PERCEPTIONS OF OCCUPATIONAL THERAPY AND OCCUPATIONAL THERAPY ASSISTANT STUDENTS SERVING AUTISTIC ADULTS 50 YEARS AND OLDER

A Thesis submitted to the faculty at Stanbridge University in partial fulfillment of the requirements for the degree of Master of Science in Occupational Therapy_

by

Faye Evangelista, Alyssa Movchan, Danni Olarig, and Aaron Ontiveros

Thesis advisor: Bill Wong OTD, OTR/L

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Certification of Approval

I certify that I have read *Perceptions of Occupational Therapy and Occupational Therapy Assistant Students Serving Autistic Adults 50 Years and Older* by Faye Evangelista, Alyssa Movchan, Danni Olarig, and Aaron Ontiveros, and in my opinion, this work meets the criteria for approving a thesis submitted in partial fulfillment of the requirements for the degree of Master of Science in Occupational Therapy at Stanbridge University.

Bill Wong

Bill Wong, OTD, OTR/L

Instructor of Occupational Therapy

ACCEPTED

Myka Persson, OTD, OTR/L

Program Director, Master of Science in Occupational Therapy

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Preface

Identity-first language (i.e., autistic person) is used throughout this document to take into account preferences of many in the autistic community (Botha et al., 2021). Using identity-first language is significant as the words the population uses to describe autistic individuals influences the perception of society, public policy, clinical practice, and research directions. Person-first language (i.e., individuals with autism) was proposed in the 1970s to create an alternative option to signify a particular disability as a self-advocate in the disability rights convention in 1974 stated, "I'm tired of being called retarded. We are people first" (People First of West Virginia, n.d.). Person-first language was created to emphasize an individual's unique experiences, needs, and strengths that may be related or unrelated to their disability. Although person-first language was constructed to give autistic adults the same standards of rights as other individuals, the person first approach has been challenged by autistic self-advocates due to two arguments: (1) autism is an identity defining feature that is central and cannot be separated from an individual, and (2) the use of this form of language may conserve stigmatizing views as attributes that are normally expressed through preceding nouns or pronouns (Botha et al., 2021). Identity-first language counteracts the risk of dividing an individual from their diagnosis, as it endorses an expression of positive social identity. Furthermore, autistic individuals need to be accurately represented and included in developing and creating interventions and policy initiatives (Edelson et al., 2021).

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Abstract

Introduction: It is estimated that approximately 1 in 100 individuals are diagnosed with autism worldwide. Existing autism research is concerned with the pediatric population; however, there is a gap in studies regarding the older autistic community. The readiness of American occupational therapy (OT) students to work with autistic older adults are being explored using an online self-assessment survey. This study aims to identify gaps in healthcare in order to increase the quality of life for autistic older adults and will be a pilot study of a larger cross-cultural research project to be completed in 2023. Objective: To explore the readiness and competence of occupational therapy students to work with autistic older adults. **Method:** A mixed methods methodology is adopted via an online survey that consists of Likert scale, multiple choice, and open-ended questions. Target participants are occupational therapy and certified occupational therapy assistant students, and recruitment will be through word of mouth and online methodologies. Results: Results describe exposure to this population in acquaintances, employment/volunteer, and within the family. The data highlights that while most participants have had experiences with autistic individuals through family, work/volunteer roles, and acquaintances, a majority were not able to describe an experience they had with an older autistic adult. Content analysis and descriptive statistics were implemented to interpret the patterns. The results also indicated that a majority of participants felt somewhat prepared to work with older autistic adults in a clinical setting. Due to the low number of occupational therapy assistant responses, we are not able to generate a meaningful comparison or conclusion between the two targeted populations. Conclusion: These findings will be used to guide proper training and fill any unidentified gaps by informing OT school

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curriculum. Professional associations have a responsibility to create resources for the occupational therapy community to work with this population.

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Perceptions of OT and OTA Students Serving Autistic Adults 50 Years and

Older

Autism spectrum disorder is identified in approximately 1 in 44 children in the United States (Centers for Disease Control and Prevention, 2022), and may cause a range of behavioral, social, and communication challenges. Much of the literature and research surrounding this topic has centered around early diagnosis and intervention, leaving a gap in knowledge regarding how the aging process impacts autism. As these individuals age into later adulthood, more research is needed to understand how aging and autism impact one another. A better understanding of autism in the context of aging may lessen the need for medical support and thus medical costs, since the rates of comorbidities such as diabetes, cardiovascular disease, and gastrointestinal disease, are higher for individuals on the spectrum (Hwang et al., 2020). Another reason for studying aging within this population is for these individuals to be understood and supported in the same way neurotypical adults are throughout their lives. Autistic individuals can increase their engagement in life, contribute to the workforce, and are able to maintain their physical and cognitive function when support is available and effectively implemented. Aging neurotypical adults steadily lose social interaction, cognition, and physical functioning. These factors worsen at a faster rate for autistic individuals (Hwang et al., 2020). An area that continually is mentioned across research, but rarely investigated or explored, is the development and change in the lifespan of autistic populations (Hwang et al., 2020; Lever & Geurts, 2018; Wallace et al., 2016; Wright et al., 2013).

