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Recruiting Hospitalized Mexican American Elders and Caregivers: Challenges and Strategies

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Abstract

Minority group members' participation in clinical research is essential for eliminating health disparities. Early recruitment procedures for a randomized control trial involving minority elders at local hospitals were unsuccessful, with challenges at hospital and individual levels. These challenges included referrals for home health care being written late during hospitalization, hospital staff reluctant to assist recruiters, ill minority elders and protective or unavailable caregivers. We met these challenges with evidence-based strategies, including changing inclusion criteria, increasing study staff, branding our study, using a consistently respectful manner, and pacing our process. After revising our approaches in various ways, we recruited close to our goal, with relatively good retention. Participants reported that benefiting the community rather than monetary reward was a strong motivator to join the study. Unexpected recruitment expenditures exceeded the recruitment budget. Our experiences include strategies that can be more cost-effective in future studies at both hospital and individual levels.

Participation in clinical research by minority group members is essential for eliminating health and healthcare disparities in the United States (National Institute of Nursing Research, 2010). Researchers have published their challenges and solutions for recruiting vulnerable populations (e.g. Fischer et al., 2011), including several articles appearing in a special issue of *Research in Gerontological Nursing* (e.g., Buckwalter, 2009). Many articles have included a special focus on recruiting elders who were Latino or of Mexican descent

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(Berger et al., 2009; Calderón et al., 2006; Gonzalez et al., 2007; Jackson et al., 2009; Loue & Sajatovic, 2008);. Focus has been on barriers and motivators for participation in research. However, recruitment of minority group members continues to be a challenge. This article demonstrates how we faced challenges for recruitment, using evidence-based strategies, under especially challenging circumstances, recruiting Mexican American (MA) elder-family caregiver dyads for an intervention during elders' brief hospitalizations.

The purpose of the randomized control trial (RCT) was to test the efficacy of a telenovela intervention, designed to increase use of home health care services (HHCS) by MA elders. Eligibility criteria for elders were: 55 years of age or older; of Mexican descent; able to read or speak Spanish or English; score 6 or more on the Short Portable Mental Status Questionnaire (SPMSQ); hospitalized; referred for HHCS; receiving daily activities of living (ADL) or instrumental ADL (IADL) assistance; with a medical or surgical diagnosis; and have a family caregiver who either co-resides or lives within a 30-minute drive of the elder's home. Criteria for caregivers were: a primary caregiver, self-identified or identified by the elder; of Mexican descent; 18 years of age or older; able to speak or read Spanish or English; and co-reside or reside within 30 minutes of the elder.

To generate initial contacts, the principal investigator (PI) and bilingual bicultural project director (PD) introduced the study to various hospital staff including case managers, nursing staff, physicians, and social workers. The PD followed protocols approved by the university's institutional review board (IRB) to identify qualifying elders on adult in-patient units. For elders who qualified, the PD asked staff (nurses, unit technicians, or other hospital personnel) to request permission to talk with potential elder participants about the study by reading the recruitment script/flyer. If potential participants gave permission to speak with the PD, she described the study and asked the elder, and the caregiver if present, if they were interested in participating. If the family caregiver was not present, the PD followed up with the elder or dyad later the same day or the next day. As soon as the elder and caregiver verbally agreed to participate, the PD conducted the consent process.

After one month of attempting to recruit participants daily (December 2009-January 2010), only one eligible elder-caregiver dyad had successfully been recruited. We made certain immediate changes that helped us start to recruit more. Although we continued to meet challenges, we successfully recruited 68 dyads during the following 15 months. The goal was to recruit at least 60 dyads (72 to allow for attrition) for the 2-year study. The 5,818 dyads that were assessed are depicted in Figure 1, with the CONSORT Flow Diagram (Moher et al., 2011).

Challenges and Strategies at Hospital and Individual Levels

Hospital Level Challenges

HHCS referrals written late during hospitalization—Initially, the major and immediate challenge was that the actual referral to prescribe HHCS was written last-minute, just before discharge, precluding our chance to administer the two intervention doses. Each intervention consisted of showing a 12-minute telenovela (a dramatized televised story), coupled with a 50-minute guided dialogue. Also, per protocol we needed time to provide

both doses of the intervention. Current stays in the hospital are typically very short (2-3 days). Thus some dyads that met all criteria could not be recruited in time for us to provide two intervention doses (reported within the “discharged too soon” category, but not counted separately, Figure 1). Also, hospital staff rarely took the time to alert the PD if an apparently eligible elder who was likely to receive a HHCS referral was admitted to their unit. Others have reported, as we found, that nurses usually did not have the time to initiate recruitment into studies (Bishop, 2009).

