

# UNIVERSITY *of* INDIANAPOLIS®

## *School of Occupational Therapy*

Caring for the Caregivers:  
An Educational Program for Caregivers of Those with a Neurodegenerative Disease

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May 2021



A doctoral capstone experience project submitted in partial fulfillment for the requirements of the Doctor of Occupational Therapy degree from the University of Indianapolis, School of Occupational Therapy. University of Indianapolis IRB status was exempt from review.

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### Abstract

**Objective:** This paper addresses the needs of caregivers of a loved one with a neurodegenerative disease by developing a virtual pilot educational and training program based on a review of the current literature. The effectiveness of education and training strategies for providing care, reducing caregiver burden, and improving mental health and quality of life served as the focus of this program.

**Method:** Eight caregivers of a loved one with Alzheimer's disease agreed to participate in a virtual pilot educational and training program via convenience sampling. Participants completed an outcome-based survey before and after implementing the program that assessed participant knowledge surrounding the provision of care for their loved one related to Alzheimer's disease and caregiver burden.

**Results:** All participants demonstrated an average response increase on all 11 knowledge-based statements. Participants who were previous caregivers demonstrated a higher average response on the pre-survey and the post-survey than current caregiver participants.

**Discussion:** This virtual pilot program's results indicate that caregivers of those with a neurodegenerative disease may benefit from additional education and training on the disease course, what to expect during care provision and safety as it relates to the completion of daily tasks.

Keywords: *caregiver, neurodegenerative disease, Alzheimer's disease, educational program, occupational therapy*

### **Caring for the Caregivers:**

#### **An Educational Program for Caregivers of Those with a Neurodegenerative Disease**

Providing care for an aging older adult can have an impact on the mental and physical health of the caregiver, in addition to uncertainties that may come with new diagnoses or conditions that their loved one may have (Alves et al., 2016; DiZazzo-Miller et al., 2017; LaManna et al., 2020; Whitebird et al., 2013). As the population of older adults increases, neurodegenerative diseases like Alzheimer's and Parkinson's are becoming more prevalent, requiring increased amounts of care from spouses, children, or other family members (DiZazzo-Miller et al., 2014; DiZazzo-Miller et al., 2017; Donovan & Corcoran, 2010). In the United States, over 16 million unpaid caregivers provide care for people with Alzheimer's disease and other related disorders (Alzheimer's Association, 2020). Moreover, increased provision of care for a loved one with a neurodegenerative disease may result in increased caregiver burden and stress, as these individuals work to provide the best care for their loved one amid daily challenges and disease progression (DiZazzo-Miller et al., 2014; DiZazzo-Miller et al., 2017; Kim et al., 2011; Liu et al., 2017; Razani et al., 2007; Terayama et al., 2018; World Health Organization, 2020).

One of the main contributors to an increase in physical and psychological caregiver burden is a lack of education and training when it comes to the safe and successful provision of care for an older adult with a neurodegenerative disease (DiZazzo-Miller et al., 2014; Edwards, 2015; Gonyea et al., 2006). Many individuals may experience increased stress and anxiety, declines in self-care, poor physical health and depression (Liu et al., 2017), and decreased social support as their loved one's condition progresses, leaving them uncertain of how to provide the

best care for themselves or their loved one (Edwards, 2015; LaManna et al., 2020; Sperling et al., 2020).

Caring for a loved one with a neurodegenerative disease amid the current COVID-19 pandemic has increased caregiver burden due to the continued decline of the care recipient during the lockdown period (Borges-Machado et al., 2020; Li et al., 2021; Mok et al., 2020; Tsapanou et al., 2020). Efforts to social distance and remain safe have led to discontinued health care and respite services in the home, leaving caregivers feeling unprepared or uncertain of how to properly care for their loved ones throughout the disease progression (Cohen et al., 2020; Greenberg et al., 2020). A study by Altieri & Santangelo (2020) indicated the prevalence of this issue, with decreased resiliency and increased symptoms of depression experienced in those providing care for a loved one with a neurodegenerative disease.

These disparities for caregivers of loved ones with neurodegenerative diseases are related to a lack of understanding and communication with healthcare professionals (Ducharme et al., 2011; Fields et al., 2018; LaManna et al., 2020; Liu et al., 2017). Furthermore, caregivers may feel the need to express their concerns for caring for their loved ones, including safety, independence, stress management, and maintaining a solid social support system (Edwards, 2015; Jennings et al., 2017). Factors such as these may disrupt occupational participation for caregivers and their loved ones, resulting in an imbalance between desired and necessary tasks and activities (Dooley & Hinojosa, 2004; Edwards, 2015). Providing education and training for caregivers from an occupational therapy perspective has demonstrated benefits regarding strategies for improving overall mental health, access to community resources, and proper safety when assisting a loved one with completion of any activity of daily living (ADL) or instrumental activity of daily living (IADL) (DiZazzo-Miller et al., 2014; DiZazzo-Miller et al., 2017; Dooley

& Hinojosa, 2004; Edwards, 2015; Piersol et al., 2017; Thinnes & Padilla, 2011; Razani et al., 2007). Therefore, occupational therapists can administer and lead supportive educational and training strategies to meet caregiver needs. The author sought to understand the needs of caregivers of a loved one with a neurodegenerative disease during the global pandemic of COVID-19. Based on those changing needs and environmental demands, the author endeavored to design a relevant and effective caregiver intervention program, advocating for occupational therapy's role in caregiver intervention.

Use of the PEO Model and Knowles' Model of Andragogy to design a program for caregivers focusing on the principles of caregiver education and training for those caring for a loved one with a neurodegenerative disease is a necessary component to the success of the program upon implementation. The virtual modules covered various topics and focused on addressing the caregiver's unique needs concerning their ability to interact with their daily environment and current occupational performance according to the PEO Model (Cole & Tufano, 2008; Dooley & Hinojosa, 2004). This model's versatility allowed consideration for each caregiver's needs and concerns while incorporating strategies for different individuals in the future. Furthermore, addressing individual caregiver needs through an assessment of environmental and occupational fit may result in more significant interaction and occupational performance among the caregiver and their loved one (Donovan & Corcoran, 2010; Dooley & Hinojosa, 2004). Doing so will help decrease caregiver burden, increase knowledge and resources for the caregiver, and improve satisfaction with the caregiver roles and occupations (Ziff et al., 2000). Knowles' Model of Andragogy guided the daily implementation of the project, focusing on how to provide the best virtual learning environment for caregivers of those with a neurodegenerative disease (Chan, 2010). The development of the virtual materials via a

discussion of interested caregivers' learned experiences allowed the author to create a virtual program that was both internally motivating and valued concerning why this information is needed (Chan, 2010). Chan (2010) and McGrath (2009) discussed the importance of facilitating a learning environment concerning internal and external motivation, according to the principles of andragogy. Therefore, the utilization of these components to create a virtual program for caregivers of a loved one with a neurodegenerative disease that addressed their needs concerning the understanding of the disease process, provision of care, and reduction of caregiver burden is necessary. In a review of the current literature and research on providing care for someone with a neurodegenerative disease, there is a focus on the effectiveness of education and training strategies for providing care, reducing caregiver burden, and improving mental health and quality of life.

