RESEARCH ARTICLE



Using concept mapping to identify recruitment and engagement strategies for inclusion of LGBTQIA+ populations in Alzheimer's disease and related dementia research

Brittany Klenczar-Castro¹ | Krystal R. Kittle² | Joel G. Anderson³ | Whitney Wharton⁴ | Andrea Gilmore-Bykovskyi⁵ | N. Maritza Dowling⁶ | Jaime Perales-Puchalt⁷ | Jason D. Flatt¹

¹Department of Social and Behavioral Health, School of Public Health, University of Nevada, Las Vegas, Nevada, USA

²Department of Health Promotion and Policy, School of Public Health & Health Sciences, University of Massachusetts Amherst, Amherst, Massachusetts, USA

³College of Nursing, University of Tennessee, Knoxville, Tennessee, USA

⁴Nell Hodgson Woodruff School of Nursing, Emory University, Atlanta, Georgia, USA

⁵Berbee Walsh Department of Emergency Medicine, School of Medicine and Public Health, University of Wisconsin-Madison, Madison, Wisconsin, USA

⁶School of Nursing, The George Washington University, Washington, District of Columbia, USA

⁷Department of Neurology, University of Kansas Alzheimer's Disease Research Center, Kansas City, Kansas, USA

Correspondence

Jason D. Flatt, Department of Social & Behavioral Health, School of Public Health, University of Nevada, Las Vegas, 4700 S. Maryland Parkway, Las Vegas, NV 89119, USA. Email: Jason.Flatt@unlv.edu

Funding information

National Institute on Aging; National Institutes of Health; Alzheimer's Association, Grant/Award Number: AARGD-22-929144

Abstract

INTRODUCTION: Past Alzheimer's disease and related dementias (ADRD) research has not considered ways to ensure the representation of diverse sexual and gender minorities. This study used concept mapping (CM) to identify strategies for engaging and recruiting LGBTQIA+ older adults living with memory loss and their caregivers into ADRD research.

METHODS: CM, involving brainstorming, thematic analysis, and rating of strategies, was conducted with 46 members from one national and three local community advisory boards. Data was analyzed using The Concept Systems Global MAX[™] web platform.

RESULTS: One hundred twenty-two solutions were identified from June through December 2022, and represented five key themes: aging focused, LGBTQIA+ specific, memory loss and caregiving support focused, physical advertisements, and other media. Promising strategies included partnering with LGBTQIA+ health centers, attending social groups for older adults, and increasing community representation in marketing.

DISCUSSION: Tailored strategies, building trust, and community involvement are essential for engaging LGBTQIA+ individuals living with memory loss or ADRD and their caregivers in ADRD-focused research.

KEYWORDS

Alzheimer's disease, concept mapping, LGBTQIA+, recruitment science

Highlights

Innovative ways to ensure the inclusion of LGBTQIA+ older adults in Alzheimer's disease and related dementias (ADRD) research can be bolstered through collaboration with key community stakeholders.

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

© 2024 The Author(s). Alzheimer's & Dementia: Translational Research & Clinical Interventions published by Wiley Periodicals LLC on behalf of Alzheimer's Association.

·

- Promising strategies for recruitment and engagement include partnering with LGBTQIA+ centers, attending social groups for older adults, and ensuring diverse representation in marketing.
- Tailored recruitment and engagement strategies are crucial for building trust with LGBTQIA+ populations to increase participation in ADRD research.

1 | BACKGROUND

It is evident that sexual and gender minorities are a growing segment of the aging population as it is estimated that by 2030, there will be nearly six million adults aged > 50 in the United States who identify as lesbian, gay, bisexual, transgender, queer, intersex, asexual, and/or additional identities (LGBTQIA+).¹ Age is the greatest known risk factor associated with the onset of Alzheimer's disease and related dementias (ADRD).² In addition to the risk that aging poses for a person, those who identify as LGBTQIA+ often experience several health disparities, including structural-, interpersonal-, and institutional-level discrimination, associated with the onset of ADRD. These include higher rates of depression, cardiovascular disease, human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS), obesity, alcohol and tobacco usage, and lower rates of preventive screenings for tests such as mammograms, pap tests, and prostate exams.¹ There are also disparities seen for health problems associated with ADRD within the LGBTQIA+ community, such as transgender and/or gender-diverse adults often facing higher rates of discrimination and victimization and greater disparities in depression, tobacco usage, heavy drinking, and cardiovascular disease.³

Moreover, many individuals within the LGBTQIA+ community often face difficulties in accessing care due to fears of discrimination, financial limitations, smaller support networks, social isolation, and stigma.^{4,5} Other lived experiences including incongruence between sex and gender have also been associated with dementia risk.⁶ Previous research has cited that LGBTQIA+ adults are 29% more likely to report subjective cognitive decline or memory problems getting worse over the past year than their cisgender (not transgender) and heterosexual counterparts.^{3,5} This is a significant finding as research suggests that subjective cognitive decline may be associated with future cognitive impairment.^{5,7} There are also system-level disparities seen within the LGBTQIA+ community as transgender and/or gender-diverse adults are often reluctant to seek out preventative care due to past discrimination but experience greater health challenges.⁸ Moreover, a recent study found that nearly 20% of transgender Medicare beneficaries aged \geq 65 had a diagnosis of dementia compared to up to 13% for cisgender older adults.⁹

