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J Aging Health 2000; 12; 490
DOI: 10.1177/089826430001200403

The Cost of Recruiting Alzheimer's Disease Caregivers for Research

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Objectives: This study examined the cost and outcomes associated with multiple recruitment strategies used to enroll participants in an Alzheimer's disease (AD) caregiver study. **Methods:** Recruitment data were collected as part of an AD caregiving intervention study and examined for number of referrals and participants, yield, personnel cost, materials cost, total cost, and cost per participant. **Results:** Recruitment rates varied by method implemented and referral source. Overall, 100 participants were enrolled for a total cost of $10,127, yielding an average per participant cost of $101.00. The Formal Recruitment Method, used at agencies with large participant pools, emerged as the most cost-effective strategy. **Discussion:** Recruitment costs varied greatly, depending on the referral sites and their available pool of participants. Substantial time, money, and personnel need to be budgeted for recruitment efforts given the expected costs, the competing pressures in the health care region, and the variability of participant response.

Rigorous clinical research entails recruiting an appropriate and adequate sample. Failure to attain an adequate sample size results in reduced statistical power and compromised generalizability, seriously limiting a project's ability to produce meaningful results (Ganguli, Lytle, Reynolds, & Dodge, 1998; Hulley & Cummings, 1988; Hunninghake, Darby, & Probstfield, 1987; Rimer, Schildkraut,

AUTHORS' NOTE: Funded by the National Institute on Aging: 1 U01 AG 13255-03. The views and opinions expressed in this publication do not necessarily reflect those of the NIA or the HRCA Research and Training Institute. We would like to thank Brooke Harrow, PhD, for her insightful comments on the manuscript. For reprints write to Barbara Amelotte Tarlow, PhD, RN, Research Associate, Research and Training Institute, Hebrew Rehabilitation Center for Aged, 1200 Centre St., Boston, Ma, 02131-1097; e-mail: tarlow@athena.hrca.harvard.edu

JOURNAL OF AGING AND HEALTH, Vol. 12 No. 4, November 2000 490-510

Lerman, Lin, & Audrain, 1996; Rosenberg et al., 1996; Thompson, Heller, & Rody, 1994; Williams, Vitiello, Ries, Bokan, & Prinz, 1988). Recruitment problems negatively affect a project by adding costly extensions of fieldwork and delays in sequential research activities that may result in study termination (Hunninghake et al., 1987).

The inclusion of diverse populations such as women, elders, and minorities as mandated in National Institutes of Health (NIH) supported research necessitates increased outreach efforts by researchers (Lovato, Hill, Hertert, Hunninghake, & Probstfield, 1997). The targeting and recruitment of any special population is known to require more time and resources to tailor strategies to their particular needs (Anderson, Fogler, & Dedrick, 1995; Ballard, Nash, Raiford, & Harrell, 1993; Swanson & Ward, 1995). Enrollment of Alzheimer's disease (AD) caregivers and care recipients is even more difficult because an eligible dyad must be recruited and cognitive impairment must be considered.

The need to recruit older participants in AD and related disorders research will only increase as the average life expectancy in the United States and worldwide increases, with life expectancy gains highest among persons older than age 85. There is an exponential rise in the number of persons with AD after age 65, with the rate nearly doubling every decade. The current prevalence of AD is estimated at 4 million people, with nearly half of all persons being cared for at home (National Institute on Aging [NIH], 1996). There is also clinical and epidemiological evidence that AD is an underrecognized disease category (Larson, 1998).

African Americans were found to have a 4 times greater risk of developing AD and Hispanics a 2 times greater risk than Caucasians (Ballard et al., 1993; Tang et al., 1998), facts that support the need to incorporate minority participants (Alzheimer's Disease Education and Referral Center [ADEAR], 1998). Recruitment and retention of minority participants, however, requires creating a culturally sensitive recruitment plan that is more labor intensive and results in increased time and personnel costs (Arean & Gallagher-Thompson, 1996; Young, Edevie, Young, & Peters, 1996). A recent study of caregivers reported that the average cost of recruiting a Caucasian caregiver was $29.92 per participant and the cost of recruiting an African

American caregiver was nearly twice that at $54.15 (Patrick, Pruchno, & Rose, 1998).

