Retaining Participants in Outpatient and Community-Based Health Studies: Researchers and Participants in Their Own Words

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Abstract
Loss to follow-up can introduce bias into research, making it difficult to develop inclusive evidence-based health policies and practice guidelines. We aimed to deepen understanding of reasons why participants leave or remain in longitudinal health studies. We interviewed 59 researchers and current and former research participants in six focus groups (n = 55) or interviews (n = 4) at three study centers in a large academic research institution. We used minimally structured interview guides and inductive thematic analysis to explore participant-level, study-level, and contextual participation barriers and facilitators. Four main themes emerged: transportation, incentives and motivation, caregiver concerns, and the social and physical environment. Themes shared crosscutting issues involving funding, flexibility, and relationships between researchers and research participants. Study-level and contextual factors appear to interact with participant characteristics, particularly socioeconomic status and disease severity to affect participant retention. Participants’ characteristics do not seem to be the main cause of study dropout. Researchers and funders might be able to address contextual and study factors in ways that reduce barriers to participation.

Keywords
research policy, altruism, focus groups, relationships in research, research participation, participant incentives

Method
We collected data using minimally structured focus groups and interviews. Focus groups are particularly appropriate for uncovering new information about complex, multidimensional issues and addressing real-world problems (Creswell, 2007; Millward, 2012). We used inductive thematic analysis to describe and understand research participation from the perspective of researchers and research participants and to explore researchers’ and participants’ perceptions of things that might influence research participants to leave or stay in studies (Guest, MacQueen, & Namey, 2012). We conducted a total of six focus groups at three sites. At each site, we conducted two focus groups: one with researchers and other study personnel, and the other with current and former study participants, all from a wide variety of longitudinal

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studies. We also conducted individual interviews with four study dropouts who responded to recruitment materials but declined to participate in focus groups. We used an iterative process throughout the project and in our inductive analysis.

Study Sites

The focus groups took place at three research centers associated with a large university located in the Western United States. One center (Site A) was chosen specifically for its research with aging populations and its large cohort of older adult patients and healthy controls. The other two sites (Sites B and C) were selected from among six clinical research centers. Of these six, four were excluded because they were not available during our study window, because they conducted primarily pediatric research, or, in one case, because the center director felt that an open recruitment and focus group format posed a threat of contamination to one or more randomized clinical trials being conducted there. While some clinical trials are conducted at the study sites, most of the research projects at all three sites are multiyear observational studies. Some studies include biological measures, from blood pressure checks and cheek swabs to more invasive procedures such as blood draws or lumbar punctures.

Site A is located in two medical buildings. Clinical assessments take place on an upper floor of a bustling patient care center with a busy reception area. Study participants are interviewed in a nearby medical office building, with dedicated interview rooms and small, quiet reception areas. Site A offers medical and support services for patients, family members, and other caregivers, and holds educational events where participants can meet and interact with one another. At any given time, Site A generally houses more than two dozen ongoing studies, including a large multiyear study of dementia and healthy aging, and a separate study of aging and cognition in Asian Americans.

Site B is located away from the university, in a small building at the edge of an inner-city neighborhood characterized by vibrant street life, social disadvantage, poverty, and homelessness. The outside door to the research center opens onto a busy sidewalk. During the day, commuters, tourists, and shoppers throng the area. At all times, area residents pass by, meet, and congregate. The center is on the second floor. An elevator and an open staircase lead to a reception area where research participants can congregate, talk with each other and the receptionist, make phone calls, use the rest room, and obtain information about services and other studies that are recruiting new participants. Site B’s research focus is on participants who are generally considered hard to retain: poor, largely minority, and marginalized populations living with HIV. Even so, most Site B studies have high retention rates, generally more than 95%. Many of the research participants live in the area, and the site is easily accessible by public transit. The center conducts participant events designed to develop an inviting atmosphere and a sense of community. There are more than a dozen interview rooms and a phlebotomy station on-site. Site B generally houses between 5 and 10 large observational and behavioral studies and, occasionally, clinical trials. Most of the studies are multiyear projects.

Site C is a clinical research center located on an upper floor of a busy hospital. The site has several examination and interview rooms, medical testing facilities, nursing services, and a clinical trials unit. The check-in desk faces a corridor that connects several departments. There is no designated space for participants to congregate, although they can use patient and family waiting rooms on the same floor. At any given time, Site C houses approximately 150 clinical and behavioral studies.

Recruitment and Participants

We first met with research center directors to discuss our study. The directors introduced us to research coordinators who helped us contact research personnel and participants for our focus groups and interviews. We recruited research personnel for our focus groups at staff meetings, on staff email lists, by posting flyers at the research centers. We emphasized that we were studying the research process, not any individual study, and that the long-term objective was to improve retention rates in future studies. Researchers at every level were eligible if they worked on prospective outpatient or community-based clinical or observational studies at the study sites or had ongoing contact with research participants at those sites.