More than 11 million caregivers in the United States provide informal care to someone living with ADRD, and this care is frequently associated with mental, physical, social, and financial challenges.^{7,10} Research rarely considers LGBTQIA+ caregivers of people living with ADRD.¹¹ Recent research has found that LGBTQIA+ caregivers of people living with ADRD face structural-, interpersonal-, and institutionallevel sources of discrimination and unique challenges with perceived stress, experience discrimination and stigma when accessing support services, and experience microaggressions that were associated with worse quality of life and greater depressive symptoms.¹¹

There is limited past research that has explored ways to recruit and engage LGBTQIA+ persons living with ADRD and LGBTQIA+ caregivers of people living with ADRD in research. A recent study with LGBTQIA+ persons living with ADRD and their caregivers highlighted the need for multifaceted approaches, such as direct referrals,¹² and presentations to community agencies, flyers, and social media.¹³ However, the majority of research has not described or determined effective ways to recruit and engage LGBTQIA+ older adults with memory loss/ADRD and their caregivers in ADRD research.

Despite increased risk factors for ADRD among LGBTQIA+ older adults and challenges faced by LGBTQIA+ ADRD caregivers, research often does not address intersectionality or the complex and interconnected social identities of individuals, such as race/ethnicity, class, gender, sexual orientation, ability, and additional diverse aspects of identity. The concept of intersectionality highlights how these identities can result in an additive or synergistic effect, creating unique experiences of discrimination and/or privilege for individuals who belong to multiple marginalized groups.¹⁴ One's identity can affect both one's exposure to risk factors for ADRD and/or one's experiences as a caregiver. It is essential to address the LGBTQIA+ communities' experiences with ADRD by incorporating their voices and experiences into research. The underrepresentation of LGBTQIA+ people living with ADRD and their caregivers in research continues to limit researchers' understanding of how ADRD impacts the community, hindering the development of targeted interventions, welcoming support services, and policies that are inclusive and effective for this population.

To bolster research participation, the research teams at the University of Nevada, Las Vegas; Emory University; and the University of Tennessee Knoxville created the first federally funded research registry (NIH R24AG06659) for LGBTQIA+ communities impacted by ADRD. The Research Inclusion Supports Equity ("RISE") Registry aims to create a network of LGBTQIA+ individuals in ADRD research through community-focused, inclusive approaches to research engagement, recruitment, and support of caregivers and people living with memory loss/ADRD. RISE serves to establish a national, integrated network of LGBTQIA+ people living with memory concerns/ADRD, or LGBTQIA+ caregivers to someone with memory concerns/ADRD, that

RESEARCH IN CONTEXT

Systematic review: The literature demonstrates that lesbian, gay, bisexual, transgender, queer, intersex, asexual, and additional identity (LGBTQIA+) populations are underrepresented in Alzheimer's disease and related dementias (ADRD) research. Recruiting and engaging this underrepresented population in research will help to ensure that diagnosis, treatment, and supportive services are welcoming for all persons with ADRD and their caregivers.

Interpretation: This study used concept mapping (CM), a participatory process involving brainstorming, thematic analysis, and ratings, with one national and three local community advisory boards (N = 46). Five themes (aging focused, LGBTQIA+ specific, memory loss and caregiving support focused, physical advertisements, and other media) were derived from 122 solutions. Promising strategies included partnering with LGBTQIA+ centers, attending social groups for older adults, and ensuring diverse representation in marketing.

Future directions: Tailored recruitment and engagement strategies and community involvement are crucial in ADRD research with LGBTQIA+ populations. Targeting agencies, organizations, and social groups catering to their needs could enhance representation.

offers opportunities to participate in research to ensure LGBTQIA+ people are represented in research findings and efforts to identify effective treatments.

The purpose of this study was to identify ways to recruit and engage LGBTQIA+ older adults with memory loss/ADRD and their caregivers in ADRD research by using concept mapping (CM) with key representatives who possess relevant expertise to generate potential strategies for recruiting and engaging LGBTQIA+ older adults living with memory loss/ADRD and their caregivers to participate in the RISE Research Registry and future ADRD-related research.

2 | METHODS

2.1 Study population

As part of a community-based participatory research approach to establishing the RISE Registry, we engaged three local community advisory boards (Las Vegas, Nevada; Atlanta, Georgia; and Knoxville, Tennessee) and one national community advisory board in the CM process online during our quarterly community advisory board meetings, which took place remotely via Webex or Zoom. Advisory board members were purposively selected by the principal investigators and/or nominated by previously invited advisory board members based on their expertise in LGBTQIA+ aging health, lived experiences as an ADRD caregiver, and/or ADRD. Advisory boards were composed of non-profit leaders, researchers, caregivers, and LGBTQIA+ community members including current and past LGBTQIA+ ADRD caregivers. They were then formally invited to join the board through a personalized invitation letter during the writing of the grant proposal. The invitation included details about the board's purpose, expectations, meeting schedule, honoraria, and any other relevant information. After notice of funding, community advisors were then contacted and given background information that outlined the board's purpose, objectives, expected contributions from advisory board members, meeting frequency, and annual \$1000 honoraria for their time and contributions. These aspects were clarified to ensure that potential members understood expectations and to assess their willingness to commit.