The research design for caregiving studies often includes eligibility criteria that are established for caregiving dyads, adding another layer of complexity to the recruitment process. A sleep disruption study, designed to include behavioral interventions implemented by the caregiver to reduce nighttime sleep disruptions of the care recipient, provides an example of this kind of selection process whereby both the caregiver and care recipient must meet eligibility criteria. Investigators for this sleep disruption study established a recruitment goal of 124 AD caregiver participants but were only able to recruit 63 out of 222 contacts for a yield of 28% (Dowling & Wiener, 1997).

Unfortunately, recruitment outcomes are not routinely reported in the literature, and the documentation of recruitment costs is rare (Swanson & Ward, 1995). The paucity of published information on recruitment issues may contribute to recruitment problems if investigators are unprepared to manage recruitment problems and if the literature lacks advice (Hunninghake et al., 1987). Between 1991 and 1999, only nine of the AD caregiving studies found in a Medline search reported on recruitment and enrollment and none of these studies included a cost analysis. Enrollment figures varied from a low of 74 to a high of 212 participants, with an average enrollment of 143 participants (Brennan, Moore, & Smyth, 1995; Haley et al., 1996; Hooker, Monahan, Bowman, Frazier, & Shifren, 1998; Knop, Bergman-Evans, & McCabe, 1998: Kramer, 1997; Logsdon & Teri, 1995: Logsdon et al., 1998; McNaughton, Patterson, Smith, & Grant, 1995; Russo, Vitaliano, Brewer, Katon, & Becker, 1995; Seltzer, Vasterling, Yoder, & Thompson, 1997; Stuckey, Neundorfer, & Smyth, 1996). Two studies reported their participant yield, which was the proportion of potential participants contacted who later enrolled, of 75% (McNaughton et al., 1995) and 53%, respectively (Logsdon et al., 1998). Another study reported a recruitment completion rate of 83%, which was the proportion of potential participant contacts identified as eligible who later enrolled (Stuckey et al., 1996). Given such variability among recruitment reporting practices, the ability to make cross study comparisons is greatly reduced. The majority of participants in the above-mentioned studies were recruited through convenience samples from academic medical centers using current

patient/client lists and AD Research Center patient registries. Recruitment results from community-based efforts was often incomplete and very limited in the literature.

Changing demographics, increases, and variability in the prevalence rates and the personal and financial cost of care combine to make the study of AD caregiving of critical importance. The lack of participants and the escalating cost of recruitment are surfacing as major concerns in the general research literature (Engelking, 1991; Farrar, 1991; Patrick et al., 1998; Taylor-Davis, Smiciklas-Wright, Davis, Jensen, & Mitchell, 1998) and specifically in the AD caregiving literature (Hunninghake et al., 1987; Swanson & Ward, 1995). In response, this study was designed to examine and compare the cost-effectiveness of commonly employed recruitment methods. Research questions driving the study stemmed from the desire to understand better how much it costs to recruit AD caregivers using a variety of methods and to evaluate the utility of social marketing principles in the recruitment process.

- What are the total costs associated with recruiting AD family caregivers?
- What are the most cost-effective means of recruiting AD caregivers?
- How does the implementation of social marketing principles affect recruitment?
- What lessons can be learned to inform investigators about the planning and implementation of recruitment efforts?

Method

TARGET POPULATION

This study examined the recruitment activities of an AD caregiving intervention study, Reach for Telephone-Linked Care (Reach for TLC), located in Boston and funded by the National Institute on Aging (NIA). The Reach for TLC project was a randomized feasibility study designed to evaluate the usefulness of a telecommunications support system that would be available 24 hours a day for the caregivers of persons with AD. The aims of the TLC study were to

1. monitor and provide information through an automated telephone conversation to help manage bothersome care recipient behaviors;
2. provide access to experts in the field of AD through a voice mail system;
3. provide a telephone connection to a network of other caregivers; and
4. provide a personalized, calming, automated telephone conversation for the care recipient.

