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Personal Meanings of Restricted and Repetitive Behaviors Among Midlife Adults with Asperger Syndrome

Leila Marie Shirley
Walden University

Walden University

College of Social and Behavioral Sciences

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Leila Marie Shirley

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Dr. Barbara Chappell, Committee Member, Psychology Faculty
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Abstract

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by

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MSEd, Old Dominion University, 1985

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Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Abstract

Restricted and repetitive behaviors (RRBs) are some of the hallmark features of autism spectrum disorder (ASD) symptomatology. There is a knowledge gap on RRBs in adults with ASD because most of the research has focused on children and adolescents. The few studies conducted on adults with ASD have included conflicting results and variable information, especially regarding the developmental trajectories of RRBs. Therefore, this study was designed to address the lived experiences of RRBs in midlife adults with Asperger syndrome. This study was guided by the conceptual frameworks of Dunn's model of sensory processing, the 2-factor model of RRBs, and phenomenological theory. A phenomenological approach was used to conduct semistructured interviews in which 15 adults with Asperger syndrome sampled worldwide described their experiences. Participants also wrote narrative accounts. The data were analyzed through interpretative phenomenological analysis. Eight basic themes emerged from the data analysis regarding the importance of RRBs to adults with Asperger syndrome: (a) anxiety, (b) calming effect, (c) intense focus, (d) routines and rituals, (e) sensory sensitivity, (f) misinterpretation by others, (g) physical stereotypies, and (h) special interests. Findings associated with these themes showed that RRBs are used by adults with Asperger syndrome as a coping mechanism for dealing with anxiety. Treatment should focus on the elimination of the anxiety rather than the RRBs, which are just a symptom of the anxiety. The implications for positive social change include the emergence of new knowledge to promote an improvement in diagnosis, treatment, advocacy, and supportive services, thereby decreasing inequalities that exist for adults with ASD.

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Dedication

This study is dedicated to the following persons who have had a profound effect on my development which I consider still a work in progress.

First and foremost, my mother, Cecilia S. Shirley, who from the very beginning strongly encouraged me to pursue academic excellence in spite of the numerous obstacles that I encountered with my own learning and development. If it were not for my mother's unconditional love for me and her steadfast faith in my abilities, I would not have reached this far in academia. She is my kindred spirit as she continues to motivate me to get this dissertation accomplished despite her having to deal with the overwhelming effects of aging and terminal illness. Her strength to continue to live despite her prognosis is a powerful testimony of what can be accomplished through faith, hope, and love. Her strong will to live is analogous to my own refusal to give up on finishing this dissertation.

Second, my former supervisor and mentor of 25 years, Cynthia E. Haggins, who worked with me on the job by allowing me to develop my various gifts and talents, as well as allowed me to focus on my special interests. She allowed me to be myself, and she challenged me on numerous occasions, giving me the equal opportunity to excel at many tasks. Most importantly, she accepted me regardless of my differences.

Third, this dissertation is dedicated to all persons who live on a daily basis with the varying symptoms of ASD.

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I would like to take this opportunity to thank several individuals who have supported me throughout this process. Without them, this dissertation would not have been possible. I would like to thank my mother, Cecilia S. Shirley, for her continuous encouragement for me to stay on this journey no matter what. I would like to thank my coworker and friend, S. Denise Grant, for putting up with me during the ups and downs of the dissertation process which I refer to as the academic roller coaster ride. I would like to thank all of those Facebook friends with their encouraging and insightful posts, including their responses to my adventurous dissertation updates. I would like to thank my Chair, Dr. Virginia Salzer, for taking on the role as Chair, as well as her ongoing encouragement, guidance, counseling, support, and feedback during the dissertation process. I would like to thank my Committee Member, Dr. Barbara Chappell, for her ongoing encouragement, guidance, and feedback during the dissertation process. I would like to thank Dr. Andrea Goldstein simply for being my University Research Reviewer. I would like to thank Susan Rueger, my editor, for the time and encouragement she gave me as we brought this dissertation to closure. Most of all, I would like to thank my Creator, the Almighty God, for making this opportunity possible by allowing me to have the intellectual prowess to accomplish such a feat.

Table of Contents

List of Tables

Chapter 1: Introduction to the Study

Introduction

Over the past 15 years, researchers have studied restricted and repetitive behaviors in persons with autism spectrum disorder (ASD) Leekham, Prior, & Uljarevic, 2011; Shuster, Perry, Bebko, & Toplak, 2014). Restricted and repetitive behaviors, also known as RRBs, constitute a core feature of ASD (Chowdhury, Benson, & Hillier, 2010; Leekham et al., 2011; Lehnhardt et al., 2013; Vannucchi et al., 2014). Research on RRBs in adults with ASD has been scarce (Lehnhardt et al., 2013), and unfortunately, the studies that were done have been inconclusive regarding causality, functionality, maintenance, trajectories, and treatment of RRBs in ASD (Harrop et al., 2014; Leekham et al., 2011). In addition, these studies were conducted predominantly with children and adolescents, highlighting the distinct knowledge gap about RRBs, especially for that of adults with ASD (Chowdhury et al., 2010; Lehnhardt et al., 2013; Lidstone et al., 2014). Researchers have recommended that further studies be conducted on persons with ASD in later developmental stages in order to determine whether or not RRBs change as the person gets older (Chowdhury et al., 2010; Coury et al., 2014).

In this study, I explored adults' experiences with RRBs in order to gain a better understanding of those experiences and the meanings they attach to them. I emphasized the importance of studying the subjective experiences of RRBs in adults with ASD in order to (a) lead to a greater societal awareness of one of the most profound, noticeable, and crippling symptoms of ASD; (b) provide more knowledge about the nature of these behaviors to promote an improvement in the quality of life for adults with ASD; and (c) provide more knowledge about these behaviors to develop more effective therapeutic intervention strategies for adults with ASD.

Background Information

From the first time researchers conceptualized autism as a disorder, restricted and repetitive behaviors, also known as RRBs, have been described as one of the hallmark features of its symptomatology, along with social skills deficits and communication difficulties (Asperger, 1944; Kanner, 1943). RRBs are a specific class of behaviors in which *restricted* refers to the insistence on sameness, resistance to change, and narrowness of interests, and *repetitive* refers to stereotypical mannerisms, compulsions, rituals, and routines (Bishop et al., 2013; Chowdhury et al., 2010; Leekham et al., 2011; Rice, 2014). While there are many different types of behaviors (with various origins and purposes), they all share the common characteristic of being restricted and repetitive. In addition, RRBs vary in their severity and occurrence among people with ASD (Bishop et al., 2013; Georgiades, Papageorgiou, & Anagnostou, 2010; Honey, Rodgers, & McConachie, 2012; Kargas, Lopez, Reddy, & Morris, 2014; Leekham et al., 2011).

Considered to be the most challenging aspect of ASD, RRBs can interfere with the completion of daily activities (Wigham et al., 2014), adaptation (Harrop et al., 2014; Leekham et al., 2011), socialization (Harrop et al., 2014; Kargas et al., 2014; Stratis & Lecavalier, 2013), skill development (Honey et al., 2012; Kargas et al., 2014; Rodgers, Glod, Connolly, & McConachie, 2012a), observational learning (Rodgers et al.,2012a; Stratis & Lecavalier, 2013), performance on discrimination tasks (Lam & Aman, 2007), and environmental exploration (Joosten, Bundy, & Einfield, 2009; Lam & Aman, 2007).

Moreover, RRBs are not only stigmatizing, but also contribute to the disabling symptomatology of ASD (Honey et al., 2012; Scahill et al., 2013). Furthermore, Honey et al. (2012) have emphasized that RRBs can cause much disruption in family functioning.

An Overview of the Research on RRBs and the Need for this Study

Although the most recent research on RRBs has included information regarding sensory differences, subtypes, and symptom trajectories, there is a knowledge gap pertaining to RRBs in adult life because the majority of the studies have focused on children and adolescents with ASDs (Boyd et al., 2010; Esbensen, Seltzer, Lam, & Bodfish, 2009; Harrop et al., 2014; Lehnhardt et al., 2013; Lidstone et al., 2014; Shuster et al., 2014). Further, the majority of researchers have used data provided from questionnaires, surveys, and diagnostic assessments completed mostly by parents, guardians, and teachers rather than those who were diagnosed with the disorder, possibly creating a response bias (Chowdhury et al., 2010; Esbensen et al., 2009; Rodgers et al., 2012a; Scahill et al., 2013; Shuster et al., 2014). As a result, incomplete knowledge exists about the manifestations of RRBs in the aging process and how they change over time (Chowdhury et al., 2010; Coury et al, 2014; Esbensen et al., 2009).

Problem Statement

While researchers have attempted to pinpoint causality, functionality, maintenance, and treatment of RRBs in adults with ASD, their findings have been inconclusive (Harrop et al., 2014; Mirenda et al., 2010; Shuster et al., 2014). Researchers have used either a 2-factor categorization of RRBs (Georgiades et al., 2010; Honey et al., 2012; Mooney et al., 2009), a 3-factor categorization of RRBs (Lam, Bodfish, & Piven, 2008), a 4-factor categorization of RRBs (Leekham et al., 2011), or a 5-factor categorization of RRBs (Bishop et al., 2013; Mirenda et al., 2010). Drawing on findings from the various studies, Chowdhury et al. (2010), Mirenda et al. (2009), and Shuster et al. (2014) have discussed a 6-factor categorization of RRBs that includes (a) stereotypies, (b) self-injurious behavior, (c) compulsions, (d) ritualistic behavior, (e) sameness behavior, and (f) restricted interests and activities. Although these important studies showed different subtypes of RRBs, researchers have failed to examine how these behaviors might change over time, and how they are expressed in adulthood. I designed my study to address this gap in the literature.

There is a distinct knowledge gap regarding RRBs in adult life since most studies on RRBs have focused mostly on children and adolescents with ASDs (Harrop et al., 2014; Lehnhardt et al., 2013; Lidstone et al., 2014; Shuster et al., 2014). Additionally, many such studies have depended on information provided from diagnostic assessments completed by parents and caretakers (Leekham et al., 2011; Mirenda et al., 2010; Scahill et al., 2013; Shuster et al., 2014). Consequently, research on RRBs across the lifespan in persons with ASD has been scarce (Chowdhury et al., 2010; Lehnhardt et al., 2013). Other researchers would benefit from knowledge about RRBs in persons with ASD in various developmental stages in order to help eliminate the bias related to parent and caretaker reports (Troyb et al., 2014). Furthermore, there has been conflicting evidence on the manifestation of RRBs in the aging process as to whether or not specific RRBs change with time (Chowdhury et al., 2010; Coury et al., 2014; Esbensen et al., 2009).

There has thus been a gap in the scholarly lifespan development literature pertaining to documentation of the role of RRBs in the midlife to latelife adult population diagnosed with ASD with regard to any further behavioral changes (improvement or deterioration) in RRBs (Chowdhury et al., 2010). In this study, I explored the meanings of the lived experiences of RRBs in adults with Asperger syndrome in order to provide more knowledge to the field of psychology regarding the function and maintenance of RRBs by analyzing first person accounts. In order to capture the essence of the lived experiences of RRBs in individuals with Asperger syndrome, I used a phenomenological research approach.

Purpose of the Study

The purpose of this qualitative study was to explore the personal meanings that midlife adults diagnosed with Asperger syndrome assign to their RRBs. I worked from the premise that such a study would contribute to scholarly and clinical understanding of RRBs in a population of adults who are underserved in receiving advocacy and services (Lehnhardt et al., 2013). More knowledge about RRBs in adults with Asperger syndrome may lead to the promotion of more intervention and supportive services. Furthermore, I built on the theoretical framework regarding perceptual and sensory processing differences of adults with Asperger syndrome by listening to their personal stories, and I contributed to an understanding of the specific needs of adults with Asperger syndrome.

I employed an empirical phenomenological model (Conklin, 2007; Moustakas, 1994) and explored the participants' lived experiences of RRBs. In-depth semistructured interviews with open-ended questions/dialogue and participant journal entries/narrative accounts were collected as original data composed of "naive" descriptions of the participants' lived experiences. I processed the data using interpretative phenomenological analysis (see Moustakas, 1994; Smith, Flowers, & Larkin, 2009). Specifically, I coded repeating and relevant ideas related to the research question and organized them into themes (Smith et al., 2009). From the themes, I developed a rich and thick description of the meanings and the essences of the participants' lived experiences with RRBs (Smith et al., 2009; Conklin, 2007; Moustakas, 1994).

Research Question

This study was guided by the overarching question, “What are the personal meanings that midlife adults with a diagnosis of Asperger syndrome assign to their restricted and repetitive behaviors (RRBs)?” More specifically, I used the semistructured interviews to make queried about areas concerning descriptions of the behaviors, the role that participants believed these behaviors served, the physical context in which these behaviors occurred, and the emotional context in which they happened.

Conceptual Framework and Theoretical Foundations

Dunn's Model of Sensory Processing

From the time when ASD was originally described by Kanner (1943) and Asperger (1944), researchers have noted that there are distinct sensory processing differences in ASD, including a variety of hypo-sensitivities and hyper-sensitivities, especially those of gustatory, tactile, and auditory stimuli (Bogdashina, 2013; Dunn, Saiter, & Rinner, 2002). Dunn theorized that RRBs are merely a reflection of sensory processing differences, including (a) an abnormal preoccupation with stereotypical and restricted patterns of interest, (b) an inflexible adherence to rituals and routines that are nonfunctional, (c) the engagement of repetitive and stereotypical motor behaviors, and (d) an intense preoccupation with parts of objects (Dunn et al., 2002). Dunn et al. (2002), as later emphasized by Hazen et al. (2014) and Bogdashina (2013), stressed that in ASD, sensory modulation differences manifest in four essential areas: sensory under-responsivity, sensation seeking, sensory over-responsivity, and sensation avoiding. With sensory under-responsivity, the individual with ASD does not react to anything, often seeming uninterested and not focused on what is going on around him or her (Dunn et al., 2002; Hazen et al., 2014). With sensation seeking, the individual with ASD searches for more stimulation, often engaging in behaviors continuously, including the demonstration of repetitive patterns of behavior (Dunn et al., 2002; Hazen et al., 2014). With sensory over-responsivity, the individual with ASD often has a heightened awareness of what is going on around him/her to the extent that there are numerous distractions contributing to behaviors that indicate over-stimulation (i.e. hyperactivity or perseverations; Dunn et al., 2002; Hazen et al., 2014; Tavassoli et al., 2014). With sensation avoiding, the individual with ASD is rule-bound, ritual-driven, and/or uncooperative, meaning that he/she is not willing to try any new activities or be in any new situations, and is only comfortable with what is familiar to him/her; therefore, behavior and interests are restricted (Dunn et al., 2002; Hazen et al., 2014). An individual with an ASD who is functioning under a sensation seeking processing pattern employs many types of repetitive behaviors due to under-stimulation, and an individual with an ASD who is functioning under a sensory over-reponsivity processing pattern often displays restricted interests and specific limited rituals during over-stimulation (Dunn et al., 2002; Hazen et al., 2014; Leekham et al., 2011). Dunn et al. (2002) explained that patterns of sensory processing are demonstrated to extremes in persons with ASD; it has been theorized in the literature that RRBs are merely used by people with ASD as a compensatory mechanism to assist with the regulation of the sensory nervous system, especially in dealing with sensory overload (Bogdashina, 2013; Kargas et al., 2014). Kargas et al. (2014), Lidstone et al. (2014), and Wigham et al. (2014) emphasized that RRBs are used in order to maintain homeostasis in the environment; therefore, RRBs help to increase sensory stimulation when under-aroused and help to decrease sensory stimulation when over-aroused. Bogdashina (2013) further theorized that all the core symptoms of ASD such as social skills impairments, communication difficulties, and repetitive behaviors originate because of various sensory modulation differences. In Chapter 2, I offer more detail on Dunn's model of sensory processing and discuss various studies that have demonstrated how sensory processing differences are associated with RRBs.

Two-Factor Model of RRBs

Factor analytic studies that examined RRBs in ASD emerged with a basic 2-factor model whenever it comes to describing RRBs (Bishop et al., 2006; Cuccaro et al., 2003; Georgiades et al., 2010; Mooney et al., 2009; Szatmari et al., 2006; Turner, 1999). Turner (1999) initially noted two primary factors that separate RRBs from each other. One factor is higher-order behaviors known as insistence on sameness (IS), and the other factor is lower-order behaviors known as repetitive motor behaviors (RMBs). IS behaviors involve compulsions, rituals, and difficulties with change (Turner, 1999);

RMBs involve hand, finger, and body mannerisms, the repetitive use of objects, and unusual sensory interests (Turner, 1999). Subsequent researchers (Bishop et al., 2006; Cuccaro et al., 2003; Georgiades et al., 2010; Mooney et al., 2009; Szatmari et al., 2006) have observed similar patterns regarding the 2-factor model of RRBs. Studies have shown that these two types of behavior may develop differently, and that RMBs and IS behaviors differ in their relationship to cognitive and adaptive functioning. IQ is more associated with RMBs (Bishop et al., 2006), and there is no relationship between IS behaviors and cognitive and adaptive functioning (Cuccaro et al., 2003; Szatmari et al., 2006). Researchers have also noted that over time, RMBs become more stabilized and IS behaviors may worsen (Cuccaro et al., 2003; Szatmari et al., 2006). In Chapter 2, I discuss additional studies on the types and subtypes of RRBs generated through factor analysis, finding between two to six subtypes of RRBs.

Symptom Trajectories Over Time in ASD

There has been an increase in the scholarly literature showing that the core symptoms of ASD subside to a specific extent during adolescence and young adulthood (Chowdhury et al., 2010; Esbensen et al., 2009; Seltzer, Shattuck, Abbeduto, & Greenberg, 2004; Shattuck et al., 2007). For some persons with ASD, there are periods of symptom aggravation in which the person manifests regression (Gillberg & Steffenburg, 1987); furthermore, there is evidence that age-related improvements are more restricted to the domain of RRBs than to the domains of reciprocal social interaction and communication (Leekham et al., 2011). For example, in a retrospective study of 38 high IQ adolescents and adults with ASD, Piven, Harper, Palmer, and Arndt

(1996) discovered that only 50% of the participants showed improvement in RRB symptoms, while more than 80% of the participants improved in both social interaction and communication. Moreover, Piven et al. (1996) suggested that RRBs might be the actual core symptom of ASD, with social interaction and communication problems being secondary symptoms. A similar trend of fewer improvements as people age pertaining to RRBs was demonstrated by Fecteau, Mottron, Berthiaume, and Burack (2003) in their restrospective study of 28 individuals with autism. In addition, Seltzer et al. (2003) found that, based on the results of the Autism Diagnostic Interview-Revised (Lord, Rutter, & LeCouteur, 1994), 87.7% of their participants continued to score above the diagnostic cut-offs in the area of RRBs, compared to 67.9% for the area of Communication, and 85.4% for the area of Reciprocal Social Interaction. Overall, it is important to have a greater understanding of RRB symptoms in order to determine the trajectories of RRBs in ASD throughout childhood and into adulthood (Chowdhury et al., 2010). In Chapter 2, I discuss and review some studies on the trajectories of RRBs in more detail, noting a pattern of development regarding specific RRBs in ASD.

Phenomenological Theory

Phenomenological theory involves studying the conscious experiences of an individual through his/her points of view; therefore, knowledge is derived from first-person accounts of one's life experiences (Moustakas, 1994; Van Manen, 2014). The qualitative approach which involved perception, imagination, thought, emotion, desire, and/or action explored the meaning and essence of an individual's experiences (Moustakas, 1994; Van Manen, 2014). In this phenomenological study, adults with

Asperger syndrome described their lived experiences of engaging in RRBs, taking into account their perceptions, thoughts, emotions, desires, and actions. I was involved with the interpretation and analysis of RRBs through the perspectives of the participants. This study thus provides knowledge and insight from the point of view of adults with Asperger syndrome regarding their symptomatology, in particular RRBs. Moreover, the information I obtained from interpretative phenomenological analysis assisted with expanding upon Dunn's model of sensory processing, the two factor model of RRB, and symptom trajectories over time in ASD with regards to RRBs.

The empirical phenomenological design involved studying in-depth semistructured interview and narrative accounts of the lived experiences of midlife adults with Asperger syndrome (see Moustakas, 1994). The original data I collected were naive descriptions that were provided through open-ended questions and written narratives (see Moustakas, 1994). Then, I analyzed the structure of the lived experiences as a result of much reflection and interpretation of the participants' accounts (see Moustakas, 1994). I made a determination what the experiences of RRBs meant for individuals with Asperger syndrome; a comprehensive analysis was provided. Chapters 3, 4, and 5 include more details on this empirical phenomenological study.

Nature of the Study

Rationale for Qualitative Approach

This study was qualitative in nature, and I used empirical phenomenological methodology (see Moustakas, 1994). Patton (2002) recommended qualitative research as a natural means of investigating a phenomenon. Unlike quantitative research that involves predetermined conditions and the manipulation of variables, qualitative research occurs in a real world environment in which an investigation unfolds naturally (Patton, 2002). In this study, I used a semistructured interview in which guiding questions served as the introduction to issues around RRBs, and then allowed participants to provide their personalized perspectives on these issues.

Phenomenon Investigated

I used an empirical phenomenological approach (Moustakas, 1994) to explore and to describe the personal meanings midlife adults with Asperger syndrome assign to their RRBs and to build on the theoretical framework regarding perceptual and sensory processing differences in adults with Asperger syndrome (Vannucchi et al., 2014). Given that the majority of research on RRBs in ASD is quantitative, qualitative research is lacking (Bolte, 2014). How middle-aged people with a diagnosis of Asperger syndrome experienced RRBs can be captured through a qualitative research design addressing the adults' lived experiences with RRBs in relation with their daily functioning in personal, family, social, and work domains (Bolte, 2014). Scholars have contended that investigating outcomes of RRBs in adults with Asperger syndrome in real life contexts offers evidence of clinical significance to providers of adults diagnosed with Asperger syndrome (Chowdhury et al., 2010; Tantum, 2014; Troyb et al., 2014).

Strategies for Validation

Validation strategies to triangulate the qualitative data collected included member checks, field notes (a reflexive journal), and thick description.