2.2 Study design

CM software from the Concept Systems Global MAX[™] web platform was used to engage advisory board members virtually during our quarterly advisory board meetings to identify ways to engage, recruit, and include LGBTQIA+ individuals in ADRD research. CM also was used to develop a more comprehensive understanding of the complexities of ADRD recruitment and ongoing engagement of the LGBTQIA+ community, so that researchers could consider best practices when recruiting diverse populations for ADRD research. CM is a mixedmethod participatory approach that uses an exploratory sequential approach in which gualitative data precedes the collection of guantitative data.^{15,16} We conducted the CM over two different advisory board meetings. The CM process involved three key phases: brainstorming, thematic analysis, and rating of solutions by level of importance of strategies (Figure 1). Advisory board members participated in all phases of the CM process. However, the research team used the CM software to create the CM after the two advisory board meetings and then presented the findings in a third meeting to refine the CM and obtain consensus on the final CM and key themes. All data were collected between June and December 2022 and the research activities were approved by the University of Nevada Las Vegas Institutional Review Board.

2.3 Measures

In addition to completion of three key phases of the CM process, participants were asked to complete two background questions developed by the research team: "Have you ever provided care to an LGBTQIA+ person experiencing memory loss/ADRD?" (Response options: yes, no, or don't know); and their area of expertise related to their role on the RISE advisory board including caregiving, ADRD or memory loss, long-term care, aging, LGBTQIA+ populations, and additional expertise areas, with an option to select all that apply.

For the brainstorming phase, advisory board members were asked a focus prompt, "What are some potential ways that we could recruit

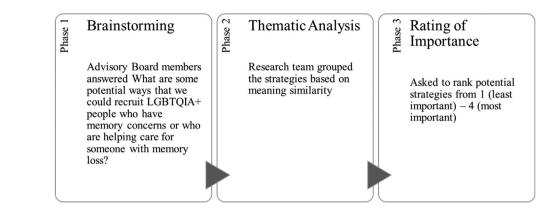


FIGURE 1 Concept mapping process.

LGBTQIA+ people who have memory concerns or who are helping care for someone with memory loss/ADRD?" to generate potential solutions. Advisory board members were asked to write a single-thought solution in response to the focus prompt but could enter multiple solutions during the brainstorming phase.

Next, the list of solutions generated from the brainstorming session was edited for grammar, multiple solutions in a submitted statement were split into separate solutions, and duplicate solutions were deleted. For the thematic analysis phase, members of our team facilitated discussions and then grouped the solutions based on similarity in meaning and named each group of solutions based on a common theme or contents. We aimed to develop 5 to 10 thematic groups from the list of solutions based on past research and guidance from the CM software.¹⁵⁻²⁰

For the rating of solutions, participants were asked to rank each solution by the level of importance from 1 (not at all important) to 4 (extremely important) in terms of how important each solution was for recruiting LGBTQIA+ people who have memory loss/ADRD or LGBTQIA+ caregivers of persons with memory loss/ADRD to participate in ADRD research. After this phase, each of the four advisory boards debriefed about the process, reactions to the findings, phases, and final CMs. This resulted in further refinement of the final thematic groups and a CM based on advisory board members' overall impressions. This process was used to ensure the trustworthiness and credibility of the data analyses, ensure saturation of thematic analysis, as well as ensure findings reflected advisory board members' perspectives and expertise.

2.4 | Statistical analysis

We used the Concept Systems Global MAXTM web platform to conduct the three-step data analysis.²¹ First, the software assisted with sorting the data and creating a similarity matrix of size *n*-by-*n*, with *n* representing the number of ideas. Next, the software used two statistical approaches to produce the CM: (1) a two-dimensional non-metric multidimensional scaling analysis²² of the similarity matrix was conducted to determine how each solution fell into a two-dimensional (X, Y) "point map," and (2) a hierarchical cluster analysis²³ to group the **TABLE 1** Characteristics of advisory board members and areas of expertise represented in brainstorming discussion (N = 46).

Characteristics	N	Percentage
Background/expertise		
Caregiver for LGBTQIA+ person with memory loss/ADRD	15	32.61
LGBTQIA+ populations	37	80.43
Aging	27	58.70
Dementia, Alzheimer's disease, memory loss, etc.	23	50.00
Caregiving	21	45.65
Long-term care	8	17.39
Other	1	2.17

Note: Participants could select more than one area of expertise. Abbreviation: ADRD, Alzheimer's disease and related dementias.

list of ideas into clusters of related statements or "cluster maps," which was used to create the final CM. The software also computed a mean level of importance for each statement. Next, we examined the cluster maps and compared how many clusters best reflected the main thematic areas. Iterative review and discussion with advisory boards were then used to develop a final CM that provided the most useful details, in which ideas fell together in the most logical way and in line with the advisory board members' expertise. This iterative process was used to identify the most promising engagement and recruitment strategies for LGBTQIA+ people living with memory loss/ADRD and LGBTQIA+ caregivers of persons with memory loss/ADRD to increase participation in ADRD research.