The TLC system is a computer-based telecommunications system that uses a computer controlled human voice to speak to persons via telephone. The caregivers communicate with the TLC system by pressing designated keys on the touch tone keypad of their home telephone. Technical specifications and details about the system's operations have been published previously (Mahoney, Tarlow, & Sandaire, 1998).

The population targeted for study was the primary family caregiver of a person with AD. Initial eligibility screening included criteria defined for both the care recipient and the caregiver. The care recipient had to have a medically confirmed diagnosis of probable AD or a Mini-Mental Status Exam of < 23. The caregiver had to be living with the care recipient and be the primary caregiver, defined as the family member who provided the greatest amount of help. Eligibility criteria were chosen in light of the need to balance population specificity with the practical necessity of recruiting an adequate sample size. Eligible caregivers were interviewed once in their home, at which time written informed consent was obtained, randomization occurred, and the baseline questionnaire administered. Intervention group caregivers were taught how to use the telephone intervention, and control group caregivers received generic AD literature. Follow-up interviews were conducted by telephone at 6 and 12 months and when the respondents' participation ended at 18 months.

RECRUITMENT PROCEDURES AND OPERATIONAL DEFINITIONS

During the planning stages of the project, potential recruitment sites were initially identified and evaluated. Projections for participant accrual were made at each site based on the eligibility criteria and an assessment of the available recruitment pool. Estimates indicated that the study sample size could be attained from five sites. These sites

included three large teaching hospitals—two of which serve large and diverse minority populations—one neurological diagnostic and treatment center, and one large adult day care center. Sequential recruitment from the five sites was planned to allow for an orderly and consistent flow of work and to avoid conflict with other studies nearing completion or waiting to start. Promotional activities were implemented shortly before enrollment began, along with staff meetings at the referral sites to initiate the recruitment process.

Prior to the start of enrollment, recruitment brochures were designed and printed, and scripts written for statewide public service and newspaper announcements. Several promotional activities were held simultaneously to raise awareness in the professional and caregiver community about the project. Announcements in advance of the research project to the professional community and key community leaders by project personnel can foster cooperation and reduce misunderstanding and opposition to the study. Social marketing theory indicates that letting the community of potential participants know about the project, providing the project with credibility, and lending a recognition factor to the experience of being asked to participate is a vital strategy. Older persons are likely to feel reassured that the research project they are being asked to participate in is legitimate if they see it on television or in the newspaper (Boult, Boult, Morishita, & Pirie, 1998). Evidence confirming the effectiveness of these public announcements for research is frequently unavailable or incomplete, but few would argue its merits (Lovato et al., 1997). The public promotional announcements were repeated throughout the entire enrollment period to keep the project visible.

Following a 3-month period of intensive promotional activity, enrollment began. The Formal Recruitment Method was the process by which potential participants were initially referred to the study by the five original referral sources. Using the Formal Recruitment Method, referrals were generated by personnel at a cooperating site who could identify and contact potential participants for enrollment into the study. Prior agreement was reached that agency personnel would give out pamphlets and talk about the project with their patients/clients, actively recruit them into the study, and follow through with a completed referral form returned to the research office. Agency staff

reviewed records of active patients/clients and scanned clinic appointment lists for potential participants.

Despite the initial efforts, recruitment goals were not met by month three and intensive recruitment efforts were implemented. Two back-up referral sites were activated and efforts to identify and enlist new recruitment sources were begun. While trying to gain access to additional large referral sources, three sites expressed reluctance to participate due to the costs associated with staff time to formally recruit participants. Agreement was reached at one clinical site to have research staff carry out the tasks of referring within the agency, thereby relieving site staff of additional work. This approach raised concerns about patient confidentiality due to medical record access and was resolved by having a professional nurse from the research staff do the chart reviews. Another site agreed to refer patients after reimbursement for staff time was negotiated. Still another site declined participation despite such offers, claiming that the added time coupled with staff shortages prohibited any research collaboration. As it became apparent that access to outside sources hinged on how burdensome or not the referral process was, the Mediated Recruitment Method was developed and implemented at subsequent sites.