We recruited study participants for our focus groups with flyers posted in reception areas and hallways or distributed by research staff. In addition, Site A researchers sent letters to former research participants who had dropped out of Site A studies, inviting them to participate in our focus group study. Our recruitment materials emphasized that we were studying the research process rather than research participants, and that their participation would help researchers conduct better future studies. We screened all volunteers who responded to our recruitment materials. Research participants were eligible if they were enrolled in studies at the research center or if they were caregivers who were responsible for transporting a patient to the study site. Other inclusion criteria were proficiency in spoken English by the subject or caregiver, age 18 or older, and current or recent participation in a prospective study of at least 6 months duration and two study visits. Study dropouts were eligible if they had left such a study at one of the study sites within the previous 4 years. Our exclusion criteria were inability to provide consent to participate in our study, and participation in or conduct of only inpatient studies or studies with cross-sectional, retrospective, or other nonlongitudinal designs. We closed recruitment for each focus group when we confirmed a maximum of 12 participants. We conducted focus groups and interviews from June 2011 through May 2012.
Data Collection

We conducted 90-min focus groups with study personnel during lunch breaks or after hours in meeting rooms located at the research centers. We asked about characteristics of studies and study participants, and factors that might help or impede the retention of participants through all phases of research. We started with questions about the attendees’ experiences as researchers, their roles, and the studies they worked on. We continued with conversations about their perceptions of participant retention and study types, target populations, participants’ characteristics, hard-to-retain study participants, follow-up protocols, and other topics that emerged in the discussions. We conducted focus groups with study participants in meeting rooms off-site or on-site at a time when most study personnel were not present. We started each focus group with warm-up questions about the types and number of studies the attendees had participated in. We then discussed their experiences as research participants, and whether and why they completed studies, missed visits, or dropped out. In addition, we asked about factors that made it easy or difficult for them to participate in research. We also conducted telephone interviews with four dropouts from Site A studies who responded to our outreach materials but said that they did not want to participate in the focus groups. Because we were especially interested in including their experiences, we offered them the option of participating via individual 30-min in-person or telephone interviews. The interviews with study dropouts covered areas similar to those discussed in focus groups, with special emphasis on why they left the studies and whether there were ways they might have been retained. We used discussion guides that were minimally structured and inductive; that is, earlier conversations informed questions and probing in subsequent groups and interviews. To minimize effects of our own preconceptions and collect data that reflected focus group participants’ perceptions and experiences rather than ours, we used minimally structured interview guides and spoke minimally during the focus groups and interviews. We made efforts not to inject our opinions and into the conversations (Bradbury-Jones, Sambrook, & Irvine, 2009). We encouraged all focus group participants to speak throughout the sessions, and probed when necessary to elicit more information.

All focus group participants received a US$40 cash incentive in appreciation of their time and trouble; interviewees received US$25. We provided meals or substantial snacks that were appropriate for the time of day when the focus groups took place. We decided a priori not to collect sociodemographic data. There were two main reasons for this decision. First, we believed that the site differences were greater and more meaningful than differences among individual participants. This would render analysis by sociodemographic characteristics of individuals misleading. Second, our stated purpose during the recruitment phase of our project was to examine the research process itself, rather than the participants in our study. We made note of the apparent age, gender, and racial/ethnic makeup of the focus groups and the ways attendees described themselves.

Data Analysis

We recorded focus groups and interviews. The digital recordings were transcribed verbatim by a professional transcription service that has been used by other qualitative researchers at our institution. We began our analysis after conducting our first focus group and continued throughout the study. We first read each transcript to get an overall view of the discussion, then we reread and identified relevant statements. We then grouped similar statements into categories, and we organized these into themes. We developed codes to represent the themes we identified, created an overall thematic matrix (Guest et al., 2012) organized into final themes and characteristics that focus group participants that were identified as having substantial effects on the ability of studies to retain participants. We identified as themes broad factors that appear to have substantial effects on the research process. We identified as characteristics the specific attributes of study participants, study design, and implementation, and the context in which studies take place. Throughout the study, one researcher (dho) manually coded the data. We used a preliminary multilevel coding scheme (participant, study, and context) to identify themes and characteristics. Another researcher (lab) reviewed and analyzed transcripts and text block on an ongoing basis, and suggested additional categories for the coding scheme.

