SELF-CARE & WELLNESS FOR CARE PARTNERS OF PEOPLE LIVING WITH DEMENTIA

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

by

Dylan Lander, Aaron Manzo, Raeana Meier, and Grace Webb

Thesis advisor: Jenna Mele, OTD, OTR/L

September 2024

Abstract

Care partners of people living with dementia have a full-time job of taking care of their loved ones. In this project, we have created a respite care manual using significant research to provide support and education for care partners and the importance of their health and wellbeing. The manual provides sessions that future participants will attend to learn and implement into their everyday lives. From previous research, it has been shown that there is limited time for care partners to participate in their desired occupations that has led them to burnout. It has been found that education programs have increased resilience and improved the quality of life for care partners and their recipients. The purpose of the manual is to educate the care partners on how to timely manage their desired occupations, stress management skills, and overall maintain their wellbeing. Further research is needed to provide additional evidence supporting the necessity of respite care manual programs for care partners of individuals living with dementia.

Keywords: Care partners, dementia, respite, manual, program, wellbeing, resilience

Table of Contents

Self-Care & Wellness for Care Partners of People Living With Dementia

In our respite care manual for care partners of individuals with dementia, we have concentrated on aiding family care partners. Our intervention consists of a manual-based respite care program. We have compared the effectiveness of this program to standard care or no intervention. Our goal was to improve care partner well-being and encourage self-care practices. One prevalent issue is that care partners of individuals with dementia frequently encounter elevated levels of stress, burnout, and feelings of social isolation (Sörensen & Conwell, 2011). Care partners may encounter challenges in effectively addressing behaviors such as agitation, wandering, and paranoia in individuals under their care (Saint Louis University School of Medicine, n.d.). Care partners may also face challenges when supporting individuals with activities of daily living, including personal hygiene, nutrition, and rest (National Institute on Aging, n.d.). Lastly, another common challenge faced by care partners is effectively managing the balance between their caregiving responsibilities and personal needs, including self-care (Piedmont, n.d.).

In response to the identified challenges, our respite care manual has offered a comprehensive solution by providing education on dementia and its progression. By doing so, care partners can be empowered to better understand and proactively address changes in their care recipients. Another solution involves providing assistance with developing a care team and organizing individuals to collaborate on caregiving responsibilities (Alzheimer's Association, n.d.). Additionally, offering guidance on effective strategies for addressing challenging behaviors and enhancing communication with individuals experiencing dementia may be beneficial (Saint Louis University School of Medicine, n.d.). Our manual provides valuable resources for care partner self-care, emphasizing stress management techniques and the significance of taking regular breaks (Piedmont, n.d.).

Occupational Therapy (OT) can provide essential resources for developing a respite care guide for care partners of individuals with dementia, as it can greatly enhance the well-being of both care partners and those living with dementia. Occupational therapists are well-equipped to assist dementia care partners in alleviating their significant burden (Martínez-Campos et al., 2022). Occupational therapists can offer care partners valuable strategies and resources to better manage their duties, ultimately decreasing stress levels and enhancing their overall quality of life. Occupational therapists are able to create customized interventions tailored for the home setting, which is where a majority of dementia care is provided. Interventions such as the Tailored Activity Program, Environmental Skill-Building Program, and Advancing Care partner Training have proven to be effective in meeting the needs of care partners and enhancing the quality of care for individuals with dementia. Finally, OT interventions for care partners of individuals with dementia are based on evidence-based research. By developing a respite care manual, occupational therapists can ensure that care partners are equipped with the latest and most effective strategies for providing care to those with dementia (Martínez-Campos et al., 2022).

Statement of Problem

Care partners of people living with dementia (PLWD) are at risk for burnout from taking care of their loved ones and their health and wellness is one of the main concerns when taking care of someone. Taking care of someone affects mental health, physical wellbeing, and financial burden (Scerbe, 2023). In most cases, family members are the care partners and take care of their loved ones 24/7, which gives them limited time to themselves if they are fortunate enough to have help (Han et al., 2023). However, taking care of loved ones in the home is beneficial for both the patient and the care partner because it is a familiar space and lowers stress levels (Vandepitte et al., 2016). According to Edwards (2015), OT interventions were implemented for lowering the risk of burnout and reducing stress levels. With the help of OT, care partners and PLWD will have an increase in motivation, maintain healthy habits, and overall increase their wellness (Vandepitte et al., 2016).

To maintain a healthy lifestyle, care partners who prioritize their self-care needs can utilize the support of OT to provide support and knowledge on self-care. It is important for care partners to know about their own health and wellness because if their psychological distress on the caretaking is high, their motivation to function psychologically and physiologically will put a burden on their everyday activities (American Occupational Therapy Association, 2020). This burden can lead to occupational alienation, deprivation and imbalance by neglecting the self-care needs for the care partner and continue to lead to disuse syndrome. For example, taking breaks for themselves, working out, working, and surrounding themselves with family and friends. Care partner’s occupations may be different after being a full-time or almost full-time care partner by not being able to work as much, taking care of their own family, and doing physical activities or hobbies. Caretaking may be their full-time job now and other occupations such as leisure activities, being a parent, or many others may not be a priority anymore.

The anticipated outcomes for this project are to provide support and strategies for maintaining self-care for care partners for PLWD. Based on research related to current dementia programs and respite care programs, we anticipate the interventions provided in the manual will provide strategies to improve caregiver self-care maintenance.

