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Creation of a Caregiver Resource Manual:

For Caregivers of Participants Attending Adult Day Services

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For Caregivers of Participants Attending Adult Day Services

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Abstract

Due to high residential care costs, individuals with dementia are remaining in their community and relying on informal caregivers (Vreugdenhil, 2014). Providing unpaid care for individuals with dementia can negatively impact the caregiver physically and psychologically resulting in caregiver burden (Thompson, Bridier, Leonard, & Morse, 2018). In previous literature, caregivers reported they lacked education on the physical, psychosocial, and environmental characteristics related to the caregiving process (Kort & van Hoof, 2014; Lestari et al., 2018; Wawrziczny et al., 2017; Weisman de Mamani et al., 2018). In attempt to decrease caregiver burden, the purpose of this doctoral capstone experience was to develop an educational resource for caregivers to increase their knowledge in relevant topic areas. The doctoral capstone experience was completed at an adult day center serving 20 participants with physical and cognitive impairments. After completing the needs assessment, caregivers were sent a survey to gather further sociodemographic and educational need information. A Caregiver Resource Manual was created during the initial 12 weeks of doctoral capstone experience and forty-eight copies were made. The Caregiver Resource Manuals were presented to caregivers in a caregiver in-service with a pre/post-test to measure knowledge gained during the in-service. Results of pre/post- test indicated an increase in knowledge of common terms and definitions relating to dementia care. Manuals were distributed to the caregivers who were unable to attend the in-service. After completion of the doctoral capstone experience, manuals will continue to be given to all caregivers upon their loved one's admission to the program.

Literature Review

Dementia, one of the most common progressive neurodegenerative conditions, is characterized by a decrease in cognitive function, language, recognition, memory, and movement (Lestari, Hamu, Rachmawati, Singkali, & Yusuf, 2018). Common types of dementia include Alzheimer's Disease, frontotemporal dementia, mixed dementia, Lewy Body dementia, vascular dementia, and multi-infarct dementia (National Institutes of Health, 2013) Forty-seven million individuals live with some form of dementia across the world (Prince, Comas-Herrera, Knapp, Guerchet, & Karagiannidou, 2016). By 2050, 131 million individuals worldwide are expected to be living with dementia (Prince, 2016). Symptoms of dementia include aphasia (language disorder), agnosia (difficulty with object recognition), apraxia (disturbance in motor function), impairments in executive function (planning, problem solving, and sequencing), mood and personality changes, decreased social ability and decreased performance of activities of daily living (ADLs) and instrumental activities of daily living (IADLs) (Gulin et al., 2018; Lestari et al., 2018). As dementia symptoms progress, the affected individual will lose the functional capacity required to live independently requiring them to move to a residential care facility or be cared for by a family caregiver (Vreugdenhil, 2014; Zuria Idura, Noorliaili, Rosdinom, Azlin, & Tuti Iryani, 2018). Due to high costs of residential care and preference to remain in their own home, more individuals are now being cared for at home by their spouse or adult children (Vreugdenhil, 2014).

According to the Alzheimer's Association (2015), in 2014 nearly 16 million caregivers were providing unpaid care to individuals with dementia amounting to 18 billion hours. Demands of caring for an individual with dementia can include assistance with ADL tasks including bathing, dressing, and grooming and IADL tasks including shopping, laundry, home

maintenance, financial management, driving (Weismande Mamani, Weintraub, Maura, Martinex, & Brown, 2018). Aside from the physical demands of caregiving, caregivers also are affected by their loved ones inappropriate, rude, and bizarre behavior symptoms (Weismande Mammani, et al., 2018). Negative outcomes such depression, social isolation, physical and emotional strain, and decreased physical health can result when caring for an individual with dementia, which leads to decreased quality of life for both the caregiver and the individual with dementia (Zuria Idura, 2018). When caring for an individual with dementia begins to negatively affect the caregiver, both physically and psychologically, it leads to the commonly known term caregiver burden (Thompson, Bridier, Leonard, & Morse, 2018). Thompson et al. (2018) defines caregiver burden as a period when a caregiver's work, health, finances, social life, and other life roles are negatively impacted by caregiving producing caregiving stressors.