Data Collection Method

I collected data using in-depth semistructured interviews with open-ended questions and dialogue. Interview questions and participant journal entries/narrative accounts were used to generate original data comprised of "naive" descriptions obtained through the open-ended questions and dialogue regarding the participants' lived experiences. Methodologists' have contended that no more than 15 participants may be used to reach thematic saturation for a qualitative study, and that long interviews with up to 10 people are sufficient for a qualitative study (Mason, 2010; Morrow, 2007).

Sources of Data

I collected the following information as data sources from each participant: (a) completed and signed application/consent forms from the individuals in order to participate in the study; (b) audio recordings of the semistructured interviews, plus word-for-word handwritten or typed transcripts of the interview; (c) journal entries/narrative accounts by the individual participants; and (d) field notes (reflexive journal) I used to make extensive documentation while conducting the study.

Analysis of Data

Phenomenological data analysis, according to Moustakas (1994), should follow a very systematic and rigorous procedure. In this study, I analyzed the data using the steps for interpretative qualitative data analysis (coding) as outlined by Smith et al. (2009). First, I examined my own experiences with the phenomenon (epoche) and bracketed everything from my past (Conklin, 2007). Second, I examined the raw data word for word, reading the transcripts repeatedly to identify all the text relevant to the research question. Third, I examined the data to look for repeating ideas. Fourth, I grouped the repeating ideas into major themes based upon specific theoretical constructs. Fifth, I richly described the major themes in sentences specific to the research question for each participant. Lastly, as each participant described their experiences with the phenomenon, I created a theoretical narrative that encompassed the overall experiences of the participants. Therefore, I constructed a combined description of the meanings and the essences of the participants' lived experiences and personal meanings that they assigned to their RRBs (Conklin, 2007; Moustakas, 1994; Moerer-Urdahl & Creswell, 2004).

Operational Definitions

Asperger syndrome: An autism spectrum disorder characterized by social skills difficulties, nonverbal communication impairments, and the engagement of restricted and repetitive behaviors. Persons with Asperger syndrome have average and above-average intelligence and have well-developed expressive language skills (Dunn et al., 2002).

Autism spectrum disorder (ASD): A group of five neurodevelopmental disorders that are classified together under the major term pervasive developmental disorder (PDD), consisting of (a) autistic disorder, (b) Asperger syndrome, (c) pervasive developmental disorder not otherwise specified (PDD-NOS), (d) childhood disintegrative disorder, and (e) Rett's syndrome (American Psychiatric Association, 2000).

Circumscribed interests: An IS RRB that involves having a limited range of interests, focus, and/or activities (Scahill et al., 2013).

Comorbidities: The occurrence of two or more mental disorders in the same individual (Mannion, Brahm, & Leader, 2014).

Compulsions: IS RRBs that are performed in accordance with some type of a rule; they are actions that are carried out in order to relieve a person from some type of a stressor (i.e. anxiety) (Rice 2014).

Empirical phenomenology: A qualitative research methodology which describes the lived experiences of a particular phenomenon in an individual, where there is a return to one's experience in order to gain a comprehensive description through a reflective structural analysis. (Moustakas, 1994).

Insistence on sameness (IS) behaviors): IS behaviors, also called higher-order RRBs, are repetitive behaviors that require more complex cognitive processes. There are four types of IS behaviors: compulsions, ritualistic behaviors, sameness behaviors, and circumscribed interests (Bishop et al., 2013; Harrop et al., 2014; Shuster et al., 2014).

Midlife adults: Adults between the ages of 35 years old and 70 years old.

Phenomenological theory: A qualitative perspective that examines the lived experiences of individuals (Van Manen, 2014).

Repetitive motor behaviors (RMBs): Also called lower-order RRBs, RMBs are very simple motor actions with the body or with a specific part of the body that occur over and over again. There are two types of RMBs: stereotypies and self-injurious behaviors (Harrop et al., 2014).

Restricted and repetitive behaviors (RRBs): A heterogeneous set of behaviors involving stereotypies, self-injurious behaviors, echolalic speech, sameness behaviors, ritualistic behaviors, compulsions, sensory interests/sensory abnormalities, and circumscribed interests (Bishop et al., 2013; Honey et al., 2012).

Ritualistic behaviors: A form of RRBs which are performed on a daily basis in exactly the same manner for the same purpose (Harrop et al., 2014; Shuster et al., 2014).

Sameness behaviors: A form of RRBs which involve a resistance to change or making an attempt to keep things in the same manner (Bishop et al., 2013).

Self-injurious behaviors: RMBs that are repeated over and over again that cause pain, redness, and/or some harm to the body (i.e. head banging, pinching self, biting self, hair pulling); these type of behaviors serve no purpose (Bishop et al., 2013; Chowdhury et al., 2010).

Sensation avoiding: A pattern of sensory processing in which the individual dodges specific activities or situations that would make him/her over-stimulated or uncomfortable; therefore, the individual prefers to do only things he/she is secure, familiar, and comfortable with (Dunn et al., 2002; Hazen et al., 2014).

Sensation seeking: A pattern of sensory processing in which the individual searches for more stimulation, often continuously engaging in specific behaviors, including that of repetitive patterns of behavior (Dunn et al., 2002; Hazen et al., 2014).

Sensory over-responsivity: A pattern of sensory processing in which the individual has such a heightened awareness of what is going on around him/her to the extent that there are numerous distractions contributing to behaviors indicative of over-stimulation (i.e. hyperactivity, perseverations). This pattern of sensory processing is also known as sensory sensitivity (Dunn et al., 2002; Hazen et al., 2014).

Sensory under-responsivity: A pattern of sensory processing in which the individual does not react to anything around him/her, often seeming uninterested or not focused. This pattern of sensory processing is also known as low registration (Dunn et al., 2002; Hazen et al., 2014).

Stereotypies: RMBs that are repeated over and over again (i.e. body rocking, head rolling, hand flapping); they serve no purpose, and they cause no injury to the body (Bishop et al., 2013; Harrop et al., 2014; Scahill et al., 2013).

Stim (stimming): Another word for stereotypies that are repeated over and over again (i.e., body rocking, head rolling, hand flapping, etc.; Bishop et al., 2013).

Assumptions

The goal of this phenomenological study was to have adult participants with Asperger syndrome describe their lived experiences regarding RRBs through in-depth semistructured interviews and journal entries/narrative accounts. To accomplish this, I made several assumptions. First, I assumed that the participants were truthfully recounting their experiences and were providing information to the best of their abilities. Since participants were given as much time as they would like to complete the interview and were given much time at home to complete journal entries and narrative accounts, I hoped that I created an atmosphere in which participants were able to discuss questions to the best of their abilities. I also assumed that the participants had insights into the nature of their RRBs. While this varied from person to person because of the lifelong experiences people have with these symptoms, I assumed that they discussed many aspects of their own RRBs. These assumptions were necessary to ensure that the experiences of adults with ASD could be fully voiced and reflected in the results of this study.

Scope and Delimitations

Scope of the Study

I conducted this empirical phenomenological study to explore and to describe in depth the lived experiences of midlife adults with Asperger syndrome pertaining to their RRBs. Data collection methods for this study consisted of semistructured interviews with open-ended questions which facilitated dialogue/conversation, and participant journal entries/narrative accounts which provided access to each participant's written thoughts and images in terms, thus offering a more realistic and a sensitive account of an individual's life (see Nicholl, 2010).

Population Delimitations

I narrowed the scope of this study to midlife adults between the ages of 35 and 70 with a diagnosis of Asperger syndrome. I chose this age interval so as to be able to recruit the necessary number of participants for the study in order to reach saturation. The participants did not include young adults under 35 years old or older adults over 70 years old. In addition, the participants did not include adults with the diagnosis of autistic disorder or adults with the diagnosis of PDD-NOS as provided by the participants themselves. It was necessary to limit the type of participants so as to obtain accurate data specific to just one type of population with ASD—midlife adults (ages 35 years old to 70 years old) with a diagnosis of Asperger syndrome.

Theoretical/Conceptual Framework Delimitations

In this study, I used Dunn's model of sensory processing (Dunn et al., 2002) to explain why the participants' engaged in RRBs. I also used phenomenological theory to explain the participants' lived experiences of engaging in RRBs. As participants emphasized the various types of RRBs along with the symptom trajectories of RRBs over time, insight and knowledge on this under-researched topic materialized. Unfortunately, other theoretical/conceptual frameworks regarding RRBs in ASD were not included, such as theories regarding the relationship between executive functioning deficits and RRBs (de Vries & Geurts, 2012; Turner, 1997; Yerys et al., 2009). Turner's (1997) hypothesis of behavioral inhibition and hypothesis of impaired generative ability were not covered in this study, although initially considered. In addition, I did not use the perceptual reinforcement theory of Lovaas, Newsom, and Hickman (1987) that explains RRBs in terms of automatic reinforcement because more research is needed pertaining to perceptual reinforcement theory in order to gain a better understanding of how it actually relates to the engagement of particular RRBs. Moreover, it was difficult to find literature on the perceptual reinforcement theory in order to really understand it better.

Limitations

Since this study only focused on midlife adults with Asperger syndrome between 35 years old and 70 years old, such information on the entire population of individuals with Asperger syndrome was not provided; therefore, the information generated by this study is not representative of all individuals with Asperger syndrome. Furthermore, any generalizations regarding RRBs to the entire population of individuals with Asperger syndrome were not made in this study. With this study being purely phenomenological in nature, it was not necessary to make any generalizations, only to develop more insight and to gain more knowledge regarding the deep exploration of RRBs in midlife adults with a diagnosis of Asperger syndrome (see Thomas & Magilvy, 2011).

Significance

Importance of Studying Trajectories of Symptom Development in ASD

Although the majority of symptoms are manifested in childhood, RRBs, along with various other characteristics of ASDs, have been documented to be life-long symptoms (Chowdhury et al., 2010). Studying the trajectory of symptom development is significant to ASD research for numerous reasons. First, as Piven et al. (1996) have shown, the stability and instability of symptomatology between childhood and later stages of development help to shed light on an accurate diagnosis of autism in adults and help in making predictions about future behaviors. Second, different behavioral trajectories help to identify various subgroups of individuals with autism who might further prove to have some biological differences (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013). Third, knowledge of symptom variations has implications for building and assessing the efficacy of appropriate supports and treatments (Seltzer et al., 2004). Finally, the findings from this study are significant in that they may lead to future studies, and they contribute to an increase in societal awareness of an often quite overlooked topic of quality of life among adults on the autism spectrum (Bolte, 2014).

Emergence of Diagnosing ASD from a Dimensional Approach

This study is significant because it provides an in-depth understanding of the neuropsychological functions that are responsible for RRBs from the ASD adult’s perspective. Findings from this study could lead to diagnosing ASD from a dimensional approach instead of a categorical approach (see Lord & Jones, 2012). As yet, there is no agreed ideal way to measure the underpinning neuropsychological pathways of ASD (Williams et al., 2014). Placing an individual's functioning level on each of a number of age or cognitive ability-based normally distributed dimensions would then be possible (Williams et al., 2014).

Potential Implications for Positive Social Change

My study is significant as a vehicle of social change because it helps to promote awareness and acceptance of adults with ASD, in particular Asperger syndrome. Given that adults with ASD have been grossly under researched, this study contributes to the emergence of new knowledge and the modification of existing knowledge on adults with ASD that can be used in assessment, diagnosis, treatment, and promote human rights by decreasing inequalities. As the status quo was challenged through this project, the results from this study will assist people with ASD, their families, their friends, the fields of education and psychology, and society with a better understanding leading to more of an inclusion of persons with ASD into the community.

Summary

Chapter 1 served as a detailed introduction to this study. I provided background information to point out the tremendous gap in the research literature pertaining to adults with ASD regarding the symptomatology of RRBs. After presenting the research problem, I provided evidence of how the problem is current, relevant, and significant. I then stated my intent for the study and offered the primary research question What are the personal meanings that midlife adults with a diagnosis of Asperger syndrome assign to their RRBs? Some theoretical/conceptual foundations regarding this study were laid out, noting mostly Dunn's model of sensory processing (Dunn et al., 2002) and phenomenological theory (Moustakas, 1994). I then highlighted the nature of this study, including the study's rationale, research methodology, and the phenomenon of RRBs being investigated. Operational definitions were provided on the common terminology I used throughout this study. Subsequently I outlined some assumptions regarding the study as well as the scope of the study, including the identification of boundaries regarding my use of both the population and theoretical/conceptual frameworks. I then briefly highlighted the study's possible limitations, noting that I did not use this phenomenological study to make generalizations of the population studied, but only to develop more insight and gain more knowledge regarding RRBs in midlife adults with a diagnosis of Asperger syndrome. The significance of the study includes not only the advancement of knowledge and practice in the fields of education and psychology, but also the promotion of an awareness and knowledge of RRBs in Asperger syndrome, thereby leading to positive social change.

Chapter 2: Literature Review

Introduction

From the moment that autism was conceptualized as a disorder, researchers have described RRBs as one of the hallmark features of symptomatology, along with social skills deficits and communication difficulties (Asperger, 1944; Kanner, 1943). RRBs are a specific class of heterogeneous behaviors in which “restricted” refers to Insistence on Sameness, resistance to change, and narrowness of interests, and “repetitive” refers to stereotypical mannerisms, compulsions, rituals, and routines (Chowdhury et al., 2010; Leekham et al., 2011; Rice, 2014). Over the past decade, researchers have attempted to study RRBs in persons with ASD regarding their etiology, definition, functionality, treatment, and trajectories; however, the findings have been inconsistent and inconclusive, meaning that researchers still do not know much regarding causality, maintenance, and potential for changes in RRBs (Harrop et al., 2014; Honey et al., 2012; Rice, 2014).

There is a distinct knowledge gap regarding RRBs in adulthood, since the majority of studies on RRBs have focused mostly on children and adolescents with ASD (Esbensen et al., 2009; Harrop et al., 2014; Lehnhardt et al., 2013; Lidstone et al., 2014). Consequently, research on RRBs across the lifespan has been scarce (Chowdhury et al., 2010; Lehnhardt et al., 2013). Furthermore, there is conflicting evidence on the manifestation of RRBs in the aging process regarding whether or not RRBs change with time (Chowdhury et al., 2010; Coury et al., 2014; Esbensen et al., 2009). Because a tremendous gap exists in the scholarly literature pertaining to RRBs in adults with ASD, I conducted this study to discover the meaning and role of RRBs in midlife adults diagnosed with Asperger syndrome.

There is not a wealth of information regarding RRBs in ASD, in particular on their etiology, function, maintenance, trajectory, and treatment. However, more studies have been published over the past decade (Leekham et al., 2011; Shuster et al., 2014). In this review of literature on RRBs in ASD, I discuss the following topics: (a) history of diagnosing ASD from Kanner and Asperger to the DSM-V; (b) the types and subtypes of RRBs resulting from factor analytic studies; (c) the sensory features and sensory modulations in ASD and their association with RRBs; (d) anxiety, depression, and other emotional disorders in ASD and their relationship to RRBs; (e) the developmental trajectories of RRBs across the lifespan; and (f) the experience of RRBs in persons with Asperger syndrome.

Research Strategy

I conducted a literature search using a variety of sources of information. Specifically, I searched psychology databases available at the Walden University online library. In the PsycINFO database, I used the general search terms *autism spectrum disorder* and *restricted and repetitive behaviors*. To narrow these searches, I added additional terms such as *adults, Asperger syndrome, rituals, repetitive, factor analysis, sensory modulation*, *anxiety*, and *trajectories*. were used to narrow down the search. I then searched other databases using the same terms; these databases were Academic Search Complete, Proquest Central, Science Direct, SAGE Premier, and Google Scholar.

Furthermore, I perused the reference sections of some of the journal articles to look for other articles related to the topic.

History of Diagnosing ASD from Kanner and Asperger to the DSM-V

Basic Description of ASD

ASD is a lifelong complex neurodevelopmental disorder that affects communication skills, social interactions, and behaviors that are manifested through the engagement of restricted, repetitive, and stereotypical behavior (Ganaie & Bashir, 2014; Shuster et al., 2014; Williams et al., 2014). ASD manifests a heterogeneous set of symptoms ranging from mild to severe (Ganaie & Bashir, 2014; Wing, Gould, & Gillberg, 2011; Zachor & Ben-Itzchak, 2014). Wing et al. (2011) proposed the concept of different autism spectra or *autisms* because of the significant overlap in symptom presentations. Autism comes from the Greek root word *autos*, which means “self.”

Early Discoveries: Leo Kanner and Hans Asperger

In 1911, the term of autism was first used by Bleuler to describe the social withdrawal of persons being detached from reality (Ganaie & Bashir, 2014). In 1943, Dr. Leo Kanner, an Austrian American psychiatrist and physician, first came up with the term autism to describe 11 children who possessed a high intelligence, but who simultaneously displayed communication deficits, had a preference for not wanting to interact with other people, and engaged in a repertoire of RRBs (Ganaie & Bashir, 2014; Kanner, 1943; Ousley & Cermak, 2014). While Kanner (1943) published his article “Autistic Disturbances of Affective Contact” describing early infantile autism, Dr. Hans Asperger, an Austrian pediatrician, studied a similar group of children whom he described as having normal intelligence and above-average language development, but as displaying qualitative impairments in social skills and exhibiting behavioral oddities in the form of restricted, repetitive, and stereotypical behaviors. Asperger (1944) referred to this group of children as having "autistic psychopathology" (Asperger, 1944; Ganaie & Bashir, 2014; Volkmar & McPartland, 2014). Unfortunately, Leo Kanner and Hans Asperger were, for many years, unaware of their similar descriptions regarding their specific groups of children with atypical development (Ousley & Cermak, 2014).

Autism, DSM-II, and DSM-III

Although Leo Kanner and Hans Asperger gave their descriptions regarding autism in their intensive case studies of children with atypical development, it was not until 1967 that infantile autism became a distinct diagnostic category under schizophrenia in the International Classification of Diseases, Eighth Revision (ICD-8; Ousley & Cermak, 2014). Moreover in 1968, autism was known as childhood schizophrenia, and there was no mention of autism in the Diagnostic and Statistical Manual of Mental Disorders, Second Edition (DSM-II; American Psychiatric Association, 1968). When the Diagnostic and Statistical Manual of Mental Disorders, Third Edition (DSM-III; American Psychiatric Association, 1980) was published, the diagnostic category known as PDD was established with the conditions of infantile autism and PDD listed immediately under PDD (Ousley & Cermak, 2014; Volkmar & McPartland, 2014). When the Diagnostic and Statistical Manual of Mental Disorders, Third Edition-Revised (DSM-III-R; American Psychiatric Association, 1987) was published, infantile autism was changed to *autistic disorder* and *childhood onset pervasive developmental disorder* was changed to PDD-NOS (Ousley & Cermak, 2014).

DSM-IV and Emergence of Asperger Syndrome

In the 1980s, English language literature began to recognize Asperger's work. A report by Wing (1981) with numerous case studies on Asperger syndrome was the catalyst for eventually including it with autistic disorder under the category of PDD when the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV; American Psychiatric Association, 1994) was published (Volkmar & McPartland, 2014). In the 1980s and 1990s, over 50 cases of Asperger syndrome were studied in depth, and researchers noted its similarities and differences to autistic disorder (Volkmar & McPartland, 2014). Although Asperger syndrome was found to be quite similar to autistic disorder in much of its symptomatology, researchers noted distinctions from autistic disorder pertaining to verbal skills, motor clumsiness, and positive family history (Volkmar & McPartland, 2014). As many years passed prior to the inclusion of Asperger syndrome under the category of PDD in the DSM-IV, there were numerous inconsistencies in the research regarding its definition. Furthermore, it was given other names, such as right hemisphere learning difficulty, semantic pragmatic language disorder, and nonverbal learning disability (Volkmar & McPartland, 2014). Since 1994, over 1700 scholarly journal articles have been published on Asperger syndrome, and it has become widely used in diagnosis by clinicians, although much controversy developed about whether or not Asperger syndrome was the exact same disorder as high functioning autistic disorder (Volkmar & McPartland, 2014).

As awareness of ASD increased into the 21st Century, there emerged an emphasis on the improvement of outcomes in autism, the provision of early intervention services, and research indicating the discovery of specific genes contributing to ASD (Lord & Jones, 2012; Volkmar & McPartland, 2014). Moreover, a dimensional approach to the functional levels of ASD was emphasized over a categorical approach covering the degree from severe to milder cases (Lord & Jones, 2012; Volkmar & McPartland, 2014). The description of Asperger syndrome in the DSM-IV (American Psychiatric Association, 1994) was replaced with a much clearer description in the DSM-IV-TR (American Psychiatric Association, 2000), although the diagnostic criteria for Asperger syndrome remained the same (Volkmar & McPartland, 2014). The revision from the DSM-IV-TR (American Psychiatric Association, 2000) was used for diagnosis throughout the decade until 2013.

DSM-V: Major Alterations and Issues for ASD

In 2013, the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V; American Psychiatric Association, 2013) included some major changes in umbrella terms. PDD was replaced with ASD. In addition, Asperger syndrome and PDD-NOS were eliminated as disorders (Ousley & Cermak, 2014; Shuster et al., 2014; Williams et al., 2014). The typical triad of impairments involving social skills, communication skills, and RRBs listed in the earlier versions of the DSM went from three domains to just two domains: social-communication difficulties and RRBs (Ousley & Cermak, 2014; Shuster et al., 2014; Volkmar & McPartland, 2014). Furthermore, other symptoms were added to include sensory processing difficulties (Shuster et al., 2014; Volkmar & McPartland, 2014). Although Asperger syndrome and PDD-NOS were eliminated in the DSM-V (American Psychiatric Association, 2013), there is a stipulation that the DSM-IV (American Psychiatric Association, 1994) diagnosis of Asperger syndrome and PDD-NOS will still be applicable to people who were diagnosed prior to the DSM-V (American Psychiatric Association, 2013) as they can retain their diagnoses (Volkmar & McPartland, 2014). Although a few studies have been conducted regarding effective diagnosis utilizing the DSM-V (American Psychiatric Association, 2013), researchers have found that there is greater specificity in the DSM-V pertaining to diagnosis; unfortunately, there is much reduced sensitivity given for specific groups of people with ASD such as very young children between 0 and 3 years, persons who display superior intelligence, and persons who would probably be eligible for the DSM-IV diagnosis of PDD-NOS (Wing et al., 2011). Because there is a lack of considerable sensitivity to these specific groups of people, there is much skepticism in accepting a DSM-V (American Psychiatric Association, 2013) diagnosis, as people who may really be in a need for a diagnosis or services may be denied the opportunity to be given assistance (Wing et al., 2011). Although most persons with a diagnosis of autistic disorder according to the DSM-IV (American Psychiatric Association, 1994) and the DSM-IV-TR (American Psychiatric Association, 2000) will be diagnosed with ASD in accordance with the DSM-V (American Psychiatric Association, 2013), unfortunately 50% to 80% of individuals who have a diagnosis of PDD-NOS under the DSM-IV (American Psychiatric Association, 1994) and DSM-IV-TR (American Psychiatric Association, 2000) will not meet the DSM-V (American Psychiatric Association, 2013) criteria for ASD (Williams et al., 2014). Furthermore, Wing at al. (2011) have argued that many persons with Asperger syndrome object strongly to the elimination of Asperger syndrome because they are concerned that under the DSM-V (American Psychiatric Association, 2013) they may be ineligible for medical and/or social services. Therefore, many persons with Asperger syndrome are concerned that they may eventually lose their diagnoses all together (Wing et al., 2011).