The purpose of this project is to share knowledge via a manual to improve resilience to care partner burnout by prioritizing the components of self-care. This manual was necessary to create because without proper self-care, unpaid care partners are at higher risk for burnout (Walter & Pinquart, 2020). There have been studies done to observe and analyze the wellbeing of care partners which include data collection methods such as surveys, questionnaires, and interventions to see care partner knowledge on programs and support groups they can attend. Our manual will be a collection of the most effective strategies from research to support maintaining caregiver self-care.

The priority of the population is care partners of PLWD who are unpaid because they receive little to no training before stepping into a role as a main care partner of a person living with dementia. Oftentimes, the role of an unpaid care partner comes unexpectedly which is the reason for lack of training, resources, and shock among the household. It is expensive to hire nurses and other healthcare practitioners to assist the care partners within the home. Family members, friends, and neighbors step in as unpaid care partners because it is often a more convenient and affordable care option.

Literature Review

The literature review reveals there is a need for OT services for care partners of PLWD. Occupational therapists have the ability to educate care partners of PLWD on how important it is to prioritize care partners' self-care as well as teach them coping and health and wellness management skills. Research has indicated that individuals who receive additional training and education experience improved levels of comfort and provide higher quality of care for both care partners and their families (Martinez-Campos, 2022). The more knowledge that is shared, the more opportunities for better care for dementia. The objective of the literature review is to demonstrate how dementia care partner programs and educational sessions can enhance quality of life and mental well-being. Additionally, the aim is to develop a care partner wellness manual for future implementation. Providing information on self-care programs for care partners will reduce the risk of burnout and increase resilience (Martinez-Campos, 2022).

According to Walter and Pinquart (2020), being a care partner for PLWD reduces the quality of life, increases psychological distress, and increases occupational deprivation. In the study, researchers addressed the importance of the needs of care partners. For example, they considered which participants responded well to group interventions or one on one sessions. The study included conducting cognitive behavioral therapy, counseling and management, and support interventions with the participants. From the results, group interventions were more effective and increased social support (Walter & Pinquart, 2020). After conducting the study on care partner participants, there was a small improvement on burden, depression, and anxiety. This study demonstrates that creating an intervention for care partners will improve burden and psychosocial distress.

Different studies have been done to take a closer look at the knowledge of dementia, whether the participants are a different population or if others have knowledge on dementia, but there are common themes in the different studies (Martinez-Campos, 2022). A few of the common themes found in research are care partners with burnout, creating programs for care partners, and self-care prioritization.

According to DiZazzo-Miller et al. (2014), being a care partner can be a burden physically, mentally, socially, and financially. The purpose of their study was to implement a manual-based respite program to improve resilience for care partners by having them attend support groups and training on everyday activities. Researchers have gathered a group of care partners of PLWD and they participated in a manual-based program that properly trained them how to assist their loved ones on everyday activities and attended peer group sessions that allowed them to share their experiences with other participants. The results of the study were positive by increasing the knowledge on proper care for care partners and reducing the likelihood of the PLWD falling or getting injured. Overall, a training manual-based program has improved the quality of care of a care partner. Cha et al. (2022) provides an overview of a Care to Plan web-based program for care partners. The web-based program was provided to the care partners for a month, including a follow up phone interview that determined what categories were implemented in the program. The categories included skills building, solving problems, therapy interventions, respite care advice, well-being exercises, support groups, and a combination of different programs (Cha et al., 2022). Participants found that the web-based program was helpful by breaking down the needs of being a care partner. After looking at both articles, creating a manual for care partners is helpful and has improved the quality of care.

One of the main common themes discovered within the literature is creating programs and support for care partners. An article written by Vandepitte et al. (2016)

described an in-home respite care program and the expected outcomes it would have if implemented. This article highlights the importance of why there should be an in-home respite care program. One of the main discoveries is that it helps keep the care recipient in a familiar environment, which lowers the stress levels for both the care partner and care recipient. This ties with the theme because respite care is traditionally an informal daily care partner responsibility. This assumes that the care partner has minimal to no assistance which causes increased stress and a decrease in mental health. The program contains a trained professional giving the care partners a break during the day to ensure they have time for personal responsibilities and self-care. This alleviates the stress of worrying and guilt about the care recipients' wellbeing while they tend to their needs.

Our research has continued with the theme of creating programs and support for care partners. An article by Boots et al. (2016) used randomized control trials to test the effects of a self-care management program for care partners. The experimental group had participants having sessions with a personal coach, online training, and an evaluation. The control group had pre and post assessments and only did an online portion of the experiment. The results of the study showed that there was an increase in self-efficiency and a decrease in depressive symptoms. This connects to our overall theme by their program improving the care partners wellbeing and quality of life.

Several studies have addressed caregiver burden and depression with regard to a lack of training or knowledge. In the articles written by Kokorelias et al. (2021) and Francis et al. (2020), they both have the common theme of describing caregiver adversities and their experiences. They both have similar results representing how education and training on dementia and dementia care positively affects not only the care administered but the emotional well-being of the caregiver. The article by Kokorelias et al. describes how the researchers conducted the study and what their results were. First, they sent out a survey asking daughters with one sibling or more about how the caregiver responsibilities were organized and distributed between each sibling. Overall, they found that the daughters had an overwhelming number of responsibilities and that led to a feeling of burnout and depression. They concluded that if they had the proper training and education on dementia, it would lessen the feeling of burnout. Similarly, Francis et al. ran a three-month trial that tested three separate groups on different types of care interventions and methods. Their results concluded that while education can be effective for the early stages of caregiving for dementia, what is effective for long-term care is OT intervention with the patient and the caregiver specifically. Both articles show the problem of caregiver burnout and depression can be combated by OT services, training, and knowledge.