We used the preliminary scheme to code the dataset in more detail, using an inductive, iterative process to revise the original coding as new insights and patterns appeared. We discussed the coding with other researchers, including a student intern who attended some focus groups and a colleague who is an expert in qualitative methods. We then created working data tables for research personnel and study participants. We asked for feedback on our coding and focus group matrices from several researchers who participated in the focus groups. The use of such informant feedback is a way of establishing dependability in qualitative research (Creswell, 2007). The data we present are based on the comments of multiple participants or discussions that took place in multiple focus groups. The quotes we chose for incorporation into the text are representative of these discussions or illustrate variations in the data.

Human Subjects

This study was approved by the Committee on Human Research (CHR) of the University of California, San Francisco Human Research Protection Program, Approval 11-05235. To protect the confidentiality of our participants, we obtained verbal consent and provided CHR-approved study information sheets. Incentives were paid in cash, receipts recorded only study ID numbers. Researchers conducting the studies that provided the pool of volunteers were
not advised if any of their staff or research participants participated in our study. We asked participants to avoid using names during the conversations, and we strictly limited access to the transcripts to our research team.

Results

We recruited 63 researchers and research participants for six focus groups at three research centers. Of those 63 individuals, 55 (85%) attended and 8 (15%) were no shows. Of these 55, 23 were researchers and 32 were current and former research participants or study dropouts. In addition to the 55 focus group participants, four study dropouts who responded to our outreach materials declined to participate in the focus groups, but agreed to individual interviews. Therefore, 59 people participated in our study. Almost all of the researchers and most of the research participants/dropouts said that they had been involved in more than one study, and many said that they had participated in multiple studies over time. Several research participants who attended the focus groups mentioned that although they were currently actively participating in a study, they had dropped out of previous studies. Five participant focus group attendees identified themselves as caregivers for participants in our focus groups and in other research studies.

About three quarters of the people who participated in our study (44/59) were women. Research participant focus groups included 13 research subjects from Site A studies, 9 from Site B studies, and 10 from Site C studies. Most research participants appeared to be middle age and older adults; six identified themselves as caregivers who were responsible for escorting research participants to and from study sites. There were very few young adults in the research subject focus groups. The subject groups were diverse; about half appeared to be or identified themselves in conversation as members of racial or ethnic minority groups; attendees in the Site A participant study group included six people who were research subjects or caregivers in a study of cognition and aging in older Chinese adults. The four study dropouts whom we interviewed by telephone described themselves as retirement-aged, but all said that they were currently self-employed or working as volunteers. The research personnel worked at three academic research centers; the focus groups included 11 researchers from Site A, 5 from Site B, and 7 from Site C. Research personnel ranged in age and professional status from young adults in their first research jobs to senior staff, and included receptionists, research coordinators, interviewers, clinicians, center directors, and principal investigators.

Analysis of data from the focus group and interview transcripts yielded four major themes: transportation, participant incentives and motivation, caregiver concerns, and the physical and social environment. Within these themes, characteristics of participants, studies, and context emerged as barriers to or facilitators of participant retention (Table 1). Three crosscutting issues: funding, flexibility, and relationships, were common to all of the themes (not shown in the tabular form).

Theme 1: Transportation

Researchers and participants alike described transportation as an important element in the retention of research participants. Within this theme, we found that multilevel characteristics act as barriers or facilitators; these include income, access to a car and other resources, comorbidity and disease severity, site accessibility, and the ability of investigators to reschedule visits and reallocate resources. Discussions also frequently centered on such contextual factors as public safety and transit options:

Like the last time they scheduled the MRI, it was at night and I couldn’t come because he’s [paid caregiver] going to accompany me . . . it sounds kind of silly but I didn’t want to come down there on the bus at night. (Participant)

If it’s local, then you can pay for a cab or a bus pass. Actually, I can’t tell you how many hours it took to figure out how to pay for bus passes . . . I don’t think we were ever able to do it. (Researcher)

Researchers said that they knew that reimbursing study participants for transportation costs was extremely important, but that funding rather than participants’ needs usually determined their ability to pay:

We can barely pay for a parking sticker . . . after NIH cuts your funding by 20% you end up with a limited budget and you face well, should I have one less staff person so I can’t analyze my data . . . or should I boost up the travel money? (Researcher)

Like their travel was reimbursed [by the private sponsor] and we were getting paid hundreds of dollars on a per-patient basis to run the study, so it gave us a lot of incentive and a lot of money to play with to actually get the patients in when they needed to get in. (Researcher)

Study protocols and personal interactions between study personnel and participants were important in meeting transportation challenges and retaining a study’s particular target population. An interviewer described taking special care with older participants, saying “Our offices are hard to find. The better I give them instructions on how to do that the smoother that goes, I think the less scared of it they are in the future.” Flexibility in the implementation phase of studies emerged as a facilitator of participant retention, allowing researchers to address individual concerns that might otherwise cause participants to drop out. A participant in a privately funded clinical study told the group how he was able to participate even though he had to travel a long distance:

I have PTSD. And so for me to take the train by myself was kind of a trip, plus I had to pay for the train before I got there. They
had someone meet me at the station, pay for my fare, and ride with me. (Participant)

Study participants’ proximity to their study site, convenient and affordable public transit, or access to a car and convenient parking facilitated participation. Researchers said that participants who lived far from study sites or who moved far away during the course of a study were very difficult to retain. Changes in participants’ employment status can affect the time they have available for study visits and

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**Table 1. Major Themes and Multilevel Barriers to/Facilitators of Participant Retention.**

| Level | Barrier characteristics | Facilitator characteristics |
|-------|--------------------------|----------------------------|
| **Theme 1: Transportation** | | |
| **Context** | Restrictive funding policies; strict line-item adherence; remote or inaccessible site; perception of poor public safety; area transit options, lack of area or on-site parking | Private funders may pay long-distance transportation costs; convenient parking; accessible public transit infrastructure |
| **Study** | Inadequate travel reimbursement; inadequate/inflexible resource allocation | Transit/parking vouchers; scheduling flexibility, knowledge of participants’ needs |
| **Participant** | Poor access to car/public transit; mobility impairment; caregiver burden; disease severity/comorbidity; cultural barriers; distance | Car ownership; familiarity with site; acculturation; English proficiency; income; willingness/ability to pay for travel |
| **Theme 2: Participant incentives and motivation** | | |
| **Context** | Funding policies; Institutional Review Board involvement | Scientific process; societal commitment |
| **Study** | Inadequate budgeting for incentives; lack of flexibility to reallocate resources; monetary incentive inadequate for participant burden; study protocols prohibit sharing information with participants; failure to reward participant’s motivations to participate in research | Monetary incentive congruent with participant burden; provision of information to participants/their doctors; salient nonmonetary incentives; participant appreciation/education events, provision of nonstudy services; provision of food during study visits |
| **Participant** | Motivations not addressed; no need for monetary incentive; lack of adequate incentive perceived as lack of respect; investigator refusal to provide information; misunderstanding of incentives | Motivation (belief in research, altruism, volunteerism, need for information about rare disease); education; study salience; feeling appreciated; desire for information; low income (need for monetary incentive) |
| **Theme 3: Caregiver concerns** | | |
| **Context** | Transit difficult to negotiate with demented or sick patient/participant | Social and material support for caregivers: respite programs, services that reduce overall burden |
| **Study** | Long/difficult caregiver questionnaires; study visits add to caregiver burden; dementia-related difficulties for caregiver; inability to schedule appointments around caregiver schedule | Flexibility in who accompanies patient; participant appreciation/education events (content and opportunity to meet other caregivers); study visit w/patient provides respite for caregiver |
| **Participant** | Highly burdened caregiver; busy schedule, other appointments; employed family caregivers’ job responsibilities; family upset by diagnosis; HIV+ elder may not have steady caregiver | Caregiver gets information about resources from study personnel and other caregivers; paid caregiver; retired caregiver; genetic studies of interest to family caregivers; caregiver participates to benefit patient/family, networking with other caregivers, connection to health care professionals |
| **Theme 4: Physical and social environment** | | |
| **Context** | Funding climate; confusing site; intimidating, unattractive, or dangerous location; poor accessibility for people with disabilities; high visibility/lack of privacy; poor community–institution relationship | Site housing many studies; social interactions among participants in different studies; site as community asset; institutional reputation |
| **Study** | Unpleasant study rooms; lack of waiting areas; intimidating site; insufficient staffing to retain large cohorts | Providing instructions/directions appropriate for older adults; welcoming atmosphere; respectful treatment of participants |
| **Participant** | Marginalization; social disadvantage; low English proficiency; mild cognitive impairment; feeling like “just a number.” | Identification as part of larger social or scientific process, strong personal identification with study focus; rare disease with no good treatment options; connection to health care delivery system |
the ability of long-distance participants to afford travel expenses:

When I joined, I was working. The flight was cheap, and I arranged other things to do there. Now I’m retired and I have time but not the money. If they could have covered some of my expenses, I might’ve stayed. (Study dropout)

Researchers who took part in the focus groups said that culture, language, and socioeconomic status (SES) have substantial effects on transportation logistics. They said that the interactions led to special challenges in getting some participants to research sites:

I should also say for [some populations], distance is an issue in a very different way. A lot of people who live, for instance, in Chinatown really don’t feel that comfortable coming up here [to a research site in another part of the city] and that’s a barrier that the rest of our cohort doesn’t experience. And it’s certainly true for the less educated, less acculturated group. (Researcher)

**Theme 2: Participant Incentives and Motivation**

Researchers and research participants repeatedly described monetary and nonmonetary participant incentives as important motivators. However, investigators said that funding levels and ethical concerns about participant coercion limit the amount of financial compensation they can offer. Funding policies and regulations can also impede the flexibility researchers need to respond to changing and emerging needs of the population during study implementation. Research participants stressed that monetary incentives should be congruent with study-related risks and burdens to participants and caregivers. Research participants from Site B, mostly poor and at best marginally employed, said that monetary incentives were the primary reason they participated in research and that they looked for studies that paid well. “I mean, the money. We’re sitting here and we’re telling you it’s the money.” They and others expressed concerns that money might persuade people with low incomes to participate in studies when otherwise they might not, although no one said that this applied to them personally. Research participants from all sites made it clear that money would not be the only motivator. This was especially true for the less educated, less acculturated group.

Participant 1: Well I wouldn’t do a smoking group sponsored by Phillip Morris [large tobacco company].

Participant 2: If you’re taking my medical information and using it to market, not to improve the field but to market, it is just queasy for some reason.

Participant 3: For these drugs to get on the market, they have to show progress with it, you know . . . the FDA won’t fund them anymore.

Although many of the research participants in Site B and C participant focus groups said that money was the most important motivator, this was not always the case. Researchers from Site A said that older, highly educated, and affluent participants sometimes did not even accept incentive payments. In all groups, the need for information and the salience of the research topic emerged as especially important motivators for patients in studies of conditions with few treatment options:

I’d say the financial incentive’s huge if it’s not something that affects you. Like if you’re a healthy control or you’re just participating “because.” But if it’s maybe a medical condition you have, for me, I would’ve done the study either way. Luckily it paid. (Participant)

However, unmet expectations could cause participants to express dissatisfaction or even to leave studies:

They really don’t tell you anything except that “if we think that you have a serious, you know, problem, we’ll let you know” . . . So it seemed like very much for me a black hole. I found that not very satisfying ‘cause it was taking a fair amount of time and that’s why I kind of just decided to leave. I thought I was going to get a little more information and I got pretty much no information out of it. (Study dropout)

While some participants emphasized the importance of perceived personal benefit in the form of information or monetary incentives, many described volunteerism and the desire to help others as important motivations. Others talked about how participation in research gave them a feeling of connection to the scientific community and enabled them to contribute to advancements in medicine. Several participants who were healthy controls in studies characterized their own altruism as part of a larger social commitment to science and population health. Some researchers said that they frequently saw this particular motivation among highly educated participants, and that education and culture played an important role, especially among immigrants. One researcher who worked primarily with immigrant populations said, “Most of the time I see the [immigrants] who are, who do have that concept, contributing to the greater good and research, are probably PhDs or if not, at least college graduates.” Another said that it is important for researchers not to project their own values onto their research subjects:

I think we’re used to the idea of like the culture we grew up in and the fact that we work here, that oh, I want to contribute to research is like even a concept. And I feel like other cultures it’s not necessarily this idea that oh, I’m contributing to science by being a research subject. (Researcher)
The discussions of motivations of altruism, volunteerism, and scientific importance were animated and enthusiastic:

Whenever I see something on the board I can qualify for, part of it is, “Oh, I’m getting a Safeway card.” But part of it I feel like maybe I’m helping a little. Plus, it’s kind of exciting. You never know what’s going to happen. (Participant)

One of us might be the clue. But just in these years, all of a sudden—you know, it’s gone from a small study . . . to be enormous . . . We’re all getting older, a lot of us ’cause Ronald Regan had the money to put into it, the whole foundation, but it has changed so much since he was first diagnosed and died. But it’s just amazing the kinds of things that are out there, all because people have gotten involved. (Participant)

They’re all like really proud to be participating in a study that they think is going to have an impact on other others who have been dealt the same situation that they’ve been dealt . . . That’s pretty significant. (Researcher)

**Theme 3: Caregiver Concerns**

Family members’ desire for information about the patient and possibly heritable conditions emerged as particularly strong motivation to keep participants in studies. Other motivators included caregivers’ desire to help family members, and the respite caregivers had during participants’ long study appointments. Conversely, difficulty accepting patients’ diagnoses or lack of useful information emerged as reasons family caregivers and patients might drop out of studies. Family caregivers who were juggling jobs and family obligations were sometimes unable to meet study obligations. Transportation and motivation were of particular importance to caregivers. Researchers described the difficulty caregivers have getting sicker patients, or those with mental health issues or increasing dementia, to study sites as a substantial barrier:

I think sometimes it makes it more difficult to travel when you have somebody that might, you know, not be very agreeable to sitting for long periods of time on a plane or that they feel like they can control. (Researcher)

Researchers who worked with HIV+ participants mentioned that older HIV+ adults sometimes do not have family or steady paid caregivers, making scheduling and participation in research difficult. Moreover, patients’ declining cognition could also change the way study personnel interact with research participants and their caregivers. Researchers acknowledged the need to address this with staff training and sensitivity:

It’s better to call the caregiver because it’s more likely that you’ll get the appointment scheduled and they’ll actually come. But at the same time, you know, the [early dementia] patient realizes that you’re not calling them to schedule that appointment and gets offended that you didn’t call them. So it’s kind of tricky to navigate . . . And even the family member might be like, “Why are you calling me to schedule this?” You know, like they’re semi in denial about what’s going on or how much they need to help out. (Researcher)

Overall, it appears that caregivers experience facilitators and barriers similar to those experienced by research participants. However, the focus group discussions highlighted the additional burdens of assisting with the study participation of sick or cognitively impaired research participants.

**Theme 4: Physical and Social Environment**

Focus group discussions frequently focused on characteristics of the physical and social environment, and how these might affect study participation. On-site parking was generally described as an important factor for those who had a car and drove to the sites. Accessibility is a product of site location and the built environment, but it was also discussed as a function of transportation options, cultural differences, participants’ level of disability, and caregiver burden. One participant emphasized that even with parking, it was difficult to arrive on-site:

I have a problem with walking. It would be real nice if somebody could pick me up. I know that’s not feasible though. So if I’m parking in a garage, I have to come across the street. I have to carry this [oxygen] everywhere I go . . . yeah, so, you know, I do what I can. But it would be helpful if I could do a whole lot by phone, a whole lot more by telephone. (Participant)

Participants and researchers repeatedly said that physically attractive, clean, welcoming study sites encouraged continued participation. Site B, where many participants are homeless or marginally housed, also provides a place where participants could come by just to relax, chat, have a cup of tea, or make a phone call; participants said that because of this they sometimes even came by in-between study visits. At the same time, many participants said that study visits conducted in unpleasant rooms and sites without comfortable waiting areas were disrespectful or made them feel unappreciated. In studies with marginalized and socially disadvantaged target populations, researchers and participants said that “official looking” or intimidating research sites, for example, those where participants had to interact with security personnel or show identification to enter, could discourage continued participation in the research that takes place there.

Institutional reputation emerged as both a participation barrier and a facilitator. Participants mentioned the university’s role as a leading research and medical institution as an incentive to participation. Some researchers noted that previous negative interactions between academia and the community sometimes made it difficult to enroll and retain participants. Participants explicitly described perceived institutional systemic conflicts of interest as disincentives:
There’s too much blurry line between companies and universities. They discovered in the last few years that professors are getting paid or some information’s being slanted or they’re leaving out some information. It’s not a clean line. I don’t want them to say, “Oh, let’s take the best 80% that it worked well on, ignore the 20 that it didn’t work well on and then we can go to the FDA.” (Participant)

Crosscutting Issues

Issues related to funding, flexibility, and relationships were common to all of the major themes that emerged in our study. Researchers said that funding policies and budgetary constraints and cuts reduce study resources and staffing levels. This in turn can affect study design and implementation, limiting follow-up protocols, staff availability, and sometimes even reducing investigators’ inclination to enroll potentially hard-to-find participants into their studies. According to some focus group participants, when studies limited follow-up visits to weekdays, it caused them to miss visits or drop out of studies when their employment or personal situation changed. Limited resources can result in smaller-than-ideal sample sizes because large cohorts require more effort for recruitment, data collection, and follow-up. Moreover, stringent rules, for example, those found in multicenter projects involving large consortia or National Institutes of Health (NIH)–funded studies, sometimes denied investigators the flexibility to quickly adjust study visit time windows and retention protocols in response to the needs of the study and the participants:

So there was a time . . . maybe just four years ago, that you could manipulate the participant incentive budget to allocate a few hundred dollars for unique transfers or taxi vouchers or food or something like that. But [the university] was audited . . . and we were told we could no longer—even though it was going towards the participant use—do it unless it was itemized in the budget. (Researcher)

