in degree and intensity (Gillberg & Gillberg, 1989, Gillberg, 1991, APA, 2000). The area of socialization was one of the aspects of the participant's lives that they wished was different. Socialization was also one of the lower ranked items on the Flanagan Quality of Life Scale at a 3.7 (Flanagan 1978, Burckhardt, Woods, Schultz, & Ziebarth 1989). Therefore, researchers are well aware there will be barriers in trying to facilitate person to person interviews with this population. Eliciting qualitative data that is rich in description can be very difficult to attain.

As researchers examining this population perhaps it is time to evaluate other means of data collection. Based on experience from this study, utilizing email as a method to follow up with the participants, this researcher found that responses via email had more focused and clear answers than answers to interview questions in the face to face interviews. This could be due to the potential of the internet having the ability to break down barriers of anxiety or uncertainty this population may have participating in a face to face interview. In utilizing the internet as a means of data collection more participants could be reached. In this study the researcher was able to interview three young adults, two females and one male. Perhaps through email facilitated interviews this researcher could have reached more participants to include in the study. Furthermore, as the ratio of males to females in Asperger's Syndrome is believed to be generally higher than in autism (Gillberg & Gillberg, 1989) future research in this subject matter should include more males.

Benford and Standen, (2011) explored the potential of using computer-mediated communication for individuals at the higher functioning end of the autism spectrum. The

researchers found that through utilizing email technology as a means of interviewing this population they were able to obtain rich data pertaining to the research question. They feel that email facilitated interviewing may help break down some of the social and communication barriers that those with Asperger's Disorder or high-functioning autism may have.

Email facilitated interviews have also been used with other populations. Ison, (2009) was able to successfully utilize this method in order to explore the experiences of individuals 18-25 with cerebral palsy who had verbal communication impairments. Egan, Chenoweth, and McAuliffe, (2006) were also successful in utilizing email facilitated interviews with traumatic brain injury survivors. Offering this type of interview as opposed to the traditional interview could potentially increase the opportunities for participant involvement across a variety of conditions that may have verbal impairments. This would allow researchers to include more participants thus increase the overall quality of their research data. However, this is still a new trend evolving in the research field. Thus one that wants to conduct this type of research should consider both the benefits and drawbacks of using computer mediated communication.

Conclusion

This study provides insight into the occupational behaviors of young adults in college with Asperger's Syndrome. In finding out more about the patterns of occupational engagement clinicians or other professionals could utilize that information and use the power of occupation in order to enhance health and well being and improve quality of life for these individuals within a college setting. Research by Law, Steinwender, and Leclair, (1998) indicates that there is a positive relationship with daily

activity, social activity, and life satisfaction, establishing the relationship between occupation and life satisfaction. Therefore by providing the supports necessary in a college environment to this population, their overall quality of life and life satisfaction should be improved.

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APPENDIX A:
Verbal Recruitment Script

Hi (participant's name),

Laura Henley is seeking several volunteers who are clients of the ECU psychology clinic to interview for her masters thesis. She helped lead a Social Effectiveness Training Group that you participated in. This study is about occupational engagement among young adults in school with Asperger's Syndrome. Participation is completely voluntary. All the information you provide will be kept confidential. The face to face interview will be recorded and will take 45-90 minutes depending on your responses. The two assessments that she would like you to complete should take you no longer than 20 minutes. Please respond with your answer or any questions you may have.

Participant answer [yes] or [no]

[yes] If you are interested I would like to go ahead and set up a time and date that would be best for you to complete the assessments and interviews which will take place in the ECU Psychology Clinic on ECU's campus.

[no] Thank you for your consideration in this manner.

APPENDIX B:
Consent Form

Consent to Participate in a Research Study

EXAMINING THE OCCUPATIONAL ENGAGEMENT OF STUDENTS WITH ASPERGER'S SYNDROME: A MIXED METHODOLOGY

Why am I being asked to participate in this research?