### **Literature Review**

The following paragraphs include an examination of the literature that guided the development of this project. The literature examined includes information on caregiver education and training, improvement of caregiver burden and mental health, and improvement of caregiver quality of life for those providing care to a loved one with a neurodegenerative disease. Moreover, the literature review incorporates current research on how the COVID-19 global pandemic has impacted caregivers of those with a neurodegenerative disease. It is essential to address the limitations of this project with the global pandemic of COVID-19. Efforts to social distance and ensure the community's safety have led to the development of virtual education and training materials for caregivers, as required by the organization's program development guidelines. Social distancing has restricted human interaction and the implementation of an in-

person support group for caregivers of those with a neurodegenerative disease as initially outlined for this project before the COVID-19 pandemic.

Caregivers are experiencing increased isolation, stress, and uncertainty with how to provide care for their loved ones due to the global COVID-19 pandemic restrictions (Altieri & Santangelo, 2020; Cohen et al., 2020; Greenberg et al., 2020; Mok et al., 2020), indicating the need for resources that are easily accessible in an alternative format. Therefore, presenting caregiver education and training in a virtual format for those caring for someone with a neurodegenerative disease has been favored by caregivers due to ease of access and efficiency while providing care for their loved ones (Ramirez et al., 2021). Incorporating current literature on the importance of addressing neurodegenerative disease caregiver needs into a virtual, pandemic-safe format is necessary to address the limitations of this program as indicated by the COVID-19 pandemic.

### **Caregiver Education and Training for the Provision of Care**

Providing education to caregivers of individuals with a neurodegenerative disease on assisting their loved one with activities of daily living has demonstrated good carryover and maintenance (DiZazzo-Miller et al., 2014; DiZazzo-Miller et al., 2017). Furthermore, caregivers may gain an increased skillset into providing care while learning strategies to improve their mental health (DiZazzo-Miller et al., 2017; Piersol et al., 2017; Terayama et al., 2018). Researchers have demonstrated the influence of educational strategies for those caring for an individual with dementia on the reduction of depression, anxiety, or other stressors that may result from the increased provision of care as the disease progresses (Piersol et al., 2017; Thinnes & Padilla, 2011; Terayama et al., 2018). The social isolation caused by the COVID-19 pandemic has demonstrated the importance of skill-based training and established routines with decreasing

caregiver and care recipient stress and anxiety when battling a neurodegenerative disease (Ercoli et al., 2021).

Intervention programs designed to build a foundational knowledge for care provision have demonstrated improved caregiver confidence and preparedness in making safe decisions for a loved one with a neurodegenerative disease (DiZazzo-Miller et al., 2017; Ducharme et al., 2011). Sperling et al. (2020) implemented a caregiver intervention program that demonstrated a reduction in caregiver burden through education about the course of the disease regarding care provision, improvement of coping skills, and utilization of community support. Gonzalez et al. (2014) and Graff et al. (2003) highlighted the benefit of skill-based education and training programs for caregivers of those with a neurodegenerative disease concerning increased feelings of caregiver competence during daily tasks. Furthermore, these programs have utilized outcome measures designed to assess knowledge of basic activities of daily living, confidence in the provision of care, performance of and satisfaction with the completion of daily tasks as a caregiver, and mental health in terms of coping strategies (DiZazzo-Miller et al., 2014; DiZazzo-Miller et al., 2017; Ducharme et al., 2011; Sperling et al., 2020).

The provision of basic knowledge in terms of the completion of hygiene activities, transfers, or food consumption can increase awareness of successful care strategies while decreasing the risk of injury to the caregiver or their loved one (DiZazzo-Miller et al., 2014; DiZazzo-Miller et al., 2017). Multiple studies illustrate the benefits of caregiver education on caregiver quality of life or overall well-being to physical health, mental health, and planning for future care strategies in terms of disease progression (DiZazzo-Miller et al., 2017; Ducharme et al., 2010; Peirsol et al., 2017; Roland & Chappell, 2019; Thinnes & Padilla, 2011). Also, educating caregivers on strengthening and receiving support during care provision for a loved



one with a neurodegenerative disease is necessary for caregiver well-being (Edwards, 2015; Piersol et al., 2017). A finding such as this is relevant, given that caregivers have identified the need for a robust social support system from family, friends, and the community (Edwards, 2015; Jennings et al., 2017; Piersol et al., 2017). Overall, occupational therapy practitioners that design caregiver education and training programs must keep the caregiver in mind, adjusting to their level of understanding regarding healthcare terminology and the benefit of shared knowledge (Corcoran & Gitlin, 2001; Fields et al., 2018).

### **Improvement of Caregiver Burden and Mental Health**

In addition to providing caregivers with education and training on caring for their loved ones with a neurodegenerative disease, it is essential to address the physical and mental stressors they may feel in the process (Chin-Ching Chung, 1997; Whitebird et al., 2013). Moreover, there was a success after the implementation of various programs to decrease caregiver burden, rates of depression or anxiety, and other stressors through strategies that target mental health and well-being (Ducharme et al., 2011; Gonyea et al., 2006; Piersol et al., 2017; Roland & Chappell, 2019; Terayama et al., 2018; Whitebird et al., 2013). Understanding the caregivers' experiences throughout the progression of their loved one's disease can help healthcare professionals tailor the supportive strategies offered in various programs (Chiao et al., 2015; Roland & Chappell, 2019). Tailored support for caregivers has led to the development of successful interventions designed to improve stress levels via awareness of coping strategies and techniques (Alves et al., 2016; Ducharme et al., 2011; Piersol et al., 2017). The implementation of programs designed to target problem-solving, developing a positive mindset about caregiving, and engagement in self-care is related to improved caregiver well-being and confidence in the provision of care for a loved one with a neurodegenerative disease (Donovan & Corcoran, 2010; Ducharme et al., 2011;

Piersol et al., 2017). Group sessions that involve the use of mindfulness techniques (Whitebird et al., 2012), reframing patterns of thinking (Piersol et al., 2017), and the benefits of exercise (Piersol et al., 2017; Whitebird et al., 2012) are some strategies that can reduce caregiver stress levels and burden while improving mental health. Transitioning to a new role as a caregiver (Alves et al., 2016; Ducharme et al., 2011) and symptom management for their loved one with a neurodegenerative disease are also techniques that can reduce caregiver stress levels or feelings of burden (Gonyea et al., 2006; Thinnes & Padilla, 2011).

