

**DEMENTIA CAREGIVERS' WILLINGNESS TO PAY FOR SUPPORT INTERVENTIONS: REVIEW OF AN INTERNATIONAL PSYCHOGERIATRICS PAPER: "A LONGITUDINAL EVALUATION OF FAMILY CAREGIVERS' WILLINGNESS TO PAY FOR AN IN-HOME NONPHARMACOLOGIC INTERVENTION FOR PEOPLE LIVING WITH DEMENTIA: RESULTS FROM A RANDOMIZED TRIAL" BY JUTKOWITZ ET AL.]**

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**Key highlights:**

- Nonpharmacologic dyadic interventions, despite being effective in mitigating dementia-related symptoms and caregiver stress, have generally not been adopted by systems of care in the United States due to issues with payment/reimbursement.
- Dementia caregivers' WTP (willingness-to-pay) for support interventions changes with time and exposure to different nonpharmacologic dyadic support programs.
- Dementia caregivers are willing to pay more for a hypothetical support program immediately following participation in a similar, nonpharmacologic dyadic intervention.
- Exposure to program elements may be necessary for families to embrace cost sharing consistent with typical copayments for home services.

People living with dementia (PLwD) demonstrate persistent impairments in cognition and functioning, and therefore require long-term support from family members. Tailored nonpharmacologic dyadic interventions provide family caregivers with knowledge and skills (e.g., instruction on communication, task and environmental strategies), which help them manage PLwD's behavioral symptoms and reduce their own stress (Jutkowitz et al., 2021). Yet, nonpharmacologic dyadic interventions have generally not been adopted by systems of care in the United States due to issues with payment/reimbursement—both PLwD and their caregivers are service recipients, but caregivers may not be Medicare beneficiaries as PLwD. Nonetheless, with emerging payment models, such as accountable

care organizations or Medicare Advantage, nonpharmacologic dyadic dementia interventions have the potential to become standard care (Boustani et al., 2019). It is imperative to understand how much family caregivers value nonpharmacologic, dyadic dementia interventions which will provide insights into the dissemination and implementation of these programs. Using data from the Dementia Behavior Study (Gitlin et al., 2021, 2016b), a study conducted by Jutkowitz and associates (2021) focuses on family caregivers of 250 community-dwelling PLwD-caregiver dyads in Maryland and Washington, DC and examines caregivers' willingness-to-pay (WTP) for a hypothetical nonpharmacologic dementia intervention at baseline, post-intervention (3-month from the baseline) and at follow-up (6 months from the baseline).

A longitudinal randomized control trial was conducted in this study, and caregivers were randomly assigned to either the treatment group (i.e., the Tailored Activity Program [TAP] or the attention control group). TAP involved providing activities tailored to PLwD, instructing caregivers in their daily use, and providing caregivers with disease education and stress reduction techniques (Jutkowitz et al., 2021). Caregivers in the attention control group received dementia education, general support, and a home safety evaluation (Jutkowitz et al., 2021). Caregivers in both groups received up to eight, 1.5 hour in-home sessions over 3 months. At each assessment (baseline, 3 months, and 6 months), caregivers were assessed for their WTP with the question "How much would you be willing to pay per session for an 8-session program lasting 3 months delivered by healthcare professionals in your home?" The response options included \$0, \$25, \$50, \$75, \$100, \$125, \$150, \$175, \$200, or other values per session. The final sample consisted of 231 caregivers (TAP:  $N = 115$ ; Control:  $N = 116$ ).

The results reveal a complex process distinguishing between caregivers willing to pay nothing (WTP = 0\$) and those willing to pay something (WTP > \$0). Following the completion of the program, some TAP caregivers, but not attention control caregivers, shifted from being willing to pay something to nothing. However, caregivers willing to pay something at baseline were willing to pay more for a hypothetical support intervention immediately following participation in TAP compared to baseline and the control group at 3 months. This could be due to the TAP caregivers' positive experiences with the program and their eagerness to learn new ways of engaging PLwD (Gitlin & Rose, 2016).

At 6 months, among caregivers willing to pay something, those in TAP were willing to pay about the same amount as stated during their baseline assessment; however, those in the attention control group were willing to pay substantially less compared to baseline and the TAP group at 6 months. These findings suggest that some TAP caregivers may continue to increase their WTP for a similar program at 6 months. However, others (including both TAP and attention control caregivers) may decrease their WTP, possibly because they were not able to recall the benefits of the program at 6 months (i.e., 3 months after completion of the program) or witnessed program benefits decline over time (Jutkowitz et al., 2017b).

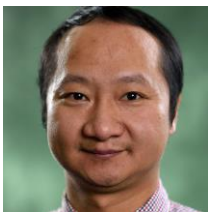
To conclude, this study is significant and innovative in several ways. Previous studies have mainly evaluated WTP among dementia caregivers at a single time point and asked caregivers about WTP for a hypothetical program of which they have limited knowledge. Using a longitudinal study design, this study reflected dementia caregivers' informed preference for a support program after exposure to a similar intervention. Moreover, the current study provides important insight as to how dementia caregivers' WTP changes with time and exposures to different programs. Furthermore, the findings suggest that being exposed to program elements may be necessary for families to embrace cost sharing consistent with typical copayments for in-home services. Last but not least, this study has implications for different stakeholders (e.g., policy makers, long-term care providers) to develop innovative payment models for TAPs and other nonpharmacologic dementia caregiver support programs.

**For further reading:**

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2. Gitlin, L. N., Marx, K., Piersol, C. V., Hodgson, N. A., Huang, J., Roth, D. L., & Lyketsos, C. (2021). Effects of the tailored activity program (TAP) on dementia-related symptoms, health events and caregiver wellbeing: A randomized controlled trial. *BMC geriatrics*, 21(1), 581. <https://doi.org/10.1186/s12877-021-02511-4>

3. Gitlin, L. N., Piersol, C. V., Hodgson, N., Marx, K., Roth, D. L., Johnston, D., Samus, Q., Pizzi, L., Jutkowitz, E., & Lyketsos, C. G. (2016). Reducing neuropsychiatric symptoms in persons with dementia and associated burden in family caregivers using tailored activities: Design and methods of a randomized clinical trial. *Contemporary clinical trials*, 49, 92–102. <https://doi.org/10.1016/j.cct.2016.06.006>
4. Gitlin, L. N., & Rose, K. (2016). Impact of caregiver readiness on outcomes of a nonpharmacological intervention to address behavioral symptoms in persons with dementia. *International journal of geriatric psychiatry*, 31(9), 1056–1063. <https://doi.org/10.1002/gps.4422>
5. Jutkowitz, E., MacLehose, R. F., Gaugler, J. E., Dowd, B., Kuntz, K. M., & Kane, R. L. (2017b). Risk factors associated with cognitive, functional, and behavioral trajectories of newly diagnosed dementia patients. *The journals of gerontology. Series A, Biological sciences and medical sciences*, 72(2), 251–258. <https://doi.org/10.1093/gerona/glw079>
6. Jutkowitz, E., Pizzi, L. T., Popp, J., Prioli, K. K., Scerpella, D., Marx, K., Samus, Q., Piersol, C. V., & Gitlin, L. N. (2021). A longitudinal evaluation of family caregivers' willingness to pay for an in-home nonpharmacologic intervention for people living with dementia: results from a randomized trial. *International psychogeriatrics*, 33(4), 419–428. <https://doi.org/10.1017/S1041610221000089>



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