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EXAMINING RESTRICTED AND REPETITIVE BEHAVIOR IN CHILDREN WITH AUTISM: A DESCRIPTIVE STUDY

by

Dawn Deann Detweiler

A Thesis
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Faculty of The Graduate College
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Dawn Deann Detweiler

EXAMINING RESTRICTED AND REPETITIVE BEHAVIOR IN CHILDREN WITH AUTISM: A DESCRIPTIVE STUDY

Dawn Deann Detweiler

Western Michigan University, 2004

This exploratory study examined the specific topographies and corresponding demographic information of restricted, repetitive and stereotyped behaviors, interests and activities of children with autism, and evaluated developmental differences between age groups. Previous literature has largely neglected this core feature of autism despite the need, and frequent call for such foundational data (Bodfish et al., 2000; Kennedy et al., 2000; Mercier et al., 2000; Turner, 1999). Participants included primary caregivers of 104 children who met DSM-IV-TR criteria for autism (American Psychiatric Association, 2000) and ranged in age from 3 to 7 years (M = 4.7). The behaviors reported as occurring most frequently and reported by the most participants (regardless of frequency) were not motor stereotypies, which are often discussed in autism research, but included verbal and complex repetitive behaviors. Statistically significant effects were found for caregiver marital status and conflict level of the household for predicting the dependent variables of the child's distress at interruption of behavior and the caregiver's disturbance by the child's behavior. It is hoped that this information will contribute to a better understanding of this area of autism and will guide future research and affect future treatment for autistic disorder.

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INTRODUCTION

Autism is a pervasive developmental disorder defined by marked impairments in the three diagnostic areas of social interaction, communication, and restricted, repetitive and stereotyped behaviors (American Psychiatric Association, 2000). In order for a diagnosis to be made, impairments in theses areas must be observed prior to age three. Parents may first notice behaviors such as indifference to physical contact and affection, and abnormalities in responsiveness and eye contact as early as infancy. Parents typically seek professional advice out of concern that their child is deaf due to a noticeable lack of babbling and speech, as well as non-responsiveness to parental voices and other noises. Autism occurs 4 to 5 times more often in males than in females and reported prevalence rates are currently as high as 3.4 cases per 1,000 individuals (Yeargin-Allsopp et al., 2003). Effective diagnosis and treatment are clearly critical to improving functioning for these children, and research has demonstrated that the earlier intervention can begin, the more lasting and beneficial behavior changes can be (Lovaas, 1987). A better understanding of the diagnostic criteria for the disorder may lead to possibilities for earlier diagnosis and intervention and represent an excellent starting point.

The third defining diagnostic feature of autism is described in the *Diagnostic and Statistical Manual – Fourth Edition (Text Revision)* as "restricted, repetitive and stereotyped patterns of behavior, interests and activities" (American Psychiatric Association, 2000, p. 75). However, while these behaviors, interests and activities play a key role in autistic disorder, much more literature has been published regarding the two other diagnostic features of autism (i.e., impairments in communication and social interaction; Lancaster, LeBlanc, & Willett, 2000). Previous research has demonstrated

that many different behaviors fall under the rubric of this third defining element. These include: stereotyped motor movements such as hand flapping and body rocking, selfinjury, tics, stereotyped manipulation of objects such as repetitively spinning the wheels of a toy car, perseveration, insistence on sameness, obsessions, compulsions, echolalia, dyskinesia, akathisia, and circumscribed interests (Charlop-Christy & Haymes, 1996; Lewis & Bodfish, 1998; Mercier, Mottron, & Belleville, 2000; Turner, 1999). Turner (1997) points out that the three factors that clearly unite these heterogeneous behaviors are the high rate of repetition, the unvarying way in which the behavior is pursued, and the fact that the behavior is considered socially inappropriate in its display. However, despite these unifying factors, the actual terminology used to describe these behaviors has been ill defined and applied inconsistently (Bodfish, Symons, Parker, & Lewis, 2000; Turner, 1997). Due to this lack of specific definition, this paper will use the terms "restricted, repetitive and stereotyped" somewhat interchangeably to refer to the heterogeneous class of behavior included in the diagnostic criteria. However, improved diagnosis and treatment of autistic disorder requires a better understanding and clinical definition of this third diagnostic element.

Developmental research has demonstrated that these behaviors are present to some extent in typically developing children, college students, and most adults (Berkson, Rafaeli-Mor, & Tarnovsky, 1999; Militerni, Bravaccio, Falco, Fico, & Palermo, 2002). Militerni et al. point out that the feature of repetitive behavior that distinguishes autistic children from typically developing children is the degree of perseveration. For example, even adults may engage in brief periods of repetitive behavior in instances of boredom or concentration (Nuzzolo-Gomez, Leonard, Ortiz, Rivera, & Greer, 2002). We all have

hobbies and favorite topics of conversation that could be labeled as "restricted interests." However, most of our behavior has been socially mediated to prevent the development of socially unacceptable perseveration. Previous research has demonstrated that the degree and severity of perseveration of autistic children with these stereotyped behaviors can interfere with learning and social behavior and may evolve into potentially dangerous self-injurious behavior (Guess & Carr, 1991; Lovaas, Newsom, & Hickman, 1987; Willemsen-Swinkels, Buitelaar, Dekker, & Engeland, 1998). As clinicians and researchers, it is essential to establish a better understanding of the course of development of these behaviors in children with autism. Again, little research presently exists in this area (Charman & Swettenham, 2001; Mercier et al., 2000; Militerni et al.; Turner, 1997).