Sustained contact, personal touches, and the relationships these engender emerged as important factors in the ability of researchers to respond to participants’ needs in scheduling, transportation, and the desire for information. Researchers said that good communication among principal investigators, coordinators, staff, and site directors provided important avenues of feedback about which retention procedures worked and which did not. On-the-ground research staff said that this was particularly important when studies were led by less-experienced principal investigators and on studies designed with limited retention protocols. Respect, or the perceived lack of it, was described as affecting confidence and trust. Participants repeatedly said or implied that it was important that they not be “treated like a number,” and that they want to be treated with respect. Perceived lack of respect by members of the study team negatively affected their confidence and trust in the research process. Researchers made frequent reference to the importance of respect and personal connection with participants:

I found that the people . . . who I followed up with on the phone after to give them test results or just to check in and make sure, you know, their hospice was working out or make sure their Medicare benefits were coming through, whatever it may be, they feel a tie to us . . . so then two months later, when I ask, “Would you be willing to come back? I know he’s in a wheelchair now and it’s going to be difficult but it would be really helpful for us,” they’re more likely to do that. (Researcher)

Researchers recognized the crucial importance of acknowledging participants as individuals. They also described individual characteristics such as education, income, cultural background, disability, or health status as important but not themselves necessarily barriers to retention:

I want to say that there’s an easy equation to determine who would be difficult to get and who would be easy, but I don’t think there is . . . Some folks, they are marginally housed. They may move around a lot, but they have a really good relationship with their case manager and we know there’s someone we can call. Some people . . . go to the library and they check their email. So the fact of someone’s housing situation or situation in terms of needing care doesn’t fully predict their ability to be retained in the study. (Researcher)

Discussion

Their comments show that researchers and research participants think in concrete, practical terms about transportation, incentives and motivation, caregiver burden, and the effects of the physical and social environment on research participation. Moreover, the discussions illustrated how participant-, study-, and contextual-level characteristics interact to encourage or hinder participation in research over time. Attendees in all focus groups saw participant SES as relevant to the ability of studies to retain participants. They often cited income, education, and culture when discussing the relative ease of participation in research, and the importance of monetary and nonmonetary incentives to lower income and higher income participants. High disease severity and comorbidity and related burdens were described as substantial participation barriers, particularly when family resources were scarce. Transportation issues, mentioned frequently by participants, might affect not only study participation but also patients’ ability to travel to medical appointments and adhere to medical treatment. Differential attrition of sicker research participants who also have transportation barriers could thus bias study outcomes. In an individual ear-based culture with inconvenient and increasingly expensive public transit, the inability of poor and marginalized individuals to simply get from one place to another can present a broader barrier to their functioning than is commonly imagined.
Conversely, access to and reimbursement for safe and convenient transportation can facilitate continued study participation. Transportation issues also might change with age; patients' need to stop driving, which has been linked to poor health outcomes including declining cognitive function (O'Connor, Edwards, Small, & Andel, 2011), can reduce individuals' ability to continue to participate in studies, and change the representativeness of cohorts over time.

Most of the barriers and facilitators that our focus group participants identified are not simply due to characteristics of research participants. Rather, they seem to result from interactions between characteristics of study participants and the larger research environment, which in combination can affect retention rates over time. This dynamic appears similar to processes in which physical limitations interact with conditions in the social and physical environment to limit full participation in society by older adults or people with disabilities (Satariano, 2005). Just as appropriate accommodations improve social participation for those populations, adjustments to funding policies, study design and implementation, and site accessibility could improve participant retention in health research. Researchers, from data collectors to principal investigators, frequently described inadequate funding and resource allocation as participation barriers because of their effects on study protocols (e.g., recruitment and retention procedures) and interaction with participants (e.g., staffing levels, study visit scheduling, sustained contact with participants). In particular, researchers often mentioned strict funding regulations as limiting the flexibility they need to achieve high retention rates. While it is not news when investigators complain about lack of adequate funding for any aspect of their projects, the focus group discussions illuminated specific ways funding policies can affect study design and implementation, and how these in turn can affect retention.

To our knowledge, our study is unique in that we asked both researchers and research participants to identify factors specifically related to the retention of participants in prospective studies. We also encouraged broad discussion of multilevel barriers and facilitators. Some of our findings reflect previous reports of relationships between loss to follow-up and participant characteristics including low SES, distance from the research site, or co-morbidities, and study characteristics, including insufficient follow-up protocols or high participant burden (Davis et al., 2002; Hessol et al., 2001; Sharma, Tobin, & Brant, 1986). Unlike our study, Davis et al. (2002) found that the implementation of multiple follow-up strategies was the most important factor in achieving high retention rates regardless of the population being studied. Our findings that relationships, including elements of trust, cultural competence, and participants' wariness of financial conflicts of interest, are crucial to participant retention are consistent with previous studies that found these to be important factors in peoples' willingness to enroll in research (Chao et al., 2011; Dilworth-Anderson, 2011; Kirkby, Calvert, Draper, Keeley, & Wilson, 2012; Manson, Garroule, Goins, & Henderson, 2004). A focus group study with African American research participants found that a lack of trust in scientific research, academic institutions, and researchers themselves, as well as the failure of researchers to share their findings with the community, were participation barriers regardless of SES or education (Williams et al., 2010). The high value of altruism, salience, and developing good relationships between researchers and participants confirms similar findings by Kost et al. (2011), whose study of the overall experience of research participants and people in various roles of research enterprise found those factors to be of more importance than financial compensation. That study also found that participants were dissatisfied when research staff did not share test results with study participants or study findings with the larger community.