You are being invited to take part in a research study about what activities you engage in throughout your day. You are being invited to participate in this research study because you are or have been a student at Eastern Kentucky University and have Asperger's Syndrome. If you take part in this study, you will be one of about 3-5 people to do so.

Who is doing the study?

The person in charge of this study is Laura Henley, an Occupational Therapy student at Eastern Kentucky University. She is being guided in this research by Peggy Wittman, Ed,D, OTR/L, FAOTA, Professor of Occupational Therapy and advisor. There may be other people on the research team assisting at different times during the study.

What is the purpose of the study?

By doing this study, we hope to learn more about the types of activities you engage in on a regular basis. We hope to learn what activities you do to take care of your self and your personal surroundings, what activities you do for fun and enjoyment, what activities you do to keep the relationships you have with other people, and what activities you do to help others. I also hope to learn about your level of satisfaction with these activities you participate in as well as how you perceive your quality of life.

Where is the study going to take place and how long will it last?

The research procedures will be conducted on Eastern Kentucky University's campus. You will need to come to campus 1 time during the study. This visit will take up to two hours. The semi-structured interview will take anywhere from 45 to 90 minutes and the two assessment forms should take you no longer than 20 minutes to fill out. If any clarification is needed from interviews or assessments, follow up will be elicited via email. The total amount of time you will be asked to volunteer for this study is the two hour visit to campus, plus anytime that may be needed for follow up which could occur over the next three months.

What will I be asked to do?

You will be asked to fill out two assessment forms. The first form you will be asked to fill out is a quality of life form. It lists 16 different activities or relationships and asks you to rank your satisfaction on a level from one to seven. Another form asks you to check off from a list which activities you participate in, how often you participate in them, and your

satisfaction in doing the activities. Finally, you will be asked to participate in an interview that will be digitally recorded and transcribed. The questions will ask you about what kinds of activities you like to do for fun, what activities you do to take care of yourself and your personal things, what activities you do to keep your friends, and what activities you do to help others.

Are there reasons why I should not take part in this study?

Since the study involves minimal risk to participants, there are no obvious reasons not to participate. Participation is voluntary and you can withdraw at any time without any penalty to you.

What are the possible risks and discomforts?

To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life. The information from the assessments and interview will be kept in a secure place by the researchers. Any presentations or publications resulting from the interview will not use names or any identifying characteristics.

Although we have made every effort to minimize this, you may find some questions we ask you (or some procedures we ask you to do) to be upsetting or stressful. If so, please contact the ECU Psychology Clinic to help you deal with these feelings. The Psychology Clinic is housed in the Cammack Building, Room 5, located on the corner of University Drive and Lancaster Avenue on the ECU campus. The phone number for the Psychology Clinic is (859) 622-2356.

Will I benefit from taking part in this study?

There is no guarantee that you will get any benefit from taking part in this study. However, some people may experience new understanding about the different kinds of activities you participate in throughout your daily life along with your level of satisfaction of those activities when filling out the assessment forms and answering interview questions. We cannot and do not guarantee that you will receive any benefits from this study.

Do I have to take part in this study?

If you decide to take part in the study, it should be because you really want to volunteer. You will not lose any benefits or rights you would normally have if you choose not to volunteer. You can stop at any time during the study and still keep the benefits and rights you had before volunteering.

If I don't take part in this study, are there other choices?

If you do not want to be in the study, there are no other choices except to not take part in the study.

What will it cost me to participate?

Participants will be responsible for transportation including fuel related expenses in order to be interviewed on Eastern Kentucky University's campus.

Will I receive any payment or rewards for taking part in the study?

You will not receive any payment or reward for taking part in this study.

Who will see the information I give?

Your information will be combined with information from other people taking part in the study. When we write up the study to share it with other researchers, we will write about this combined information. You will not be identified in these written materials.

We will make every effort to prevent anyone who is not on the research team from knowing that you gave us information, or what that information is. For example, your name will be kept separate from the information you give, and these two things will be stored in different places under lock and key.

However, there are some circumstances in which we may have to show your information to other people. For example, the law may require us to show your information to a court to tell authorities if we believe you are a danger to yourself or someone else. Also, we may be required to show information that identifies you to people who need to be sure we have done the research correctly; these would be people from such organizations as Eastern Kentucky University.

