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Characterization and Utilization of Preferred Interests: A Survey of Adults on the Autism Spectrum

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ABSTRACT

This descriptive study examined the role that preferred interests played in an adult population with autism spectrum disorders—how preferred interests are viewed retrospectively during childhood, as well as how adults on the spectrum have incorporated these interests into their current lives. Results showed that participants have a positive view of preferred interests, view preferred interests as a way to mitigate anxiety, and engage in vocational and avocational pursuits around their preferred interests. Findings support a strength-based view of preferred interests with the majority of participants articulating that their areas of interest were positive, beneficial, and should be encouraged.

KEYWORDS

Asperger syndrome; autism; occupations; preferred interests; quality of life

Introduction

Preferred interests are arguably the most prevalent behaviors within the population of individuals on the autism spectrum (Esbensen, Seltzer, Lam, & Bodfish, 2009); however, they are also some of the most vigorously debated. Some professionals in the field focus on the potential of preferred interests in terms of an individual's social and employment opportunities, while others argue that these interests have a negative impact on adaptive behavior, including a restricted focus that may impact social communication and engagement. The Diagnostic and Statistical Manual V (American Psychiatric Association, 2014) characterized these preferred interests as “highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest)” (p. 50). Researchers have gathered data to categorize preferred interests in adults with autism spectrum disorder (ASD) as compared to neurotypical adults or NT's, and have found that adults on the autism spectrum show significantly higher preference for sciences, history and culture, animals, information and mechanical systems, belief systems, and machines and technology. NT individuals reported more interest in

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sports and games (Jordan & Caldwell-Harris, 2012), which are often deemed more socially acceptable by the dominant culture.

Historically, the autism literature has termed the preferred interests of individuals with ASD negatively. Mercier, Mottron, and Belleville (2000) referred to them as “restricted interests,” Vismara and Lyons (2007) called them “perseverative interests,” while other researchers labeled them “circumscribed interests” (Boyd, Conroy, Mancil, Nakao, & Alter, 2007; Klin, Danovitch, Merz, & Volkmar, 2007; Lam, Bodfish, & Piven, 2008). These terms are consistent with the traditional view that preferred interests are problematic and need to be extinguished. While the subject matter of the interests, themselves, including science, history, and engineering, may be viewed as having potential positive impact, it is often the intense manner in which the individuals engage in these interests that researchers have labeled as problematic. Some professional experts and parents feel it is the approach to these interests that may interfere with the development of social relationships by limiting topics of conversation and common points of interest (Klin et al., 2007), and also contribute to behavioral rigidity (Turner-Brown, Lam, Holtzclaw, Dichter, & Bodfish, 2011).

A paradigm shift

The autism field is showing a shift away from this deficit-focused perspective, and autobiographical accounts and small qualitative studies are starting to highlight the positive aspects of preferred interests and how they can evolve over time (Dunn et al., 2013; Mercier et al., 2000). Researchers are also changing their language, and exploring the benefits of incorporating these interests. Winter-Messiers and colleagues (2007) renamed these fascinations “special interest areas” (SIAs), arguing that these interests are potential strengths and that *using* these interests, rather than *discouraging* them, can lead to better outcomes. For occupational therapists, Winter-Messiers’ description of SIAs is analogous to the profession’s value of meaningful occupations (American Occupational Therapy Association, 2014). In this article, we will refer to these interests as “preferred interests,” as that is the term identified by a focus group of adults with ASD who assisted with the survey development in this study as a reasonable descriptor.