We and others have found that caregivers often play an important role in participation through all phases of research. Caregiving can cause physical and emotional stress and affect the health of family members, particularly older adults caring for disabled relatives (Perkins et al., 2013; Schulz & Beach, 1999). An analysis of a cohort of dementia patients found associations between study dropout and nonfamily caregiving and increased family caregiver burden, and concluded that caregivers' well-being could be an important factor in retaining dementia patients (Coley et al., 2008). Our findings indicate that the burdens of managing the research participation of a physically or cognitively impaired adult can form substantial participation barriers for family caregivers who work and have conflicting responsibilities.

Limitations

A limitation of focus group research is that the sample might not represent the population of interest. As in most focus group research, participants in this research were self-selected, and the researchers and study subjects we talked with might not be typical of such groups in other venues. In this project, we had a special concern that hard-to-retain respondents and dropouts might self-select out of the sample. To address this, we made a special effort to recruit study dropouts, and we included a center that serves marginalized, poor, homeless, minority, and HIV+ individuals, and people who experience substance abuse and mental disabilities—populations long considered to be hard to reach for enrollment and follow-up (Badawi, Eaton, Myllyluoma, Weimer, & Gallo, 1999; BootsMiller et al., 1998; Cotpple, Compton, Ben-Abdallah, Horne, & Claverie, 1996; DiFranceisco et al., 1998; Hessol et al., 2001). Moreover, the focus group format and convenience sampling generate rich information not easily found using other research designs (Creswell, 2007). Because we were aware that our interpretive analysis of participants' descriptions of research participation could be colored by our own experiences as researchers, we used informant feedback throughout the study to increase reliability.

Other limitations result from the nature of our study design. We had access to study participants and expert
researchers in several research centers; this access provided multidimensional perspectives. However, our study took place at one institution, which limits generalizability. Our findings are based on the perceptions and experiences of researchers and participants in a wide range of health studies. We had no access to study records and were unable to verify details of the studies they described. We are unable to report differences by race/ethnicity, gender, or age. These gaps provide roadmaps for future mixed-methods studies and studies that focus on particular participant populations.

**Implications for Research Policy and Practice**

Recently, there has been substantial focus on patient-centered health outcomes in health care research and delivery. Study designs that take into account patient- or participant-centered research outcomes could maximize recruitment and retention. This is not amenable to a one-size-fits-all approach; patient-centered health and research outcomes depend on the priorities of the study population and policymakers who seek to address them equitably and efficiently. These priorities might include, for example, relieving the burden of disease for individuals and communities, addressing social health determinants, providing information and resources, or widely disseminating or implementing findings. The latter might be a particularly important motivation for participation in research. Our findings regarding nonmonetary incentives indicate that many research participants of all SES levels are motivated to enroll and stay in studies they believe to be scientifically or socially important, but that financial compensation is an effective motivator for many others.

Relationships between researchers and research participants are pivotal in maintaining high retention rates. However, investigators cannot address every issue at every level. Structural and institutional barriers may be overwhelming, especially when research policies or inadequate funding limit retention strategies available to investigators. To attain high response rates in diverse study populations, it might be effective to evaluate the impact of individual, study, and social factors, and develop approaches tailored to target populations and communities. For example, Williams et al. (2010) argue that pervasive barriers to African American participation in Alzheimer’s disease research can be overcome if researchers maintain a durable presence in the community. Research in Native American communities sometimes requires formal collaboration with tribal authorities (Manson et al., 2004). Integrating the needs and preferences of the individuals, communities, and populations involved in research also requires funders’ and policymakers’ willingness to provide resources for effective, flexible, and culturally competent retention protocols. Prospective studies of retention of socially disadvantaged, disabled, or other clinically relevant populations, discussions with key informants, or the addition of questions on national surveys or and study visit questionnaires are examples of strategies that could provide important information to investigators and funders alike. Changes in research policy cannot eliminate the effects of contextual factors or social disadvantage on participant retention; however, they can make research more inclusive and relevant to diverse and aging populations.

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