

Brain and Body Fitness Group for Those With Dementia and Their Caregivers Through Community Partnership: A Program Evaluation

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ABSTRACT

Introduction: The growing prevalence of dementia calls for nonpharmacological interventions to reduce negative quality of life effects for those living with dementia and their caregivers. Brain and Body Fitness, a community-based collaborative group program, engages people living with dementia and their caregivers through a combination of physical, cognitive, and socialization strategies, to maximize health benefits for sustained functioning.

Methods: Using an adapted form of the Patient-Reported Outcomes Measurement Information System (PROMIS) Applied Cognition tool, ex post facto data were collected from both participants affected with Alzheimer's disease and related dementias and their caregivers during 12 biweekly sessions of the Brain and Body Fitness program conducted from 2017 through 2021.

Results: Brain and Body Fitness program participants were affected by 4 quality of life indicators: anxiety, sleep, fatigue, and depression. Data reveal significant reductions in anxiety symptoms and significant improvements in fatigue for affected participants. Anecdotally, the program demonstrates nonsignificant trends of overall mood improvement.

Conclusions: Given the positive outcomes, communities may consider adopting a similar program to provide additional support for participants.

INTRODUCTION

The use of medication to treat and/or cure underlying diseases associated with Alzheimer's disease and related dementias (ADRD) has been researched with limited potential.¹ Given the scarcity of effective medical treatments or interventions that prevent or cure ADRD, there is a need to assess the effectiveness of nonpharmacological interventions and their impact on health outcomes.

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Multiple metaanalyses review the preventive and/or management effects of high and moderate physical activity for various forms of ADRD.²⁻³ Additionally, the use of cognitive stimulation therapy has shown slower cognitive decline when utilized in early stages of dementia.⁴ Further, socialization has been recommended for nonpharmacological treatment options for those living with ADRD to minimize loneliness, isolation, and stress.⁵

Multimodal engagement strategies combining physical, cognitive, and socialization activities have been developed. This strategy, sometimes referred to as Language-Enriched Exercise Plus Socialization (LEEPS), is a program based on a study from the University of Arizona to engage people with ADRD to potentially maximize benefits for sustained function and to slow cognitive decline.⁶

Costs of formal and informal care for those with ADRD are significant. Outside of direct care provided, there are additional costs to consider, such as time and potential loss of income for informal (nonprofessional) caregivers (eg, spouse, adult child). Nationally, the Alzheimer's Association⁷ reports that over 11 million Americans provide unpaid care for people with ADRD, providing an estimated 16 billion hours of informal caregiving valued at nearly \$272 billion. Without these informal caregiving efforts, many people would either not receive needed care or would be required to pay.⁸ With informal caregiving also comes relationship stressors,⁹ and caregivers may experience varying degrees of adverse effects on their psychosocial and physical health.¹⁰

Consensus on how to measure quality of life (QoL) for those

with ADRD is lacking.¹¹ However, 4 functional QoL and mood measures regularly appear in the literature: anxiety, depression, sleep, and fatigue. A meta-analysis by Kuring et al¹² found an association between the 4 most common forms of dementia and anxiety, yet there is not clarity on whether anxiety is a causal risk factor for, a prodromal symptom of, or comorbid with, a dementia diagnosis. These same findings were revealed for dementia and depression, though both anxiety and depression are often underrecognized and untreated in those with ADRD and their caregivers.¹⁴ Identification of a diagnosis of depression and/or anxiety is important for treatment to begin as early as possible since meaningful clinical benefit has been shown for people with ADRD.¹⁴

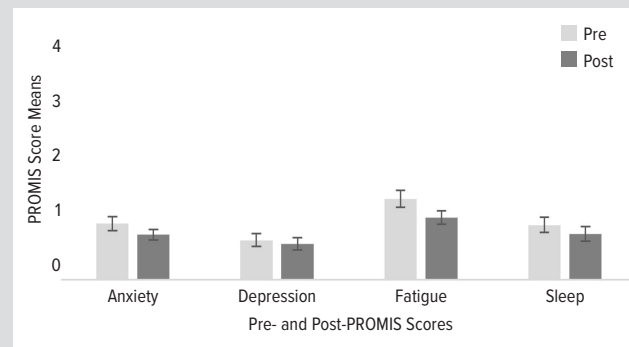
Another mood measure is related to sleep disturbance, which has a significant impact on many areas of health, including but not limited to incidence of depression, risk of infectious disease, and occurrence and progression of major medical illnesses.¹⁵ Sleep disturbances are prevalent in people with ADRD; lack of sleep hygiene may precipitate the transfer to residential care for a person with ADRD.¹⁶

The final mood measure is fatigue, which also is connected to sleep disturbance.⁵ Carvalho et al⁵ hypothesized that fatigue may be a clinical marker for accelerated brain aging. The connection between brain aging and ADRD is noted such that fatigue, as a mood measure, may be an appropriate indicator of QoL for those with ADRD.¹⁷

In 2007, Arkin⁶ developed a LEEPS program with success, positing that there is a clinical rationale for providing these combined interventions. La Rue et al¹⁸ adopted this approach in 9 rural Wisconsin communities during 2010-2014 with encouraging outcomes related to stability in cognition, mood, and physical performance. See Appendix for a summary of the LEEPS program.