Providing caregivers with strategies they can use to increase their social supports or access to community resources is another component of intervention that may decrease feelings of caregiver burden and stress while improving mental and physical well-being (Edwards, 2015; Jennings et al., 2017; LaManna et al., 2020; Thinnes & Padilla, 2011). Multi-faceted educational interventions have demonstrated improved outcomes with the caregiver role, pointing to the need for caregiver inclusion during health care practices to address caregivers' mental and physical health (LaManna et al., 2020; Ostwald et al., 1999). Individuals in the field of occupational therapy have demonstrated the benefits of interventions that focus on helping the caregiver and their loved one at the same time, facilitating positive behaviors and attitudes when it comes to the provision of care (Donovan & Corcoran, 2010; Edwards, 2015; Dooley & Hinojosa, 2004). Moreover, providing educational strategies to caregivers to reduce the symptoms of depression and anxiety while relieving burden has been shown to improve the mental health and well-being of their loved ones (Terayama et al., 2018; Ostwald et al., 1999), even during the midst of the COVID-19 pandemic (Borges-Machado et al., 2020). Creating specific interventions that involve modifying caregiver behaviors to effectively manage their mental health is more beneficial than

generalized strategies for those who are not currently providing care for a loved one with a neurodegenerative disease (Gonyea et al., 2006; Jennings et al., 2017).

### **Improvement of Caregiver QoL**

In addition to intervention strategies designed to educate caregivers on the provision of care and reduce burden, health care professionals must maximize their knowledge on community resources that can improve caregiver quality of life (Roland & Chappell, 2019; Ziff et al., 2000). Kim et al. (2011) discussed the relationship between decreased caregiver quality of life and the number of hours spent in this role, indicating the importance of a comprehensive approach to resource provision from the health care team. The field of occupational therapy can positively influence caregiver quality of life and overall burden through targeted caregiver and patient intervention (Dooley & Hinojosa, 2004) including anxiety management strategies and feelings of competency during care provision (Burke et al., 2017).

Other caregiver-centered intervention programs illustrate a similar effect, highlighting the importance of addressing multiple components of caregiver need concerning improved well-being and life satisfaction (Burke et al., 2017; Liu et al., 2016; Sperling et al., 2020). Therefore, the relevance of a multi-component approach to caregiver intervention is demonstrated through both current and past research in multiple health care concentrations, especially in the field of occupational therapy. Hogan et al. (2004) further illustrated the role of occupational therapists when providing support to caregivers of those with a neurodegenerative disease, addressing the adverse effects of constant care provision while improving the overall quality of life.

Research regarding an occupational therapist's role in helping caregivers find positive meaning in the provision of care is lacking, even with the benefit of occupational adaptation and modification from this rehabilitation field (Donovan & Corcoran, 2010). DiZazzo-Miller et al.

(2017) and Edwards (2015) solidified this need by demonstrating the benefit of holistic occupational therapy practice with various components of caregiver quality of life, including physical health, after self-care training and education in a variety of domains. Therefore, it is essential to illustrate these benefits through continued program development, advocacy, and research concerning overall quality-of-life improvement in caregivers. The author seeks to address the needs of caregivers of a loved one with a neurodegenerative disease amid the global COVID-19 pandemic by developing and implementing a virtual program designed to provide educational training and increased knowledge for the provision of care and strategies to reduce caregiver burden, using the occupational therapy practice skillset.

### **Methods**

The methods section described below is separated into two parts. The first will describe the processes related to completing the needs assessment, which served as the foundation for the virtual educational program. Second, the reader will find a description of the processes that contributed to the virtual educational program's design and data collection to determine its effectiveness.

#### **Needs Assessment**

##### **Needs Assessment Participants**

The author utilized purposeful sampling and survey methodology to collect experiences and opinions from rehabilitation professionals, nurses, a social worker, and members of a previous Alzheimer's disease caregiver support group on the need for an education and training program for caregivers of those with a neurodegenerative disease. An occupational therapist, a physical therapist, a social worker, and five registered nurses were among the staff level practitioners surveyed, with all of the registered nurses being part of the Nursing Intervention

and the Care of the Hospital System Elderly (NICHE) Team at Schneck Medical Center. In addition to surveying staff-level practitioners, the author contacted a registered nurse and former Alzheimer's disease caregiver support group leader at Schneck Medical Center. This registered nurse participated in the needs assessment via phone interview. Finally, the author obtained access to 26 caregivers in the area who had previously attended the Alzheimer's disease caregiver support group held at Schneck Medical Center, 12 of which participated in the needs assessment via phone interview. Of these individuals, only one was currently providing care to a loved one with Alzheimer's disease. The remaining 11 individuals had care recipients in a long-term care facility or had care recipients who passed away due to disease progression. All hospital-based individuals surveyed were female; of the caregiver participants, nine were female, and three were male.

### **Needs Assessment Procedures**

The author designed the following questionnaires for participants in the needs assessment based on current research and success with open-ended interviews (Borges-Machado et al., 2020; Corcoran & Gitlin, 2001; Edwards, 2015; Liu et al., 2016), questionnaires (Altieri & Santangelo, 2020; Gonzalez et al., 2014; Terayama et al., 2018), and surveys (Altieri & Santangelo, 2020; Alves et al., 2015; Cohen et al., 2020; DiZazzo-Miller et al., 2014; LaManna et al., 2020; Li et al., 2020; Roland & Chappell, 2019) for caregivers and healthcare professionals working with those with a neurodegenerative disease. An open-ended, interview-style questionnaire consisting of five questions and space for additional comments was issued to one occupational therapist, one physical therapist, and one social worker within the Home Services department at Schneck Medical Center. This questionnaire was designed to assess the needs of caregivers for persons with neurodegenerative diseases from each professional's perspective. Also, the author attended a

Nursing Intervention and the Care of the Hospital System Elderly (NICHE) Team meeting at Schneck Medical center to administer a seven-question, open-ended, interview-style questionnaire to five registered nurses. This questionnaire was designed to assess the needs of caregivers for persons with neurodegenerative diseases from a nurse's point of view. The five-question phone interview administered to the registered nurse and former Alzheimer's disease caregiver support group leader was designed to assess her experiences, interactions, and the needs of those caregivers who came to the monthly support group meetings. For the 12 former Alzheimer's disease caregiver support group attendees, seven open-ended, interview-style questions designed to assess their experience in caring for their loved one with Alzheimer's disease were administered via phone interview. The needs assessments were conducted between January 18 and January 25, 2021. See Appendix A for the questions that were administered to the hospital-based individuals and caregiver participants. All participants in the needs assessments were informed that their identifying information, personal stories, and opinions would be kept confidential per the Health Insurance Portability and Accountability Act (HIPAA).