Our study focuses on the readiness and competence of occupational therapy (OT) students and occupational therapy assistant (OTA) students to work with older autistic adults. Readiness is defined as "the quality or state of being ready," while competence is defined as "the quality or state of having sufficient knowledge" (Merriam-Webster, n.d.). In focusing on these two qualities, we are also examining participant self-efficacy, or belief in their own abilities in working with this population (Bandura, 1997).

Purpose

The purpose of our research was to study the perceptions of occupational therapy and occupational therapy assistant students working with and supporting autistic older adults over 50 years old, to determine how current students felt about their own abilities while working with this population and what educational or life experiences lead to positive interactions. The data will compare and contrast the perceptions of the two targeted populations with working with older autistic adults. The purpose of this study was to also address the gaps in knowledge about the older autistic adult community and provide them with the same resources and support that their neurotypical counterparts receive in healthcare.

Statement of Problem

Little focus has been on how autistic individuals experience changes into middle and late adulthood compared to early childhood autism. Researchers estimate the total lifetime cost of autism per individual is between \$2.4 million and \$3.2 million (Rogge & Janssen, 2019). This cost could be dramatically decreased with further research on this population and community. With a significant gap in knowledge about older autistic adults, they are unable to experience the quality of life their neurotypical counterparts experience in regard to healthcare practitioner preferences, support, and management in activities of daily living healthcare professionals will allow us to promote training which can lead to an increase in the well-being of older autistic adults.

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Literature Review

A common theme throughout the literature is how characteristics of the diagnosis change over time. Heterogeneity in autism refers to the phenotypic and genetic profile within the individual (Pelphrey et al., 2011). Interplay between genes, brain functioning, and behavior throughout development ultimately contributes to adaptability and cognitive functioning.

Many changes take place during this transition between middle to late adulthood. Sensory sensitivity was found to increase in autistic individuals compared to the general population (Lever & Geurts, 2018). Furthermore, while neurotypical adults experience a decrease in executive functioning with age, this decrease is more profound in autistic individuals (Wallace et al., 2016). Autistic adults experience worse anxiety and depression as they age, in comparison to their neurotypical adult counterparts, which impedes functioning and causes significant deficits in occupations (Wallace et al., 2016). Independence in daily activities is lower for autistic individuals over 40 years old when compared to neurotypical adults of the same age (Hwang et al., 2020). In two separate studies involving autistic adults aged 19-88, Lever and Geurts (2018) and Wallace et al. (2016) found there were significant changes in symptom severity for autistic persons from childhood into adulthood. Symptoms that changed in severity from childhood and adolescence into middle and late adulthood were repetitive and restrictive behaviors, sensory sensitivities, and verbal communication.

Another similarity these studies found is that social challenges significantly affected overall outcomes of executive function. Heterogeneity in earlier autism research was once the focal point for determining challenges that affect quality of life. Researchers now realize that support, social engagement, and applied coping mechanisms in early development are a large determining factor in quality of life during the transition from adolescence into adulthood (Walsh et al., 2011). Hwang et al. (2020) also conducted a study with a similar design, which found that daily functioning impairments were consistent, but improvement was possible. The level of impairment in activities of daily living plateaus when an individual is 30-39 years old. This can be attributed to these individuals struggling to find balance in their youth, and their family or guardians finding them the appropriate support. As these individuals age, they become more aware of their symptoms, often leading to learning effective self-regulation techniques. This mitigates deficits and impairments in functioning. Autistic individuals are more aware of their triggers regarding sensory sensitivity and are able to avoid frustration and maladaptive behavior by learning effective coping techniques (Hwang et al., 2020). By the time the individual is in their 30s, challenges that present themselves regarding their diagnosis can be identified. During this period, physical function and ADLs are often improved. Even though autism symptoms may decrease with age, older autistic adults may not attain typical levels of social functioning (Wright et al., 2013).

The activity of mirror neurons is associated with social interactions by allowing one to understand and sympathize with another's experiences. Autistic individuals were believed to have a decrease in mirror neuron functioning in older adulthood. However, Enticott et al. (2012) found that mirror neuron functioning was not associated with age in autistic individuals. This means that autistic individuals may have social challenges, but outcomes may be improved with age, proper support, and social inclusion. More evidence and research is needed on how behavior and communication skills can be improved as the individual ages into older adulthood. Students and practitioners need research in these areas to better support this population in practice.

External Factors Affecting Successful Aging

Another common theme is how co-occurring conditions affect the autistic community. Aging well is defined as avoiding disease and disability, maintaining physical and cognitive functioning, and having an active engagement in life (Hwang et al., 2020). Only 3.3% of autistic individuals are aging well. These factors of aging well typically decrease with age in neurotypical functioning adults and are more difficult for autistic individuals to maintain (Murphy et al., 2012). Murphy et al. (2012) conducted a study comparing brain regions between autistic individuals and neurotypical adults. Characteristics and symptoms of autism were dependent on variable factors such as autism subtype, age, intelligence quotient, and comorbid conditions (Murphy et al., 2012). Symptoms of comorbid conditions along with autism are higher in middle adulthood. By the time the individual reaches age 65, they often have a better handle on their symptoms. They implement effective coping strategies and can better control outcomes (Lever & Geurts, 2018). Obesity and hypertension are some of the lifestyle factors that can increase the risk of comorbid diseases or other chronic medical conditions in autistic individuals. These cooccurring conditions in autistic individuals often present additional challenges, however social support positively affects outcomes (Hwang et al., 2020).