In 2017, the urban county of Eau Claire, Wisconsin, adopted and adapted a LEEPS-based program. This collaboration between the Aging and Disability Resource Center (ADRC) of Eau Claire County and the Young Men's Christian Association (YMCA) of the Chippewa Valley was named the Brain and Body Fitness (BBF) program. The BBF program is funded through grants, the ADRC, and YMCA, and there is no cost to participate. The BBF coordinator, an employee of the YMCA, utilized a LEEPS instruction manual provided by the Wisconsin Department of Health Services to develop a curriculum for BBF, modifying the LEEPS format to a group setting with multiple dyads of those with ADRD ("participants with ADRD") and their caregivers. Over the course of 12 weeks, dyads attended two 90-minute sessions per week led by the BBF coordinator and the BBF instructor, who also was employed by the YMCA. Following introductions, each session began with 10 minutes of group exercise and 10 minutes of cognitively stimulating activities for the dyads, alternating between the two activities for a total of 60 minutes.

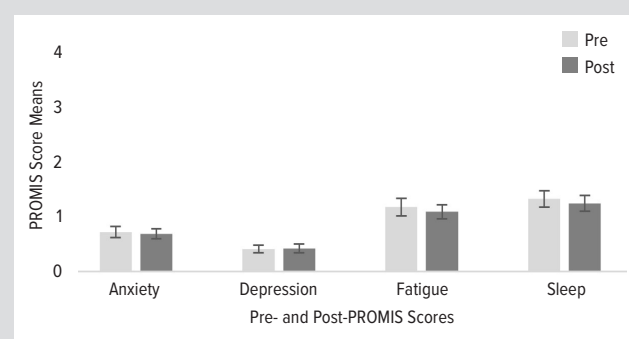
Figure 1. Brain and Body Fitness Affected Participants' PROMIS Scores



Abbreviation: PROMIS, Patient-Reported Outcomes Measurement Information System.

Error bars represent ± 1 SD from the mean.

Figure 2. Brain and Body Fitness Affected Caregivers' PROMIS Scores



Abbreviation: PROMIS, Patient-Reported Outcomes Measurement Information System.

Error bars represent ± 1 SD from the mean.

The session concluded with 30 minutes of informal socialization. Additionally, the group occasionally met outside of class for optional events in the community to enhance socialization.

This study explored 2 research questions: (1) Does the BBF program impact functional QoL indicators for participants with ADRD? and (2) Does the BBF program impact functional QoL indicators for caregivers?

METHODS

Participant Recruitment and Data Collection

Following attainment of the Institutional Review Board approval (#202221226), this study utilized ex post facto data collected by the YMCA of the [area blinded] during the 12 biweekly sessions conducted between 2017-2021 with 3 cohorts per year. Recruitment was based on snowball sampling, and it was assumed that only those who wanted to participate in the program did so. The BBF program is advertised to the community through the YMCA and ADRC. No records are kept related to those who may decline program participation. The BBF program is targeted specifically to participants with ADRD who live in the community (rather than a congregate setting).

Data were collected from both participants with ADRD and their caregivers. Participation was voluntary and required written consent. Class sizes ranged from 6 to 25 participants. Data collected by the YMCA did not include a report of diagnosis or severity of participants' ADRD.

