

Benefits of an Anti-Amyloid Therapy Support Group

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Background

Lecanemab and Donanemab are monoclonal anti-amyloid therapies (AAT) with FDA-approval for treatment of mild cognitive impairment and mild dementia due to Alzheimer's disease (AD). AAT became the first disease-modifying therapy for Alzheimer's disease in 2023. AAT have potential barriers; requiring a more extensive evaluation for eligibility, several medical contraindications, require ongoing monitoring for safety, potential serious side effects (ARIA) and require a caregiver to complete a treatment course. When our institution began offering AAT, there were an overwhelming number of questions and concerns from patients and caregivers which couldn't all be answered during an office visit. An AAT support group was developed as an outlet for these concerns.

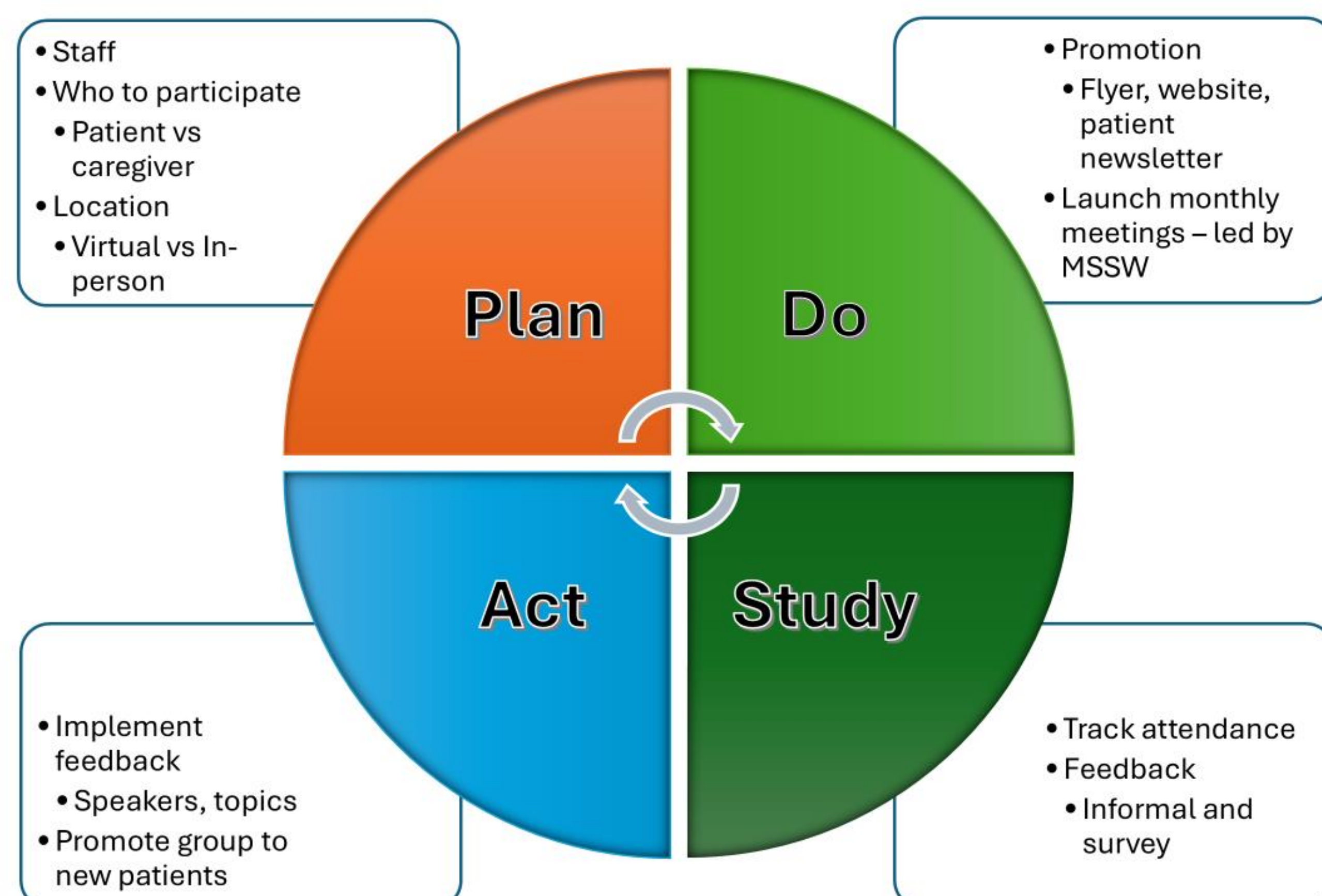
Aim Statement

By October 2024, we will establish a monthly facilitated support group for at least 12 participants (patients and/or caregivers) who have started anti-amyloid therapy. By December 2025, we will increase and maintain attendance by 50%.