Successful aging is significantly impacted with social support (Wallace et al., 2016). Autistic adults often have smaller social support networks which affects how prominent autism characteristics are (Lever & Geurts, 2018). Social support in older age is just as impactful as support in youth. Additionally, autistic individuals often have fewer and lower quality friendships as they age (Wallace et al., 2016). More

studies and research are needed in this area to determine whether decreased social support directly affects executive functioning (Wallace et al., 2016). By the time autistic adults reach older adulthood, strong community support is needed with activities which are inclusive, allow one to be involved with their peers and increases personal satisfaction with increased participation (Hodges et al., 2004). Higher social engagement and inclusion leads to an increase in family outcomes (Gilmour et al., 2012). Difficulties in social interactions and communication often leads to lowered social engagement and participation (Hwang et al., 2020). These difficulties, along with sensory sensitivities, are a common barrier for social participation and leisure activities (Hwang et al., 2020). Social connections often wane for neurotypical adults but are decreased significantly when compared to autistic adults (Hwang et al., 2020). Community participation commonly is significantly decreased from adolescence into adulthood.

Autistic individuals are often at a disadvantage regarding employment, physical and mental health, social relationships, and quality of life (Wright et al., 2013). Employers often do not know the capabilities of each autistic individual, and lack of accommodation prevents consistent employment (Gerhardt & Lanier, 2011). Of those older autistic individuals in the workforce, most have menial jobs, which lead to low quality of life and lowered mental health (Lin et al., 2012). Some autistic individuals do not disclose their diagnosis to have a higher chance of gaining employment. However, by failing to disclose their diagnosis, these individuals do not receive the accommodations they need to successfully thrive in the workplace (Holtz et al., 2006).

Gaps In Evidence

Autistic adults each face unique medical challenges and have a varying level of support. Understanding how autistic adults age successfully would allow for a higher quality of life and increased social engagement. Further research needs to be conducted examining how sensory sensitivities change with older age, and how this impacts occupational performance and functioning. While education and research are thoroughly studied in autistic children, the same efforts need to be made for autistic adults. Longitudinal studies are needed to determine how symptoms change, how executive function is affected, and how cognition changes over a person's lifespan. Specific studies are needed on how prevalent repetitive and restrictive behaviors are in the transition into older adulthood. Additionally, there is a lack of research regarding the development of evidence-based interventions that effectively improve the transition into adulthood (Ruble et al., 2018). More research needs to be conducted to assess the various skill levels of autistic adults to find where limitations and challenges arise (Baker, 2005). From these assessments autistic individuals can be better supported socially, occupationally, emotionally, and with behavior regulation.

Clinical Significance

Occupational therapy practitioners may utilize resources to improve the quality of life of older autistic adults. With further information on successful aging, physical and cognitive impairments can be mitigated. New skills can be taught and implemented for social engagement and inclusion. Studies regarding autistic children often have parents in mind. The same level of attention and consideration needs to be given to family members, caregivers, and aging autistic adults. Adults need periodic checkups for support and care that is age appropriate. Further research and evidence

need to be made available so employers can make appropriate accommodations for this population.

Ethical Considerations

Ethical considerations are the regulations that researchers abide by in order to adhere to participants' confidentiality and rights. Research ethics are significant due to scientific integrity between the research community and the society. The following information are ethical guidelines considered when conducting the study: Voluntary participation, informed consent, anonymity and confidentiality. Lastly, an institutional review board approval was received on August 28, 2022.

Informed Consent

Prior to potential involvement of participants, researchers have the responsibility to explain any expectations before gaining their consent. In a research study informed consent is significant as it ensures that the participants have proper knowledge about what the study entails, giving them the opportunity to choose whether they would like to engage or withdraw from the study at any given point. Our study had been posted to many online platforms including private Facebook groups, CommunOT, and through Stanbridge University. To guarantee that participants are well informed of their expected contribution to the study and any risks they may encounter while participating, the research team had attached an informed consent form, the research team disclosed that the study is voluntary and anonymous with minimal to no foreseeable risks.

Anonymity and Confidentiality

Maintaining the confidentiality and anonymity of the participant's information was a main priority. Our thesis collaborators, Dr. Kristy Coxon and Dr. Caroline Mills of Western Sydney University, will have access to the data after the completion of our thesis to perform the second half of the cross-cultural study in Australia in 2023. The data will be used to compare and contrast the perceptions and abilities of occupational therapy students while working with autistic older adults 50 years and older.