In a study aiming to determine needs of caregivers, it was found that caregivers felt they needed assistance with home help, finances, social support, and leisure exploration and participation (Wawrziczny, Pasquier, Ducharme, Kergoat, & Antoine, 2017). Caregivers expressed a need for information regarding the disease progression and ways to manage difficult behavioral situations such as night problems and aggressive behaviors (Wawrziczny et al., 2017). Caregivers reported they often do not feel prepared for their caregiver role and lack of awareness and knowledge regarding resources for personal wellbeing. Caregivers across various studies reported they feel they needed education on diagnosis (Wawrziczny et al., 2017; Weisman de Mamani et al., 2018; Zuria Idura, 2018), behaviors (Wawrziczny et al., 2017; Weisman de Mamani et al., 2018), social support (Van Knippenberg et al., 2018; Wawrziczny et al., 2017; Zuria Idura, 2018), benefits of physical activity (Lestari et al., 2018), driving cessation (Byszewski, Power, Lee, Rhee, Parson, & Molnar, 2017; Pyun, Kang, Kim, Baek, Wang & Kim,

2018), home modifications (Kort & van Hoof, 2014), and advanced directives (Bosisio, Jox, Jones, & Truchard, 2018; Lendon et al., 2018;). Education in these areas could decrease caregiver burden by increasing positive aspects of caregiving including feelings of accomplishment, self-efficacy, satisfaction, sense of meaning, personal growth, self-respect, and improved relationships (Grover, Nehra, Malhotra & Kate, 2017; Zuria Idura, 2018). Results of a study that aimed to examine emotional stress reactivity in dementia caregivers revealed that caregiver resources aimed to increase a caregiver's competence, mastery, and coping skills would be beneficial to reduce daily stress for caregivers (Van Knippenberg et al., 2018). The purpose of this doctoral capstone experience (DCE) was to develop an educational resource for caregivers of individuals with dementia to increase their knowledge in attempt to decrease caregiver burden.

Overview of Site and Project

Adult day services strive to improve the quality of life for community-dwelling individuals with dementia and their family caregivers by providing respite services (Rokstad, Engedal, Kirkevold, Benth, and Selbæl, 2018). Adult day services provide participation in meaningful structured activities, a safe environment, socialization, health monitoring, and ADL assistance (Rokstad et al., 2018; Lendon, Caffrey & Lau, 2016). By providing daytime medical care and socialization, adult day services aim to improve the quality of life of individuals with dementia and their caregivers and delay institutionalization or nursing home placement (Lendon et al., 2016). This DCE was completed at A Caring Place Adult Day Services (ACP). ACP offers Person-Centered Care for individuals with cognitive and physical impairments aged 50 years and older (Catholic Charities Indianapolis, 2018). ACP provides socialization, programming, fall prevention and walking programs, medication administration and health monitoring through

Person-Centered Care, which promotes the personal worth, independence, hope and self-confidence for each unique individual (A Caring Place Adult Day Services).

Service Provision Model

ACP follows the community-based service delivery model approach by serving the older adult community under a nonprofit organization. The community-based service delivery model approach was used to guide this DCE by providing education to the caregivers of the individuals attending ACP who are suffering from progression of dementia and other age-related illnesses. This project aimed to educate caregivers on aspects of caregiving that they may experience in order to increase the quality of life of and maintain occupational performance at home and within their community for the caregiver and their loved one. Within this project it was crucial to consider the background, socioeconomic status and education level of all individuals in the community in order to make the educational resource useable to all caregivers upon admission at ACP.

Theory

The model that guided this DCE was the Person-Environment-Occupation (PEO) model. The PEO focuses on the fit between the person, occupation and environment (Cole & Tufano, 2008). The better the fit there is between the person, environment and occupation the better the occupational performance (Cole & Tufano, 2008). Within this model, change is always happening, and any change causes the whole model to shift (Cole & Tufano, 2008). This model was important to this DCE because change in both the caregiver and care recipient physically or mentally affects the fit between their person, environment and occupation. Dementia is a progressive disease meaning change can happen at any point in the course of the disease and the individual and their caregiver will have to adapt their occupation and environment in order to

safely remain at home (Lestari, 2018). The overall goal of this educational resource guided by the PEO model was to decrease caregiver burden by increasing the fit between their person, environment, and occupation.

Using the community-based service delivery model and the (PEO) model, the goal of this DCE was to create an educational caregiver resource manual to be distributed to the caregivers of ACP. This Caregiver Resource Manual was intended to increase education for the caregivers of ACP in attempt to decrease caregiver burden and increase overall quality of life for the individuals with dementia and their caregivers at ACP.

Screening and Evaluation

Initial needs assessment began at initial interview with the program director at ACP. Possible project topics consisted of program development opportunities to assist staff members, participants attending ACP, and/or caregivers. After further discussion, email contact, and one more in person meeting, it was concluded that ACP could benefit most from an educational caregiver resource. The program director explained that she had collected much research relating to potential topic areas over her past 30 years in geriatrics. She had been wanting to create a resource for ACP but never had the time. Although much of the research and materials she had collected were outdated, her collection of research was a great starting point to gain topic ideas.

Next, a SWOT analysis of the current caregiver interaction/programming was completed. The results of the SWOT analysis were used in the intervention plan to determine strengths, weaknesses, opportunities and threats (Aguilar, 2017). Aguilar (2017) found that the SWOT analysis along with other analysis evaluated her interventions effectiveness.

