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Forum

Community-Engaged Recommendations for Empowering People Living With Dementia to be Research Collaborators

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Abstract

As cases of Alzheimer's disease and related dementias (ADRD) increase worldwide, research design has placed additional emphasis on social and behavioral factors that affect ADRD symptomatology and quality of life. Despite this, few studies have incorporated people living with ADRD as research partners. We propose 5 community-engaged recommendations for incorporating people living with ADRD into future research as full collaborators. The proposed recommendations center the experiences of people living with ADRD as crucial contributions to scientific inquiry. The guidelines are based on experiences at a 2-day "Empowering Partnerships" workshop in 2019; post workshop activity continued through 2021 with ongoing collaborations, analysis, and reflective practice. The workshop and subsequent conversations engaged a network of people living with ADRD, informal carepartners, and researchers to collectively build their capacities to partner in all aspects of person-centered research. To empower people living with ADRD as research partners, we recommend that research teams (a) create a flexible schedule of communication and/or meetings to accommodate a wide range of ADRD symptoms, (b) generate team-specific communication strategies/guidelines, (c) incorporate lived experiences of people living with ADRD into research protocols, (d) involve people living with ADRD in all aspects of a project, beginning in the developmental stages, and (e) incorporate skilled facilitators to facilitate communication between stakeholder groups. This multi-vocal approach to research will diversify ADRD research and ensure that projects align with the priorities and capacities of principal stakeholders by incorporating individuals with a wide range of cognitive capabilities that more fully represent the diversity of ADRD experiences.

Keywords: Alzheimer's disease and related dementias, Community-based participatory research, Recruitment and retention, Social stigma

Since 2012, more than half of all National Institute of Aging (NIA) grants in the United States have been allocated to researching Alzheimer's Disease and Related Dementias (ADRD) (NIA, 2020a). Specifically, the NIA's strategic directions plan for 2020–2025 prioritizes behavioral and social factors in several research goals, including improving the understanding of social effects on general aging ("Goal B") and supporting studies that investigate how stress affects the health of ADRD carepartners ("Goal D-5"; NIA, 2020b).

Despite the increased interest in behavioral ADRD research, it appears that investigators have not fully considered the extent to which people living with ADRD can contribute to *and strengthen* scientific inquiry. Past health-related community-engaged research has demonstrated the necessity of involving stakeholders in all levels of research, including development and implementation, to create valid study designs and ensure that research addresses the concerns/needs of the community (Israel et al., 2005). Community-engaged methodology has also been effective at drawing in communities that feel alienated and/or excluded by the research process, especially low socioeconomic status and underrepresented communities (Israel et al., 2017).

Researchers who may wish to integrate people living with ADRD as equal collaborators, however, face a problem: Since little ADRD-specific community-engaged research has fully incorporated people living with ADRD (see review later), specific guidelines for partnering with people living with ADRD in all steps of research have not been developed. Incorporating community-engaged approaches by including people living with ADRD as collaborative partners could facilitate a more thorough understanding of behavioral and social aspects of the ADRD experience, as has been demonstrated by the positive impact that person-centered care has had in long-term services and supports (van Haitsma et al., 2020). Further, the lack of comprehensive stakeholder engagement in ADRD research likely contributes to stigmatization of people living with ADRD by tacitly reinforcing the assumption that people living with ADRD are no longer competent (Kim et al., 2019). The stigmatic perspective overlooks that many people are diagnosed in the early stages of the syndrome and may maintain many skills/abilities for several years (Ito et al., 2011; Veitch et al., 2019).

This paper aims to recommend best practices for community-engaged collaborations with people living with ADRD. We

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propose five community-engaged recommendations that integrate people living with ADRD, and their informal carepartners, as equitable partners in academic research *vis a vis* an exploration of how their engagement can strengthen methodology. We seek to incorporate individuals with a wide range of cognitive capabilities to better represent the diversity of ADRD experiences.

Our suggestions are based on our experiences at an Empowering Partnerships (EP) workshop hosted by LiveWell and funded by a Eugene Washington Patient-Centered Outcomes Research Institute Engagement award. LiveWell is an ADRD services provider located in Southington, Connecticut; their mission includes "positively transforming the way [people living with ADRD] are viewed, engaged, and supported" (Shivers, n.d.). The EP workshop sought to engage a network of people living with ADRD, informal carepartners, researchers, and local/national stakeholders to collectively build their capacities to partner in all aspects of person-centered outcomes and clinical effectiveness research.