Self-advocates have led this shift in labeling from the more deficit-focused language, such as “restricted,” “circumscribed,” and “obsessions,” to more strength-based language. The Autistic Self Advocacy Network, a leading group of adults on the spectrum (Autism Self Advocacy Network, 2011) described special interests as “narrow but deep,” with individuals often engaging in these interests for long periods of time. Winter-Messiers and colleagues (2007) found that individuals with ASD became more enthusiastic, motivated, and used more appropriate social interaction language and communication

skills when they were asked to speak about their preferred interest area. This is a dramatic shift from the deficit-based view that these interests inhibit social interactions, while also highlighting their potential for positive impact. Other researchers have found similar positive implications for the use of preferred interests to increase social behavior (Boyd et al., 2007; Koegel, Vernon, Koegel, Koegel, & Paullin, 2012; Vacca, 2007; Winter-Messiers, 2007; Winter-Messiers et al., 2007). Studies have shown that incorporating interests into dyadic play can increase both joint attention (Kryzak & Jones, 2015; Vismara & Lyons, 2007) and social behavior toward typical peers (Koegel et al., 2012). Research also suggests that using preferred interests has been shown to play a role in reducing anxiety in individuals with ASD (Kaboski et al., 2014).

Viewed in this positive light, the naturally-motivating aspects of preferred interests are highlighted. Ryan and Deci's (2000) conceptual framework of Self-Determination Theory (SDT) identified the three basic psychological needs that underpin this type of intrinsic motivation: feelings of competence, relatedness, and autonomy. Researchers are starting to see that active and purposeful engagement in preferred interests can help individuals feel more competent, autonomous, and related to others (Kryzak & Jones, 2015), thereby contributing to their motivation. Yet, restricted interests are still often deemed problematic through a professional lens versus a strength that may be critical to develop and support.

There is a lack of large-scale empirical research examining how adults with ASD view their interests—not only retrospectively, but also how their interests have evolved over time. Contrary to literature and parent reports that their children's preferred interests interfere with their function (Klin et al., 2007; Turner-Brown et al., 2011), individuals with autism often hold a different view of these interests, the role they play in their lives, and their impact on function. The first-person perspective then is critical to understand how preferred interests are conceptualized and viewed as positive or negative. The purpose of this study is to survey how adults on the spectrum view their preferred interests and examine how these views are influenced by demographic variables, including gender, age, type of diagnosis, age of diagnosis, and educational level.

Methods

Research design

This study was a descriptive study using survey methodology to examine views of preferred interests among adults with ASD. The study received institutional review board approval from New York University. All participants provided electronic informed consent that contained information

about the purpose of the study, procedures, benefits of participation, voluntary participation, and contact information of the researchers.

Participants

Adults with ASD were solicited to voluntarily participate in an online survey. Participants were invited to take a 29-item survey and answer one open-ended question about their preferred interests. The sample was self-selected with participants responding to recruitment emails sent to 25 support and self-advocacy groups for adults with ASD. There were 98 initial respondents, all of whom accessed the survey through a web link, provided consent, and clicked on the survey. Participants were only included if they completed all questions on the survey. Of the 98 initial respondents, there were 12 respondents who only completed the demographic information and were removed from the sample, leaving 86 participants over the age of 18.

Instrument

The lead author developed the survey in conjunction with a focus group of adults ($n = 5$) on the autism spectrum. The initial survey was then peer reviewed for feedback on clarity of items by key stakeholders, which was a small group of 20 adults with ASD. Modifications were made to the study survey based on this final round of stakeholder feedback. The final survey consisted of 29 items including six demographic questions (gender, age, type of diagnosis, age at diagnosis, co-morbid diagnosis, and level of education); 22 Likert scale items (a 5-point scale ranging from 1 = “strongly agree” to 5 = “strongly disagree”) that reflected both positive (“Focusing on my preferred interests has helped more than hindered my success in life”) and negative (“I feel that the preferred interests of my childhood served as an obstacle during social situations”) statements; and one open-ended question that invited the participant to provide additional information about preferred interests.

Procedures

The survey was sent electronically to 25 support and self-advocacy groups, who were then asked to forward to listservs and share with members. Contacts for these groups were retrieved via a Google web search using specific keywords such as Autism, Asperger’s, Autism/Asperger support groups, and Autism/Asperger organizations. Researcher contacts with local and national support groups for adults with ASD were also used to post the survey. Individuals were provided with a direct link to the survey, which was open online for a period of 3 months, with reminder emails sent each month for a total of three requests for participation.