Findings from SWOT analysis:

S- Catholic Charities and ACP held a caregiver support group once a month at a south and north location, which was a strength of the caregiver programming at ACP. Another strength was that ACP provided transportation to and from the facility, which took the stress of transportation off the caregiver.

W- Providing transportation was also weakness because it decreased staff and caregiver interaction. Instead, the majority of staff and caregiver interaction consisted of discussing details over the phone. The greatest weakness was that there were not a specific set of resources to be given to caregivers of participants upon admission or anytime throughout the experience.

O-By creating a universal educational caregiver resource, caregivers will have the opportunity to receive education without increasing time or communication demands of the staff and caregivers.

T- Threats to this educational resource include lack of understanding of materials due to low education level. This emphasized the importance of considering health literacy throughout this DCE. Another threat to this program was that not all participants at ACP had the same diagnosis, requiring different education for each caregiver. After completing the SWOT analysis, it was determined that an educational resource that was understandable by all educational levels and for all types of caregiver was needed. This educational resource would be given to all current caregivers as well as new caregivers upon enrolling their loved one at ACP.

After initial research, it became apparent that sociodemographic data including gender, age, and primary diagnosis for the individuals attending ACP, as well as, each caregiver's age, gender, living situation, level of education and current work status, would be needed to develop an appropriate caregiver resource specific for the caregivers of ACP participants (van

Knippenberg, de Vugt, Ponds, Verhey, & Myin-Germeys, 2018; Wawrziczny, Pasquier, Ducharme, Kergoat, & Antoine, 2017). Surveys containing questions regarding sociodemographic information for the participant and their caregiver were sent home with 20 participants. Prior to the 20 questions, a short paragraph was included introducing the DCE student and explaining the purpose of the project. After two weeks, eight of the surveys were returned. In order to increase participation for the sociodemographic survey, it may have been beneficial to follow-up with a phone call in effort to obtain the requested information. Appendix A includes the sociodemographic survey used for this DCE.

Results of the surveys concluded that the participants' mean age were 74.9 with a range of 67-89. Seventy-five percent of the participants were male and 25% were female. Half of participants' primary diagnoses were dementia while the other four were recorded as schizophrenia paranoid type, traumatic brain injury (TBI), stroke or brain trauma, and inability to live alone due to assistance needed with basic needs. The length of time that the participants had been attending ACP ranged from four months-to- five years. Table 1A details sociodemographic survey results for participants

The survey of the eight respondents concluded that caregiver's ages ranged from 45-75 with a mean age of 59. Seventy-five percent of the caregivers were female and 25% were male. Of the eight caregivers that responded to the survey, four were the spouse of the participant, three were children of the participant, and one was a sibling of the participant. All of the caregivers lived full time with the participant. Three of the caregivers reported having one or two other adults living in the home that are able to assist with caregiving. One of the caregivers had a 14-year-old child living at home who assisted in care of the participant. All other caregivers lived alone with the participant. Caregiver education levels ranged from 11th grade to a master's

degree. Fifty percent of the caregivers were retired, while 25% of caregivers worked full time and 25% worked part time, five-to-20 hours per week. Table 2A includes sociodemographic survey results for the caregivers.

While waiting for responses for the demographic survey, a literature review of scholarly research along with communication with the program director was completed to determine the topic areas most appropriate for the caregivers at ACP. The program director had more than 30 years of geriatric specific experience working as a licensed social worker (LCSW). A social worker is trained to be equipped with skills in counseling, education, case management and dementia care all used in caregiver support services, making this feedback reliable for this educational resource (Anderson, Dabelko-Schoeny, Fields, & Carter, 2015).

Screening and Evaluation for the most appropriate way to implement caregiver education has similarities and differences based on setting. When comparing the adult day setting to a home health setting the individuals treated could be very similar regarding age, diagnoses, living situations etc. Different from the Caregiver Resource Manual created during this DCE, that is targeting the dementia population as a whole, caregiver education in the home health setting is given based on each individual's specific needs (Lannin, 2003). Topic areas addressed in home based rehabilitation could include physical, psychosocial and cognitive issues as well as home management and community integration (Lannin, 2003). The individual and their caregiver are screened and evaluated in those areas and the education is focused on each individual's specific strengths and weaknesses at the time (Lannin, 2003). After reviewing the sociodemographic survey, it was apparent that ACP had a diverse participant and caregiver population, therefore in order to ensure sustainability of this Caregiver Resource Manual it was important to make it broad and universal in order to be useful to as many caregivers as possible.

