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DEMENTIA OF THE ALZHEIMER'S TYPE IN ADULTS WITH DOWN  
SYNDROME: KNOWLEDGE AMONG GRADUATE STUDENTS IN PHYSICAL  
THERAPY, OCCUPATIONAL THERAPY, AND SPEECH-LANGUAGE  
PATHOLOGY

By

Abigail Donaway

B.A.- University of Louisville, Louisville, KY 2024

A Thesis  
Submitted to the Faculty of the  
School of Medicine of the University of Louisville  
in Partial Fulfillment of the Requirements  
for the Degree of

Masters of Science  
in Communicative Disorders

Department of Otolaryngology Head and Neck Surgery and Communicative Disorders  
University of Louisville  
Louisville, Kentucky

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A Thesis Approved on  
Date of the defense  
by the following Thesis Committee:

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Alan Smith, Ed.D., Thesis Advisor

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Rhonda Mattingly Williams, Ed.D., Committee Member

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Karen Barako Arndt, PhD., Committee Member

## DEDICATION

To my family and friends, thank you for supporting me.

## ACKNOWLEDGMENTS

I thank the Communicative Disorders Department at the University of Louisville for the instruction, encouragement, and support I have received. I thank Dr. Smith for encouraging me to write a thesis, and for his guidance and mentorship these last two years; Michael Frazure, for teaching me research methods; and Dr. Pitts, for serving as thesis director.

## ABSTRACT

### DEMENTIA OF THE ALZHEIMER'S TYPE IN ADULTS WITH DOWN SYNDROME: KNOWLEDGE AMONG GRADUATE STUDENTS IN PHYSICAL THERAPY, OCCUPATIONAL THERAPY, AND SPEECH-LANGUAGE PATHOLOGY

Abigail Donaway

April 12, 2024

This non-experimental study utilized a convenience sample (N = 322) to investigate graduate students in physical therapy (PT), occupational therapy (OT), and speech-language pathology's (SLP) knowledge of the connection between Down syndrome and dementia of the Alzheimer's type (DAT). Ninety-two-point-five percent of participants were female, and 79.80% were white. All participants completed a survey comprised of items relating to information about general knowledge (i.e. facts) of the association between DS and DAT, the signs/symptoms that occur in each stage of dementia of the Alzheimer's type for people with Down syndrome, and familiarity regarding the diagnosis and care.

Descriptive and summary statistics indicated the persistence of misconceptions regarding the connection between DS and DAT among graduate students in PT, OT, and SLP training programs. Group comparisons were conducted to identify differences



according to discipline (PT, OT, or SLP) and the relationship of knowing individuals diagnosed with DAT, DS, neither, or both. ANOVA analyses revealed knowledge of the stages of DAT as they relate to DS appeared stronger for OT students when compared to their PT peers; no statistically significant difference was noted per SLP students.

Kruskall-Wallis and ANOVA analyses revealed no statistically significant difference in knowledge across disciplines regarding general knowledge about DS and DAT and familiarity of diagnosis and care parameters, respectively. Spearman's rank correlation revealed a statistically significant result among the respondents' connection to an individual with both DS and DAT and increased scores per accuracy of facts and familiarity (diagnosis and care) when compared to knowing someone with only DS or DAT.

## TABLE OF CONTENTS

ACKNOWLEDGMENTS .....	iv
ABSTRACT.....	v
CHAPTER 1 INTRODUCTION .....	1
CHAPTER 2 METHODS .....	8
CHAPTER 3 RESULTS .....	14
CHAPTER 4 DISCUSSION.....	20
REFERENCES .....	27
APPENDIX: ABBREVIATIONS .....	32
CURRICULUM VITAE.....	33

## CHAPTER 1

### INTRODUCTION

Down syndrome (DS) ranks among the most prevalent chromosomal conditions globally, occurring in approximately 1 out of every 700 live births in the United States (National Down Syndrome Society, 2021). Today, the number of people who carry the diagnosis is approximately 250,000 to 400,000 (in the United States) and more than 5 million worldwide (Hartley et al., 2015; Presson et al., 2013; de Graaf et al., 2020; National Down Syndrome Society, 2021). Within the past 30 years there has been a significant increase in life expectancy for individuals with DS, now exceeding 60 years of age. In 1983, the average lifespan of a person with DS was 25 years of age (Bittles & Glasson, 2004; de Graaf, Buckley, & Skotko, 2017). Secondary to the increase in life expectancy, there is an increased risk in the development of age-related disorders including cardiovascular disorders, hearing impairments, obesity, and dementia of the Alzheimer's type (DAT) (Smith, 2001; Roizen & Patterson, 2003; Rimmer et al., 2004; Zigman & Lott, 2007; Esbensen, 2010; Moran et al., 2013).