Data collection and analysis

Data were collected using Survey Monkey, an online survey platform. The data were downloaded from the survey into a Statistical Package for the Social Sciences (SPSS) file (Version 21.0; IBM Corporation, Armonk, NY) for data analysis. Descriptive statistics, frequencies, and percentages were determined for respondents' demographic information. Additionally, percentages were calculated to examine Likert response to assess participants' agreement/disagreement as to how their interests impacted them both in school and currently. The open-ended question that gave the participant a chance to add information on their specific interests was coded separately by the authors, and the answers were grouped into categories.

Results

Participant characteristics

Participant demographics for the study are presented in [Table 1](#). The sample relied on participants self-reporting that they had ASD, with questions ensuring sample validity as much as possible, including type of ASD, age of diagnosis, and the professional who established the diagnosis. If respondents stated they were self-diagnosed, their survey was excluded from the data analysis. Of the 86 participants who completed the survey, six were self-diagnosed. These surveys were excluded, resulting in 80 participants who completed the survey and were included in the analysis. Participants were given the opportunity to answer an open-ended question about their specific interests; not all chose to answer this question, but the categories identified ($n = 21$) are presented in [Table 2](#).

Adults on the spectrum's views of preferred interests

To understand how adults with ASD view their preferred interests, participants reported current and retrospective information on their preferred interests. Adults on the autism spectrum viewed their preferred interests, both retrospectively and currently, as strengths, and interests that should be encouraged. [Figure 1](#) presents participants' strong views supporting the positive (81.0%) and calming (92.4%) nature of their preferred interests.

Participants reported that, as children, they engaged in activities that involved their preferred interests at a high rate (87.3%), and the majority of parents (53.2%) were supportive of these preferred interests. However, only 10.1% of participants reported that their teachers were supportive of their preferred interests. Adults with ASD felt very strongly (96.2%) that children's preferred interests should be encouraged and that being able to focus on these interests has helped (62.0%) more than hindered their success in life.

Table 1. Study population.

	<i>N</i>	Proportion (%)
Gender		
Males	38	47.5
Females	42	52.5
Age group (years)		
18–22	9	11.3
23–30	10	12.5
31–40	16	20.0
41–50	21	26.3
51–60	19	23.8
61–70	4	5.0
70+	1	1.3
Diagnosis		
Asperger's	66	82.5
High functioning autism	8	10.0
Autism	6	7.5
Co-morbid diagnosis		
None	48	60.0
ADHD ^a	4	5.0
Anxiety	4	5.0
Depression	8	10.0
ADHD +Anxiety	2	2.5
ADHD +Depression	1	1.3
Anxiety +Depression	9	11.3
ADHD +Anxiety +Depression	4	5.0
Level of education		
Some high school	3	3.8
High school/GED ^b	6	7.5
Some college/technical degree	23	28.8
College	21	26.3
Advanced degree	27	33.8
When diagnosed		
Child	16	20.0
Adolescent	6	7.5
Adult	58	72.5

^aAttention deficit hyperactive disorder.

^bGeneral educational development.

Preferred interests seem to shift, as 68.4% of participants reported engaging in different interests as an adult as compared to their interests as a child, although 19% of the respondents did report they engaged in similar interests throughout their lives. Similar to childhood, adults currently engaged in their preferred interests at a high rate (86.1%). Many adults now used these interests to engage others in conversation (46.8%)—compared to using interests to

Table 2. Categories of preferred interests.

Categories ^a	# of participants who stated preferred interest
Creative arts: reading, writing, art, and music	9
STEM: science, technology, engineering, and math	8
History and education	2
Television and games	2

^aCategories adapted from Jordan and Caldwell-Harris (2012).