3 | RESULTS

A demographic breakdown of advisory board members' expertise can be found in Table 1. The advisory board members (N = 46) included LGBTQIA+ ADRD caregivers (n = 15, 33%), and/or professionals with overall expertise in LGBTQIA+ populations (n = 37, 80%), aging (n = 27,59%), ADRD (50%), caregiving (46%), and/or long-term care (17%).

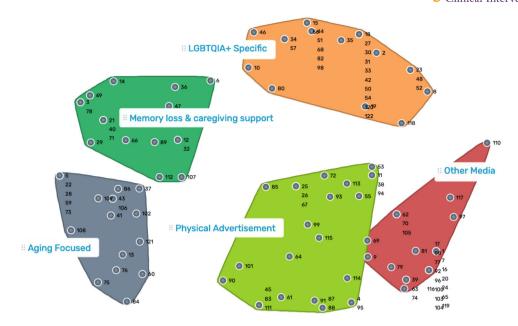


FIGURE 2 Concept map with thematic areas and solutions.

3.1 | Brainstorming and concept map

The brainstorming sessions generated a total of 122 solutions provided by advisory board members. A full list of all the statements can be found in Appendix SA in supporting information.

In terms of findings from thematic analyses, there were five key themes (Figure 2), which included aging focused, LGBTQIA+ specific, memory loss and caregiving support focused, physical advertisements, and other media. Aging focused recruitment methods represented targeting agencies and organizations that provide social and health services to older adults; LGBTQIA+ specific methods represented places, groups, or organizations that openly welcome members of the LGBTQIA+ community and focused on the unique needs of this population. For the memory loss and caregiving support theme, solutions focused on recruitment methods that targeted both people living with memory loss/ADRD and those providing care to them. The final themes focused on advertisements and were divided into physical advertisements and other media. Physical advertisements included in-person efforts such as partnering with community organizations at in-person events and providing community presentations, advertising in magazine or newspaper ads, billboards, posters, flyers, and direct mailings while other media included advertisements displayed through technological media such as television, social media, radio, podcasts, and search engine ads.

3.2 | Importance

Mean scores represented the average ratings by advisory board members for the 122 solutions, rated from 1 (not at all important) to 4 (extremely important). As displayed in Table 2, the top five overall strategies by importance included: (1) recruiting through LGBTQIA+

TABLE 2	Ten most important recruitment strategies organized by
mean score r	ating.

Most cited outreach solutions	Mean (SD)	Thematic area
1. LGBTQ+ health centers	3.76 (0.43)	LGBTIQA+ focused
2. Partnering with the local Alzheimer's Association chapters for LGBTQ+ forums	3.76 (0.51)	LGBTIQA+ focused
3. LGBTQ+ social groups for older adults	3.72 (0.45)	LGBTIQA+ focused
4. Information sessions at LGBTQ+ centers	3.67 (0.67)	LGBTIQA+ focused
5. Marketing that shows diverse community representation	3.56 (0.64)	Other media
6. Working with LGBTQ+ senior housing locations	3.54 (0.64)	LGBTIQA+ Focused
7. LGBTQ+ caregiver center	3.52 (0.75)	LGBTIQA+ Focused
8. Calling all LGBTQ+ centers and advertising via their groups and newsletters	3.52 (0.75)	LGBTIQA+ Focused
9. Connect with LGBTQ+ health providers	3.48 (0.81)	LGBTIQA+ Focused
10. Alzheimer's Association caregiver support groups	3.48 (0.50)	Memory Loss & Caregiving Support

Abbreviation: SD, standard deviation.

health centers (mean = 3.76), (2) partnering with the local Alzheimer's Association chapters (mean = 3.76), (3) attending LGBTQIA+ social groups for older adults (mean = 3.72), (4) providing information sessions at LGBTQIA+ centers (mean = 3.67), and (5) marketing that

TABLE 3 Most important recruitment strategies by thematic area.