Multiple studies have explored the potential benefits of OT interventions in dementia care, with a focus on improving the quality of life for both individuals with dementia and their care partners. Edwards (2015) conducted a qualitative study examining the experiences and challenges of family care partners, suggesting that occupational therapy interventions could help alleviate their burden. Within this study, four areas were discovered that can pinpoint the need for support of care partners. The areas were obstacles and challenges, support networks, emotions, and healthcare thoughts (Edwards, 2015). All of these areas were seen to have an impact on the experience of a care partner. Each area contributes knowledge about the enhancement of quality of life and support for individuals with dementia and their care partners. Additionally, they offer comprehensive insights into the difficulties faced by care partners and suggest strategies that occupational therapists can implement to provide support.

We have discovered that the articles give information on how to educate care partners by providing manuals and training programs to train them on providing knowledge and improve their quality of care (Martínez-Campos et al., 2022). However, there is a gap in knowledge surrounding how licensed occupational therapists can directly educate and train care partners to prioritize their self-care and how they can implement their needs in their everyday schedule. All of the articles reviewed share the common theme of either educating the care partner through a training program and discovering that there is a lack of evidence for occupational therapists educating care partners on the importance of their self-care and health and wellness. Another gap that is seen in research is that care partners have little or no information on resources for the care partners. The respite care program created in this thesis is bridging the gap between care partners and the importance of their health and wellness.

The argument about the clinical significance of the evidence provided by the studies on dementia care and the family caregiver training programs underscores the necessity for occupational therapists to integrate comprehensive dementia care and care partner support into their practice. Given the growing population of adults with dementia, it's imperative that occupational therapists are equipped with the knowledge and skills to provide adequate care to this demographic, as well as support to their care partners. The implications of these studies suggest that by enhancing the education of future occupational therapists in prioritizing self-care needs to prevent burnout, they will be better prepared to meet the complex needs of care partners of PLWD. Effectively engaging with care partners and sharing essential knowledge and strategies for self-care will make a positive impact on care partners.

With the evidence suggesting that the family caregiver training program is a valuable tool for educating family care partners, occupational therapists should consider incorporating similar community-based skill-building programs into their practice. Such programs can help address common challenges faced by care partners, providing them with the skills necessary to improve the quality of life for both them and the individuals with dementia they care for (Edwards, 2015).

Based on the findings from the studies reviewed, there is strong evidence supporting the integration of comprehensive dementia care education for OT students and the implementation of educational programs for family care partners of individuals with dementia. There is moderate evidence indicating that such educational interventions can significantly improve the care provided to individuals with dementia and enhance the well-being of their care partners. While the studies reviewed provide promising insights, they also highlight the need for further research in this area, particularly involving larger and more diverse participant groups. Overall, the literature supports the adoption of educational interventions aimed at improving dementia care and caregiver support within OT practice but calls for additional research to address gaps and ensure the generalizability of findings.

Occupational therapists should take a proactive role in seeking out or developing educational programs and resources focused on care workshops and manuals focusing on the needs of the care partner in order to better themselves and their quality of life. They should advocate for the inclusion of comprehensive dementia care training on prioritizing self-care within OT educational curriculum to prepare future practitioners for the challenges of working with this population.

The current state of research in dementia care and caregiver knowledge indicates that there is room for further improvement in enhancing the quality and practicality of the experience of being a care partner for a person living with dementia. Additional research and efforts are needed to better serve care partners in their efforts to avoid burnout and in promoting their mental health. There is strength in the evidence from the articles presented demonstrating that methods like training orientations and programs can support dementia care partners and their journey of caretaking. However, as previously mentioned there is space for research on how licensed occupational therapists can train and support care partners with their health and wellness. Throughout the research it is seen that it is common for care partners to experience burnout, prioritizing their self-care needs, and adapting to their role as a care partner. By providing comprehensive training and occupational therapy services, we can minimize inefficiencies in the care process and improve resilience for care partners. While previous research has shown how occupational therapists can help with dementia patients, we believe that it is important to focus on how occupational therapists can support and provide education to care partners on their health and wellbeing.

Statement of Purpose

The purpose of this project is to create a respite care manual for care partners of PLWD that focuses on components of individualized self-care. This manual has been composed of three different sessions focusing on the different components of the Canadian Model of Occupational Performance and Engagement (CMOP-E), The components of person, environment, and occupation will be the themes in each session combining these ideas with self-care (Cole & Tufano, 2019). Our project has three main objectives from the creation of this manual. The first objective is to make care partners aware that there are resources and tools to improve quality of life as a care partner. The second objective is to reflect on the importance of self-care. The last objective is to reduce burnout by utilizing meaningful occupations to promote self-care. The expected result for our project is to create a manual guiding future thesis groups on implementing the sessions which will in the future improve care partner quality of life.