Hospital staff's reluctance to assist with entrée—Recruiters found staff members uncomfortable or too busy to ask patients for permission to enter the room to explain the study. Resistance by staff to approach patients for recruiters to talk with them has been acknowledged by other researchers (Weierbach et al., 2010).

Other hospital challenges—Interruptions included routine nursing care, primary care practitioner visits, meals, procedures, and tests, often not previously scheduled. Another challenge was the number of patients who were unable to participate in the study because they were in isolation status. The risk of non-nursing research staff's inadvertently spreading infection during various recruitment and research procedures precluded participation by these patients. It is possible the sample was skewed by our excluding these patients, but they were not tracked.

Hospital Level Strategies

Change of study protocols in response to HHCS referrals written late during hospitalization. We changed original study protocols after the first month of attempting to recruit and having only recruited one dyad. First, we deleted the inclusion criterion of elders' having been referred for HHCS, although we knew this would restrict our sample size for addressing the long-term effects of the intervention. Second, we deleted the requirement to recruit participants only if there would be time for two doses of the intervention. (Figure 1 shows both totals.)

We also increased our team staff dedicated to the recruitment and consent process. We trained our interventionist graduate research assistant, a 25% employee, whose original responsibility was to provide the intervention, to recruit and consent. We also trained other non-intervention team members to conduct the same processes and baseline and post-tests, to decrease the waiting time for participation. We also hired two additional bicultural recruitment personnel, using indirect funds, spending approximately \$4,000 above what was budgeted.

In the instances when staff members were reluctant to request permission for entrée to speak with patients, we explained this IRB requirement. We also reminded hospital staff to use the IRB-approved recruitment script. Staff became more cooperative as we increased our visibility and branded the study, as described below.

Increasing visibility of the study in response to hospital staff's reluctance to assist with entrée—The PI and PD continued to attend staff meetings and present updates on the study. The PI attended monthly staff meetings on each unit. She brought

snacks to these meetings to increase goodwill and show appreciation to staff for helping the team. Sometimes the PI and recruiter role-played requesting assistance and a staff member assisting us with gaining entrée into the patient's room. These presentations were kept very short (i.e., about 3-5 minutes), just long enough to stimulate interest and promote goodwill.

The PI frequently accompanied recruiters, to increase visibility and further legitimize their activities. The nurse CEO of the on-campus hospital distributed flyers at all-hospital nurse retreats to show support. The directors of case management at both hospitals endorsed the study similarly to their hospital staff and management staff members. Other researchers' methods have supported our findings that in response to organizational challenges, education and support by administration were critical (Mackin, Herr, Bergen-Jackson, Fine, Forcucci, & Sanders, 2009). We presented certificates of appreciation with formal letters, with copies to their managers, to staff members who had been helpful. This continued to keep our study visible to both staff members and administration. We met with nursing students and nursing instructors who had clinical assignments at the on-campus hospital, explained the participant criteria, and requested they remind their preceptors to contact the PD if they identified qualifying participants. Additionally, we screened out elders in isolation as soon as we knew this status, to prevent staff's and our team's spending time on dyads we should not recruit.

Branding the study—Branding was a way to both increase visibility and legitimize our efforts. For example, we added ENCASA (Elder aNd Caregiver Assistance and Support At-home) team members' photographs to all flyers, and also taped the flyers to the boxes of treats we brought to staff. Also, after an addendum approval by IRB, we added a brief invitation to learn more about the study on the on-site hospital's electronic sign, located both at the entrance and near the cafeteria at the on-site hospital (Figure 2). We printed "business cards" with study information to distribute to nurses, social workers, case managers, students and faculty; and we put copies of consent forms and the PD's and PI's cards, which we gave to participants, in attractive school-color College of Nursing packets. We purchased "College of Nursing" polo shirts in the university's color for each team member involved in recruitment to wear. Other researchers have also reported success through increased visibility and branding, for example, by bringing to staff snacks with attached messages about the study (Weierbach et al., 2010) and recognizing helpful staff with acknowledgement to their supervisors (Segre et al., 2011).