Outreach solutions	Mean score (SD)	Thematic area
1. Having a visible presence at memory loss or memory concern clinics within local institutions	3.33 (0.75)	Aging focused
2. Workshops for folks working directly with elder patients	3.24 (0.91)	Aging focused
3. Memory care units at Assisted Living	3.22 (0.78)	Aging focused
4. Mental health/wellness providers	3.2 (0.75)	Aging focused
5. Partnering with home care services	3.15 (0.91)	Aging focused
1. LGBTQ health centers	3.76 (0.51)	LGBTQIA+ specific
2. Partnering with the local Alzheimer's Association chapters for LGBTQ+ forums	3.72 (0.45)	LGBTQIA+ specific
3. LGBTQ social groups for older adults	3.67 (0.67)	LGBTQIA+ specific
4. Information sessions at LGBTQIA+ centers	3.54 (0.64)	LGBTQIA+ specific
5. Working with LGBTQ+ senior housing locations	3.52 (0.75)	LGBTQIA+ specific
1. Alzheimer's Association caregiver support groups	3.48 (0.49)	Memory loss & caregiving support
2. Caregiver support programs	3.42 (0.57)	Memory loss & caregiving support
3. Alzheimer's Association affinity groups	3.38 (0.79)	Memory loss & caregiving support
4. Partnering with aging organizations	3.37 (0.62)	Memory loss & caregiving support
5. Partnering with senior day care facilities	3.28 (0.72)	Memory loss & caregiving support
1. Marketing that shows diverse community representation	3.56 (0.64)	Other media
2. Recruit through Facebook pages geared toward LGBTQIA+/cognitive impairments/dementia/Alzheimer's	3.36 (0.79)	Other media
3. Spanish media	3.35 (0.63)	Other media
4. Ask current participants to share with their networks	3.33 (0.79)	Other media
5. Make sure to advertise/network outside of social media for those who do not have it	3.28 (0.83)	Other media
1. Support groups	3.15 (0.80)	Physical advertisement
2. Affirming faith communities	3.12 (0.59)	Physical advertisement
3. Having free health care information and brief health screenings at Pride events	3.12 (0.71)	Physical advertisement
4. Partnering with Meals on Wheels programs	3.08 (0.82)	Physical advertisement
5. Conduct presentations at atypical places in rural areas that are largely invisible	3.04 (0.87)	Physical advertisement

Abbreviation: SD, standard deviation.

shows community representation (mean = 3.56). Additionally, the five most important recruitment strategies by thematic area are displayed in Table 3.

4 DISCUSSION

By using CM with community advisory board members with diverse expertise in LGBTQIA+ populations, aging, ADRD, and caregiving, we identified five promising areas (aging focused, LGBTQIA+ specific, memory loss and caregiving support focused, physical advertisements, and other media) for engaging and recruiting LGBTQIA+ older adults experiencing memory loss/ADRD and their caregivers to participate in ADRD research. Some promising recruitment strategies to consider included recruiting and partnering with LGBTQIA+-related centers and providing information sessions, partnering with the local Alzheimer's Association chapters, attending LGBTQIA+ social groups for older adults, and using marketing that is tailored and ensures diverse community representation.

Similar to an intervention study, Innovations in Dementia Empowerment and Action (IDEA), conducted with LGBTQIA+ persons living with subjective cognitive decline and their caregivers that highlighted the need for multifaceted approaches, we identified that partnership with community agencies and the use of physical advertisements and social media hold promise for recruitment.^{12,13} However, additional efforts focused on leveraging memory loss and caregiving support groups may also hold promise for recruitment and engagement of LGBTQIA+ persons living with memory loss/ADRD and their caregivers into ADRD research.

The inclusion of LGBTQIA+ individuals into ADRD research is of paramount importance as indicated by previous research citing the importance of inclusion of this population in research to formulate a stronger understanding of the various ways marginalization has impacted their health, ADRD risk, and ways to promote and improve

Translational Research **7 of 9**

care for everyone.²⁴ It is clear that it is crucial and urgent to address the disparities and challenges faced by marginalized communities as health disparities are longstanding and continue to impact these communities' risk for ADRD into older age. It also is important to note the ways in which intersectionality plays a significant role in shaping experiences and challenges. For instance, LGBTQIA+ adults may face discrimination not only based on their sexual orientation and/or gender identity but also related to their age, race/ethnicity, socioeconomic status, HIV status, and/or ability. These multiple social identities can be sources of discrimination and marginalization that can exacerbate barriers related to health-care access, social support, and economic stability. These barriers can make caring for someone with ADRD or experiencing memory loss even more challenging due to health and social inequities, hesitancy to access care, social isolation, and lack of legal protections.

The efforts conducted during the CM activity aim to pave the way for more targeted and sensitive care approaches for future ADRD research. The RISE Registry provides not only an opportunity for researchers to connect with registrants who are LGBTQIA+ caregivers and people living with memory loss/ADRD but also the possibility to access tailored recruitment strategies and assess their effectiveness.

A noteworthy finding of the CM activity was the emphasis on the importance of identifying LGBTQIA+ community-specific organizations to engage this population in ADRD research. The significance of using LGBTQIA+ organizations for recruitment extends beyond this study as prior research has highlighted the importance of targeting community-specific and affirming resources as a means to recruit and engage hard-to-reach and underrepresented populations. For example, by targeting LGBTQIA+ community organizations to recruit older adults, one study was able to obtain a 70% response rate to their survey.²⁵ By engaging with organizations and agencies that LGBTQIA+ people trust, there may be unique opportunities to engage LGBTQIA+ people with memory loss/ADRD and their caregivers in ADRD research. Additionally, partnership with community organizations can help researchers mitigate the distrust often felt by marginalized members of the LGBTQIA+ community including racial/ethnic minorities, people from lower socioeconomic backgrounds, transgender older adults, persons aging with HIV/AIDS, those in rural communities, and those with intersectional backgrounds. Moreover, LGBTQIA+ people have cited community and interpersonal connections as an effective recruitment strategy.²⁶ Additionally, the incorporation of marketing strategies and communication that represent intersectional identities of those who are often not included in research may promote more trust among diverse and underrepresented LGBTQIA+ groups.²⁷