One known etiology in the development of DAT in individuals with DS is the presence of an extra 21st chromosome. The anomaly has been found to produce the amyloid precursor protein (APP) gene on the proximal portion of the long arm of the chromosome (Zigman & Lott, 2007). The gene has been found to have a causal association with DAT because it creates copious amounts of amyloid- $\beta$  ( $A\beta$ ) plaque

deposition (Zigman, 2013; Zigman & Lott, 2007). This plaque has been found in the cerebral cortex of many people who develop DAT and can also lead to neurofibrillary tangles, neuronal death, brain atrophy, and vessel impairments (Bittles & Glasson, 2004; Zigman, 2013). The excess in the production of these deposits in people with DS accelerates the aging process at a rate greater than what is typically observed in the general population (Carfi et al., 2014). The overall risk for DAT in individuals with DS has been found to be as high as 80% by age 65, with a mean age diagnosis of 55.41 (Bittles & Glasson, 2004; McCarron et al., 2017; Sinai et al., 2018). Additionally, the signs and symptoms of early onset DAT have been observed as early as the third decade of life in individuals with DS (Hithersay et al., 2018; Fortea et al., 2020). Therefore, individuals with DS have been identified as the most significant demographic prone to early-onset DAT (Hartley et al., 2015).

DAT is the most common type of dementia that affects memory, thinking, and behavior (Alzheimer's Association, 2023). In aging adults with DS, research has found that the earliest signs of DAT are changes in an individual's behavior and personality (Ball et al., 2006; Strydom et al., 2010; Carr & Collins, 2014). These behaviors include aggression, depression, apathy, irritability, worry, decreased appetite, weight loss, reduced participation in activities of daily living (ADLs), social withdrawal, and stubbornness (Smith, 2001; Ball et al., 2006; Janicki et al., 2010; Lin et al., 2013; Carr & Collins, 2014; Sauna-Aho et al., 2018). For individuals with DS, neurological changes (e.g., memory loss and executive dysfunction) tend to follow the aforementioned behavioral changes (Ball et al., 2006). This is a reverse of what is seen in the general population (Ball et al., 2006; Carr & Collins, 2014).

Identifying behavioral and cognitive changes early, provides families and professionals with greater opportunities to leverage existing resources and treatments, and possibly slow the progression of the disorder (Walaszek et al., 2022; Esralew et al., 2013). However, apart from DAT, DS has well documented complex medical issues associated with the syndrome. These issues may alter patients' behaviors and personalities in ways that mirror DAT. These other medical or psychiatric conditions can obfuscate the etiologies of the changes and disrupt early diagnosis (Steingass et al., 2011; Brothman, 2014). Additionally, it is difficult for caregivers and health professionals to determine behavioral and cognitive signs associated with DAT due to pre-existing intellectual disabilities often associated with DS (Menendez, 2005).

Another complicating factor in the diagnostic process is the limited availability of standardized screening instruments tailored for individuals with DS to assess their cognitive abilities. Standardized screening instruments commonly employed with the general population have been found to lack accuracy and standardization when applied to individuals with DS. This is attributed to the fact that many individuals with DS display a cognitive baseline at or below the criteria denoting cognitive impairment prior to the onset of DAT (Smith, 2001; Silverman et al., 2021). Instead, it is suggested that caregivers and healthcare professionals working with adults with DS measure the individual's daily functioning and behaviors throughout their aging process to determine if there is any deviance that may result from cognitive impairment (Silverman et al., 2021). These deviances could then be compared to the signs and symptoms associated with the early, middle and late stages of DAT in individuals with DS (Walaszek et al., 2022).

Due to the growing numbers of aging individuals with intellectual disabilities, a National Task Group on Intellectual Disabilities and Dementia Practices (NTG) have met to determine the issues that are faced by caregivers and healthcare professionals in the face of increasing cognitive decline, some attributable to dementia, among individuals with intellectual disabilities (Bishop et al., 2015). The group ascertained some of the challenges of caregivers and professionals face and have attempted to deal with these issues by creating awareness campaigns targeted at caregivers who needed to access diagnostic services and healthcare providers (NTG, 2012a), by developing educational materials and training curricula for healthcare professionals (NTG, 2013; Moran et al., 2013; Jokinen et al., 2013; NTG, 2014), and by developing guidelines and recommendations for dementia-related care and advocacy (Bishop et al., 2015). Additionally, the group continues to call for targeted research towards determining the knowledge and awareness caregivers and healthcare providers have and resources still needed to better this knowledge base, promote advocacy, and encourage early diagnosis of DAT.

As a result of the NTG, further research has been completed to examine the knowledge base of direct care workers, case managers, healthcare professionals, social services staff, and caregivers regarding the associations between DS and DAT (Walaszek et al., 2022; Ilacqua et al., 2019). Data has determined that many professionals have a general lack of knowledge of the increased risk of individuals with DS developing DAT and many have underutilized the available resources to gain this knowledge (Carling-Jenkins et al., 2012; Walaszek et al., 2022). Healthcare professionals and caregivers alike are shown to be unaware of the early stage's behavioral and personality changes that may indicate cognitive decline and DAT (Walaszek et al., 2022; Ilacqua et al., 2019).

