Recruitment and Retention: Challenges and Opportunities for the Alzheimer Disease Center

“Now that we have them, how do we keep them?”

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Outline

- Barriers to recruitment and retention
- Theory based approaches to improving retention
- Practical tips (experiential)
- Conclusions
Barriers to Recruitment and Retention

Researcher:

– Failure to gain trust
– Failure to establish credibility
– Lack of sensitivity to health and cultural beliefs
– Narrow definition of diverse populations
– Ineffectual communication of the study’s rationale
– Ineffectual communication of the relevance of the research to the participants’ community
– Complexity of forms and procedures
– Time consuming, inconvenient protocols

Curry L, Jackson J. *GSA Publication* 2003
Barriers to Recruitment and Retention (Cont’d)

Research Institutions:

– Medical research is viewed with suspicion
– Academic institutions may be viewed as elite entities that do not care about the welfare of minority communities
– Inadequate institutional resources for outreach
– Lack of support for faculty from diverse backgrounds
– Burdensome policies for conducting research
– Limited access to health care at academic medical centers
– Town/Gown issues

Curry L, Jackson J. GSA Publication 2003
Barriers at the Participant Level

- Attitudes, health beliefs
- Illness
- Differences in health behaviors
- Negative perceptions about the possible benefits of participating
- Belief that findings for health research will reflect poorly on individuals, their families, or their communities
- Low literary level may be a barrier
- Language barriers
- Increasing age

Curry L, Jackson J. *GSA Publication* 2003
Most Common Barriers to Retention

- Intervening illnesses
- Death
- Refusal
- Unable to locate
- Competing demands

Proportion will vary by cultural and socioeconomic groups.

Expect and plan for ~20% loss per year when enrolling multi-ethnic frail elders.
Approaches to Enhance Retention

- Establish credibility among the population
- Partner with physicians who provide care to the population of interest
- Directly acknowledge past medical abuse of minority participants coupled with specific plans to protect participants in your study.
- Central involvement of community opinion leaders
- Timely feedback of study results to the community and the participants

Curry L, Jackson J. *GSA Publication* 2003
Themes from the Literature on Recruitment and Retention

- Trust and connection with the community
- Involvement of ethnic and racial researchers at all levels of the project
- Clear communication regarding potential benefits of participation is important
- Cultural sensitivity on the part of the research team and the institution

Curry L, Jackson J. GSA publication 2003
The Problem

- Historically most geriatric mental health studies have been 85-90% White

- Where are the minority elders and why are traditional methods of recruitment and retention less successful in these groups?
What is the “Consumer Approach?”

- Entails understanding the needs of the community and tailoring the research study to meet those needs.

- In order for recruitment and retention to be successful, the research team must work in concert with the community to understand the access barriers that are specific to each minority group.

Critical Components for the Consumer Approach when Designing Research

- Consultation with community opinion leaders - a Community Action Board can provide guidance with regard to the most effective recruitment and retention strategies for the community of interest and can help with mid-course changes if there are problems with retention.

- Gate keepers (primary care doctors)
  - Advantage → higher proportion of potentially eligible participants that come from referrals meet eligibility criteria and the PCP can help the study track the participant over time and can reinforce the importance of staying in.

- Representative consumers should view all contact materials and procedures to provide guidance
Critical Components for the Consumer Approach when Designing Research (Cont’d)

Usually takes the form of focus groups, advisory boards, where you can collaboratively develop methods by overcoming fear, stigma, etc.

– Include staff who are ethnically similar to the consumer or have experience working with the community or are actual members of the target community.

– Rationale: Increases the comfort level of the participants and provides a meaningful social connection that in part of the “glue” that helps a participant want to stay in a study over time.
Consumer Centered Model to Address Barriers to Recruitment and Retention of Mental Health Patients

- Compare use of this model to traditional approaches
- Consumer centered approach lead to similar recruitment **BUT** better retention ($x^2=6.2 \ p<0.05$)
- Most efficient recruitment methods were by:
  - Provider referral
  - Face-to-face contact
- Experienced recruiter did better than a less trained “ethnically matched” recruiter ($x^2=36.00 \ p<0.01$)

Barriers to Recruitment and Retention

- Participants’ health
- Time
- Transportation barriers
- Stigma about the condition
- Lack of information about the condition and about the study

Additional Barriers of Minority Elders

- Fear and mistrust of science
- Stigma associated with mental health problems and specifically cognitive deficits (individual and family)
  - connect with trusted institutions
- Participant burden, much higher in low income persons
  - May have little utility in committing time when there are major competing demands

Additional Barriers of Minority Elders (Cont’d)

- Each cultural group and community is likely to have its own set of concerns regarding:
  - Mistrust
  - Stigma
  - Burden

- There is no uniform way to address this across all groups of minority elders
  - Do not assume that successful methods in one community will work in a new place
There is a need to do qualitative research to better understand the barriers and promoters of retention in your unique setting and to let this information inform a modification of the design of the recruitment and retention methods used.

