

UNDERSTANDING THE CAREGIVER'S PERCEPTION OF PHYSICAL ACTIVITY ON
DISEASE PROGRESSION FOR A PERSON LIVING WITH DEMENTIA

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Dementia is an umbrella term used to describe cognitive disabilities marked by a decline in a person's mental health and reasoning, to the extent in which they impair a person's activities of daily living and communication skills. According to the World Health Organization (2023), nearly 55 million people have a form of dementia, costing more than a trillion dollars annually. Moreover, Alzheimer's Disease is the most common dementia diagnosis and is the form most easily recognized by the public (Mehta & Schneider, 2021; Monfared et al., 2022). Although aging is the strongest known risk factor, dementia is not an inevitable consequence of growing old (Seifert et al., 2022). Therefore, the implementation of global prevention and early identification strategies is critical in reducing the speed of dementia diagnoses. Research draws conclusions that one promising prevention strategy is exercise yet many often fail to incorporate it into their routines early enough, or decide to neglect it totally (Mortimer, 2019; De la Rosa et al., 2020; Alty et al., 2020). Through an interview and research analysis, this project explored a caregiver's perspective on the importance of quality and consistent physical exercise for a person living with dementia, in addition to addressing a major gap in dementia caregiver research.

Review of Literature

Recent research provides direct correlations between the identification of modifiable risk factors and disease onset or progression, the most significant being physical activity and exercise. De la Rosa et al., (2020), along with others, suggested that the promotion of lifestyle changes before symptoms are recognized in older adults, and in early disease stages, can delay about one-third of the world's dementia cases. For this reason, alterations in how individuals study the correlative and causative factors of dementia are rapidly proliferating. Subsequently, one of the greatest challenges associated with a dementia diagnosis is the need for sufficient

caregivers to provide support for patients when their cognitive functions become impaired. Due to the unpredictability of dementia and its timeline, the diagnosis often poses a significant burden on patients and their family and/or associated caregivers (Chiari et al., 2020). Likewise, the guidance of people living with dementia (PLWD) requires a comprehensive team and thus, family caregivers often serve as the backbone of adequate care for PLWD. Livingston (2020) concluded that interventions to affect dementia progression are appropriate regardless of where a person with dementia is in their diagnosis timeline. To that end, caregivers serve as viable change agents in the delay of dementia progression by targeting potentially modifiable risk factors that include exercise, chronic disease management (hypertension, diabetes, depression), smoking cessation, and social interaction (Najar et al., 2019). Caregivers are uniquely positioned to promote risk reduction through activities such as physical exercise for PLWD.

Additionally, modern evidence has been able to derive direct correlations between physical exercise and the delay of dementia progression (Mortimer, 2019). For example, the results of various randomized trials reported by De la Rosa et al., (2020) proposed that exercise leads to increases in brain functioning, improved initiative, a lower risk for associated cardiovascular concerns, and a return of autonomy. Adequate levels of physical activity or exercise that have been suggested to promote change in older adults included thirty minutes of moderate intensity aerobic exercise five days a week or twenty minutes of vigorous intensity exercise three days per week (De la Rosa et al., 2020).

Although previous studies have examined the effects of physical activity in preventing dementia and delaying disease progression, there was little evidence found that examines a caregiver's point-of-view regarding the benefit of consistent exercise for PLWD in improving overall health outcomes (Alty et al., 2020). Similarly, the literature lacks exploration surrounding the importance of the caregiver's perspective, despite caregivers often being the most influential

change agents in the life of PLWD. Therefore, the aim of this research study was: *To determine to what degree caregivers value exercise and recognize the benefits of exercise for PLWD.*

Methodology

This qualitative case study explored the caregiver's perspective on the importance of quality and consistent physical exercise for PLWD. Hence, the team of researchers sought to understand a caregiver's view on exercise and the disease progression of PLWD. Before data collection, researchers anticipated that some caregivers would have not yet considered the significance of exercise in their role. Therefore, the question synthesized for this research was: *To what extent do caregivers value exercise and recognize the benefits of exercise for PLWD under their current or previous care?*

An in-person interview was conducted at a local senior center with a family caregiver present at the caregiver support group at the designated center. Participant inclusion criteria included English-speaking, currently serving or serving within the past six months as a caregiver for PLWD in any capacity (long-distance, in home, facility, etc.), and at least eighteen years of age. Given the unique population of interest, and difficulty procuring family caregivers due to their extensive responsibilities, a case study approach with one participant was employed.

Data collection occurred, following informed consent approved by the Institutional Review Board (IRB). Brief demographic data was collected and included age, gender, race, relationship to the individual with a dementia diagnosis, and how long they had been caring/cared for the identified individual. A quiet space, away from other distractions, was used to conduct the interview. During the interview, the researcher took notes, but an audio recording was also employed to aid in verbatim transcription by the student researcher at a later time. The data was analyzed by the student researcher and her research mentor, Dr. Donna Roberson, PhD, FNP-BC, for context and to aid in answering the proposed research question. All data was stored

on an East Carolina University (ECU) research data drive with access only permitted to the researcher and faculty mentor. The participant was sent a \$25 Target gift card mailed to their home address to reimburse for time spent in the interview. The participant's name and address were removed from the data file, once gift card tracking was complete, to ensure standards of participant confidentiality were maintained. The participant who volunteered to be interviewed cared for his mother for the past three years and the mother was living with progressing Alzheimer's Disease. Detailed demographic data was not stored to avoid identification of the participant and maintain privacy. The following interview questions were asked of the participant with refining questions asked as needed:

1. When you hear the word exercise, what comes to mind? Do you associate exercise with physical health, mental health or both?
2. What do you know about exercise and its relationship to brain function?
3. Do you include exercise in your daily care routines with your person living with dementia? If yes, what type of exercises do you include?
 - a. (If they include exercise in their care routine) How do you think exercise has affected your loved one's condition and functioning?
 - b. (If they do not incorporate exercise in their care routine) Do you believe it would be feasible to start incorporating exercise into your care plan?
4. Do you believe exercise is or could be a useful tool in delaying dementia progression?