Additionally, these caregivers and providers are unaware of how and when to document these changes, and the informal and formal evaluations available to determine if the individual with DS is showing cognitive declines attributable to DAT or another comorbidity (Walaszek et al., 2022).

Of the healthcare professionals evaluated in the above studies, limited research has evaluated the knowledge of rehabilitation professionals inclusive of physical therapy (PT), occupational therapy (OT), and speech-language pathology (SLP) regarding the association between DS and DAT and the resources available to access (Raj et al., 2020; Saccasan & Scerri, 2020). Similarly, there is limited published evidence related to the knowledge base of students in these respective graduate programs (Saccasan & Scerri, 2020). Of the research available, the data indicated a shortage of in-depth knowledge of how to manage and care for individuals with DS and DAT and highlights the need dementia training programs through graduate program curriculum (Saccasan & Scerri, 2020). The push to improve patient experience, accessibility to care, and the promotion of better health outcomes necessitates an inter-professional collaborative experience with PT, OT, and SLP. It is essential that graduate students in the healthcare professions, specifically rehabilitation, develop a full and accurate grasp of the nature of DAT in individuals with DS through their academic and clinical coursework irrespective of their chosen discipline. The purpose of this study is to investigate possible deficits in knowledge of the association between DAT and DS among graduate students matriculating through accredited training programs in PT, OT, and SLP in the United States.

## Research Hypotheses

The research hypotheses are as follows:

**H<sub>1</sub>:** There will be a statistically significant difference between a graduate student's field of study and their general knowledge (i.e., facts) of the association between dementia of the Alzheimer's type and Down syndrome.

**H<sub>2</sub>:** There will be a statistically significant difference between a graduate student's field of study and their knowledge of the signs/symptoms that occur in each stage of dementia of the Alzheimer's type for people with Down syndrome.

**H<sub>3</sub>:** There will be a statistically significant difference between a graduate student's field of study and their familiarity regarding the diagnosis and care of dementia in patients with Down syndrome.

**H<sub>4</sub>:** There will be a statistically significant association between a graduate student's relationship/connection with individuals who have dementia of the Alzheimer's type, Down syndrome or both diagnoses and their general knowledge (i.e., facts), knowledge of the signs/symptoms that occur in each stage, and familiarity regarding the diagnosis and care.

## Null Hypotheses

The null hypotheses are as follows:

**H<sub>01</sub>:** There will not be a statistically significant difference between a graduate student's field of study and their general knowledge (i.e., facts) of the association between dementia of the Alzheimer's type and Down syndrome.



**H<sub>02</sub>:** There will not be a statistically significant difference between a graduate student's field of study and their knowledge of the signs/symptoms that occur in each stage of dementia of the Alzheimer's type for people with Down syndrome.

**H<sub>03</sub>:** There will not be a statistically significant difference between a graduate student's field of study and their familiarity regarding the diagnosis and care of dementia in patients with Down syndrome.

**H<sub>04</sub>:** There will not be a statistically significant association between a graduate student's relationship/connection with individuals who have dementia of the Alzheimer's type, Down syndrome or both diagnoses and their general knowledge (i.e., facts), knowledge of the signs/symptoms that occur in each stage, and familiarity regarding the diagnosis and care

## CHAPTER 2

### METHODS

#### Participants

This non-experimental study utilized a convenience sample (N = 322) to investigate possible deficits in knowledge (i.e., facts, accuracy, familiarity) of the association between DAT and DS among graduate students matriculating through accredited training programs in PT, OT, and SLP in the United States. All participants were asked to complete an online survey concerning their knowledge base about DAT and DS with the following categories represented: general facts about DAT and DS (Ilacqua et al., 2019), accuracy regarding the stages of dementia in patients with DS (Walaszek et al., 2022), and familiarity about diagnosis and care (Ilacqua et al., 2019). The researchers used a between groups design to analyze responses from the aforementioned graduate student groups. Approval was granted by the Institutional Review Board (IRB) of the University of Louisville (#23.0505).

The researchers contacted PT, OT, and SLP program directors across the United States by e-mail. Each director received an explanation of the current study and a link to the survey instrument via Qualtrics. Participating programs forwarded the link to their students voluntarily under advisement that only responses from first- and second-year PT, OT, and SLP graduate students would be included in the study. A total of 332 responses were received between September 12, 2023 and September 25, 2023. Inclusionary criteria

included enrollment as a first- or second-year graduate student in an accredited PT, OT, or SLP training program. There were no gender, age-related, ethnic background, or health status requirements per this study. This study excluded all other non-therapy disciplines. Undergraduate students, faculty personnel, and/or staff members were also excluded from participating. After data screening, 10 responses were excluded, with 322 eligible responses remaining. The sample (N = 322) utilized in this study consisted of 225 SLP graduate students (69.9%), 48 OT graduate students (14.9%), and 49 PT graduate students (15.2%), most of whom were white (79.8%) and female (92.5%).