More empirically-based research is needed on the DSM-V (American Psychiatric Association, 2013) pertaining to its use in diagnostic decisions; meanwhile, there is always the possibility that modifications will eventually being made to the DSM-V (Ousley & Cermak, 2014).

Types and Subtypes of RRBs Resulting from Factor Analytic Studies

Overview of RRBs

RRBs are defined as a heterogeneous set of behaviors involving stereotyped motor movements, self-injury, echolalic speech, ritualistic and compulsive acts, sensory interests/sensory abnormalities, and circumscribed interests (Bishop et al., 2013; Honey et al., 2012; Richler et al., 2010). Although some studies have been conducted on RRBs in order to gain a better understanding of their etiology, type, and function, there has been a lack of consensus regarding an operational definition for RRBs (Honey et al., 2012; Leekham et al., 2011; Rice, 2014).

While RRBs are examined as a multidimensional construct with a number of related but separate entities, research on RRBs have assisted with implications for theory, etiology, assessment, trajectories, and treatment of ASD (Honey et al., 2012; Mulligan et al., 2014). RRBs are considered to be a part of typical early development in toddlers, and are also indicative of the symptomatology for a variety of other conditions like intellectual disabilities, obsessive-compulsive disorder, Tourette's syndrome, dementia, deafness, blindness, and language impairments, there are a wide variety of these behaviors present in ASD to much excess in that RRBs are one of the core defining features of ASD (Honey et al., 2012; Mulligan et al., 2014; Scahill et al., 2013). Most individuals with ASD display RRBs to some degree (Mulligan et al., 2014). It is noted that in ASD, RRBs are much more pronounced pertaining to frequency, duration, intensity, and types than other disorders (Leekham et al., 2011).

Challenges of RRBs

RRBs are considered to be one of the most challenging aspects of ASD and can interfere with the completion of daily activities (Wigham et al., 2014); adaptation (Harrop et al., 2014; Leekham et al., 2011), socialization (Harrop et al., 2014; Kargas et al., 2014; Stratis & Lecavalier, 2013), skill development (Honey et al., 2012; Kargas et al., 2014; Rodgers, et al., 2012a), observational learning (Rodgers et al., 2012a; Stratis & Lecavalier, 2013), performance on discrimination tasks (Lam & Aman, 2007), and environmental exploration (Joosten et al., 2009; Lam & Aman, 2007). Research has shown that RRBs vary in type, frequency, and intensity and are considered to be stigmatizing, contributing to the disabling symptomatology of ASD (Honey et al., 2012; Scahill et al., 2013). Furthermore, Honey et al. (2012) emphasized that RRBs can cause much disruption in family functioning.

Types of RRBs

Although generally under-researched, the various studies which focused on RRBs in the past decade have demonstrated that there are several types of RRBs, especially those obtained through factor analytic studies (Honey et al., 2012; Leekham et al., 2011; Shuster et al., 2014). Some studies have indicated six subtypes of RRBs (Bishop et al., 2013; Chowdhury et al., 2010), five subtypes of RRBs (Esbensen et al., 2009; Lam & Aman, 2007; Mirenda et al., 2010), four subtypes of RRBs (Honey et al., 2012; Leekham et al., 2011; Scahill et al., 2013), three subtypes of RRBs (Lam et al., 2008), and two subtypes of RRBs (Georgiades et al., 2010; Harrop et al., 2014; Richler et al., 2010). Most researchers have concluded that RRBs come from basically two general types of repetitive-behavior categories: the lower-order RMB RRBs and the higher-order IS RRBs (Bishop et al., 2013; Harrop et al., 2014; Shuster et al., 2014).

Repetitive Motor Behaviors. RMBs are defined as lower-order RRBs which are very simple motor actions with the body or with a specific part of the body that occur over and over again (Harrop et al., 2014; Shuster et al., 2014). Moreover, RMBs can involve physical manipulation or sensory manipulation of an object. There are two basic types of RMBs: (a) stereotypy and (b) self-injurious behavior. Both are behaviors which are repeated many times over again and serve no purpose (Bishop et al., 2013; Harrop et al., 2014; Scahill et al., 2013). Some examples of stereotypy RMBs include body rocking, head rolling, spinning objects, shaking objects, repeating phrases, humming, hand flapping, turning a light switch off and on, playing a song repetitively, tapping feet on the floor, repeatedly smelling objects, and opening and closing doors several times

(Georgiades et al., 2010). Some examples of self-injurious RMBs behaviors are head banging, pinching self, biting self, hitting self, and hair pulling; such actions usually cause redness, bruising, and some harm to the body (Chowdhury et al., 2010). Although most RMBs are maladaptive, they can also serve as a social function, an instrumental function, or an escape function (Scahill et al., 2013). Much of the research on RMBs have indicated that RMBs are more frequently present in younger persons with ASD and become less frequent as the person with ASD gets older (Esbensen et al., 2009; Lam et al., 2008). Additionally, RMBs were associated with a lower IQ and are more present in individuals who have problems with adaptive skills (Esbensen et al., 2009; Harrop et al., 2014; Lam et al., 2008).

Insistence on Sameness. IS are defined as higher-order RRBs which involve more complex cognitive processes. As a result of various factor analytic studies, there are four types of IS: (a) compulsions, (b) rituals, (c) sameness, and (d) circumscribed interests (Bishop et al., 2013; Harrop et al., 2014; Shuster et al., 2014). Compulsions are behaviors that are performed in accordance with some type of a rule; they are actions that are carried out in order to relieve a person from some type of discomfort, like anxiety (Rice, 2014). Examples of compulsions are putting objects in a certain order, ensuring that a specific activity is completed a certain way, washing one’s hair over and over again, counting something a specific number of times, checking a written paper repeatedly for writing errors, and hoarding bottle caps in the car. Rituals are actions that are performed on a daily basis in exactly the same manner. Examples of rituals are taking the same route to school every day; when eating food, always eating the meat first, the starch second, and the vegetable third; wearing a certain color pants everyday; and, going to bed every night with a specific light on.

Sameness are extreme behaviors that involve a resistance to change or making an attempt to keep things in the same manner. Examples of sameness behaviors are insisting that objects remain in the same place all the time, objecting to visiting new places, insisting on walking in a certain type of pattern, disliking any changes in another person's appearance, insisting on sitting in a particular place, and becoming upset if one's routine is interrupted (Bishop et al., 2013). Circumscribed interests are behaviors involving a limited range of interests, focus, and activities. Examples of circumscribed interests and behaviors are being strongly attached to a specific object or being preoccupied with one specific topic (i.e. fans, air conditioners, train schedules, state capitals, etc.) (Scahill et al., 2013). Much research on IS has shown that there is either no relationship or a positive relationship between IS and IQ and age (Bishop et al., 2013). In addition, Bishop et al. (2013) suggested that IS may be representative of a construct which might be associated with some biological pathways that are relevant to ASD. Furthermore, as various studies have discovered much familial qualities regarding IS behaviors, there is the possibility that some IS behaviors may be associated with certain genetic susceptibilities.

As current research on the types of RRBs in ASD is in its infancy, there is little understanding regarding the etiology, function, maintenance, and treatment for RRBs (Honey et al., 2012; Leekham et al., 2011; Mulligan et al., 2014). Although many subtypes of RRBs have been discovered through factor analytic studies, Honey et al. (2012) and Shuster et al. (2014) have emphasized that ongoing further study is needed into the symptomatology of all the behaviors considered to be RRBs to make the determination whether RRBs are one specific domain of ASD or are multiple domains of ASD. Most studies concluded with the vast heterogeneity of RRBs, the only consistency found from the studies was that there are higher-level RRBs and lower-level RRBs. Furthermore, some researchers have argued that dividing up the RRBs based into higher level and lower level is entirely too broad (Esbensen et al., 2009) and lacks completeness (Honey et al., 2012).

Although much of the data had indicated that some RRBs are more frequently present in younger persons (i.e. stereotyped movements and circumscribed interests) while other RRBs are more present in older persons (i.e. ritualistic behaviors and sameness behaviors), other research had shown opposite evidence (Esbensen et al., 2009). Moreover, as some research had indicated that certain types of RRBs (i.e. motor stereotypy) are influenced by one's level of intellectual functioning, other types of RRBs (i.e. insistence of sameness or need for routines) are not (Esbensen et al., 2009).

As a result of the restricted age ranges used in the studies and many that focused primarily on youth, it was difficult to make any generalizations from children to adults regarding RRBs (Honey et al., 2012; Chowdhury et al., 2010). Furthermore, it was recommended that studies in the future be conducted on larger samples of people of a variety of ages in order to represent the population accurately (Honey et al., 2012). Honey et al. (2012) and Chowdhury et al. (2010) have suggested studying the association between age and RRBs across the lifespan in order to gain better information on the manifestation of these symptoms. Overall, there has been the need to study RRBs in depth looking at not only the progression of RRBs from childhood throughout adulthood, it is also necessary to study the heterogeneity of RRBs in order to discover the types of RRBs that are or are not related to each other (Honey et al., 2012).

With many factor analytic studies on RRBs, there was the concern about the utilization of certain assessments in order to perform the factor analysis (Bishop et al., 2013; Leekham et al., 2011). As most studies used just the RRB items from the Autism Diagnostic Interview-Revised (ADI-R) (Rutter, LeCouteur, & Lord, 2003), Bishop et al. (2013) and Leekham et al. (2011) have questioned solely using the ADI-R for factor analysis as it is still not very clear whether the RRBs in ASD in this assessment is reflective of reality. Bishop et al. (2013) and Honey et al. (2012) recommended that other types of assessments also be used in factor analysis of RRBs, particularly the Repetitive Behavior Scale-Revised (RBS-R) (Bodfish, Symons, Parker, & Lewis, 2000), which focuses exclusively on RRBs. Bishop et al. (2013) and Honey et al. (2012) stressed that using the RBS-R would give more detail to the factor analytic results of RRBs.

Sensory Features/Sensory Modulation in ASD and RRBs

From the time when autism was first discovered, it was noted by Kanner (1943) and Asperger (1944) that persons with ASD exhibited unusual responses to sensory stimuli. They observed the children with a range of hyper-sensitivities and hypo-sensitivities to taste, smell, visual, tactile, and auditory stimuli (Bogdashina, 2013; Dunn et al., 2002; Hazen et al., 2014). As the years passed, various sensory hypotheses emerged explaining how important sensory processing played a major role in the development of the core autistic symptoms, including that of RRBs (Bogdashina, 2013; Dunn et al., 2002; Hazen et al., 2014). A high frequency of abnormal sensory symptoms have been noted in persons with ASD, with at least 1 standard deviation from the norm and a prevalence estimate between 69% and 95% (Hazen et al., 2014).

Dunn's Sensory Processing Model

In 1997, Dunn developed a major sensory processing model which emphasized that there are four basic patterns of sensory processing which influence the development of behavioral responses. They are sensory under-responsivity (also known as low registration), sensation seeking, sensory over-responsivity (also known as sensory sensitivity), and sensation avoiding (Dunn et al., 2002). These patterns of sensory processing occur in every individual as he/she interacts with his/her environment; however, in persons with ASD, there are difficulties with sensory modulation which can be problematic, noticeable, and too extreme, often interfering with daily living and other routines (Dunn et al., 2002; Tavassoli et al., 2014). With sensory under-responsivity, the individual with ASD does not react to most stimuli, often seeming to be uninterested and not focused on what is going on around him or her (Dunn et al., 2002; Hazen et al., 2014). With sensation seeking, the individual with ASD searches for more stimulation, often engaging in behaviors continuously, including the demonstration of repetitive patterns of behavior (Dunn et al., 2002; Hazen et al., 2014). With sensory over-responsivity, the individual with ASD often has a heightened awareness of what is going on around him/her to the extent that there are numerous distractions contributing to behaviors that indicate over-stimulation, such as hyperactivity and perseverations (Dunn et al., 2002; Hazen et al., 2014; Tavassoli et al., 2014). With sensation avoiding, the individual with ASD is rule-bound, ritual-driven, and/or uncooperative. The person's behavior and interests are restricted to the point that he/she is not willing to try any new activities or be in any new situations (Dunn et al., 2002; Hazen et al., 2014). Bogdashina (2013) noted an increase in research on sensory processing differences in persons with ASD. It has been theorized in the literature that RRBs are merely used by people with ASD as a compensatory mechanism to assist with the regulation of the sensory nervous system, especially when dealing with sensory overload (Bogdashina, 2013; Kargas et al., 2014). Kargas et al. (2014), Lidstone et al. (2014), and Wigham et al. (2014) emphasized that RRBs are used in order to maintain homeostasis in the environment; therefore, RRBs help to increase sensory stimulation when under-aroused and help to decrease sensory stimulation when over-aroused. Bogdashina (2013) further theorized that all the core symptoms of ASD, such as social skills impairments, communication difficulties, and repetitive behaviors, originate because of various sensory modulation differences.

Link Between Sensory Modulation Differences and RRBs

Research over the past several years have linked sensory modulation differences to RRBs. Although results have been rather inconsistent, most studies have supported some type of a correlation between sensory processing difficulties and RRBs (Chen et al., 2009; Boyd et al., 2010; Lidstone et al., 2014; Wigham et al., 2014). Originally, it was Lovaas et al. (1987) and Turner (1999) who theorized about an association between sensory processing and RRBs.

In a study conducted by Chen et al. (2009), 29 children between the ages of 8 years old and 16 years old with high-functioning autism or Asperger syndrome were administered the Embedded Figures Test (Witkin, Oltman, Raskin, & Karp, 1971). Their parents/caretakers also completed the Short Sensory Profile (Dunn, 1999; McIntosh, Miller, Shyu, & Dunn, 1999) and the Childhood Routines Inventory (CRI) (Evans et al., 1997). Although sensory processing abnormalities and RRBs did not affect any of the cognitive tasks involved with the Embedded Figures Test (Witkin et al., 1971), the RRBs did affect the speed of completion of the cognitive tasks. A significant association was found between sensory abnormalities and RRBs, especially in the areas of tactile, visual, and auditory over-responsivity (Chen et al., 2009). Furthermore, the children who exhibited more RRBs had more sensory processing abnormalities in comparison to the children who displayed less RRBs (Chen et al., 2009). Chen et al. (2009) suggested that RRBs may be more related to modulation difficulties in the areas of sensory over-responsivity and much less to modulation difficulties in the areas of sensory under-responsivity and sensation seeking.

The RRBs that were measured in the study by Chen et al, (2009) involved examining more higher-order RRBs (i.e. rituals and routines) instead of lower-order RRBs (stereotypies). This study focused more on higher-order RRBs with children who had more advanced cognitive skills and a true representation of the types of RRBs were not displayed (Chen et al., 2009). Chen et al. (2009) noted a limitation to this study was that recruitment bias might have existed in that the children might have been more cooperative and less impaired in the display of their symptoms of autism. In addition to just utilizing children with ASD, Chen et al. (2009) suggested that a future study be conducted by comparing children with ASD with typically developing children in the areas of sensory processing and RRBs.

In a study conducted by Boyd et al. (2010), 67 children with autism and 42 children with a developmental delay were observed and assessed to examine the association between sensory processing patterns and repetitive behaviors. Three sensory processing constructs were assessed in the children: sensory over-responsivity, sensory under-responsivity, and sensation seeking (Boyd et al., 2010). The following measures were used with the children: the Visual Reception Scale of the Mullen Scales of Early Learning (Mullen, 1995), the Repetitive Behavior Scales - Revised (RBS-R) (Bodfish, Symons, & Lewis, 1999), the Sensory Experiences Questionnaire (SEQ) (Baranek et al., 2006), the Sensory Profile (SP) (Dunn, 1999), the Sensory Processing Assessment for Young Children (SPA) (Baranek, 1999), and the Tactile Defensiveness and Discrimination Test-Revised (TDDT-R) (Baranek, 1998). The mental age was controlled and factor analysis and statistical regression were used to analyze the data. Boyd et al. (2010) found significant associations between sensory over-responsivity and repetitive behaviors for both children with autism and children with developmental delays. The more the repetitive behaviors the children exhibited, the higher the level of sensory over-responsivity that was measured, especially pertaining to stereotypies, compulsions, and ritual/sameness behaviors. No association was found between sensory under-responsivity and repetitive behaviors (Boyd et al., 2010). There was a small association found between sensory seeking and only the RRBs that involved ritual/sameness behaviors

(Boyd et al., 2010). Boyd et al. (2010) concluded that this study could be used as a basis for future experimental studies. Additional research was recommended to determine how repetitive behaviors affect children's adaptive functioning and to understand why these three sensory processing constructs of sensory over-responsivity, sensory under-responsivity, and sensation seeking are different from each other.

Lidstone et al. (2014) conducted a two-part study examining the relationship between RRBs, sensory modulation differences, and anxiety in children with ASD between the ages of 2 years old and 17 years old. The first part of the study involved 120 parents completing the Repetitive Behavior Questionnaire-2 (RBQ-2) (Leekham et al., 2007) on their children; the second part of the study involved 49 of the parents from the first part of the study completing the Spence Children's Anxiety Scales-Parent Version (SCAS-P) (Spence, 1998) and the Sensory Profile (Dunn, 1999). A factor analysis was conducted during the first part of the study; two major types of RRBs were found: RMBs and IS (Lidstone et al., 2014). The second part of the study was to determine if a relationship existed between specific types of RRBs, sensory processing, and anxiety. Lidstone et al. (2014) discovered that the RRBs of IS were associated with anxiety and that the RRBs of RMBs were not associated with anxiety. Moreover, IS was more associated with the following the sensory processing patterns of sensory avoiding and sensory sensitivity.

Although the study by Lidstone et al (2014) provided a wealth of information on sensory modulation differences and RRBs along with the role of anxiety in ASD, they recommended that this study be repeated using other types of questionnaires and assessments to determine consistency of specific sensory modulation differences with specific RRBs. Moreover, Lidstone et al. (2014) recommended that the sample of participants be larger and more representative of the population with ASD. Suggested research included having more females with ASD and more persons with ASD of varying intellectual abilities (Lidstone et al., 2014). Longitudinal studies were suggested in order to examine the developmental trajectories of RRBs and the role that sensory modulation differences play pertaining to the development, the maintenance, and the function of RRBs (Lidstone et al., 2014).

Wigham et al. (2014) investigated the interplay between sensory processing abnormalities and RRBs, and collected parent/caregiver report data for 53 children with ASD between 8 and 16 years old. The parents/caregivers completed the following outcome measures: the Short Sensory Profile (SSP) (Dunn, 1999; McIntosh et al., 1999), the Spence Children's Anxiety Scale (SCAS) (Spence, 1998; Nauta et al., 2004), the Intolerance of Uncertainty Scale - Parent's Version (IUS-P) (Boultier, Freeston, South, & Rodgers, 2014), and the Repetitive Behavior Questionnaire (RBQ) (Turner, 1996). Wigham et al. (2014) found evidence for relationships between RRBs and sensory processing differences. Sensory under-responsivity was more associated RMBs and some IS behaviors, while sensory over-responsivity was more associated with IS behaviors exclusively. As anxiety and intolerance for uncertainty were also measured, Wigham et al. (2014) found that they were related much to sensory modulation difficulties and RRBs. They also explained that intolerance of uncertainty would lead to anxiety which could be controlled by engaging in RRB, as a way of sensory regulation in the environment.

Although much was discovered by Wigham et al., (2014), a problem with this study was a small sample size. Moreover, by using only questionnaires and surveys completed by parents/caretakers, not enough information on the actual sensory modulation constructs of sensory under-responsivity and sensory over-responsivity were studied (Wigham et al., 2014). Wigham et al. (2014) suggested that further studies be conducted using fewer questionnaires and more observations. Lastly, another limitation was that only children with a high-functioning form of ASD were participants. Wigham et al. (2014) concluded that the study would not be generalizable to the population of persons with ASD.

Based on the results of the studies conducted by Chen et al. (2009), Boyd et al. (2010), Lidstone et al. (2014), and Wigham et al. (2014), it is concluded that a strong association between RRBs and sensory modulation differences exist, especially with sensory over-responsivity. Moreover no significant relationship between sensory modulation differences and sensory under-responsivity had been observed. The studies by Chen et al. (2009), Boyd et al. (2010), Lidstone et al. (2014), and Wigham et al. (2014) demonstrated how the sensory modulation differences and RRBs were correlated with each other; these studies were in children and adolescents. Unfortunately, there had been no direct studies on adults that just focused on RRBs regarding sensory modulation differences. While there have been some studies on adults with ASD concerning sensory modulation differences, they focused more on general autistic traits, leading to nothing specific on the role of RRBs with regards to sensory modulation differences (Robertson & Simmons, 2012; Tavassoli et al., 2014). Hazen et al. (2014) emphasized that although there are correlations between sensory modulation differences and RRBs, it is not clear enough whether the correlations are causative or whether they are due to some type of shared pathophysiology.