Data Analysis

The content of this research was intended to be a qualitative study with five to eight participants, but due to study limitations and time constraints, one interview was conducted, and the research results were transitioned to reflect a case study. The PI and research mentor

reviewed the transcript individually and then met together to discuss the story gleaned from the case study.

The participant was friendly and open, sitting in a relaxed manner on a chair in front of the PI and the research mentor. He equated the word “exercise” with walking, weightlifting and going to the gym. He reported that exercise is “good for you, I know it helps improve blood flow to your brain.” He acknowledged other physical benefits to being active but admitted not currently exercising regularly himself. As he spoke, he realized that exercise could help his mother too. “I would love to bring her to the center and see her moving with other women. I think she would really like that.” He reminisced that his mother used to love walking around her neighborhood and said she probably would love walking regularly again. The barrier the participant identified was the time it would require starting regular walking, “it just feels like one more thing to do, which is why I have not done it so far.” The PI validated this point, noting that having access to a safe area or facility to walk would also be of importance. The participant did not know if exercise would help delay dementia progression, but his participation in this case study has prompted him to start exercise with his mother. His final comment was, “I think she needs it and would really enjoy it. Maybe even going on some of those trips they offer here at the center would do her good.”

Conclusion

As the prevalence of those diagnosed with dementia continues to rise, caregivers are becoming more instrumental. Because caregivers are seen as vital change agents in the outcome for PLWD, it is important to ensure that research does not neglect this population group. This case study interview with a participant from a caregiver support group established that this caregiver does believe that exercise is significant for PLWD, but the interviewee was unsure of how best to incorporate exercise into their already busy caregiver roles. The caregiver was able

to acknowledge the benefits of exercise for himself and how those benefits could be transferable to his mother's life. He did not have knowledge of the role of exercise in disease delayment.

While the strength of this case study is limited to the perspective of one individual, similar notions as our participant are likely. This case study suggests that although caregivers recognize the importance of exercise, further investigation should focus on establishing clear and feasible interventions for caregivers to best implement physical activity into their care routines for their own health and for PLWD. Likewise, this study recognized a gap in caregiver knowledge about exercise and its direct correlation to delaying dementia progression. Therefore, supplemental education could help caregivers understand the significance of exercise. Caregivers do want strategies to delay dementia progression and improve quality of life. Since this study recognized the importance of one caregiver's perspective, additional qualitative work is required to gain insight from caregivers with various backgrounds and diverse care situations. From this study, one can draw conclusions about the critical nature of caregiver perspectives for further investigation involving related research.

References

- Alty, J., Farrow, M., & Lawler, K. (2020). Exercise and dementia prevention. *Practical Neurology*, 20(3), 234–240. <https://doi.org/10.1136/practneurol-2019-002335>
- Chiari, A., Vinceti, G., Adani, G., Tondelli, M., Galli, C., Fiondella, L., Costa, M., Molinari, M. A., Filippini, T., Zamboni, G., & Vinceti, M. (2020). Epidemiology of early onset dementia and its clinical presentations in the province of Modena, Italy. *Alzheimer's & Dementia Association*, 17(1), 81–88. <https://doi.org/10.1002/alz.12177>
- De la Rosa, A., Olaso-Gonzalez, G., Arc-Chagnaud, C., Millan, F., Salvador-Pascual, A., García-Lucerga, C., ... & Gomez-Cabrera, M. C. (2020). Physical exercise in the prevention and treatment of Alzheimer's disease. *Journal of Sport and Health Science*, 9(5), 394-404.
- Livingston, Gill. (2020). Dementia prevention, intervention, and care: 2020 report of the *Lancet* Commission. *Lancet* 396(10248), 413-446. doi:10.1016/S0140-6736(20)30367-6
- Mehta, R. I., & Schneider, J. A. (2021). What is ‘Alzheimer’s disease’? The neuropathological heterogeneity of clinically defined Alzheimer’s dementia. *Current Opinion in Neurology*, 34(2), 237–245. <https://doi.org/10.1097/wco.0000000000000912>
- Mortimer, J. A., & Stern, Y. (2019). Physical exercise and activity may be important in reducing dementia risk at any age. *Neurology*, 92(8), 362–363. <https://doi.org/10.1212/wnl.0000000000006935>
- Najar, J., Östling, S., Gudmundsson, P., Sundh, V., Johansson, L., Kern, S., Guo, X., Hällström, T., & Skoog, I. (2019). Cognitive and physical activity and dementia. *Neurology*, 92(12), 1322–1330. <https://doi.org/10.1212/wnl.0000000000007021>
- Seifert, I., Wiegelmann, H., & Lenart-Bugla, M. (2022). Mapping the complexity of dementia: factors influencing cognitive function at the onset of dementia. *BMC Geriatrics*, (22). Article 507. <https://doi.org/10.1186/s12877-022-02955-2>

Tahami Monfared, A.A., Byrnes, M.J., & White, L.A. (2022). Alzheimer's Disease: Epidemiology and clinical progression. *Neurology and Therapy* 11, 553–569.
<https://doi.org/10.1007/s40120-022-00338-8>

World Health Organization. (2023, March 15). *Dementia*. World Health Organization.
<https://www.who.int/news-room/fact-sheets/detail/dementia#:~:text=Key%20facts,nearly%2010%20million%20new%20cases>