

UNIVERSITY *of* INDIANAPOLIS[®]

School of Occupational Therapy

Family Education Program in Caring for an Individual with Down Syndrome and Dementia

Drew Flynn

May 1, 2023



A capstone project submitted in partial fulfillment for the requirements of the Doctor of Occupational Therapy degree from the University of Indianapolis, School of Occupational Therapy.

Under the direction of the faculty capstone advisor:

Alissia Garabrant, OTD, MS, OTR

Assistant Professor, Fieldwork Coordinator

Abstract

In recent years, the prevalence of dementia in individuals with Down syndrome has increased due to the increased life span (Barnes, 2010; Maaattaa et al., 2011). However, there is a lack of information available for caregivers experiencing this with their loved ones (Barnes, 2010). The purpose of this project is to increase knowledge on the topic, caregiver confidence, ability to find resources and awareness of caregiver burnout. Six individuals participated in a three-part Dementia and Down Syndrome Training Series, which consisted of three different topics. Through a pre and post survey, the main findings of this study revealed increased family education leads to improved knowledge, confidence, and ability to find resources for caregivers providing for individuals with Down syndrome and dementia.

Down Syndrome Indiana (DSI) is an organization that helps advocate and provide abundant resources for people with Down syndrome. The organization serves the greater Indianapolis area, Terra Haute, and South Bend. Their mission statement is “Dedicated to enhancing the lives of individuals with Down syndrome” (Dsindiana, 2022). The DSI programs intend to promote the inclusion of individuals with Down syndrome in their greater community. Down syndrome designs programs that offer support and resources to families, caregivers, educators, employers, and professionals who serve individuals with Down syndrome (Dsindiana, 2022). One new issue that has recently come to DSI’s attention is that “According to the National Down Syndrome Society, about 30% of people with Down syndrome who are in their 50s have Alzheimer’s dementia. About 50% of people with Down syndrome in their 60s have Alzheimer’s dementia (Alzheimer’s Association, 2022). Due to this report, DSI wants to focus serving the older Down syndrome and have a program that would be able to share knowledge and resources of Down syndrome and dementia.

This Doctoral Capstone Experience (DCE) will focus on developing a program that will provide knowledge and resources on how to take care of an individual with Downs syndrome and Dementia. The program is a three-part training series where family members and caregivers will learn knowledge and resources so they can provide better care to their loved one. The purpose of my DCE will share the outcome of how the family training program will increase confidence in the ability to care for an individual with Downs Syndrome and Alzheimer’s disease, raise awareness of caregiver burnout, and the increase the ability to find resources for care.

Background

Correlation between Down Syndrome and Alzheimer’s

Down syndrome is a common genetic disorder caused by a third copy of the twenty-first chromosome leading to intellectual disability and comorbidities (Santoro et al., 2021). In

recent years, as medical technologies have advanced, the lifespan of people with Down syndrome has grown, unfortunately leading to older adults with Down syndrome being diagnosed with dementia at a high rate (Barnes, 2010; Maaattaa et al., 2011). The pathology of dementia in Down syndrome is unknown; however, a correlation on why individuals have such a high rate of dementia in older age can be made. The amyloid precursor protein is believed to be the reason for the increased rate due to the third chromosome twenty-one producing more amyloid precursor protein, which creates plaque in the brain (Santoro et al., 2021). With the rise in dementia in individuals with Down syndrome, one would assume that there would be a rise in resources, yet research states there is a lack of resources (Barnes, 2010). Barnes mentions when discussing the cases of dementia and Down syndrome, different needs that need to be assessed, such as the lack of tools assessing dementia in individuals with intellectual disabilities, the need for dementia care education in the community living/group home settings, and the lack of funding for staff to meet the needs of seniors with Down syndrome and Alzheimer's (2010, p 10). The high rate of dementia in Down syndrome and the low rate of resources and care guides the focus of my Doctoral Capstone Experiences.

Caregivers are confused about what dementia looks like in people with Down syndrome and if there are any treatments. Santoro et al. (2021) found that some symptoms of Alzheimer's in people with Down syndrome included memory loss, impaired executive function, and inhibiting previous existing skills (p.4501). Castro et al. (2017) discuss how the effects of dementia start way before symptoms start showing. Castro et al. discuss deeper that the effect of Alzheimer's happens earlier due to the amyloid precursor protein in people with Down syndrome, making it much more difficult to find a treatment. (2017, p 804). Fonseca et al. (2016) discuss how most instruments used for dementia were developed from studies of individuals with normal intellectual development (p124). The literature addressed parents'

concerns about their loved one with Down syndrome. To further develop my DCE, I researched ways of caring for individuals with Down syndrome and dementia.