### **Needs Assessment Data Analysis**

After the needs assessments with each of the key stakeholders were completed, the author was able to discern the need for an educational training program for caregivers of those with Alzheimer's disease. This included content that participants may find most valuable in addition to current research on the benefit of educational programs for caregivers of a loved one with a neurodegenerative disease (DiZazzo-Miller et al., 2017; DiZazzo-Miller et al., 2014; Ducharme et al., 2011; Sperling et al., 2019; Terayama et al., 2018). Using qualitative data analysis strategies similar to Edwards (2015), the author analyzed all survey results thematically. The

themes identified provided a foundation for the educational programming for caregivers of people with neurodegenerative diseases. Four common themes surrounding the needs of caregivers of people with a neurodegenerative disease were identified. These themes included: knowing more about the disease progression, the caregiver role during the disease course, accessing community resources and caregiver support, and assistance and safety with daily tasks (transfers, bathing, dressing, eating, and medication management) as the care recipient's condition progresses. These key themes and support from previous literature surrounding this topic served as the foundation for developing a virtual neurodegenerative disease caregiver education program, outlined in detail.

### **Educational Program Development**

#### **Program Participants**

Participants in the virtual caregiver education program were recruited via convenience sampling from the group of former Alzheimer's caregiver support group attendees who had previously participated in the needs assessment. Of these 12 individuals, six females agreed to participate. Only one individual in this group was currently providing care to a loved one with Alzheimer's disease. The other participants had care recipients who had died or who were currently in a long-term care facility. Also, participants were recruited via convenience sampling from the Schneck Medical Center Facebook page, as operated by the Schneck marketing team. Interested participants were required to respond to the Facebook post by February 9, 2021, by calling the Schneck Medical Center Home Services Office Phone. These individuals were eligible to participate in the virtual caregiver education program if they were new or current caregivers of a loved one recently diagnosed with Alzheimer's disease. One male and one female,

both of whom were current caregivers of a loved one with Alzheimer's disease, responded to the Facebook post and were eligible to participate.

Eight individuals participated in the virtual education program for caregivers of those with Alzheimer's disease. Of these eight participants, three were current caregivers, and five were previous caregivers. Individuals were required to have access to a computer, the internet, and a working e-mail address to participate. Prior to the program implementation, the author called all interested participants to make sure they were still interested in participating and confirming their e-mail addresses. All participants were informed that their identifying information and opinions were kept confidential and per HIPPA. Communication with participants was completed via the HIPPA compliant and secure Schneck Medical Center phone and e-mail system to ensure confidentiality.

### **Educational Program Procedures**

Due to the COVID-19 pandemic and the restrictions put in place by Schneck Medical Center, this Alzheimer's disease caregiver educational program was piloted virtually via a series of three educational and training modules featuring the author as the educator and host. The author partnered with the Schneck marketing team to film the modules made available as an accessible community resource after the pilot program. The author created an outcome-based pre/post-survey to assess increased participant knowledge, based on the educational content covered in each module and previous literature featuring pre-/posttest designs for educational and training programs for caregivers of those with a neurodegenerative disease. The success of a pre/posttest design for the assessment of a training program or a series of interventions for caregivers of those with a neurodegenerative disease from Alves et al. (2015), Dizazzo-Miller et al. (2017), Dizazzo-Miller et al. (2014), Dooley & Hinojosa (2004), Ducharme et al. (2011),



Gonyea et al. (2006), Sperling et al. (2019), Terayama et al. (2018), and Whitebird et al. (2012), was used to guide the development of this outcome-based pre/post-survey. This survey consisted of 11 knowledge-based statements that participants rated on a five-point Likert scale (1=strongly disagree to 5=strongly agree).

See Appendix B for the detailed pre/post-survey that was administered. Google forms were used to create the pre/post survey sent to each participant via the secure hospital-based e-mail system one week before the first virtual module was released and two days after the third virtual module was released. This pre/post survey was created to assess any change in knowledge among previous and current caregivers and determine the success of the virtual Alzheimer's disease caregiver education program. In addition to the 11 knowledge-based items, the post-survey contained four opened-ended, opinion-based questions about the pilot program; participant responses were optional.

Program implementation occurred between February 15, 2021, and March 15, 2021. One virtual module was released to participant e-mails each week for three weeks after the pre-survey was completed, giving participants one week to view each module. These virtual modules were created based on the needs assessments conducted with key stakeholders in the implementation of this pilot program and recent literature that included the benefit of a caregiver training program or intervention group for those providing care to a loved one with a neurodegenerative disease. Findings from Dizazzo-Miller et al. (2017), Dizazzo-Miller et al. (2014), Dooley & Hinojosa (2004), Ducharme et al. (2011), Gonyea et al. (2006), Sperling et al. (2019), and Terayama et al. (2018) on the relevance of education and training programs or interventions for caregivers of those with a neurodegenerative disease were used to guide the content created for each virtual module.

The first virtual module contained one educational video, with content regarding the early, middle, and late stages of Alzheimer's disease, the caregiver role during each stage, and local community resources that may benefit the caregiver and the care recipient at each stage (Ducharme et al., 2011; Gonyea et al., 2006; Sperling et al., 2019, Terayama et al., 2018). The second virtual module consisted of a series of five brief training videos that included demonstrations of safe transfers, dressing, bathing, feeding and eating, medication management techniques, and how to manage care recipient behaviors during these tasks (Dizazzo-Miller et al., 2017; Dizazzo-Miller et al., 2014; Dooley & Hinojosa, 2004). The third virtual module included an educational video on recognizing symptoms of stress and depression, strategies for stress relief and coping with caregiver burden, and local community resources for virtual or in-person caregiver support (Gonyea et al., 2006; Sperling et al., 2019). This module also contained an attached resource guide for caregivers, including local and national resources for themselves and their loved ones. See Appendix C for the links to the videos included in modules one through three and the additional resources made available to participants and the site to ensure the sustainability and adaptability of this program in the future.

The author contacted participants each week via the HIPPA compliant and secure phone system at Schneck Medical Center to ensure that they received the automated e-mail. If participants did not receive the e-mail initially via the automated system, it was forwarded to them. All virtual Alzheimer's caregiver educational modules were made available on the Schneck Medical Center website on the community resource page. Caregivers who participated in the virtual educational program were given direct access to these resources once they completed the post-survey after viewing module three.

### **Educational Program Survey Data Analysis**

A Microsoft Excel spreadsheet was utilized to collect data from all participant responses on the pre-survey and post-survey. More specifically, this Excel spreadsheet was used to track and analyze pre and post-survey scores and any change in scores. Descriptive statistics, including the mean and mode, were used to assess the change in knowledge from the pre-survey to the post-survey for all participants and as a comparison between previous and current caregiver participants, similar to the process of data analysis outlined in Ducharme et al. (2011). The descriptive statistics were calculated via Microsoft Excel. Additionally, the author utilized the automatically calculated percentage of participant responses for each value on the Likert scale for the 11 knowledge statements on the pre-and-post survey via Google Forms. These data analysis measures were completed to assess the effectiveness of the implemented virtual educational program for caregivers of a loved one with Alzheimer's disease. After the pre/post-survey results were collected and finalized from previous and current or new caregivers, knowledge-based outcomes were assessed. Responses from the open-ended questions on the post-survey were identified thematically, based on common themes that the author noted.