Anxiety, Depression, and Other Emotional Disorders in ASD and RRBs

Prevalence of Psychiatric Comorbidity in ASD

Individuals with ASD often display high rates of psychiatric comorbidity along with the symptoms of social-communication deficits and restricted and repetitive behaviors (Matson & Cervantes, 2014; Mazzone, Ruta, and Reale, 2012). Psychiatric comorbidity can exacerbate problems pertaining to general functioning, learning acquisition, social-skills development, and behavioral control (Joshi et al., 2013; Mazzone et al., 2012). The type of psychiatric comorbidity widely studied ranged from emotional dysregulation and adjustment difficulties (Samson et al., 2013) to mental health disorders in particular anxiety disorders (Blakeley-Smith, Reaven, Ridge, & Hepburn, 2012; Williams, Leader, Mannion, & Chen, 2015), attention-deficit/hyperactivity disorder (ADHD) (Mayes, Calhoun, Mayes, & Molitoris, 2012), depression (Pouw, Rieffe, Stockmann, & Gadow, 2013), and oppositional defiant disorder (ODD) (van Steensel, Bogels, & deBruin, 2013). Studies have demonstrated numerous variations in psychiatric comorbidity amongst people with ASD, and the rates of psychiatric comorbidity were much more significant among people with ASD than people without ASD (Joshi et al., 2013; Mazzone et al., 2012). Studies have examined psychiatric comorbidity in children with ASD (Rodgers et al., 2012a; Skokaukas & Gallagher, 2012), in adults with ASD (Joshi et al., 2013), and in both children and adults with ASD (Davis et al., 2011; Mannion et al., 2014). Although the percentages of specific psychiatric disorders with ASD have greatly varied from study to study, the consensus from the studies have concluded that approximately 70% to 80% of persons with ASD have at least one major psychiatric disorder (Davis et al., 2011; Stratis & Lecavalier, 2013), and that approximately 40% to 50% of persons with ASD have two or more major psychiatric disorders (Stratis & Lecavalier, 2013). The rates of psychiatric disorders more common in ASD range from 55% to 58.3% for anxiety disorders, 31.6% to 45% for ADHD, 23.3% to 30% for ODD, and 13.3% to 15% for major depression (Amr et al., 2012; Stratis & Lecavalier, 2013). Although many psychiatric disorders coexist with ASD, anxiety has been found to be the single most prevalent disorder amongst individuals with ASD. Specific phobias, generalized anxiety disorder, separation anxiety disorder, obsessive-compulsive disorder, and social phobia (Mannion et al., 2014; Williams et al., 2015) are the most common anxiety disorders.

Connection Between RRBs and Psychiatric Disorders in ASD

As psychiatric comorbidity in ASD profoundly affects preexisting compromised social skills, worsens difficulties with adaptive functioning, increases the engagement of disruptive behaviors, and contributes to emotional dysregulation, the core symptoms of ASD, such as RRBs, become specifically more pronounced (Joshi et al., 2013; Samson et al., 2013). Unfortunately, there are only a few studies which have investigated the relationship between RRBs and psychiatric comorbidity in ASD (Joshi et al., 2013;

Stratis & Lecavalier, 2013). However, there are three studies that have found positive correlations between a specific psychiatric disorder and RRBs (Rodgers et al., 2012a; Rodgers et al., 2012b; Stratis & Lecavalier, 2013).

Stratis and Lecavalier (2013) investigated the relationship between RRBs and psychiatric comorbidities in 72 children between the ages of 5 and 17 years of age with a diagnosis of ASD. The parents/caretakers of these children completed the following questionnaires: the Social Communication Questionnaire (SCQ) (Norris & Lecavalier, 2010), the RBS-R (Bodfish, Symons, & Lewis, 1999), the Child Symptom Inventory-4 (CSI-4) (Gadow & Sprafkin, 2002), and the Adaptive Behavior Assessment System, 2nd Edition (ABAS-II) (Harrison & Oakland, 2003). Stratis and Lecavalier (2013) performed a hierarchical multiple regression analysis on the results from the questionnaires, and RRBs were significantly associated with psychiatric disorders. Based on the multiple regression analysis, specific RRBs were found to be a predictor of a specific psychiatric comorbidity: (a) ritualistic and sameness behaviors were predictive of anxiety disorders, depression, and ODD; and (b) stereotypical behaviors were predictive of ADHD (Stratis & Lecavalier, 2013). Moreover, an interesting finding emerged from this study. A negative correlation was found between restricted behaviors and interests and depression; therefore, Stratis and Lecavalier (2013) suggested that restricted behaviors and interests might be a protective factor from depression for persons with ASD.

Although the study by Stratis and Lecavalier (2013) demonstrated results that indicated a strong relationship between RRBs in ASD and psychiatric comorbidities, there were some limitations to the study. First, the researchers depended too much on questionnaires completed by parents and caretakers instead of completing a more thorough assessment of each child through direct interviews and clinical observations (Stratis & Lecavalier, 2013). Second, the children's level of functioning was only determined by their level of adaptive functioning and not by both IQ and adaptive functioning. Stratis and Lecavalier (2013) emphasized that in order to obtain a more accurate level of functioning for persons with ASD, both IQ and adaptive functioning would need to be included. Stratis and Lecavalier (2013) suggested that this study could lead to further research in understanding how RRBs and psychiatric illnesses are related to each other in terms of their etiologies and their commonly possible interventions. Furthermore, there are implications for further neurobiological and genetic research.

A study that focused on the relationship between RRBs in ASD and psychiatric comorbidities, especially anxiety, was conducted by Rogers et al. (2012a). The purpose of the study was to determine the relationship between RRBs and anxiety by comparing the amount of RRBs performed by children with ASD who exhibited high levels and low levels of anxiety. (Rodgers et al. 2012a). The types of RRBs which were studied were repetitive movements, sameness behaviors, the repetitive use of language, and circumscribed interests (Rodgers et al., 2012a). Sixty-seven children between the ages of 8 and 16 years old with ASD were placed into two groups, high anxiety and low anxiety, based on their scores on the SCAS-P (Spence, 1998). Parents/caretakers of the children completed the RBQ (Turner, 1995). Rodgers et al. (2012a) found a significant difference in the frequency of RRBs between both groups of children. The children who displayed high levels of anxiety engaged in more RRBs than the children who displayed low levels of anxiety. The highest levels of anxiety were associated especially with children who demonstrated the RRBs of IS and circumscribed interests.

The study by Rodgers et al. (2012a) supported the prior research of Spiker, Lin, Van Dyke, and Wood (2011) and Sukhoddsky et al. (2008) pertaining to the positive relationship between RRBs and anxiety disorders. Nevertheless, the study has some limitations. First, the study relied too much on the questionnaires completed by the parents/caretakers instead of utilizing observations, interviews, and more objective measures (Rodgers et al., 2012a). Second, the study used assessment instruments which were standardized only on children with typical development, not fully representing the population of people with ASD. If the assessment instruments were standardized on individuals with ASD, better validation to the study would have resulted (Rodgers et al., 2012a). Third, because the study was cross-sectional, it did not allow the researchers to get an understanding of the overall direction of the association between RRBs and anxiety. Rodgers et al. (2012a) recommended longitudinal studies over cross-sectional studies to investigate the trajectory of RRBs and their relationship to anxiety. Lastly, the study only used children with ASD who had normal IQs, which were not representative of the entire ASD population. Rodgers et al. (2012a) recommended utilizing persons with ASD who have a variety of ability levels. Regardless, the study was valuable as it has further implications for understanding the roles of anxiety with RRBs in ASD.

Rodgers et al. (2012b) conducted a study to measure the relationship between anxiety and RRBs by making a comparison between children with ASD and children with Williams syndrome. Thirty-four children between the ages of 8 and 16 years old with ASD, and 20 children between the ages of 6 and 15 years with Williams syndrome participated in the study. Their parents/caretakers completed two questionnaires, RBQ (Turner, 1995) and SCAS-P (Spence, 1998). An ANCOVA was performed on the results from the questionnaires, and discovered that the children with ASD experienced higher anxiety levels than the children with Williams syndrome. Moreover, a significant main effect was found between panic disorder, separation anxiety disorder, social anxiety disorder, and obsessive-compulsive disorder (OCD) (Rodgers et al., 2012b). Therefore, children with ASD experienced overall more frequent RRBs than the children with Williams syndrome (Rodgers et al., 2012b). A strong positive correlation was found between RRBs and anxiety in the children with ASD while a weak correlation was found between RRBs and anxiety in the children with Williams syndrome (Rodgers et al., 2012b). Rodgers et al. (2012b) concluded that the high level of RRBs may play a significant role in the development and in the maintenance of anxiety in ASD compared to that of other developmental disorders.

Although Rodgers et al. (2012b) found a strong link between RRBs and anxiety in children with ASD, the study had some limitations. First, the study relied too much on parent questionnaires instead of utilizing more formal clinical assessments; the utilization of questionnaires alone made differentiation between RRBs and anxiety very difficult (Rodgers et al., 2012b). Second, Rodgers et al. (2012b) noted that there might be problems regarding the representativeness of the findings as the parents who participated in the study might have been somewhat biased regarding reporting their children's symptoms. The study by Rodgers et al. (2012b) has implications for the fields of psychology and counseling such as (a) alerting professionals that persons with specific developmental disabilities experience psychiatric comorbidities; therefore, professionals be given the knowledge to assess mental health issues whenever conducting an evaluation on the person suspected of having ASD; and (b) assisting professionals with designing particular interventions tailored towards persons experiencing anxiety along with ASD.

Based on the studies conducted by Stratis and Lecavalier (2013), Rodgers et al. (2012a), and Rodgers et al. (2012b), it was concluded that there is a significant link between restricted and repetitive behaviors (RRBs) and psychiatric comorbidities, in particular anxiety disorders, especially specific phobias, generalized anxiety disorder, separation anxiety disorder, obsessive-compulsive disorder, and social phobia. To reinforce the findings by Rodgers et al. (2012a), Rodgers et al. (2012b), and Stratis and Lecavalier (2013), Mannion et al. (2014) made the following recommendations for further study. First, study the symptoms of the disorders so the symptoms of psychiatric comorbidities can be distinguishable from the symptoms of ASD. Second, research needs to explore the age-related differences regarding psychiatric comorbidities in ASD, especially pertaining to onset, course, and symptom presentations. Third, assessment instruments should be standardized on persons with ASD to detect psychiatric comorbidities in persons with ASD. Fourth, some persons with ASD may have difficulty accurately completing paper and pencil assessments, like surveys and questionnaires, so physiological assessments are needed. Finally, more research is needed to compare psychiatric comorbidities in persons with ASD other persons with similar psychiatric comorbidities.

Developmental Trajectories of RRBs Across the Lifespan

As the prevalence of ASD increased significantly over the past 2 decades more individuals were being diagnosed in adolescence and adulthood (Magiati, WeiTay, & Howlin, 2014). Limited research exists on the outcomes past childhood; therefore, there is scarce knowledge on the developmental trajectories of ASD (Howlin & Moss, 2012; Magiati et al., 2014; Vannucchi et al., 2014). There were a few clinical accounts on the lifespans of persons with ASD which demonstrated a great heterogeneity in development, whether some persons lose specific skills over the course of time, other persons may reach a skill plateau in adolescence, and other persons may make progress in development throughout adulthood (Seltzer et al., 2003). As a result of limited research on the developmental trajectories in ASD, support and services for adults have been either limited, costly, or nonexistent (Howlin & Moss, 2012; Magiati et al., 2014). Although some studies have focused on the developmental trajectories pertaining to the social skills deficits and the communication delays in ASD, fewer efforts have been placed on the developmental trajectories of RRBs (Howlin & Moss, 2012; Vannucchi et al., 2014).

Researchers have conceptualized that RRBs in ASD have their own specific developmental trajectories; however, not much is known about the factors that may predict the trajectories of RRBs, as well as to be able to note if RRBs tend to increase/decrease in frequency or improve/worsen in symptomatology over the course of the lifespan (Chowdhury et al., 2010; Esbensen et al., 2009; Richler et al., 2010). Although there has been an increasing interest over the past decade in studying the developmental trajectories of RRBs, the majority of such studies focused on children and adolescents, with mixed results (Chowdhury et al., 2010; Richler et al., 2010). For those studies conducted on adults with ASD, it has been discovered that some symptoms of RRBs usually continue throughout adolescence and adulthood while social impairments and communication deficits often improve with much variability (Leekham et al., 2011; Vannucchi et al., 2014). One recent study discovered that for children and adults with ASD who are very high functioning and who have achieved optimal outcomes, the majority of the symptoms of RRBs subsided to the extent that most of those participants who had an original ASD diagnosis lost their diagnoses because they demonstrated no symptomatology (Troyb et al., 2014). As some studies on both children and adults with ASD symptomatology showed contradictory results regarding RRBs improving or worsening over time, there is not enough information in the literature to arrive at a sound conclusion (Troyb et al., 2014; Vannucchi et al., 2014).

Studies have been conducted to look at the developmental trajectories of RRBs, to determine whether variables such as IQ, gender, age, social skills, language/communication skills, and types of RRBs were a taken into consideration (Esbensen et al., 2009; Vannucchi et al., 2014). Richler et al. (2010) suggested that the different types of RRBs probably have their own particular developmental trajectories as one type of RRB develops in early childhood and another type of RRB develops in later childhood. Some studies have found that stereotyped movements and restricted interests are more frequent in young children with ASD while ritualistic behaviors and sameness behaviors are more frequent in older children and adults with ASD (Esbensen et al., 2009; Lam & Aman, 2007). Esbensen et al. (2009) stressed that while some RRBs demonstrate age-related differences, other RRBs do not. Regardless, many researchers have documented an overall trend that RRBs in general remain stable or abate with age (Chowdhury et al., 2010; Esbensen et al., 2009). Richler et al. (2010) stressed it is important to study the developmental course of RRBs in depth because of the overall cascading impact on an individual's level of functioning; RRBs can complicate the already developing social skills deficits and communication difficulties. Furthermore, researchers have discovered in adults negative correlations between RRBs and employment status, the ability to maintain close relationships, and the maintenance of basic living skills (Howlin & Moss, 2012).

Evidence of Developmental Trajectories of RRBs

Some studies have shed a little light on the developmental trajectories of RRBs; some focused primarily on children (Richler et al., 2010), others focused on both children and adults (Esbensen et al., 2009), and others focused exclusively on adults (Chowdhury et al., 2010). Richler et al. (2010) examined RRBs in children to determine if they changed during the course of childhood development, and what specific variables were predictive of the various trajectories. Longitudinal data were gathered by studying 192 children under 3 years old, and then followed up on them at the ages of 3, 5, and 9 years old. At the age of 2, these children were diagnosed with either ASD, PDD-NOS, or a Developmental Disorder (DD) (Richler et al., 2010). Parent interviews were conducted and children were observed (Richler et al., 2010). At various time periods, parents completed the ADI-R (Rutter et al., 2003) and the Vineland Adaptive Behavior Scales

(Sparrow, Bella, & Cicchetti, 1984), and at the same time the children were assessed with the Autism Diagnostic Observation Schedule (ADOS) (Lord et al., 2000), the Mullen Scales of Early Learning (MSEL) (Mullen, 1995), and the Wechsler Intelligence Scale for Children-Third Edition (Wechsler, 1991) or the Differential Ability Scales (Elliott, 1990). As most of the assessments were given to the children at the ages of 3, 5, and 9 years old, there was much variability in the diagnoses of ASD, and the number of participants in the study declined over time (Richler et al., 2010). Based upon the test results, two major types of RRBs emerged: RMBs and IS (Richler et al., 2010). The RMBs studied were repetitive use of objects, unusual sensory interests, hand/finger mannerisms, and other complex repetitive mannerisms (Richler et al., 2010). The IS behaviors studied were resistance to changes in the environment, difficulties with changes in routine, and compulsions/rituals (Richler et al., 2010). For RMBs, results indicated that as the children got older, RMBs decreased demonstrating a negative correlation; for IS behaviors, results indicated that as the children got older, IS behaviors increased demonstrating a positive correlation (Richler et al., 2010). Moreover, it was discovered that the cognitive ability of the child had a negative effect on RMBs, but no effect on IS behaviors; it was concluded that higher cognitive ability is associated with less RMBs (Richler et al., 2010). Because RMBs are affected by cognition, Richler et al. (2010) suggested that RMBs may be the result of brain abnormalities that are involved with sensory and motor activity. Pertaining to IS behaviors, it was discovered that social and communicative abilities may be connected with IS behaviors, and IS behaviors increased in children who demonstrated more social and communication deficits (Richler et al., 2010). Furthermore, it was observed through the course of time that as RMB behaviors were less frequent, a change in diagnoses indicated a milder type of ASD, and as RMBs were more frequent in diagnoses, that indicated a more severe type of ASD (Richler et al., 2010).

Even though Richler et al. (2010) pointed out obvious developmental trajectories for specific subtypes of RRBs in children with ASD, this study had some limitations. First, the study was too subjective because it relied more on parental reports of RRBs and less on the observations and the assessments of the clinicians; moreover, there was a need for other data to be collected on the children, such as teacher reports and direct observations to support the study (Richler et al., 2010). Second, the sampling of children might not have been truly representative of the children who are usually referred for a diagnosis of ASD because early diagnosis of ASD was not commonplace. In addition, Richler et al. (2010) believed that the sample of children was more representative of the severer forms of autism and less of the milder forms. Third, the number of children in the sampling who were diagnosed with developmental disabilities was very small as well as too heterogeneous pertaining to developmental disability. Richler et al. (2010) suggested utilizing a more homogeneous group to represent that population, such as intellectual disability. Fourth, with the same sample of participants having been used over a period of several years, the results from the study did not take into account whether any of the children had any type of intervention that would have helped to reduce the RRBs. Since such accounts were not mentioned in the study, the variables studied might have been affected by outside factors (Richler et al., 2010). From this study, Richler et al. (2010) suggested that the original conceptualization about RRBs being just one category be abandoned because RRBs are too heterogeneous and complex to study.

Esbensen et al. (2009) examined a sample of 712 children, adolescents, and adults with ASD to determine if there were any age-related differences in RRBs, the types of RRBs, and factors that influenced the impact of RRBs, such as age. Esbensen et al. (2009) used data on RRBs from prior studies conducted between 1998 and 2005; all of the participants had been given the diagnosis of ASD from a prior study using a variety of assessment instruments. The participants ranged from 2 years old to 62 years old. RRBs were measured through the utilization of the RBS-R (Bodfish et al., 2000). Comparisons of RRBs were made between six groups of participants (Esbensen et al., 2009). Bivariate correlations and multiple regression analyses were carried out on all of the data (Esbensen et al., 2009). Upon examining RRBs and age, a significant negative correlation was found between repetitive behaviors and age, meaning that adults displayed less repetitive behaviors than children (Esbensen et al., 2009). Upon examining the specific types of repetitive behaviors with age, age was significantly negatively correlated with the RRB-subtypes of stereotypical movements, self-injurious behaviors, compulsive behaviors, ritualistic/sameness behaviors, and restricted interests; in other words, as the individual with ASD ages, there is less RRBs amongst all of the RRB-subtypes (Esbensen et al., 2009). Upon examining RRBs and their association with age and severity of each of the subtypes of RRBs, Esbensen et al. (2009) noted that the patterns of age-related differences in each subtype were based on the type of slope, with the slope being the steepest for restricted interests and the dullest for stereotyped movements. Esbensen et al. (2009) concluded that restricted interests were the most prevalent of the RRBs across all age groups, and that stereotyped movements were the least prevalent of the RRBs across all age groups. Moreover, Esbensen et al. (2009) concluded from their study that RRBs decrease in frequency and in severity across the lifespan.

Although Esbensen et al. (2009) found a decrease in the frequency and severity of the symptoms of RRBs with age, leading to the concept that RRBs are heterogeneous behaviors, this study had several limitations. First, the study used modified data from cross-sectional studies to examine symptom abatement pertaining to RRBs. It was difficult to determine symptom changes in persons with ASD from mere cross-sectional data (Esbensen et al., 2009). In addition, any differences in RRBs could have been due to cohort differences instead of developmental changes (Esbensen et al., 2009). Second, the study used data on a variety of individuals with ASD who were originally given a diagnosis of ASD from various diagnostic assessments. It would have been preferable to have used the same diagnostic assessments for more consistent and accurate results. Third, utilizing data from a variety of studies could have lead to some type of a systematic bias in their study (Esbensen et al., 2009). Fourth, the results from this study are limited because much of the data collected on each participant were based mostly on parental reports of RRBs and not objective measures, like observations. This indicates that while some parents may have more likely reported the RRBs of their young children, they may have been less likely to report the RRBs in their adult children (Esbensen et al., 2009). Furthermore, Esbensen et al. (2009) recommended conducting longitudinal studies in order to accurately study the trajectories of RRBs across the lifespan.

A study that focused exclusively on adults with high-functioning ASD regarding their RRBs was conducted by Chowdhury et al. (2010). Thirty-four adults between 19 and 28 years old participated in the study along with their parents; the parents completed the ADI-R (Lord et al., 1994) and the RBS-R (Bodfish et al., 2000). With the RBS-R (Bodfish et al., 2000), there were two forms that parents completed: a current form which rated behaviors that were present over the last month, and a lifetime form which rated specific behaviors present during the course of the person's life. Statistical analyses of the assessments included t-tests and a one factor within subject ANOVA (Chowdhury et al., 2010). The results indicated an abatement of the symptoms of RRBs in the young adults, as more than 20% of the participants displayed no symptomatology of RRBs in adulthood (Chowdhury et al., 2010). The subscales of RRBs which demonstrated the most improvement over time were the Compulsive Behavior subscale and the Stereotypical Behavior subscale (Chowdhury et al., 2010). The subscale of RRBs which demonstrated the least improvement over time was the Restricted Behavior subscale, especially that of Circumscribed Interests (Chowdhury et al., 2010). In addition, restricted behaviors and sameness behaviors were found to be present for all the participants (Chowdhury et al., 2010). In these young adults with a high-functioning ASD, there was a very low base rate discovered for specific symptoms, in particular self-injurious behavior, unusual preoccupations, and unusual sensory interests (Chowdhury et al., 2010).

Although the study by Chowdhury et al. (2010) had several strengths, including two distinct methods of data collection and a retrospective design, there were some limitations. First, the sample was rather small for it being a quantitative study (Chowdhury et al., 2010). Second, the sample was more for convenience, meaning that the sample might not be fully representative of the population of adults with a high-functioning ASD. In addition, the sample might have included more adults which manifested a less severe display of RRB symptoms. Third, the sample used mostly Caucasian males, meaning that it may be difficult to make generalizations regarding other ethnic groups and females with high-functioning ASD (Chowdhury et al., 2010). With regard to the study's retrospective design, Chowdhury et al. (2010) pointed out that there might have been the possibility of informant recall bias, although difficult to prove. Furthermore, Chowdhury et al. (2010) recommended more longitudinal studies with regards to the trajectories of RRBs.