Most previous research in the area of restricted and repetitive behaviors has focused on determining the function and decreasing the occurrence of motor forms of these behaviors. Different theories have been postulated regarding the function of these behaviors including socially mediated reinforcement such as escape and avoidance of unwanted tasks (Durand & Carr, 1987; Murphy, MacDonald, Hall, & Oliver, 2000; Shabani, Wilder, & Flood, 2001), automatic sensory reinforcement (Britton, Carr, Landaburu, & Romick, 2002; Foxx & Azrin, 1973; LeBlanc, Patel, & Carr, 2000; Lovaas et al., 1987; Patel, Carr, Kim, Robles, & Eastridge, 2000; Stein & Niehaus, 2001), and sensory regulation (Gal, Dyck, & Passmore, 2002) among the most common. Lovaas et al. (1987) hypothesized that stereotypic behaviors in autism serve as powerful unconditioned reinforcers that require no prior conditioning. Other researchers have supported this hypothesis by using stereotypies as reinforcers to decrease dangerous and destructive behaviors (Charlop-Christy & Haymes, 1996). Most of this research has

included limited or single subjects and has been largely idiosyncratic in nature. While understanding individual differences is critical in developing individual treatment, important commonalities in the development and form of repetitive behaviors that could be key to providing better treatment may be overlooked and under-researched.

The limited previous research leaves many essential questions unanswered resulting in a weak research foundation. A lack of cross-sectional and longitudinal research results in a limited understanding of the relationship between stereotypic behaviors and developmental stages. It is not known if commonalities exist in the age of onset or in the topography of these behaviors (Turner, 1999). In their literature review, Gray and Tonge (2001) found that although infants and preschoolers tended to exhibit relatively no ritualistic or stereotyped behaviors, older children and adults did tend to exhibit those behaviors, leading one to believe that the developmental process itself may have some effect on these behaviors. Militerni et al. (2002) also noted developmental differences in the appearance of these behaviors when they found that younger children with autism displayed more motor and sensory stereotypies while older children with the disorder displayed more complex ritualized behaviors such as obsessions, compulsions and unusual knowledge of one subject area. One of the only published studies using interviews with high-functioning individuals with a diagnosis of autism and their families indicated that these restricted and repetitive behaviors were not fixed, but evolved over time (Mercier et al., 2000). These individuals reported that their behaviors changed over time as they developed knowledge of social norms, and as they matured and developed different interests. That is, as they developed different interests, they decreased the frequency and intensity of their restricted behaviors and interests, and sometimes

completely ended them. This finding supports the hypothesis that the developmental process may play some role in the topography and possibly the intensity of these behaviors. It remains to be determined whether restricted and repetitive behaviors in children with autism worsen or improve with age. Research examining these developmental questions is essential.

We also have very limited research regarding demographic effects in relation to stereotypy. Wolery and Garfinkle (2002) concluded that there is far too little information regarding children's family characteristics, and ethnicity in the existing literature on autism. Developmental research has demonstrated that demographic factors such as socioeconomic status, number of siblings, race, ethnicity, and parental factors such as marital status, level of education, physical and mental health and external support systems all can serve as risk or resilience factors in a child's development. It logically follows that research on autism should also examine the relation between these factors and the diagnostic criteria for the disorder. Challenges arise in evaluating these factors, however, due to the fact that many of the factors themselves contribute to the accessibility of services for many children. Statistically we can expect that most children receiving treatment are from relatively stable families of higher socioeconomic status who are able to both fund and adhere to treatment. Future research should consider this possible caveat and examine the effects of these demographic variables as thoroughly as possible.

In addition, individual characteristics of the child such as age, race, gender, level of education, verbal ability, cognitive skill level, and autism severity should also be assessed in relation to the occurrence of stereotyped behaviors. Previous research has

demonstrated a relation between the severity of stereotyped behaviors and the overall severity of autistic disorder (Bodfish et al., 2000; Campbell et al., 1990; Howlin, Goode, Hutton, & Rutter, 2004; Lewis & Bodfish, 1998). Militerni et al. (2002) found a correlation between the number of repetitive behaviors and severity of autism as measured by individual Childhood Autism Rating Scale (CARS) scores. Further research addressing individual characteristics should also include an assessment of possible links between environmental factors (e.g., school attendance, number of caregivers, opportunities for social interaction, number of siblings) and restricted and repetitive interests (Kennedy, Meyer, & Knowles, 2000; Wolery & Garfinkle, 2002).

The heterogeneity of topographical forms of stereotyped behaviors may be part of the reason for researchers' neglect of this area of study (Militerni et al., 2002). This heterogeneity can make data collection and analysis challenging. For these reasons, researchers frequently collapse stereotyped behaviors into categories such as simple motor or movement stereotypies, and more complex behaviors such as adherence to routine, ordering, a need for sameness or an unusual knowledge and interest in one subject (Rutter, 1996; Turner, 1999). While this may sometimes be useful for ease of data collection and analysis, it can result in a potential loss of critical information (Lovaas et al., 1987). For example, when research broadly describes behaviors as simply repetitive or restricted, important information may be excluded. Critical differences in both topography and function may exist between motor behaviors such as hand flapping and compulsions such as ordering or a restricted interest in one subject area. Limited previous research has focused on specific topographies of the broader class of repetitive behaviors (Campbell et al., 1990; Rojahn, Tasse, & Sturmey, 1997); therefore, much

more emphasis is required in this area. In order to more accurately diagnose and treat autism, we need to develop better clinical and operational definitions of restricted and repetitive behaviors that take into account the significance of their form and content as well as their function (Kennedy et al., 2000; Rutter, 1996; Turner, 1999).