Using the Mediated Recruitment Method, site personnel acquainted themselves with the research project and briefly introduced the project to their patients/clients verbally and distributed project literature. AD caregivers then referred themselves by sending in a mail back response form, which was included in the literature. The referral process was expedited using this method because self-referral participants were included under the purview of the Boston Reach project site's Institutional Review Board (IRB) protocol. The Mediated Recruitment Method was implemented at 67 sites: all 47 AD support groups, 18 adult day programs, and two large health care agencies.

Community Directed Promotions were those recruitment strategies designed to reach potential participants in the community, who were unknown to the researchers. Social marketing theory has provided a theoretically based systematic method of market research and social behavior change (Aggleton, 1997; Gries, Black, & Coster, 1995; Lefebvre & Flora, 1988). "Social marketing is defined as the

design, implementation, and control of programs seeking to increase the acceptability of a social idea or practice to a target group" (Gries et al., 1995, p. 348). Principles derived from social marketing theory guided the design of the Community Directed Promotional efforts (Lefebvre & Flora, 1988) and included the following:

- *Product:* Investigators need to develop a study that people want to join. Because caregiving is stressful, the intervention was designed to support families based on input from the targeted population and pilot testing (Mahoney, 1998). Participants could select from any of four intervention options to use 24 hours a day.
- *Price:* Studies need to minimize the burden of participation. Arrangements were made for one in-home interview with follow-up interviews conducted by telephone at the participant's convenience. Bilingual interviewers were also available 7 days a week, including evenings.
- *Place:* Multiple sources need to be identified through which the target group will be reached. Additional recruitment sites were identified through personal and professional contacts, key community leaders, current caregivers, reviewing relevant literature, keeping abreast of developments in the local health care environment, and expanding the catchment area.
- *Promotion:* Specific strategies need to be generated to outreach and inform the target group about the research. Nine different promotional strategies were implemented that included a range of activities, from small group presentations to advertisements in a minority newspaper with a circulation of 80,000 people.

The use of social marketing strategies was revisited 10 months into the field, and a recruitment manager and assistant were employed to implement additional social marketing strategies. Advice from a marketing consultant resulted in new leads for public advertising, targeted community mailing lists, and the redesign of introductory letters and brochures. Two paid newspaper recruitment advertisements were created, one targeted to the African American community and the other to older adults who receive a research registry newsletter for those interested in research participation. A Web page describing the study and including an online, self-referral form was established and linked to two national Web sites for people interested in AD. A project announcement was sent via a professional e-mail group to 80 physicians

who practiced inside the newly expanded catchment area. A direct mailing was sent to 8,000 older females in the targeted area. Although this strategy was expensive in materials, the total cost was moderated by the use of volunteers for this one activity. A colleague sent brochures, supplied by the project, as a professional courtesy to 200 AD caregivers who recently completed her study (recycled participant list). Finally, project brochures were inserted into the research institution's employee newsletter mailing.

Concurrent with efforts to increase the number of referral sources, eligibility criteria were reviewed and relaxed where possible, such as expanding the catchment area from 60 to 80 miles from Boston. Expanding the catchment area allowed for the recruitment of participants from two other states.

Cost-Effectiveness Analysis

All information associated with recruitment costs and enrollment figures was systematically recorded during the active recruitment phase for analysis after enrollment closed. The cost of personnel included their computed hourly rate and fringe benefits. Activities included in the personnel costs were those project-related tasks carried out by all staff supported by the grant, including both research staff and agency staff. Drafting of promotional materials, letter writing, introductory and follow-up phone calls, and individual and group presentations are illustrative of those tasks. The number of minutes staff spent on a specific activity were initially recorded then averaged and applied to all similar subsequent activities. The number of hours multiplied by the hourly rate for each person engaged in recruitment by category of method used was calculated and then all personnel costs were summed for a total personnel cost.

The Formal Recruitment Method was the only recruitment method in which salaried agency personnel recruited study participants without additional reimbursement. Six professional colleagues who referred participants from their respective agencies declined reimbursement. Two municipal agencies were guided by institutional policies that excluded recruitment reimbursement. Because similar

benefits may not be available to other investigators, we have included in the results section an estimate for the cost of recruiting those participants that the grant did not support.