In summary, screening and evaluation for this DCE consisted of interviews with the program director at ACP, SWOT Analysis, and a sociodemographic survey. Limited sociodemographic responses resulted in a less accurate representation of the participant population at ACP. However, the responses were useful in representing the sociodemographic differences among the caregivers that will be receiving this Caregiver Resource Manual.

Implementation Phase

After extensive online literature review, review of site mentor's materials collected during her 30+ years of geriatric work, and collaboration with the site mentor the following sections were determined to be included in the Caregiver Resource Manual:

1. Diagnoses (Wawrziczny et al., 2017; Weisman de Mamani et al., 2018; Zuria Idura, 2018)
2. Caregiver Burden (Thompson et al., 2018, Zuria Idura, 2018)
3. Preparing for Doctors Appointments
4. Advance Directives and Legal and Financial Worksheets (Bosisio, Jox, Jones, & Truchard, 2018; Lendon et al., 2018)
5. Understanding and Managing Behaviors (Wawrziczny et al., 2017; Weisman de Mamani et al., 2018)
6. Home Safety as you Age in Place (Kort & van Hoof, 2014; Vreugdenhill, 2014)
7. Home Programming Activities (Lestari et al., 2018)
8. Depression (Aguilar, 2017)
9. Guidance for Continued Driving (Byszewski, Power, Lee, Rhee, Parson, & Molnar, 2017; Pyun, Kang, Kim, Baek, Wang & Kim, 2018)
10. Support Groups

Once topics were finalized more extensive research was conducted to gather relevant data for each section. The student visited the Alzheimer's Association to gather information from a local representative on the included topics. Student referred to occupational therapy textbooks and

researched websites from reputable organizations including the Hartford foundation, EasterSeals Crossroads, and the National Institute for Health to compile the most updated and accurate information for each topic area.

For the readers ease, each section began with an overview introducing the importance of the section and detailing what was going to be included. Following the overview, topics were further explained as well as how they could be applicable to their role of caregiving. In order to ensure health literacy was addressed, all of the topics were described using language that could be understood by individuals of many educational levels (Matsuyama, Wilson-Genderson, Maghanaki, Vachhani, Paasche-Orlow, 2011). After reviewing the educational levels of the caregivers at ACP, obtained in sociodemographic surveys, it was determined that information should not surpass the high school education level. However, in some sections handouts from various associations were provided using more advanced language and increased detail for further topic knowledge if the caregiver chose.

Once each section was in draft form, the site mentor reviewed the section and provided feedback. After consultation with the site mentor and staff social worker it was determined that the best way to disseminate the Caregiver Resource Manual would be to host a caregiver in-service for all interested caregivers. Twenty current caregivers were sent invitations to the in-service.

In order to ensure all 20 caregivers, as well as future caregivers, could have a copy of the Caregiver Resource Manual, 48 copies were created. Binders and binder tabs were ordered online. Once the binder resource was completed and revised, student scanned the final copy to the Catholic Charities printing office for duplication.

After assembling all 48 binders a final review was completed. It was concluded that it would be beneficial to include a section on humor at the end of the material to emphasize the importance of humor and laughter in the caregiver process. A miscellaneous section was also added for the caregiver to add any resources that they collect throughout their caregiving journey.

Leadership

During the implementation phase of this DCE many leadership skills were required. This project was self-directed and required leadership to ensure that everything was ordered on time, caregivers were informed, and site mentor had sections in a timely manner for critique. A weekly planning guide was completed during the first two weeks and adapted as needed to assist with project timeline.

The secondary focus of this DCE was administration. Student assisted with completion and submission of major administrative documents including: Title VI Bus Grant Renewal, 2019-2020 Budget, Medicare Re-mediation, Medicare Re-validation, and Title III CICOA Grant Renewal. Student took leadership with navigating computer online system while program director and social worker located needed documents and statistics to be inputted into the computer. Student took leadership with inputting bills and invoices into online payment system as well as assisting with credit card reports each month during DCE.

Staff Development

During this DCE at ACP there were multiple staffing changes. During the first week on-site a physical therapist, driver and kitchen aide were beginning new positions and trained simultaneously with student. During remainder of the DCE a CNA was hired and a bus driver increased his hours to assist with the program assistant/kitchen aid position as another staff

member had to significantly cut her hours. While new staff members were being trained it was important for all staff members to cover the empty positions. The student was able to assist with coverage of these positions while positions were advertised and other staffing positions were adjusted. With each new hire and change in position the individual had to complete appropriate paperwork as well as be trained in new position requirements. The student was able to assist program director with updating position description forms to be completed by employees. The student was also able to assist these staff members with their transition and help them as needed until they felt confident completing their roles independently.

During this DCE two of the staff members were studying and being trained to obtain their Program Assistant Certification. After reviewing and becoming knowledgeable of the certification content, student was able to assist the staff members in their preparation for their certification exam. This consisted of three, 2-hour training sessions with the program director, student, and the two staff members.