### **Results**

All eight participants in the pilot virtual educational program for caregivers of those with Alzheimer's disease completed the pre-survey before having access to the virtual education and training videos in modules one through three; however, only seven completed the post-survey by the deadline of March 15, 2021. Therefore, omission of the post-survey data for the participant who did not complete the post-survey by the deadline ensures accuracy of the results. This individual was a previous caregiver participant. Of the seven participants who completed the post-survey, six completed the open-ended questions included at the end of the post-survey. The

individual who did not complete the open-ended questions at the end of the post-survey was a current caregiver participant.

Overall, the participant response average for both previous and current caregivers on all knowledge statements increased from the pre-survey to the post-survey, as seen in Table 1. All participants demonstrated the most significant average response increase on knowledge statement three after being provided access to the contents of modules one through three. Percent values for participant responses on knowledge statement number three for the pre-survey were 62.5% disagree (5), 25% neutral (3), and 12.5% agree (1), and 42.9% strongly agree (3) and 57.1% agree (4) for the post-survey. The second-largest average response increase was demonstrated by participants on knowledge statement 11, from the pre-survey to the post-survey. Percent values for participant responses on knowledge statement number 11 for the pre-survey were 12.5% strongly disagree (1), 37.5% disagree (3), 50% neutral (4), and 42.9% strongly agree (3). Percent values for participant responses on the post-survey for knowledge statement number 11 were 42.9% agree (3) and 14.3% neutral (1). For the post-survey, one participant responded with "neutral" for knowledge statements six and 11. All other participant responses on the post-survey were either "strongly agree" or "agree" for all knowledge statements.

**Table 1**

*Caregiver educational program participant (previous and current caregiver) survey results*

Caregiver Knowledge Statement	Pre-Survey Average	Post-Survey Average	Change from Pre-Survey to Post-Survey
1. I understand the stages of Alzheimer's disease and what to expect when caring for my loved one.	3.38	4.57	1.19

2. I know when to ask for help when caring for my loved one with Alzheimer's disease.	3.50	4.57	1.07
3. I know where to go for help or who to contact when caring for my loved one with Alzheimer's disease.	2.50	4.43	1.93
4. I am aware of safe techniques to use when providing care to my loved one with Alzheimer's disease.	3.00	4.43	1.43
5. I know at least 2 effective techniques for increasing my loved one's participation in daily tasks.	3.00	4.43	1.43
6. I feel confident providing care to my loved one with Alzheimer's disease.	3.13	4.29	1.16
7. I can recognize at least 2 signs of personal stress as it relates to providing care for my loved one with Alzheimer's disease.	3.50	4.57	1.07
8. I know 2 effective stress management strategies to use while providing care to my loved one with Alzheimer's disease.	2.88	4.57	1.69
9. I know at least 2 signs of depression as it relates to caregiver burden.	3.13	4.57	1.44
10. I know at least 2 coping strategies to use as it relates to caregiver burden.	3.00	4.43	1.43
11. I know at least 3 community resources that I can access for my own self-care needs and the needs of my loved one with Alzheimer's disease.	2.38	4.29	1.91

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*Note.* All values are expressed as the mean (average) response for each knowledge statement on a five-point Likert scale (1=strongly disagree, 2=disagree, 3= neutral, 4=agree, 5= strongly agree).

When comparing the response averages on each knowledge statement between previous caregiver participants and current caregiver participants, previous caregiver participants had higher response averages on all knowledge statements on both the pre-survey and the post-survey after being provided access to the contents of modules one through three (see Table 2). Current caregiver participants demonstrated lower response averages on all knowledge statements on the pre-survey than previous caregiver participants. However, current caregiver participants demonstrated increased response averages on all knowledge statements on the post-survey. The response averages for all knowledge statements for the current caregiver participants were lower than the previous caregiver participants' post-survey (see Table 2). Previous caregiver participants demonstrated the most significant average response increase on knowledge statements three and 11 from the pre-survey to the post-survey. However, the previous caregiver participants' smallest average response increase was on knowledge statement seven, which related to signs of stress. Current caregiver participants demonstrated the most significant average response increase on knowledge statements five and eight from the pre-survey to the post-survey. Current caregiver participants demonstrated the smallest average response increase on knowledge statement two, from the pre-survey to the post-survey.

**Table 2**

*Caregiver educational program previous v. current caregiver participant survey results*

Caregiver Knowledge Statement	Previous Caregiver Pre-	Previous Caregiver Post-	Change from Pre-Survey to	Current Caregiver Pre-	Current Caregiver Post-	Change from Pre-Survey to

	Survey Average	Survey Average	Post- Survey for Previous Caregivers	Survey Average	Survey Average	Post- Survey for Current Caregivers
1. I understand the stages of Alzheimer's disease and what to expect when caring for my loved one.	3.80	5.00	1.20	2.67	4.00	1.33
2. I know when to ask for help when caring for my loved one with Alzheimer's disease.	3.80	5.00	1.20	3.00	4.00	1.00
3. I know where to go for help or who to contact when caring for my loved one with	2.80	4.75	1.95	2.00	4.00	2.00

	Alzheimer's disease.						
4.	I am aware of safe techniques to use when providing care to my loved one with Alzheimer's disease.	3.60	4.75	1.15	2.00	4.00	2.00
5.	I know at least 2 effective techniques for increasing my loved one's participation in daily tasks.	3.00	4.75	1.75	1.67	4.00	2.33
6.	I feel confident providing care to my loved one with Alzheimer's disease.	3.80	4.75	0.95	2.67	3.67	1.00



7.	I can recognize at least 2 signs of personal stress as it relates to providing care for my loved one with Alzheimer's disease.	4.00	4.75	0.75	2.67	4.33	1.66
8.	I know 2 effective stress management strategies to use while providing care to my loved one with Alzheimer's disease.	3.40	4.75	1.35	2.00	4.33	2.33
9.	I know at least 2 signs of depression as it relates to caregiver burden.	3.80	5.00	1.20	2.00	4.00	2.00

10. I know at least 2 coping strategies to use as it relates to caregiver burden.	3.60	4.75	1.15	2.00	4.00	2.00
11. I know at least 3 community resources that I can access for my own self-care needs and the needs of my loved one with Alzheimer's disease.	2.80	4.75	1.95	1.67	3.67	2.00

