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Research Participation Among Older Adults With Mobility Limitation

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Abstract

The purpose of this qualitative descriptive study was to examine reasons for participation in clinical research among older adults with mobility limitation. A purposive sample of 20 men and 20 women aged 70 years or older was recruited. Data were collected by audiotaped telephone interviews using a semi-structured interview guide and transcribed verbatim. Participants expect privacy, professionalism by research staff, and respectful treatment. Benefits to protocol adherence include personal education, comparison of their health status with that of others, opportunity to maintain vitality, and altruism. Barriers to protocol adherence are apprehension, in particular a negative impact on their health care, randomization to the control group, and experimental drugs; and inconvenience. Factors promoting study completion are obligation, reciprocity, receipt of test results, health promotion, and socialization. Implications include meeting expectations, providing health education and study results to participants, reducing barriers to participation, and presenting opportunities for interaction with others.

Keywords

aged; clinical research; mobility limitation; qualitative study

Research on issues affecting older adults requires participation of sufficient numbers of individuals in studies to obtain statistically significant findings for pharmacologic and non-pharmacologic therapies. However, a number of factors adversely affect participation of older

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adults in clinical studies. Known health changes of older adults that impact participation include mobility limitation, cognitive decline, sensory changes, and multiple preexisting comorbidities that often contribute to polypharmacy (Hancock, Chenoweth, & Chang, 2003; Maas, Kelley, Park, & Specht, 2002; Siu, 2007; Townsley, Selby, & Siu, 2005). Maximizing participation is critical to obtaining the information from studies needed to understand the effects of drugs and other treatments in older adults; thus, promoting evidenced-based practice.

Problem

Mobility limitation, a potential barrier to participation in clinical research, refers to difficulty with activities such as walking and/or stair climbing. In 2003, more than one third of community-dwelling adults aged 65 years or older reported activity limitations (National Center for Health Statistics, 2005). Activity limitations increase with age from 26% in those 65 to 74 years of age to 64% in those 85 years or older (National Center for Health Statistics, 2005). Given the growing proportion of older adults (U.S. Census Bureau, 2004) accompanied by the prevalence of mobility limitation in older adults, attention needs to be directed to reasons for participation of older adults with mobility limitation in clinical research so as to guide strategies to enhance recruitment and improve retention and protocol adherence. Adequate recruitment, reduction of dropout rates, and good adherence to clinical study protocols are important in ensuring sufficient power in a study to detect an effect if it exists.

Research on factors that motivate clinical study participation among older adults is limited (Chang, Hendricks, Slawsky, & Locastro, 2004; Marcantonio et al., 2008; Resnick et al., 2003; Resnick, Ory, Coday, & Riebe, 2005; Tolmie, Mungall, Loudon, Lindsay, & Gaw, 2004; Townsley et al., 2006). Chang et al. (2004) conducted a qualitative ancillary study in a randomized clinical trial of behavioral therapy in veterans with heart failure. The first 57 patients who completed the intervention and/or the first outcome assessment participated in a telephone interview about their experiences in the study. The most frequently reported reason for study participation was personal benefit. Additional reasons were helping others, being appreciative to the Veterans Affairs, receiving recommendations about the study from trusted health care providers, having positive impressions of the recruiter, and getting monetary incentives.

A retrospective Scottish study regarding recruitment of respondents aged between 70 to 82 years revealed several reasons for participation in a clinical trial of vascular disease prevention (Tolmie et al., 2004). Mailed semi-structured questionnaires were used to collect data in two stages. Older adults reported reasons for participation in research to be “personal benefit,” “health checks,” “peace of mind,” “curiosity,” “helping others,” and “supporting research.” A limitation of this study was the retrospective study design, which did not allow the researchers to clarify or expand on themes in the data.

In a two-phase study to understand attitudes of older adults toward cancer research, 425 respondents aged 70 years and older attending oncology clinics and diagnosed with cancer were mailed a self-administered questionnaire (Townsley et al., 2006). Of the 94 respondents, 17 were also interviewed using a grounded theory method with open-ended questions. Many of the older adults indicated that they did not actively seek out studies on their own; however, they participated in studies that were recommended by their physician. Older adults also indicated a desire to help future patients.