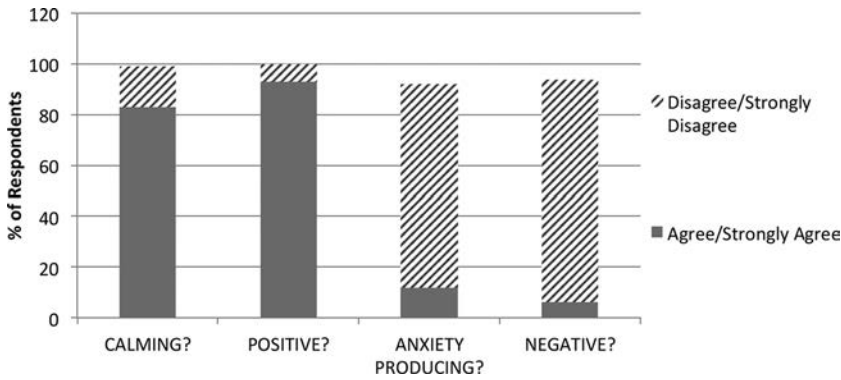


Figure 1. View of preferred interests.

engage in conversation as a child (31.6%). The sample was split as to whether the focus on interests has been an obstacle in social situations, with 30.4% of participants reporting it has been an obstacle and 32.9% indicating their focus on interests has not been an obstacle in social situations.

The majority of respondents ($n = 69$) reported that they currently have a job or are in an educational or training program that incorporates their preferred interests. In the open-ended question, participants stated how their interests have changed over time and are utilized in current vocational and avocational pursuits. Many participants identified preferred interests as a “lifeline” and recommended that professionals assist adults with autism to “develop a niche” and support these interests.

Demographic differences in views of preferred interests

In general, views on preferred interests were similar for known groups (gender, age, educational level, and diagnostic), but there were key differences highlighted in the analysis. Males ($n = 42$) and females ($n = 38$) had similar views of preferred interests; although, males reported a higher rate of parent (61.9%) and teacher (31%) support as compared to females (43.2% and 13.5%, respectively). Although both groups reported a very low percentage for teacher support of preferred interests in the classroom, it was even lower for females (5.4%) as compared to males (14.3%). Age appeared to impact responses in parent and teacher support, and encouragement of preferred interests. The youngest participants (18–22 years, $n = 9$) reported the highest percentage of agreement for parent support (66.6%) and teacher support (33.3%). This is in contrast to those aged 31 to 40 years ($n = 16$; 43.8% parent; 18.8% teacher), and although a small sample, those aged 61 to 70 ($n = 4$; 25% parent support; 0% teacher support). Very few teachers actually encouraged use of preferred interests in the classroom, with a high of 20% for those 23 to 30 years—a group who may have had the immediate benefit of college

classes around specific interests—to a low of 4.8% for age group 41 to 50 years ($n = 21$), and 0% for 61 to 70 years. The type of diagnosis (ASD, Asperger Syndrome, High Functioning Autism) did not show any marked differences in responses. However, time of diagnosis seemed to impact those diagnosed in adolescence, who viewed preferred interests as an obstacle in social situations (50%), as compared to those diagnosed in childhood (18.8%) or adulthood (31.6%). The majority of the participants did not have a co-morbid diagnosis ($n = 47$), but for those who did, preferred interests were found to be positive and calming to 100% of those with an Anxiety Disorder ($n = 4$) as compared to those with Attention-Deficit/Hyperactivity Disorder (ADHD) ($n = 4$), with 75% of participants viewing preferred interests as positive or calming.

Finally, this was a highly-educated sample with 27 participants having an advanced degree beyond a bachelor's level. This group used their preferred interests at a much higher frequency to engage others in conversations (70.4%) compared to all other level of education groups, which had little variance in the responses, ranging from 33.3% to 36.8%. Degree completion appeared to be related to higher rates of current employment or educational training that was related to their preferred interests—especially for students with either advanced or college degrees—with 89.9% and 81.5%, respectively, reporting employment or training related to these interests. This is in comparison to those who did not complete their educational degree (66.6% of participants who had some high school, and 78.9% with some college).