Validity

To ensure the highest form of validity is reached in our research, we emphasized that our participants did not feel pressured in any way to select specific choices while completing the online survey. We gathered valuable input from our advisor, who is a stakeholder in the autistic community, and from our collaborators to ensure the appropriate methodology has been selected and conducted. We thoroughly defined the exclusion and inclusion criteria to avoid misinterpreted or misunderstood data.

Sampling Criteria

Participant recruitment was conducted through Stanbridge University, American Occupational Therapy Association's (AOTA) CommunOT platform, and a Facebook group called OT4OT. Information about the study as well as the opportunity to participate was emailed to members of Occupational Therapy Association of California.

Inclusion criteria consisted of participants currently enrolled in a masters or graduate level occupational therapy program or OTA program in the United States. Exclusion criteria consisted of participants who are enrolled in bridge programs, were former certified occupational therapy assistant and/or participants that have taken or attempted taking the National Board for Certification in Occupational Therapy exam. These students are licensed occupational therapy assistants and gathered experiences in the field before enrolling in occupational therapy programs. Our study prefers students with no previous professional experiences as occupational therapy practitioners, as this truly represents the pre-service experience.

The second portion of our study will be conducted in Australia as our current study concludes. Due to the fact that we want to provide as similar a sample as possible for comparison purposes for the second portion of the study, the best recourse is to exclude any individual who has taken a state licensing exam previously.

Theoretical Framework

The Person-Environment-Occupation (PEO) model recognizes that occupational performance is a product of the relationship between people, their varied environments, and their occupations (Law et al., 1996). In this model, the person is defined holistically as a collection of mind, body, and spiritual attributes. This includes individual skills, life experiences, self-concept, cultural background, health, motor and sensory skills, and cognition. When engaging in occupations, the person and these attributes affect the performance outcome. The environmental domain is defined broadly to include physical, social, cultural, institutional, virtual, and socioeconomic environments that support or hinder occupational performance. Lastly, occupation is understood as any task or activity the person engages in to fulfill their need for self-maintenance, life satisfaction, or expression. This model acknowledges the transactional relationship between the person, their environment, and occupational demands. Neither domain exists independently of one another and each continuously influences occupational performance. When there is congruence between the person, environment, and occupation, engagement is facilitated and occupational performance is increased. However, the opposite is true as well, with incongruent domains leading to hindered engagement and decreased performance. Additionally, the PEO model considers temporal aspects of when occupational routines are occurring. This includes durations over days, weeks, years, and acknowledges that all three domains and performance may change as the individual ages. This model allows practitioners to analyze the transactions between the client, their environment, and occupation and identify incongruencies that require intervention.

In the PEO model, the person is assumed to be an intrinsically motivated, ever-changing being that continuously interacts and influences their environment. Aspects of the person include physical, cognitive, and affective factors — all centered around human spirituality (Cole & Tufano, 2020). Physical factors include strength, range of motion, and endurance, whereas cognitive factors include processing, reasoning, memory, and motor planning. Affective factors are defined as thoughts and feelings that influence self-concept, desires, and interpersonal relationships. Our target population is autistic adults aged 50 years and older. After extensive literature review, this age range of 50 years and older was deemed appropriate due to the gap in knowledge of how aging affects this specific population. Our intervention will be a self-reported questionnaire to gauge OT and OTA students' readiness and competence to work with older autistic adults.

The environment is defined as any context in which interaction occurs for an individual. This can range from the home, the neighborhood, and community environments to much larger social, cultural, or institutional environments. Law et al. (1996) identifies that while there are many types of environments, they are all equally important in influencing occupational performance. An environment will contain many animate and inanimate elements that can be a support or barrier to performance. An example of an environmental barrier that hinders performance may be a department store with loud music and bright monitors, which negatively impacts occupational performance in individuals with hypersensitivities to stimuli. On the other hand, an environmental support may take the form of a room that has been adapted to reduce external noises, have neutral colors, provide adequate space to move around, and have the option to engage in sensory experiences.

Law et al. (1996) defines occupations as any activity that "meet the person's intrinsic needs for self-maintenance, expression and fulfillment within the context of his/her personal roles and environment" (p. 17). Engagement in occupations is necessary to live a full and meaningful life. As mentioned by Stevenson et al. (2011), after the age of 22 many autistic individuals are left without services that address their changing health needs, mental wellbeing, and social support. As a result, engagement in occupations may be negatively impacted. When examined as a whole, the person, environment, occupation dynamic produces occupational performance. When there is greater congruence between these three components, the individual is more successful in their occupational performance. Applied to our study, we are examining how the person, environment, and occupation factors impact performance for autistic older adults.

Methodology

Data Collection

The responses from the qualitative survey were collected through our password protected email address that can only be accessed by us and our collaborators. Access was restricted to others to increase the confidentiality and privacy of the participants. The responses from the closed-ended and open-ended questions were coded to identify common themes and patterns. Data analysis determined the strengths and limitations regarding the OT and OTA students when working with autistic adults. The data collected was used to spread awareness of the successful patterns preferred by this community. Unsuccessful patterns were also identified so they can be avoided by future healthcare practitioners. The data collected from the Likert scale questions was analyzed to identify patterns among student responses when working with this population. The data provided an insight on how to increase quality of care for an underserved population. Data results have implications on how to educate future OT and OTA students, and other healthcare practitioners that may work with older autistic adults.