A one-size-fits-all approach is likely to fail! …Which presents particular challenges for studies that need to retain multi-ethnic participants.
Strategies to Overcome Barriers
Grounded in the Consumer Approach

- Media campaigns to increase knowledge about the study
- Provision of transportation that is safe & reliable
- Provision of monetary incentives to complete follow-up assessments
- Continuity of research staff and data collection points that facilitate relationship building over time
- Flexible convenient locations for follow-up data collection, allow for partial participation

Other Key Features that Can Improve Retention

- Community lectures/presence in community organizations
- Community feedback
- Very experienced culturally competent staff, ethnically match staff, or use of community member recruiters
- Develop trusting, helpful relationships with your network of referring doctors
Other Key Features that Can Improve Retention (Cont’d)

- Pre-scheduled interviews that coincide with service delivery (avoid holidays, vacations, doctor’s appointments)
- Regular contact with participants between scheduled data collection times
  - Holiday, birthday cards
  - Phone calls to touch base and update
  - Updates in health status, hospitalizations etc. from family and PCPs
Other Key Features that Can Improve Retention (Cont’d)

- Shorter, less burdensome follow-up data collection approaches
Downsides of Consumer-Centered Models

- Costly in terms of **time** and **effort**
  - Finding ethnically matched recruiters can be difficult
  - Training community members without research experience can be time consuming but in the upside you are building capacity for future research and providing jobs for persons in need of employment.
Benefits of Greater Retention

- Cost savings by getting the most out of the high cost of recruitment
- More generalizable samples
- Improved power in the analyses
- Build community capacity for future research
Social marketing: The application of marketing techniques to influence the behavior of target audiences to improve their welfare.

The NIA funded study, Resources for Enhancing Alzheimer’s Caregiver Health (REACH) used a modified version of the social marketing approach.

Nichols L, et al. *J Aging Health* 2004
Principles “the 6 P’s”

- **Participants** ➔ Define the target audience
- **Products** ➔ Develop the intervention, must be recognized as very important or addressing a serious problem by the potential participant
- **Place** ➔ Improve accessibility, make this convenient and culturally acceptable

Nichols L, et al. *J Aging Health* 2004
Principles “the 6 P’s” (Cont’d)

- Price ➔ Time, Inconvenience, and Money (must make every effort to minimize price)
- Promotion ➔ Advertise the study
- Partners ➔ Develop & work with partners. Partners can assist with recruitment, referrals, space, screening, and credibility.

Nichols L, et al. *J Aging Health* 2004
Social Marketing Approach: Identifying Participants

- Identify target audience
- Develops program components that address: audience needs, perceptions, and values

Nichols L, et al. *J Aging Health* 2004
Developing the Product

- In clinical research the “intervention” is the “product” and must be scientifically valid and grounded in theory… but must also meet the needs, wants, interests or desires of research participants. This is particularly important when recruiting participants with great unmet need for health services.

- Intervention must address a problem that is perceived as serious and amendable to the intervention.

- Think about what is competing for the participants’ time and energy? And try to develop an intervention that will be feasible in the context of the participants competing demands.
Managing the Price

In terms of:  
- Money
- Time
- Effort
- Psyche

- Minimize price as much as you can
  - Survey length
  - Where you collect the data
  - Who presents the study
Improving Accessibility (PLACE)

- The more accessible the place, the easier recruitment and retention will go more smoothly.
Promoting the Study

- Advertising
- Media relations
- Promotional events

- Need to frame these efforts in culturally appropriate ways.
- CAB can help inform this process.
Less/More Successful Approaches to Recruitment in REACH

- Newspaper ads didn’t generate referrals, relatively expensive
- Senior focused newsletters from local hospitals. Newsletters from Alzheimer’s Organizations were more successful.
- Targeted mailing, especially personalized letters were more successful.
- Untargeted “mass” mailings were not successful.
- Across the REACH sites, television and radio media approaches had variable success.
- Community outreach (talks, lectures, meeting of local service organizations, churches, adult-day-care centers) were considered to be successful.

Strategies used by the UCLA RCMAR and Pepper Center Recruitment Cores

- Both Centers have large multi-ethnic Community “Action” Boards that are mainly constituted from the leading service provider and advocacy organizations in our county.

- In the case of the RCMAR Center, the CAB helps the center select and prioritize the pilot studies to be funded with an eye toward the community’s research priorities as one criterion.

- Once selected the CAB meets the researcher and brainstorms about the best community partners for the project, looking carefully for a critical match in terms of interests and priorities and provides introductions to the community.
Strategies used by the UCLA RCMAR and Pepper Center Recruitment Cores

- RCMAR pilot investigators learn community participatory research methods and present their study designs to the CAB and receive feedback on modifications that are aimed at enhancing recruitment and retention.

- CAB members also review lead materials, consent forms, surveys and all data collection tools that participants are likely to see.

- CAB members provide insights into types and sizes of financial incentives that are likely to be appealing to participants and their families. The CAB also tries to identify likely barriers to participation or factors that will make follow-up difficult.
Strategies used by the UCLA RCMAR and Pepper Center Recruitment Cores

- CAB members continue to meet regularly with the researcher to trouble shoot all issues that come up with regard to recruitment and retention.

- Pilot study investigators are strongly encouraged to include key CAB members in the analysis and report writing phases of the project and to turn to the CAB members for guidance with regard to dissemination of the study results back to the participants, their families, and communities.
Working with Partners

- Congruence between the aspirations/goals of the researchers with the partners is a big plus.

- Often times are conduits to target audiences

- Especially if located in a convenient/credible location (service provider’s office)

- In REACH partner referrals accounted for ~50% of the caregiver participants.

- Barriers to partnering
  - Staff turnover at partnering agency
  - Structural changes in partners
  - Conflicts between partners
Conclusions

- There is little empiric quantitative evidence that identifies “best practices” for retention.
- Theory driven approaches that inform the design and implementation of studies appear to have the highest recruitment rates but it is unclear whether these same approaches translate into better retention.
- It is too early to tell whether the community participatory framework that the UCLA RCMAR and Pepper Recruitment Cores have adopted will result in higher rates of retention than more traditional investigator driven follow-up designs.