Measures

The YMCA of the [area blinded] obtained data utilizing an adapted form of the Patient-Reported Outcomes Measurement Information System (PROMIS) Applied Cognition tool.¹⁹ The PROMIS tool, modified by the YMCA, included several items to assess 4 dimensions of mental health: anxiety, depression, fatigue, and sleep quality. Participants responded using a 5-point scale ranging from "0=never" to "4=always." Participants with ADRD and caregivers individually (with rare exception an affected partner required assistance from the caregiver) completed the modified PROMIS tool before and after participation in the group program. Cronbach's alpha analysis determined that each subscale had good to excellent reliability for both BBF participants with ADRD and their caregivers. Specifically, anxiety (ADRD $\alpha=0.87$ pre-score; $\alpha=0.84$ post-score; caregivers $\alpha=0.84$ pre-score; $\alpha=0.81$ post-score) was measured by 4 items (eg, "My worries were overwhelming"). Depression (ADRD $\alpha=0.92$ pre-score; $\alpha=0.95$ post-score; caregivers $\alpha=0.90$ pre-score; $\alpha=0.84$ post-score) was measured by 4 items (eg, "I felt depressed"). Fatigue (ADRD $\alpha=0.94$ pre-score; $\alpha=0.84$ post-score; caregivers $\alpha=0.93$ pre-score; $\alpha=0.91$ post-score) was measured by 3 items (eg, "I felt run down"). Sleep (ADRD $\alpha=0.82$ pre-score; $\alpha=0.90$ post-score; caregivers $\alpha=0.89$ pre-score; $\alpha=0.88$ post-score) was measured by 4 items (eg, "I had poor sleep quality").

Data Analysis Plan

For the primary outcomes analysis, quantitative data were available from multiple BBF cohorts from 2017 through 2021. This resulted in data from 49 participants with ADRD and 38 caregivers. Paired sample *t* tests were conducted, using 1000 bootstrapped samples for calculation 95% (CIs) calculation and effects size estimates, to compare pre-scores and post-scores on the 4 PROMIS subscales. Note that this strategy does not account for shared variance among the affected participant and caregiver dyads, although sample size precluded dyadic statistical analysis. Additionally, informal qualitative feedback to query the effectiveness of the program was solicited from the dyads via email sent by the BBF program coordinator at the conclusion of each cohort, most often with the dyads collaborating in their written feedback.

RESULTS

Regarding the first research question about whether the group program affects functional QoL indicators for participants with ADRD, results demonstrated improvements across the course of

the program in anxiety ($t_{48}=2.01$; $P=0.049$; $d=0.29$; 95% CI, 0.0005–0.4586) and fatigue ($t_{48}=2.29$; $P=0.026$; $d=0.33$; 95% CI, 0.0478–0.4715) (Figure 1). Nonsignificant improvements were found for participants with ADRD on depression ($t_{48}=0.65$; $P=0.52$; $d=0.09$; 95% CI, -0.1714–0.3344) and sleep ($t_{48}=1.28$; $P=0.21$; $d=0.18$; 95% CI, -0.1041–0.4715).

Results did not suggest that functional QoL indicators for caregivers changed because of their program participation. No significant changes for caregivers were observed in anxiety, ($t_{37}=0.29$; $P=0.771$; $d=0.05$; 95% CI, -0.2175–0.291), fatigue, ($t_{37}=0.657$; $P=0.52$; $d=-0.01$; 95% CI, -0.1992–0.3903); depression ($t_{37}=-0.07$; $P=0.95$; $d=0.11$; 95% CI, -0.2028–0.1896), or sleep ($t_{37}=0.72$; $P=0.47$; $d=0.12$; 95% CI, -0.1659–0.3501) (Figure 2). Although no statistically significant improvements for caregivers were noted, informal qualitative feedback submitted via email indicated that caregivers perceived several benefits from their participation.

DISCUSSION

The BBF group community program is unique in its format in that dyads consisting of participants with ADRD and their caregivers met collectively within the community. Originally the BBF program, hosted in Eau Claire County, began in 2014 under the name of LEEPS and was based on incorporating physical exercise, cognitive engagement, and social interaction—all of which have been shown to impart positive benefit for those with ADRD.^{2–3,20} Small changes were made to the LEEPS program, and the name was changed to BBF to better capture the program's essence. Anecdotally, participation in the BBF group program positively impacts the dyads' quality of life. Notably, the means for all 4 PROMIS scores—for both participants with ADRD and caregivers—were below the midpoint on the scales, suggesting good to moderate functional QoL.

For participants with ADRD, statistically significant differences were noted as a result of BBF program participation on the anxiety and fatigue PROMIS measures, and nonsignificant trends toward differences were seen in depression and sleep. Practically, participants with ADRD reported reductions in levels of anxiety and fatigue from the beginning to end of the program. Similarly, the nonsignificant trends suggest mean differences moving in the direction of lowered levels of depression and sleep problems as well. Since anxiety and depression may contribute to decreased overall functioning and accelerated cognitive decline,²¹ results illustrate the important benefits that participation in a group BBF program might have for those with dementia.