Participants

Respondents were 20 occupational therapy students and one occupational therapy assistant student. All participants were enrolled in an occupational therapy program or occupational therapy assistant program in the United States. Three occupational therapy student respondents indicated they previously worked as OTAs and were disqualified from the survey results. Our final survey sample totaled 18 respondents, including 17 occupational therapy students and one occupational therapy assistant student as seen in Table 1.

Table 1.

Are you currently an OT or OTA student?	What gender do you associate with?	State of your OT Program
Occupational therapy student ($n = 17$), occupational therapy assistant ($n = 1$)	Females $(n = 14)$, males $(n = 3)$, other/neither $(n = 1)$	California $(n = 7)$, Idaho (n = 4), Illinois $(n =3), Virginia (n = 2),South Carolina (n =1), Nebraska(n = 1)$

Respondent Demographics (N = 18)

We posted our survey and flyer to a variety of online platforms such as AOTA CommunOT platform, OT specific Facebook groups, and Occupational Therapy Association of California's email blast. These platforms provided us the best chance of recruiting our specific population. A QR code was on our flyer which led participants straight to our survey. Prior to starting our survey, we included a statement that clearly explained that our survey is completely voluntary, and responses were used for research purposes. We also explicitly stated that there are no repercussions for not completing the survey, no personal identifying information was asked of them, and that completing this survey involved minimal to no risk.

Study Design

Our research design was based on a participatory research approach because our advisor is a stakeholder and part of the autistic community. This approach was advantageous because it included a direct collaboration with future healthcare practitioners and a stakeholder. This approach included knowledge from our stakeholder regarding preferences and experiences to better improve the quality of care given to autistic adults in healthcare settings. Integrating the experiences of stakeholders, and OT and OTA students promotes reliable and acceptable data. Our study also focused on a qualitative approach with descriptive quantitative information derived from Likert scale questions. A Google form was utilized to allow all responses, questions, and comments to be emailed directly to the private researcher email.

Our survey included 24 questions –12 closed-ended, 7 open-ended, and 5 Likert scale– which will provide us with valuable data and also keep participants interested. Completion of the survey was estimated at 15-20 minutes. The closed-end questions were included to determine survey eligibility, establish demographic information, and determine perceptions of readiness and competence for working with the autistic adult population. Personal identifying information such as name, address, and phone number were not asked at any time during the survey. Open-ended questions were incorporated to give us a greater understanding of the participants' perspectives and personal experiences with the autistic adult population. This portion of the survey allowed participants to express their successful and unsuccessful encounters when working with autistic adults.

Lastly, the Likert scale questions were based on a 5-point scale which included the following choices: not confident, somewhat confident, fairly confident, moderately confident, and very confident. These questions were included to help us determine the confidence levels of the participants when working with autistic adults. Questions in this section covered topics such as if participants felt confident providing services to autistic adults and if they recognized their feelings.

Results

A total of 18 respondents met the inclusion criteria for this analysis. Demographic information is provided in Table 1. A majority of respondents were female (14), and OT students (17). In response to *years of experience working with autistic individuals*, half indicated they had between 1-5 years of experience working with this population, seven indicated none or less than 1 year of experience, and two indicated more than 5 years of experience. However as shown in Table 2, nearly all respondents (17) indicated they had no experience supporting autistic adults aged 50 years and older.

Table 2.

Years of Experience (N=18)

Years of experience working with autistic individuals	Years of experience working with older autistic adults (ages 50+)

None or less than one year (*n*=7), 1-5 years (*n*=9), more than 5 years (*n*=2)

No experience (n=17), 1-3 years (n=1)

In Table 3, respondents described a time in which they had an encounter with an autistic individual. These answers were coded for the context in which they met this individual as either "acquaintance," "family," "none," or "work/volunteer." A majority of encounters occurred through work or volunteer experiences (7), acquaintances such as friends, neighbors, or community organizations (5), or family experiences (3). A majority (14) respondents reported they were unable to describe a time in which they had success supporting older autistic people. One participant did report a successful community experience with a 35-year-old autistic adult; however, this did not meet our criteria of older autistic adults. Regarding experiences with older autistic people, Table 4 shows what resources respondents had prior to that experience, and what resources they wished they had afterwards (respondents were able to list multiple types of resources in this section). All respondents (18) reported not having any resources that helped them in their encounter with an autistic individual, and many (11) stated a desire for formal training such as workplace training, seminars, lectures and laboratory training, pamphlets, or research articles. Others indicated a desire for resources in the format of audiovisual media (3) such as streaming services, podcasts, or books, or social media (2) like YouTube or Facebook. Six respondents identified "none," as resources they would have liked to have after

the encounter.

Table 3.

Encounters and Successes (N=18)

Describe a time when you had an encounter with an autistic individual	Describe a time when you had success supporting older autistic people
Work/volunteer (<i>n</i> =7), acquaintance (<i>n</i> =5), family (<i>n</i> =3), none (<i>n</i> =3)	Work/volunteer (<i>n</i> =2), family (<i>n</i> =2), none (<i>n</i> =14)

Table 4.