#### Setting and Instrumentation

Graduate students in PT, OT, and SLP training programs completed an online survey via the Qualtrics platform. The survey was accessible by tablet, laptop, smartphone, or desktop computer, and was designed to take 15 minutes or less. The survey was open for approximately two weeks, and respondents were asked to complete the survey once. Prior to accessing the survey, participants were informed of the possible risks and benefits of the study, and that the opening, completion, or submission of the survey implied consent for inclusion. Participants were advised that there were no foreseeable risks other than possible discomfort from answering personal questions. The survey requested no personal identifying information. Responses were stored on a password protected computer behind a locked door.

## Variables

### Independent Variables

The online survey comprised demographic probes regarding gender, ethnicity, discipline (PT, OT, SLP), and university designation (freshman, sophomore, junior, senior, 1<sup>st</sup> year graduate student, 2<sup>nd</sup> year graduate student, faculty). The responses were self-administered. The independent variables enabled comparison of the dependent variables.

### Dependent Variables

The dependent variables focused on the elements related to factual knowledge, stage identification, and familiarity regarding the varied facets of DAT and DS. The survey also queried whether respondents knew someone with DAT only, knew someone with DS only, or had a connection with someone carrying both diagnoses. Five statements (i.e., facts) about DAT and/or DS were offered. The researchers synthesized the survey instrument from a previous study on DAT and/or DS (Ilacqua et al., 2019). Respondents indicated their degree of agreement with the statements using a five-point Likert scale spanning: strongly agree, somewhat agree, neutral, somewhat disagree, and strongly disagree. Responses including *strongly agree* and *somewhat agree* were recoded and scored as correct. *Neutral*, *somewhat disagree*, and *strongly disagree* responses were recoded and scored as incorrect. This was the inverse for one statement which was false (i.e. “Individuals with DS will develop DAT at some point in their lifetime”). Responses including *strongly disagree* and *somewhat disagree* were recoded and scored as correct.

*Neutral, somewhat agree, and strongly agree* responses were recoded and scored as incorrect. Responses were coded where 1 = correct and 2 = incorrect.

Respondents were also asked to identify the most appropriate stage (e.g., early, middle, late) for which various signs/symptoms of DAT were most likely associated in patients with DS. The nine areas included: memory loss, executive function deficits, deterioration of speech, behavior/personality changes, seizures/epilepsy, decline in activities of daily living (ADLs), lack of response to the environment, inability to walk, and Parkinsonian features. The aforementioned items were pulled from a study by Walaszek et al. (2022). The responses were recoded as 1 = early stage, 2 = middle stage, and 3 = late stage.

The instrument also surveyed respondents' familiarity regarding the diagnosis and care of individuals with DAT and DS. Respondents indicated their degree of agreement with the statements using a five-point Likert scale spanning: strongly agree, somewhat agree, neutral, somewhat disagree, and strongly disagree. Responses including *strongly agree and somewhat agree* were recoded and scored as correct. *Neutral, somewhat disagree, and strongly disagree* responses were recoded and scored as incorrect.

Responses were coded where 1 = correct and 2 = incorrect.

Lastly, the survey queried whether respondents knew someone with DAT only, knew someone with DS only, or had a connection with someone carrying both diagnoses. The answer choices were dichotomous in nature. Responses were coded where 1 = yes and 2 = no.

## Data Analysis

All completed surveys were exported to Microsoft Excel and numerically coded in preparation for analysis. The data were then exported to SPSS Version 29 for statistical analyses. Descriptive and summary statistics characterized demographics, as well as scores related to respondents' factual knowledge, stage identification, and familiarity regarding the varied facets of DAT and DS. The data also reflected respondents' knowledge of individuals with DS, DAT, or both.

Hypothesis (**H<sub>1</sub>**) suggested that there will be a statistically significant difference between a graduate student's field of study and their general knowledge (i.e., facts) of the association between DAT and DS. The data did not pass the test of homogeneity and so the parametric test Analysis of Variance (ANOVA) could not be used. As such, a Kruskal-Wallis (non-parametric) test was completed to determine the presence of statistical difference between the three independent groups: PT, OT, and SLP.

Hypothesis (**H<sub>2</sub>**) suggested that there will be a statistically significant difference between a graduate student's field of study and their knowledge of the signs/symptoms that occur in each stage of DAT for people with DS. The data were normally distributed and an ANOVA along with a Bonferroni Correction (post-hoc) were completed to examine differences between groups.

Hypothesis (**H<sub>3</sub>**) suggested that there will be a statistically significant difference between a graduate student's field of study and their familiarity regarding the diagnosis

and care of dementia in patients with DS. The data were normally distributed and an ANOVA was completed to examine the differences between groups.

Hypothesis (**H<sub>4</sub>**) suggested that there will be a statistically significant association between a graduate student's relationship/connection with individuals who have dementia of the Alzheimer's type, Down syndrome or both diagnoses and their general knowledge (i.e., facts), knowledge of the signs/symptoms that occur in each stage, and familiarity regarding the diagnosis and care. A Spearman's rank correlation (non-parametric) was used to measure the strength and direction of the relationship between the variables because the assumption of normal distribution was not met.

