

Assessing Alzheimer’s Disease Knowledge in Rural Communities Before and After a Family-Based Focus Group with Tailored Resource Sharing



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Key Takeaways: Significant increases in Alzheimer’s Disease knowledge observed one week and one month after the family-based focus groups and resource sharing. Most participants generally expressed interest and value in reviewing the provided resources; others felt their existing understanding was adequate or were not motivated to read the provided material.

INTRODUCTION	METHODS	RESULTS	CONCLUSIONS																																																			
Family support is critical for Alzheimer’s disease (AD) and related dementias (ADRD) care in rural communities, where access to formal services is often limited^{1,2}. Early detection and prevention can improve long-term outcomes for persons living with dementia and family members, making it essential that families understand ADRD, recognize early signs, and know when and how to seek support³. - There is limited research examining effective methods to strengthen AD knowledge for families in rural communities before a family member experiences cognitive decline. Objectives: - Assess whether family members’ AD knowledge improved following a family-based focus group discussion that included tailored resource sharing - Explore participants’ feedback on reviewing resources	Sample: 15 families in rural South Carolina, USA (N=63 members, Mage=55.98 years, range=18-99 years; all families included at least one older adult aged 55+) Pre-Survey (1 week before focus group) Basic Knowledge of Alzheimer’s Disease⁴ + desired information One-time facilitated family-based focus group and resource sharing Post-Survey (1 week after focus group) Basic Knowledge of Alzheimer’s Disease⁴ + open-ended resources use Follow-Up Survey (1 month after focus group) Basic Knowledge of Alzheimer’s Disease⁴ + open-ended resources use Analytic Approach: Paired samples t-tests and thematic analysis	AD Knowledge Increases Significant increases in AD knowledge one week (p=.009) and one month (p=.001) after the family-based focus groups and resource sharing (Table 1) Resource Review Feedback Over half reviewed materials due to perceived value, while non-review reflected time limits, low motivation, or perceived adequate knowledge (Table 2) <table><caption>Table 1. Descriptive Summary of Demographic Characteristics and Basic Knowledge of Alzheimer’s Disease (BKAD) Scores</caption><tr><th></th><th>Total Sample (N=63) M(SD)</th><th>Gen1 (n=23) M(SD)</th><th>Gen2 (n=35) M(SD)</th><th>Gen3 (n=5) M(SD)</th></tr><tr><td>Age (years)</td><td>55.98 (19.21)</td><td>74.78 (10.15)</td><td>48.66 (11.37)</td><td>20.80 (1.92)</td></tr><tr><td>Gender (% Woman)</td><td>60.32%</td><td>60.86%</td><td>57.14%</td><td>80.00%</td></tr><tr><td>Survey 1</td><td>28.44 (3.04)</td><td>27.13 (3.87)</td><td>29.00 (2.21)</td><td>30.60 (1.14)</td></tr><tr><td>Survey 2</td><td>29.32 (3.02)</td><td>28.57 (3.22)</td><td>29.57 (2.90)</td><td>31.00 (2.24)</td></tr><tr><td>Survey 3</td><td>29.46 (3.29)</td><td>28.26 (4.25)</td><td>30.00 (2.47)</td><td>31.20 (1.30)</td></tr></table> <i>Note:</i> Total possible score on BKAD is 32, with higher scores indicating greater AD knowledge; Survey 1 was taken up to one week before the family-based focused group, Survey 2 was taken one week following the family-based focus group, and Survey 3 was taken one month following the family-based focus group <table><caption>Table 2. Representative Quotes Regarding Resource Review</caption><tr><th></th><th>Category</th><th>Quotes</th></tr><tr><td rowspan="4">Reasons for Reviewing Resources (55.56%)</td><td>Gaining New Information</td><td>“I just feel I need to be educated early and often” “Informative info!” “There were some questions I had that were answered by the material provided so I reviewed it”</td></tr><tr><td>Confirming and Advancing Existing Knowledge</td><td>“Reinforce current knowledge on the topic” “Further information on items we discussed” “To further my knowledge on the disease”</td></tr><tr><td>Learning More to Help Others</td><td>“To learn more so I can potentially help others in the future” “Want to know more and be able to potentially help others”</td></tr><tr><td>General Interest</td><td>“I am interested” “I was interested in what it said”</td></tr><tr><td rowspan="4">Reasons for Not Reviewing Resources (44.44%)</td><td>Lack of Time</td><td>“No time” “Haven’t had quiet free time in the past week” “Just haven’t had a chance yet” “Lack of time so far, but plan to for sure!”