Resources

Resource(s) prior to experience	Resource(s) desired after
(N=18)	experience (<i>N</i> =18)
None (<i>n</i> =18)	Social media (<i>n</i> =2), formal training (<i>n</i> =11), audiovisual media (<i>n</i> =3), none (<i>n</i> =6)

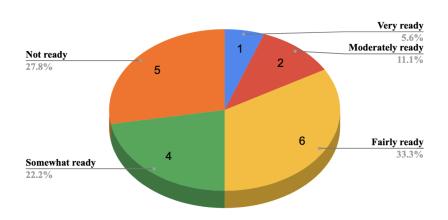
**Note*. Participants were allowed to choose more than one category for these responses.

With regards to respondents' levels of readiness to work with older autistic adults in a clinical setting (Figure 1), 1 reported "very ready", 2 "were moderately ready," 6 were "fairly ready," 4 were "somewhat ready," while 5 reported "not ready." These responses illustrated a generally positive perception of readiness among respondents. Figure 2 recorded levels of preparedness, with 4 identifying with "moderately prepared," 4 as "fairly prepared," 6 as "somewhat prepared," and 4 as "not prepared." In Figure 3, level of competence was recorded as 3 being "moderately competent," 6 as "fairly competent," 3 as "somewhat competent," and 6 as "not competent."

Figure 1.

What Is Your Level of Readiness to Work With Older Autistic Adults in a Clinical

Setting?

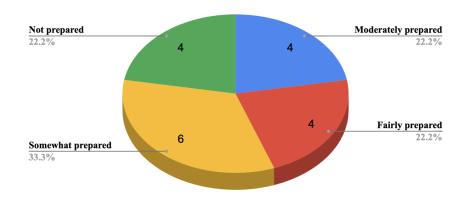


What is your level of readiness to work with older autistic adults in a clinical setting?

Figure 2.

What Is Your Level of Preparedness to Work With Older Autistic Adults in a Clinical

Setting?

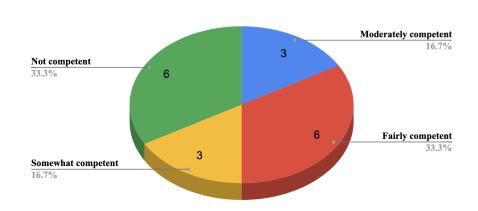


What is your level of preparedness to work with older autistic adults in a clinical setting?

Figure 3.

What Is Your Level of Competence With Regards to Working With Older Autistic

Adults?



What is your level of competence with regards to working with older autistic adults?

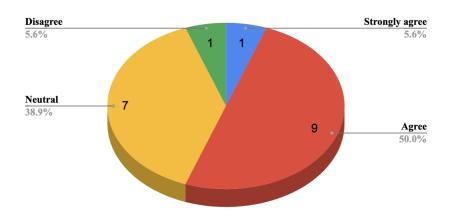
Respondents were then asked to rate their agreement with a series of statements. In Figure 4, they were asked rate their agreement with "I feel confident

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that I recognize the person's thoughts and feelings," and 9 respondents agreed, while 7 identified with neutral, 1 chose "strongly agree," and 1 chose "disagree." The next statement (Figure 5) of "I feel confident that I am aware of when the person is scared or concerned," received broad agreement (13) responses and the remaining (5) were neutral. Next, Figure 6 stated "I feel confident that I advise and support the person in making decisions," received a majority agreement (11), with some identifying with "neutral" (6), and "strongly disagree" (1). Figure 7 stated "I feel confident that I explain how the treatment plan works or is expected to work so that the patient understands them," a majority of respondents agreed (10), with 5 in disagreement, 1 "strongly disagree," and 2 reporting "neutral." Lastly, respondents were asked about their confidence to "provide services appropriate to the client's needs," (Figure 8) and a majority (11) broadly agreed, with 5 in general disagreement, and 2 reporting "neutral."

Figure 4.

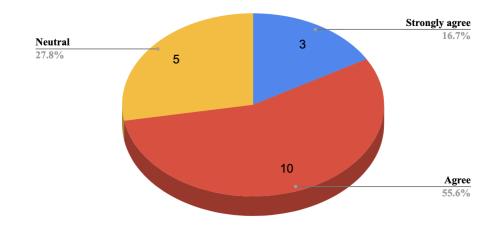
I Feel Confident That I... Recognize the Person's Thoughts and Feelings



I feel confident that I recognize the person's thoughts and feelings

Figure 5.

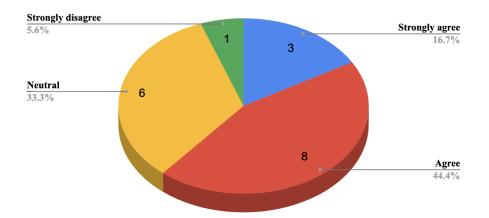
Am Aware of When the Person Is Scared or Concerned



Am aware of when the person is scared or concerned

Figure 6.