## CHAPTER 3

### RESULTS

#### Descriptive Statistics

Descriptive and summary statistics characterized demographics, as well as scores related to respondents' factual knowledge, stage identification, and familiarity regarding the varied facets of DAT and DS. The data also reflected respondents' relationship/connection with individuals with DS, DAT, or those with both diagnoses. A total of 322 participants were included in the study, of whom 92.5% were female and 79.8% were White. Descriptive and summary statistics as well as category scores are shown in Table 1. Table 2 provides frequencies for respondents' relationship/connection to individuals with DS, DAT, or both diagnoses.

Table 1. Descriptive and Summary Statistics (N = 322)

Variable	N	%	Mean	SD	Min	Max
<b>Discipline</b>						
Physical Therapy	49	15.2				
Occupational Therapy	48	14.9				
Speech-Language Pathology	225	69.9				
<b>Factual Knowledge (Overall)</b>						
			43.17	31.03	0	100.00
Physical Therapy			45.71	36.74	0	100.00
Occupational Therapy			44.68	32.09	0	100.00
Speech-Language Pathology			42.62	29.33	0	100.00
<b>Stage Identification (Overall)</b>						
			54.62	15.49	11.11	88.88
Physical Therapy			49.88	16.37	11.11	77.77
Occupational Therapy			57.63	15.49	22.22	88.88
Speech-Language Pathology			55.00	15.14	11.11	88.88
<b>Familiarity of Diagnosis/Care (Overall)</b>						
			3.59	1.05	1.00	5.00
Physical Therapy			3.56	1.06	1.67	5.00
Occupational Therapy			3.63	0.95	1.00	5.00
Speech-Language Pathology			3.59	1.07	1.00	5.00



Table 2. Frequencies (N = 322)

Variable	Yes (%)	No (%)
Relationship/Connection		
DS	208 (64.6)	114 (35.4)
DAT	182 (56.5)	140 (43.5)
Both Diagnoses	20 (6.2)	302 (93.8)

Respondents in all groups achieved mean scores of less than 50% on items pertaining to factual knowledge of DAT and DS. Mean scores ranged from 49.88-57.63% on questions assessing identification of the stages of dementia in individuals with DS. Familiarity of diagnosis and care ranged from a low of 3.56 to 3.63 crossing all three disciplines. It is important to note that responses for the familiarity section used a five-point Likert scale spanning: strongly agree, somewhat agree, neutral, somewhat disagree, and strongly disagree. For this study, respondents rated “neutral” as a score of 3. Lastly, approximately 65% of respondents indicated they “knew” someone with DS and 56.5% suggested they had a relationship/connection with someone diagnosed with DAT. Only 6% of respondents indicated they “knew” someone with both diagnoses.

#### Accuracies

Questionnaire Item	Accuracy (%)
<i>Factual Knowledge</i>	
Individuals with DS are at an increased risk of developing dementia (Alzheimer’s type). (T)	47.82
Individuals with DS will develop DAT at some point in their lifetime. (F)	23.91
Approximately 50-70% of individuals with DS will develop DAT by the sixth decade of life. (T)	42.86
Most individuals w/DS show characteristic changes (i.e., plaques) in their brains consistent with DAT by the third decade of life. (T)	45.03
Changes in behavior and/or personality is most commonly the first sign/symptom of DAT in individuals w/DS. (T)	56.21
<i>Stages</i>	
Memory Loss (Early)	54.34
Executive Functions Deficits (Early)	37.88

Deterioration of Speech (Early)	18.32
Changes in Behavior and/or Personality (Early)	67.39
Seizures/Epilepsy (Late)	49.37
Decline in ADLs (Middle)	57.76
Unresponsive to Environment (Late)	70.80
Unable to Walk (Late)	92.23
Parkinsonian Features (Late)	43.47

Perceptions

<i>Familiarity of Diagnosis/Care</i>					
	Percentage*				
	SD	SWD	N	SWA	SA
I feel confident in my ability to distinguish the signs/symptoms of DS from the signs/symptoms of DAT.	48.8	23.3	9.9	15.2	2.8
I am familiar with cognitive test batteries that can differentiate the chronic cognitive impairments of DS from the characteristics of DAT.	45.3	23.6	5.9	20.2	5
I am aware of available resources that provide support and/or information regarding the issues of DS and DAT.	14	21.4	20.2	32.3	12

\*(SA) strongly agree, (SWA) somewhat agree, (N) neutral, (SWD) somewhat disagree, and (SD) strongly disagree

### Comparisons

Kruskall-Wallis non-parametric analysis tested the null hypothesis that the distribution of general knowledge (i.e., facts) of the association between DAT and DS is the same across the disciplines of PT, OT, and SLP. The results were not significant,  $H(2) = .405, p = .817$ . Therefore, there is no significant difference between disciplines regarding general knowledge (i.e., facts) of the association between DAT and DS. As such, the null hypothesis will be retained.