Theoretical Framework

The theoretical framework that is implemented into our manual is the CMOP-E. The CMOP-E is an occupational performance model that is comprised of three main components which include person, environment, and occupation (Cole & Tufano, 2019). The model shows three circles encompassing each other. The innermost circle represents the person component which comprises spirituality, affective, physical, and cognitive abilities. All of the components relate to a care partner's well-being, which is what the manual created by the research team aims to improve. The middle circle represents occupation. This model defines occupation as anything performed by a person in the environment and includes three domains of leisure, self-care, and productivity. Specifically for the manual, we are going to focus on maintaining self-care. The last component is the outer circle which is the environment.

For this model, the environment includes physical, social, cultural and institutional environments that the client is exposed to. When focusing on self-care, the environment plays a major role in how effective self-care is. All aspects of the CMOP-E (person, environment, and occupation) are intertwined with one another, and research demonstrates that each of the components affects one another in both positive or negative ways. The respite care manual will focus on improving self-care strategies and maintenance. Self-care is an important routine and component in daily life that is often deprioritized or even neglected in caregivers' lives. Self-care includes socializing, participating in meaningful occupations, leisure time, and personal health maintenance. The manual will provide information and skills on what self-care is and how care partners can prioritize their self-care needs. These components of self-care are connected to each of the categories of the CMOP-E including the person, occupation, and environment. The manual will consist of three sessions educating care partners on different strategies for caregivers to implement self-care time in their schedule. The manual will teach future participants health and wellness management skills to prevent burden on care partners. Each of the three sessions will focus on a separate component which are communication, self-reflection, and coping management skills. These components are directly related to the CMOP-E components. The first session with the theme of communication is related to the environment and is focused on communicating with others around them and sharing personal experiences. The second theme is self-reflection which is related to the person component by reflecting on who they are as people and how they can intertwine that with self-care as a caregiver. The third theme is coping management skills and that is related to the occupation component by using occupations like hobbies and activities to cope with the stresses of being a caregiver.

Methodology

The project was implemented by the research team, creating a manual for care partners of PLWD. The objective of this program is to empower care partners of individuals living with dementia by offering structured support sessions based on the CMOP-E.. Each session was thoughtfully designed to focus on a key component of the model: Person, Occupation, and Environment. These elements are essential for comprehending and improving the caregiving experience. The second session, titled "The Occupation-Centered Session," is dedicated to examining meaningful activities that caregivers participate in, such as self-care, productivity, and leisure. Its goal is to optimize these activities in order to alleviate stress and enhance overall well-being. This session highlights the importance of balancing caregiving responsibilities with other significant activities and encouraged caregivers to integrate therapeutic practices into their daily routines, ultimately benefiting both themselves and PLWD. The final session, titled "The Environment-Centered Session," examines the impact of various environmental factors—including physical, social, cultural, and institutional elements—on the caregiving experience. This session covers potential modifications and supports that can be implemented in both home and care settings to enhance occupational performance for caregivers and PLWD. Participants will also learn how to establish a stress-relieving space conducive to practicing mindfulness, aimed at mitigating stress and preventing burnout.

Future participants will have one hour class a day in person to learn more about the topics they choose from. During each session, future participants will first listen to other people’s experiences. Getting experience from others will encourage the future participants to share their own experience with other future participants to express their vulnerability and gratitude. Being vulnerable will teach the future participants to gain coping skills and be more comfortable sharing their own experiences with others. They will process learned concepts through conversation with other participants. Lastly, future participants will have the opportunity to connect their new knowledge to their current situation through self-reflection and in a group setting.

The advantages of the specific methodology selected is that the future participants will learn and implement their own experiences to their situation that will help them improve their knowledge on the importance of self-care and how they can implement their wellness needs with caregiving. By listening to others facing similar challenges, individuals may find comfort in hearing they are not alone with the challenges that come with the role of being a care partner. Acquiring new strategies in health and wellness for the care partner improves their quality of life and positively impacts their family members with dementia. Research suggests that similar sessions can improve the quality of life for caregivers and their family members with dementia (Edwards, 2015).

We have reviewed literature on current care partner education programs and respite programs to synthesize the most successful strategies to improve health and wellness of care partners in order to reduce care partner burnout. Materials we used to create our manual included published data and research that are related to self-care, burden prevention, and resilience for care partners of PLWD. The manual provided sessions designed to teach participants self-care and wellness management skills. At the end of the sessions, future participants will have a better understanding of how they can apply their new knowledge into their current situations. Future participants will also gain knowledge on the importance of their self-care needs and why they need to prioritize themselves as well.

Possible Limitations

Several limitations could have impacted the development of our research and the creation of the respite manual. A primary limitation was the potential for conflict of interest. Personal experiences and perspectives as care partners or familiarity with dementia care among group members could have possibly introduced unintended bias during its development. Funding sources can be a possible limitation in future implementation of the program. Funding would need to cover location, materials, and staffing for the sessions. Academic and research limitations could have also affected the project, as the study only includes using databases provided by Stanbridge University. This could limit the project by only being supported by certain resources or studies. Finally, the manual was developed as a conceptual guide without the opportunity for hands-on testing or feedback from actual care partners. This restricted our ability to refine the manual based on practicality or real-time adjustment. Future research should look into pilot testing and collecting user feedback to confirm the manual's effectiveness.