The cost of materials included standard office supplies, special materials, printing costs, copying, and mailing. The cost of materials used according to category of recruitment method was recorded and then summed for a total materials cost. Cost-effectiveness was determined by comparing the cost per participant for each type of recruitment method. The mean cost per participant for each type of method resulted from the sum of personnel and material costs, divided by the number of participants in each recruitment category. A total mean cost per participant was calculated from the sum of all personnel and material costs for all categories, divided by the total sample. Personnel and material costs associated with participant retention were not included as part of recruitment costs.

Results

TOTAL COSTS ASSOCIATED WITH RECRUITMENT

Recruiting the sample cost $7,619 for personnel and $2,508 for materials, for a total cost of $10,127. The mean cost per participant was $101.00 (see Table 1). The 143 referrals to the project resulted in 118 people who completed the telephone screen and were found to be eligible, for an 83% eligibility rate. Of the 118 eligible people, 100 persons were enrolled, which was an 85% recruitment completion rate, similar to that found in the one other AD caregiving study that reported the completion rate (Stuckey et al., 1996). The 143 referrals produced 100 participants, a yield of 70%, which compares favorably with that reported in the AD caregiving literature (Dowling & Wiener, 1997; Logsdon et al., 1998; McNaughton et al., 1995). The sample was generated during a 22-month period with just fewer than 5 people being enrolled each month on average. Enrollment varied from month to month, ranging from a low of 0, to a high of 8, with higher rates of enrollment coming in late winter and spring and lower rates coming in the summer months and holiday periods.

Table 1
All Recruitment Methods by Enrolled Participants and Estimated Cost

	Referrals and Inquiries	*Enrolled Participants*	*Yield (%)* [a]	*Cost of Personnel*	*Cost of Materials*	*Total Cost*	*Cost per Participant* [b]
Formal Recruitment Method	111	73	.66	$5,435	$879	$6,314	$86
Mediated Recruitment Method	19	15	.79	$1,729	$200	$1,929	$129
Community Directed Promotions	13	12	.92	$455	$1,429	$1,884	$157
Total	143	100	.70	$7,619	$2,508	$10,127	$101

a. Yield is defined as the proportion of referrals and inquiries that resulted in an enrolled participant.
b. Cost per participant is the total cost per recruitment method divided by the number of enrolled participants.

COST-EFFECTIVENESS BY RECRUITMENT METHOD

The Formal Recruitment Method, implemented at 13 referral sources, produced the largest proportion of the total sample (73%) at the lowest cost. The Formal Recruitment Method produced 111 referrals and 73 participants, a yield of 66%. The cost of personnel and materials was $5,435 and $879, respectively, for a total cost of $6,314, or $86 per participant in recruitment costs. Of the two types of referral sources, the seven academic medical centers produced the most participants; 56 out of the 73 participants enlisted using the Formal Recruitment Method (see Table 2).

Some participants were referred to the study by agencies that were not reimbursed for the time their staff spent in recruitment activities. There were 39 participants referred by eight agencies that absorbed an estimated $2,087 in personnel costs for recruitment activities. Staff at the agencies that were reimbursed for their recruitment activities averaged about 2 hours of effort to produce one referral. Nonreimbursed agency personnel costs were estimated by averaging the hourly wages for a registered nurse and medical secretary ($26.76) multiplied by 2 (hours) and by the 39 "no-cost" participants. The calculations of recruitment costs shown in Table 2, however, focus on grant-

Table 2
Formal Recruitment Method by Enrolled Participants and Estimated Cost

	Referrals and Inquiries	*Enrolled Participants*	*Yield (%)* [a]	*Cost of Personnel*	*Cost of Materials*	*Total Cost*	*Cost per Participant* [b]
Metropolitan University affiliated, teaching hospitals (n = 7)	89	56	.63	$2,756	$679	$3,435	$61
Community-based agencies (n = 6)	22	17	.77	$2,679	$200	$2,879	$169
Total	111	73	.66	$5,435	$879	$6,314	$86

a. Yield is defined as the proportion of referrals and inquiries that resulted in an enrolled participant.
b. Cost per participant is the total cost per recruitment method divided by the number of enrolled participants.

supported expenses and exclude these nonreimbursed agency personnel costs.