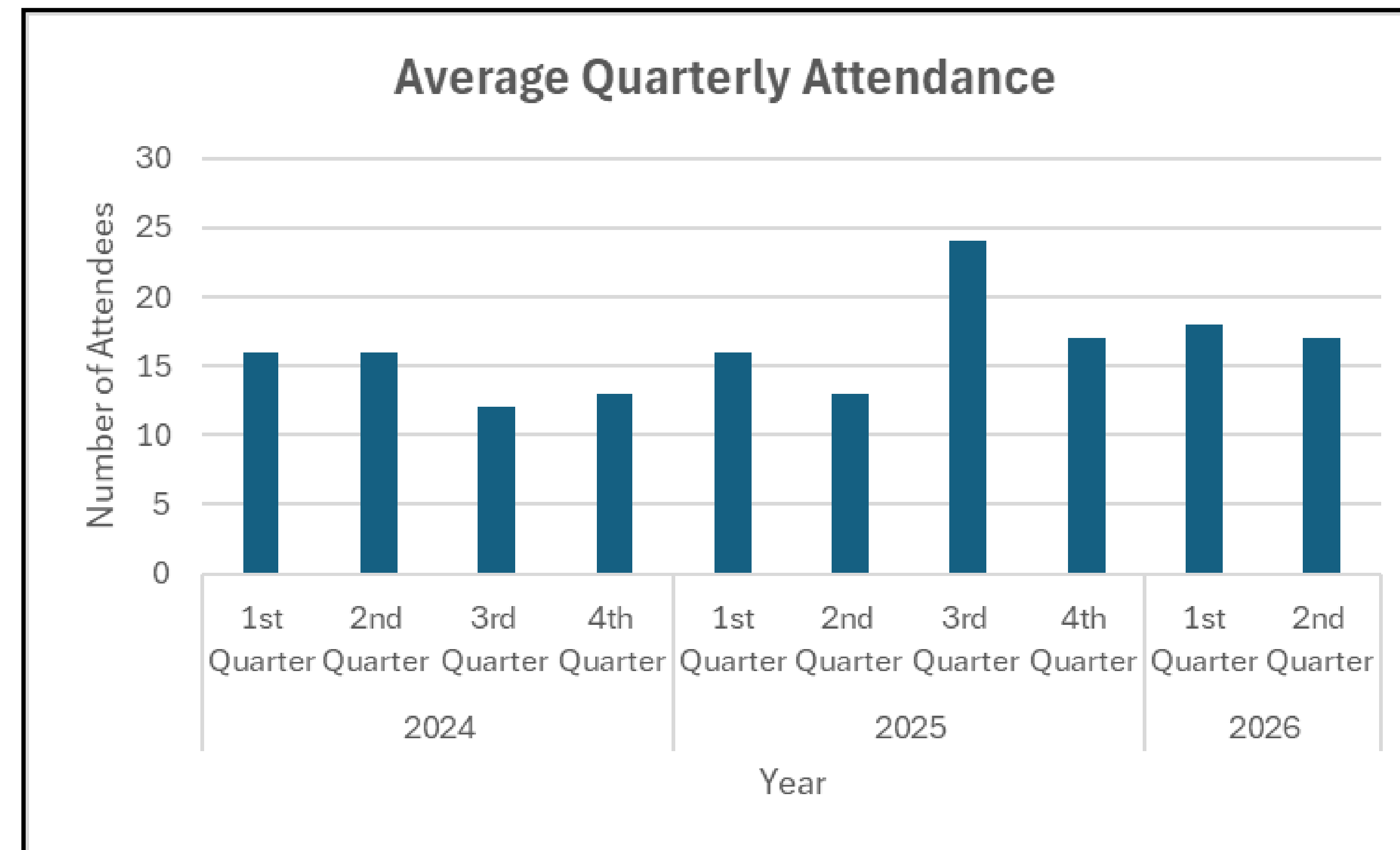
Methods

- A small team was formed to organize the support group. Monthly virtual meetings were planned for patient-caregiver dyads. Meetings included a speaker, clinical updates on AAT and a general question and answer session. Electronic and printed flyers were created to promote the support group. Medical providers encouraged attendance.
- Using Plan-Do-Study-Act (PDSA) quality improvement methodology, a short survey was developed for patient-caregiver dyads to provide feedback for the support group structure. Survey responses were analyzed to count responses and review attendee comments. Excel software used for registration was utilized to track attendance and interest of the support group.

PDSA Cycle



Outcomes



Important Survey Results:

- 7 patient-caregiver dyads completed the survey
- 100% of respondents found the virtual platform effective
- 100% of respondents said the time and frequency of the support group met their expectations
- In the prior 12 months, 86% of respondents had attended the support group 6 – 10 times
- 29% of respondents said the support group made them feel more confident about receiving AAT

Lessons Learned

Benefits Seen by Staff

Empowerment

- Instances of patients who have elected to start AAT because of shared experience discussed at support group
- 1 caregiver offered to teach caregivers who were hesitant about lecanemab SQ how to use the autoinjector