Ethical and Legal Considerations

In developing this respite care manual for care partner of individuals living with dementia, it is important to address both ethical and legal considerations of this project. Although this project did involve direct implementation or intervention at this stage, the following considerations are key for future researchers and practitioners who will use the manual.

One of the ethical considerations in this project is the necessity for informed consent and confidentiality. While our current work does not involve direct implementation, future researchers using this manual must obtain informed consent from all participants. Participants should be fully informed about the nature of the intervention, its objectives, and any potential risks or benefits. Ensuring participants are fully aware of what they are consenting to is key to maintaining high ethical standards. Furthermore, both care partners and the individuals with dementia should have their privacy and confidentiality protected. Any future researchers collecting data during future implementation of this manual must securely store and handle the information with utmost private measures.

Conclusion

In conclusion, the project aimed to develop a comprehensive respite care manual that focused on the self-care for care partners of PLWD. By using the CMOP-E, the manual addressed the person, environment, and occupation components to enhance caregivers' quality of life and reduce burnout. With this manual, we planned to help care partners improve their knowledge and implement self-care strategies, leading to better overall wellness and promoting self-care maintenance. Through structured sessions focusing on communication, self-reflection, and coping management skills, care partners will gain valuable insights and tools to manage their caregiving responsibilities more effectively.

This project was intended to make a meaningful impact on the lives of unpaid caregivers, ultimately benefiting both the caregivers and the people they care for. By emphasizing self-care and other strategies, the manual aims to foster a supportive and sustainable caregiving environment. The manual's approach to self-care empowers care partners to take better care of themselves, thereby enhancing their ability to care for their loved ones with dementia. Ultimately, the expected outcomes of this project include increased awareness of self-care resources, improved self-care practices among care partners, and reduced care partner burnout.

By addressing the emotional, physical, and social needs of care partners, this project aligns with the core values of occupational therapy, which emphasize holistic care and the importance of meaningful occupations (Cole & Tufano, 2019). The manual serves as a valuable resource for care partners, providing them with the knowledge and skills needed to navigate the challenges of caregiving while maintaining their own well-being.

The development of this respite care manual represents a significant step towards supporting and empowering unpaid caregivers. By providing practical strategies and fostering a sense of community and support, this project aims to make a lasting difference in the lives of care partners and the individuals they care for.

References

Alzheimer's Association. (n.d.). *Respite care*. https://www.alz.org/help-support/caregiving/care-options/respite-care

American Occupational Therapy Association (2020). Occupational therapy practice framework: Domain and process—Fourth edition. *The American Journal of Occupational Therapy, 74*(Suppl. 2), 1-87. https://doi.org/10.5014/ajot.2020.74s2001

Boots, L. M., de Vugt, M. E., Kempen, G. I., & Verhey, F. R. (2016). Effectiveness of the blended care self-management program "Partner in Balance" for early-stage dementia caregivers: Study protocol for a randomized controlled trial. *Trials, 17,* Article 231. https://doi.org/10.1186/s13063-016-1351-z

Cha, J., Peterson, C. M., Millenbah, A. N., Louwagie, K., Baker, Z. G., Shah, A., Jensen, C. J., & Gaugler, J. E. (2022). Delivering personalized recommendations to support caregivers of people living with dementia: Mixed methods study. *JMIR Aging, 5*(2), Article e35847 https://doi.org/10.2196/35847

Cole, M. B., & Tufano , R. (2019). *Applied theories in occupational therapy: A practical approach.* Slack Incorporated.

DiZazzo-Miller, R. Samuel, P. S., Barnas, J. M., & Welker, K. M. (2014). Addressing everyday challenges: Feasibility of a family caregiver training program for people with dementia. *American Journal of Occupational Therapy, 68*(2), 212-220. https://doi.org/10.5014/ajot.2014.009829

Edwards, M. (2015). Family caregivers for people with dementia and the role of occupational therapy. *Physical & Occupational Therapy in Geriatrics, 33*(3), 220–232. https://doi.org/10.3109/02703181.2015.1031926

Francis, T., Tomita, M., Binkewicz, K., Dinatale, K., Anderson, V., Grandolph, L., Tse, D., Vasisko, & S., Grandolph, L. (2020). Effects of OT-based interventions to reduce perceived burden and depression of caregivers of older adults with dementia. *American Journal Occupational Therapy, 74*(1), Article 7411515378. https://doi.org/10.5014/ajot.2020.74S1-PO3405

Kokorelias, K. M., Nguyen, L., Elane, G., Wasilewski, M. B., Rittenberg, N., & Cameron, J. I. (2021). Daughters' experiences of shared caregiving to a parent with dementia. *Scandinavian Journal of Caring Sciences, 35*(3), 853-859. https://doi.org/10.1111/scs.12901

Martínez-Campos, A., Compañ-Gabucio, L. M., Torres-Collado, L., & Garcia-de la Hera, M. (2022). Occupational therapy interventions for dementia caregivers: Scoping review. *Healthcare, 10*(9), Article 1764 https://doi.org/10.3390/healthcare10091764

National Institute on Aging. (n.d.). *What is respite care?* https://www.nia.nih.gov/health/caregiving/what-respite-care

Piedmont. (n.d.). *Caring for a loved one with dementia a practical guide for caregivers.* https://www.piedmont.org/media/file/2023-06-PHC-SixtyPlus-Dementia-Caregivers-Guide.pdf