The Mediated Recruitment Method produced 19 referrals and 15 participants, for a yield of 79%. The cost of personnel and materials was $1,729 and $200, respectively, for a total cost of $1,929 or $129 per participant. This recruitment method produced 15% of the total sample. Of the two types of referral sources, the adult day programs and larger health care services produced the most participants, 11 of the 15 participants secured using the Mediated Recruitment Method (see Table 3). The difference in yield between adult day programs and AD support groups was 92% and 57%, respectively, and the difference in cost per participant was $41 for adult day and a staggering $369 for AD support groups.

Community Directed Promotions was the least efficient recruitment method, producing the smallest proportion of the sample (12%) at the highest cost. This recruitment method produced 13 referrals and 12 participants, a yield of 92%. The cost of personnel and materials was $455 and $1,429, respectively, for a total cost of $1,884 or $157 per participant. Of the nine different types of promotional activities, the public service/general and targeted announcements produced the

Table 3
Mediated Recruitment Method by Enrolled Participants and Estimated Cost

	Referrals and Inquiries	*Enrolled Participants*	*Yield (%)* [a]	*Cost of Personnel*	*Cost of Materials*	*Total Cost*	*Cost per Participant* [b]
Adult day health programs (n = 20)	12	11	.92	$374	$78	$452	$41
Alzheimer's disease support groups (n = 47)	7	4	.57	$1,355	$122	$1,477	$369
Total	19	15	.79	$1,729	$200	$1,929	$129

a. Yield is defined as the proportion of referrals and inquiries that resulted in an enrolled participant.
b. Cost per participant is the total cost per recruitment method divided by the number of enrolled participants.

most participants, 5 of the 12 participants. It was possible to document referrals from only three of the promotional strategies used, preventing the calculation of cost per participant within this category (see Table 4).

THE EFFECT OF SOCIAL MARKETING PRINCIPLES ON RECRUITMENT

The use of social marketing strategies produced mixed results—some were productive and inexpensive; others were costly and produced no participants. Public service announcements were the most effective of the Community Directed Promotions. Personnel costs were low and material costs were high using Community Directed Promotions, a finding that agrees with that reported in the literature (Dowling & Wiener, 1997; Patrick et al., 1998). The high materials cost was due in large part to the high cost of a single mass mailing. If the mass mailing cost was omitted, it would bring the total costs for this method down to $772, or a $64 per participant cost, suggesting that a combination of the other promotional activities could be a cost effective approach.

Some social marketing strategies such as a mass mailing were implemented once, evaluated, and then abandoned because of poor

Table 4
Community Directed Promotions by Strategy and Estimated Cost

	Referrals and Inquiries	*Enrolled Participants*	*Yield*[a]	*Cost of Personnel*	*Cost of Materials*	*Total Cost*	*Cost per Participant*[b]
Posters and brochures (> 2,000 pieces)	0	0	—	$35	$125	$160	N/A[c]
Public service general/targeted announcements (11 total)	5	5	100%	$71	$0	$71	$14
Paid newspaper announcements (2 total)	0	0	—	$18	$168	$186	N/A
Direct mail, voter registration list (8,000 pieces)	0	0	—	—	$1,112	$1,112	N/A
Generic mailing, social and health agencies (75 pieces)	0	0	—	$27	$24	$51	N/A
Physician's e-mail group (80 members)	0	0	—	$18	0	$18	N/A
Web page (74 "hits")	0	0	—	$286	0	$286	N/A
Project staff[d] (3 personnel)	4	3	.75	0	0	0	0
Recycled study names (200 participants)	0	0	—	0	0	0	0
Unknown	4	4	100%	0	0	0	N/A
Total	13	12	.92	$455	$1,429	$1,884	$157

a. Yield is defined as the proportion of referrals and inquiries that resulted in an enrolled participant.
b. Cost per participant is the total cost per recruitment method divided by the number of enrolled participants.
c. For purposes of allocating cost per participant by promotional category, a zero number of participants and a zero cost was assigned to categories for which validation of source or cost was not available.
d. This category includes self-referrals resulting from direct personal and professional contact with project staff, exclusive of other recruitment activities.