In a mixed methods study with 50 older adults, participants were interviewed about their willingness to participate in two study protocols involving interviews, neuropsychological testing, venipunctures, and brain imaging with and without lumbar puncture (LP; Marcantonio et al., 2008). About two-thirds (64%) of the participants reported willingness to participate in the protocol with LP, whereas more than three-fourths (76%) of them expressed willingness

to participate in the protocol without LP. In addition to LP, other factors cited as barriers to study participation in the planned protocol were venipunctures, long interviews, and transportation. The most potent motivator to study participation was altruism.

Resnick et al. (2003) asked eight research nurses to write about their views of the facilitators and barriers that older women experience during recruitment into exercise intervention studies following hip fracture. Using content analysis, the researchers identified seven facilitators of study participation by older women: individualizing care, emphasizing benefits of the study, eliciting support from others, demonstrating expertise, using role models, using appropriate timing, and making a good impression. Time commitments and lack of support from others, such as clinicians and family members, were identified as barriers to participation experienced by older women. Resnick et al. (2005) conducted focus groups with 122 older adults about their perspectives on screening prior to beginning an exercise program and the effect of screening on their willingness to adopt an exercise program. Screening had different meanings for older adults, depending on their current physical activity level and health status. Some considered screening a benefit by enhancing confidence and motivating adoption of an exercise program, but for others screening acted as a barrier by reducing confidence and requiring extra steps, such as obtaining clinician permission. This study illustrates that screening activities can be perceived differently, and these perceptions can impact study participation.

Although these studies provide important insight about participation in clinical research, two of the studies were conducted with respondents who were currently enrolled in a specific study (Chang et al., 2004; Tolmie et al., 2004), other studies concerned a planned study protocol (Marcantonio et al., 2008) or focused on screening (Resnick et al., 2005), and only one study was concerned with participation in clinical research of older adults with mobility limitation (Resnick et al., 2003). In the latter study, the focus was limited to older women post-hip fracture and the qualitative data were collected from the viewpoint of research nurses. No studies have been reported about factors that motivate research study participation from the perspective of older men and women with mobility limitation.

Purpose

The purpose of this study was to describe reasons for study participation from the perspective of older adults with mobility limitation, in particular their expectations of participation, benefits and barriers to adherence to clinical study protocols, and factors promoting study completion. This study was informed by Social Cognitive Theory, which states that there is a dynamic continual interaction between the person, his or her behavior, and the environment (Bandura, 1986). Social Cognitive Theory recognizes the interplay between biophysical, psychosocial, and environmental factors influencing behavior, such as study participation. Social Cognitive Theory holds that persons who believe that they are capable of performing a specific behavior and that the behavior will result in beneficial outcomes will be more likely to initiate and maintain the behavior, for example, study participation. The research questions were the following:

1. What expectations do older adults with mobility limitation report for participation in clinical studies?
2. What benefits do older adults with mobility limitation report for adhering to clinical study protocols?
3. What barriers do older adults with mobility limitation report for adhering to clinical study protocols?
4. What factors do older adults with mobility limitation report as contributing to the completion of clinical study protocols?

Methods

Design

A qualitative descriptive approach (Sandelowski, 2000) was used to conduct this study. Open-ended questions were designed to gather data by telephone interview to describe reasons why older persons choose to participate in studies.

Sample

After obtaining Institutional Review Board approval, a purposive sample of 20 men and 20 women aged 70 years and older was recruited from the Pittsburgh Pepper Center Registry via recruitment letters. Using the Registry was a way to obtain a broader sample that was not limited to those enrolled in a particular study. Recruitment letters were sent to 164 Registry participants; 62 (38%) called the research office to learn more about the study; of these, 40 (65%) were eligible. Inclusion criteria were a self-defined mobility limitation and previous participation in at least one clinical study (defined as a study with people). Exclusion criteria included overt signs of dementia, as evidenced by an inability to respond appropriately to the interviewer, and unable to use a telephone for an interview. Participants were reimbursed \$10.