The impact of the BBF group program is encouraging for those who seek to attenuate decline in functioning. Additionally, with an estimated 65% to 70 % of those diagnosed with dementia experiencing symptoms of depression,²² any mitigation of such symptoms is beneficial. Participation in the BBF program may provide one avenue of ADRD symptom reduction. Also encour-

aging are participants' lowered fatigue levels throughout the BBF program as increased fatigue may result in a more rapid progression of brain aging,⁵ while lowering fatigue may assist in halting and/or slowing brain aging. Lastly, maintaining or improving sleep hygiene may increase the chance that a person with ADRD can remain at home for a longer period instead of transferring to a residential care setting.¹⁶

For BBF program caregivers, there were no statistically significant improvements on the PROMIS scales; however, qualitative feedback submitted via email indicated that caregivers perceived several benefits from their participation with their affected loved one, one of which appears to be social connections.

Social connections impact health. Holt-Lundstad noted humans are "wired" to be social, such that our brains and bodies expect proximity to others.^{23(p251)} Social "disconnections" may "influence multiple health outcomes"^{23(p253)} and chronic inflammation has been hypothesized as contributing to cognitive health. There is growing evidence that loneliness from social disconnection affects health as well.²⁴ Biddle et al noted that "older adults with less frequent social contact and community activities experience more rapid cognitive decline and increased incidence of dementia."²⁵ Given the increasing evidence that social connections positively impact health, the BBF group program—with its socialization emphasis—may be an important intervention for all aging adults, regardless of the presence of ADRD.

CONCLUSIONS

Given the group approach in a community setting, the Brain and Body Fitness group program is a unique multimodal intervention. The program hypothesizes that this approach of combining physical exercise and cognitive stimulation in a group setting will have positive effects on cognitive and physical health for persons with ADRD and their caregivers.

Analysis of PROMIS data indicated that participants with ADRD experienced significant decreases in anxiety and fatigue across the duration of the BBF program and slight, but nonsignificant reductions in depression and increases in sleep quality. Data did not indicate any changes of these outcomes for caregivers. However, in anecdotal communications with program staff, caregivers have reported stress relief, appreciation for social interaction, and a place where they can find support from other caregivers. It is also reassuring that reported levels of depression were very low for participants with ADRD and caregivers at both time points. It should be noted that, in the absence of a control group, we cannot be certain that the positive changes across time among participants with ADRD were due only, or primarily, to participation in the BBF program. However, the typical course of ADRD entails reductions across time. Results of this analysis are encouraging and warrant further research through continued community collaboration.

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Appendix: Available at www.wmjonline.org

REFERENCES

1. Thunell J, Chen Y, Joyce G, et al. Drug therapies for chronic conditions and risk of Alzheimer's disease and related dementias: A scoping review. *Alzheimers Dement*. 2021;17(1):41-48. doi:10.1002/alz.12175
2. Barreto Pde S, Demougeot L, Pillard F, Lapeyre-Mestre M, Rolland Y. Exercise training for managing behavioral and psychological symptoms in people with dementia: a systematic review and meta-analysis. *Ageing Res Rev*. 2015;24(Pt B):274-285. doi:10.1016/j.arr.2015.09.001
3. Guure CB, Ibrahim NA, Adam MB, Said SM. Impact of physical activity on cognitive decline, dementia, and its subtypes: meta-analysis of prospective studies. *Biomed Res Int*. 2017;2017:9016924. doi:10.1155/2017/9016924
4. Treiber KA, Carlson MC, Corcoran C, et al. Cognitive stimulation and cognitive and functional decline in Alzheimer's disease: the Cache County Dementia Progression Study. *J Gerontol B Psychol Sci Soc Sci*. 2011;66(4):416-425. doi:10.1093/geronb/gbr023
5. Carvalho DZ, St Louis EK, Boeve BF, et al. Excessive daytime sleepiness and fatigue may indicate accelerated brain aging in cognitively normal late middle-aged and older adults. *Sleep Med*. 2017;32:236-243. doi:10.1016/j.sleep.2016.08.023
6. Alzheimer's Association. 2022 Alzheimer's disease facts and figures. 2022;18:1-119. Accessed August 1, 2022. <https://adrag.org/wp-content/uploads/2024/02/alzheimers-facts-and-figures-1.pdf>
7. Rabarison KM, Bouldin ED, Bish CL, McGuire LC, Taylor CA, Greenlund KJ. The economic value of informal caregiving for persons with dementia: results from 38 states, the District of Columbia, and Puerto Rico, 2015 and 2016 BRFSS. *Am J Public Health*. 2018;108(10):1370-1377. doi:10.2105/AJPH.2018.304573
8. Ablitt A, Jones GV, Muers J. Living with dementia: a systematic review of the influence of relationship factors. *Ageing Ment Health*. 2009;13(4):497-511. doi:10.1080/13607860902774436
9. Fauth E, Hess K, Piercy K, et al. Caregivers' relationship closeness with the person with dementia predicts both positive and negative outcomes for caregivers' physical health and psychological well-being. *Ageing Ment Health*. 2012;16(6):699-711. doi:10.1080/13607863.2012.678482
10. Bowling A, Rowe G, Adams S, et al. Quality of life in dementia: a systematically conducted narrative review of dementia-specific measurement scales. *Ageing Ment Health*. 2015;19(1):13-31. doi:10.1080/13607863.2014.915923
11. Kuring JK, Mathias JL, Ward L. Prevalence of depression, anxiety and PTSD in people with dementia: a systematic review and meta-analysis. *Neuropsychol Rev*. 2018;28(4):393-416. doi:10.1007/s11065-018-9396-2
12. Qazi A, Gutzmann H, Gul S. Depression and anxiety in dementia subjects. In: Verdelho A, Gonçalves-Pereira M, eds. *Neuropsychiatric Symptoms of Cognitive Impairment and Dementia*. Springer International Publishing; 2017:181-198.
13. Orgeta V, Qazi A, Spector A, Orrell M. Psychological treatments for depression and anxiety in dementia and mild cognitive impairment: systematic review and meta-analysis. *Br J Psychiatry*. 2015;207(4):293-298. doi:10.1192/bjp.bp.114.148130
14. Irwin MR. Why sleep is important for health: a psychoneuroimmunology perspective. *Annu Rev Psychol*. 2015;66:143-172. doi:10.1146/annurev-psych-010213-115205