Further research in the area of restricted, repetitive and stereotyped behaviors is essential for many reasons. As clinicians, better understanding of this key diagnostic criterion might lead to more accurate diagnosis and improved treatment. An understanding of the developmental process of these behaviors and their initial forms will allow for earlier diagnoses. Earlier diagnosis leads to the possibility of earlier intervention, which has been shown to result in more successful treatment outcomes and individual improvements (Charman & Swettenham, 2001; Gray & Tonge, 2001). There are also important issues of social validity for pursuing additional research in this diagnostic area. Individuals with autism and their family members interviewed by Mercier et al. (2000) reported improved pride and self-esteem, happiness, and greater social acceptance after learning to self-monitor and reduce or eliminate stereotyped behaviors. Parents and family members also reported satisfaction with observed improvements in daily functioning. In order to provide the improved treatment called for by caregivers and family members of individuals with autism, we must first have a more complete understanding of the processes involved in the onset, development, and progression of restricted and repetitive behaviors (Lewis & Bodfish, 1998; Mercier et al.).

Because it is important to better understand the relation between stereotypic behaviors and developmental stages, the current study includes participants who

represent a developmental range of ages. An optimal starting age for this developmental range was determined to be three years. Gray and Tonge (2001) point out that most diagnoses of autism are determined between the ages of 30 to 54 months and that parents often begin noticing developmental problems and delays by this time. The upper age limit for participation (seven years) was selected to create a broad enough range to display significant developmental changes, providing for the power of comparison between age groups that has been absent in previous research. Because parents can be expected to provide accurate and specific information regarding behavior observed in their children (Gray & Tonge; Lord, 1995; Militerni et al., 2002), parental observations of stereotypic behavior were utilized for the current study. Such a developmental approach has been suggested in many previous studies (Charman et al., 2001; Mercier et al., 2000; Rutter, 1996; Turner, 1999).

This explorative study was designed to contribute information regarding the specific topographies and corresponding demographic information of restricted, repetitive and stereotyped behaviors, interests and activities, as well as to provide developmental comparisons between age groups. Previous literature has largely neglected these areas despite the need, and frequent call for such foundational data (Bodfish et al., 2000; Kennedy et al., 2000; Mercier et al., 2000; Turner, 1999). It is hoped that a better understanding of this information will guide future research and lead toward more accurate and possibly earlier diagnosis as well as more effective treatment for autistic disorder and the behaviors encompassed in its third diagnostic feature.

METHOD

Participants

Participants included primary caregivers of 104 children who met DSM-IV-TR criteria for autism (American Psychiatric Association, 2000) and ranged in age from 3 years to 7 years (M = 4.7). Respondents to the survey totaled 121, however, the data of 17 were excluded from analysis based on criteria listed below. Staff and administrators of the Autism Society of America in several states were contacted and asked to include an Internet address for the study's survey site in their monthly newsletters or to post the Internet address in a prominent location. In addition, information was posted on several Internet listservs and message boards for caregivers of children with autism, including The Autism Message Board, Help 4 Autism Message Board, AUT-2B-HOME, Autism List, Parents of Autistic Children, Autism ABA, AUTINET Forum, Developmental Delay, Autism Aspergers, Parenting Autism, and Our Kids. Participation was completely voluntary and depended on individuals linking to the Internet survey site and completing the survey. Participants responded from a total of 28 states in the continental United States (see Table 1). All foreign responses were excluded (n=3). Caregivers identified themselves as 88 mothers (85%), 2 fathers (2%), 10 "parents" (10%), 3 grandmothers (3%), and 1 aunt (1%). Mean caregiver age was 36 years. These caregivers reported information on 80 boys (77%), and 24 girls (23%) who represented 31 three-year-olds (30%), 20 four-year-olds (19%), 22 five-year-olds (21%), 14 six-yearolds (13%), and 17 seven-year-olds (16%).

Table 1

Participant Geographical Information (N=104)

State	Number Responding		
AL	Alabama	. 3	
AR	Arkansas	1	
ΑZ	Arizona	4	
CA	California	6	
CT	Connecticut	1	
FL	Florida	3	
GA	Georgia	8	
IA	Iowa	1	
ID	Idaho	1	
IL	Illinois	6	
LA	Louisiana	3	
MA	Massachusetts	1	
MD	Maryland	2	
MI	Michigan	3	
MO	Missouri	2	
NH	New Hampshire	6	
NJ	New Jersey	5	
NY	New York	2	
ОН	Ohio	6	
OK	Oklahoma	1	
OR	Oregon	2	
PA	Pennsylvania	8	
TN	Tennessee	4	
TX	Texas	21	
VA	Virginia	1	
VT	Vermont	1	
WA	Washington	1	
WI	Wisconsin	1	

Forty-nine percent of these children were diagnosed with additional disorders including Aspergers, Pervasive Developmental Disorder Not Otherwise Specified (PDD/NOS), Mental Retardation (MR), and Cerebral Palsy (see Table 2). Six children diagnosed with Chronic Tic Disorder, Tourette's Syndrome or seizure disorders were excluded from participation. The data of eight respondents who did not complete the survey were also excluded from analysis.

Table 2

Diagnoses in Addition to Autism (N=104)

Diagnosis	Number Reported	Percentage	
Aspergers	15	14	
PDD/NOS	28	27	
MR	5	5	
Cerebral Palsy	3	3	

Several other demographic factors were evaluated from the survey results. Table 3 contains information regarding the number of children reported to be in each household. Forty-five children (43%) obtained a diagnosis of autism from only one source, twenty-six (25%) from two sources, twenty-five (24%) from three sources, and eight (8%) from four sources. Thirty-six children (35%) were receiving in-home educational services. Additional caregiver information was also evaluated. Nineteen caregivers (18%) reported completing a high school education, twelve (12%) reported completing a

technical or trade school, fifty-eight (56%) obtained a college or university degree, and fifteen (14%) completed graduate school. Forty-seven (45%) of caregivers reported that they were stay-at-home parents with no outside occupation.