As the studies conducted by Chowdhury et al. (2010), Esbensen et al. (2009), and Richler et al. (2010) focused on the developmental trajectories of RRBs, they concluded that RRBs mostly decreased with age, in particular that of RMBs. Moreover, IS behaviors remained stable over time with age, although they might increase with age or decrease with age depending on subtype. In general, adults displayed fewer RMBs than children, decreasing both in frequency and in severity (Chowdhury et al., 2010; Esbensen et al., 2009; Richler et al., 2010). Across all age groups, discovered that restricted interests were the most prevalent RRB subtype with stereotyped movements being the least prevalent (Chowdhury et al., 2010; Esbensen et al., 2009; Richler et al., 2010).

Another common finding was that RMBs were less frequent in persons with milder types of ASD, whereas RMBs were more frequent in persons with a more severe type of ASD (Richler et al., 2010). Therefore, it is concluded that age and autism severity have the tendency to impact the developmental trajectories of RRBs (Chowdhury et al., 2010; Esbensen et al., 2009; Richler et al., 2010).

As the studies by Chowdhury et al. (2010), Esbensen et al. (2009), and Richler et al. (2010) depended mostly on parental report measures for data collection, it was difficult to study in depth the specific trajectories of RRBs. More longitudinal studies in the future were highly recommended with sampling methods that obtain participants who would be more representative of the population of individuals with ASD (Chowdhury et al., 2010; Esbensen et al., 2009; Richler et al., 2010). Longitudinal studies would be able to capture how individuals with ASD develop the various types of RRBs over time, they would also explore those various factors that contribute to a decrease in RRBs over time, leading to the possible abatement of symptoms.

Experience of RRBs in Persons with Asperger Syndrome

Emergence of Asperger Syndrome

In 1944, Asperger syndrome was first described in detail by the Austrian pediatrician Dr. Hans Asperger utilizing the terminology "autistic psychopathology" (Asperger, 1944; Khouzam, El-Gabalawi, Pirwani, & Priest, 2004; Wilkinson, 2008). In his research, Asperger (1944) noted a group of children who displayed a significant impairment in social interactions, as well as manifested a heterogeneous display of behavioral oddities, such as what is now known as RRBs (Khouzam et al., 2004;

Lehnhardt et al., 2013; Wilkinson, 2008). Although these children exhibited normal intelligence and well-developed language skills, they demonstrated motor clumsiness, and an interest in memorizing specific facts and figures (Khouzam et al. 2004). For several decades after Asperger's discovery, few psychologists were aware of this type of ASD until 1981, when Dr. Lorna Wing (1981) advocated for its attention in the field of psychiatry and psychology.

Eventually Asperger syndrome was included in the DSM-IV (American Psychiatric Association, 1994). Based on the DSM-IV (American Psychiatric Association, 1994), there were several criteria that must be met in order to obtain a diagnosis of Asperger syndrome; they are (a) impairment in social interactions, (b) restricted, repetitive, and stereotypical behaviors, (c) an impairment in social, occupational, or other areas of functioning to the point of being clinically significant, (d) no delay in language skills development, (e) age-appropriate cognitive development, self-help skills, and adaptive behavior, and (f) does not meet the criteria for any other PDD or schizophrenia.

Although more attention has been given to Asperger syndrome over the past 2 decades in terms of diagnosing and testing children and adolescents, there is a lack of adequate information on adults with Asperger syndrome (Lehnhardt et al., 2013; Roy, Dillo, Emrich, & Ohlmeier, 2009; Wilkinson, 2008). Roy et al. (2009) pointed out that with Asperger syndrome in adults, the most profound effect on a person is in terms of the development and in the maintenance of relationships with other people; moreover, the majority of persons with Asperger syndrome appear withdrawn with few social contacts.

Evidence on Comparing RRBs in Asperger Syndrome with RRBs in High-Functioning Autism

Few studies have concentrated on RRBs in adults with Asperger syndrome. The literature indicated that RRBs are definitely present in persons with Asperger syndrome, and the studies have not addressed RRBs in terms of their overall etiology, development, maintenance, function, treatments, and types, with the exception of circumscribed interests (Lehnhardt et al., 2013; Ozonoff, South, & Miller, 2000; Wing, 1981). Considered one of very few studies through the utilization of the Repetitive Behavior Interview (Turner, 1997), Ozonoff et al. (2000) compared children and adolescents with Asperger syndrome with circumscribed interests with children and adolescents with high-functioning autism. They found that children and adolescents with Asperger syndrome displayed a higher level of circumscribed interests than children and adolescents with high-functioning autism.

Another major study that made an actual comparison of RRBs in persons with Asperger syndrome with RRBs in persons with high-functioning autism was done by South, Ozonoff, and McMahon (2005). From data gathered from various assessments, 61 participants between the ages of 7 years old and 20 years old were selected for the study; they were divided into three groups: 21 were in the high-functioning autism group, 19 were in the Asperger syndrome group, and 21 were in the typical development group (South et al., 2005). Persons with Asperger syndrome and high-functioning autism were diagnosed with the ADI-R (Lord et al., 1994), which was more of a parent/caretaker interview, and the Autism Diagnostic Observation Schedule-Generic (ADOS-G) (Lord et al., 2000) which was more of a standardized assessment. In the study, two-parent report semistructured interview measures were used with all the participants: the Repetitive Behavior Interview (RBI) (Turner, 1997) and the Yale Special Interests Interview (YSII) (South, Klin, & Ozonoff, 1999). From the interview measures on RRBs, results indicated that both children with high-functioning autism and Asperger syndrome demonstrated the same types of RRBs, that of lower-order and that of higher-order repetitive behaviors (South et al., 2005). Pertaining to RRBs in general, there were absolutely no differences found between persons with high-functioning autism and persons with Asperger syndrome; the only differences noted in RRBs dealt with age, in which there were more RRBs displayed in younger children than older children regardless of their type of ASD diagnosis (South et al., 2005). South et al. (2005) concluded that there are no differences in the manifestation of RRBs and no separate patterns of repetitive behavior in high-functioning autism and Asperger syndrome.

Although the South et al. (2005) study was one of the first of its type to examine and to compare RRBs in children with both high-functioning autism and Asperger syndrome, the study demonstrated several weaknesses. First, it was difficult to compare the rates of the various types of repetitive behaviors with each other due to the utilization of different assessment instruments (South et al., 2005). It would have been more ideal to have used just one measure that would have captured the frequency and the severity of RRBs to make a more accurate conclusion (South et al., 2005). Second, the study relied too much on measures utilizing parent interviews to gather data and less on objective assessments (South et al., 2005). Third, because the study was cross-sectional, it did not allow the researchers to examine the development of RRBs over the course of time. The cross-sectional data obtained may not authentically show the presentation of RRBs in individuals as they develop (South et al., 2005). Merely comparing the ages of different children cannot predict the precise course of RRB development in specific individuals. South et al. (2005) recommended that more longitudinal studies be done to not only note the developmental trajectories of RRBs, but to move away from the debate on high-functioning autism as being different from Asperger syndrome (South et al., 2005). There should be more of a focus on the coherent traits in ASD and less on categorical distinctions. Furthermore, South et al. (2005) concluded that future research focus less on the sameness and differences between high-functioning autism and Asperger syndrome, and focus more on the behavioral manifestations and neurological mechanisms underlying both of these disorders.

Summary and Conclusions

This literature review focused on many themes with regards to RRBs in ASD. First, a brief historical synopsis of ASD was provided beginning with Kanner (1943) and Asperger (1944) describing children displaying various autistic symptomatology and ending with the development and the implementation of the DSM-V (American Psychiatric Association, 2013). Second, the major types of RRBs were described in detail based upon the results obtained from numerous factor analytic studies, in particular RMBs and IS (Honey et al., 2012; Leekham et al., 2011; Shuster et al., 2014). Third, studies were reviewed which demonstrated a relationship between sensory modulation differences, such as sensory under-responsivity, sensation seeking, and sensory over-responsivity and the manifestation of the symptoms of RRBs (Bogdashina, 2013; Hazen et al., 2014; Kargas et al., 2014). Fourth, studies were reviewed which demonstrated a relationship between RRBs and psychiatric comorbidities such as anxiety disorders, ADHD, ODD, and depression (Joshi et al., 2013; Stratis and Lecavalier, 2013). Fifth, the developmental trajectories of RRBs across the lifespan were highlighted, although there was not enough information provided by the research to determine if there were age-related differences pertaining to RRBs (Chowdhury et al., 2010; Esbensen et al., 2009; Richler et al., 2010). Lastly, insufficient literature was found regarding Asperger syndrome and RRBs, but a study was reviewed that discovered there were no differences between RRBs and Asperger syndrome and RRBs and high-functioning autism (South et al., 2005).

With numerous studies having been reviewed for this study, it is concluded that many studies did not allow for examining the symptoms of RRBs in adults with Asperger syndrome. Many of the studies exhibited several limitations, which made generalizations to adults with Asperger syndrome difficult. Thus, a major gap in the literature is manifested. First, the majority of the studies focused mostly on children and adolescents with ASD (Esbensen et al., 2009; Harrop et al., 2014). Second, most of the studies were cross-sectional, so as not to capture the developmental trajectories of RRBs (Chowdhury et al., 2010; Lehnhardt et al., 2013). Third, the studies tended to utilize semistructured interviews that relied too much on the reports of parents and caregivers. Such interviews might have contributed to bias (Esbensen et al., 2009). Moreover, the interviews were not conducted with the individuals with ASD. Fourth, semistructured interview measures, which were standardized on persons with typical development, may not be truly representative of the population of individuals with ASD (Rodgers et al., 2010a). Lastly, many of the studies used samples that were too small for quantitative studies (Chowdhury et al., 2010). As the studies were primarily quantitative, it was difficult to search for qualitative studies, as there were none listed in the most recent literature search.

The purpose of my study was to conduct qualitative research which addressed the gaps in the literature of lived experiences of RRBs in midlife adults with Asperger syndrome; therefore, the knowledge obtained through my study will assist with understanding RRBs pertaining to their etiology, definition, functionality, treatment, and trajectories. Furthermore, societal awareness will be promoted on an underserved population of midlife adults with ASD. The next chapter provides information on how my study was implemented (methodology); my role; how the participants were recruited; how the data were collected, organized, and analyzed; the actions which were implemented to ensure trustworthiness; and ethical procedures.

Chapter 3: Research Method

Introduction

The purpose of this qualitative phenomenological study was to explore the personal meanings that midlife adults diagnosed with Asperger syndrome assign to their RRBs. Given that this study was phenomenological, I worked to capture the experiential meanings of a phenomenon by using complex and rich descriptions (see Finlay, 2009). Therefore, I anticipated that there would be an expansion of existing knowledge and the establishment of new knowledge regarding the lived experiences of RRBs of adults with Asperger syndrome.

This qualitative study addressed the problem of the knowledge gap in the field of psychology of adults with ASD, in particular Asperger syndrome and RRBs. Because research on RRBs across the lifespan in persons with ASD has been scarce (Chowdhury et al., 2010; Lehnhardt et al., 2013) and has included conflicting evidence on the manifestation of RRBs in the aging process (Coury et al., 2014; Esbensen et al., 2009), I have worked to present information pertaining to the etiology, function, and maintenance of RRBs in people with Asperger syndrome. In this study, I have also sought to promote an awareness in society of the needs and outcomes of adults with Asperger syndrome (see Vannucchi et al., 2014).

This third chapter includes detailed information on the research method I used for this study. First, I present the research design and the rationale by stating the research question, describing the phenomenon studied, and making note of the research tradition. Second, I describe my role as the researcher, with an emphasis on my major duties, the relationship between me and the participants, and any ethical issues or biases. Third, I thoroughly discuss the methodology, including (a) the recruitment and the selection of the participants; (b) the instrumentation used, including the data collection methods; and (c) the data analysis plan. Fourth, issues of trustworthiness are discussed, including strategies to insure credibility, transferability, dependability, and confirmability. Fifth, I elaborate on ethical procedures and concerns in dealing with the participants, the data, and the data collection process. The chapter concludes with a summary.

Research Design and Rationale

Research Question

This study was guided by the following overarching research question: What are the personal meanings that midlife adults with a diagnosis of Asperger syndrome assign to their RRBs? More specifically, the semistructured interview queried areas regarding descriptions of the behaviors, the role that participants believed these behaviors served, the physical context in which these behaviors occurred, and the emotional context in which they happened.

Phenomenon Studied

I studied the lived experiences and meanings associated with the RRBs of midlife adults between 35 years old and 70 years old with a diagnosis of Asperger syndrome. RRBs are a heterogeneous set of behaviors in which *restricted* refers to a general insistence on sameness, resistance to change, and narrowness of interests, and *repetitive* refers to stereotypical mannerisms, compulsions, rituals, and routines (Chowdhury et al., 2010; Leekham et al., 2011; Rice, 2014). According to the DSM-V (American

Psychiatric Association, 2013), RRBs are one of the two essential defining features of ASD.

While RRBs are considered a part of typical early development in toddlers and are considered indicative of the symptomatology for a variety of other conditions, like intellectual disabilities, obsessive-compulsive disorder, Tourette's syndrome, dementia, deafness, blindness, and language impairments, there is a wide variety of these behaviors present in ASD (Honey et al., 2012; Mulligan et al., 2014; Scahill et al., 2013). Most individuals with ASD display some type of RRB to a specific degree (Mulligan et al., 2014). Furthermore, RRBs are much more pronounced in ASD pertaining to frequency, duration, intensity, and types than in those behaviors in other disorders (Leekham et al., 2011).

Research Tradition

I used an empirical phenomenological qualitative research approach to gain an in-depth understanding of a psychological phenomenon as manifested in the thoughts, perceptions, language, and behaviors of the participants (see Aspers, 2009; Conklin, 2007; Morrow, 2007). The psychological phenomenon I explored in this study was the RRBs of midlife adults with a diagnosis of Asperger syndrome. My goal was to obtain an insider's (emic) view of the phenomenon (i.e., RRBs) as it occurred in a natural or real life setting (see Morrow, 2007; Nastasi & Schensul, 2005; Richards & Morse, 2013). RRBs were captured on an idiographic scale relying on open-ended semistructured interview data and written journal entries/narrative accounts from the participants who were midlife adults with a diagnosis of Asperger syndrome (see Morrow, 2007; Nastasi

& Schensul, 2005). Moreover, I collected, analyzed, and interpreted data throughout the study until reaching saturation (see Morrow, 2007; Nastasi & Schensul, 2005; Richards & Morse, 2013).

As this study progressed, I first took on an active role in observing, interviewing, collecting, and interpreting data; however, the participants (i.e., adults with Asperger syndrome) took on a more active role later in the study through a process known as member checking (Morrow, 2007; Nastasi & Schensul, 2005). Member checking is the process in which the researcher gives some of the participants the opportunity to review some of the data that has been collected and interpreted on the participants; such a procedure assists in ensuring the credibility of the study (Krefting, 1991; Nastasi & Schensul, 2005).

During this study, I gained a more in-depth understanding of the phenomenon (RRBs) which was experienced by the participants (see Conklin, 2007; Morrow, 2007). As a result, participants shared their innermost experiences regarding RRBs, which resulted in the creation of knowledge due to the participants sharing their innermost experiences regarding RRBs (Conklin, 2007; Morrow, 2007; Nastasi & Schensul, 2005; Richards & Morse, 2013).

I chose a qualitative, empirical phenomenological research method because I sought to capture the innermost experiences of the adults with Asperger syndrome, and only qualitative research can capture the essence of their lived experiences (see Morrow, 2007; Richards & Morse, 2013). I selected qualitative over quantitative research simply because a construct/behavior was being studied, needing much interpretation of a more subjective nature (see Morrow, 2007; Richards & Morse, 2013). Moreover, unlike quantitative research, which relies on a single perspective, qualitative research focuses on multiple perspectives from the participants, which are all considered to be of equal value to each other (Richards & Morse, 2013). Given that the majority of research on RRBs in ASD has been quantitative, qualitative research has been lacking (Bolte, 2014). Furthermore, scholars have noted that investigating the RRBs in adults with Asperger syndrome within real life contexts is likely to present evidence of clinical significance to service providers of adults diagnosed with Asperger syndrome (Chowdhury et al., 2010; Tantum, 2014; Troyb et al., 2014).

Role of the Researcher

Major Role of the Researcher

My major role as the researcher was that of an observer-participant; such a role was multidimensional and involved me taking on a rigorous set of responsibilities throughout the study. Although I was an observer-participant, approximately 25% was that of observer and 75% was that of participant.

I observed by carefully watching and listening to the participants during the interview process. Furthermore, I made interpretations from the interviews using field notes, in the form of a reflexive journal (see Richards & Morse, 2013).

I participated in the following activities: (a) planning the study by creating a written procedure for engaging in qualitative research, recruiting the participants, and developing interview questions for the participants (see Richards & Morse, 2013); (b) implementing the study by collecting data from semistructured interviews, journal entries/narrative accounts, and field notes (reflexive journal) (see Nastasi & Schensul, 2005; Richards & Morse, 2013); (c) analyzing and interpreting the data by engaging in thick description (see Conklin, 2007; Moerer-Urdahl & Creswell, 2004); (d) synthesizing data by taking the thick descriptions of the phenomena and integrating these descriptions into a complete whole in order to capture the meaning/essence of the phenomenon for the group of participants (see Conkin, 2007; Nastasi & Schensul, 2005); and, (e) writing about and reflecting on the phenomenon with the purpose of advancing knowledge and awareness in the field of psychology (see Nastasi & Schensul, 2005; Richards & Morse, 2013). Furthermore, by actively participating, I was the primary data collection instrument. The quality of the data collected was thus dependent upon how I observed, interviewed, and analyzed the data (see Nastasi & Schensul, 2005).

The Relationship of the Researcher to Participants

I only recruited participants who experienced the phenomenon (RRBs) under study. The participants selected had no familial, friendship, occupational, romantic, professional, or educational relationship with me. Prior to recruiting participants for the study, I had no interactions with the participants, verbal or written. During the course of the study, the relationship between me and the participants was strictly a professional relationship and collaborative in nature (see Morrow, 2007). The relationships became closer because the participants disclosed emotional and sensitive information; it was my primary responsibility to treat the participants with dignity and respect (see Morrow, 2007). Moreover, I was guided by the values of cultural sensitivity and egalitarianism as suggested by Morrow (2007).

Ethical Issues and Biases Pertaining to the Researcher

Ethical Issues. In this study, I acted strictly in accordance with the Ethics Code of the American Psychological Association (APA, 2002), especially Standard 8 (Standards on Research and Publication), Standard 3 (Standards on Human Relations), and Standard 4 (Standards on Privacy and Confidentiality; Fisher, 2009). Although I gave incentives for research participation in the form of a $50.00 gift card, such an incentive was non-coercive, and it was given to the participants for their efforts and time (see Fisher, 2009). Regardless, if the participants decided to withdraw at any time during the course of the study, they had the opportunity to keep the $50.00 gift card. Because the participants were disclosing sensitive and personal information about themselves, I believed it to be fair to provide the participants with some type of compensation (Fisher, 2009). In accordance with the Ethics Code of the American Psychological Association, in particular Principle D (Justice; APA, 2002), participants were entitled to fair compensation for their participation in the research.

Biases. In this study, I set aside any specific biases regarding ASD. ASD, especially Asperger syndrome, is present in both maternal and paternal sides of the Shirley family, although most have been undiagnosed. I have first-hand experiences with ASD, although my philosophy on each person with ASD *being unique* enables me to be open to different experiences and new knowledge on the "autistic experience". I kept field notes (a reflexive journal) in which my past knowledge, personal experiences, and assumptions regarding the phenomenon (RRBs) were bracketed in order to gain a better understanding of each participant's own experiences with RRBs (Conklin, 2007; Finlay, 2009; Groenewald, 2004; Moustakas, 1994). On an ongoing basis, I engaged in the process known as *epoche* which means to refrain from any type of judgment. Therefore, the phenomenon was viewed by me as if it was being experienced for the very first time (see Conklin, 2007; Finlay, 2009; Moerer-Urdahl & Creswell, 2004; Moustakas, 1994). Furthermore, Moustakas (1994) emphasized that it is important that researchers who are performing phenomenological studies have some type of a connection to the studied phenomenon at hand.

Methodology

Participant Selection Logic

Participant population. The participant population for this study was midlife adults between the ages of 35 years old and 70 years old with a diagnosis of Asperger syndrome.

Sampling method. Participants were primarily selected through purposeful, homogenous sampling; the participants were selected based on their diagnostic characteristics and their experiences with the phenomenon (Groenwald, 2004; Richards & Morse, 2013). Moreover, the sampling technique was guided by the research question regarding the ideographic nature of the phenomenon (Nastasi & Schensul, 2005). Furthermore, purposeful homogenous sampling is highly recommended whenever conducting a phenomenological analysis (Smith et al., 2009).

Another sampling method utilized was snowball sampling. Snowball sampling is when participants already in the study recommend other persons with similar diagnostic characteristics to participate (Groenwald, 2004; Richards & Morse, 2013).

These sampling strategies were chosen because the overall purpose of this qualitative study was to investigate natural phenomena in which experimental controls were not possible to implement (Nastasi & Schensul, 2005).

Participant participation criteria. Participants were selected based on three criteria: (a) they have a diagnosis of having Asperger syndrome; (b) they are between the ages of 35 years old and 70 years old; and (c) they have completed at least 2 years of college or the equivalent in a vocational/trade school.

In order to participate in the study, the participants were required to complete three questions on an application/consent form, which included age, diagnosis, and educational level. The participants were not coerced to answer these questions so as not to discourage them from participating in the study. In addition to a few introductory questions, the application/consent form primarily consisted of detailed guidelines for participating in the study, including rights and responsibilities.

Participant selection and recruitment procedures. The number of participants anticipated for this qualitative study would be between five and fifteen persons; I recruited and interviewed participants until saturation was reached. *Saturation* is defined as whenever there are enough participants who have been interviewed to the extent that the data becomes overly repetitive and there are no new ideas emerging (Mason, 2010). According to Richards and Morse (2013), the collection of data continues until each category is thick and rich; whenever the data offers no new questions and no new directions**,** then there is no need to keep recruiting participants (Morrow, 2007). Englander (2012) stressed that at least three persons should participate in a phenomenological study. According to Smith et al. (2009), the number of participants in a phenomenological dissertation study should be between four and ten persons.