Advise and Support the Person in Making Decision

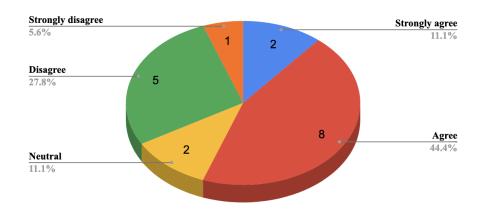


Advise and support the person in making decision

Figure 7.

Explain How the Treatment Plan Works or Is Expected to Work so That the Patient

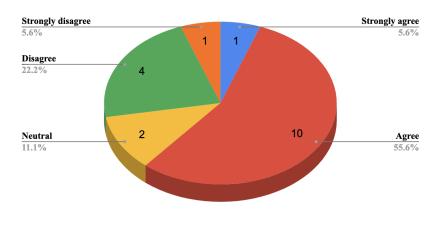
Understands Them



Explain how the treatment plan works or is expected to work so that the patient understands them

Figure 8.

Provide Services Appropriate to the Client's Needs.



Provide services appropriate to the client's needs.

Discussion

When practitioners work with the autistic population, most of the curriculum taught in OT and OTA programs are focused on the pediatric population. These trends

also present in our study. When working with older autistic adults, eligible participants had experiences though family, volunteer and/or employment opportunities, or none at all. Our study finds that little is known about how older autistic adults age, if they have more similar experiences in the aging process, and how to support them in later life.

Those who have taken part in our study found that there are little resources when attempting to gather knowledge or support for this population. Occupational therapy programs may group older autistic adults with other conditions, rather than speak about the needs and outlook of this population. For example, when learning about older adults, universities may speak more about comorbidities, psychosocial factors, biomechanical problems, among other topics that prevent older adults from aging well. Our study finds that students studying occupational therapy would benefit from having their university include curricula that targets older autistic adults. This would not only contribute to student's knowledge, but students would be more confident and to better support this population when they become licensed practitioners.

One solution that occupational therapy programs could integrate within their program standards is community involvement with older autistic adults. Volunteer hours could be partaken in the many settings where older autistic adults engage in occupations. Settings could include assisted living homes, senior living centers, worksites, classes, fitness centers, gyms, among other places where students can learn and observe processes and domains exhibited by this population.

Another potential resource in this area are individuals who share lived experiences via social media. One of the advantages of social media is the ability to share a unique or intimate perspective with other users. This could mean the

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individual, a caretaker, or an associate documenting lived experiences with other users on the platform. There are endless possibilities of what an older autistic adult would share with others in their unique perspective. With more stories or experiences being shared, the easier it may be to identify common themes or patterns that each community could support. Many discussions are taking place online on progressive thoughts and movements. Older autistic adults, as well as their support systems, can add their experiences and perspective to the conversation to increase awareness, involvement, and representation.

Limitations

There are several limitations that the research team have encountered in the research study. One of the greatest limitations is the number of OTA students that have responded to the questionnaire. Out of the 18 respondents, only 1 OTA student participated in the study. Due to the lack of responses from OTA students, the researchers were unable to generate a meaningful conclusion between OT and OTA students' perceptions when working with autistic older individuals. Another limitation is the longevity of the survey's availability to the public. Due to the limited survey window of 3 weeks, the researchers were not able to gather varying data from different OT and OTA students across the United States; However, in that short time span, the researchers were able to collect data from 18 participants in various states: CA, VA, SC, IL, ID, and NE.

Further limitations appear in the study such as the limited sample size of the participants. The researchers were aware that there are several surveys posted in CommunOT, OT4OT, and many other occupational therapy platforms. The large quantity of surveys in the OT platform may be considered as a limitation as some participants may have chosen to use their time completing a different survey instead

of the survey we have presented. Furthermore, based on the data collected, all of the participants reported that they have only completed level I fieldwork or have not been in fieldwork at all. This is considered a limitation as the participants in the study have only been exposed to OT fieldwork for a week at most which may differ from the experience of other future practitioners who have completed a level II fieldwork as they have the experience of working in the field for three months.

After analyzing the data, the research team highlighted that only 4 participants stated that they had more than five years' experience of working with autistic individuals through family or friends. One exception was a respondent who reported working with a 35-year-old autistic adult who did not meet our study's definition of older adult. Although the participant shared their experience with an autistic individual, the research team is unable to utilize this data due to the definition of autistic older adults being 50 years of age or older. A final limitation that the researchers have encountered is receiving a response about access to resources about autistic older adults as one of the participants discussed their preferred resources for autistic children instead. The research team was unable to analyze 2 responses in the data due to invalidity.

Future Implications and Application to Occupational Therapy

This study exhibits how the perceptions of OT and OTA students serving autistic older adults may be used as a form of guidance for healthcare practitioners. Through this study, the researchers hope to gain the attention of the AOTA's Representative Assembly to develop the standards of this population in future curricula. As exhibited from the data, a great number of future practitioners did not receive any form of training concerning autistic older adults. This study highlights the need for healthcare curricula targeted towards older autistic adults, as most of the content being taught is focused on autism in pediatrics. This study encourages textbooks to provide more materials pertaining to autistic older adults in the future. Autism is a life-long condition; therefore, as practitioners, we should focus on autism throughout the lifespan. Another method to increase the knowledge of future practitioners is through community involvement with this population.