Table 3

Number of Children in the Household

Number of Children	Number Reported	Percentage
,		
1	20	19%
2	46	44%
3	27	26%
4	10	10%
5	0	0%
6	1 1 j	1%

The majority of caregivers were married (88%). Five (5%) caregivers were single, three (3%) were divorced, three (3%) were separated, and one (1%) caregiver was remarried. Twenty-four caregivers (23%) reported excellent support from extended family members, forty-five (43%) reported good or average support, and thirty-five (34%) reported poor support from extended family. A majority of caregivers (63%) and children (55%) were reported to have good/average overall health. Most caregivers reported an income ranging from \$35,000 to 99,999.

The distribution of household income reported corresponded with the most recent statistics from the Statistical Abstracts of the United States (2000) census data. However, the percentage of caregivers who reported an income of \$15,000 or less was lower than the national average (see Table 4).

Table 4

Distribution of Caregiver Household Income

Household Income	Number Reported	% Reported	% U.S. Census
Under \$15,000	2	2%	9.6%
\$15,000-24,999	10	10%	11.5%
\$25,000-34,999	9	9%	12.0%
\$35,000-49,999	17	16%	15.9%
\$50,000-74,999	36	35%	21.5%
\$75,000-99,999	14	13%	12.6%
\$100,000-149,999	9	9% -	
\$150,000-199,999	5	5%	— 17.0%
\$200,000 and above	2	2%	

A majority of caregivers (54%) reported a low conflict level within the household, and 37% reported a moderate conflict level. Additionally, as expected, a majority (70%) of participating caregivers obtained a degree from either a college or university or a graduate school. This was significantly higher than the national average reported by the

U.S. Census Bureau from 2003, which reported that 27.2% of the population aged 25 and older had obtained a Bachelor's Degree or higher. Finally, 45% of caregivers reported that they currently stay at home with the autistic child. This figure corresponded with findings published by the National Institute of Child Health and Human Development (NICHD) which stated that 39-42% of mothers remain at home with children from birth to 6 years of age (NICHD Early Child Care Research Network, 2003).

Procedure and Materials

The survey was conducted through an online Internet site called Survey Monkey. This site provided the tools and format for creating a survey and ensured the encryption and confidentiality of all data collected. The Internet survey created included a Demographic portion that provided information such as the caregiver's level of education, number of children in the household, and income level of household, and a Behavior Assessment portion that evaluated the restricted, repetitive and stereotyped nature of 52 behaviors of the child with autism. Participants first encountered a screen that explained the purpose of the study and the requirements for participation. This screen stated that all information collected would be completely anonymous, that continuing the survey signaled their consent for participation, and that they could withdraw from the survey at any time by simply exiting. Participant surveys that withdrew without answering all questions were excluded from data analysis.

Demographic Portion. Participants next encountered the demographic portion of the survey. In this section 22 questions were asked regarding demographic information such as the age, gender and additional diagnoses of the child, the state they are living in, caregiver age, occupation, marital status, and household income and conflict levels.

Eight of these questions were open-ended and the remaining 14 provided multiple responses of which 11 permitted the caregiver to select only one response and 3 that permitted multiple responses. See Appendix A for a sample of the format and order of questions.

Behavior Assessment Portion. The Behavior Assessment portion of the survey was developed by the author based largely on scale items included in the Repetitive Behavior Scale (RBS; Bodfish et al., 2000) as well as scale items included in the Gilliam Autism Rating Scale (GARS; Gilliam, 1995). This portion of the survey addressed 52 specific behaviors such as body rocking, head nodding, hand flapping, spinning in circles, self-injury, counting, arranging, unusual interest in one subject area, and insistence on same routine. Table 5 gives the specific descriptions that parents saw on the survey screen of the complex behaviors included for scoring. The screens that caregivers saw for Motor/Vocal non-injurious behaviors and Self-injurious behaviors looked identical to this in format without a definition of behavior (e.g., Hand Flapping was simply listed at the top of the screen with rating questions below), due to the fact that the behavior titles were more self-descriptive than the Complex behaviors. For each specific behavior, participants were asked to code how frequently the behavior occurred (i.e., never, weekly/monthly, daily, or hourly), the child's response to interruption of the behavior (i.e., calm or distressed), and whether the behavior disturbs the caregiver (i.e., yes or no). Participants were instructed to base their responses on current observations and recollections of their child's behavior in the last month. Behaviors to be rated were ordered by type (i.e., motor/non-injurious, self-injurious, and complex). See Appendix B for a list of the order behaviors were presented in. Responses were selected

Table 5

Descriptions of Complex Behaviors

Behavior	Description
Arranging/Ordering	Arranging objects in a particular pattern or
	place, or a need for things to be symmetrical
Completeness	Insisting on a door being open or closed or
	Taking all items out of containers or spaces
Washing/Cleaning	Excessively cleaning certain body parts or
	Obsessively picking at loose threads or lint
Checking	Repeatedly checking doors, windows, drawers,
	clocks, locks, etc.
Counting	Counting items or objects, counting to a certain
	number or counting in a certain way
Hoarding/Saving	Collecting, hoarding, or hiding specific items
Repeating	Needing to repeat routine events such as coming
	in & out of a door, getting up & down from a
	chair, or putting clothing on & taking it off
Touching/Tapping	Needing to touch, tap, or rub items, surfaces or
	people
Eating/Mealtime Issues	Strongly preferring or insisting on eating or
	drinking only certain things, eating or drinking
	in a set order, or insisting that items are arranged
	or prepared in a certain way
Play Issues	Insisting on certain play activities, following
	rigid routines during play, or insisting that others
	do certain things during play
	5 -5. 7

electronically (i.e., mouse-click) for each behavior (see Appendix C for a sample survey screen). If a behavior's frequency was reported as "never," participants were permitted to continue to the next behavior screen without responding to the questions regarding the child's response to interruption and whether or not the behavior disturbed the caregiver.