Can my taking part in the study end early?

If you decide to take part in the study, you still have the right to decide at any time that you no longer want to participate. You will not be treated differently if you decide to stop taking part in the study.

The individuals conducting the study may need to end your participation in the study. They may do this if you are not able to follow the directions they give you, if they find that your being in the study is more risk than benefit to you, or if the agency funding the study decides to stop the study early for a variety of scientific reasons.

What happens if I get hurt or sick during the study?

If you believe you are hurt or if you get sick because of something that is done during the study, you should call Laura Henley at 502-744-6302 immediately. It is important for you to understand that Eastern Kentucky University will not pay for the cost of any care or treatment that might be necessary because you get hurt or sick while taking part in this study. That cost will be your responsibility. Also, Eastern Kentucky University will not pay for any wages you may lose if you are harmed by this study.

Usually, medical costs that result from research-related harm cannot be included as regular medical costs. Therefore, the costs related to your care and treatment because of something that is done during the study will be your responsibility. You should ask your insurer if you have any questions about your insurer's willingness to pay under these circumstances.

What if I have questions?

Before you decide whether to accept this invitation to take part in the study, please ask any questions that might come to mind now. Later, if you have questions about the study, you can contact the investigator, Laura Henley at 502-744-6302 or Dr. Peggy Wittman at 859-622-6323. If you have any questions about your rights as a research volunteer, contact the staff in the Division of Sponsored Programs at Eastern Kentucky University at 859-622-3636. We will give you a copy of this consent form to take with you.

What else do I need to know?

You will be told if any new information is learned which may affect your condition or influence your willingness to continue taking part in this study.

I have thoroughly read this document, understand its contents, have been given an opportunity to have my questions answered, and agree to participate in this research project.

Signature of person agreeing to take part in the study

Date

Printed name of person taking part in the study

Name of person providing information to subject

APPENDIX C:
Occupational Behaviors Satisfaction Checklist
(OBSC)

¶ 1. Do you like to do this activity?

	Yes, by myself	Yes, with others	No	Not sure
Acting/drama	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Board games/card games	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Collecting things (stamps, dolls, cars, etc...)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cooking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dancing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fishing/hunting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Gardening/yardwork	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Golf	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Horseback riding	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Internet (Facebook, etc...)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Martial Arts	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Model cars	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Music (listening, singing, playing, etc...)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Painting/coloring/drawing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Photography	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Playing sports	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Doing puzzles (crossword, etc...)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Reading	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sewing/needlework	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Shopping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Swimming	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Playing video/computer games	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Volunteering	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Watching television	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Water sports (skiing, surfing, etc...)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Writing (poems, stories, journaling, etc...)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Attending religious activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Community outings (dining out, concerts, movies, etc...)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Occupational Behaviors Satisfaction Checklist, (OBSC) Wittman, P. & Vaught, E. 2010

*2. How often do you do this activity?

	At least once a week	At least once a month	At least once a year	Never
Acting/drama	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Board games/card games	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Collecting things (stamps, dolls, cars, etc...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cooking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dancing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fishing/hunting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gardening/yardwork	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Golf	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Horseback riding	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Internet (Facebook, etc...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Martial Arts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Model cars	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Music (listening, singing, playing, etc...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Painting/coloring/drawing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Photography	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Playing sports	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doing puzzles (crossword, etc...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Reading	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sewing/needlework	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Shopping	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Swimming	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Playing video/computer games	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Volunteering	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Watching television	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Water sports (skiing, surfing, etc...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Writing (poems, stories, journaling, etc...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Attending religious activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community outings (dining out, concerts, movies, etc...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* 1. How satisfied are you with your doing of this activity?

(Please read each item and circle the number that best describes how satisfied you are at this time. Please answer each item even if you do not currently participate in an activity or have a relationship. You can be satisfied or dissatisfied with not doing the activity or having the relationship.)