Involvement may also come in the form of social media, which is a great influence on the population as individuals gather most of their news from social media platforms. This may be used as a potential resource as a great number of the population share their lived experience via social media. A resource that may educate future practitioners is through searching the hashtags such as #actuallyautistic on Twitter to learn about the perspective and opinions of autistic older adults. Other forms of social media such as YouTube can be used to self-educate about autistic older individuals by watching vlogs. Future research concerning the autistic older adult population is further a significant implication as it provides new information that is substantial for future practitioners to learn.

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Appendix A

Survey Questions

Screening Questions

- 1. Are you currently an OT or OTA student?
 - OT student
 - OTA student
 - Neither
- 2. If you are an OT student, are you currently a Certified Occupational Therapy Assistant (COTA) or are you attending a bridge program (OTA to OT program)?
 - Yes
 - No
- 3. Have you attempted the NBCOT licensing exam?
 - Yes
 - No
- 4. When did you begin your program? [two options: multiple choice and open ended answer]
 - Less than 12 months
 - 12-24 months
 - More than 12 months
- 5. What gender do you associate with?
 - Female
 - Male
 - Other
 - Decline to Answer
- 6. Have you completed fieldwork? Check any that apply:
 - No
 - Level I rotation (An in-depth experience in delivering evidence based occupational therapy services to clients)
 - Level II rotation (Introduce students to the fieldwork experience, to apply knowledge to practice, and to develop understanding of the needs of clients)
 - Doctoral Capstone (A mentored learning experience with in-depth exposure)
- 7. Have you taken a pediatrics course in your program?
 - Yes
 - No

Qualitative Questions

8. How many years of experience do you have working with older autistic ADULTS (50 years and older)?

- 9. What state is your program in?
- 10. What are your experiences working with autistic individuals? (Please include the setting and age range. If you do not have experience, write N/A)
- 11. What were some of the challenges and successes from this encounter?
- 12. What are some resources you had access to during this experience? If not, what resources did you want to have? (Ex: seminar training..?)
- 13. What do you think are the needs for autistic elderly?
- 14. Do you have previous experiences with autistic individuals?
 - a. Yes
 - b. No
- 15. If yes to above question (#9), what age was that individual? (check all that apply)
 - a. Child (less than 18 years)
 - b. Adult (18 49 years)
 - c. Older adult (50+ years)
- 16. If yes to above question (#15), what setting did this interaction occur in? (check all that apply)
 - a. Family member
 - b. Friend, neighbor, or acquaintance
 - c. Volunteer or paid position
 - d. Other
- 17. What is your level of readiness to work with older autistic adults in a clinical setting?
 - a. Not at all ready
 - b. A little ready
 - c. I don't know
 - d. Somewhat ready
 - e. Very ready
- 18. What is your level of preparedness to work with older autistic adults in a clinical setting?
 - a. Not at all prepared
 - b. A little prepared
 - c. I don't know
 - d. Somewhat prepared
 - e. Very prepared
- 19. What is your level of competence with regards to working with older autistic adults?
 - a. Not at all competent

- b. A little competent
- c. I don't know
- d. Somewhat competent
- e. Very competent

Demographic Questions

- 1. Where have you attended your OT/OTA program?
- 2. In what setting have you encountered autistic individuals?

For the context of the following questions, please respond based on your interactions with **OLDER AUTISTIC ADULTS**.

For the following questions please rate your confidence level on a scale from 1 to 5:

- 1= not confident
- 2=somewhat confident
- 3= fairly confident
- 4=moderately confident
- 5=very confident

I feel confident that I....

- 1. Recognize the person's thoughts and feelings
- 2. Am aware of when the person is scared or concerned
- 3. Advise and support the person in making decisions about their treatment
- 4. Explain how the treatment plan works or is expected to work so that the patient understands them
- 5. Provide services appropriate to the client's needs

Appendix B

Electronic Information Sheet Informed Consent

Aaron Ontiveros, Alyssa Movchan, Danni Olarig, and Faye Evangelista, a graduate student in the Master of Occupational Therapy Program at Stanbridge University, is conducting a research to study the readiness and competency of OT and OTA students to work with autistic older adults over 50 years old. You are being asked to complete this survey because of your clinical experience as an OT/OTA student.

Participation is voluntary. The survey is 20 questions long and will take approximately 20 minutes to complete.

There are no foreseeable risks involved in this study. Please try to answer all questions; however, if you feel uncomfortable, you may skip any questions. Your responses are anonymous.

Please contact the group or the principal investigator if you have any questions or concerns.

Research Team stanbridgeasd@gmail.com

Dr. Bill Wong OTD OTR/L bwong@stanbrige.edu

If you have questions about your rights as a research participant please contact the Stanbridge University Institutional Review Board (IRB) through:

Phone: (949) 797-9090 Email: <u>irb@stanbridge.edu</u>



Appendix C