The sample was on average 79.58 ($SD = 4.98$) years of age, White ($n = 37$, 92.5%), married ($n = 25$, 62.5%), retired ($n = 34$, 85.0%), with slightly less than a high school education ($M = 11.98$ years, $SD = 1.21$), and an annual household income $< \$50,000$ ($n = 21$, 65.6%). The participants in this study were similar to those in the Registry ($N = 1,037$) in terms of age ($M = 73.5$ years, $SD = 7.5$), race ($n = 911$, 88.5% White), and marital status ($n = 602$, 58.1% married). We oversampled for men to gain their perspectives, because women outnumber men in the Registry at 67.1%, which is consistent with this age cohort.

On enrollment in the Registry, participants completed a short Registry survey consisting of single-item self-ratings of mobility (How would you rate your mobility? 1 = *excellent* to 5 = *poor*), balance (How would you rate your balance? 1 = *excellent* to 5 = *poor*), and pain (How often do you have pain? 0 = *never* to 3 = *always*). The Registry survey included single items with dichotomous Yes/No responses about assistive devices (Do you use any assistive devices for walking?), falls (Have you had a fall in the last year?), and comorbidities (Has a doctor ever told you that you have had arthritis?) with particular attention on disorders affecting mobility. Evidence of stability was seen over 1 year in the following Registry survey items: mobility ($r = .70$), balance ($r = .70$), pain ($r = .52$), use of assistive devices ($\kappa = .74$), and arthritis ($\kappa = .59$), suggesting good reliability (S. Albert, personal communication, October 20, 2008). When examining age and health status, evidence of criterion-related validity for the Registry survey was found among the 164 Registry participants who were sent recruitment letters. Balance was significantly correlated with age ($r = .19$, $p = .015$). Participants who fell were significantly older than those who did not fall, $t(160) = -2.924$, $p = .004$. Significantly worse ratings of mobility, $t(160) = -8.123$, $p = .0001$ and balance, $t(160) = -7.256$, $p = .0001$ were evident in users than non-users of assistive devices. Participants with arthritis, a prevalent comorbidity, compared with those without arthritis had worse ratings of mobility, $t(160) = -3.097$, $p = .002$; balance, $t(160) = -2.337$, $p = .021$; and pain, $t(160) = -5.989$, $p = .0001$, and were more likely to use assistive devices (23.9% vs. 6.7%, $p = .013$).

Using Fisher's exact tests and Mann-Whitney U tests, the 40 participants were compared with the 124 nonparticipants who received recruitment letters on Registry survey items. As shown in Table 1, the participants and nonparticipants were very similar with one exception. Nearly 82% ($n = 9$) of the participants reported that if they fell last year, they got hurt, whereas about 41% ($n = 9$) of the nonparticipants reported that if they fell last year, they got hurt ($p = .034$).

Data collection

Data were collected by one interviewer (DR), a doctoral nursing student, under the supervision of the principal investigator (EAS) and qualitative methodologist (EO). All of the telephone interviews were audiotaped and lasted 25 to 40 minutes. The audiotaped interviews were immediately transcribed verbatim and checked for accuracy by the interviewer. We have found from our previous studies that older adults are receptive to data collection and intervention delivery by telephone. A semistructured interview guide with open-ended questions was implemented and became more focused based on the ongoing iterative process of concurrent data collection and analysis used in qualitative research. Sample questions included “What do you see as advantages to participating in studies?” “What concerns do you have about participating in studies?” “How do you feel about participating in future studies for people who have difficulty getting around?” Sociodemographic data were collected at the end of the interview using a standardized questionnaire.

Data analysis

Data were analyzed using a qualitative descriptive approach (Sandelowski, 2000). Transcripts were analyzed by two coders in batches of six to eight interviews. The senior coder (EO) has had experience in qualitative data analysis as a primary investigator and the other coder was the interviewer (DR). Each coder independently read the transcripts line by line and elicited as many codes as possible from the data. Codes refer to words that reflect the meaning in the data. They then met and discussed the data, further analyzing the transcripts. Similar codes were combined into categories that subsumed several individual codes. Codes were consistently compared with one another. Codes were sorted into broader categories as the ongoing iterative process of interviewing and analyzing transcripts continued. Categories subsume related codes and lead to larger themes. These themes were guided by the four research questions of the study. Theoretical saturation was reached as less and less new information was found in the transcribed interviews. Eventually, 100% consensus was attained after analysis of all interview data.

