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Methodological Question Being Answered: How can we improve representation of racial minorities in dementia research/clinical trials?

Abstract

Aims: African-Americans (AAs) have a higher risk for late-onset Alzheimer's disease (AD) than white Americans, however they are under-represented in clinical trials data. Community partnerships address health disparities, and may help to develop and sustain care approaches that positively impact community elders. Informed by principles of community based participatory research (CBPR), these partnerships can bring together researchers and communities for mutual learning and education.

Methods: This was pilot funded by two academic clinical trial teams convened a minority advisory board (MAB) tasked with using CBPR approaches to target dementia stigma in AA communities, raise support awareness and improve AA representation in research. MAB goals included 1.) Use of snowball sampling to assemble a membership composed of clinician-researchers, community organizers and families with lived dementia experience; 2) Co-development and delivery of community programs that engage AA and address dementia stigma; 3) Collection of data on perceived community needs with respect to how the MAB and affiliated research centers might best serve their interests and concerns.

Results: Two interactive presentations were held in March and April of 2018. Presentations provided a concise summary of AD/dementia including issues specific to AA a focus on stigma & managing stigma, family and community resources and information on the experience of research participation. A key feature was an interactive panel including clinical and lived-experience experts, former research participants and community support agency staff. Pre/Post program survey evaluations of 37 attendees, mean age 65.47 (SD 11.18), 75.7% African-American, found 97.3% agreed or strongly agreed the program was useful. Respondents generally increased their intention to use services and supports and suggested receptivity to research participation.

Conclusions: Data from racial and ethnic minorities can provide unique insights on dementia initiation, course and outcomes. Preliminary experience suggests that a CBPR approach to research participation may help address the gap in representation.

Introduction

In spite of increased rates, dementia-related stigma burden may be higher in racial & ethnic U.S. minorities. Cumulative 25-year dementia risk at age 65:

- 38% African-Americans (AA)
- 32% Latinos
- 30% Whites
- 28% Asian-Americans

However, there is a striking lack of diversity in dementia research samples.

Barriers to participation in dementia research studies among U.S. minorities include:

- Dementia-related stigma
- Lack of community awareness of normal aging vs. dementia
- Inadequate access to support and services
- Concerns regarding data confidentiality, fear of exploitation/harm from research participation

Methods

The project convened a 16 member minority advisory board (MAB) to co-develop community-focused communication on dementia facts, dementia-related stigma and on raising awareness of the diverse types of aging/dementia research being conducted in the community, including observational studies and clinical trials. Two interactive presentations were held in March and April of 2018 and information on community barriers/needs and potential interest in research was collected. Experience/findings informed the community outreach/engagement component of a National Institute of Aging (NIH) Alzheimer's Disease Research Center research grant proposal.

MAB Logistics

- Initial referrals solicited from clinician groups and a CDC-funded network of community advisors
- Meetings held monthly for a year-long period, conferencing available for those not able to make in-person sessions.
- Meetings in a central location accessible to public bus-lines
- Modest compensation for time/travel.
- Organizing staff distributed meeting agendas and minutes

Community-based participatory research (CBPR) principles for MAB implementation and program development:

- Membership of clinician-researchers, community organizers/social service agency (Alzheimer's Association) and families with lived dementia experience
- Bidirectional and iterative input
- Use of lived-experience members as a source of other lived-experience membership referrals
- Collaboratively establish clear & time-limited goals
- Co-develop & and deliver community programs that engage AA and address dementia stigma
- Data collection methods/questionnaire adapted from existing instruments based on MAB input
- Emphasize a multi-stakeholder approach (giving/sharing, long-term community investment) vs. short-term focus on enrollment

Presentation format/content

- 2 programs delivered in early 2018 in urban locations
- Interactive panel including clinical and lived-experience experts, former research participants and support agency staff
- Concise summary of AD/dementia including issues specific to 1) AA & differentiation of normal aging vs. dementia; 2) a focus on stigma & managing stigma; 3) family and community resources and 4) information on the experience of research participation.
- Minimize 'lecturing'/didactic approach to specifically address stigma & attitudinal barriers to care-seeking/research participation. Program featured an interactive panel including clinical and lived-experience experts, former research participants and social service support agency staff
- Take advantage of existing educational venues, coordinate advertising with settings that provide services to minority elders
- Rehearse presentations to ensure that the final program balanced time constraints with sharing of personal experience/difficulties and testimonials
- Provide accurate and balanced information on interventional vs. observational trials, safeguards for confidentiality & risk (i.e. providing a biological sample will not be linked to social security number/benefits)
- Conclude with a focus on caring for the caregiver (Figure 1)

Results

Table 1 provides descriptive information on pilot attendees. Pre/Post program survey evaluation, mean age 65.47 (SD 11.18), 75.7% African-American, found 97.3% agreed or strongly agreed the program was useful. Participants noted their own struggles and challenges with not being aware of early dementia symptoms, stigma and diagnosis disclosure concerns, and had questions about ongoing trials/research opportunities as well as sources of community/clinical support. Respondents generally increased their intention to use services and supports and suggested receptivity to future research participation. Specific comments/suggestions for future programs were noted (Figure 2).