15. Webster L, Costafreda Gonzalez S, Stringer A, et al. Measuring the prevalence of sleep disturbances in people with dementia living in care homes: a systematic review and meta-analysis. *Sleep*. 2020;43(4):zsz251. doi:10.1093/sleep/zsz251
16. Ball LJ, Birge SJ. Prevention of brain aging and dementia. *Clin Geriatr Med*. 2002;18(3):485-503. doi:10.1016/s0749-0690(02)00027-7
17. Arkin S. Language-enriched exercise plus socialization slows cognitive decline in Alzheimer's disease. *Am J Alzheimers Dis Other Dement*. 2007;22(1):62-77. doi:10.1177/1533317506295377
18. La Rue A, Felten K, Turkstra L. Intervention of multi-modal activities for older adults with dementia translation to rural communities. *Am J Alzheimers Dis Other Dement*. 2015;30(5):468-477. doi:10.1177/1533317514568888
19. PROMIS. HealthMeasures. Updated March 27, 2023. Accessed June 1, 2022. <https://www.healthmeasures.net/explore-measurement-systems/promis>
20. Ruthirakuhan M, Luedke AC, Tam A, Goel A, Kurji A, Garcia A. Use of physical and intellectual activities and socialization in the management of cognitive decline of aging and in dementia: a review. *J Aging Res*. 2012;2012:384875. doi:10.1155/2012/384875
21. Gonzales MM, Insel PS, Nelson C, et al. Cortical Atrophy is Associated with Accelerated Cognitive Decline in Mild Cognitive Impairment with Subsyndromal Depression. *Am J Geriatr Psychiatry*. 2017;25(9):980-991. doi:10.1016/j.jagp.2017.04.011
22. Fritze F, Eht U, Hortobagyi T, Ballard C, Aarsland D. Depressive symptoms in Alzheimer's disease and lewy body dementia: a one-year follow-up study. *Dement Geriatr Cogn Disord*. 2011;32(2):143-149. doi:10.1159/000332016
23. Holt-Lundstad J. The major health implications of social connection. *Curr Dir Psychol Sci*. 2021;30(3):251-259. doi:10.1177/0963721421999630
24. National Academies of Sciences, Engineering, and Medicine; Division of Behavioral and Social Sciences and Education; Health and Medicine Division; Board on Behavioral, Cognitive, and Sensory Sciences; Board on Health Sciences Policy; Committee on the Health and Medical Dimensions of Social Isolation and Loneliness in Older Adults. Social Isolation and Loneliness in Older Adults: Opportunities for the Health Care System. National Academies Press (US); February 27, 2020. Accessed June 1, 2022. doi:10.17226/25663
25. Biddle KD, d'Oleire Uquillas F, Jacobs HIL, et al. Social engagement and amyloid- β -related cognitive decline in cognitively normal older adults. *Am J Geriatr Psychiatry*. 2019;27(11):1247-1256. doi:10.1016/j.jagp.2019.05.005

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