	Delighted	Mostly pleased	Satisfied	Mixed	Mostly dissatisfied	Unhappy	Terrible
Acting/drama	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Board games/card games	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Collecting things (stamps, dolls, cars, etc...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cooking	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Dancing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fishing/hunting	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gardening/yardwork	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Golf	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Horseback riding	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Internet (Facebook, etc...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Martial Arts	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Model cars	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Music (listening, singing, playing, etc...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Painting/coloring/drawing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Photography	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Playing sports	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Doing puzzles (crossword, etc...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Reading	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sewing/needlework	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Shopping	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Swimming	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Playing video/computer games	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Volunteering	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Watching television	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Water sports (skiing, surfing, etc...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Writing (poems, stories, journaling, etc...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Attending religious activities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community outings (dining out, concerts, ...)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

APPENDIX D:
Flanagan's Quality of Life Scale

QUALITY OF LIFE SCALE (QOLS)

Name: _____ **Age:** _____ **Date (mm/dd/yyyy):** _____

Please read each item and circle the number that best describes how satisfied you are at this time. Please answer each item even if you do not currently participate in an activity or have a relationship. You can be satisfied or dissatisfied with not doing the activity or having the relationship.

	Delighted	Mostly Pleased	Satisfied	Mixed	Mostly Dissatisfied	Unhappy	Terrible
1. Material comforts home, food, conveniences, financial security	7	6	5	4	3	2	1
2. Health – being physically fit and vigorous	7	6	5	4	3	2	1
3. Relationships with parents, siblings & other relatives – communicating, visiting, helping	7	6	5	4	3	2	1
4. Having and rearing children	7	6	5	4	3	2	1
5. Close relationships with spouse or significant other	7	6	5	4	3	2	1
6. Close friends	7	6	5	4	3	2	1
7. Helping and encouraging others, volunteering, giving advice	7	6	5	4	3	2	1
8. Participating in organizations and public affairs	7	6	5	4	3	2	1
9. Learning – attending school, improving understanding, obtaining additional knowledge	7	6	5	4	3	2	1
10. Understanding yourself – knowing your assets and limitations – knowing what life is about	7	6	5	4	3	2	1
11. Work – job or in home	7	6	5	4	3	2	1
12. Expressing yourself creatively	7	6	5	4	3	2	1
13. Socializing – meeting other people, doing things, parties, etc	7	6	5	4	3	2	1
14. Reading, listening to music, or observing entertainment	7	6	5	4	3	2	1
15. Participating in active recreation	7	6	5	4	3	2	1
16. Independence, doing for yourself	7	6	5	4	3	2	1

Sub-total (for internal use only)							
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Total score: _____

Quality of Life Scale (QOLS), Flanagan, J. (1978). Updated in 1989 by Burckhardt, C.

APPENDIX E:
Interviewing Protocol

Opening Instructions:

- 1.) Introduction
- 2.) Thank participant for coming
- 3.) Offer water/drink
- 4.) Inform participant about study
- 5.) Review the consent form
- 6.) Get the consent form signed
- 7.) Begin interview

This is a sample of questions that may be asked during the interview. Other probes may be used to elicit data.

- 1.) Please describe your daily routine upon waking up each morning.
- 2.) What do you find most enjoyable about these activities? Least enjoyable?
- 3.) Which areas of your daily life would you like to make changes, if any?
- 4.) Please tell me about your sleeping habits.
- 5.) To what extent do you engage in meal planning and preparation?
- 6.) Please describe how you manage your money.
- 7.) What do you do to regularly maintain your health?
- 8.) Please tell me about your post secondary educational experiences.
- 9.) Please describe any employment experiences you have had.
- 10.) Please tell me about your time management skills.
- 11.) Please describe the activities you engage in for pleasure and enjoyment?
- 12.) Please describe your relationships with your parents, siblings, other family members, and friends.
- 13.) Please tell me about the activities you engage in with others.

CLOSING

- 1.) Thank them for coming
- 2.) Give them a copy of my contact information should they have any questions at a later point
- 3.) Show them out