Another important method of recruitment may involve tapping into social groups for LGBTQIA+ older adults to ensure interpersonal connections and aging supports are considered. Research has described the benefits of using social networks as it can allow interactions with participants who are not involved in support groups or have not actively disclosed their identity and may otherwise choose to ignore research advertisements that recruit LGBTQIA+ people.²⁸ This recruitment method may also be useful when reaching small subgroups of an already underrepresented population, though it should be

noted that there are risks of biases when tapping into smaller social networks or using snowball sampling techniques as these groups may not be representative of the general LGBTQIA+ aging population.²⁹ This may limit the generalizability of your study findings as this particular subset of individuals may not represent the broader LGBTQIA+ community. Additionally, it should be noted that because snowball sampling relies on social ties, referrals and networks, and word of mouth for recruitment, the data obtained may be less representative of those with diverse backgrounds and experiences, as well as those who are unwilling to participate in the research. Additionally, we may not be able to reach those who are socially isolated, possess more distrust of the scientific community, or who are hesitant to use available resources, which could lead to gaps in understanding of experiences. While our study used snowball sampling in terms of recruitment of advisory board members to promote the inclusion of LGBTQIA+ older adults impacted by ADRD, it required us to prioritize inclusivity over the representativeness of the data and related findings from this study.

Responses obtained from the advisory board members also suggested using caregiver-focused organizations or support groups as a useful recruitment method. However, prior research has cited challenges with this recruitment strategy as it has proven to be cumbersome due to the time and resources required to build trust and offer support to diverse caregivers.³⁰ Furthermore, it can be difficult to ensure those disseminating the information within the caregiving agencies have a firm understanding of the research project, can prioritize promoting the study while providing needed support to caregivers, and that support group facilitators are convinced it will be beneficial to the caregivers they serve. Future research seeking to use caregiver support groups in promoting diverse representation in ADRD research should consider partnerships that provide mutual support and resources, account for the time it takes for research teams to build rapport and trust with the staff within these caregiver organizations and support group members, and gain entrée to recruit and engage with LGBTQIA+ caregivers of persons with ADRD.

The importance of using physical and online advertisement materials to recruit LGBTQIA+ individuals in research has been echoed and shown to be effective in prior studies. Researchers who used the Every Door Direct Mail (EDDM) program, by the US Postal Service as well as Google and Facebook advertisements to obtain survey data from rural LGBTQIA+ residents with a 62% response rate.³¹ However, while this study demonstrates the effectiveness of online and physical advertisements, there was less participation from LGBTQIA+ older adults, with 85% of respondents being between 21 and 40 years old. Due to the large number of rural residing LGBTQIA+ community members (15%-20% of the LGBTQIA+ community or 3+ million),³² future research should consider tailoring advertising methods to promote their representation in ADRD research.

By ensuring representation through the use of the recruitment methods identified above, we can gain a more comprehensive understanding of the impact of ADRD on LGBTQIA+ older adults and their caregivers, identify specific risk and protective factors, tailor interventions to meet their needs, and ultimately advance equitable and inclusive health-care practices for an often-underrepresented group.

4.1 | Limitations

The present study, despite its valuable contributions, is not without limitations. One of the primary limitations lies in its use of crosssectional data, which provide only a snapshot of the participants' experiences at a particular moment in time. As a result, the findings may not fully capture the dynamic nature of recruitment and engagement strategies that may be most effective for recruiting LGBTQIA+ persons with memory loss/ADRD and caregivers. Additionally, while the involvement of community advisory board members from LGBTQIA+ organizations brought significant expertise and insights, it is crucial to acknowledge that their perspectives might not represent the entirety of those well versed in the recruitment and engagement of LGBTQIA+ populations impacted by ADRD. Other community members, researchers, and professionals in the field may hold differing viewpoints and expertise, underscoring the need for future research and a diverse range of perspectives to ensure broader generalizability. Despite these limitations, this research serves as a crucial stepping stone in shedding light on potential strategies for recruiting and engaging LGBTQIA+ individuals with memory loss/ADRD and caregivers, and it underscores the importance of continued efforts to foster inclusivity and representation in ADRD research. The collaborative approach taken to obtain these recruitment strategies, which included obtaining feedback from experts in relevant areas about possible recruitment strategies, reporting findings for review and reflection from the advisory board demonstrates ways in which to build trust, identifying best practices in engaging community members and groups traditionally underrepresented in research, and can help to ensure collaboration among the community and the research team.

5 CONCLUSION

The strategies discussed within this paper offer valuable insights and actionable recommendations for researchers, institutions, and policy makers seeking to bridge the gap in LGBTQIA+ representation in ADRD research. The suggestions brought forth by the advisory board members highlight the need for tailored outreach efforts that resonate with the LGBTQIA+ community's unique needs and concerns. The strategies presented amplify the need for collective and collaborative efforts that address the underrepresentation of LGBTQIA+ communities in research participation. Future research should leverage these strategies to amplify outreach efforts and provide a space for open dialogue and raise awareness about the importance of ADRD research within LGBTQIA+ communities.