Two final items included in this portion asked participants to identify the one behavior that they felt occurred most frequently as well as the one behavior that they would be most likely to seek treatment to change or eliminate. These questions were asked to determine whether participants' open-ended responses would vary from the rating scores previously recorded, or whether behaviors would be identified that were not included in the original 52 rating questions.

RESULTS

The scores from the first question participants were asked for each behavior (i.e., how often the behavior occurs) were evaluated in three different ways. First, the mean frequency for each of the 52 behaviors was calculated. Each caregiver report of the frequency of the behavior was given a corresponding numeric value (i.e., never (0), weekly/monthly (1), daily (2), or hourly (3)). Scores were totaled for each behavior and divided by the number of participants to produce a mean score. The mean scores closest to 3 determined which behaviors received the highest scores (indicating that they were reported as occurring the most frequently). Means ranged from .15 (Biting Self) to 1.88 (Repeating Sounds). The five behaviors reported as occurring most frequently included Repeating Sounds (1.88), Eating/Mealtime Issues (1.6), Need for Completeness (1.5), Repeating DVD/CD (1.46), and Arranging/Ordering (1.42) (see Figure 1).

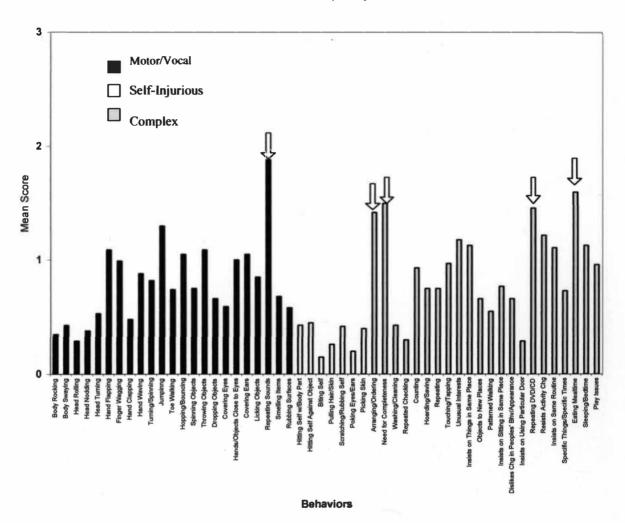
Next, in order to determine which behaviors caregivers reported as most commonly occurring regardless of the frequency of the behavior, a count of all non-zero scores (i.e., a 1, 2 or 3) was performed for each of the 52 behaviors. The number of caregivers reporting any occurrence of a behavior ranged from 14 (Biting Self) to 91 (Repeating Sounds). The most reported behaviors were Repeating Sounds (91), Arranging/Ordering (86), Repeating DVD/CD (86), Need for Completeness (85), Resisting Activity Change (83), and Jumping (82) (see Figure 2).

Finally, in order to determine which behaviors were most reported as occurring on an hourly basis, a count was performed for the number of responses chosen as "hourly" (i.e., 3). The number of caregivers responding that a behavior occurred hourly ranged from 0

(Biting Self, Pulling Hair/Skin, Head Rolling, & Body Rocking) to 35 (Repeating Sounds).

Figure 1

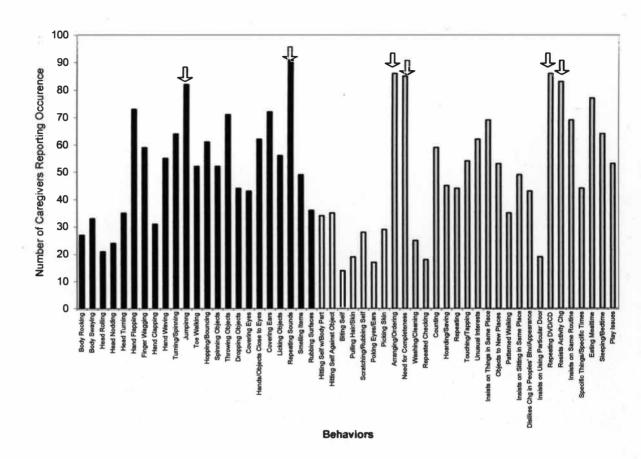




The six behaviors most reported as occurring hourly were Repeating Sounds (35), Eating/Mealtime Issues (22), Repeating DVD/CD (17), Unusual Interest in One Subject Area (14), Touching or Tapping Objects (13), and Need for Completeness (13). Commonalities were found between these three analyses of the behavior frequency data.

Figure 2





First of all, three behaviors were included as most reported in all three of the frequency analyses. These behaviors were Repeating Sounds, Need for Completeness and Repeating DVD/CD. Additionally, two behaviors (i.e., Eating/Mealtime Issues and Arranging/Ordering) were included as most reported in 2 of the 3 frequency analyses.