Saint Louis University School of Medicine. (n.d.). *Training manual for facilitators of family/friend caregiver support groups*. https://www.slu.edu/medicine/internalmedicine/geriatric-medicine/aging-successfully/pdfs/caregiver-support-training-manual.pdf

Scerbe, A., O'Connell, M. E., Astell, A., Morgan, D., Kosteniuk, J., Panyavin, I., DesRoches, A., & Webster, C. (2023). Digital tools for delivery of dementia education for caregivers of persons with dementia: A systematic review and meta-analysis of impact on caregiver distress and depressive symptoms. *PLoS One*, *18*(5), Article e0283600. https://doi.org/10.1371/journal.pone.0283600

Sörensen, S., & Conwell, Y. (2011). Issues in dementia caregiving: Effects on mental and physical health, intervention strategies, and research needs. *The American Journal of Geriatric Psychiatry*, *19*(6), 491-496.

Walter, E., & Pinquart, M. (2020). How effective are dementia caregiver interventions? An updated comprehensive meta-analysis. *The Gerontological Society of America, 60*(8), 609-619. https://doi.org/10.5014/ajot.2020.74S1-PO3405

Wakefield, C. J. (2020). Community respite service utilisation and dementia care: A review of literature. *Australian Journal of Advanced Nursing, 37*(2), 31-37.

Vandepitte, S., Van Den Noortgate, N., Putman, K., Verhaeghe, S., & Annemans, L. (2016). Effectiveness and cost-effectiveness of an in-home respite care program in supporting informal caregivers of people with dementia: Design of a comparative study. *BMC Geriatrics, 16*(1), Article 207. https://doi.org/10.1186/s12877-016-0373-4

Appendix

Understanding Dementia

Dementia encompasses a variety of cognitive impairments that exceed normal age-related changes, affecting memory, reasoning, and daily functioning. Although the incidence of dementia is more pronounced in institutional settings like nursing homes and long-term care facilities, it is important to emphasize that these institutions do not cause dementia. Rather, individuals with dementia often find themselves in these environments due to their need for specialized care and support, which may be challenging to deliver in a home setting (Seitz et al., 2010). Dementia can be reversible or irreversible (Judge & Dawson, 2020). Reversible dementia may be caused by factors like thyroid disorders or infections, while irreversible dementia leads to permanent, progressive cognitive decline (Duinkerke et al., 2004; Insel & Badger, 2002). Diagnosing dementia requires a comprehensive evaluation that includes a review of medical history, interviews with family members, physical and neurological examinations, assessments of mental status, and laboratory tests (Insel & Badger, 2002). Primary care physicians typically conduct initial evaluations and screenings. Neurologists carry out detailed neurological assessments, while geriatricians focus on age-related conditions. Psychiatrists, particularly those specializing in geriatrics, address psychiatric symptoms. Neuropsychologists perform in-depth cognitive testing, and social workers or psychologists gather patient history and provide support. There is currently no cure for dementia, underscoring the need for non-pharmacological interventions to support affected individuals and their families (Judge & Dawson, 2020).

This manual serves as a thorough resource designed to assist care partners of individuals living with dementia. Its main objective is to educate and empower care partners by equipping them with the essential knowledge and skills required to effectively manage their caregiving duties while also prioritizing their own well-being. In summary, the manual seeks to provide care partners with the tools and strategies necessary to strike a balance between their caregiving responsibilities and personal health, ultimately enhancing the quality of life for both care partners and those they support.

Dementia Symptoms and Challenges

The most commonly diagnosed type of dementia is Alzheimer's disease, which can be categorized into mild, moderate, or severe stages (Judge & Dawson, 2020). Following this, vascular dementia ranks as the second most frequently diagnosed form, resulting from inadequate oxygenated blood supply to the brain. This condition may arise from small transient ischemic attacks—often regarded as minor strokes—major strokes, or unmanaged high blood pressure. Furthermore, Lewy body dementia is another acknowledged type, encompassing two related diagnoses: dementia with Lewy bodies and Parkinson's disease dementia.

The primary cognitive symptoms of dementia encompass challenges with short-term memory, attention, and orientation to time, place, and person (Judge & Dawson, 2020). Individuals may also experience difficulties with visuospatial processing, language production and comprehension, as well as executive functioning (Judge & Dawson, 2020). Furthermore, those affected by dementia often struggle to perform daily activities, including managing finances, grocery shopping, engaging in leisure activities and hobbies, and executing self-care tasks (Judge & Dawson, 2020). Dementia is a progressive condition that typically progresses through three primary stages: early, middle, and late (Alzheimer’s Society, n.d.). During the early stage, often referred to as mild dementia, symptoms are generally subtle but begin to affect daily living. The middle stage, known as moderate dementia, is characterized by more pronounced symptoms and a greater requirement for support. In the late stage, or severe dementia, symptoms become significantly more pronounced.

Dementia care partners encounter a variety of challenges while providing care for their loved ones. The following are some key issues they face:

1. Emotional and Mental Strain: Care partners frequently experience elevated levels of stress, depression, and anxiety (Sörensen & Conwell, 2011).
2. Physical Health Risks: The demands of caregiving can adversely affect the care partners physical well-being.
3. Learning and Adapting: As the disease progresses, care partners must continually acquire new knowledge and adapt their approaches to care (Bethesda, n.d.).
4. Assuming Multiple Roles: With increasing dependency from the person with dementia, care partners often take on additional responsibilities (Bethesda, n.d.).
5. Balancing Caregiving with Other Responsibilities: Care partners must find ways to manage their caregiving duties alongside other life commitments.
6. Managing Challenging Behaviors: Dementia may result in difficult behaviors that care partners need to learn to address effectively (Alzheimer's Society, n.d.).
7. Financial Strain: The costs associated with caregiving can be substantial and create financial pressure.