Credibility of the qualitative data

In qualitative research, there is an acknowledgment that individuals construct their own meanings of their situations and there is not a “right” or a “wrong,” but the onus is on the researcher to demonstrate that the interpretation/analysis of the data is as close to the meaning of the research participants as possible. Thus, the researcher must demonstrate that the findings are credible by seeking confirmation from the research participants themselves. Consistent with a qualitative descriptive approach in which data are simultaneously collected and analyzed, feedback from each participant was sought as the results emerged. Over the course of the 6-month data collection period, codes identified by participants in the early telephone interviews were continually validated with participants in later telephone interviews. Thus, credibility of findings was demonstrated by sharing the findings with the research participants and hearing from them that they agree with the findings, or more specifically, that they resonate with the findings. In addition, clinicians and researchers from multiple disciplines (geriatric medicine, physical therapy, occupational therapy, and public health) who have worked with older adults with mobility limitation agreed with the findings during a presentation of the study at the Pittsburgh Pepper Center.

Results

A discussion of the themes that were developed corresponding to each of the four research questions of the study follows. Table 2 identifies and describes these themes.

Expectations of participation

Older adults verbalized three expectations regarding participation in clinical studies. One expectation was privacy with the belief that professional conduct of staff members was an indication of their ability to maintain confidentiality. Privacy included sharing test results with the primary care provider (PCP) only if specific permission to do so was granted. "I don't have any concerns as long as everything is private."

Second, professionalism, including the quality and knowledge of the staff, was viewed as an indicator of the credibility of the study and a validation of the choice of older adults to participate. One participant commented on the expertness of a registered dietician, an indicator of professionalism:

Well, the person that was assigned to head up the group that I participated in was a very fine nutritionist and she held the interest of our group and I saw that as a great advantage to continuing in the study.

Third, respect for the age, functional status, and willingness of the older adult to participate was regarded as necessary in studies. Respect was demonstrated through acknowledgment that multiple appointments, numerous or long questionnaires, and travel were potential burdens that require limiting the number of on-site appointments, reducing the number of questionnaires, allowing questionnaires to be completed at home or via telephone, and providing assistance with transportation and parking in close proximity to the study site.

And my husband went with me. I always had him with me because he was crippled from a stroke years ago and I would have him come with me and we went down and they was real good with him while I was taking the tests. Well, they offered him something to drink, something to snack on and made him comfortable where ever he was at.

Benefits to adherence

Four factors were verbalized as benefits to adherence to clinical study protocols, both to the older adult participant as well as to others. First, personal education, defined as knowledge gained during the study regarding health and self-care issues, was identified as an important factor leading to a decrease in fear of the aging process. Personal education was regarded as a tool used in the management of current conditions as well as the prevention of new disorders. One participant spoke of learning about advances in health care.

It's an education...I hope to continue going with the new technology, the new ways of helping people to gain more knowledge and not be fearful so they don't go into different illnesses that comes from being fearful...new technology is helping people to think more clearly than being afraid to move on to the next level in our lives.

Not surprisingly, participants expressed a desire for knowledge and measures to improve mobility and prevent falls. "There might be something you can do to be able to walk better or be more mobile." This finding may partially be explained by the inclusion criterion of mobility limitation.

A second benefit to older adults was the ability to compare themselves to others, in particular those with similar conditions or of comparable age. The realization that there were adults who were less healthy or had greater mobility limitation was a motivation to comply with protocols. "like limitations. You need to have some guidance...Seeing how they're handling the same situations and deciding whether I'm handling it better than they are."

Third, others cited curiosity, a need to remain personally challenged and vital, and an interest in the latest form of treatment as reasons for participating in studies. One stated,

I just enjoy it. It's not really a difficult thing for me at all. Well, I like going to school to begin with and I have gone back to school several times and taken extra classes simply because I like to keep alert and to learn new things. And I find that by getting out with people and working in groups, that this is another way of learning and staying up with your own age level.