Next, an analysis was performed of the questions regarding whether the child displayed distress at interruption of behaviors reported as occurring and whether the caregiver is disturbed by the behavior. Responses to these questions were dichotomous (e.g., "Does Not Disturb Me (1)" or "Disturbs Me (2)"). To determine which behaviors

caregivers reported as most typically resulting in distress with interruption, a count was performed for all responses of "Distressed if Interrupted" (i.e., 2) across all behaviors. Because not all caregivers responded to this question (i.e., if the behavior did not occur), the results of the count were then divided by the number of times the behavior was endorsed as occurring at any level of frequency. The resulting percentages are reported. The six behaviors reported as resulting in the most distress with interruption were Eating/Mealtime Issues (90%), Resists Activity Change (89%), Objects to New Places (87%), Play Issues (87%), Insisting on Sitting in the Same Place (84%) and Insisting on Things Remaining in the Same Place (84%) (see Table 6).

The six behaviors reported as disturbing caregivers most were Biting Self (100%), Hitting Self with Object (83%), Hitting Self with Body Part (82%), Pulling Hair/Skin (84%), Eating/Mealtime Issues (77%), and Licking Objects (77%) (see Table 7).

Caregivers reported which behaviors they felt occurred most frequently and which behaviors they would choose to change or end in an open-ended format to determine whether these responses would vary from the rating scores previously recorded, or whether behaviors would be identified that were not included in the other 52 rating questions.

Ninety-nine caregivers responded to the open-ended question regarding which behavior they felt occurred the most frequently. Thirty different behaviors were identified and the number of caregivers reporting each behavior ranged from 1-11. The six behaviors reported to occur most frequently were Repeating Sounds/Words (11), Hand Flapping (11), Insisting on the Same Routine (6), Repeating DVD/CD (6), Arranging and Ordering (6), and Screaming (6). Four behaviors that were not included in

the original 52 behaviors were reported by caregivers. These behaviors were Screaming, Eye Blinking, Toileting Behaviors, and Throwing Tantrums. Eighty-four caregivers

Table 6

Most Reported Behaviors Resulting in Distress with Interruption for the Child

Behavior	Percent Reported	
Eating/Mealtime Issues	90%	
Resists Activity Change	89%	
Objects to New Places	87%	
Play Issues	87%	
Insisting on Sitting in Same Place	84%	
Insisting on Things Remaining in Same Place	84%	

responded to the open-ended question regarding which behavior they would most like to seek treatment to change or end. Twenty-eight different behaviors were identified and the number of caregivers reporting each behavior ranged from 1-7. The six behaviors reported to be the ones caregivers would seek to change or end were Resists Activity Change (7), Eating/Mealtime Issues (7), Repeating Sounds/Words (7), Tantrums (7), Screaming (7), and Hand Flapping (7). Screaming, Eye Blinking, Throwing Tantrums, Toileting Behaviors, Hitting Others and Humming were the behaviors identified on this question that were not included in the original 52 that were evaluated. Both open-ended

questions resulted in overlap of the most commonly reported responses of Repeating Sounds/Words, Hand Flapping, and Screaming.

Table 7

Most Reported Behaviors That Disturb Caregivers

Behavior	Percent Reported	
Biting Self	100%	
Pulling Hair/Skin	84%	
Hitting Self with Object	83%	
Hitting Self with Body Part	82%	
Eating/Mealtime Issues	77%	
Licking Objects	77%	

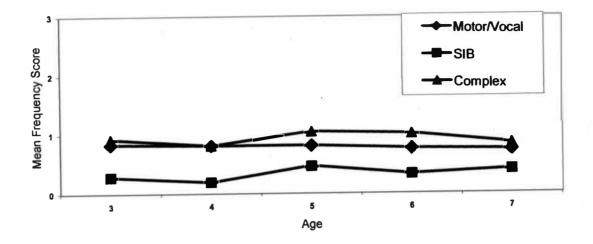
A stepwise multiple regression analysis was performed across all ages for coded demographic factors to determine which demographic factors predicted higher scores on the three dimensions measured (i.e., mean frequency of behavior occurrence, distress at interruption of behavior, and caregiver disturbance by behavior). Demographic factors included in this analysis were child's school status, child's age, child's overall health, caregiver education, caregiver marital status, household income, number of children in the household, conflict level of the household, number of residential relocations, and perception of extended family support. For the dependent variable frequency of behavior, no demographic factors were found to be significant predictors. For the

dependent variable of "Distress at Interruption of Behavior" at an alpha level of .05, the effect of caregiver marital status was statistically significant, F = 6.15, p = .015 (i.e., in households with married caregivers, the children displayed less distress at interruption of behaviors). The effect of the conflict level of the household was also statistically significant, F = 7.18, p = .009, for the dependent variable "Distress at Interruption of Behavior" (i.e., the higher the conflict level of the household, the more the child was distressed at interruption of behaviors). For the dependent variable "Caregiver Disturbance by Behavior," the effect of caregiver marital status was statistically significant, F = 8.59, p = .004, and the effect of the conflict level of the household was also statistically significant, F = 7.00, p = .01 (i.e., in households with married caregivers, the caregivers were less likely to be disturbed by behaviors, and, in households with higher conflict levels, caregivers were more likely to be disturbed by behaviors).

An analysis of behavior frequency by age and type of behavior (i.e., Motor/Vocal (non-injurious), Self-injurious, and Complex) was also performed. Behavior frequency scores were totaled for every age group (i.e., 3, 4, 5, 6, and 7-year-olds) for each type of behavior and the mean was calculated by dividing the total behavior frequency score by the number of children in the group and the number of behaviors represented in each behavior group. There were 23 "Motor/Vocal (Non-injurious)" behaviors, 7 "Self-injurious" behaviors, and 22 "Complex" behaviors included in the 52 behaviors evaluated. Results demonstrated that Complex behaviors were more common for all age groups, followed by Motor/Vocal (Non-injurious) and finally Self-injurious behaviors.