Role of Respite Care

Benefits:

- Prevent burnout
- Decrease psychological and physical stress
- Participate in meaningful occupations
- Increase the quality of life for the PLWD and care partners
- Care partners will take time to take care of themselves for health and well being

How Respite care services will serve PLWD and families:

- Reflect on the importance of self-care for the care partners
- Care partners will learn how to maintain a balance of being a care partner and participating in meaningful occupations
- Communicating with other care partners and sharing experiences to decrease isolation

Mission and Vision

Our mission is to teach, advise, and support care partners with their knowledge on the importance of self-care and wellness. Teaching care partners the importance of prioritizing their self-care needs will be taught through a manual that involves sessions to implement their knowledge into their current situation. Care partners will learn management skills on how to maintain a balance of taking care of their loved one and themselves.

Our vision is to decrease the stress and burnout of being a care partner and to increase their health and wellbeing. Care partners deal with a great amount of stress who may not receive any breaks. The respite care manual is a guide for care partners to understand how to implement their meaningful occupations while being a care partner.

Session Description

The focus of this program is to empower care partners of persons living with dementia (PLWD) by providing structural support sessions centered on the Canadian Model of Occupational Performance and Engagement (CMOP-E). Each session is designed to address a key element of the model: Person, Occupation, and Environment. These components are vital in understanding and enhancing the caregiving experience.

The Person-Centered session revolves around the care partner's own experiences, skills, and emotional well-being. It emphasizes understanding the care partners' identity and personal values, as these values have a significant impact on their caregiving role. The session will emphasize the importance of self-care, leisure, and productivity; assessing how these areas impact the care partners' overall well-being. Participants will be encouraged to reflect on their personal coping strategies and their ability to manage stress and prevent burnout. Ultimately, the goal is to help care partners recognize the importance of their own well-being in the caregiving process and to also encourage the development of self-care routines that support emotional and physical health.

The Occupation-Centered session is aimed at exploring the meaningful activities, or occupations, that care partners engage in. These activities could be related to self-care, productivity, and leisure, with a focus on how they can be optimized to reduce stress and improve well-being. The session will highlight the importance of maintaining a balance between caregiving duties and other meaningful activities. The session's goal is to empower care partners to incorporate therapeutic activities into their daily routines that promote both their well-being and that of the PLWD.

The Environment-Centered session focuses on how different environmental factors impact the caregiving experience. These factors include physical, social, cultural and institutional that the care partner might be exposed to. This session will address the modifications and supports that can be implemented in the home or care environment to enhance both the care partner and the PLWD’s occupational performance. This session teaches participants to modify their own environments to create a space they can go to practice mindfulness to reduce stress and burnout.

Session I: Person

This session will be based on the person component from the Canadian Model of Occupational Performance and Engagement (CMOP-E). This session will explore the domains of the CMOP-E which are self-care, productivity, and leisure as it relates to a person's spirituality and affective, physical, and cognitive abilities. The objectives for this session include understanding how one can be used within self-care, productivity, and leisure to reduce burnout. The second objective is to share and be exposed to experiences from peers to reduce feelings of isolation. The last objective for this session is to navigate ways to express oneself and find what is meaningful to them besides being a care partner.

This session should be forty-five minutes long and should include the following components:

- Introduction on the session theme
- Journaling warm-up activity
- Optional pair and share to learn and hear experiences from peers

- Main activity: Self-Care
- Reflection on session
- Closing statements

The introduction includes information on the person component of the model. Be sure to include how leisure, self-care, and productivity can be built upon the individual's spirituality and affective, physical, and cognitive abilities. Journaling warm-up activity completed solo by the participants. This is a five-minute reflection where the participant can write down activities they enjoy, how they are feeling, any feelings of burnout, or emotions they are feeling. The purpose of this is to have them acknowledge and process any feelings they are bottling up with the goal of relieving stress or isolating thoughts (Perkins, 2021). Optional sharing time will be available after with the goal of finding support amongst peers going through similar struggles or emotions as a care partner. The main activity will have the participants pick one self-care task they would like to achieve or add into their weekly routine. They will write it down on a sticky note, and then write down the obstacles that are in their way from completing the task. Then they will brainstorm and reflect on ways to integrate this meaningful task into their lives. They will be able to share with the group when completed to facilitate further ideas and compilation. After the main activity is complete, a reflection will be facilitated to reflect on how the participants felt during this session and what they gained from the experience. Closing statements will include how connecting with oneself will combat the feelings of burnout and isolation.