AUTHOR CONTRIBUTIONS

Jason D. Flatt was responsible for the study concept and design. Jason D. Flatt and Brittany Klenczar-Castro were responsible for data analysis. Jason D. Flatt and Brittany Klenczar-Castro interpreted the data. Brittany Klenczar-Castro and Jason D. Flatt drafted the article. Brittany Klenczar-Castro, Jason D. Flatt, Whitney Wharton, Joel G. Anderson, Krystal R. Kittle, Andrea Gilmore-Bykovskyi, N. Maritza Dowling, and Jaime Perales-Puchalt revised the article. Jason D. Flatt, Joel G. Anderson, and Whitney Wharton obtained the funding to support time for the research and were responsible for study supervision.

ACKNOWLEDGMENTS

The successful completion of this research endeavor has been greatly enriched by the invaluable contributions and guidance of numerous individuals and organizations. We wish to extend our sincere gratitude to these individuals for their unwavering support and insightful input and are deeply appreciative of the members of our esteemed advisory board who dedicated their time and expertise to shaping the direction of this research. Their constructive feedback, thoughtful suggestions, and critical insights significantly enhanced the quality and rigor of our work and provided directions for future research. This work was supported by grant number R24AG066599 (Wharton, Anderson, Flatt, Klenczar, Kittle, Gilmore-Bykovskyi, Dowling, Perales-Puchalt, Manly), K01AG056669 (Flatt), K01MD014177 (Perales-Puchalt), and P30AG072973 (Perales-Puchalt) from the National Institute on Aging, National Institutes of Health. This work was also supported by a grant from the Alzheimer's Association, AARGD-22-929144 (Flatt). The funding organizations played no role in the design and conduct of the study; in the management, analysis, and interpretation of the data; or in the preparation, review, or approval of the article.

CONFLICT OF INTEREST STATEMENT

Brittany Klenczar-Castro is supported by NIA grants R01AG083177 and R24AG066599, and AARGD-22-929144. Dr. Krystal R. Kittle is supported by AARF-22-927069, NIA R01AG083177, and P30AG062429. Dr. Joel G. Anderson is supported by NIA R24AG066599 and R01AG083177 and serves on the Board of Directors of Healing Beyond Borders (unpaid). Dr. Whitney Wharton is supported by NIA R24AG066599, R01AG066203, RF1AG051514, R01AG083177, and P30AG064200. Dr. Andrea Gilmore-Bykovskyi is an employee of the University of Wisconsin-Madison and, in the last 36 months, reports grants from the NIH and the NIA. Dr. N. Maritza Dowling is supported by R24AG066599 and R01AG083177. Dr. Jaime Perales-Puchalt is supported by K01MD014177 and P30AG062429. Dr. Jason D. Flatt is supported by NIA grants K01AG056669, R01AG083177 and R24AG066599, and AARGD-22-929144. Author disclosures are available in the supporting information.

DISCLAIMER

The findings and conclusions in this article are those of the authors and do not necessarily represent the official position of the National Institute on Aging, National Institutes of Health, or Alzheimer's Association.

CONSENT STATEMENT

This research (Protocol # UNLV-2022-79) was approved by the University of Nevada Las Vegas, Human Subjects Review Committee, and informed consent was obtained from all participants.

ORCID

Jason D. Flatt ¹ https://orcid.org/0000-0003-1244-738X

REFERENCES

- 1. Alzheimer's Association. 2023 Alzheimer's disease facts and figures. Alzheimer's Dement. 2023;19(4);1598-1695. doi:10.1002/alz.13016
- 2. Guerreiro R, Bras J. The age factor in Alzheimer's disease. *Genome Med.* 2015;7(1):106. doi:10.1186/s13073-015-0232-5
- Brennan-Ing M, Seidel L, Larson B, Karpiak SE. Social care networks and older LGBT adults: challenges for the future. J Homosex. 2014;61(1):21-52. doi:10.1080/00918369.2013.835235
- Safer JD, Coleman E, Feldman J, et al. Barriers to health care for transgender individuals. *Curr Opin Endocrinol Diabetes Obes*. 2016;23(2):168.
- Flatt JD, Cicero EC, Lambrou NH, et al. Subjective cognitive decline higher among sexual and gender minorities in the United States, 2015-2018. *Alzheimer's Dement*. 2021;7(1):e12197. doi:10.1002/trc2. 12197
- Brooke B, Lidan Z, Scheraza DK, Jane AK. Sex and gender differences in risk scores for dementia and Alzheimer's disease among cisgender, transgender, and non-binary adults. *Alzheimer's Dement*. 2023;20(1)1-11. doi:10.1002/alz.13317
- 7. Alzheimer's Association. 2018 Facts and figures. *Alzheimers Dement*. 2018;14(3):367-429.
- Pharr JR, Batra K. Propensity score analysis assessing the burden of non-communicable diseases among the transgender population in the United States using the behavioral risk factor surveillance system (2017-2019). *Healthcare*. 2021;9(6):696. doi:10.3390/ healthcare9060696
- Hughto JMW, Varma H, Babbs G, et al. Disparities in health condition diagnoses among aging transgender and cisgender medicare beneficiaries, 2008-2017. Front Endocrinol. 2023;14:1102348. doi:10.3389/ fendo.2023.1102348
- Larson EB, Stroud C. Meeting the challenge of caring for persons living with dementia and their care partners and caregivers: a report from the National Academies of Sciences, Engineering, and Medicine. JAMA. 2021;325(18):1831-1832. doi:10.1001/jama.2021.4928
- Anderson JG, Flatt JD, Jabson Tree JM, Gross AL, Rose KM. Characteristics of sexual and gender minority caregivers of people with dementia. J Aging Health. 2021;33(10):838-851. doi:10.1177/ 08982643211014767
- Fredriksen-Goldsen KI, Jones BR, Hoy-Ellis C, et al. Aging with pride: innovations in dementia empowerment and action (IDEA). *Contemp Clin Trials Commun.* 2023;35:101169. doi:10.1016/j.conctc.2023. 101169
- Fredriksen-Goldsen K, Teri L, Kim HJ, et al. Design and development of the first randomized controlled trial of an intervention (IDEA) for sexual and gender minority older adults living with dementia and care partners. *Contemp Clin Trials*. 2023;128:107143. doi:10.1016/j. cct.2023.107143
- Gopaldas A. Intersectionality 101. J Public Policy Mark. 2013;32(1_suppl):90-94. doi:10.1509/jppm.12.044
- 15. Kane M, Trochim WMK. Concept Mapping for Planning and Evaluation. Sage Publishing; 2007;50.
- van Bon-Martens MJ, van de Goor LA, Holsappel JC, et al. Concept mapping as a promising method to bring practice into science. *Public Health*. 2014;128(6):504-514. doi:10.1016/j.puhe.2014.04.002
- Cook K, Bergeron K. Using group concept mapping to engage a hard-to-reach population in research: young adults with life-limiting conditions. *Int J Qual Methods*. 2019;18:1609406919891315.
- Concept Systems Incorporated. Concept Systems Global MAX[™].
 2022. Accessed on May 1, 2020. Available at: www.conceptsystems. com/toolsandmethods