Figure 3

Behavior Type by Age



DISCUSSION

The results of this research provide important information on specific topographies of repetitive behavior. First, the behaviors reported as occurring most frequently were not motor stereotypies, which are often discussed in autism research, but instead included verbal and more complex behaviors (i.e., Repeating Sounds/Words, Eating and Mealtime Issues, Need for Completeness, Repeating a DVD or CD, Arranging and Ordering). Similarly, the behaviors most commonly endorsed by caregivers (regardless of level of frequency) also included verbal and more complex behaviors (i.e., Repeating Sounds/Words, Arranging and Ordering, Repeating a DVD or CD, Need for Completeness, Resisting Activity Change). Additionally, an age analysis demonstrated that topographies included in the complex group were most common for all age categories. The current findings may be generalized to a population of U.S. children with autism aged 3 to 7 due to the variety of demographic factors represented by the responding sample. However, it is important to note that, compared to national averages, this study had a smaller representation of individuals in the lowest income bracket (i.e., \$15,000 and below) and a higher representation of caregivers with a four-year degree or higher. Although these discrepancies exist in the sample, statistical analysis in the form of regression analysis did not indicate that these factors were significantly predictive of results supporting the notion that these results are generalizable. However, future research should specifically focus on recruiting from these groups in order to make comparisons to the current research.

The findings of this study differ from the results of Militerni et al. (2002) and the literature review of Gray and Tonge (2001), who found that younger children with autism displayed more motor and sensory stereotypies while older children with the disorder displayed more complex ritualized behaviors. Militerni et al. examined the behaviors of 121 children with autism aged 2-11. Because the mean age for the current research was 4.7, it would be expected, based on the research of Militerni et al., that a higher number of motor behaviors would be reported as occurring most frequently. However, since Militerni et al. examined a larger range of ages and implemented a different method of statistical analysis, it is unknown what the current study's results might have demonstrated if the exact methods of Militerni et al. had been replicated. Future research should have an increased focus on the complex repetitive behaviors and restricted interests that occurred commonly for children in our sample in order to determine more specifically the type and topography of behaviors demonstrated at various developmental stages.

When caregivers were allowed to self-report the behavior they felt occurred most frequently and the behavior they would most seek to change or end, six additional behaviors emerged which were not included in the original survey. Screaming, eye blinking, throwing tantrums, toileting behaviors, hitting others and humming were the behaviors identified that were not included in the original 52 that were evaluated. Tantrums, hitting others and toileting behaviors may not appropriately fall under the rubric of repetitive behaviors or restricted interests, but may, instead, have been reported based on the parents desire to change or end what might be better classified as problem behavior or skills deficits. More specific information would need to be collected on the

nature of these behaviors in order to discuss their inclusion in the category of stereotypies. However, it may be that screaming and humming are more specific topographies of the behavior "Repeating Sounds or Words", and that eye blinking may be an additional specific form of a "Motor/Vocal" stereotypy that should be examined more carefully in future research.

It is important to consider that the behaviors reported as causing the most distress with interruption did not correspond to the behaviors reported as disturbing caregivers most. If caregivers are not bothered as much by these behaviors and know that interruption will lead to the child's distress, it is highly likely that they do not continue to interrupt the behavior. This may allow for an increase in the rigidity and severity of these behaviors over time, eventually leading to serious caregiver concern regarding their occurrence. Future research should consider the fact that treatment of the behaviors reported as causing the most distress at interruption might require specific planning in order to minimize the child's distress and might be more difficult to implement.

A stepwise multiple regression analysis did not find that age was a significant predictor of the dependent variables (i.e., frequency of behavior occurrence, distress at interruption of behavior, and caregiver disturbance by behavior). Because previous research has demonstrated a relation between age and type and severity of behavior (Gray & Tonge, 2001; Mercier et al., 2000; Militerni et al., 2002), it is suggested that future research examine this area more fully. A possible limitation of the current research may be the limited range of ages. Future research should include a larger sample size representing a broader developmental range.

Analysis did find a significant effect for two demographic factors in predicting the dependent variables of "Distress at Interruption of Behavior" and "Caregiver Disturbance by Behavior." These predictive factors were the marital status of the caregiver and the conflict level of the household. This finding demonstrates that households where the caregivers were single, divorced, or separated, and households with a higher level of conflict resulted in the child showing higher levels of distress at interruption of behaviors and the caregiver reporting a higher level of disturbance by behaviors. This corresponds with previous developmental research (Kennedy, Meyer, & Knowles, 2000; Wolery & Garfinkle, 2002) indicating that such factors can influence a child's developmental process. These findings indicate the importance of family stability and level of conflict in the development and successful treatment of repetitive behaviors and restricted interests. Researchers and clinicians should consider the fact that, in children from households with single, divorced or separated caregivers or households with high levels of conflict, it may be more difficult to treat restricted and repetitive behaviors due to the child's higher level of distress at the behavior's interruption. Additionally, because caregivers may be more disturbed by behaviors occurring in households with these characteristics, it may be the case that tensions and conflict levels within the household could be exacerbated by the occurrence of behaviors and adherence to treatment protocols might be difficult. Additional services, such as concurrent family counseling, may be helpful in order to achieve the best treatment outcomes when addressing these behaviors.