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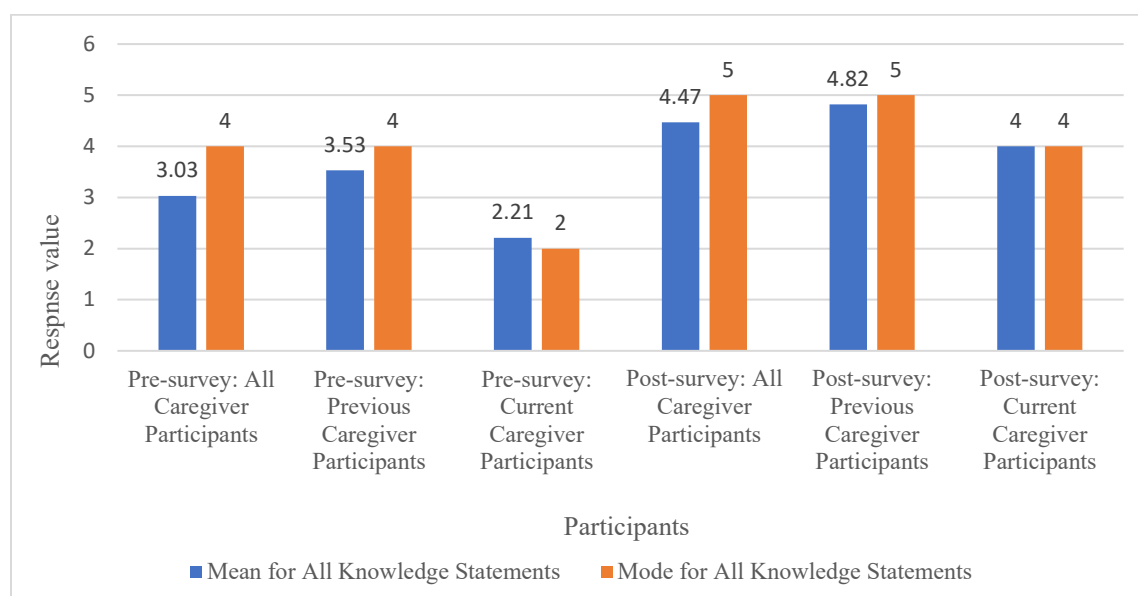
*Note.* All values are expressed as the mean (average) response for each knowledge statement on a five-point Likert scale (1=strongly disagree, 2=disagree, 3= neutral, 4=agree, 5= strongly agree).

When comparing the overall average response from all participants on the pre-survey and the post-survey, there was a higher overall average response for both previous and current caregiver participants on the post-survey (see Figure 1). Current caregiver participants demonstrated the most significant average response increase for all knowledge statements from

the pre-survey to the post-survey. Previous caregiver participants demonstrated the least average response increase from the pre-survey to the post-survey. Additionally, the mode, or most frequently recorded response from all participants, increased from the pre-survey to the post-survey (see Figure 1). Current caregiver participants demonstrated the most significant mode increase from the pre-survey to the post-survey, compared to previous caregiver participants and all participants (see Figure 1).

**Figure 1**

*Caregiver Educational Program Participant Survey Results (Mean & Mode)*



*Note.* The values shown are expressed as the mean (average) and mode (most frequent) in relation to response value for all knowledge statements from all caregiver participants and previous versus current caregiver participants. Each knowledge statement was rated on a five-point Likert scale (1=strongly disagree, 2=disagree, 3= neutral, 4=agree, 5= strongly agree).

In terms of the open-ended response questions, six participants provided feedback on their experience and satisfaction with the virtual educational program for caregivers of a loved one with Alzheimer's disease. For each of the four questions, the author identified common

themes based on participant responses. For question one ("What did you find most helpful about these virtual modules?"), participants stated that the education and training provided to them was informative, clear, and easily understood. The second question ("Would you recommend a similar program to others?") resulted in similar answers, as participants stated that they would recommend this program to others if it was offered virtually again or in-person. However, responses to question three ("How likely would you be to participate in this program again if it was offered virtually? Or if it was offered in person?") were varied among participants, given that three were current caregivers and three were previous caregivers. The three current caregiver participants stated that they would be willing to participate again. Of these three participants, one stated that they would prefer the program to be in-person, one stated that they would prefer the program to be virtual, and the other had no preference. The previous caregiver participants who responded to this question stated that they would not participate again because they were no longer fulfilling a caregiver role. For question four (What other materials or information would you have included in this program if any?), some participants suggested including previously covered information in the educational and training videos and the resource guide. Two participants found the information comprehensive and stated that there was nothing they would add.

### **Discussion**

Several studies found that caregiver intervention programs designed to educate and train caregivers of a loved one with a neurodegenerative disease can lead to improved caregiver confidence and reduced burden when providing their loved one with appropriate care (DiZazzo-Miller et al., 2017; Ducharme et al., 2011; Sperling et al., 2020). Similarly, participants in this virtual pilot program demonstrated an average increase in knowledge from the pre-survey to the

post-survey after viewing the educational and training content included in modules one through three. Notably, participants demonstrated the most significant average response increase on knowledge statement three, with 62.5% disagree on the pre-survey to 57.1% agree and 42.9% strongly agree on the post-survey. Knowledge statement number 11 had the second-largest average response increase, with 50% neutral on the pre-survey to 42.9% agree on the post-survey. It is essential to acknowledge the similarities in these knowledge statements, as each addresses awareness relating to community resources or assistance when caring for their loved one or their own self-care needs.

Recognizing access to community resources as a primary caregiver need has been demonstrated through these program development efforts and mirrored in recent literature. For example, LaManna et al. (2020) report that community resources and social support opportunities for caregivers may help decrease caregiver burden and stress. All but one participant responded with "strongly agree" or "agree" to all knowledge statements on the post-survey, indicating that participants increased their knowledge regarding the course of Alzheimer's disease, what to expect as a caregiver, safe strategies to incorporate during daily tasks, accessing community resources, and caregiver support. DiZazzo-Miller et al. (2014) indicated that educational programs designed to build skills among caregivers of those with dementia are necessary to reduce the difficulties that many of these caregivers may experience related to caring for their loved ones, further supporting the outcome of this program development.

Previous caregiver participants demonstrated a higher response average on both the pre-survey and the post-survey than current caregiver participants, demonstrating the benefit of experience with newly acquired knowledge related to this population (Edwards, 2015). The most

significant average response increase occurred for previous caregiver participants on knowledge statements three and eleven, mirroring the overall average response increase among all participants. A finding such as this may result from the high number of previous caregiver participants compared to the low number of current caregiver participants. Findings such as these demonstrate the importance of access to community resources and caregiver support as a necessity for educational and training programs for caregivers of loved ones with Alzheimer's disease, no matter the experience level (LaManna et al., 2020). Recognizing signs of personal stress related to the provision of care was an area that previous caregiver participants were proficient in, as they demonstrated a lower average response increase on knowledge statement seven. Terayama et al. (2018) report that educating caregivers of those with dementia can reduce their burden and improve mental health. Therefore, the educational content designed to address caregiver burden may have been more beneficial for the previous caregiver participants if they had not already experienced the stressors associated with caring for a loved one with Alzheimer's disease.