Over the course of this DCE student was able to utilize leadership and staff development in order obtain beyond entry-level occupational therapy practitioner skills in program development and administration. Self-directed leadership was utilized to construct and finalize the Caregiver Resource Manual timely, as well as to plan the caregiver in-service for the discontinuation phase. Leadership skills required time management, communication, and organization. Leadership was also utilized during administrative tasks as many major administrative documents were completed during the DCE that required extensive research, patience, and forward-thinking. Administrative tasks during this experience promoted staff development in administrative aspects including staff training and updates to position descriptions. Staff development was also vital to this DCE during the implementation of the

Caregiver Resource Manual, as the social worker and program director will continue to distribute this Caregiver Resource Manual to all new participants after completion of this DCE.

Discontinuation and Outcome

The caregiver in-service was completed on Wednesday March 27, 2019. Twenty caregivers were sent an invitation one month before the in-service with a requested return annotating their attendance. Eight caregiver responses were received. Out of the eight received, three of them stated they would be out of town and would like to reschedule. On the afternoon prior to the in-service, 14 caregivers were called and reminded of the caregiver in-service. The three caregivers that noted that they would be out of town were not called until the week following the in-service in attempt to reschedule. Two of the participants lived alone and requested to receive the information themselves, therefore their primary contact was not notified. After making the calls six caregivers were scheduled to attend the caregiver in-service. If caregivers were unable to make it at the scheduled time they were asked to choose another date/time to come to ACP to receive their manual personally.

Four of the six caregivers that noted they would be present attended the in-service presentation. The presentation was 50 minutes. The presentation began with a pre-test including 10 questions (see Appendix B for pre/post test questions). Caregivers scores ranged from 0-3 correct answers on the pre-test (see Table 1B for results of pre-test). Student presented material and caregivers were encouraged to ask questions throughout the presentation. Post-test was administered after presentation. All caregivers were able to answer 6-8 questions during allotted time. Due to length of presentation, only ~3-4 minutes was allotted for post-test and then answers were reviewed to ensure that all caregivers knew the correct answers. Post-tests were not collected, but caregivers reported their final score on the post-test after going over the

answers as a group. The number of questions correctly answered increased by 5-7 points for each caregiver when comparing pre/post test results (see table 2B for scores on the post-test and increase in number of correct answers).

During the remainder of student's DCE, caregivers were contacted and encouraged to come to ACP to receive their manual with a one-on-one presentation from student. Five additional caregivers were able to come in to receive the Caregiver Resource Manual. The Caregiver Resource Manuals were presented individually to the five caregivers with a 15-minute overview. The caregivers were encouraged to ask questions.

All caregivers unable to receive their manual during the student's on-site presentation will receive their manual at a later date by program director or social worker. The program director was given a list of caregivers that have and have not received the Caregiver Resource Manual at the end of the DCE. The program director attended the caregiver in-service and received instruction from the student on how to present the manual and explain the sections appropriately. The social worker was unable to attend the in-service but was educated on how to present the Caregiver Resource Manual to caregivers.

After completion of the students DCE the Caregiver Resource Manual will continue to be distributed to all new caregivers upon their loved one's enrollment. The social worker and program director expressed confidence that the Caregiver Resource Manual will be used for years to come. The program director received copy of the Caregiver Resource Manual to be used when additional copies of the resource are needed. Program director also received a digital copy of all resources included in the manual in the case that sections would need to be updated in the future. The program director plans to have future students examine the resource yearly to ensure that all materials are still applicable and appropriate. The program director also received a copy

of the pre/posttest given during the in-service, and reported at a time of multiple new admissions she may hold another caregiver in-service in the future.

Response to Society Needs

All caregivers that received the Caregiver Resource Manual during student's DCE were receptive to the information included. Overall caregivers were thankful for the information and reported that the resource would be used in their daily caregiving processes. Caregivers reported that the Advance Directives and Legal and Financial Worksheets Section and the Preparing for Doctors Appointments Section would be the most beneficial for organizing their loved one's information and wishes.

Caregivers across many studies reported they needed education on diagnosis (Wawrziczny et al., 2017; Weisman de Mamani et al., 2018; Zuria Idura, 2018), behaviors (Wawrziczny et al., 2017; Weisman de Mamani et al., 2018), social support (Van Knippenberg et al., 2018; Wawrziczny et al., 2017; Zuria Idura, 2018), benefits of physical activity (Lestari et al., 2018), driving cessation (Byszewski, Power, Lee, Rhee, Parson, & Molnar, 2017; Pyun, Kang, Kim, Baek, Wang & Kim, 2018), home modifications (Kort & van Hoof, 2014), and advanced directives (Bosisio, Jox, Jones, & Truchard, 2018; Lendon et al., 2018). Therefore, these topics were the most important to address for the caregivers of ACP. Caregivers were informed during presentation of Caregiver Resource Manual that this manual contained the most up to date resources commonly requested by caregivers but was not all-inclusive. Caregivers were encouraged to continue to add to their knowledge and continue to reach out to collect information during their caregiving journey. The student explained that this Caregiver Resource Manual was created to give them structure, knowledge, and organization in order to assist with decreasing caregiver burden and enabling their loved ones to age-in place for as long as possible.