results and high cost. The timing of a strategy can affect recruitment results as well as the nature of the strategy. The delay in publication of a targeted newsletter describing the research project resulted in three referrals being received shortly after enrollment closed. The Web page

produced no referrals but did receive 74 "hits." The Web page was continued throughout the recruitment period, however, because it incurred little additional cost once designed and acted as a constant project advertisement. Online project announcements and self-referral mechanisms may prove more fruitful in the future as more people purchase personal computers and use the Internet. The physician's e-mail group announcement brought some inquiries, interestingly from distant, more rural clinicians. The use of a commercial vendor for a list of potential participants was investigated but found to be not useful. It became evident that the list to be provided was old, increasing the likelihood that the list would include care recipients that would have been institutionalized or deceased.

Discussion

Analysis of the recruitment process revealed a range of factors that influenced recruitment costs. The academic medical centers drew from large geographic areas and had sizable pools of potential participants, whereas the community-based agencies frequently had smaller and more stable populations of patients that produced fewer participants. Recruiting from the academic medical centers using the Formal Recruitment Method was the most cost-efficient method. The high personnel costs associated with the Formal Recruitment Method reflected the lengthy and complex process of gaining access to an urban medical center and maintaining rapport with the staff. This finding is supported by the literature (Hulley & Cummings, 1988; Hunninghake et al., 1987; Friedman, Furberg, & DeMets, 1996).

During the planning stage, potential referral sites need to be identified, initial entrée secured, and realistic assessments made of the number of available potential participants who meet study criteria and who may be willing to participate. Project presentations need to be made to administrators and staff, multiple in-person contacts are necessary to train or encourage those persons actually making the referrals, and numerous phone calls need to be made until the exchange of necessary information is accomplished. Obtaining institutional review board approval at a cooperating site, a precondition to starting recruitment, can easily take 2 to 3 months. Having a recruitment coordinator

organize and spearhead this time-consuming activity can greatly facilitate entrée into another institution as well as the ongoing management of recruitment activities (Anderson et al., 1995; Dowling & Wiener, 1997; McNeely & Clements, 1994). Entrée into any institution is time consuming and labor intensive, resulting in high costs early in the recruitment process. Once referrals begin, the cost per participant is reduced as more referrals accrue, highlighting the advantage of accessing sites with large participant pools.

Having a well-respected advocate at the host institution is an important advantage. Specific strategies utilized in this project included securing the cooperation of recognized experts in the field of AD from the larger referral sources to serve as paid project advisory board members. At the single largest referral source, a clinical nurse specialist was supported part-time by the project to serve in the role of triage nurse for the intervention.

Considering that 67 sites agreed to refer participants using the Mediated Recruitment Method, the fact that only 15 caregivers actually enrolled in the study using this method was a disappointing result. The high personnel costs incurred resulted from the considerable time and effort required by research staff to identify and secure any referral source, regardless of the size of the potential pool of participants. Within the Mediated Recruitment Method category, substantial differences in yield and cost were evident between adult day programs and AD support groups, revealing how inefficient it was to recruit through AD support groups. Community-based support groups frequently have a membership less than 10 people and only half the membership attend meetings regularly, making the group leaders' estimates of potential participants unreliable. Anecdotal notes kept by the investigators indicated that some support group leaders and staff at smaller agencies believed that most caregivers were overburdened and that participation in a research project would only increase their stress. The research was not seen as an opportunity but rather as a burden to their clients. Agency staff frequently saw their role as advocates and gatekeepers to filter information and protect their clients. Alternatively, the few support group leaders who accepted the investigator's offer to make a group presentation expressed the idea that they had a responsibility to share research possibilities and to let the members decide whether to participate.

In spite of vigorous, intensive, and continuous recruitment efforts, this project fell short of its recruitment goals, reflecting the shared experience of many investigators (Dowling & Wiener, 1997; Lovato et al., 1997; Swanson & Ward, 1995). Factors in the research environment, in addition to the recruitment process, affected recruitment. Health care costs have grown exponentially with technological innovations; insurers are reluctant to reimburse for experimental, unproven treatments; and health care provider institutions are carefully weighing the burdens and benefits of cooperating with research projects (Engelking, 1991; Farrar, 1991).