Altruism was expressed as a fourth benefit to protocol adherence. Altruism was expressed as an interest in providing information that may not necessarily assist older persons such as themselves due to their advancing age or mobility limitation, but would provide insight into the care of the next generation. Identified were concerns for children and grandchildren as well as future generations. An informant explained,

I'm anxious, really anxious, to help other people. You see, I'm 78 years old and when I see people who are 60 and they are not able to get around, I wonder what can I do to help them...if there's anything coming up, can I help.

Education of the medical community was included within the theme of altruism. Of concern was the need for researchers to provide answers to medical personnel regarding the best approach to caring for older adults. "Just to be hopefully a part of a group that will provide some answers for the community." There was an acknowledgement that a combination of understanding personal experiences and the study of health care issues specific to older adults was the best way to provide answers. An interviewee stated,

I just think it's a good thing. That's all and then if you want to know something you have to go to the people that know something. I'm sort of opposed to animal research. I think, you know, hey you want to know something, ask me. I've already lived through most of it.

Barriers to adherence

Two barriers to older adults adhering to clinical study protocols were evident in the data. First, apprehension was expressed regarding sharing adverse test results with their PCP, which may have harmful effects on their future health care. Other concerns included fear of a negative interaction with their PCP if new conditions were diagnosed as a result of study participation, potentially being interpreted as a lack of trust in their PCP. Concerns also included random assignment to the control group resulting in the participants receiving no direct benefit from their participation. Concerns regarding the use of experimental drugs, including the replacement of current medications with experimental drugs and side effects from investigational drugs, were cited.

Well, the medication ones I do, because I'm always concerned that I might be in the group that gets no medication and if I have a particular problem that medication will help, that concerns me a little bit. And then again as far as getting the trial drug, I worry that it might be something that I am allergic to. And then it might do me more harm than good. Those are my two concerns about medication trials.

Inconvenience was identified as a second barrier to adhering to protocols and included the frequency and duration of study visits, traveling for tests and appointments, parking, and accessibility. Numerous and time-consuming appointments were considered an occasional deterrent when considering study participation. Problems included the distance required to travel, a need to drive during inclement weather, a need to maneuver through congested inner city streets, and the availability and cost of parking close to the study site to reduce the amount of walking required.

The only concern I have is if I have to drive. I drive but I only drive local. I would not like to drive into Pittsburgh. I don't think I could drive into Pittsburgh. That's my only concern. The driving and the parking.

Once on site, accessibility was important. “If I am in a building with an elevator and easy access I can do it.”

Factors promoting study completion

Five factors contributed to older adults’ choices to complete a study. First, the belief that one has an obligation to complete what was started was frequently expressed by informants, despite signing a consent form and knowing that they may withdraw at any time. “I know they don’t want people dropping out...it makes the results not as good. So I stayed because when I went in I felt I had made that promise.” The exceptions were an adverse reaction to an intervention or investigational drug or a change in health status.

Second, reciprocity as a way to give back to the medical community for care received was also evident in the data. Participants conveyed a sense of importance in being part of something much bigger than themselves during retirement. One informant stated that giving back was a compelling reason to see a study through to completion.

I think that most, I don’t know whether all older people, you know, most people do it for selfish or their own interest. But if they knew that it would benefit future findings or research or cures for the disease and it’s just not for you because you are old and sick and can’t do too much anyway, but you’d be helping humanity in the future. A noble cause.

This theme was reinforced through the sharing of knowledge via newsletters and/or meetings with older adults as a way of reciprocating them for their personal contribution to medical science.

I was very pleased that every few years the person that headed up the study held a meeting...and gave us an update on what was happening locally as well as nationally with the study. A newsletter...was also useful in keeping the interest of me and I think the other women.

Several themes captured personal advantages to participation in studies. Third, laboratory tests and radiographs administered during the course of the study were viewed as valuable aids to monitor health status. The administration of tests that would not be given during routine care with a PCP and the ability to obtain some tests without the added costs of a copayment encouraged completion of the study. “They usually give you a pretty good check-up and I find something that I don’t know I had.”