Individual Level Challenges

Ill elders—Ill elders understandably had low energy capacity or endurance, pain, fatigue when returning from treatments (e.g., dialysis), or were heavily medicated to control pain, as well as normal changes of aging, such as being hard-of-hearing, and co-morbidities, making it difficult for them to stay alert or even awake, and difficult to start or continue the screening and consent process. These challenges would require the recruiter to postpone the recruitment session and return later. Also, sometimes physicians, staff members, and caregivers believed the research procedures might tire their elder loved one and would discourage participation. Our observation that family members sometimes acted as

protective gatekeepers has been reported by others (Mackin et al., 2009; Sisk, Horowitz, Wang, McLaughlin, Hebert, & Tuzzio, 2008).

Minority elders—Potential participants being of a minority posed challenges to recruitment in response to a general distrust of research, especially in today's political context related to immigration, and especially in the southwest where Arizona Senate Bill 1070, which requires law enforcement agencies to check immigration status of individuals they encounter (Immigration Policy Center, 2011), caused some patients to be afraid of being recruited into the study. Anti-immigrant sentiments had been expressed fervently in the public/political discourse (Jones, 2010). At least six staff members and three patients or caregivers overtly expressed concerns about prejudice, racial profiling, or immigration status issues as reasons for not wanting to participate. There were likely other potential participants who chose not to divulge these concerns. Fear of discrimination has been reported as a major reason for not participating in studies (The PEW Hispanic Report, 2010) as well as a major reason for not using health services such as HHCS (Barr & Wanat, 2005; Ennis, Rios-Vargas, & Albert, 2011).

Elder-caregiver dyads—Recruitment was time consuming partly because both participants needed to agree to participate in the study before we could recruit either one. This required additional planning and coordination through telephone messages and waiting at the hospital for family caregivers to arrive between work and other obligations.

Individual Level Strategies

Pacing, including caregivers, and reiterating the study in response to ill elders. In consideration for ill elders, we paced the recruitment presentation and the intervention, according to ill elders' need for rest and recuperation. For example, we interrupted the recruitment or consent process if the elder needed to rest, to eat, or visit on the phone. When possible, we included and enlisted other family members to encourage participation. We also found that we frequently needed to respond to questions about whether we provided direct services.

Employing personalismo and respeto in response to minority elders—We consulted with the ENCASA Community Advisory Council as an initial strategy, in response to the pervasive political climate. We were consistent in our approach in clarifying our purpose to both staff members as well as to dyads, modeling respect rather than discrimination in the politically edgy context of our border state. Language was an important factor in recruiting monolingual Spanish speaking elders. Others have also found that being able to present the study in Spanish was very important (Berger et al., 2009; Jackson et al., 2009).

The recruitment team used culturally appropriate methods to establish rapport and build a trusting relationship with potential elder and caregiver participants (Murphy et al., 2007). We employed *personalismo*, showing human-to-human regard and friendliness, taking the time to establish trust by giving personal attention (Espino & Oakes, 2007) during every contact. It also includes demonstrating *respeto*, respectful deportment, including, but not

limited to, polite manners; and having cultural humility (constant self-reflection to acknowledge, respect, and accommodate diversity; National Alliance for Hispanic Health, 2001).

Adjusting our timeline in response to recruiting elder-caregiver dyads—We took the time and effort to contact family caregivers if they were not at the hospital during our regular recruitment hours. Team members stayed late to accommodate caregivers' work schedules.

Other Issues

Proactive rather than Passive Recruitment

We recruited 100% of our dyads using face-to-face (proactive) recruitment, as opposed to any potential participants' responding to flyers (reactive recruitment). This was the norm as reported by other researchers with similar populations (Calderón et al., 2008; Larson, Ferng, Wong-McLoughlin, & Wang, 2009; Mackin et al., 2009). None of our dyads were recruited by anyone other than the research team. A few hospital staff (one case manager, two residents, and one physician) attempted to initiate recruitment in five cases, by telling us about potentially eligible participants. However, each of these potential participants either did not agree for us to approach them and explain our study, or did not meet criteria. Other studies also found that potential participants did not self-initiate participation. Toobert et al. noted that this may be a positive occurrence because self-selected samples could be biased (2010).