Overall Learning

Throughout DCE the student interacted with participants, caregivers and staff to develop a Caregiver Resource Manual that would be inclusive to all participants. The student began with observing and interacting with participants in order to learn their strengths as well as learn about the progression of their diagnoses. The student mailed out demographic surveys to initially gain some information about the caregivers of the participants (refer to Appendix A). The student worked with all staff members including the program director, social work, program supports, physical therapist and kitchen staff to learn their role at ACP and learn from their interactions with the participants. After completion of the Caregiver Resource Manual, the student increased interaction with caregivers through phone calls, caregiver in-service and one on one meetings to present Caregiver Resource Manual. In doing this, the student was able to learn about the participant from the caregiver's perspective as well as advocate for each participant individually. The student felt confident that she knew participants from day to day interactions and was able to guide each caregiver presentation differently based on knowledge of their loved one.

During this DCE, the student was able to participate in six complex administrative documents. Completion of these documents took a combination of verbal, written and oral communication with the program director, the executive director of Catholic Charities, the staff social worker and other Catholic Charities employees in order to ensure all of the correct information and documentation was collected prior to submission.

Overall Learning- Leadership and Advocacy

During this DCE the student advocated for the needs of the caregivers. Although ACP is intended to assist all caregivers by providing respite care and transportation, their program was lacking a specific set of resources to assist caregivers with their daily caregiving processes. The

student advocated for the Caregiver Resource Manual project and took on leadership with developing the manual. The student advocated for the occupational therapy profession when presenting the manual to all caregivers.

Among other administrative tasks completed during DCE, the student attended Catholic Charities 100th Anniversary two-day conference with the program director. At this conference, the student was introduced to program directors and executive directors of Catholic Charities across Indiana. Through discussions with various attendees, the student described and advocated for her project and experience at ACP. Through conversations with program directors of Catholic Charities refugee program, the adoption clinic, and the crisis center, the student advocated for the role of occupational therapy and how it would benefit the individuals served in their programs. During conference student demonstrated professionalism, confidence, and excellent communication skills in order to represent ACP and the University of Indianapolis' School of Occupational Therapy.

The student also assisted with the administrative task of the 2019-2020 budget with the program director of ACP and her direct supervisor. During budget planning, additional staffing that was currently advertised for was going to be cut for the 2019-2020 budget, including the part-time occupational therapist. The program director's supervisor felt cutting these staff members would assist ACP in meeting their budget for the following year. Student advocated for the need of a staff occupational therapist within the ACP facility and the benefits the position would have for the participants. The program director agreed with the need for a staff occupational therapist and made some adjustments to include hours for a part-time occupational therapist in the 2019-2020 budget.

Overall the student gained many skills in leadership, advocacy, and communication while on site during this DCE. The knowledge gained relating to administration and program development have taught the student skills beyond entry-level occupational therapy practitioner that will be integrated into everyday practice as an occupational therapy practitioner.

References

- Aguilar, A. (2017). Coping with Behavioral Symptoms of Dementia: Educating Caregivers to Lower Stress. *Doctor of Nursing Practice (DNP) Projects*. 101.
- Alzheimer's Association. (2015). 2015 Alzheimer's disease facts and figures. *Alzheimer's & Dementia: The Journal of the Alzheimer's Association*, 11(3), 332-384. doi: 10.1016/j.jalz.2015.02.003
- Anderson, K. A., Dabelko-Schoeny, H. I., Fields, N. L., & Carter, J. R. (2015). Beyond respite: the role of adult day services in supporting dementia caregivers. *Home Health Care Services Quarterly*, 34(2), 101-112.
- Atherton, N., Bridle, C., Brown, D., Collins, H., Dosanjh, S., Griffiths, F., ... & McShane, R. (2016). Dementia and Physical Activity (DAPA)-an exercise intervention to improve cognition in people with mild to moderate dementia: study protocol for a randomized controlled trial. *Trials*, 17(1), 165.
- Bosisio, F., Jox, R. J., Jones, L., & Truchard, E. R. (2018). Planning ahead with dementia: what role can advance care planning play? A review on opportunities and challenges. *Swiss Medical Weekly*, 148(5152).
- Byszewski, A., Power, B., Lee, L., Rhee, G. G., Parson, B., & Molnar, F. (2017). Driving and dementia: workshop module on communicating cessation to drive. *Canadian Geriatrics Journal*, 20(4), 241.
- Catholic Charities Indianapolis. (2018) A Caring Place Adult Day Services. Retrieved from <http://www.archindy.org/cc/indianapolis/caringplace.html>
- Cole, M. & Tufano, R. (2008). Applied theories in occupational therapy: A practical approach. Thorofare, NJ: SLACK Incorporated.