Session II: Occupation

This session will be based on the occupation component from the CMOP-E. This session will explore the domains of self-care, productivity, and leisure as it relates to occupation. Meaningful occupations are promoted by occupational therapists not only as mandatory everyday tasks but also as a way to reduce stress and promote well-being (Jackson & Bekmuratova, 2020). The first objective of this session is for the participants to recount and discover meaningful occupations. The second objective for this session is for participants to understand how meaningful occupations can improve quality of life and reduce burnout. The last objective for this session is to plan a small window in their week where they can apply a set timeframe to complete their meaningful occupation. This session should be forty-five minutes long and should include the following components:

- Introduction on the session theme
- Main activity: Vision Board Creation
- Vision Board Sharing
- Reflection on session
- Closing statements

The introduction should include information on what a meaningful occupation is, and how they can reduce stress and promote a person's well-being. The Vision Board activity will have the participants cut out words or images from an array of magazines to represent their meaningful occupations. They will take these and glue them onto a poster. After this they will share their posters with the peers. This will allow them to share their meaningful occupations while also discovering new ones to apply to their lives. After the main activity is complete, a reflection will be facilitated to reflect on how the participants felt during this session and what they gained from the experience. The reflection should also include a discussion on how the participants can implement a time in their week to complete their meaningful occupations. Closing statements will include how participating in one's meaningful occupations will combat the feelings of burnout and improve quality of life for care partners.

Session III: Environment

This final session will be based on the environment component of the CMOP-E. This session will explore the domains of self-care, productivity, and leisure as it relates to the components of environment. Environment has a major impact on a person as it is composed of physical, social, cultural, and institutional factors in one's life. Meditation is used to practice mindfulness which ultimately reduces stress and burnout (Jones et al., 2020). The first objective is for the participants to utilize their environments to regulate their nervous system. The second objective is to learn to create their own peaceful environment to practice mindfulness. The last objective is to take moments throughout their day to breathe and practice mindfulness.

This session should be forty-five minutes long and should include the following components:

- Introduction on the session theme
- Warm-up: Nature walk
- Main activity: Mindful Meditation
- Reflection on session
- Closing statements

The introduction should include an explanation on what the schedule will be for the last session. Explain to the participants the warm-up activity and the main activity. The warm-up activity will be a nature walk anywhere outside. This walk can be used as a social time or as a self-reflection time, participants have the option. At the end of the walk, the main activity will begin. The main activity will be a mindful meditation session outdoors. The group will sit and be led through a group meditation. Afterwards, the group will reflect on this session and the program as a while and share what they gained from participating. Closing statements will include how participants can practice mindfulness in their personal environments they are exposed to.

Outcomes of the Program

There are three intended outcomes for this program. They include but are not limited to:

1. Utilize personal self-care tools and practices to prioritize wellness for oneself
2. Utilize meaningful occupations to reduce burnout and promote wellness
3. Utilize one's physical environment to improve wellbeing and reduce stress

References

Alzheimer's Society. (n.d.-a). *The progression, signs and stages of dementia.* https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/how-dementia-progresses/progression-stages-dementia

Alzheimer's Society. (n.d.-b). *Facing new dementia challenges? Our guide can help.* https://www.alzheimers.org.uk/blog/dementia-challenges-guide

Bethesda. (n.d). *5 unique challenges Alzheimer's caregivers need to overcome.* https://bethesdahealth.org/blog/5-unique-challenges-alzheimers-caregivers-need-to-overcome/

Duinkerke, A., Williams, M. A., Rigamonti, D., & Hillis, A. E. (2004). Cognitive recovery in idiopathic normal pressure hydrocephalus after shunt. *Cognitive and behavioral neurology, 17(3)*, 179-184. https://doi.org/10.1097/01.wnn.0000124916.16017.6a

Insel, K. C., & Badger, T. A. (2002). Deciphering the 4 D's: cognitive decline, delirium, depression and dementia–a review. *Journal of advanced nursing, 38(4)*, 360-368. https://doi.org/10.1046/j.1365-2648.2002.02196.x

Jackson, M., & Bekmuratova, S. (2020). The use of mindfulness to increase participation in meaningful occupations for individuals with chronic pain. *The American Journal of Occupational Therapy, 74*(4_Supplement_1). https://doi.org/10.5014/ajot.2020.74s1-po5732

Jones, J., Herrera, G., Johnson, S., Mistry, P., Kornblau, B., & Oliveira, D. (2020). Mindful meditation to reduce stress in young adults. *The American Journal of*

Occupational Therapy, 74(4_Supplement_1). Article 7411515449p1 https://doi.org/10.5014/ajot.2020.74s1-po8513

Judge, K. S., & Dawson, N. T. (2018). Cognitive and Emotional Function: Health Conditions. In *Functional Performance in Older Adults* (4th ed., pp. 184–187). essay, F.A. Davis Company.

Perkins, N. A. (2021). Increasing emotional intelligence (EI) through self-reflection journals: Implications for OT students. *The American Journal of Occupational Therapy, 75*(Supplement_2), Article 7512505090p1 https://doi.org/10.5014/ajot.2021.75s2-po90

Seitz, D., Purandare, N., & Conn, D. (2010). Prevalence of psychiatric disorders among older adults in long-term care homes: A systematic review. *International Psychogeriatrics*, *Suppl. Focus on Mental Health Issues in Long-Term-Care Homes, 22(7)*, 1025-39. https://doi.org/10.1017/S1041610210000608

Sörensen, S., & Conwell, Y. (2011). Issues in dementia caregiving: effects on mental and physical health, intervention strategies, and research needs. *The American journal of geriatric psychiatry : official journal of the American Association for Geriatric Psychiatry, 19(6)*, 491–496. https://doi.org/10.1097/JGP.0b013e31821c0e6e