Hypothesis (**H<sub>2</sub>**) suggested that there will be a statistically significant difference between a graduate student's field of study and their knowledge of the signs/symptoms that occur in each stage of DAT for people with DS. The data were normally distributed and a one-way repeated measures ANOVA was completed. The results were significant such that a student's field of study appears to impact their knowledge of the signs/symptoms that occur in each stage of DAT for people with DS,  $F(2,319) = 3.314, p = .038$ . Post hoc analysis with a Bonferroni adjustment revealed that OT students' accuracy was statistically significantly increased when compared with PT students' scores (7.75 (95% CI, 0.23 to 15.27),  $p = .041$ ) but not SLP students' scores (2.63 (95% CI, -3.26 to 8.51),  $p = .852$ ). As such, the null hypothesis will be rejected.

A one-way repeated measures ANOVA was also completed to test the null hypothesis that there are no differences between a graduate students' field of study and their familiarity regarding the diagnosis and care of dementia in patients with DS. The results were not significant,  $F(2,319) = .062, p = .940$ . Therefore, there is no significant

difference between discipline and a student's familiarity regarding diagnosis and care of dementia in patients with DS. As such, the null hypothesis will be retained.

A Spearman's rank-order correlation was run to assess the relationship between respondents' connection with individuals carrying a diagnosis of DS, DAT, or both and its impact on scores related to facts, stages, and familiarity regarding diagnosis and care. There was no association identified related to "knowing" a person with DS or DAT individually; however, a statistically significant (but negligible correlation) was identified with respect to respondents' scores per accuracy of facts,  $r_s(320) = -.222, p < .001$ , and familiarity (diagnosis and care),  $r_s(320) = .235, p < .001$  when a connection/relationship is present with an individual diagnosed as having both DAT and DS. As such, the null hypothesis will be rejected; however, it is important to note the negligible correlation identified and its impact on the collective hypothesis overall.

### Summary

Overall, the respondents' mean accuracy scores were very low for the factual knowledge and stage identification items related to DAT and DS. No statistically significant differences between disciplines regarding general knowledge (i.e., facts) were identified. However, knowledge of the stages of DAT as they relate to DS appeared stronger for OT students when compared to their PT peers; no statistically significant difference was noted per SLP students. Familiarity of diagnosis and care parameters were largely neutral crossing all three disciplines. Review of the relationship/connection (i.e., knowing) respondents had with individuals diagnosed with DAT, DS, or both disorders, evidenced consistent scores for individual diagnoses but not both. There was no association identified related to "knowing" a person with DS or DAT individually;

however, a statistically significant (but negligible correlation) was identified with respect to respondents' scores per accuracy of facts and familiarity (diagnosis and care) when a connection/relationship is present. The results obtained from hypotheses testing are summarized in Table 3.

Table 3. Summary of Tested Null Hypotheses

Hypothesis	Statement	Results
<b>H<sub>01</sub></b>	There will not be a statistically significant difference between a graduate student's field of study and their general knowledge (i.e., facts) of the association between dementia of the Alzheimer's type and Down syndrome.	Retain
<b>H<sub>02</sub></b>	There will not be a statistically significant difference between a graduate student's field of study and their knowledge of the signs/symptoms that occur in each stage of dementia of the Alzheimer's type for people with Down syndrome.	Reject
<b>H<sub>03</sub></b>	There will not be a statistically significant difference between a graduate student's field of study and their familiarity regarding the diagnosis and care of dementia in patients with Down syndrome.	Retain
<b>H<sub>04</sub></b>	There will not be a statistically significant association between a graduate student's relationship/connection with individuals who have dementia of the Alzheimer's type, Down syndrome or both diagnoses and their general knowledge (i.e., facts), knowledge of the signs/symptoms that occur in each stage, and familiarity regarding the diagnosis and care.	Reject

## CHAPTER 4

### DISCUSSION

As life expectancy has increased for individuals with DS over the past decades, there has become a greater need for health care providers to be aware of the changes that occur at the onset of DAT and the treatment options available to manage the disease (de Graaf, Buckley, & Skotko, 2017; Walaszek et al., 2022). Review of the literature evidenced a gap regarding the knowledge base of students training to become rehabilitation professionals (Saccasan & Scerri, 2020). As such, it is essential that graduate students in the healthcare professions develop a full and accurate grasp of the nature of DAT in individuals with DS through their academic and clinical coursework irrespective of their chosen discipline. The purpose of this study sought to investigate possible deficits in knowledge of the association between DAT and DS among graduate students matriculating through accredited training programs in PT, OT, and SLP in the United States.