Dementia and Down Syndrome Family Training Series

In developing a training series program for families and caregivers, the literature became the training series' content guidelines. The literature included experiences and information on the following: staff experience with individuals with Down syndrome and dementia care in group homes, lifestyle factors of people with Down syndrome and dementia versus only Down syndrome, caregiver response, and a program called "Positive Approach to Care" that increased understanding of caring for an individual with only dementia.

One study of shared staff experiences in caring for people with Down syndrome and Alzheimer's found the staff had a limited understanding of Alzheimer's disease's impact on Down syndrome and used an ad hoc approach to developing strategies to better care for the impacted individuals (Iacono et al., 2014). The literature also showed the importance of lifestyle factors in individuals with Down syndrome and Alzheimer's and individual with only Down syndrome. That study found a significant difference between the two groups on where the participants lived. The findings showed that people with Alzheimer's lived in an institutionalized setting while people with just Down syndrome lived in an independent/supported setting (Kenshole et al., 2017). This may suggest that moving someone with Down syndrome who is developing Alzheimer's into an institution may be the best way to support them (Kenshole et al., 2017).

Literature also found that caring for someone with Down syndrome and Alzheimer's may also fall on one person, harming their well-being (Solmina & Hawkins, 1998). Literature also found specific impressions that parents have that include parents concerned about who will care for their loved one in an absence. A study also stated that a person with Down

syndrome and dementia would have an increased need, the caregiver would have decreased independence, and make difficult decisions (Post, 2002). The literature supports the idea that caregivers could be experiencing different troubles and that this population could benefit from the training series my DCE developed. A gap in the literature was that no specific applications would support families and help them care for an individual with Down syndrome and Alzheimer's. There is little research to support this specific population, meaning it is essential to address these service gaps further. (Carling-Jenkins 2012). An important aspect found in the literature was implementing a course called "Positive Approach to Care," created by an occupational therapist named Teepa Snow (Ehlman, 2018). I earned the certification of this course through past employment. I knew that the key content of this course, which is used for dementia only, would be able also to relate to dementia and Down syndrome. Ehlman et al. found that the certification course can improve knowledge and facilitate change in how to care for a person with dementia (2018). I was able to use the content of the course to construct the training series content better and strengthen my DCE's effectiveness.

Literature has made it clear that the need for support and resources for families caring for a loved one with Down syndrome and Alzheimer's are needed. Through my Doctoral Capstone Experience, I will develop a program that works with the caregivers of people with Down Syndrome and Alzheimer's and teach them occupationally focused ways to improve their care for their loved one and ease their occupational performance for themselves. The program will be a three-part series addressing the signs and symptoms of Alzheimer's in people with Down syndrome, what to do when their loved one is diagnosed with Alzheimer's, and how to find care in the late stages of Alzheimer's. The Person-Environment-Occupational-Performance model (PEOP) will guide the training series and analyze the occupational performance of individuals with Down syndrome and dementia and their caregivers. Using

Allen's Cognitive level will address the individual with Down syndrome and dementia cognitive disability. The theory and frame of reference will be used to construct a pre-and post-survey to collect the participants' outcome measures.

Project Design and Implementation Draft

After analyzing the needs assessment, assessing the research, and meeting with stakeholders, there was evidence of a lack of resources and information to care for someone with Down syndrome and dementia. This lack of resources leads to strain on families and the inability to properly care for an individual with such a unique need. My DCE addressed the issues by holding a three-part training series to address various topics relating to Down syndrome and dementia. This online series over Zoom will meet in the evening to give out information and provide a welcoming space to prompt discussions.

The first step in developing this program was to advertise for the series. My project was featured in the weekly newsletter that Down Syndrome Indiana sends out to participants across the state. The advertisement included information such as a brief personal background of myself, the purpose of my project, a summary of what the series will cover, the dates of meetings, and my contact information. I received emails from people interested in my series, and most would also share their stories in the email. Next, a list was created of all the people interested, and I sent them the meeting link and specific reminders of meeting dates. Next, I began creating the content I would present. The first presentation was the signs and symptoms of dementia in people with Down syndrome. The first presentation is structured to be more of an introduction to what Dementia and Alzheimer's disease is and what it would look like in an individual with Down syndrome. The second talk focuses on specifics on what to do if your loved one is diagnosed with dementia; this focuses on handling specific situations and tips caregivers should know. The last session focuses on finding care and resources, especially for late-stage Alzheimer's. All resources used in the sessions are from

research, specific dementia training I have received, and resources given to me by my site mentor. The three outcome measures are increasing confidence in caring for an individual with Down syndrome and Alzheimer's, increased caregiver awareness, and increased ability to access resources or care. The outcome measures will be recorded through a pre-survey and post-survey given at sessions one and three.