Community-Engaged Research and ADRD

The nature of ADRD symptoms must be accounted for when developing inclusive research plans. Most ADRD diagnoses are progressive illnesses, characterized by a decline in cognitive ability over time (Kandel et al., 2012), but symptoms vary significantly between diagnoses. Further, at the individual level, there is substantial interpersonal variation in the manifestation of symptoms for each diagnosis. Representing a range of ADRD experiences can support generalizability across the heterogenous population of people living with ADRD. A research strategy that encourages reciprocal knowledge sharing would also provide an opportunity for people living with ADRD to reframe their lived experiences as valuable insight for research projects (see Bennett et al., 2022, for an example of how lived experiences can inform research). Lived experiences are defined as "a representation and understanding of a researcher or research subject's human experiences, choices, and options and how those factors influence one's perception of knowledge" (Given, 2008, p. 490).

This paper bases its recommendations on a specific community-engaged methodology—community-based participatory research (CBPR)—that is particularly suited to maximize the collaborative potential of people living with ADRD. CBPR is characterized by integrating community members into research via consensus-based planning that creates a horizontal structure that situates all participants as equally valuable partners (Atalay, 2012; Lorenc, 2019). The flexibility and multivocality of CBPR methodology make it a uniquely appropriate framework to incorporate varied ADRD etiologies into research.

Examples of Past Research

Previous publications within ADRD research that utilize community-engaged methodology have occasionally classified people living with ADRD as "stakeholders" but generally have not fully integrated people living with ADRD into protocol design. Morgan et al. (2014) partnered with various stakeholders, including familial carepartners, to study ADRD in a rural community but did not include people living with ADRD as research partners. Other community-based research recruiting people living with ADRD as research participants, but not as full partners, includes development of Play Interventions in nursing homes (Li, 2022), evaluation of the viability of using health coaches to supplement services (Goldfarb et al., 2022), and assessment of wearable personal activity monitors for research (Hassan et al., 2017).

Some investigations have considered input from people living with ADRD directly on topics such as deception in research (Day et al., 2011), but fall short of fully including people living with ADRD in all aspects of the project. People living with ADRD have been active participants in performing arts interventions aimed at reducing ADRD stigma (Harris & Caporella, 2019) and reducing cognitive disfunction in institutional settings (Danila et al., 2018). In both cases, people living with ADRD did not seem to play a role in protocol design or manuscript preparation. Frank et al. (2020) described a case study in which people living with ADRD formed a stakeholder group at a research summit and successfully influenced the meeting's agenda and content. Yet, this case study focused on meeting/conference logistics and not research. Although these findings are valuable, they stop short of empowering people living with ADRD at all stages of ADRD to be fully contributing partners in research.

In other cases, community-engaged research projects pertinent to ADRD do not directly investigate the experiences of people living with ADRD. Examples include engagement with carepartners (Etkin et al., 2012; Morhardt et al., 2010), recruitment in underrepresented populations (Medina, 2021; Yu et al., 2021), documenting cultural attitudes regarding ADRD (Wong et al., 2022), and investigating diagnosis patterns (O'Bryant et al., 2013).

Two notable examples of people living with ADRD participating in research more fully exist. Tanner (2012) recruited three people living with ADRD as co-researchers in a project centered on recording the experiences of "seldom-heard" older adults. Tanner concludes that when people living with ADRD conduct interviews of other people living with ADRD the quality of interviews improve while simultaneously providing social benefit to the co-researchers. Littlechild et al. (2015) collaborated with 11 people living with ADRD and 11 informal carepartners to evaluate experiences during transitions in dementia services and hospital discharges in order to assess the impact of community-engaged research on people living with ADRD. The authors conclude that although collaborative research has benefits, research teams must fully critique their processes to ensure that community patterns are truly benefitting, especially in historically marginalized communities. Crucially, both of these papers demonstrate the feasibility of including people living with ADRD as research partners and the latter outlines ways this type of work may benefit participants although helping shape research. We argue the present paper builds on the findings of Tanner (2012) and Littlechild et al. (2015) by identifying specific CBPR recommendations which can serve as a roadmap for other researchers who hope to meaningfully engage people living with ADRD.

The Current Project

Relevance

People living with ADRD, and their carepartners, are rarely asked to contribute to the research process, beyond acting as participants. Past community-engaged research, however, has demonstrated that comprehensive community involvement in protocol design and implementation improves stakeholder buy-in and research quality.