During the recruitment phase, Boston was the site of a rapidly changing health care environment that included the emergence of large managed care programs and megamergers among large academic medical centers. Changes in the health care delivery system negatively impacted the Boston based project. Two of the five original referral sources, large urban medical centers, merged under a single umbrella just prior to the start of recruitment. This merger resulted in a 4-month moratorium on new admissions to the two clinical services from which referrals were originally expected. The staff downsizing that resulted from the merger required another round of negotiation and networking with reassigned staff with regard to the recruitment process. Tensions associated with the merger created a defensive and competitive climate among clinicians, many of whom became reluctant to refer their patients to other professionals. Provider barriers to enrollment, such as the time commitment by physicians and intrusion in the physician/patient relationship, are increasingly cited as impediments to successful recruitment across a variety of clinical settings (Boult et al., 1998; Dowling & Wiener, 1997; Farrar, 1991; McNeely & Clements, 1994).

The atmosphere of competition seen internally to the merged institution was repeated in the broader health care community. One large, potential referral site that had recently converted to a for-profit managed care facility refused to participate in any randomized study due to concerns of appearing to offer differential treatment to their enrollees. This same agency had also merged with a large visiting nurse association (VNA) in the area, resulting in the loss of that potential referral site also. During the course of recruitment for this study, a directory of research opportunities published by the local Alzheimer's

Association listed 45 separate clinical research studies open to people with AD and their families in our catchment area (Alzheimer's Association of Eastern Massachusetts, 1997). While trying to enlist more referral sources, investigators frequently met with no response to letters and calls to agency representatives. Some agencies agreed to refer but then made no or meager referrals.

Professionals who were clinicians/researchers had direct access to the target population and were at an advantage enlisting study participants for their own research agendas, leaving a diminished pool for the REACH project. Gaining access to a health care institution is a complex and many-layered process that can involve policies and politics that are outside the purview of the investigators. Entrée into a referral site can be denied—not on the merits of the proposed research but by the needs of the host institution's gatekeepers to keep intact an accessible and ready pool of participants for their own research agenda (Dowling & Wiener, 1997).

Recruitment at small referral sources was similarly affected by changes in the larger health care environment. Smaller agencies and support groups frequently reported being overwhelmed with requests from outside professionals looking for research participants. The physician/director of one community-based elder agency was declining all requests for research referrals until the staff and advisory board were able to develop a formal policy to guide their responses. A support group leader on hearing the project's request for referrals reported that it was the fourth such request in less than 3 weeks. Agencies serving ethnic minorities can feel under siege by research requests due in part to the 1994 NIH guidelines for the inclusion of minorities (Lovato et al., 1997). Although there is no strategy available to directly affect the events occurring in the broader health care sector, ongoing monitoring of the local health care environment can alert investigators to changes that may impact their study and signal the need for contingency plans.

Conclusions

The results of this study indicate that a well-planned, multipronged, and flexible recruitment plan is the most productive for recruiting AD caregivers. Investigators reporting on their recruitment experiences

across a range of research designs concurred (Dowling & Wiener, 1997; Friedmanet al., 1996; Lovato et al., 1997; Patrick et al., 1998). Investigators need to keep focused on the goal of recruitment to produce an adequate sample on time and in budget. Adequate planning is critical to successful recruitment. Planning includes budgeting for enough personnel, materials, and time to conduct the recruitment process, using realistic estimates of the potential pools and establishing contingency plans for underenrollment. Multiple recruitment strategies need to be implemented early, before the start of enrollment, including social marketing strategies to broadcast the project to the targeted population. Monitoring enrollment is essential. Short- and long-term goals need to be established early and the accrual rates routinely compared with the established goals. Finally, action needs to be taken as soon as enrollment rates fall to secure the desired sample size and to facilitate an even workload for staff.

The particular research design requirements for individual projects directly affect the cost of recruitment, such as the setting, desired sample size, single- or multisite projects, and the inclusion of any special sub-populations. It was evident in this project that the research environment also impacts recruitment and does so in ways that are less predictable and less manageable. Keeping abreast of changes in the research environment and being open to new and innovative recruitment ideas is perhaps the best defense from the unanticipated consequences of change in the larger health care environment.

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