In order to recruit participants into this study, I engaged in two recruitment phases. First, I made contact with the Global and Regional Asperger Syndrome Partnership (GRASP), as there is a local support group which meets monthly in Norfolk, Virginia; I sent an e-mail to the moderator of this local GRASP support group to inform her of the research study. The moderator of the GRASP support group invited me via e-mail to come to the local support group meetings to discuss the study. I attended two support group meetings: one on February 14, 2017 and one on April 11, 2017. At the meetings, I discussed the details of the study, gave out flyers advertising the study, and passed out consent forms to interested persons. As a result, one person consented to be in the study.

Second, I contacted various ASD support groups on Facebook to obtain permission to post an advertisement announcing this study. An announcement advertising the study along with the necessary contact information was posted on the following Facebook groups: Adults with Asperger's Syndrome, Facebook Aspies, Autistic Women’s Appreciation Secret Society, You Might Be An Aspie If, and WrongPlanet.net. From these Facebook groups, 34 persons responded in an e-mail that they were interested in participating in the study. Unfortunately, some of the interested persons were either too young or did not have a diagnosis of Asperger syndrome. I sent an email to those interested individuals who met the criteria for participation. Eleven persons responded enthusiastically that they wanted to participate. Then, application/consent forms were e-mailed to these 11 persons, and times for interviews were scheduled. As a result, three of these 11 participants helped with recruiting an additional person to participate in the study; therefore, snowball sampling was used.

Participant details. The 15 participants for this study had a diagnosis of Asperger syndrome and were between 35 years old and 58 years old, with nine males and six females. Pertaining to geographical area, 14 resided in North America (the United States) and one resided in Europe (Austria). The educational level of the participants were heterogeneous with three having a PhD, four having a Master's degree, four having a Bachelor's degree, one having an Associate's degree, one having 4 years of college, and two having 2 or more years of vocational training.

Instrumentation

The following information was collected as data sources: (a) a signed and completed application/consent form from the individual with Asperger syndrome in order to participate in the study; (b) audio tapes of the semistructured interview of the individuals, plus word-for-word handwritten or typewritten transcripts from the interviews; (c) journal entries/narrative accounts by the individuals; and (d) field notes (reflexive journal) for making extensive notes while conducting the study. As multiple sources of data were being collected, I was the primary data collection instrument (Nastasi & Schensul, 2005).

Signed/completed application/consent forms. The application/consent forms developed by me were completed/signed by the participants prior to their involvement in the study. The application/consent form was a method to collect data on the participants' personal/demographical information. The rights of the participants were discussed, including: (a) the right to be informed about the purpose of the study; (b) the right to be informed about the details of the study along with the amount of time needed for participation; (c) the right to privacy and to anonymity; (d) the right to ask questions regarding the study; (e) the right to refuse to participate in the study without any negative consequences; (f) the right to refuse to answer specific questions; and (g) the right to withdraw from the study at any time (see Richards & Morse, 2013).

Recorded semistructured interview with word-for-word written or typewritten transcripts. Englander (2012) stressed that the interview was one major way for collecting data about the lived experiences of a phenomenon. Being rich in description and detail, the interview enabled me to collect intimate information, especially that of an individual's past experiences. Having the primary role of a data collection instrument in a phenomenological study, the interview had two major purposes: first, to explore the stories behind the lived experiences of the participants, and second, to serve as a relationship builder between the participants and me (see Ajjawi & Higgs, 2007). In addition, the interview gave the participants the opportunity to share their experiences from their perspectives in their own words (see Nastasi & Schensul, 2005). In my study, semistructured interviews were conducted because they gave the participants the opportunity to discuss their experiences without being pressured to answer the questions in a specific manner (Ajjawi & Higgs, 2007). The interviews were taped to capture word-for-word transcripts (written and typewritten) of the rich data to be analyzed on each participant. I designed each interview question which was used in the study. The interview questions were as follows:

1. Tell me something about the types of restricted and repetitive behaviors that you engage in? What do they look like and when do you engage in them?
2. Tell me something about the advantages (benefits) of engaging in restricted and repetitive behaviors?
3. Tell me something about the disadvantages (problems) of engaging in restricted and repetitive behaviors?
4. Do you engage in different restricted and repetitive behaviors when you are in a negative situation versus a positive situation?
    a. What types of restricted and repetitive behaviors do you engage in when experiencing a negative situation?
    b. What types of restricted and repetitive behaviors do you engage in when experiencing a positive situation?
    c. Why do you think these might be different?
5. Tell me about some emotions that you experience whenever engaging in restricted and repetitive behaviors?
6. Can you give me an example of restricted and repetitive behaviors that you engaged in as a child?
7. Can you give me an example of restricted and repetitive behaviors that you engage in as an adult?

Journal entries/narrative accounts. Besides the interview, Englander (2012) stressed that another major way to collect data about the lived experiences of a phenomenon was to get the participants to compose journal entries/narrative accounts, as they are rich in description and detail. In this study, the participants were asked to engage in two written reflective exercises regarding their experience(s) with RRBs. Specifically, they were asked to reflect upon two specific times in their lives in which RRBs had a strong impact on them (Nastasi & Schensul, 2005). In other words, participants were asked to describe in detail some times in their lives, especially the situation(s) that precipitated RRBs, the reason(s) for engaging in the phenomenon, and the consequences involved from engaging in the phenomenon, including the sharing of thoughts, feelings, perceptions, etc. Ajjawi & Higgs (2007) stress that these reflexive written exercises include not only the actual experiences of the phenomenon, but also to include explanations and interpretations.

Field notes (reflexive journaling). Another important source of data were through field notes, also known as reflexive journaling. In this study, I kept a journal in which I recorded research activities, informal observations, contacts, impressions, and conversations with the participants (Ajjawi & Higgs, 2007; Nastasi & Schensul, 2005). Moreover, I shared my assumptions, knowledge, and biases regarding the studied phenomenon so as to distance myself from what I already knew about RRBs (Nastasi & Schensul, 2005). Field notes were the process in which I described my own experiences and behavior pertaining to my study. In my study, three types of field notes were collected: (a) the schedule and logistics regarding the study, (b) a methodology log, and

(c) a personal diary which reflected my thoughts, ideas, and feelings, including frustrations, questions, and problems regarding the research (see Ajjawi & Higgs, 2007).

Data Collection Strategies

When my study began, I was solely responsible for the overall collection of data with regards to the use of medium, time, place, and frequency with participant input. In the beginning, I e-mailed an application/consent form to each participant to complete. Each participant then e-mailed a copy of the signed application/consent form back to me. Next, within 1 week of obtaining the signed application/consent form, I scheduled a 50 minute semistructured interview with each participant. Depending upon each participant's circumstances, the interview between participant and I took place through a conference meeting on the computer, utilizing either the Facebook chat feature or the Facebook instant messaging feature. The interviews conducted through the Facebook chat feature were audio-recorded. Some interviews were conducted through a telephone conference because the participants did not have access to the Facebook chat feature. The telephone conferences were on speakerphone, so they were also audio-recorded.

Within 2 to 3 weeks of the interview, I asked each participant to submit two journal entries/narrative accounts of some experience in his/her life with RRBs. The journal entries/narrative accounts were submitted to me via e-mail. As data were being collected, I recorded and transcribed the data, and placed a copy of the transcribed data into a pocket folder assigned to each participant. The process for collecting data lasted 2 months as every detail was recorded for description and researcher interpretation. For data backup, all interviews were duplicated, including the application/consent form and the journal entries/narrative accounts. Each participant was assigned a file with a number as a way of identifying participants. Each participant’s name was removed to ensure anonymity.

Prior to the end of the study, each participant was given his/her own personalized data profile which summarized the findings based on the participant's responses. Therefore, each participant was given the opportunity to provide feedback via e-mail through a questionnaire which I developed. This opportunity gave the participant the chance to ask questions and give some input.

At the completion of the study, the participants were debriefed through an e-mail summaryThe participants were given the overall results, and an explanation on what was done with all the data collected. There were no requirements for follow-up interviews.

Data Analysis Plan

The primary data collection methods of semistructured interviews, journal entries/narrative accounts, and field notes (reflexive journal) were used to answer the research question. The procedures for analyzing the data were done through the stages of interpretative phenomenological analysis as outlined by Smith et al. (2009). A series of steps were accomplished on the data pertaining to each participant. First, the raw data were examined word for word; the data were read over and over again. I examined all text which was relevant to the research question. Second, the semantic content and language of the data were explored as I made detailed notes of the main points (repeating ideas) as found in the data. Third, patterns that were detected were highlighted in different colors to illustrate the themes that were emerging. Fourth, I searched for connections between the themes through the utilization of subsumption, numeration, and function (see Smith et al., 2009). Fifth, I examined the emergent themes across all participants and looked for commonalities. Sixth, I created a theoretical narrative of the overall experiences of the participants with regard to RRBs. According to Auerbach and Silverstein (2003), the theoretical narrative is the final step that links my concerns to the subjective experiences of the participants.

While collecting and analyzing the data, I implemented the following actions as outlined by McLeod (2012): (a) had an open mind to the point of amazement; (b) engaged in phenomenological reduction by bracketing any assumptions; (c) practiced horizontalization, in which all meanings to an experience were considered equal; (d) used imaginative variation so the essential characteristics of the phenomenon of RRBs were distinguished from those characteristics which were not deemed important; (e) developed an empathetic presence towards the person who experienced the phenomenon; (f) spent an enormous amount of time in deep thought about the phenomenon; (g) gave much attention to all detail regarding the phenomenon, to the extent that it is magnified and amplified; and (h) attuned myself to the events/objects of the phenomenon as it is lived by the participants.

Issues of Trustworthiness

For this study, trustworthiness involved the constructs of credibility, dependability, transferability, and confirmability. Trustworthiness was very important to the study to maintain internal validity, reliability, external validity, and objectivity (see Krefting, 1991; Nastasi & Schensul, 2005). With my study, a variety of specific techniques were used to establish trustworthiness, thus more authenticity; such techniques were triangulation, member checking, reflexive journal, thick description, and audit trail (see Krefting, 1991; Nastasi & Schensul, 2005).

Credibility

Credibility gave the study its truth value; it is the qualitative approach to the quantitative concept of internal validity (Krefting, 1991). To secure credibility, triangulation, member checking, and a reflexive journal were used (see Nastasi & Schensul, 2005). Triangulation took place by different types of data collection methods and more than one conceptual framework (see Nastasi & Schensul, 2005). Member checking was used by having the participants review their own personalized data profiles and then providing feedback to me (Nastasi & Schensul, 2005). This was done through by a questionnaire which was created by me for the participants.

I kept a reflexive journal. I made notes of my thoughts, impressions, and perceptions as well as made note of any biases/past experiences so as to bracket them from the study (Nastasi & Schensul, 2005). The reflexive journal had the following components: (a) the schedule and logistics regarding the study, (b) a methodology log, and (c) a personal diary which reflected my thoughts, ideas, and feelings, including frustrations, questions, and problems regarding the research (Ajjawi & Higgs, 2007).

Dependability

Dependability gave the study consistency; it is the qualitative approach to the quantitative concept of reliability (see Krefting, 1991). To secure dependability, triangulation and an audit trail were used (see Nastasi & Schensul, 2005). Triangulation took place through the utilization of different types of data collection methods and more than one conceptual framework (see Nastasi & Schensul, 2005). An audit trail took place as I engaged in systematic organization and detailed record keeping, which allow a possible review (audit) of the study. Moreover, the organization and record keeping were precise and detailed so to allow a possible replication of the study.

Transferability

Transferability gave the study applicability; it is the qualitative approach to the quantitative concept of external validity (see Krefting, 1991). To secure transferability, thick description was used (see Nastasi & Schensul, 2005). Thick description gave rich and detailed information on each participant, as well as the step by step procedures regarding the entire study. Therefore, such information would allow other people in the field to access the transferability of findings (Nastasi & Schensul, 2005).

Confirmability

Confirmability gave the study neutrality; it is the qualitative approach to the quantitative concept of objectivity (see Krefting, 1991). To secure confirmability, triangulation and a reflexive journal were used (see Nastasi & Schensul, 2005). Triangulation was achieved by having different types of data collection methods, and more than one conceptual framework (see Nastasi & Schensul, 2005). A reflexive journal of notes was kept by me; it consisted of three types of field notes: (a) the schedule and logistics regarding the study, (b) a methodology log, and (c) a personal diary which reflected my thoughts, ideas, and feelings, including frustrations, questions, and problems regarding the research (Ajjawi & Higgs, 2007).

Ethical Procedures

Treatment of Human Participants

The possibility of psychological distress exists when interviewing participants. In my study, participants were given the option to have a face-to-face interview, an interview over the computer (i.e. Facebook chat feature), or an interview over the computer through instant messaging (IM). These options allowed the participants to be in an environment where they were more comfortable and familiar, so as to minimize psychological distress. Each participant had complete control over when, where, and how he/she responded to the interview process. Since the interview questions were semistructured and open-ended, there was always the possibility for participants to disclose information which was not relevant to the study. Whenever participants began to disclose any irrelevant information, I made every effort to redirect the conversation in a friendly and cordial manner.

Many ethical issues were addressed primarily through the application/consent form. Participants were told that (a) their participation was voluntary, (b) they could withdraw from the study at any time without penalty, (c) all information provided would remain confidential, and (d) the participant's identity would not be disclosed so as to ensure privacy.

Treatment of Data

The data to be collected were as follows: (a) completed/signed application/consent forms; (b) recorded semistructured interviews with word-for-word written or typewritten transcripts; (c) journal entries/narrative accounts; and (d) field notes (reflexive journal). Such data were placed into a pocket folder for each participant with all documents scanned into computer files for each participant. Such files (with the hard copy being the pocket folder and the electronic copy being the file) were given an identification number. Each pocket folder/file had all identifying information removed so as to protect the identity of the participant. Any e-mails with the participant's names on them were placed into a pocket folder and scanned into an individual's file; then, all e-mails from the participants were deleted so as not to leave a trace of their identity.

While this study was being conducted, all electronic files were stored on a computer which was password protected; and the pocket folders with the participants' information in them were stored in a binder in a locked file cabinet. I was the only individual to have access to this information.

At the conclusion of the study, all electronic files were transferred to a removable flash drive which was stored in a small locked file cabinet in my desk. In addition, the pocket folders for participant were placed into a binder and into the small locked file cabinet in my desk. All the data in my desk will be stored there for 5 years. After 5 years, all data collected from the study (the application/consent forms, semistructured interview transcripts, journal entries/narrative accounts, and field notes/reflexive journal) will be destroyed by my personal shredder. In addition, the data stored on the flash drive will be erased at that time.

Summary

Chapter 3 provides a detailed narrative of the research methodology which was used for my study. The research design and rationale included the study's major research question and a description of the phenomenon. The section on the study's research tradition elaborated on the qualitative empirical phenomenological approach by discussing its importance and its relevance to the study of RRBs in Asperger syndrome. My role as the researcher was highlighted, as well as the collaborative relationship between the participants and me. Any ethical issues and possible biases by me were addressed. The recruitment process of the participants into the study included the sampling methods, the participant participation criteria, and the participant selection procedures. The instrumentation was explained regarding the specific sources of data collection, the strategies for data collection, and the plan for data analysis. Methods used in the study to ensure trustworthiness were highlighted, to include triangulation, member checking, reflexive journal, thick description, and audit trail. Procedures for maintaining ethics in dealing with participants, the utilization of data, and the storing of data were discussed. As this chapter focused on the research plan and methodology used, the next chapter will provide more detail regarding the study, including the data collection process, the data analysis, and the results.

Chapter 4: Results

Introduction

The goal of my phenomenological study was to explore the personal meanings of RRBs among midlife adults with a diagnosis of Asperger syndrome. This study consisted of 15 adults between the ages of 35 years old and 70 years old, who identified themselves as having at least 2 years of college and/or 2 years of vocational training. The study was guided by the following question: What are the personal meanings that midlife adults with a diagnosis of Asperger syndrome assign to their RRBs? In this chapter, I give an account of the setting of the study, discuss the participants' demographic characteristics, describe the methods of data collection, provide an analysis of the data, highlight the issues of trustworthiness, and provide a thorough illustration of the results.

Setting

I conducted this study with 15 middle-aged adults between the ages of 35 years and 58 years. The criteria for their participation in the study were that they had a diagnosis of Asperger syndrome and had a minimum of 2 years of college and/or 2 years of vocational training. Each participant was given a semistructured interview: nine through the Facebook Video Chat feature, three through the Facebook Instant Messaging feature, and three through a telephone conference. I conducted three of the interviews via telephone conference because participants were unable to use the Facebook Video Chat feature or the Facebook Instant Messaging feature. Twelve of the interviews were audio-recorded through an Olympus (VN-541PC) digital voice recorder. The three interviews conducted through the Facebook IM feature did not need to be audio-recorded because a transcript of the interview was automatically stored on my computer. I transcribed the 12 interviews that were audio recorded, and retranscribed the three interviews that were done through instant messaging. The interviews were conducted on the dates and the times the participants and I selected. Moreover, there were no personal or organizational conditions that influenced the participants or their experiences at the time of the study that might have affected the interpretation of the results.

All of the semistructured interviews were conducted in a private room in my home (12 over the computer and three via telephone). The room was devoid of noises and other distractions, making it conducive for me to process the views presented by the participants regarding their lived experiences with RRBs.

In addition to the semistructured interviews, 13 out of 15 of the participants submitted two journal entries/narrative accounts each regarding their personal experiences with RRBs. The participants were given 3 weeks after the interview to write their experiences and submit them to me via e-mail. Unfortunately, two of the participants who engaged in the interview process choose not to submit their journal entries/narrative accounts even after being reminded on two different occasions to write and submit them. Because they completed the interviews, they were still included as participants in the study.

Demographics

Because I recruited the participants for this study through various autism support groups on Facebook and the GRASP, 14 of the participants resided in North America (United States) and 1 of the participant lived in Europe (Austria). Their ages ranged from

35 years old to 58 years old, all of them with a diagnosis of Asperger syndrome. Table 1 below includes demographic data on the participants such as their gender, their age, their educational level/vocational training completed, and their field of study.

Table 1

Demographical Information of the Participants

Participant	Gender	Age	Educational/vocational training	Field of study
Participant 1	Male	47	Master’s degree	Social Work
Participant 2	Female	41	Bachelor’s degree	Linguistics
Participant 3	Female	41	Bachelor’s degree	Physics
Participant 4	Male	35	Bachelor’s degree	Computer Science
Participant 5	Male	52	PhD	Marketing
Participant 6	Female	58	4 years of college	Nursing
Participant 7	Male	44	2 years' vocational training	Computers
Participant 8	Male	44	Master’s degree	History
Participant 9	Female	35	Master’s degree	Literature
Participant 10	Male	38	Associate’s degree	Unknown
Participant 11	Female	52	Master’s degree	Business Admin
Participant 12	Male	37	PhD	French
Participant 13	Male	51	PhD	History
Participant 14	Male	35	3 years vocational training	Electrician
Participant 15	Female	39	Bachelor’s degree	Journalism

Data Collection

Each participant in this study participated in one semistructured interview with eight open-ended questions. Participant 10 gave the shortest interview, which lasted 20 minutes, and Participant 6 gave the longest interview, which lasted 1 hour, 25 minutes. All of the interviews were transcribed by hand with each stored in a designated pocket folder for participant and placed into a 3-inch binder. Thirteen out of 15 participants submitted two journal entries/narrative accounts each. For these, I asked the participants to furnish a description of two of their RRBs, noting the reasons for engaging in the behaviors and the consequences of performing the behaviors, taking into account their thoughts, perceptions, feelings, beliefs, and so on. The journal entries/narrative accounts varied in detail and length. For instance, Participant 4 described his two RRBs in just one half of a single-spaced page (the shortest version), whereas Participant 12 described his two RRBs in five double-spaced pages (the longest submission). Like the interview transcripts, the journal entries/narrative accounts were stored into a designated pocket folder for each participant and placed into a 3-inch binder. Journal entries/narrative accounts were e-mailed to me as an attachment from the participant.

In addition to storing them in a pocket folder and placing them in a 3-inch binder, I scanned each of the interview transcripts and the journal entries/narrative accounts and stored them on a flash drive, each as its own file (for example, Participant 1 was designated as P1 Interview Transcript and P1 Journal Entry/Narrative Account).

I encountered no unusual circumstances in data collection. Overall, the data collection process lasted 3 months.

Data Analysis

In this study, I collected two types of raw data from each participant: the written transcripts from the semistructured interview with open-ended questions and two journal entries/narrative accounts. Data analysis was conducted in various stages. In order to analyze the data, I used the stages of interpretative phenomenological analysis (see Smith et al., 2009) as a guide, thereby leading to the development of the essential themes in relation to the research question.

First, I immersed myself in the raw data by reading and re-reading them several times. Second, I explored the semantic content and language of the data in depth, and made detailed notes for each participant. Each set of notes were basically a summary of the main points mentioned in the data, including my commentary. I centered my commentary on descriptive comments, linguistic comments, and conceptual comments as suggested by Smith et al. (2009). Third, emerging patterns that were detected in the raw data per participant were highlighted in different colors in order to illustrate how the different themes emerged (highlighters of various colors were used for themes and subthemes). As the emergent themes were developing, I reflected on how the themes connected to the research question; such themes easily fell into place as they clearly illustrated the lived experiences of each participant (see Smith et al., 2009). Fourth, I searched for connections among each of the themes found per participant by using subsumption, numeration, and function (see Smith et al., 2009). Fifth, I examined the emergent themes across all of the participants, looking for the commonalities in the participants. Because there were 15 participants, the themes that emerged with the majority were decided upon as the themes that fell into place with the research question. As a result of the phenomenological analysis, eight basic themes emerged: anxiety; calming effect; intense focus; routines and rituals; sensory sensitivity; misinterpretation by others; physical stereotypies; and special interests. Table 2 shows the major themes that I discovered through the interview transcripts and the journal entries/narrative accounts according to each participant.