Objective

We aim to define best practices for community-engaged research collaborations with people living with ADRD. We seek to incorporate individuals with a wide range of cognitive capabilities to more fully represent the diversity of experiences among people living with ADRD.

Empowering Partnerships Workshop

The workshop took place over two days at an independent community-based location in October 2019. Activities included collaborative creation of communication ground rules, lectures about research design, testimonials from people living with ADRD, sharing of motivations to participate in ADRD research, breakout groups to develop prototype research projects, and commitment to future action (see Supplement 1 for the full workshop agenda and brainstorming worksheets). LiveWell recruited 35 participants for the event—people living with ADRD (N = 12), their informal carepartners (N = 9), and researchers (N = 14). Specific ADRD diagnoses self-reported by participants during workshop discussions included AD, frontotemporal dementia, and vascular dementia. Researchers included university faculty, graduate students, postdoctoral scholars, arts educators, occupational therapists, registered nurses, and person-centered care consultants.

Workshop participants split into four breakout groups and each breakout group developed an outline of a prototype research plan. All groups included people living with ADRD, informal carepartners, and researchers. In one group, three researchers, four people living with ADRD, and three informal carepartners developed a project aimed at reducing ADRD stigma. Researchers took a lead role and informally interviewed the other participants about their experiences with ADRD. The team constructed an intervention-based design examining whether interactions between people living with ADRD and younger adults could reduce impressions of stigma.

In addition to the workshop, collaborations occurred before and after EP. People living with ADRD and informal carepartners sat on advisory councils for several months to inform workshop design. Collaborations continued after the workshop when a researcher and a person living with ADRD met frequently over the following year to develop a draft for a grant proposal using the prototype developed in the breakout groups. This researcher-person living with ADRD team also organized semi-regular virtual meetings to involve other participants in developing the research idea and strengthening collaborative bonds. Finally, LiveWell hosted and facilitated follow-up meetings after the EP workshop where facilitators and participants shared updates on experiences, learning, and opportunities to get involved in research, education, advocacy, and community happenings (REACH). Initial meetings occurred in person, but subsequent events occurred virtually due to COVID-19. These post workshop conversations and collaborations were essential for fleshing out the specifics of our recommendations.

The information presented here was synthesized post hoc via analysis of the authors' notes from the workshop, discussion about effectiveness of various aspects of the workshop, and via documents generated during the workshop (see Supplementary Material 2 for additional details). Although all three authors are PhD researchers, which we deemed appropriate given that other researchers are the target audience, the voices of people living with ADRD are reflected throughout our recommendations. This started with EP—the weaknesses and suggested guidelines are a product of our experiences and observations during and after the workshop. While writing, we also consulted with workshop participants to gather their insights and feedback; those perspectives formed the backbone of our proposed recommendations. For example, we offered two community partners a two-page summary of the key takeaways from this article while we were preparing the manuscript. This gave the partners a chance to weigh in on the final form of the article without having to read several thousand words of academic prose and prompted the researchers to be mindful of creating lay summary documents.

Barriers to Research Collaboration

We identified two overarching barriers to incorporating people living with ADRD as research partners. These barriers summarize concerns raised by people living with ADRD and informal carepartners during a group discussion on developing "shared values" and "creating an inclusive environment." First, medical research is often organized with a top-down hierarchical model in that funding agencies and researchers determine the priorities and terms of projects. Participants in the EP workshop voiced that they felt their concerns had not been appropriately addressed in past clinical research participation and that research projects that did not incorporate people living with ADRD in the planning/development stages may not reflect the priorities of people living with ADRD. Discussion centered on simplifying informed consent processes to ensure that long-term expectations of participants are in line with the goals of the research, particularly in clinical trials. This barrier was partially mitigated during EP by asking people living with ADRD to volunteer ground rules that would aid successful communication and also by emphasizing the importance of their voices before smaller breakout sessions. That principle was extended to all subsequent meetings, including empowering people living with ADRD to plan meetings and set agenda items.

Second, some people living with ADRD at EP reported that they were intimidated by or did not understand the academic research model. These concerns were attributed to poor experiences with past research (especially clinical trials), worry that a lack of formal education would be disqualifying, and a general lack of understanding about the research process including what role a person living with ADRD could have in a project. This barrier was partially mitigated by formal training on research design during the workshop and by sharing drafts of the recommendations in this manuscript with a person living with ADRD and their informal carepartner.