Discussion

The results of the current study are consistent with Winter-Messiers and colleagues' (2007) strength-based paradigm. Most of the participants viewed their preferred interests as strengths and something that should be encouraged. A large majority of participants felt that focusing on their preferred interests was also a positive and calming experience leading to a decrease in their overall anxiety. This benefit is especially important for this population, as a high percentage of individuals with ASD experience significant levels of anxiety (Wood & Gadow, 2010). These preferred interests could be viewed as relevant to avocational as well as vocational pursuits, leading to meaningful occupation where strengths and talents are leveraged (Hough & Koenig, 2014a, 2014b). An overwhelming majority of respondents were able to pair their preferred interests with their education and/or training. Several participants, however, did recognize that if they would have been able to focus on their preferred interests, their employment outcomes may have improved.

A large portion of the survey was dedicated to learning about the encouragement of preferred interests by parents and teachers. SDT also tells us that engaging purposefully in preferred interests can be a great motivator: helping individuals feel more comfortable, confident, and related to those around

them (Kryzak & Jones, 2015). The majority of the participants (53.2%) indicated that their parents were supportive of their preferred interests. As a child, 40.5% of participants agreed or strongly agreed that their parents encouraged them to talk about their preferred interests. The support of the parents, contrary to the concerns identified by many researchers, may have been a contributing factor to many respondents' positive perception of preferred interests.

However, the participants did not experience this level of support from their teachers. While most participants (87.3%) felt that teachers *should* incorporate preferred interests into the classroom, most did not report that this happened in their school. Only 10.1% of the participants felt their teachers were supportive of their preferred interests, and many reported that their teachers were unaware of or even discouraged their interests. This negative perception of preferred interests is particularly interesting as these interests are naturally and intrinsically motivating, and the challenge of motivating students with ASD to tackle academic tasks is widespread in the literature (Koegel, Singh, & Koegel, 2010). This highlights an important gap in the educational practices of supporting students on the spectrum and the potential for incorporating preferred interests. This finding may indicate a lack of awareness of the teachers' part on the existence, importance, and power of students' preferred interests. Practitioners could leverage the motivation that students' special interests provide—offering creative ways to increase participation and productivity in curricular activities (Lanou, Hough, & Powell, 2012).

These findings also suggest that many adults with ASD have changing preferred interests across the lifespan, with 68.4% of respondents reporting the topic of their preferred interest shifted from childhood to adulthood; however, they continue to engage in that area of preferred interest at a high rate. The focus may shift, but the intensity of engagement remains. When viewed positively, these preferred interests can directly relate to both vocational and avocational pursuits. Employment opportunities that leverage individuals' preferred interests could lead to successful professional experiences and contribute to individuals' overall well-being (Hough & Koenig, 2014a, 2014b). This is particularly important given the current poor outcomes and employment rates for adults with ASD (Cederlund, Hagberg, Billstedt, Gillberg, & Gillberg, 2008; Eaves & Ho, 2007).

Limitations

The findings of this study are limited because respondents self-identified to participate and were not randomly selected. A primary issue is the validity of the reported autism diagnoses and reporting of related symptoms, which were not standardized or validated. Although the results cannot be

generalized to a larger population, the data does provide some indication of how adults on the spectrum view their preferred interests.

Recommendations for future research

Future research should investigate specific areas of preferred interests and lifespan trajectory. Results of this research could inform the development of strength-based assessments and interventions.

Implications for occupational therapy practice

This survey demonstrates the importance of a continued paradigm shift away from the deficit-focused view of preferred interests toward one that recognizes the strengths and potential of these personal pursuits.

- Therapists and educators can identify and encourage individuals' preferred interests by incorporating these interests into therapeutic and educational experiences.
- Steps can be taken to explore individuals' preferred interests and identify ways they can be utilized to provide positive, calming experiences.
- Professionals working with adults with autism can recognize and leverage the potential that preferred interests have for both avocational and vocational pursuits.

Conclusion

This survey explored current and retrospective preferred interests among adults with autism and how they have incorporated these interests into their current lives. The present study offers further support for utilizing interests as strengths in the classroom and workplace, and highlights the need for further research on the positive effects of engagement in interests, and their positive use in interventions.

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