Current caregiver participants demonstrated a lower average response on the pre-survey than previous caregiver participants, indicating a gap in knowledge and experience regarding caring for their loved one with Alzheimer's disease. In previous studies, caregivers have experienced uncertainty regarding providing care for their loved ones with Alzheimer's disease, especially as the disease progresses (Edwards, 2015; LaManna et al., 2020; Sperling et al., 2020). Therefore, there are similarities in the literature and the pre-survey data for current caregiver participants in this pilot virtual educational program regarding the needs of caregivers of a loved one with a neurodegenerative disease. Current caregiver participants demonstrated an increase in knowledge on the post-survey, based on a higher average response increase on all knowledge

statements. Furthermore, the highest average response increase for current caregiver participants was on knowledge statements five and eight, indicating the benefit of training caregivers to maximize their loved one's independence while learning how to manage personal stress (DiZazzo-Miller et al., 2017; Sperling et al., 2020; Terayama et al., 2018).

Knowing when to ask for help during care provision was a knowledge statement that current caregiver participants demonstrated the least average increase from the pre-survey to the post-survey, indicating that these individuals may have already had prior experience with asking healthcare professionals for help or seeking support from others. Edwards (2015) and Liu et al. (2016) discussed that healthcare professionals, including occupational therapists, address caregivers' needs with Alzheimer's disease through community resources and social support. Analysis of the outcome measures from this virtual pilot program indicates the impact that professional knowledge and community resources can have on caregivers of a loved one with Alzheimer's disease.

Overall, the participants' average responses for all knowledge statements increased after implementing the virtual pilot program. These results indicate that education and training on daily care for the loved one and self-care for the caregiver are necessary components to increasing occupational performance in multiple contexts (DiZazzo-Miller et al., 2017; Dooley & Hinojosa, 2004; Edwards, 2015). The mean for all knowledge statements demonstrated the most significant increase from the pre-survey to the post-survey for current caregiver participants, indicating that the content covered in modules one through three was relevant to the experiences of current caregivers who are navigating their loved one's disease progression (DiZazzo-Miller et al., 2014; DiZazzo-Miller et al., 2017). Previous caregiver participants may have skewed the outcome of the pilot virtual educational program, given that there was a larger

number of these individuals who had previously experienced the process of being a caregiver to a loved one with Alzheimer's disease.

Similarly, analyzing the mode, or most frequently recorded response, demonstrated a similar pattern for all participants. Although the mode for all participants increased from the pre-survey to the post-survey, current caregiver participants demonstrated the most significant mode increase from the pre-survey to the post-survey. These results further solidify the need to recognize deficits in caregivers' occupational performance and maximize their knowledge for care provision through educational and training strategies (DiZazzo-Miller et al., 2014; DiZazzo-Miller et al., 2017; Dooley & Hinojosa, 2004; Edwards, 2015).

In analyzing the themes from the open-ended responses at the end of the post-survey, it is vital to recognize the commonalities among the six responses that occurred. Overall, the six participants that responded to the open-ended questions had similar feelings about the virtual pilot program. These participants stated that they found the program informative and easily understood and would recommend this program to others if given the option. Therefore, results from these open-ended questions are similar to those found in the literature regarding the benefit of education and training for caregivers of Alzheimer's disease (DiZazzo-Miller et al., 2014; DiZazzo-Miller et al., 2017; Ducharme et al., 2011; Edwards, 2015). Given that most participants had already experienced the caregiver role, half of them stated that they would no longer participate in this program if offered again. A larger group of participants with various needs is necessary to reach more community members within this population (DiZazzo-Miller et al., 2017).

There was diversity among responses relating to this program's format in the future, indicating the need for healthcare professionals to create easily accessible resources for



community members who encounter similar caregiving experiences (Liu et al., 2016). Some participants stated that they would have added concepts to the program that were already included, indicating that they did not access all the content in each module or the content was not clear to them. According to the outcome measures, all participants were able to increase their knowledge surrounding the provision of care for their loved ones with Alzheimer's disease and self-care strategies for themselves as they relate to the profession of occupational therapy. It would be beneficial to assess a larger population of current caregiver participants for an in-person program led by an occupational therapist to address carryover and knowledge gained through participation in future program development efforts.

### **Future Research**

The outcome of these program development efforts demonstrated the importance of accessible community resources for caregivers of a loved one with Alzheimer's disease concerning proper education, training, and relief of burden. Previous and current caregiver participants demonstrated an average response increase on all knowledge statements after accessing the educational and training content in modules one through three. These results indicate that the program content was relevant to the needs of these individuals. Additionally, advocating for the needs of caregivers of those with Alzheimer's disease can be done through successful intervention strategies in occupational therapy practice. Future program development efforts should focus on providing more opportunities for hands-on training and social support for caregivers as this relates to occupational therapy practice. Examining the idea of role change, increasing their loved one's independence in daily tasks, maintaining their mental and physical well-being, and learning about successful techniques to use during care provision are all ways that caregivers can benefit from a program like this one. Edwards (2015) suggested that

occupational therapists possess the knowledge and skills to address the unique needs of caregivers and their loved ones with Alzheimer's disease, addressing occupational imbalance throughout the disease progression. Implications for future program development efforts to occupational therapy practice should include strategies for "family caregivers to create a safer and more positive environment for both the caregiver and care recipient" (DiZazzo-Miller et al., 2017, p. 8).

### **Limitations**

A small sample size of individuals from the same region may have contributed to the lack of diversity in responses on the outcome measure after implementing the virtual pilot educational program. An extended response deadline for the social media post may have been helpful to give more individuals the opportunity to see the post and share the post, resulting in more than two respondents who were current caregivers. Also, there may have been a component of previous caregiver bias from the five participants who had a loved one that had either already passed away or was currently in a long-term care facility due to Alzheimer's disease. Therefore, many of them may have already known about the educational and training strategies provided in modules one through three.

Consideration of limited reliability and unknown validity of the outcome measure are two factors that may have been a limitation to this program development effort. Also, technical difficulties occurred with the secure, automated e-mail system used to send the content of modules one through three to participants. Three participants had to have the e-mails forwarded to them each week, as they did not receive them via the automated e-mail system. The data collected from the outcome measure may have been skewed, given that only seven participants responded to the post-survey by the deadline. It is essential to recognize that some participants

may not have watched all of the content or accessed the resource guide before taking the post-survey. Some participants may not have understood the knowledge statements or interpreted them differently, impacting their level of agreement with each statement. Moreover, this pilot education and training program was delivered asynchronously, preventing participants from asking questions or seeking clarity from the author.

## **Conclusion**

The program development project addresses the needs of caregivers of those with a neurodegenerative disease through education and training strategies to provide care, reduce caregiver burden, and improve mental health and quality of life. The outcome measure results indicate that an increase in knowledge occurred for all participants (previous and current caregivers) after accessing the educational and training content provided through the virtual pilot program for caregivers of those with Alzheimer's disease. Current caregiver participants demonstrated the most significant average response increase from the pre-survey to the post-survey when examining all items' mean and mode in the data set. Previous caregiver participants demonstrated higher average responses on all knowledge statements on the pre-survey and the post-survey, indicating the benefit of experience with newly acquired knowledge. Despite a small sample size, a majority of which included previous caregiver participants, this virtual pilot program's success can be measured by the increase in knowledge and awareness of community resources as reported by participants. The versatility of the virtual modules included in the program contributes to future sustainability efforts, allowing for the addition of content or transition to an in-person format.