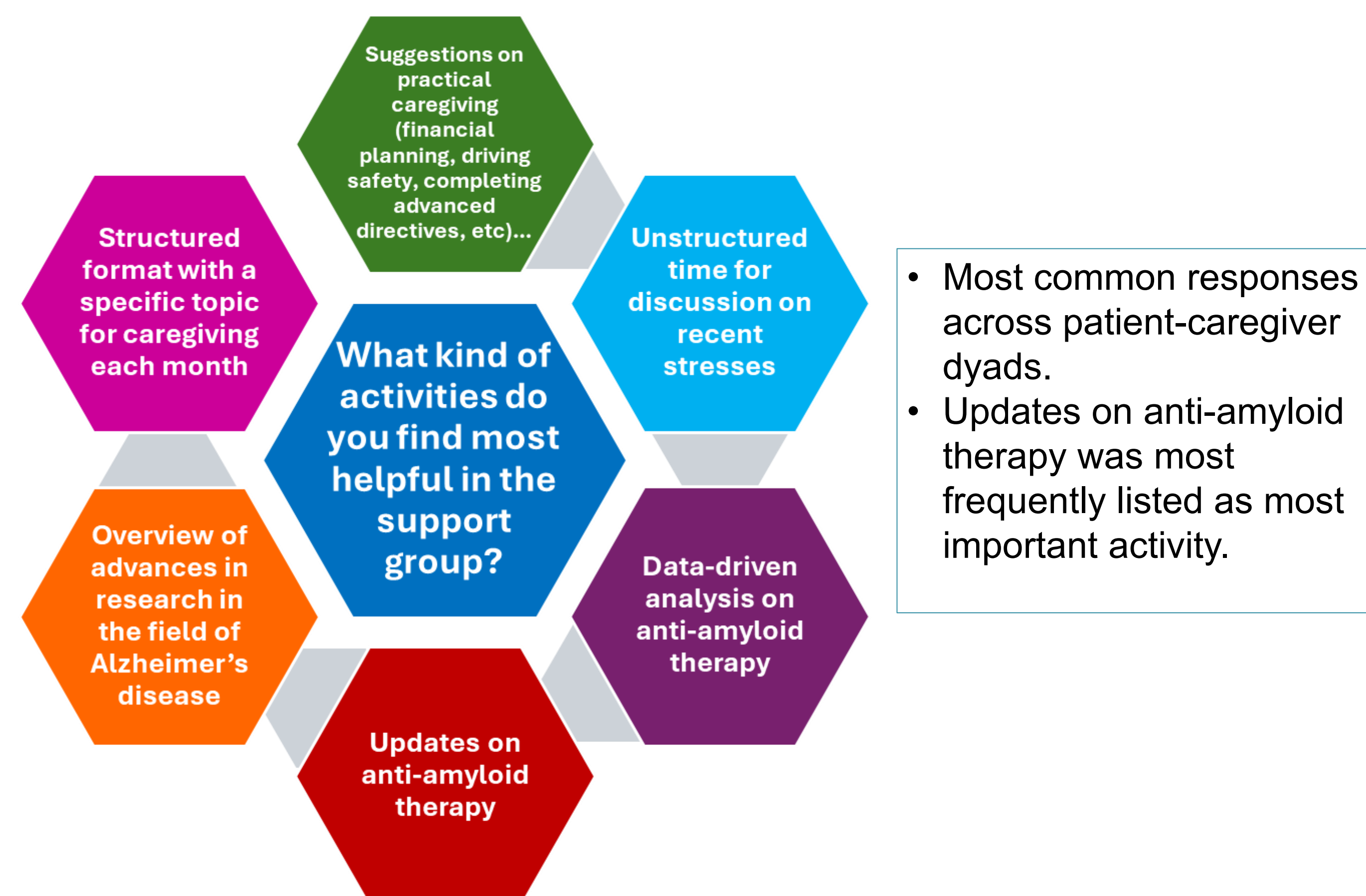
Community

- Many participants have been attending the support group since it started in 2024
- Attend other caregiver support activities together

Platform for communication

- Ability to provide updates on AAT (PET scan availability, SQ dosing, etc)
- Selected topics for common concerns – driving, communication
- Agenda for guest speakers – OT driving evaluator, Speech therapy, Pharmacy

What activities do patient-caregiver dyads find most helpful in support group?



- Most common responses across patient-caregiver dyads.
- Updates on anti-amyloid therapy was most frequently listed as most important activity.

Patient-Caregiver Dyad Feedback

What do patient-caregiver partners find most beneficial in AAT Support Group?

"Knowing there are others in the same situation, others talking about their AAT gives us hope, we appreciate the care from the team and the concern from other participants."



"It's good to hear what others have to say about their own journeys with AAT and how they cope with the ups and downs of disease. I like knowing I'm not alone in this fight."



"It's candid, well-intentioned, comforting to communicate with people on the same journey."

Future Directions

- Determine a meaningful patient and caregiver response to an AAT Support Group
- Reduce logistics-related stress
- Increase reported peer-support satisfaction

References

- Bender JL, Babinski S, Wong G, et al. Establishing best practices in cancer online support groups: protocol for a realist review. *BMJ Open* 2021;11:e053916. doi:10.1136/bmjopen-2021-053916
- Ziegler E, Hill J, Lieske B, Klein J, vonden Knesebeck O, Kofahl C. Empowerment in cancer patients: Does peer support make a difference? A systematic review. *Psycho-oncology*. 2022;31(5):683-704. doi: 10.1002/pon.5869.