Overcoming Barriers to Collaboration

We propose five recommendations to propagate equitable community-engaged collaborations between researchers and people living with ADRD. The overarching theme of our recommendations is that a collaborative model must allow for and incorporate the differing abilities of people living with ADRD at all stages and also empower people living with

ADRD to engage with the research process by defining their own role and terms of participation. This stands in contrast to typical hierarchical research power structures which ultimately highlight the inabilities of people living with ADRD.

Recommendation 1: Recurring and Flexible Meeting/Communication Format

Engagement of people living with ADRD should be maximized by a schedule of recurring meetings or formalized communications occurring over an extended period of time. This ensures that relationships can be nurtured to develop mutual respect and allow for shorter duration of contact to avoid fatigue. Further, the composition of participants can fluctuate over time. Ideally, researchers and facilitators would be present at all events, but people living with ADRD would be assured that there would be no negative consequences if they are unable to participate at times. This accommodation reflects the variability of ADRD symptoms and that some individuals may feel uncomfortable participating in group activities on a "bad day." Flexible attendance/participation also allows individuals with more advanced symptoms to continue participating and contribute insight from a rarely included perspective. The goal would be to build a group of collective, fluctuating, and diverse voices in which each individual can enter and exit as they prefer in accordance with their evolving cognitive abilities.

We developed this guideline based on the success of breakout groups at the EP workshop; breakout groups met twice during the course of the two-day workshop for two hr and about 85 min. Participants were empowered to "take a break when the group wants" to mitigate possible fatigue. This guideline creates a mechanism for participants to set their own terms for degree of participation, which differs from typical IRB protocols that are limited to notifying participants they may choose to stop participating at any time.

Recommendation 2: Share Communication Strategies

Space should be created for people living with ADRD to continually share their strategies or experiences that have helped alleviate communication issues in the past. This will help raise their voices in the collaboration and provide an opportunity to share strategies with their peers to maximize the abilities of all collaborators. Researchers would also learn how to improve their interactions with their ADRD-diagnosed partners.

Although this general advice provides a valuable starting point, guidelines should be customized for each research team. For example, if a team member is experiencing hearing loss it may be necessary to consider additional accommodations such as visual aids or audio equipment; in studies with online meetings, it is important to consider ways to support equitable access to technology.

The EP workshop incorporated a nascent version of this guideline by asking people living with ADRD to recommend rules or guidelines to improve communication. The following are communication guidelines suggested by participants of the EP workshop:

1) Empower the person living with ADRD to respond first.
2) Resist the urge to speak on behalf of people living with ADRD.
3) Give people living with ADRD extra time to process and respond to questions (20–90 s).
4) Avoid side conversations when someone is speaking.
5) Speak clearly and project one's voice.
6) Pay attention to the speed with which one speaks.

Many of these recommendations were similar to common support group rules (Herrmann et al., 2019), broadly focused on fostering a quiet, attentive, and patient environment to help people living with ADRD feel comfortable offering their input.

Recommendation 3: Frame Lived Experiences as Research Contributions

Foremost attention should be paid to the lived experiences of people living with ADRD. Many people living with ADRD will not have a research idea prepared prior to collaboration but do hold the unique knowledge of what it feels like to be diagnosed with ADRD and the unparalleled capacity to generate knowledge that could enhance their quality of life. Emphasizing the value of their experiences provides an opportunity for researchers to document unique perspectives and will hopefully alleviate the concerns of people living with ADRD that their voices are not valued in this context. This guideline creates mutual benefit for community partners and researchers by guaranteeing that projects will be directly relevant to people living with ADRD, the primary stakeholders in ADRD research. It also diversifies the scope of potential research projects by drawing in perspectives that are not often considered while developing projects.

This principle was reflected in the EP workshop breakout groups; people living with ADRD and informal carepartners highlighted research priorities directly applicable to their past experiences. These topics included simplification of clinical trial informed consent to help set realistic expectations, evaluation of the impact of social activities on well-being of people living with ADRD, and mechanisms for reducing perceptions of stigma.