Table 2

Themes Across Participants

Theme	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12	P13	P14	P15
Anxiety	X	X	X	X	X	X	X	X	X	X	X	X		X	X
Calming effect	X		X		X	X	X		X	X	X	X	X	X	X
Intense focus	X	X	X	X	X	X	X	X	X		X	X		X	X
Routines & rituals			X	X	X	X	X		X	X	X	X	X		X
Sensory sensitivity	X		X		X	X		X	X					X	
Misinter-pretation by others		X		X	X	X	X	X			X	X	X		X
Physical stereotypies	X	X	X		X		X	X	X	X	X	X	X		X
Special interests	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X

Note: P = Participant.

Evidence of Trustworthiness

The goal of this study was to provide research that clearly described the essences of the lived experiences of RRBs in midlife adults with a diagnosis of Asperger syndrome. In order to maintain the authenticity of the data, I focused on the evidence that gave rise to trustworthiness of credibility, dependability, transferability, and confirmability.

Credibility

To ensure credibility in this study, I used triangulation, member checking, and a reflexive journal, as suggested by Nastasi and Schensul (2005). Through triangulation, I used more than one type of data collection method, such as the semistructured interview and the journal entries/narrative accounts. Collecting more than one type of data helped to provide consistency in the results, thereby confirming validity. Through member checking, each participant was given the opportunity to review the results of the study, in particular the themes and concepts which emerged as the research took place. Upon reviewing their own personalized data profiles, the participants submitted to me a questionnaire with a section to provide some written comments. Being able to give feedback to this study was essential for the participants, as it gave them the opportunity to voice their own thoughts and give their own input. By using a reflexive journal, I made notes regarding the study, which included the interview schedule, the recruitment of participants, some logistical data, a methodology log, and personal information regarding my thoughts, ideas, and feelings concerning the research. The reflexive journal was organized into several areas, as suggested by Ajjawi and Higgs (2007). Such a journal was important to the study because it could lead to the use of an audit trail.

Dependability

To ensure dependability in this study, triangulation and an audit trail were implemented as outlined by Nastasi and Schensul (2005). Through triangulation, I used more than one type of data collection method, such as the semistructured interview and the journal entries/narrative accounts. Collecting more than one type of data helped to provide more consistency in the results. An audit trail took place throughout the study in which I kept detailed records regarding the collection and the storage of data, a weekly diary on the progress of implementing the study, and a reflexive journal which assisted persons in learning more about the study so it could possibly be replicated. Although there was detail in the audit trail, the steps in implementing the study were not broken down into an exact order, as was planned; however, there is sufficient detail to repeat the study.

Transferability

To ensure transferability in this study, thick description took place as emphasized by Nastasi and Schensul (2005). I provided a thick description of the personal experiences of individuals with Asperger syndrome regarding their RRBs. Participants were able to describe their RRBs, including the advantages and disadvantages of engaging in RRBs, the feelings experienced whenever engaging in RRBs, how RRBs were manifested in a positive situation vs. a negative situation, and a personal account of engaging in RRBs in childhood vs. adulthood. The information obtained through the utilization of thick description would provide in the future for other researchers and colleagues in the fields of psychology and education with valuable information on the behavioral differences of adults with Asperger syndrome, therefore leading to more research on adults with ASD.

Confirmability

To ensure confirmability in this study, triangulation and a reflexive journal were used as described by Nastasi and Schensul (2005). Through triangulation, I used more than one type of data collection method such as the semistructured interview and the journal entries/narrative accounts. Collecting more than one type of data helped to provide more consistency in the results, thereby promoting objectivity. Through utilizing a reflexive journal, I made notes regarding the study, including the interview schedule, the recruitment of participants, some logistical data, a methodology log, and my personal information regarding my thoughts, ideas, and feelings concerning the research. The reflexive journal was organized into several areas as suggested by Aijawi and Higgs (2007). Unfortunately, the reflexive journal was not as detailed as originally planned. Journal topics were more specific in some areas and more general in other areas; however, there is sufficient detail to repeat the study.

Results

In this qualitative study, eight themes integral to the research question emerged. Moreover, quotations from the interview transcripts and the journal entries/narrative accounts are provided to support the identified themes. Furthermore, to ensure confidentiality, participants in this study were identified as either Participant or P and were given one of the numbers from one to fifteen.

Theme 1: Anxiety

The most predominant theme among the participants was that they experienced intense anxiety the majority of the time, and that RRBs were the essential mechanism that they performed in order that the anxiety would substantially decrease. For 14 out of 15 of the participants, they emphasized how RRBs helped to relieve them from anxiety. Based on their interviews and journal entries/narrative accounts, Participants 3, 4, 5, 6, 7, 8, 11, 12, 14, and 15 explained the essential reason for engaging in RRBs being that of anxiety. For instance:

> Participant 3 remarked, “I can be peaceful and stay on my schedule and routine, or I can go off my routine and pay the price of anxiety and meltdown. I wish I could be more adaptable, but my routines are very restrictive and necessary for my peace of mind.”
>
> Participant 4 reported, “I do tend to get anxiety if I do not do them.”
>
> Participant 5 said, "I do it in some situations to relieve me from anxiety."
>
> Participant 6 stated, "It can help my brain to maybe function better, like if my brain is on fire or if I feel like I am in brain failure, or panic attacks, or anxiety, or major depression, or can’t focus, or having a meltdown."

Participant 7 remarked, "I do it when I get anxious or worried about something."

Participant 8 reported, "Well, first of all, it helps to burn off anxiety. If I don’t do these sorts of things, the interior pressure of anxiety is great. Restricted and repetitive behaviors serve the purpose of burning off anxiety."

Participant 11 said, "Repetitive behavior can relieve you from anxiety, like when I am really stressed out."

Participant 12 reported, "When you talk about anxiety and stuff like that, in terms of emotions, I experience some type of relief. So, listening to that radio at night helps me to fall asleep. If I am super nervous, the rocking helps let it out."

Participant 14 stated, "The repetitive thoughts about the subject matter can distract me from and filter out things I don’t like and lower my anxiety."

Participant 15 reported, "I feel better once I’ve done them. I tend to be very edgy, even panicky if I don’t do them."

In conclusion, based on the reports of the participants, engaging in RRBs reduces high levels of anxiety for individuals with Asperger syndrome.

Theme 2: Calming Effect

In the interview transcripts and journal entries/narrative accounts, the participants described in detail the feelings they experienced as a result of engaging in RRBs. Twelve out of 15 of the participants reported a calming effect whenever engaging in RRBs. When asked about the advantages of engaging in RRBs, Participants 1, 3, 5, 7, 8, 9, 10, 11, 13, and 14 reported a sense of satisfaction.

> Participant 1 reported, "The way I use my hands, I tend to have my hands clasped a lot, and I use one hand to rub on the other because I am anxious all the time. Like that is my default setting as I am always doing some type of stim to calm myself down."

> Participant 3 stated, "I have great joy when I am dancing. Peace of mind and satisfaction when I do my rituals regarding the seasons. I have a great sense of peace when everything is in order."

> Participant 5 said, "There is this thing where I still pick up with phrases, plus talking to myself. I have certain phrases that I like to use such as “deeply hurt and disappointed”. There is a certain satisfaction in the sense of using certain phrases over and over again."

> Participant 7 remarked, "I enjoy target shooting. I enjoy archery. I enjoy, you know, sports involving repetitive things. Fishing, it’s not team sports, but it is

more individual sports. Very much, fishing is the same thing you do over and over again – the thing, shooting a BB gun or a bow and arrow, it is repetitive. It is very enjoying and relaxing for me to do that."

Participant 8 reported, "Stimming keeps me calm, secure. It helps me to deal with things better."

Participant 9 remarked, "I suspect this repetitive behavior is a stress reaction, or a way for me to soothe or combat my anxiety by doing something familiar over and over. The very nature of it being repetitive is why it is soothing. I do not have to think about what I am doing, but I have to focus enough that I cannot think too much about other issues. It is a way to relax my mind without overwhelming it."

Participant 10 stated, "It is something that gives me a warm, fuzzy feeling. When I am doing it, it feels like getting a big hug from the activity. Like, if I watch a favorite Star Trek episode, it’s calming and it makes the world make sense. It is calming."

Participant 11 reported, "Other benefits: it gives me comfort. Doing routines gives me comfort almost like comfort food. It is soothing, and I enjoy it."

> Participant 13 stated, "Emotions experienced when engaging in restrictive and repetitive behaviors: satisfaction and a sense of well being if I can restore things to the order that I want to leave them in."

> Participant 14 said, "Comfort, security, purpose, confidence, and excitement are the emotions that I experience when engaging in restricted and repetitive behaviors."

> Participant 15 remarked, "They keep me calm."

In conclusion, participating in RRBs gives the participants positive feelings of comfort and satisfaction. In essence, there is a calming effect from performing RRBs.

Theme 3: Intense Focus

In the interview transcripts and in the journal entries/narrative accounts, the participants often described their experiences of being in deep thought whenever they engaged in RRBs. In this study, 13 out of the 15 participants mentioned their experiences of being in deep thought. They appeared to become so deeply engrossed into the subject matter. Intense focus was found to be an emerging theme, especially when a specific subject or a special interest, as indicated by Participants 1, 2, 6, 7, 11, and 14.

> Participant 1 reported, "I get so deep into the subject matter. I don’t want to understand anything superficially. I want to go deep. That is what led me into social work and things like that. I remember being a teenager being fixated on

psychology, philosophy – the kind of books I was reading all the time. To this day, these are the topics I go after becoming good at what I do now."

Participant 2 said, "I did really well in the (Hebrew) class, and within a few weeks was tutoring several of my fellow classmates. The class went much slower than I had anticipated, so I was vastly over-prepared. But, it was nice to be over-prepared, rather than being under-prepared."

Participant 6 stated, "I used to be so good (referring to sports), so I insisted on playing with the boys. I had to be as good as a boy. It just wasn't one time, but all the time, 12 hours a day, and that's why I got a scholarship playing college ball – college basketball. Talk about repetitious? That's why I got so freakin' good. Being hyperfocused."

Participant 7 remarked, "I do computer work for my profession, and it is a lot of repetitive stuff. Doing a gap analysis or going in and finding the needle in the haystack. I know this is happening, to be able to go through something over and over and over again until I figure it out. It's fun and it's good in that way."

Participant 11 reported, "It gives me something to focus on. Something to become extremely good at (my breeding program is recognized worldwide). I have become an expert in my breed. I've written two books on them as well. I give

> seminars all around the country, teaching aspiring AKC judges everything they need to know to correctly judge Harriers (a breed of dog)."

> Participant 14 remarked, "I can get so focused into an interest that I can learn an interest or hobby much faster than the average person. I will think about the interest at every angle and use a vast amount of mental energy on it."

In addition, some participants indicated just how much that engaging in RRBs had allowed them to be able to focus and to function better, as indicated by Participants 3, 5, 9, 12, and 15.

> Participant 3 reported, "The other thing is I can focus which allows me to become an expert in my special interest. The reason why I became a great dancer is that I can focus on it, watching videos – there are some videos that I watched a thousand times on repeat, and I imitate the dancers perfectly."

> Participant 5 said, "An advantage to restricted and repetitive behavior is that it keeps you focused."

> Participant 9 reported, "Having repetitive behaviors, I check things a lot. I have to make to-do lists. I have to break down everything I have to do. I have this notepad, “Today’s Plan of Attack”, and I write down what I do every day on this,

> and then things do not get lost. I’m able to be extremely functional because I do the repetitive behaviors."

> Participant 12 remarked, "Another is that I will find myself doing a lot of it when I am in deep thought or introspection mode, even to the point of dissociation. I don’t know if there is a word for that particular emotion in terms of letting yourself go deep inside of yourself."

> Participant 15 stated, "The benefit of engaging in restrictive and repetitive behaviors is giving my mind something to focus on so that my thoughts don’t race."

In conclusion, RRBs are of great benefit to individuals with Asperger syndrome as they keep the participants on a deeper level of concentration so they can focus, thereby leading them into areas of accomplishment.

Theme 4: Routines and Rituals

Routines and rituals fall under the higher order type of RRBs, known as IS (Harrop et al., 2014; Shuster et al., 2014). Based on the transcripts from the interviews and the journal entries/narrative accounts, the participants discussed the importance of having routines and rituals as a way to help them deal with change, as well as to surround their lives with a sense of organization. Eleven out of the 15 participants discussed their need for routines and rituals. Participants 3, 4, 9, 11, 13, and 15 discussed some of their routines and rituals.

> Participant 3 reported, "My house has decorations. One of my special interests is decorating for every seasonal period, like Christmas, Valentine’s Day, St. Patrick’s Day, Easter, Fourth of July, and periods when people don’t decorate. For me, the reason I do that is that it brings order to my world. It helps me accept the changes of the seasons, and of course, change is hard. The seasons changing throws me off, so I decorate."

> Participant 4 said, "There are routines that I repetitively do. Also, like when I am in restaurants, I usually like to order the same thing. I don’t like changing clothing during the day. I like to keep on one outfit for the entire day. I have specific routines that I adhere to throughout the entire day."

> Participant 9 reported, "I have rituals like every time I shower, I have to shower in a certain order, and I have to do certain things while I am in the shower. I have to shave every time I am in the shower. It has to be done in order. And so I have to shampoo my hair and then I shave, and then I put the conditioner in my hair, then I use soap. It has to be done in order, and if I don’t do it in order, then I have to start over. It seems like so much of my life is rituals."

> Participant 11 remarked, "I can get into a routine like my morning rituals in getting ready for work: like I go into the bathroom, then into the shower, washing my hair first, then wash my body in a certain pattern. If something new comes along, my routine gets messed up. When there is a new pattern or a new routine, it takes me a couple of days to learn it. Once it becomes a habit for me, I can breeze right through it."

> Participant 13 stated, "In the kitchen, all the spices and all the kitchen gear have their exact places, and I fell an almost bodily pain if someone puts something into the kitchen closets differently. I don't mean say put the stuff into a different closet, but not in the right order of: blue saucepan on bottom, yellow saucepan in the middle, and red saucepan on top. I can freak out if red is in the middle and yellow is on top."

> Participant 15 remarked, "I am very routine-oriented, but having kids have thrown that part of me off. My only firm ritual now is my bathing routine: floss and brush teeth, shampoo, wash body (always in the same order), rinse, condition hair, hose shower down, rinse conditioner out, squeegee shower, wash hands, and apply sprays (also in the same order each time)."

To sum it up, for persons with Asperger syndrome, routines and rituals are an essential part of their lives, therefore, bringing order to their situations.

Theme 5: Sensory Sensitivity

As individuals with Asperger syndrome experience various sensory issues, such as sensory over-responsivity, sensation seeking, or sensation avoiding. Various RRBs surface as a response to these sensory processing differences, as theorized by Dunn (Dunn et al., 2002). In the interview transcripts and the journal entries/narrative accounts, seven out of the 15 participants noted sensory issues related to engaging in RRBs. Participants 1, 3, 5, 8, 9, and 14 discussed various sensory issues whenever engaging in RRBs.

> Participant 1 reported, "I am always doing some type of stim to calm myself down. And it is usually something done with my hands. If I am doing something with my hands a lot, that means something is really bothering me. Sometimes I am aware of it, sometimes I'm not. The sensory nervous system is always on high alert."

> Participant 3 said, "I have a very restrictive schedule. It brings both frustration and balance. I am always in conflict between the two. In order for me to feel balance and to minimize sensory overload, I have to adhere to a schedule. Each day of the week has certain activities assigned to it."

> Participant 5 stated, "One of the things I like is deep pressure. When other people drive and I sit in the front seat, I pull the seat back as far as I can because I like

the feeling of pressure against my legs. The deep pressure is more of a sensory-like thing. I feel the pressure against my legs, sometimes can be very calming."

Participant 8 reported, "I am stressed out sensory-wise a lot of ways. For example, when the weather's changing or when the wind is blowing, I tend to wring my hands a lot."

Participant 9 remarked, "I find I do this particular repetitive behavior (referring to playing a video game over and over again) more when I am dealing with health issues or simply too loaded sensory-wise to focus on a book. I also use this repetitive behavior in conjunction with other repetitive behaviors when I am very anxious such as playing this video game while keeping the show Gilmore Girls on in the background."

Participant 14 reported, "Very frequently, I will distract myself in my mind (referring to daydreaming), if I am overwhelmed by anything in the present moment – the most common reason being overwhelmed by external stimuli due to my hypersensitivity prevalent with Asperger's. This behavior has become a habit from my mind creating it as a type of compensation for my Asperger syndrome. I am at the age (in my 30s) in which I have to accept this behavior, as I cannot go without it unless I want to having disabling anxiety."

In summary, the participants related their experiences of RRBs with various sensory sensitivities as reflected in some of the literature on persons with ASD, especially in the areas of sensory over-responsivity and sensation avoiding (Dunn et al., 2002).

Theme 6: Misinterpretation by Others

In my study, several participants described how other people reacted to them whenever they engaged in RRBs. Often, there was a concern of being misunderstood more due to the repetitive behaviors than anything else. Ten out of 15 of the participants brought up some type of concern, ranging from how the repetitive behaviors might be annoying to other people, to how RRBs might interfere with the development of relationships. Participants 2, 4, 5, 7, 8, 12, and 13 expressed that one disadvantage of engaging in RRBs was that other people found RRBs to either be irritating or distracting.

> Participant 2 reported, "Other people find restricted and repetitive behaviors annoying."

> Participant 4 said, "When I find a phrase, joke, or sound that I find amusing, I tend to reuse that same phrase over and over ad nauseum. This is probably because I want to participate in social settings, but don’t have the conversational skills to consistently come up with original things to say. Doing this makes me feel socially included and connected temporarily, but upon reflection, I do realize that I’m probably being more annoying to others than interesting."

Participant 5 stated, "I found that when I speak in the classroom, I can’t keep myself from pacing. I know it’s distracting to some people. Over the years, even though I cannot stop it, I may walk to one side of the classroom and stay there for a while, and then I can walk to the other side like being at the other end of the continuum – I tend to pace, that is something that I do."

Participant 7 remarked, "It is really hard for me to let go of something when I am really trying to find out something. So, I do this to try to find out what the problem is. Sometimes coworkers can get frustrated with me to the point that it’s not worth it, or won’t bother with it anymore, or even lie about it. Kinda have difficulty with wanting to figure out what’s wrong as well as to be aware of what my coworkers really really want. They are not always happy with the repetitiveness."

Participant 8 reported, "The disadvantage would be that people are particularly annoyed by or consider such behaviors to be rude. The behavior will be misinterpreted as rude by others. People would perceive it negatively because of their expectations. Could interpret it as a lack of awareness, a lack of intelligence, or whatever."

Participant 12 reported, "It can make getting through everyday life harder depending on the behavior. The behaviors make it less easy to go with the flow.

> Like if I am at the airport and I am rocking, people may think this is a mentally deficient person. That all is a big disadvantage. People don’t really get it. Like if you share a bench with somebody and start rocking, that person will become annoyed."

> Participant 13 stated, "And my habit of continually whistling has already driven colleagues out of the room. In fact, I was fired at least three times for just whistling (office disruption they said). I can’t help it – most of the time I don’t realize that I am whistling."

Participant 15 stressed the need to do RRBs in private due to other peoples’ reactions to her. She also the importance of RRBs in her life:

> Participant 15 remarked, "My stims/repetitive behaviors are much more integral to who I am. I didn’t think to do them in the first place, so as long as no one forces me to stop them (and no one does). I simply let them run, and don’t try to think to stop them. Nonetheless, I generally have to limit them to private settings because they attract attention and make others nervous. So, that can be a problem. And I have to force myself to stay alert to do that which is tiring."

Participant 6 expressed how much that RRBs can interfere with the development of interpersonal relationships, leading to a lonely existence:

> Participant 6 stated, "It messes with my relationships, and people don't understand you. And it increases isolation which is not good. Isolation really is not that healthy. But then there is another part of it that is good as long as I need my space, but then too much space is not healthy either. And then when you're isolated long enough where you are not engaging with anybody, you feel bad."

Theme 7: Physical Stereotypies

In my study, physical stereotypies, also known as RMBs, emerged as a major theme because of its importance to the participants. Such RRBs involved hand, foot, finger, toe, and body movements. The results from my study indicated that 12 out of the 15 participants reported that they engaged in some type of RMB ranging from simple fidgeting with fingers to body rocking. Out of the 12 participants who engaged in RMBs, two engaged regularly in one RMB, three engaged in two RMBs, five engaged in three RMBs, one engaged in four RMBs, and one engaged in five RMBs. Table 3, below, illustrates the number of RMBs that each participant reported which they engaged. Note: Participants 4, 6, and 14 did not report that they engaged in any RMBs.

Table 3

Breakdown of Number of RMBs Per Participant

Participant	Number of RMBs For Each Participant
Participant 1	4 RMBs
Participant 2	2 RMBs
Participant 3	5 RMBs
Participant 4	None
Participant 5	1 RMB
Participant 6	None
Participant 7	3 RMBs
Participant 8	3 RMBs
Participant 9	2 RMBs
Participant 10	3 RMBs
Participant 11	3 RMBs
Participant 12	3 RMBs
Participant 13	1 RMB
Participant 14	None
Participant 15	2 RMBs

In my study, 19 different RMBs were reported by the participants. Table 4, below, provides a list of the RMBs, along with the specific participants who regularly engaged in them.

Table 4

Types of RMBs Reported by Participants

Repetitive Motor Behaviors (RMBs)	Participant's Reported Behavior
Wringing hands vigorously	Participants 1 and 8
Rocking	Participants 1, 3, 8, 10, and 12
Moving foot back and forth between the covers	Participant 9
Rubbing nose with both hands	Participant 10
Twisting hair	Participant 15
Picks at self	Participants 1, 2, 4, 7, and 15
Wiggles toes	Participant 2
Bites nails and cuticles	Participants 3 and 13
Pacing	Participants 3, 5, 7, and 8
Licking fingers	Participant 3
Rubbing hands and thighs	Participant 3
Sucking tongue	Participant 7
Jiggles legs	Participants 9 and 12
Bites fingers	Participant 10
Bounces up and down with heels of the feet	Participant 11
Knee tapping	Participant 12
Outlining hands with fingers	Participant 11
Chewing	Participant 3
Fidgeting with hands	Participants 1, 2, and 11

Another finding that emerged was that many of the participants associated RMBs with a negative situation. Nine out of 15 of the participants stated that RMBs usually resulted from a negative situation. Participants 1, 2, 3, 7, 8, 9, 10, 11, and 15 described the RMBs that they engaged in whenever faced with a negative situation.