In week 12 of DCE, I shared the finding of the participant's results from the pre-and post-survey with the staff of DSI. All presentations were recorded, and the videos and other resources were posted to the Down Syndrome Indiana website. The goal will be for future families to come to Down Syndrome Indiana for information about dementia and be able to find it all on the website.

Project Outcomes

I created a pre-training and post-training survey to provide the participants of the Down Syndrome and Dementia Training Series. The reason was to collect four outcome factors; the current knowledge of Down syndrome and dementia, confidence in caring for an individual with Down syndrome, awareness of caregiver burnout, and the ability to find resources.

Research has suggested that there is evidence that people with Down syndrome and dementia require a specific demand, yet there is little outside support causing a crisis response in the family home (Carling-Jenkins et al. 2012). Since there is a problem in the family home, I wanted to keep this project client-centered (the family and the caregivers) by giving them outside resources to increase their knowledge and help give them support.

The pre-survey and post-survey were distributed via email with a prompt and a link to a Google form questionnaire. The pre-survey was emailed out a week before the first training series date, and the post-survey was emailed out a week after the last training series date. The pre-survey and post-survey used the same questions asking the participants to rate themselves to questions on a Likert scale from 1-10, "1= the least" and "10 = the most". Four questions

related to the target outcome factors; confidence, knowledge, awareness, and ability.

Question 1 addresses the self-reflection on the knowledge of Down syndrome and dementia.

Question 2 addresses confidence in caring for an individual with Down syndrome and dementia. Question 3 addresses the awareness of caregiver burnout. Question 4 addresses the ability to find resources for dementia. There was also an option to ask any questions or add any additional thought, which allowed the participant to ask any questions, tell them what they enjoyed, or give a suggestion. Participants were informed that the survey would be used to show how effective Down Syndrome and Dementia Training Series would have on the participants, hoping to continue sharing this information.

The pre-survey had 6 participants, and the post-survey had 3 participants. The purpose of the pre-and post-survey was to see a change in the participants' confidence, knowledge, awareness, and ability. The participants answered the same four questions before and after the training. Question 1 (Knowledge) from the pre-survey had an average answer of 6.8, and from the post-survey, an average answer of 8.6, a 26% increase (see Table 1). Question 2 (Confidence) from the pre-survey had an average response of 5.8, and the post-survey had an average answer of 8, resulting in a 38% increase (see Table 1). Question 3 (Awareness) had an average answer of 9.3 from both the pre-and post-survey, resulting in no change (see Table 1). Lastly, Question 4 (Ability) had an average response of 6 for the pre-survey and 9 for the post-survey resulting in a 50% increase (see Table 1). From these results, the Dementia and Down Syndrome Family Training series effectively teaches people about Down syndrome and dementia to feel better about providing care to their loved ones.

Summary

The life expectancy of individuals with Down syndrome has increased, but the prevalence of dementia has also increased (Barnes, 2010; Maaattaa et al., 2011).

Unfortunately, there is a lack of information available for caregivers experiencing this, which

leads to decreased confidence and ability to care for their loved ones (Barnes, 2010).

According to Post (2002) individuals with both Down syndrome and Alzheimer's will have an increase in dependence, which will ultimately lead to a decrease in caregiver independence. This project aimed to increase knowledge on the topic, caregiver confidence, ability to find resources and awareness of caregiver burnout.

Through a three-part training series, participants learned about the signs and symptoms of dementia in someone with Down syndrome, how to care for them, and how to find resources. Each topic was presented separately via live Zoom meetings. Pre and post surveys were provided to measure four factors including knowledge of Down syndrome and dementia, confidence in caring for these individuals, awareness of caregiver burnout, and ability to find resources. Using the pre- and post-survey, participants answered four questions rating themselves on a scale of 1-10, 1 being the least and 10 being the most, for each of the above factors. Table 1 shows the results of the surveys, and the percent change after the participants have completed the training. The results of the survey show the following three factors had an increase in change; knowledge of Down syndrome and Dementia, confidence in caring for these individuals, and ability to find resources for caregivers providing for individuals with Down syndrome and Dementia. The results of the survey show that the training series was an effective way to help families and caregivers provide for their loved ones with Down syndrome and dementia.