Figure 1: Caring for the Caregiver

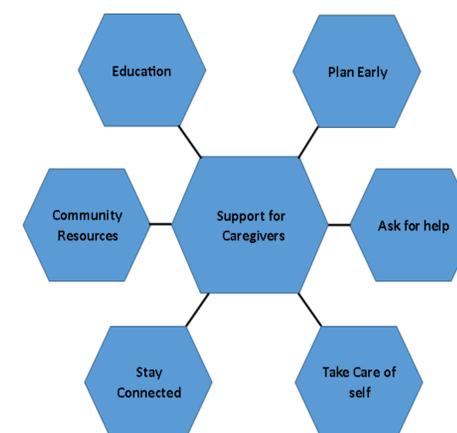


Figure 2: Input regarding the program or suggestions for future topics of interest

- Openness to the impact of slavery and inequality in our society/USA
- Great presentation for a lay person to advance
- More informational meetings like the one presented and more often
- Expand on the causes of dementia/Alzheimer's
- Add description of other brain diseases
- Steps to address early diagnosis and description of the assessments processes
- Include yoga, bilateral exercises, ballet and other holistic approaches
- Address the concept of Sun-downing
- Provide Virtual Dementia Tour experience
- Support and training with facilitators to help caregivers manage family with Alzheimer's
- Explanation of available resources other than Alzheimer Association and health care providers
- Information on where the studies/research is being done and how to get involved
- Results of clinical trials; return of findings to the community

"Thanks for organizing such a wonderful education program. It was especially inspiring and useful to hear from the caregivers' perspective and know more about their concerns and coping strategies. Would like to know more how could different practitioners work together interdisciplinary team to address the concerns from client and their caregivers."

Table 1: Descriptive information on pilot attendees

Variable	Mean (SD) or N (%)
Pre-program evaluation	
Age, n= 32	65.47 (11.18)
Female	29 (78.4)
Race	
White	3 (8.1)
African-American	28 (75.7)
Other/Did not provide	6 (16.2)
Hispanic	1 (2.7)
Personal experience with memory problems or dementia	34 (91.9)
Personal experience (can choose more than 1):	
Self	4 (11.8)
Family member	31 (91.2)
Friend	3 (8.8)
Other	1 (2.9)
Types of support used in the past	
Social service agency	11 (29.7)
Occupational/physical therapy	10 (27.0)
Support group	7 (18.9)
Alzheimer's Association	9 (24.3)
Healthcare provider	12 (32.4)
Transportation services	8 (21.6)
Home-care services	7 (18.9)
Legal advice/guidance	7 (18.9)
None	8 (21.6)
Other	3 (8.1)
"I believe that support or treatment for memory loss or dementia is available in my community" * N (%)	3.95 (0.91)
Strongly Disagree	0 (0.0)
Disagree	5 (13.5)
Neutral	1 (2.7)
Agree	22 (59.5)
Strongly Agree	9 (24.3)
"If I had memory loss or dementia, I would not want my family to know" * N (%)	2.20 (1.35)
Strongly Disagree	13 (35.1)
Disagree	13 (35.1)
Neutral	2 (5.4)
Agree	3 (8.1)
Strongly Agree	4 (10.8)
Post-program evaluation	
"This program was helpful to me" * N (%)	4.57 (0.56)
Strongly Disagree	0 (0.0)
Disagree	0 (0.0)
Neutral	1 (2.7)
Agree	14 (37.8)
Strongly Agree	22 (59.5)

Likert scales, strongly disagree= 1 and strongly agree = 5

Conclusions

Preliminary experience suggests that a CBPR approach to dementia research participation may help raise awareness on health disparities in dementia outcomes and the opportunities for individuals and families to access support and be involved in dementia-related research studies. While more labor-intensive than standard community education, this approach, sustained over time may help to address the under-representation of racial and ethnic minorities in research.

References

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