Fourth, participants cited the personal advantage of health promotion from participation in studies. For example, one participant discussed a study of calcium supplements versus placebo. Unaware of her group assignment, she expressed positive benefits of participation during the study in the form of development of an exercise routine and improvement in eating habits as well as increased knowledge about nutrition. An added benefit was learning that she had indeed been given the calcium supplement. Another participant described an intervention study for back pain that resulted in such an improvement in her pain and function that she cancelled the planned back surgery. Similarly, many older adults stated that maintaining good health at an advanced age was a reason to complete a study. One informant stated,

I feel that I’ve got something to add and I would like to be checked for it. I am 91 now and my health has been excellent and my body has remained pretty much the same as when I was much younger and I am beginning to think that somehow I got through everything that I did and there must be a reason for it so I actually have looked forward to having this done (clinical studies).

Personal advantage was also manifested within the fifth theme of socialization. Group interventions were viewed as positive, providing opportunities to meet other retirees and a motivation to maintain protocol adherence. One stated,

Health-wise, I think it's really good and it helps me out a lot, too. And I enjoy going there (to group clinical study interventions) because to me it's just like a big family gathering. We've gotten very close to each other.

Discussion

These findings describe the experience of older adults with mobility limitation considering participation in clinical research and suggest multiple strategies to promote study participation, which are both generic and specific to mobility limitation (see Table 3). Older adults have a wealth of information to share and are excited to teach others, viewing their lives and experiences as excellent sources of contributing answers to clinical research questions. Professionalism by and personal attention from the researchers are strategies that demonstrate respect for the wisdom, advanced age, health and functional status, and time commitments of older adults (Cassidy, Baird, & Sheikh, 2001). Further, staff members are expected to possess knowledge of older adults' concerns and potential mobility limitations, interact appropriately with them, and maintain their confidentiality.

Benefits to adherence include personal education, the ability to compare self with others in an effort to rate one's own level of health including one's functional status, an opportunity to maintain vitality, and a sense of altruism. These findings are consistent with others reporting benefits such as monitoring personal health status, receiving self-care education, sharing findings with the research participants and their PCP, being reimbursed for time and travel, and receiving incentives for participation (Adams, Silverman, Musa, & Peele, 1997; Marcantonio et al., 2008; Ory et al., 2002). These results indicate that older adults perceive or anticipate personal benefits from research participation; thus, they may believe that they will receive individualized treatments found in routine clinical care rather than protocolized research treatments. To prevent therapeutic misconception from occurring, investigators must clarify the differences between research and treatment with their research participants (Lidz & Appelbaum, 2002).

Fears and inconvenience can act as barriers to adherence in clinical research. Older adults expressed fears about the impact of adverse test results, suggesting that counseling and referral are important strategies in reducing apprehension. Studies that include randomization and experimental medications are less desirable to them, suggesting that education about these issues is crucial and that assurance be given that research regulations and guidelines are followed.

Inconveniences related to testing burden, transportation, and parking should be avoided whenever possible. Special attention must be paid to these potential inconveniences when designing a clinical study of older adults with mobility limitation. Study site location and access are important issues for older adults with mobility limitation who are considering participation in clinical studies. Avoidance of prolonged or numerous site visits can increase protocol adherence. Transportation issues may be addressed by offering reimbursement for travel and parking, arranging parking close to the study site, ensuring easy access for those using assistive devices, and offering transportation solutions, such as a van and driver and public transportation to and from the study site. Telephone or home visits for data collection and intervention delivery should be implemented when possible.

Several factors work to promote study completion, specifically feeling obligated to the investigator, reciprocity, receipt of medical test results, health promotion, and the opportunity

to interact with others. Researchers can promote the sense of importance and belonging among older adults as incentives to complete longitudinal studies. Providing individual test results, summaries of key findings pertinent to mobility using lay terminology to enhance readability and comprehension, and socialization can potentially motivate older adults to complete clinical studies. Group interventions, when possible, add to the companionship and motivation of participants. Other considerations when building a sense of camaraderie are the inclusion of older adults as members of the research team. Older adults as team members can help provide the socialization that is desired among participants and promote a sense of trust that may not be achieved with younger team members. Also, a liaison to a community can have a huge impact when attempting to gain the trust of a specific population (Areal & Gallagher-Thompson, 1996).