Conclusion

The Down Syndrome and Dementia Family/Caregiver Training Series is effective in improving the knowledge, confidence, and ability to find resources for caregiver providing for individuals with Down syndrome and dementia. Through educational training sessions participants gained information about the signs and symptoms of dementia in Down

syndrome, how to care for these individuals, and the ability to find resources. In the meetings participants expressed how this training was beneficial and helped them gain an understanding on a specific problem in the Down syndrome community. Participants expressed in the surveys and over Zoom how helpful they found the information provided. Hopefully this training series is just the start of the resources that DSI will create. All the presentations and information are posted on the DSI website with the goal that future families that need help can be led to the information. My site mentor and project coordinator of DSI, Stephanie Gardner, along with the rest of the DSI staff, will update the webpage with new information related to Down syndrome and dementia. The future for the occupational therapy profession has many opportunities that could be started or continued at DSI as it pertains to Down syndrome and dementia, whether it is continuing the training series or starting a program where someone could physically meet with the families. As research continues, occupational therapists should continue to engage with this population experiencing this increasing problem and increase education and awareness for families and caregivers providing for their loved ones with Down syndrome and dementia.

References

- Alzheimer's Association, (2022) Down syndrome and Alzheimer's disease. Alzheimer's Disease and Dementia. Retrieved March 11, 2022, from <https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia/down-syndrome>
- Barnes I. (2010). The challenge of providing dementia care for people with Down syndrome. *Canadian Nursing Home*, 21(1), 4–10.
- Carling-Jenkins, R., Torr, J., Iacono, T., & Bigby, C. (2012). Experiences of supporting people with Down syndrome and Alzheimer's disease in aged care and family environments. *Journal of Intellectual & Developmental Disability*, 37(1), 54–60.
<https://doi.org/10.3109/13668250.2011.645473>
- Castro, P., Zaman, S., & Holland, A. (2017). Alzheimer's disease in people with Down's syndrome: the prospects for and the challenges of developing preventative treatments. *Journal of Neurology*, 264(4), 804–813. <https://doi.org/10.1007/s00415-016-8308-8>
- Cleveland Clinic. (2019). Caregiver burnout; causes, Symptoms & Prevention. Cleveland Clinic. Retrieved February 21, 2023, from <https://my.clevelandclinic.org/health/diseases/9225-caregiver-burnout#:~:text=is%20caregiver%20burnout%3F-Caregiver%20burnout%20is%20a%20state%20of%20physical%2C%20emotional%20and%20mental,are%20able%2C%20physically%20or%20financially.>
- Dsindiana. (2022, March 1). *Down syndrome Indiana*. Down Syndrome Indiana. Retrieved March 8, 2022, from <https://dsindiana.org/>
- Ehlman, M. C., Nimkar, S., Nolan, B. A. D., Thomas, P., Caballero, C. E., & Snow, T. (2018). Health Workers' Knowledge and Perceptions on Dementia in Skilled Nursing Homes: A Pilot Implementation of Teepa Snow's Positive Approach to Care Certification Course. *Journal of Continuing Education in the Health Professions*, 38(3), 190–197.
<https://doi.org/10.1097/CEH.0000000000000216>

Fonseca, L. M., Yokomizo, J. E., Bottino, C. M., & Fuentes, D. (2016). Frontal lobe degeneration in adults with Down syndrome and Alzheimer's disease: A review. *Dementia and Geriatric Cognitive Disorders*, 41(3–4), 123–136. <https://doi.org/10.1159/000442941>

Iacono, T., Bigby, C., Carling-Jenkins, R., & Torr, J. (2014). Taking each day as it comes: Staff experiences supporting people with Down syndrome and Alzheimer's disease in group homes. *Journal of Intellectual Disability Research*, 58(6), 521–533. <https://doi.org/10.1111/jir.12048>

Kenshole, A. V., Gallichan, D., Pahl, S., & Clibbens, J. (2017). Lifestyle factors and Alzheimer's disease in people with Down syndrome. *Journal of Applied Research in Intellectual Disabilities*, 30(Suppl 1), 58–66. <https://doi.org/10.1111/jar.12369>

Määääättää, T., Määääättää, J., Tervo-Määääättää, T., Taanila, A., Kaski, M., & Iivanainen, M. (2011). Healthcare and guidelines: A population-based survey of recorded medical problems and health surveillance for people with Down syndrome. *Journal of Intellectual & Developmental Disability*, 36(2), 118–126. <https://doi.org/10.1080/13668250.2011.570253>

Moran J. et al., (2018), Alzheimer's Disease & Down syndrome: Practical Guidebook for Caregivers, National Down Syndrome Society, 1st edition

Snow, T.. (2012). The GEMS®: Brain change model. Positive Approach to Care. <https://teepasnow.com/about/about-teepa-snow/the-gems-brain-change-model/>.