The findings of this study indicated that students in the aforementioned disciplines lacked adequate knowledge on various aspects of dementia including general facts, stage identification of DAT, and familiarity of diagnosis and care parameters. However, two groups were found to be more accurate in their knowledge of this connection. The first group identified were individuals in OT graduate programs who correctly identified signs in each stage of DAT in individuals with DS. These results were statistically significant compared to their PT counterparts, but not students in SLP

programs. The second group were respondents who had a connection (i.e., knew someone with) to individuals with both DS and DAT. This group was found to be more accurate across the general knowledge questions and reported feeling more confident in the diagnosis and subsequent treatment as compared to respondents who only knew individuals with DS or DAT, or who had no relation. This finding is consistent with previous research which has found that individuals who have a personal connection with someone who is affected by a disease significantly enhances their understanding of the disease due to having firsthand experience of the symptoms, challenges and emotions related to the disease that provides context to the facts learned (Centers for Disease Control and Prevention, 2023a; Centers for Disease Control and Prevention, 2023b).

The research found all disciplines lacked a baseline of general knowledge of the connection between DS and DAT. Less than half of the respondents were able to accurately determine if statements were factual or were aware of available resources to gather this information. Forty-seven percent of students reported they “somewhat agree” or “strongly agree” with the item “individuals with DS are at an increased risk of developing dementia (Alzheimer’s type)”. This finding is in line with previous research that has noted that practicing healthcare providers and students alike are unaware of the increased likelihood of the development of DAT in persons with DS (Carling-Jenkins et al., 2012; Saccasan & Scerri, 2020). Students appear to acknowledge these deficits in general knowledge as over 70% reported that they do not feel confident in their ability to distinguish the signs/symptoms of DS from the signs/symptoms of DAT. Research supports these findings by reporting that new graduates who are transitioning to professionals in their field feel inadequate, underprepared, and doubt their competence in

their ability to diagnose and treat a variety of disorders (Opoku et al., 2020; Opoku et al., 2021).

Of the general knowledge statements, 56% of respondents were able to correctly identify that behavioral and personality changes were the most common first signs and symptoms of DAT in individuals with DS. This is important to note since for the general population, memory is often noted as the first changes seen with DAT (Ball et al., 2006; Carr & Collins, 2014). It is common for clinicians to assume that behavioral changes are a progression of DS and not dementia, resulting in delayed diagnosis until they move further along in the stages (Steingass et al., 2011; Brothman, 2014). When tested on stage identification the mean accuracy scores were very low: 54%, among all cohorts. Research has shown that working with people with dementia is a specialized area of practice resulting in a lack of confidence and knowledge across all fields (Raj et al., 2020; Saccasan & Scerri, 2020; Quick et al., 2022). However, findings did show that knowledge of the stages of DAT as they relate to DS appeared stronger for OT students when compared to their PT peers. OT students may have an advantage over PT respondents in regard to their understanding of the stages of dementia due to their education focusing on the impact of dementia on daily functioning and the environmental modifications used to benefit this population. While on the other hand, PT's education has a stronger emphasis on addressing physical impairments related to dementia which often occurs as the disease progresses. Additionally, 68% of individuals stated that they are unfamiliar with cognitive test batteries to aid in the diagnosis of DAT in people with DS. Research among general practitioners have shown similar findings where one third of the sample have expressed limited confidence in their diagnostic skills of dementia among the general public and the



local diagnostic and support services available to them (Turner et al., 2004). The lack of knowledge between the connection of DS and DAT can result in the delay of diagnosis and treatment due to practitioners believing that the signs and symptoms are a result of DS, rather than the development of DAT (Brotman, 2014).

Apart from respondents' graduate training programs, an additional factor that appeared to impact score accuracy centered on whether the individual had a personal or professional relationship with individuals with both DS and DAT. Students who knew people with both DS and DAT were found to have more accurate answers to questions regarding facts and familiarity (diagnosis and care) as compared to respondents who only "knew" someone with DS or DAT, which showed to have no statistical significance. This relates to having a deep understanding of the difference between how DS presents versus DAT signs. Findings have shown that when individuals who are the closest to the person with DS, including family members and direct support professionals, are often the first to notice and respond to subtle changes to baseline behaviors and cognitive function (Ilacqua et al., 2019; Walaszek et al., 2022). The study's findings are comparable to other studies where clinicians who had clinical exposure to patients with both DS and DAT felt more confident in their ability to diagnose and treat individuals with this dual diagnosis (Raj et al., 2020; Saccasan & Scerri, 2020). Though working with individuals with dementia is a part of SLPs, OTs, and PTs professional duties, many practicing clinicians have a lack of clinical exposure to individuals with DS and DAT similar to our respondents' background (Skaalvik et al., 2010; Nagle et al., 2013; Zerafa and Scerri, 2016). This lack of exposure can lead to gaps in future clinicians' knowledge and may limit their role in diagnosing and providing effective treatment.

Past research has identified similar findings on the knowledge gap among healthcare professionals regarding the connection between DS and DAT (Carling-Jenkins et al., 2012; Walaszek et al., 2022). Crossing all three disciplines, only 18% felt confident in their ability to distinguish DS signs and symptoms from DAT, while 44.3% of respondents reported to being aware of available resources that provide support and/or information regarding the issues of DS and DAT. In order to help close the gap related to a general lack of knowledge, previous research has shown promising results when individuals in healthcare fields are trainings on DAT and DS and other intellectual disabilities have been utilized (Walaszek et al., 2022). Both graduate level education courses and continuous professional education courses have been found to increase confidence among providers in their ability to detect signs earlier and provide effective treatment (Saccasan & Scerri, 2020; Walaszek et al., 2022). Students and professionals should be aware of the high probability of the diagnosis of DAT among aging adults with DS and understand what constitutes the warning signs of this disease to provide the upmost care.