Recommendation 4: Incorporate People Living With ADRD in All Stages of Research

CBPR best practices dictate that community stakeholders play a role in all parts of the research process, including the initial design. We observed success with this principle at the EP workshop in two ways. First, people living with ADRD were consulted prior to the workshop and played a role in forming the agenda. This ensured an inclusive structure to the proceedings (e.g., brainstorming of communication strategies, emphasis that breaks are okay during breakout groups). Second, during the breakout groups people living with ADRD had a voice in determining which topics would be considered for developing mock research proposals. One person living with ADRD was a persistent advocate for this principle—asking researchers at both the EP workshop and in subsequent communication if a person living with ADRD had been consulted any time a past finding was mentioned. In short, securing buy-in before research discussion started fomented lively discussion and high engagement from all parties involved. Researchers should carry this principle forward to future projects.

Recommendation 5: Importance of Skilled Facilitators

Each research team should incorporate skilled facilitators as partners; at least one of the facilitators should be a person living with ADRD or, if nobody living with ADRD wishes to be a facilitator, someone who has experience working and interacting with people living with ADRD. Further, skilled facilitators can encourage a horizontal power structure by drawing out the abilities of people living with ADRD, rather than allowing a default set-up of the researcher making most decisions and then asking people living with ADRD for approval/input after the fact.

Skilled facilitators should be responsible for managing the ADRD-specific accommodations made by each team. Our first suggested guideline—allowances for flexible attendance/participation—necessitates that regular updates are sent to all team members to keep everyone abreast of continued progress. An example of this collaborative communication might include keeping written notes and taking photos that can be disseminated to all members for feedback. Facilitators could also schedule a personal phone call with participants who prefer verbal updates or arrange optional supplemental sessions focused purely on repeating progress from previous interactions. Making formalized progress updates available for all members has a secondary effect of creating a record that people living with ADRD can access at any time to help mitigate the effects of memory impairment. Facilitators can also ensure communication ground rules developed by the team are respected during all interactions, helping people living with ADRD feel more included. Lastly, facilitators can also draw out and validate the experiences and feelings of people living with ADRD by prioritizing them in group discussions and creating space for people living with ADRD to share.

The authors concluded that including a skilled facilitator as a team member is necessary after reflecting on our experiences at the EP workshop for two reasons: (a) the authors drew on past experiences working with people living with ADRD during the breakout groups to facilitate productive conversation; it should not be assumed that all researchers will have this level of experience/comfort interacting with people living with ADRD—a facilitator will enable researchers with varying past experience to participate, and (b) traditional research does not incorporate the other suggested recommendations thus there is no existing mechanism to facilitate implementation. A facilitator can fill that gap.

Possible Benefits and Future Directions

Key hallmarks of ADRD include memory loss and behavioral symptoms that wax and wane. These symptoms, and changes in symptoms, would be significant impediments in traditional research design. But the proposed community-engaged framework can be used to incorporate the voices of people living with ADRD. Specifically, the suggested guidelines will allow for people at all stages of ADRD to participate, in contrast to other research that screens/vets people living with ADRD—usually resulting in only people in the early stages being involved. A more diverse team of partners will be able to offer greater insight into what questions and topics people living with ADRD prioritize for investigation at all stages. This mindset could also extend to carepartners of people living with ADRD, helping to create more holistic conversations and encourage inclusivity (Dilworth-Anderson et al., 2020).

In the spirit of CBPR principles, Recommendation 2—open sharing of communication strategies—draws on the past experiences of the community (i.e., people living with ADRD and their informal carepartners) to simultaneously encourage mutual sharing of ideas while also promoting a research agenda that responds directly to the needs of the community. Sharing communication strategies has a secondary benefit of providing opportunities for individuals at different stages of ADRD to teach and learn from their peers, providing an immediate benefit for the community collaborators.

Prior to the workshop, EP participants living with ADRD reported trepidation about engaging in academic research based on poor prior experiences and a general lack of knowledge about the specifics of research design. These sentiments reflect the “recruitment crisis” in ADRD research (Bartlett et al., 2019; Fargo et al., 2016). CBPR principles have been leveraged to improve research participation in other health-related fields (Greiner et al., 2014; McElfish et al., 2018; Skinner et al., 2015). The proposed framework may have similar benefits for ADRD research by improving stakeholder engagement.

Encouragingly, our conclusions broadly align with Frank et al. (2020) who note that people living with ADRD attributed positive experiences in conference planning to group-led governance, personal interactions with researchers, and opportunities to discuss personal experiences with other people living with ADRD, despite initial trepidation about their ability to meaningfully contribute to the proceedings.