Snow, T. (n.d.) Positive Approach care Training, Written/Oral (Slides 1-48) LCC, <https://teepasnow.com/>

Soliman A, & Hawkins D. (1998). Clinical. The link between Down's syndrome and Alzheimer's disease: 2. *British Journal of Nursing*, 7(14), 847–850. <https://doi.org/10.12968/bjon.1998.7.14.5638>

Appendix

Table 1. Outcomes

Factors	Pre-survey	Post-survey	Percentage Change
	(Avg)	(Avg)	(%)
Knowledge	6.8	8.6	26%
Confidence	5.8	8	38%
Awareness	9.3	9.3	0%
Ability	6	9	50%

DCE Timeline at Down Syndrome Indiana

Week	DCE Stage (orientation, screening/ evaluation, implementation, discontinuation, dissemination)	Weekly Goal	Objective	Tasks	Date complete
1	Orientation	1.) Complete Orientation	-Start on detailed timeline -Complete Orientation process	-Brainstorm meeting dates for “Big group” meeting with site mentor -Discuss Goals and Objectives with Site mentor -Complete Orientation video -Organize Capstone Folder with old needs assessment, goals and objectives, and MOU -Finalize MOU	1/13

2	Evaluation	<p>1.) Complete updated Literature Review/Needs Assessment</p> <p>2.) Finalize Timeline</p> <p>3.) Start on Intro and Background of Paper</p>	<p>-Establish Outcome measures</p> <p>-Complete Need Assessment/SWOT Analysis</p> <p>- Confirm meeting dates for large group discussion</p> <p>-Discuss with site mentor what individualized meetings would look like</p> <p>-From gathered information,</p>	<p>-Create pre- and post- survey for participants</p> <p>-Continue to find/create content that would contribute to the family training</p> <p>-Continue researching updated articles</p> <p>-Finalize question for Needs Assessment</p> <p>-Gather any current resources from the company and analysis with SWOT.</p> <p>-Email/introduce yourself to possible families</p> <p>-create a talking point pamphlet and log what common questions/concerns are present</p>	1/20
3	Evaluation	1.) Complete Literature Review	<p>-Finalize Outcome measures</p> <p>-Finalize what resources will be created</p>	<p>-From gather information from needs assessment and literature review, start creating content that would help family engage in caring for their loved ones with ADLS</p> <p>-Discuss with site mentor/faculty mentor on what data would be most beneficial to collect.</p>	1/27

4	Evaluation/ Implementation	<p>1.) Finalize Content that will be shared</p> <p>2.) Finalize how Data will be collected</p> <p>3) Host Round Table discussion meeting</p>	<p>-Organize information that is gathered into categories</p> <p>-Finalize pre and post survey and get it approved by site mentor and facility mentor.</p> <p>-Prepare for Round table discussion, could be this week or could be Week 5, discuss with site mentor on what would work best</p>	<p>-Talk with site mentor about possible categories and what to focus on</p> <p>-Add/complete any research from site mentor suggestion</p> <p>-Find a way to analyze the data</p> <p>-Show interest in wanting to meet with families individually</p> <p>-Hand out pre-survey (finalize if this will be a google link, word doc, or something else, discuss with site mentor)</p> <p>-Create content could be split into two meetings</p>	2/3
5	Implementation	1.) Schedule a second and third round table meeting.	<p>-look to expand to as many people as possible</p> <p>Group meeting dates:</p> <p>-Meeting #1: 2/8</p> <p>-Meeting #2: 2/22</p> <p>-Meeting #3: 3/8</p> <p>-Hand out post-survey</p>	<p>-Respond to emails and create a handout for families that</p> <p>-complete any follow up task related to individual meetings</p>	2/10
6					2/17
7					2/24
8					3/3
9					3/10
10	Discontinuation	<p>1.) Begin Dissemination Process</p> <p>2.) Hand out Post survey</p> <p>3.) Process Date</p>	<p>-Organize all data that is collected and meet with site mentor about data collected</p> <p>-Start collecting post-survey 3/13.</p>	<p>-start creating webpage</p> <p>-Send out reminders</p>	3/17

			-Once all data is collected process the data	-Create table to show collected data	
11	Preparing for dissemination	1.) Continue dissemination process	-set up a meeting with staff and volunteers of DSI to disseminate -Create webpage so there can be a transfer to site responsibility of DCE	-Add information from content and from data that was collected. -	3/24
12					3/31
13					4/7
14	Dissemination	1.) Disseminate	Complete poster and paper -finish web page Disseminate at Monday Morning Staff meeting	-Complete all task related to objectives.	4/14