Several limitations existed within this study. First, the convenience sample was primarily a white, high school educated, middle-income group of older adults, which limits transferability of the findings to more diverse ethnic and socioeconomic groups. However, based on a report by Musa et al. (2003), the Registry participants are broadly representative of the surrounding community. Second, selection bias may have been present because 38% of those receiving recruitment letters opted into the study. Although this rate is higher than seen in general recruitment mailings, those who responded may be different than those who did not respond. Third, a potential bias exists among the participants based on prior participation in research and an expressed willingness to consider future studies regarding mobility through Registry participation. However, their prior experiences as research participants can be instructive to investigators. The participants reported previous involvement in a variety of intervention and observational studies, such as drug studies, healthy lifestyle studies focused on modifying eating behavior and physical activity, and longitudinal studies with annual visits and/or questionnaires, which would enhance transferability of the findings to other older adults considering participation in clinical research. The findings can not easily be transferred to older adults who have refused participation in clinical studies. Fourth, interviews were somewhat shorter in comparison to other qualitative interviews, which could be due to the difficulty of some older adults to sit for extended periods of time, hearing difficulties during telephone conversations, and memory recall related to past participation in studies.

Application

Recommendations for future research include comparing older adults with mobility limitation with the general population on motivations and behaviors related to research. Studies are needed to understand issues unique to ethnically diverse older adults with mobility limitation within the scope of the challenges they face when considering participation in research. Another suggestion would be to attempt to study those older adults with mobility limitation who are naïve to research or have refused to participate in clinical studies in the past. Studies with these groups would prove challenging in their design given the potential reluctance on the part of those who choose not to volunteer for such studies to participate in any research. The information gleaned from such a study could have valuable implications for future recruitment, retention, and adherence efforts.

The findings from this study are consistent with findings from previous qualitative studies in which personal benefit, curiosity, social interaction, and altruism are reasons for participation in research whereas clinical trial design features act as deterrents. In addition, these findings extend our understanding by highlighting unique reasons expressed by older adults with mobility limitation for study participation, such as the opportunity to compare oneself with others and the possibility to improve one's functional status. Given the prevalence of mobility limitation among older adults, these findings from participants who have lessons to share are important and can be helpful to investigators desiring to promote participation of older adults

in many clinical studies. By understanding why older adults with mobility limitation choose to participate in research, investigators are better positioned to recruit older adults into studies, retain them once enrolled, and promote their adherence to protocols. Advanced age (Bayer & Tadd, 2000) and mobility limitation need not be exclusions from some clinical studies. Investigators should assess study eligibility criteria for unjustified age (Bayer & Tadd, 2000) and mobility restrictions. Clinicians can encourage older adults with mobility limitation to consider enrolling in relevant studies. By informing potential participants of appropriate clinical studies and encouraging enrollment, greater numbers older adults with mobility limitation may reap benefits from clinical research.

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Table 1

Characteristics of Participants and Nonparticipants

Characteristic	Participants (<i>N</i> = 40)	Nonparticipants (<i>N</i> = 124)
Age in years, <i>M</i> (<i>SD</i>)	79.58 (4.98)	78.50 (4.02)
White, % (<i>n</i>)	92.5 (37)	95.2 (118)
Married, % (<i>n</i>)	62.5 (25)	62.6 (77)
Female, % (<i>n</i>)	50.0 (20)	49.2 (61)
Live with someone, % (<i>n</i>)	69.2 (27)	71.8 (89)
Self-rated mobility, <i>M</i> (<i>SD</i>)	2.84 (0.82)	2.89 (0.85)
Self-rated balance, <i>M</i> (<i>SD</i>)	3.13 (0.96)	3.09 (0.95)
Use assistive devices, % (<i>n</i>)	23.7 (9)	17.7 (22)
Fall in last year, % (<i>n</i>)	28.9 (11)	17.7 (22)
If fell last year, got hurt, % (<i>n</i>) ^a	81.8 (9)	40.9 (9)
If fell last year, > 1 fall, % (<i>n</i>)	18.2 (2)	22.7 (5)
How often pain, <i>M</i> (<i>SD</i>)	1.42 (1.03)	1.44 (0.97)
Comorbidities, % (<i>n</i>)		
Arthritis	70 (28)	72 (89)
Hypertension	65 (26)	65 (81)
Cancer	38 (15)	28 (35)
Fracture since age 50	23 (9)	19 (24)
Osteoporosis	20 (8)	20 (25)
Inner ear problems	18 (7)	8 (10)
Depression	15 (6)	15 (19)
Diabetes	15 (6)	19 (24)
Glaucoma	15 (6)	11 (13)
Congestive heart failure	10 (4)	7 (8)
Myocardial infarction	10 (4)	16 (20)
Peripheral neuropathy	10 (4)	7 (8)
Stroke	5 (2)	6 (7)
Chronic obstructive pulmonary disease or asthma	3 (1)	11 (14)
Macular degeneration	3 (1)	7 (9)
Parkinson's disease	3 (1)	2 (2)