> Participant 1 reported, "I know I pick at my hair a lot, I pick at my eyebrows a lot, my eyelashes. I do rock when I get a little worked up or nervous about something. I feel the need to fidget a lot, but I keep it under control."

> Participant 2 said, "I have the tendency to be fidgety and pick at myself a lot (especially my fingers) whenever I am under stress."

> Participant 3 stated, "Usually everything is exaggerated in a negative situation, as I pace a lot more than usual. I go in circles more fast instead of a relaxed pace. There is more nail biting – like I rip up my fingers doing this, and I bleed. I will go online to look up medical symptoms obsessively, causing more stress. I start walking and rubbing my thighs really fast. I rub the top of my head to calm myself down. Negative is more stereotypical and physical-like behaviors."

> Participant 7 remarked, "One of the things I still do at 44 is suck my tongue as a child would suck his thumb. I also have dug at scars, although I do that a lot less now than when I was a child. But, I still do it. I do it when I get anxious or worried about something."

Participant 8 reported, "It is more common in a negative situation based on the samples I mentioned. If the atmosphere is calm, there would be less of a need to stim. Anxiety level rises in a negative situation, therefore a reason for engaging in the behavior. In negative situations, I tend to wring my hands a lot. I could start rocking."

Participant 9 reported, "But in a negative situation, like if something unexpected happens, or I get yelled at, or like somebody is really nasty to me in the parking lot, or something like that, then I cry. I mean that is one of the ways I handle it. I rock. I rock back and forth. And, I have this little stuffed cat that I keep in my purse, and I sit there, and I rub the cat's head constantly. And, that's in a very negative situation, like those things I just mentioned are almost involuntary."

Participant 10 remarked, "Well, if it's like if something bumps into me, that makes me think of something else negative, then I start biting my fingers again. I tend to bite my fingers more in a negative situation. Repetitive behaviors are here for mostly negative things. Positive situations don't bring them on."

Participant 11 stated, "If it is a negative situation, I step away, remove myself, or calm myself down by using repetitive behavior, then that is not a bad thing. If I cannot get away from the negative situation, I may get locked into my repetitive

> behaviors like a loop thing. In a negative situation, well I tend to fidget. I run one of my fingers outlining the edge of all my fingers. I also rub my fingers back and forth."

> Participant 15 reported, "The situations in which I turn to this stim are usually unbearable anxiety, nervousness, or exhaustion. For example, if I've had an awkward conversation, I stew about it a lot and find myself twisting my hair, tucking the ball of it behind my ear, and pressing it against the chair or bed, over and over."

In summary, negative situations or negative feelings can precipitate RMBs by the participants. Such behaviors can assist the person with dealing with stress and high anxiety levels.

Theme 8: Special Interests

In my study, a major theme that was present among all of the participants who engaged in RRBs was special interests. Special interests are a part of the IS-type of RRBs, often referred to as *circumscribed interests* (Harrop et al., 2014; Shuster et al., 2014). The participants spoke with high regard about their special interests, noting the benefits and the positive feelings/situations that they produced. Table 5, below, provides a detailed breakdown of the special interests in the interviews/narrative accounts by each of the participants.

Table 5

Special Interests of the Participants

Participant	Special Interests
Participant 1	Philosophy, logic, and psychology
Participant 2	Linguistics, French, and music
Participant 3	Dance, choreography, and decorating for the seasons and holidays
Participant 4	Science fiction
Participant 5	Chicken and egg problems; gardening
Participant 6	Landscaping, medicine, sports, and legal issues
Participant 7	Individual sports, like fishing, archery, and target shooting
Participant 8	Mineral collecting
Participant 9	Literature, science fiction, and fantasy
Participant 10	Star Trek
Participant 11	Dogs (breeding and showing them)
Participant 12	Photography, French, and architecture
Participant 13	Aircraft, history, chronology, and arms and armor
Participant 14	Cartoons and Japanese anime
Participant 15	Mysteries and collecting fountain pens

Participants 3, 6, 10, 11, 12, 13, and 15 elaborated in detail on several advantages of having circumscribed interests.

> Participant 3 reported, "I have repeated rituals of decorating for the seasons. I have elaborate decorating schemes that don't miss a single time period in the year. I believe that every part of the year deserves celebration and recognition on some level. It also soothes me and calms me when the seasons and months keep changing. In other words, it brings order to chaos for me and helps me cope with change."

> Participant 6 stated, "Besides the gardening and the landscaping, I used to be so good at sports, I would play with my brothers. I insisted on playing with the boys. I had to be as good as a boy – it just wasn't sometimes, but all the time, 12 hours a day, and that's why I got a scholarship playing college ball – college basketball. 1 did it 12 hours a day, rain, shine, etc. It didn't matter. Talk about being repetitious? That's why I got so friggin good. If I did more repetitious behaviors in other areas, I'd be highly successful."

> Participant 10 remarked, "I like Star Trek. When I found out they made novels for it, I was at the library all the time. I liked the idea of everybody being welcomed. I liked all the different worlds and aliens. I really got into it with the designs of the ships and the technology. In the 1990's, I started creating my own characters and ships for Trek. I thought this was innovative. I have since

discovered that others did the same thing. People (the fans) have made their own Star Trek series, etc."

Participant 11 reported, "It gives me something to focus on, something to become extremely good at (my breeding program is recognized worldwide as I've sold pups to Europe, South America, and the Caribbean, as well as all over the US and Canada). I have become an expert in my breed (I've written two books on them as well), and I give seminars all around the country, teaching aspiring AKC judges everything they need to know correctly how to judge Harriers. Those things give me a great sense of accomplishment and pride, as well as satisfaction."

Participant 12 stated, "With the restricted interests, the advantage is it is inherently interesting to me. It's kinda like self-actualization, and it's also interesting because you get to be an expert on things. There is an affiliation with these restricted interests being obscure cultural things being good for trivia. It is knowledge that not everybody has. These special interests can be especially impressive to other people."

Participant 13 said, "Well, my PhD is in history. One of my special interests. My dissertation was a study on guilds and craftsmen companies from 1066 to 1625. It was a very rewarding subject – the more so, as it was a totally new thing. There had been case studies before, but no one ever before had tried to give an overview

> of all guild activities in England, Scotland, Wales, and Ireland. To this day, some people say my dissertation is the definitive word on the subject."

> Participant 15 stated, "I perceive that my special interest (collecting fountain pens) is unusual in this age, but it is useful and means something to me, and that is enough. I feel good about this special interest, and I am happy that I've infected several others with it (as collectors say). At the same time, I am happy to encourage others, particularly the autistics in my life to find their own special interests."

In retrospect, the special interests of the participants are very circumscribed to the extent that there is a sense of accomplishment and expertise in those specific areas. The participants believe that special interests are the positive aspect of engaging in RRBs. Moreover, special interests are often associated with positive situations, leading to satisfaction, achievement, and accomplishment.

Summary

In Chapter 4, the participants' personal meanings of RRBs were richly described as a result of the utilization of interpretative phenomenological analysis (IPA) as outlined by Smith et al. (2009). The themes which emerged, such as anxiety, calming effect, intense focus, routines and rituals, sensory sensitivity, misinterpretation by others, physical stereotypies, and special interests, were predominant among the majority of the participants. The participants reported from the semistructured interviews and the journal entries/narrative accounts that they engaged in RRBs in order to reduce anxiety with 50% of the participants made note of coping various sensory sensitivities. As a result of engaging in RRBs, the participants reported a calming effect, and the RRBs allowed them to focus and to concentrate better. Therefore, RRBs were used as a coping mechanism by middle-aged adults with Asperger syndrome in order to deal with anxiety and various stressors. Misinterpretation by other people was another noteworthy theme discovered, as other people tend to find the RRBs annoying or distracting. Also, the person with ASD might be misunderstood as being intellectually disabled or emotionally unstable.

The types of RRBs which were noted as being the most important to middle-aged adults with a diagnosis of Asperger syndrome were that of routines and rituals, special interests, and physical stereotypies. It was emphasized that such RRBs were necessary whenever faced with a positive situation versus a negative situation. It was noted that special interests were predominant in positive situations, and that physical stereotypies were more prevalent whenever dealing with negative situations. Also, routines and rituals were used by the adults with ASD in order to provide structure and organization in their lives.

In Chapter 5, an interpretation of the findings are provided and compared with that of the literature which was reviewed in Chapter 2. Moreover, the limitations of this study are addressed. Recommendations for further research are provided. Furthermore, implications for positive social change are discussed for practice, methodology, theory, and further research.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

The purpose of this study was to explore the lived experiences of RRBs in midlife adults with a diagnosis of Asperger syndrome in order to gain a better understanding of those experiences and the meanings that they attach to them. I conducted this empirical phenomenological study using semistructured interviews and journal entries/narrative accounts to capture a realistic and a sensitive account of the participants' lived experiences (see Nicholl, 2010). Specifically, I sought to delve into the subjective experiences of RRBs in adults with Asperger syndrome, thereby promoting a greater societal awareness and offering more knowledge regarding adults with ASD with further implications for research, treatment, and positive social change.

The following themes emerged from participant data: anxiety; calming effect; intense focus; routines and rituals; sensory sensitivity; misinterpretation by others; physical stereotypies; and special interests. The participants reported that they engaged in RRBs to reduce intense anxiety, which is due to various sensory sensitivities and environmental stressors. As a result of engaging in RRBs, the participants reported a calming effect, as well as being able to increase concentration and focus. I concluded that RRBs are used as a coping mechanism. The types of RRBs which were noted as being the most important to midlife adults with that of Asperger syndrome are that of routines and rituals, special interests, and physical stereotypies; such RRBs are necessary whenever dealing with both positive situations and negative situations. Based on the majority of data collected, special interests are the RRBs that are more predominant in positive situations, and physical stereotypies are more prevalent in negative situations, although both could exist in either type of situation.

Interpretation of the Findings

Findings Based on the Literature Review

The relationship between anxiety and RRBs. A major finding from this study was that 100% of the participants reported intense anxiety as their reason for engaging in RRBs. Oftentimes, the participants reported that RRBs help to alleviate anxiety. The studies in the literature have demonstrated that anxiety disorders are highly prevalent in individuals with ASD (Mannion et al., 2014; Stratis & Lecavalier, 2013; Williams et al., 2015). Although the studies highlighted in the literature review did not focus on adults with ASD regarding the relationship between RRBs and anxiety, the studies showed positive correlations between RRBs and anxiety in children with ASD (Rodgers et al., 2012a; Rodgers et al., 2012b; Stratis & Lecavalier, 2013). Hence, the findings from this study confirm what is in the literature on the relationship between anxiety and RRBs; moreover, the findings extend knowledge from children to adults, as a large gap in the literature exists regarding anxiety and RRBs in adults with ASD. Furthermore, this study can pave the way for future studies on adults with ASD regarding the relationship between RRBs and anxiety.

The two major categorizations of RRBs in adults with ASD. Another finding emerged from this study showing that the types of RRBs prevalent in adults with Asperger syndrome are those specifically from two basic categories: the lower-order RRBs known as RMBs and the higher-order RRBs known as IS (Bishop et al., 2013;

Harrop et al., 2014; Shuster et al., 2014). The participants in this study reported that they engaged in predominantly physical stereotypies (a form of RMBs), and special interests and routines and rituals (forms of IS). This study confirms findings in previous studies that these two major types of RRBs exist amongst adults with ASD. Unfortunately, the literature review focused on research that found RMBs to be more present in younger persons with ASD and less frequent in older persons with ASD (Esbensen et al., 2009; Lam et al., 2008). This study disconfirms such specific information found in the literature review because physical stereotypies were one of the major themes discovered on the lived experiences of RRBs of midlife adults with Asperger syndrome. In fact, the theme of physical stereotypies is a very strong theme that emerged from this phenomenological study.

Sensory sensitivities and RRBs. Another theme that was prevalent throughout this study was that of sensory sensitivity with regard to adults with Asperger syndrome engaging in RRBs. About 50% of the participants reported some type of sensory sensitivity whenever they discussed their experiences with engaging in RRBs. In the literature, researchers highlighted various types of sensory sensitivities such as sensory under-responsivity, sensory over-responsivity, sensation seeking, and sensation avoiding (Dunn et al., 2002; Hazen et al., 2014). These studies examined the relationship between sensory processing difficulties and RRBs (Boyd et al., 2010; Chen et al., 2009; Lidstone et al., 2014; Wigham et al., 2014). Most notably, the studies showed significant associations between sensory over-responsivity and engaging in RRBs (Boyd et al., 2010; Chen et al., 2009; Lidstone et al., 2014; Wigham et al., 2014). Like the studies in the literature review, the most notable sensory processing difficulty reported by participants in this study was that of sensory over-responsivity. Such a finding confirms those in the literature pertaining to the relationship between sensory sensitivities and RRBs in ASD. Furthermore, the findings extend knowledge to that of the relationship between sensory sensitivities and RRBs in adults with ASD, as the studies in the literature review only focused on children and adolescents.

Findings not present in the literature review. The other major themes I found in this study regarding RRBs in adults with ASD were not covered in the literature review. I thus consider these themes as independent from the literature review and not associated with any of those studies. They are as follows: calming effect; intense focus; and misinterpretation by others. Such findings do not confirm or disconfirm knowledge in the field with regards to the literature review. They do, however provide new knowledge about RRBs regarding specific issues that apply to adults with ASD, in particular Asperger syndrome.

Findings Based on Conceptual Frameworks and Theoretical Foundations

Most of the themes that emerged as a result of this phenomenological study confirm and expand knowledge based on the following conceptual frameworks and theoretical foundations: Dunn's model of sensory processing (Dunn et al., 2002) and the 2-factor model of restricted and repetitive behaviors (Turner, 1999).

Dunn's model of sensory processing. Dunn theorized that RRBs in ASD are reflections of various sensory processing differences. Such sensory processing differences are manifested as sensory under-responsivity, sensory over-responsivity, sensation seeking, and sensation avoiding (Dunn et al., 2002). As sensory processing differences exist to various degrees in persons with ASD, the most notable finding from this study is how most of the RRBs of the participants are merely the result of sensory over-responsivity as reflected in the semistructured interview responses and in the journal entries/narrative accounts. The theme of sensory sensitivity was predominant, and participants reported a heightened awareness leading to RRBs that would assist with calming down the sensory nervous system (see Dunn et al., 2002; Hazen et al., 2014; Tavassoli et al., 2014). The findings from this study indicate the reasons for engaging in RRBs with some of the predominant themes being that of sensory sensitivity and calming effect, thus confirming Dunn's model of sensory processing (Dunn et al., 2002).

The two-factor model of RRBs. Turner (1999) theorized that there are two primary factors that separate RRBs from each other whenever it comes to their classification: one factor, known as higher-order behaviors, is termed as IS, and the other factor, known as lower-order behaviors is termed as RMBs. The findings from this study show the importance of engaging in these two types of RRBs based on the reports from the participants in the semistructured interviews and in the journal entries/narrative accounts. The specific behaviors that participants noted to be important were physical stereotypies (RMBs), routines and rituals (IS), and special interests (IS). These findings confirm that the 2-factor model explains the various types of RRBs. Such findings also extend knowledge about the purposes of the different types of RRBs because physical stereotypies (RMBs) are more prevalent whenever there are negative situations, and special interests and routines and rituals are more notable in positive situations. Such knowledge helps to explain the possible origins and purposes of RRBs.

Limitations

In this study, I focused exclusively on midlife adults between 35 years old and 70 years old with Asperger syndrome who had at least 2 years of college and/or vocational training. Moreover, information on the entire population of individuals with Asperger syndrome could not be provided because any of the information generated by this study was not representative of all individuals with Asperger syndrome. Therefore, it would be difficult to make any type of generalizations regarding the lived experiences of RRBs to the entire population of individuals with Asperger syndrome.

The results of the study were restricted with regards to symptom trajectories over time in ASD because the participants did not provide enough detailed answers to the interview questions which focused on childhood RRBs and adulthood RRBs. Based on the data gathered through the semistructured interview questions and the journal entries/narrative accounts, no themes from this qualitative study emerged with regard to symptom trajectories. Therefore, this study was unable to generate enough information to support or refute the trajectories of RRBs over time. Moreover, the specific gap in the literature regarding changes in RRBs was not addressed as I had anticipated.

Lastly, another limitation to this study dealt with the recruitment of participants. When participants were recruited, they were not required to submit professional documentation as proof that they had a diagnosis of Asperger syndrome. I made the assumption that participants had a professional diagnosis as they were members of one or more of the ASD support groups and were giving me accurate information about themselves. I recommend in future studies that participants submit some type of proof that they have a professional diagnosis of Asperger syndrome.

Recommendations

From this study, there are two recommendations for further research. First, I recommend that this study be repeated with midlife adults with Asperger syndrome with one modification: the participants do not have to have at least 2 years of college and/or 2 years of vocational training in order to participate. This would allow for a more heterogeneous sample which is representative of midlife adults with Asperger syndrome. I recommend that this study be repeated, as there are not many qualitative studies on ASD, especially for that of adults with Asperger syndrome.

Second, I recommend that a qualitative phenomenological study examine the lived experiences of RRBs in young adults with Asperger syndrome and the lived experiences of RRBs in midlife adults with Asperger syndrome. A comparison between the lived experiences of RRBs in young adults with that of RRBs in midlife adults would offer more information regarding symptom trajectories over time. It would assist comparing symptomatology between young adults and midlife adults, and it may offer more insight into their perceptions, feelings, and thoughts regarding RRBs by making a comparison across two generations. With the addition of the utilization of surveys and questionnaires, such a study could become more of a mixed-methods study.

Implications

Implications for Positive Social Change

The results from this study provide knowledge on RRBs in midlife adults with Asperger syndrome. Moreover, the results are based on the participants' lived experiences, taking into account their feelings, thoughts, attitudes, beliefs, perceptions, etc. As information on adults with ASD has been scarce because few studies were conducted, this qualitative study is one of its own kind, leading the way to an overall awareness of ASD in adults with implications for society, individuals with ASD, and the fields of psychology and education, impacting research and practice, thus facilitating positive social change.

For society, the results from this study can promote awareness and encourage acceptance of adults with ASD as it contributes to the emergence of new knowledge and the modification of existing knowledge regarding RRBs. In effect, assessment, diagnosis, treatment, advocacy, and supportive services can increase, thereby helping to decrease any inequalities that may exist for the adult with ASD. Therefore, the promotion of human rights takes precedence. As the status quo is challenged through this study, the results can lead to more an inclusion of persons with ASD into the community.

For individuals with ASD, the results of this study can be vast, because society with its agencies, organizations, and institutions will become more educated to decrease prejudice, discrimination, and other injustices committed towards people with ASD. As a result, the individual with ASD will be provided with more opportunities for inclusion in areas such as employment, housing, education, training, transportation, health, mental health, recreation, etc. With an increase in opportunities across agencies, organizations, and institutions, the individual with ASD can maximize his/her own potential, leading to independence and self-sufficiency.

Research and practice in the fields of psychology and education can benefit by this study because it can provide information to the researchers so they can implement additional studies on the lived experiences of individuals with ASD. First-person accounts of their various symptomatologies and what it means to them can be explored. In effect, the fields of psychology and education can gain a better understanding of the thoughts, perceptions, opinions, emotions, etc., of persons with ASD. In turn, such an exploration of the mind of persons with ASD can be helpful to design appropriate intervention strategies, treatments, assessments, and supports. In addition, learning about the connections between RRBs and anxiety in ASD can lead to the development of assessments that can measure the degrees of anxiety based on the types and frequency of RRBs. Moreover, knowing about the symptomatology of adults with ASD can lead to more accurate diagnoses in adults, as well as help psychologists and educators in making predictions about behaviors in future situations.

Conclusion

Based on the findings of this study, it is concluded that RRBs are used as a coping mechanism to relieve anxiety in persons with ASD. Moreover, RRBs are instrumental with calming the person, as well as providing organization and structure to the individual’s life. Instead of concentrating on administering treatments and other interventions to getting the person with ASD to decrease the frequency of RRBs or to extinguish them all together, it is strongly recommended that psychologists address the crippling anxiety that the person with ASD is experiencing, not the RRBs, as the RRBs are just symptoms of the anxiety.

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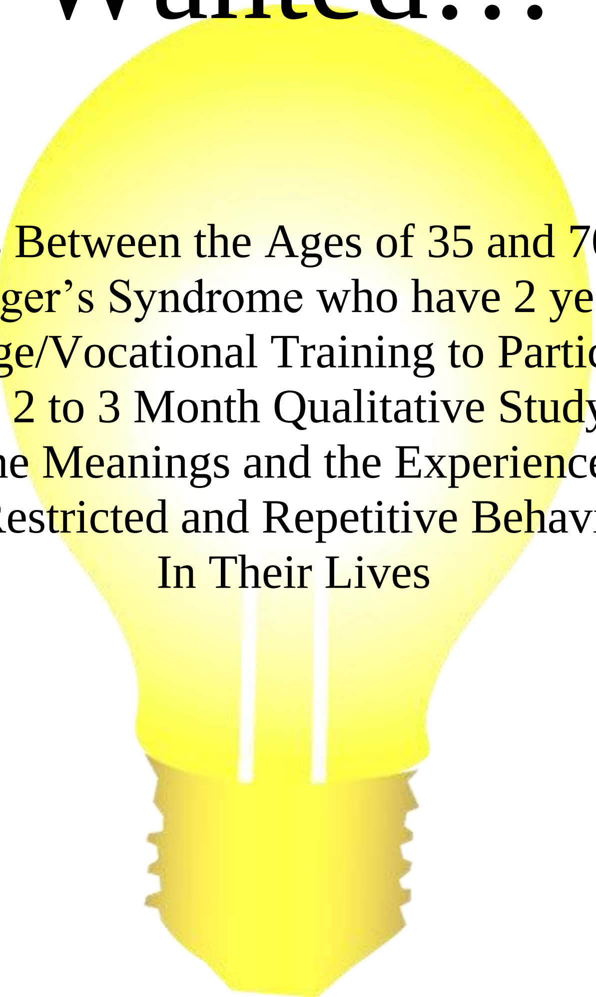
Appendix: Advertisement Flyer to Participate in the Study

Help

Wanted!!!



Adults Between the Ages of 35 and 70 with
Asperger's Syndrome who have 2 years of
College/Vocational Training to Participate
in a 2 to 3 Month Qualitative Study on
the Meanings and the Experiences
of Restricted and Repetitive Behaviors
In Their Lives