- Gulin, S. L., Perrin, P. B., Peralta, S. V., McDonald, S. D., Stolfi, M. E., Morelli, E., ... & Arango-Lasprilla, J. C. (2018). The Influence of Personal Strengths on Quality of Care in Dementia Caregivers from Latin America. *Journal of Rehabilitation, 84*(1).
- Grover, S., Nehra, R., Malhotra, R., & Kate, N. (2017). Positive aspects of caregiving experience among caregivers of patients with dementia. *East Asian Archives of Psychiatry, 27*(2), 71.
- Kort, H. S., & van Hoof, J. (2014). Design of a website for home modifications for older persons with dementia. *Technology and Disability, 26*(1), 1-10.
- Lannin, N. (2003). Goal attainment scaling allows program evaluation of a home-based occupational therapy program. *Occupational Therapy in Health Care, 17*(1), 43-54.
- Lestari, D. I., Hamu, A. H., Rachmawati, S., Singkali, D. P., & Yusuf, A. (2018). The Effect of Physical Activity to Decreased of Dementia (Mild, Moderate and Severe) in Elderly: A Systematic Review.
- Lendon, J. P., Caffrey, C., & Lau, D. T. (2018). Advance directive documentation among adult day services centers and use among participants, by region and center characteristics: National Study of Long-Term Care Providers, 2016.
- Matsuyama, R. K., Wilson-Genderson, M., Kuhn, L., Moghanaki, D., Vachhani, H., & Paasche-Orlow, M. (2011). Education level, not health literacy, associated with information needs for patients with cancer. *Patient education and counseling, 85*(3), e229-e236.
- National Institutes of Health. (2013). *The Dementias: Hope Through Research*. NIH Publication No. 13-2252.
- Prince, M., Comas-Herrera, A., Knapp, M., Guerchet, M., & Karagiannidou, M. (2016). World Alzheimer report 2016: improving healthcare for people living with dementia: coverage, quality and costs now and in the future.

- Pyun, J. M., Kang, M., Kim, S., Baek, M., Wang, M., & Kim, S. (2018). Driving Cessation and Cognitive Dysfunction in Patients with Mild Cognitive Impairment. *Journal of Clinical Medicine*, 7(12), 545.
- Rokstad, A. M. M., Engedal, K., Kirkevold, Ø., Benth, J. Š., & Selbæk, G. (2018). The impact of attending day care designed for home-dwelling people with dementia on nursing home admission: a 24-month controlled study. *BMC Health Services Research*, 18(1), 864.
- Thompson, C. J., Bridier, N., Leonard, L., & Morse, S. (2018). Exploring stress, coping, and decision-making considerations of Alzheimer's family caregivers. *Dementia*, 1471301218809865.
- van Knippenberg, R. J., de Vugt, M. E., Ponds, R. W., Verhey, F. R., & Myin-Germeys, I. (2018). Emotional reactivity to daily life stress in spousal caregivers of people with dementia: An experience sampling study. *PloS One*, 13(4), e0194118.
- Vreugdenhil, A. (2014). 'Ageing-in-place': Frontline experiences of intergenerational family carers of people with dementia. *Health Sociology Review*, 23(1), 43-52.
- Wawrziczny, E., Pasquier, F., Ducharme, F., Kergoat, M. J., & Antoine, P. (2017). Do spouse caregivers of young and older persons with dementia have different needs? A comparative study. *Psychogeriatrics*, 17(5), 282-291.
- Weisman de Mamani, A., Weintraub, M. J., Maura, J., Martinez de Andino, A., & Brown, C. A. (2018). Stigma, expressed emotion, and quality of life in caregivers of individuals with dementia. *Family Process*, 57(3), 694-706.
- Zuria Idura, A. M., Noorliaili, M. T., Rosdinom, R., Azlin, B., & Tuti Iryani, M. D. (2018). Caring for Moderate to Severe Dementia Patients-Malaysian Family Caregivers Experience. *International Medical Journal Malaysia*, 17(1).

Appendix A

Sociodemographic survey

Hello, my name is Samantha Farmer. I am an occupational therapy student at the University of Indianapolis completing my Doctoral Capstone at A Caring Place Adult Day Services, Catholic Charities Indianapolis, Inc. The purpose of my project is to develop a caregiver resource guide to assist with the physical and psychological aspects of caregiving. In order to get a better idea of the population this resource guide will be serving I have developed a few demographic questions which are listed below. If you are interested in participating, please complete the questions below and return to A Caring Place ADS as soon as possible.