Community Solidarity

Recruitment was facilitated by bilingual, bicultural research team members' pointing out to potential recruits that their participation would benefit the shared community, by helping educate the community about HHCS as a resource for keeping elders at home. Participants volunteered comments to the PD that helping the community was more of an incentive than the subject pay. Other studies with Hispanic individuals also reported that the purpose of the study (to improve the health of the MA community) was rated as even more important than other aspects (Kneipp, Lutz, & Means, 2009; Larson et al., 2009). Also, the necessity to reiterate that the study did not provide direct services occurred in previous studies (Crist, Parsons et al., 2009).

Limitations

Although combined strategies provided overall recruitment success, we have no measure for identifying which specific strategies were more successful. For example, we cannot determine whether the electronic sign improved recruitment.

Research Implications

Limited application—Eliminating the recruitment criterion that the elder be referred for HHCS was a trade-off, enabling us to recruit more participants, but limiting the sample size for evaluating the intervention. Relaxing this criterion and including elders not referred for HHCS decreased our final sub-sample for assessing whether or not the intervention

increased HHCS use. This sub-sample totaled 16 of 68 dyads (24%), making it difficult to assess the distal outcome of the intervention (increased use of HHCS), although we were able to analyze pre- and post-test data on other variables. However, the other protocol change, deleting the second dosage, did not show differential effects. Buckwalter (2009) reported that one-third of all clinical trials fail to recruit projected sample numbers, sometimes because of overly restrictive recruitment criteria. Our future studies will now be able to benefit from the established partnerships with key personnel in the recruitment setting, in order to facilitate earlier identification and recruitment of specific samples (Weirbach et al., 2010), in our case, elders who will receive HHCS referrals.

Partnerships—As we have done in past studies, we used community-based participatory research (CBPR), asking for input, and collaborating with the “community” (Crist & Escandón-Domínguez, 2003), in this case, in the hospital setting. We viewed in-patients, their families, and staff at the hospital as the community with which to collaborate (Crist, Parsons et al., 2009).

We enriched our partnerships by inviting elders and caregivers who expressed opinions about the telenovela, or concerns about healthcare disparities, to join the ENCASA Community Advisory Council after they completed their 6-month participation in the study. We also invited interested nurse managers and unit technicians to join the ENCASA council. We have found their combined input a very important addition to our partnership. Other research supports the success of emphasizing the benefits to the community of scientific research in building trust and enhancing recruitment (Larkey, Gonzalez et al., 2009; Grady et al., 2006).

Budgeting—Budgets for recruitment are rarely reported (Berger et al., 2009; Buckwalter, 2009), although Toobert and colleagues costed out their recruitment expenses by participant (2010). Some of our unexpected costs were not funded. One example is that recruiters added minutes used on their own personal cell phones to contact each other to ensure timely and smooth transitions between the recruitment-data collection-intervention steps. Costs can be better anticipated in future studies. Also, planning for time needed to establish initial partnerships and support of the study at all levels will be necessary. Additionally, we needed to take a no-cost extension for the study because of our slow start in recruiting for the longitudinal study.

In conclusion, our feasibility study was instructive, reminding us that strategies should include accurately estimating numbers of eligible participants and timelines, consistently branding, using *personalismo* in every elder/caregiver encounter, continuing a CBPR approach, and having an adequate recruitment budget. Such strategies are essential to meet recruitment goals for RTCs with vulnerable populations. In this way, interventions to eliminate disparities can be supported by adequate samples which will provide significant and applicable data.

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Flow Diagram

Figure 1.
Flow Diagram

Watch a Telenovela!

The UA College of Nursing is seeking family caregivers and elders to watch a 12-minute telenovela while the elders are in the hospital.

You will qualify if:

Caregivers and elders are of Mexican descent

The elder is 55 years of age or older

Contact: _____, _____, or _____
[recruiters' first names]

____ - ____ - ____
[phone number]

All calls are confidential. A small monetary gift will be provided.

[PI's name and credentials]

Figure 2.
 Electronic sign posted in on-site hospital.