- Trochim W, Kane M. Concept mapping: an introduction to structured conceptualization in health care. *Int J Qual Health Care*. 2005;17:187-191.
- 20. Trochim WMK. An introduction to concept mapping for planning and evaluation. *Eval Program Plann*. 1989;12:1-16
- Bickman L, Rog DJ. Concept mapping for applied social research. In: The SAGE Handbook of Applied Social Research Methods. 2nd ed. SAGE Publications, Incorporated; 2009:435.
- 22. Shepard RN. Multidimensional scaling, tree-fitting, and clustering. *Science*. 1980;210(4468):390-398. doi:10.1126/science.210.4468.390
- Beckstead JW. Using hierarchical cluster analysis in nursing research. West J Nurs Res. 2002;24(3):307-319. doi:10.1177/ 01939450222045923
- Flatt JD, Cicero EC, Kittle KR, Brennan-Ing M. Recommendations for advancing research with sexual and gender minority older adults. J Gerontol B Psychol Sci Soc Sci. 2022;77(1):1-9. doi:10.1093/geronb/ gbab127
- Fredriksen-Goldsen KI, Kim HJ. The science of conducting research with LGBT older adults- an introduction to aging with pride: National Health, Aging, and Sexuality/Gender Study (NHAS). *Gerontologist*. 2017;57(suppl 1):S1-S14. doi:10.1093/geront/gnw212
- Wood SF, Brooks J, Eliason MJ, et al. Recruitment and participation of older lesbian and bisexual women in intervention research. Womens Health Issues. 2016;26(Suppl 1):S43-S52. doi:10.1016/j.whi.2016. 04.003
- Lunn MR, Lubensky M, Hunt C, et al. A digital health research platform for community engagement, recruitment, and retention of sexual and gender minority adults in a national longitudinal cohort study-the PRIDE Study. J Am Med Inform Assoc. 2019;26(8-9):737-748. doi:10. 1093/jamia/ocz082
- 28. Browne K. Snowball sampling: using social networks to research nonheterosexual women. Int J Soc Res Methodol. 2005;8(1):47-60.
- Raina SK. Establishing association. Indian J Med Res. 2015;141(1):127. doi:10.4103/0971-5916.154519
- Leslie M, Khayatzadeh-Mahani A, MacKean G. Recruitment of caregivers into health services research: lessons from a user-centred design study. *Res Involv Engagem.* 2019;5:17. doi:10.1186/s40900-019-0150-6
- Myers KJ, Jaffe T, Kanda DA, et al. Reaching the "hard-to-reach" sexual and gender diverse communities for population-based research in cancer prevention and control: methods for online survey data collection and management. *Front Oncol.* 2022;12:841951. doi:10.3389/ fonc.2022.841951
- 32. Movement Advancement Project. April 2019. Where We Call Home: LGBT People in Rural America. Accessed on August 1, 2020. Aailable at: www.lgbtmap.org/rural-lgbt

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Klenczar-Castro B, Kittle KR, Anderson JG, et al. Using concept mapping to identify recruitment and engagement strategies for inclusion of LGBTQIA+ populations in Alzheimer's disease and related dementia research. *Alzheimer's Dement*. 2024;10:e12477. https://doi.org/10.1002/trc2.12477