#### LIMITATIONS

The present study has several limitations. This study could have benefited from a larger sample size consisting of equal respondents from all domains. Of the respondents, 69% were SLP graduate students, 14.9% were OT graduate students, and 15.2% were PT graduate students. Additionally, this study was limited by the possibility of ascertainment bias. Participants were recruited from study advertisements distributed by program directors of American universities with graduate PT, OT and SLP programs via email. This study population may represent students who are more involved in the programs or

who have interest in working with individuals with DS or DAT currently or who have in the past. This study did not differentiate students' current year in their program, potentially skewing results regarding the knowledge base. Additionally, some respondents could be from environments with more exposure to the target population than other individuals. Therefore, the results of this study may be an over-representation of students' knowledge, familiarity, and resource utilization. It is also possible that students utilized outside resources to aid in their answering of the knowledge questions.

### CONCLUSION

Healthcare providers play a vital role in supporting and educating individuals with DS and DAT as well as their caregivers. This study supports previous research findings on a shortage of in-depth knowledge among healthcare providers regarding facts and familiarity they have about individuals with DS and DAT (Raj et al., 2020; Saccasan & Scerri, 2020; Quick et al., 2022). This study suggests that students in SLP, OT, and PT graduate school programs may not receive adequate information needed to support individuals with a dual diagnosis. To address these deficiencies, training programs must be designed to educate future clinicians at the graduate level. In addition, the development and deployment of continuing education programs would make current clinicians aware of the correlation between DS and DAT. Future research should focus on assessing the effectiveness of training programs in both academic coursework for graduate students and continuing education for professionals. It is only by developing, deploying, and evaluating these programs that the knowledge gap about treating those with a dual diagnosis can be diminished. Though this task is difficult and multi-faceted, the result will make the lives

of people with DS and DAT better, as professionals are better prepared to navigate the next stage of life development with their patients.

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## APPENDIX: ABBREVIATIONS

DAT	Dementia of the Alzheimer's Type
DS	Down Syndrome
OT	Occupational therapy/therapist
SLP	Speech-language pathology/pathologist
PT	Physical therapy/therapist

## CURRICULUM VITAE

NAME: Abigail Donaway

ADDRESS: Department of Communicative Disorders  
Speech-Language Pathology  
MDA Building School of Medicine  
627 S. Preston St., Suite 620  
University of Louisville  
Louisville, KY 40292

CONTACT: [ARDONA01@louisville.edu](mailto:ARDONA01@louisville.edu)  
(502) 619-9301

### EDUCATION

& TRAINING: B. A., Psychology (Cum Laude)  
University of Louisville  
Louisville, KY  
2019-2022

M. S., Communicative Disorders  
University of Louisville  
Louisville, KY  
2022-2024

### RESEARCH

EXPERIENCE: University of Louisville  
Louisville, KY  
Department of Communicative Disorders  
Research mentor: Dr. Alan Smith  
Master's thesis project entitled Dementia of the Alzheimer's Type in Adult with Down Syndrome: Knowledge Among Graduate Students in Physical Therapy, Occupational Therapy, and Speech-Language Pathology

PRESENTATIONS: Donaway, A., Smith, A., & Pitts, T. (2024). Dementia of the Alzheimer's

Type in Adult with Down Syndrome: Knowledge Among Graduate Students in Physical Therapy, Occupational Therapy, and Speech-Language Pathology. Poster presentation at the Graduate Student Regional Research Conference, April 12, Louisville, KY.

#### CLINICAL

EXPERIENCE: Home of the Innocents Kosair for Kids Complex Care Center,  
Louisville, KY

January 2024 – April 2024

Provided inpatient, acute care to children and adults with complex communication and swallowing disorders secondary to a variety of congenital and acquired etiologies including deaf-blind, cerebral visual impairments, tracheostomy, and vented patients at a pediatric skilled nursing facility.

enTECH, Louisville, KY

August 2023 – December 2023

Provided outpatient services to pediatric and adult populations with speech and language deficits secondary to a variety of congenital and acquired etiologies. Fit clients with alternative and augmentative communication devices necessary for their communicative needs.

Baptist Health Floyd, New Albany, IN

June 2023 – August 2023

Evaluated and treated disorders of speech sound production, language, cognition, voice and swallowing to in- and out-patient populations. Gained experience with Modified Barium Swallow Studies, videostroboscopy, and tracheo-esophageal prostheses.

Minors Lane Elementary, Louisville, KY

January 2023 – April 2023

Planned and conducted therapy with diverse students targeting mixed articulation, language, and pragmatic goals.