</td></tr><tr><td>Unmotivated</td><td>“Too lazy” “Haven’t been motivated”</td></tr><tr><td>Did Not Retain Resources</td><td>“My mother-in-law took it to read” “Not in person to receive printed material”</td></tr><tr><td>Seen as Unnecessary</td><td>“My wife is a MD and I receive information from her in layman’s terms” “Symptoms of AD not yet reached concern level for anyone in our family. They will come, but just have not reached concern level.”</td></tr></table> <i>Note:</i> Endorsement rates and quotes are drawn from responses collected one week after the focus group. While categories remained the same, 60.32% of participants had reviewed resources by the time of the second follow-up survey administered one month after the focus group.		Total Sample (N=63) M(SD)	Gen1 (n=23) M(SD)	Gen2 (n=35) M(SD)	Gen3 (n=5) M(SD)	Age (years)	55.98 (19.21)	74.78 (10.15)	48.66 (11.37)	20.80 (1.92)	Gender (% Woman)	60.32%	60.86%	57.14%	80.00%	Survey 1	28.44 (3.04)	27.13 (3.87)	29.00 (2.21)	30.60 (1.14)	Survey 2	29.32 (3.02)	28.57 (3.22)	29.57 (2.90)	31.00 (2.24)	Survey 3	29.46 (3.29)	28.26 (4.25)	30.00 (2.47)	31.20 (1.30)		Category	Quotes	Reasons for Reviewing Resources (55.56%)	Gaining New Information	“I just feel I need to be educated early and often” “Informative info!” “There were some questions I had that were answered by the material provided so I reviewed it”	Confirming and Advancing Existing Knowledge	“Reinforce current knowledge on the topic” “Further information on items we discussed” “To further my knowledge on the disease”	Learning More to Help Others	“To learn more so I can potentially help others in the future” “Want to know more and be able to potentially help others”	General Interest	“I am interested” “I was interested in what it said”	Reasons for Not Reviewing Resources (44.44%)	Lack of Time	“No time” “Haven’t had quiet free time in the past week” “Just haven’t had a chance yet” “Lack of time so far, but plan to for sure!”	Unmotivated	“Too lazy” “Haven’t been motivated”	Did Not Retain Resources	“My mother-in-law took it to read” “Not in person to receive printed material”	Seen as Unnecessary	“My wife is a MD and I receive information from her in layman’s terms” “Symptoms of AD not yet reached concern level for anyone in our family. They will come, but just have not reached concern level.”	- Findings provide preliminary evidence for effectively using family-based focus groups and resource sharing to strengthen AD knowledge in rural communities. - These results support long-term goal of facilitating more timely diagnosis and intervention of AD. - Future work should explore which aspects of focus group and/or resource sharing best support enhanced knowledge for family members across age groups. REFERENCES, FUNDING, & CONTACT 1. McCarthy, M. J., Garcia, Y. E., Remiker, M., Hustead, M. L. R., Bacon, R., Williamson, H. J., ... & Baldwin, J. (2023). Diverse rural caregivers for individuals with Alzheimer’s disease or related dementias: Analysis of health factors at the individual, interpersonal, and community level. <i>Aging & Mental Health</i>, 27(1), 94-100. https://doi.org/10.1080/13607863.2022.2026880 2. Ho, J. Y., & Franco, Y. (2022). The rising burden of Alzheimer’s disease mortality in rural America. <i>Social Science and Medicine - Population Health</i>, 17, 101052. https://doi.org/10.1016/j.ssmph.2022.101052 3. Dubois, B., Padovani, A., Scheltens, P., Rossi, A., & Dell’Agnello, G. (2016). Timely diagnosis for Alzheimer’s disease: a literature review on benefits and challenges. <i>Journal of Alzheimer’s Disease</i>, 49(3), 617-631. https://doi.org/10.3233/JAD-150692 4. Wiese, L. K., Williams, C. L., Tappen, R. M., & Newman, D. (2020). An updated measure for investigating basic knowledge of Alzheimer’s disease in underserved rural settings. <i>Aging & Mental Health</i>, 24(8), 1348–1355. https://doi.org/10.1080/13607863.2019.1584880 We’d love to hear your thoughts! Contact Abby Stephan at atsteph@clemson.edu Funded by the Johns Hopkins Alzheimer’s Disease Resource Center for Minority Aging Research (1P30AG059298) ALZHEIMER’S ASSOCIATION AAIC>26
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