Thank you in advance for your feedback!

PARTICIPANT INFORMATION

- Age _____
- Gender _____
- Length of time attending A Caring Place _____
- Diagnosis _____

CAREGIVER INFORMATION

- Age _____
- Gender _____
- Relationship to participant _____
- Living situation
 - Any other adults living in the house who assist with care of participant?

 - Any children living in the house? If yes, please list their ages.

- Highest level of education _____
- Employment status _____
 - Hours per week _____

Table 1A

Sociodemographic results for Participants

Age	Gender	Length of time attending ACP	Primary diagnosis
84	Male	6 months	Inability to live alone due to assistance needed with basic needs
76	Male	3+ years	Dementia
75	Female	4 months	Dementia
70	Female	Over 1 year	Schizophrenia paranoid type
79	Male	1 year	Dementia
59	Male	5 years	Traumatic Brain Injury
89	Male	1 year	Dementia
67	Male	~4 years	Stroke/brain trauma

Table 2A

Sociodemographic results for caregivers

Age	Gender	Relationship to Participant	Other adults living in the home?	Any children living in the home? Ages?	Highest level of education	Employment status	Hours per week
62	Female	Wife	No	No	High School	Retired	0
66	Male	Husband	2	No	Master's degree	Retired	0
54	Female	Daughter	1	Yes, 14	Bachelor's degree	Full-time employment	40
45	Female	Daughter	1	No	College	Full-time	40+
75	Female	Wife	No	No	High School	Retired	0
56	Female	Sister	No	No	11 th grade	Advantage senior care	5 hours per week
57	Male	Son	No	No	College	Semi-retired	20
60	Female	Wife	No	No	Graduate degree	None	0

Appendix B

Caregiver Resource Manual In-Service Pre/Post Test
March 27, 2019

1. When caring for an individual begins to negatively affect the caregiver, both physically and psychologically, it leads to what commonly known term?
____ Caregiver Burden _____
2. A record of changes that your loved one has experienced since his/her last appointment that should be filled out daily and taken to each doctor's appointment for reminders of recent changes and behaviors
____ Care-Log _____
3. Instructions on how you loved one wants their medical care to be handled in emergency situations when they are unable to verbalize their wishes.
____ Advance Directives _____
4. Term that defines the trend of older adults preferring to live in their homes or apartments as they age verse moving to a new place with a higher level of care.
____ Age-in- place _____
5. Has been found to assist with regulating appetite, aid with sleep, relieve restlessness and tension, and maintain strength and coordination.
____ Exercise/Physical Activity _____
6. Activities that help your loved one remember past joys, such as telling stores, looking through photos, re-reading letters and greeting cards from the past, baking special family recipes and creating scrapbooks.
____ Reminiscence Therapy _____

7. Although common, can be hard to diagnosis due to overlapping symptoms including: social withdrawal, difficulty concentrating, impaired thinking, isolation, and loss of interest in hobbies and activities.

_____Depression_____

8. Requires several areas of the brain to receive and process sensory data to get you places; may need to be limited or discontinued.

_____Driving_____

9. Aim to help caregivers better deal with the physical and emotional challenges of caregiving through sharing and listening.

_____Support Groups_____

10. Decreases anxiety, stimulates hormones, improves muscle tone and enhances metabolism.

_____Laughing/Humor_____

Table 1B

Results of Pre-Test

	Caregiver 1	Caregiver 2	Caregiver 3	Caregiver 4
Question 1	Stress	Resentment	Blank	Burn Out
Question 2	Daily Memo- Behavior Notes	Care Plan	Blank	True Log
Question 3	Pre-Care Living Will	Living Will	Yes	Directive or living will
Question 4	Assisted Living	Home-Health	Blank	In home caregiving
Question 5	Exercise	Exercise	Blank	Blank
Question 6	Talking, Taking Part in these daily activities	Dementia	Blank	Blank
Question 7	Blank	Blank	Blank	Blank
Question 8	Blank	Blank	Blank	Blank
Question 9	Blank	Blank	Blank	Blank
Question 10	Blank	Blank	Blank	Blank
Score	+3	+2	+0	+1

The table above displays the results of the caregiver pre-test. For question 2, Daily Memo-Behavior Notes was accepted as a correct answer. For question 3, living will was accepted as a correct answer.

Table 2B

Results of Post-Test

	Caregiver 1	Caregiver 2	Caregiver 3	Caregiver 4
Number of correct answers in allotted time	8	8	6	7
Increase in number correct compared to pre-test	+5	+6	+6	+6