Possible limitations of this research are that, due to the fact that it was Internet-based (requiring a computer), certain families might not have had access to participation as a

result of limited finances, skills or time. One possible indication of this is the lower percentage of responses from caregivers reporting a household income level of \$15,000 or below. Although statistical analysis in this study did not find significant effects for this demographic factor, future research may want to consider multiple methods of contact possibly including paper-based and phone/verbal survey techniques in order to capture a socioeconomic level that may have been inadvertently overlooked in the current study.

It is hoped that the information provided in this research will serve to guide future research and lead toward earlier and more accurate diagnosis as well as more effective treatment for autistic disorder and the behaviors encompassed in its third diagnostic feature. If clinicians are currently monitoring and assessing young children for more simple "Motor/Vocal" stereotypies in order to determine if a diagnosis of Autistic Disorder is warranted, it is possible that a diagnosis might be missed even though more "Complex" stereotypies are present. A more thorough understanding of specific behavior topographies that are typically demonstrated at certain ages should improve our ability to more accurately assess and diagnose children suspected to have the disorder at an earlier age allowing earlier intervention to lead to more lasting and beneficial changes in behavior (Lovaas, 1987). Better knowledge of the specific behavior topographies and the developmental stages they occur at will allow for more specific tailoring of treatment plans addressing those behaviors.

This research provides important information on specific topographies of repetitive behaviors and restricted interests, as well as on corresponding demographic factors and how they relate to these behaviors. Because this study was not longitudinal, limited information was obtained on the developmental progression of stereotypic behaviors.

This information could be obtained from future longitudinal research utilizing a larger sample size. In addition, future research should address comparisons to a sample of typically developing children in order to obtain more complete information regarding the developmental process of these behaviors. Finally, replication of the current study is recommended in order to better determine the ability to generalize the current results.

Appendix A

Demographic Portion of Survey

Appendix A

Demographic Portion of Survey

Behavior Assessment Survey					Exit this survey >		
2. Demog	raphic In	formatio	on				
Before you please take household.	_	•		•		•	
* 2. What is	the age of	the child y	ou based th	is survey	informatio	n on?	
6							
* 3. What is	the gender	of this ch	ild?				
Male	Fema	ile					
V	ر			ie.			
* 4. What co	anditions ha	e this chil	d been form	ally diagn	osed with?	CHECK	
ALL THAT		is this thin	a been form	ally diagn	osed with:	(CIIECK	
Autism	Aspergers	PDD/NOS	Mental Retardation	Cerebral Palsy	Tourette's Syndrome	Chronic Tic Disorder	
	_			-	-	-	

Appendix B

Presentation Order of Behaviors Surveyed

Appendix B

Presentation Order of Behaviors Surveyed

- 1. Body Rocking
- 2. Body Swaying
- 3. Head Rolling
- 4. Head Nodding
- 5. Head Turning
- 6. Hand Flapping
- 7. Finger Wagging
- 8. Hand Clapping
- 9. Hand Waving
- 10. Turning/Spinning
- 11. Jumping
- 12. Toe Walking
- 13. Hopping/Bouncing
- 14. Spinning Objects
- 15. Throwing Objects
- 16. Dropping Objects
- 17. Covering Eyes
- 18. Hands/Objects Close to Eyes
- 19. Covering Ears
- 20. Licking Objects
- 21. Repeating Sounds
- 22. Smelling Items
- 23. Rubbing Surfaces
- 24. Hitting Self w/Body Part
- 25. Hitting Self Against Object
- 26. Biting Self
- 27. Pulling Hair/Skin

- 28. Scratching/Rubbing Self
- 29. Poking Eyes/Ears
- 30. Picking Skin
- 31. Arranging/Ordering
- 32. Need for Completeness
- 33. Washing/Cleaning
- 34. Repeated Checking
- 35. Counting
- 36. Hoarding/Saving
- 37. Repeating
- 38. Touching/Tapping
- 39. Unusual Interests
- 40. Insists on Things in Same Place
- 41. Objects to New Places
- 42. Patterned Walking
- 43. Insists on Sitting in Same Place
- 44. Dislikes Change in

 Behavior/Appearance of Others
- 45. Insists on Using Particular Door
- 46. Repeating DVD/CD
- 47. Resists Activity Change
- 48. Insists on Same Routine
- 49. Insists on Specific Things at Specific Times
- 50. Eating/Mealtime
- 51. Sleeping/Bedtime
- 52. Play Issues

Appendix C

Behavior Assessment Screen

Appendix C

Behavior Assessment Screen

Behavior Assessment Survey

Exit this survey >>

33. Arranging/Ordering

Arranging objects in a particular pattern or place or a need for things to be symmetrical

* 114. Arranging/Ordering

Never Weekly or Daily Hourly

115. How does your child respond when this behavior is interrupted?

Calm if Distressed if interrupted

116. How do you feel about your child displaying this behavior?

It does not disturb me

It disturbs me

<< Prev Next >>

Appendix D

Human Subjects Review Board Approval

Date: February 6, 2004

To: Linda LeBlanc, Principal Investigator

Dawn Detweiler, Student Investigator for thesis

From: Mary Lagerwey, Ph.D., Chair

Re: HSIRB Project Number: 03-10-23

This letter will serve as confirmation that your research project entitled "Examining Restricted and Repetitive Behavior in Children with Autism: A Descriptive Study" has been **approved** under the **expedited** category of review by the Human Subjects Institutional Review Board. The conditions and duration of this approval are specified in the Policies of Western Michigan University. You may now begin to implement the research as described in the application.

Please note that you may **only** conduct this research exactly in the form it was approved. You must seek specific board approval for any changes in this project. You must also seek reapproval if the project extends beyond the termination date noted below. In addition if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: February 6, 2005

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