^aFisher's exact test, *p* = .034.

Table 2

Themes Corresponding to Research Questions

Research Question	Theme	Description of Theme
Expectations of participation?	Privacy	Confidentiality regarding participation and individual test results
	Professionalism	Staff exhibit appropriate behavior
	Respect	Acknowledgement of one's age, health and functional status, and willingness to participate
Benefits to adherence?	Personal education	Knowledge of health and self-care issues, including prevention
	Comparison of self with others	Incentive to care for self when informed of age or functional status norms or when able to match up to others
	Vitality	Desire to keep one's mind active and fulfill a need for knowledge (curiosity)
	Altruism	Desire to improve care of others with similar health issues, promote health of future generations, and assist researchers to find answers
Barriers to adherence?	Apprehension	Concerns regarding test results and future health care, random assignment to the control group, and experimental drugs
	Inconvenience	Frequency and duration of study visits, transportation, parking, and accessibility
Factors promoting study completion?	Obligation	Commitment to finish what was started
	Reciprocity	Give back to the medical community
	Receipt of medical test results	Access to medical tests that may not be part of routine care
	Health promotion	Maintain or improve one's health and functional status
	Socialization	Opportunity to meet others involved in the study

Table 3

Implications of Study Findings

Themes	Implications
Privacy, professionalism, and respect	Assure confidentiality regarding storage of information and publication of data
	Provide a private room for assessments when indicated
	Provide consent forms for release of individual test results to primary care providers
	Clarify the differences between research and treatment to prevent therapeutic misconception
	Incorporate community liaisons as a way to build trust
	Employ professional research team members and post credentials of all team members
	Require professional attire for research staff
	Provide professional atmosphere (dedicated space, décor, amenities)
	Provide personal attention, for example, address the subject by name and accommodate mobility limitation
	Provide immediate attention by not overscheduling appointments, which increases waiting time
Personal education, comparison of self with others, vitality, and altruism	Provide information in lay terms regarding health issues, including prevalence and evidence-based practices for mobility limitation
	Maintain knowledgeable professional staff on site to answer questions
	Provide age-adjusted normative data for comparison, for example, functional status norms
	Schedule group interventions when possible
	Use thought-provoking instruments and questionnaires when possible
	Provide challenging interventions when indicated
	Educate older adults regarding the need for research, for example, hold information sessions at senior citizen centers
	Identify expected outcomes of a study, for example, improve understanding of issues related to health and functional status of older adults
	Delineate benefits to participants, future generations, and the medical community
	Discuss results of tests
Apprehension and inconvenience	Provide counseling or referral if results of tests are abnormal
	Provide education regarding the need for random assignment to treatment and control groups
	Provide education regarding experimental treatments, such as drugs and therapies addressing mobility limitation

Themes	Implications
Obligation, reciprocity, receipt of medical test results, health promotion, and socialization	Limit number and duration of medical tests or questionnaires given at any one appointment
	Perform data collection and deliver interventions by telephone or home visits when possible
	Arrange parking close to the study site
	Ensure easy access for persons using assistive devices
	Provide handicap accessible bathroom facilities
	Refund parking or bus fare
	Provide a van and driver
	Provide information about public transportation
	Limit site visits when possible
	Provide education regarding the importance of completing the study and future implications
	Keep subjects updated on study progression
	Provide incentives appropriate to the research activities required
	Provide a written summary of study results and their implications for adults with mobility limitation
	Highlight positive changes in health and functional status
	Use group interventions when appropriate
	Provide group meetings for updates on the study and dissemination of results
	Employ older adults as members of the research team, including older adult recruiters