Using the Alzheimer’s Association Helpline as a Recruitment Tool

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CADRE: Collaborative Alzheimer Disease Research Exchange

1 FRAME, FRAMEWORK
2 a nucleus or core group especially of trained personnel able to assume control and to train others; *broadly*: a group of people having some unifying relationship *<a cadre of lawyers>* [a cadre of clinicians/researchers]
3 a cell of indoctrinated leaders active in promoting the interests of a revolutionary party
Key Issues

- Recruitment to dementia research projects is challenging and costly
- Researchers have limited reach to potential participants for various reasons
  - Access
  - Time
  - Funding
  - Expertise
  - Relationships
Alzheimer’s Association

- Provide services statewide
- Have access to family members and persons with dementia [pwd] via their network of services
- Have or develop a relationship with the families and pwd via their services
CADRE

- Developed through the ideas generated at Indiana Discovery Network for Dementia meetings
  - A group of clinicians, researchers, primary care providers in Indianapolis collaborating on addressing issues of AD patients, families and providers
- CADRE proposal funded by Roybal Center at IU CAR
Specific Aims

1. Develop a collaborative system to identify, inform and recruit potential participants to AD research projects through the Alzheimer’s Association Helpline.
   a. Determine criteria that leads to successful recruitment and follow-up versus an unsuccessful attempt
   b. Identify the best mechanism to share or link willing research participants with researchers.
Specific Aims

2. Assess the feasibility and acceptability of recruitment through the AA Helpline using well-trained S/Vas recruiters.
   a. Evaluate the effectiveness of the training program for Helpline S/V
   b. Evaluate the effectiveness of the culture change process with the S/V
Preliminary Data

- From pilot study the IADC Education Core has undertaken with AAGI and the U of I CAC:
  - Can recruit using Helpline Staff/Volunteers
  - N=57 completed baseline interviews
  - N=38 completed follow-up interviews (21 by phone interview, 17 by mail)
Lessons Learned

- S/V became comfortable asking if caller was interested in research
- First time callers to Helpline are not put off by the question about research participation
- A key feature of the Helpline is the rapport and relationship that quickly develops between the caregiver and S/V answering the call
Lessons Learned

- The longer the Helpline service, the more receptive the caller was to participate.
- Staff that spent the most time answering the helpline had the highest number of recruits and the highest percentage of completed baseline interviews.
- Staff felt a stronger commitment to being successful because they felt recruiting participants was job related.
- Increased training/modeling of recruitment questions by phone and consistent internal quality control is necessary.
- 5 calls to participants may be the upper limit in attempts to contact; beyond 5 calls, likelihood of getting a completed follow-up was very small.
CADRE included:

- Training--increased and on-going
- Script was adhered to more closely than pilot
- One Staff made all follow-up calls
- Culture shift at the AAGI
  - Staff/volunteers like to provide services
  - 6-month trial will likely be acceptable but on-going research recruitment will involve a shift in culture
  - Importance of recruitment is recognized nationally for the ADCs and the Alzheimer’s Association
  - Very positive collaboration
Figure 1: CADRE Study Design

Call received by the AA Helpline

Helpline service provided by staff or volunteer

Is the caller a person with AD/dementia or a family caregiver?

Yes: Ask if caller interested in research opportunities?

Read script about research gateways (IDND web site, information packet by mail)

Add information packet to regular AA mailer

NO: Ask why?

Record all responses. Analyze for trends or patterns

NO: usual service
Figure 1: CADRE Study Design

At 2 weeks follow-up call as per regular service. Plus ask:
- Did you receive information in mail?
- Did you visit the web site?
- Are you interested in a particular study?

**YES:** Encourage them to call the number provided.

**NO:** Ask why
Analyze responses for trends or patterns

Follow up with study coordinator to track success. Track variables associated with successful vs. unsuccessful recruitment (1-3 months)
CADRE Results

- Recruitment and tracking is hard work and time consuming!

- From the Clinical Core Coordinator and Clinical Trial Coordinators:
  - CADRE was important in that we furthered partnerships among the Alzheimer’s Association, IU-CAR and the IADC
  - Appreciated support of the AA in their mission to promote and raise awareness about importance of research
CADRE

- Reinforced importance of the collaboration between the AA and the study sites in willingness and ability to support research
- Reinforced that recruitment is a challenge
- Further projects could help provide more insight into how information can get to those who are interested in participating in research
<table>
<thead>
<tr>
<th>Types of Callers</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eligible to receive research info [CG or PWD]</td>
<td>818</td>
</tr>
<tr>
<td>Professionals</td>
<td>311</td>
</tr>
<tr>
<td>Others (info only; query, etc)</td>
<td>653</td>
</tr>
<tr>
<td>Total Calls</td>
<td>1782</td>
</tr>
</tbody>
</table>
## Results: Helpline Callers Relationship to Person with Dementia

<table>
<thead>
<tr>
<th>Relationship to PWD</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult Child</td>
<td>427</td>
</tr>
<tr>
<td>Spouse</td>
<td>215</td>
</tr>
<tr>
<td>Self</td>
<td>32</td>
</tr>
<tr>
<td>Sibling</td>
<td>22</td>
</tr>
<tr>
<td>Grandchild</td>
<td>23</td>
</tr>
<tr>
<td>Niece/nephew</td>
<td>17</td>
</tr>
<tr>
<td>Friend</td>
<td>23</td>
</tr>
<tr>
<td>Other</td>
<td>59</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>818</strong></td>
</tr>
</tbody>
</table>
CADRE Results

- Of the 818 callers eligible to receive info on 4 local studies recruiting subjects:
  - 257 agreed to have information sent
  - 4 families called coordinators
  - 2 participants were enrolled into 2 separate studies
  - 1 person was interested and returned paperwork but has not scheduled a screening visit
- NCRAD received 0 calls
CADRE Results

- Reminder calls were made to 102 participants who were sent information.
- S/V talked to 33 of those and learned:
  - Information was important AA should provide it to callers
  - Had shared Helpline number with others
  - Most common reason given re: if they had reviewed info
    - Had not had a chance to read the packet
    - Need more time to review; overwhelmed
    - Patient could not participate (died, moved to LTC)
CADRE Results

- May be that callers to the Helpline are too stressed to focus on research participation at the present time
- May call months later or next year depending on where they are in the process
- At midpoint information was also distributed via support groups [49 groups statewide]
  - N= 257 attendees
  - 0 calls to date
Conclusions

- Distributing information any way possible is important and a good thing to do.
- Building relationships with patients and caregivers is critical.
- Tracking, however, is very time consuming relative to the data collected.
- Coordinators felt if they could initiate the call they may have been more successful.
Conclusions

- Further development or innovation is needed to improve the efficiency of this methodology.
- Need to identify different sources of referral for participants.
  - With the Clinical Core and Clinical Trial Coordinators have implemented a research registry (with IRB approval)
  - With IDND are exploring having primary care providers refer patients
- Takes a lot of time!!!
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