It is important to note that there is nothing particularly unique about the accommodations required to give people living with ADRD a seat at the table. Similar principles must be considered when collaborating on research involving mental illness, substance abuse, and other diagnoses. This raises questions of why people living with ADRD have rarely been as involved in previous collaborations. It is particularly interesting that one of the breakout groups from the EP meeting concluded that researching ways to reduce stigma is a high priority for people living with ADRD. Our proposed guidelines focus on what each person *can* do and not what they *cannot* do, implicitly pushing back against ADRD stigma that devalues the personhood of people living with ADRD. Approaching research in a collaborative and egalitarian manner may help people living with ADRD feel less stigmatized by conveying cultural value to their experiences.

Limitations

A limitation of this work is that it has not been applied across a diversity of regions and populations. Many communities that are generally underrepresented in research are also underrepresented in ADRD research (e.g., racial/ethnic minorities; Chin et al., 2011). Researchers must work to ensure that these methodologies engage underrepresented communities rather than relying on existing research networks. A strength of our approach is that it fully incorporates the priorities of people living with ADRD which will add new perspectives to research design *and ensure the relevance of the findings to the target population*. Further, by explicitly looking to break down existing power structures via the centering of lived experiences of people living with ADRD, our guidelines offer opportunities for improved outreach with historically marginalized communities.

There is no guarantee that our recommendations will fit perfectly in all contexts. For example, the move toward a less hierarchical, collaborative research team is made in direct response to feelings that the voices of people living with ADRD have not been fully considered in research and in response to feelings of stigma. If community partners have not participated in prior research or feel less stigmatized they may prefer that scientists take a leading role in developing protocols.

Similarly, although it is laudable to incorporate people living with ADRD at all stages, it is possible that too much heterogeneity in cognitive impairment may impede the ability of facilitators to find an appropriate rhythm for research activity in terms of both length/frequency of sessions and amount of time dedicated to orienting all team members to the current state of the project. A possible mitigation technique would be involving community members with like diagnoses.

Our recommendations are largely grounded in CBPR. CBPR sits at one end of the community-engaged research spectrum, emphasizing flexibility that allows for customization to best facilitate full equality in both decision-making and ownership (Key et al., 2019; Sullivan & Siqueira, 2010). Scientists should not feel beholden to a CBPR model if the collaborative levels of other community-engaged methodologies are more appropriate. The overall goal of including people living with ADRD as collaborators should not be sacrificed in pursuit of a project that perfectly adheres to CBPR principles.

For some researchers, the extended time needed to meet CBPR ideals may be in tension with career progress. Funding applications should be realistic about the extended timeline that may be necessary, and these projects may require financial support from established centers or foundations that are not reliant on specific grants. Scholars should also consider the long-term benefits of CBPR that help offset up-front commitments. A well-run CBPR team will likely improve recruitment procedures which, in turn, removes a significant burden from the researcher. Alternatively, scholars with a more compressed research timeline may consider shorter-term CBPR methods currently being developed (Radonic et al., 2023).

Conclusion

Our proposed recommendations are intended to foster more inclusive ADRD research collaborations, ensuring that people with a wider range of ADRD symptoms feel empowered to share their perspectives. This approach has the long-term benefit of strengthening research by centering priorities on those most affected ADRD. We hope to remind other scientists that ADRD stigma cuts both ways; even researchers are excluded from opportunities that may positively affect their own personal journeys when they do not listen to the voices of people living with ADRD. Our suggestions should be viewed as a starting point encouraging more nuanced discussion that helps advocate for mutually beneficial progress toward improved life experiences for people living with ADRD. As others leverage the flexibility of community-engaged methods to build upon our ideas, we suggest starting with a simple question: Has anyone living with ADRD been consulted?

Supplementary Material

Supplementary data are available at *The Gerontologist* online.

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Conflict of Interest

None declared.

Data Availability

We cannot make all notes and communication from this project available to other researchers given that a portion of our methodology—participant observation—is based on self-reflection and also because many of our notes/documents include personal information. We do offer, however, to answer any specific questions from other researchers about our process, either in writing or verbally. This project was not pre-registered.

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Author Contributions

E. E. Griffith contributed data collection and analysis, drafting of the manuscript, and final approval of the manuscript. M. Lepore and J. K. Monin contributed to the design of the work, data collection and analysis, critical revision of the manuscript for intellectual content, and final approval of the manuscript.

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