Program development efforts, much like this one, have demonstrated improved caregiver confidence (Ducharme et al., 2011), increased knowledge regarding safety and assistance with

daily tasks (DiZazzo-Miller et al., 2014; DiZazzo-Miller et al., 2017), reduced caregiver burden, and improved mental health (Sperling et al., 2020; Terayama et al., 2018). The profession of occupational therapy can continue to influence individuals within this population through efforts to educate and train caregivers of those with a neurodegenerative disease, according to the principles of best practice now and in the future. This program development project contributes to the current literature surrounding caregiver education and training programs for those caring for a loved one with a neurodegenerative disease, demonstrating the importance of this concept within the future of occupational therapy practice.

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## Appendix A

## Assessing Caregiver Needs from A Social Worker's Point of View:

1. What do you think is a social worker's most important role regarding caregiver support of those caring for a loved one with Alzheimer's or other related diseases?
2. What do you see as the most common activities that are lost when individuals care for a loved one with a neurodegenerative disease? Have you had any firsthand experiences with this during interactions with caregivers?
3. What need, if any, is there for a caregiver support group for those with Alzheimer's and other related disorders?
4. What do you see as the most common caregiver needs when it comes to providing care?
5. What have you seen as the most common requests of caregivers of a loved one with Alzheimer's disease when it comes to providing them with the resources that they need, from a social worker's perspective?

Additional Comments:

## Assessing Caregiver Needs from A Rehabilitation Professional's Point of View:

1. What do you think is a physical therapist's/occupational therapist's most important role regarding caregiver support for those caring for a loved one with Alzheimer's or other related diseases?
2. What do you see as the most common activities/occupations that are lost when individuals care for a loved one with a neurodegenerative disease? Have you had any firsthand experiences with this during treatment sessions or interactions?
3. What need, if any, is there for a caregiver support group for those with Alzheimer's and other related disorders?
4. What do you see as the most common caregiver needs when it comes to providing care?
5. Research has shown that caregivers of those with a neurodegenerative disease can benefit from OT/PT interventions. What do you think are the most common/important interventions for this population?

Additional Comments:

## Assessing Needs of Caregivers of Those w/Alzheimer's and other related diseases:

\*Administered to five registered nurses on the NICHE Team

1. What do you think caregivers' biggest physical needs are when caring for their loved one? Social support needs?
2. Why would caregivers of those with neurodegenerative diseases (NDD) find a caregiver support group beneficial?
3. What is the biggest challenge when it comes to addressing the needs of caregivers?
4. What resources do you feel would be the most beneficial for caregivers and/or the NICHE Team to have access to with a new caregiver support program (ex. resources to help continue the program)?
5. Thinking about the NDD population and their caregivers, how do you perceive that their caregivers would handle the physical and mental challenges that come with a progressive disease?
6. Given your knowledge about rehab professionals, how do you think occupational therapists can work to address this issue?

7. Please provide any additional comments or thoughts relating to the need for program development in relation to caregiver support when caregiver for those with Alzheimer's and other related disorders.

Phone Interview Questions for Former Leader of Alzheimer's Caregiver Support Group:

1. What kind of advice did your caregivers typically ask for?
2. What do they see as their biggest needs in relation to caring for a loved one?
3. Who did you have come and speak to the group?
4. What kind of feedback did you get from caregivers? What was meaningful to them?
5. Anything to share from personal conversations with caregivers (feelings of isolation, worries, stresses, etc.)?

Phone Interview Questions for Previous Alzheimer's Caregiver Support Group Attendants:

1. When your loved one was first diagnosed....
  - a. Did you know when to ask for and where to go for help?
  - b. Did you know much about the disease?
  - c. Did you know who to contact with questions?
2. Looking back on your experience, what do you think would be the most important thing you would want a new caregiver to know?
3. What was the hardest part about being a caregiver (i.e. physical, emotional/mental, lack of social support, etc.)?
4. What was the biggest challenge for you as a caregiver?
5. If you could go back in time, what would you do differently?
6. What would you tell your best friend/someone you know if you could give them advice?
7. Tell me about what a typical day was like for you as a caregiver or an important experience you had.

## Appendix B

Please rate the following statements using the following scale:

**1= Strongly Disagree, 2= Disagree, 3= Neutral, 4= Agree, 5= Strongly Agree**

1. I understand the stages of Alzheimer's disease and what to expect when caring for my loved one.
2. I know when to ask for help when caring for my loved one with Alzheimer's disease.
3. I know where to go for help or who to contact when caring for my loved one with Alzheimer's disease.
4. I am aware of safe techniques to use when providing care to my loved one with Alzheimer's disease.
5. I know at least 2 effective techniques for increasing my loved one's participation in daily tasks.
6. I feel confident providing care to my loved one with Alzheimer's disease.
7. I can recognize at least 2 signs of personal stress as it relates to providing care for my loved one with Alzheimer's disease.
8. I know 2 effective stress management strategies to use while providing care to my loved one with Alzheimer's disease.
9. I know at least 2 signs of depression as it relates to caregiver burden.
10. I know at least 2 coping strategies to use as it relates to caregiver burden.
11. I know at least 3 community resources that I can access for my own self-care needs and the needs of my loved one.

Post-Survey Follow-Up Questions:

Please Type Your Answer to the Following Questions.

1. What did you find most helpful about these virtual modules?
2. Would you recommend a similar program to others?
3. How likely would you be to participate in this program again if it was offered virtually?  
Or if it was offered in person?
4. What other materials or information would you have included in this program, if any?

## Appendix C

## Links to Virtual Educational and Training Videos Administered to Caregivers:

- Module 1: <https://youtu.be/yaE-WabSbm8> (12:10)
- Module 2:
  - Transfers: <https://youtu.be/waNRYjhbL1A> (9:42)
  - Dressing: <https://youtu.be/ywBOyNdqf7w> (3:06)
  - Bathing: <https://youtu.be/pLoQdps5YWE> (6:17)
  - Feeding/Eating: <https://youtu.be/aVN9N1Rr6LM> (5:04)
  - Medication Management: <https://youtu.be/bda0f2U8u2U> (6:41)
- Module 3: <https://youtu.be/Et5ixmqrjbU> (8:18)

## Links to Additional Modules Created for Schneck Medical Center:

- Can be used and adapted to the needs of various populations.
  - Module 4: <https://voicethread.com/share/17078151/>
  - Module 5: <https://voicethread.com/share/17146185/>
  - Module 6: <https://voicethread.com/share/17210725/>

## Caregivers' Guide to Alzheimer's:

- A PDF Resource Given to Participants in the Virtual Education and Training Program
- Link to PDF via the Internet for download and printing purposes (9 pages total):  
<https://schneckstage.blob.core.windows.net/schneckmedical/medialibraries/schneckmedical/documents/resource-guide-alz.pdf>