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Understanding Recruitment and Retention in Neurological Research

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Abstract

Cognitive deficits in participants and the abrupt and traumatic way in which many neurological conditions present are two examples of the unique challenges in recruiting and retaining subjects with neurological injury for research studies. The purpose of this investigation was to identify obstacles to recruitment and retention in three ongoing research studies. These studies involve persons with neurological disorders across the continuum of care, from those newly diagnosed and with emergent presentation to those with more established, chronic neurological conditions. For the purpose of this analysis, we evaluated the effectiveness of the strategies employed to improve participation rates. The first study was an NIH funded project designed to identify biomarkers of vasospasm in persons (N=496) with aneurysmal subarachnoid hemorrhage (SAH) who presented to the neurovascular intensive care unit (NINR, RO1 NR004339). The purpose of the second study was to examine bio-behavioral interactions in family caregivers (N=59) of persons with a primary malignant brain tumor (PMBT) recruited in the community setting. The third project involved recruiting persons (N=1019) within an outpatient neurosurgical center to participate in a research registry. To determine differential effectiveness of strategies, consent and attrition rates were calculated at serial points over time in three studies and recruitment and retention strategies were compared. Sentinel time points in participants' disease trajectories played a key role in determining whether those who were approached to participate gave consent and were retained, particularly in the studies involving persons with aneurysmal SAH (consent = 85%; retention = 89%) and persons with PMBTs and their caregivers (consent = 68%; retention = 83%). In addition, several specific recruiter and interviewer training techniques were associated with higher recruitment and retention. Targeted strategies to improve participation rates are vital for neuroscience nurses involved in any aspect of clinical research, including those who conduct studies, assist with data collection, and recruit potential participants.

Intro

Research has led to tremendous advances in the field of neuroscience. Basic science research has set the stage for technological, pharmaceutical, and behavioral interventions, which show a great deal of promise in improving the lives of persons with a neurologic disorder. The translation of basic science research to clinical practice, however, is dependent upon studies that are able to recruit and retain participants over time. Unfortunately, recruitment in neurological research is challenging due to potential barriers such as cognitive dysfunction in the participant and the often traumatic onset of neurologic insult. In other areas of health care

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research, participants are typically screened for cognitive dysfunction and those that do not meet criteria are excluded from participation. In neuroscience research, however, participants with cognitive deficits are often the target of recruitment efforts, rather than those who are screened out of the study. Clinically applicable research in neuroscience, then, must involve samples that do not systematically exclude groups of people based on cognitive performance.

Recruitment and retention in neurological research can also be challenging due to a typically traumatic onset of neurologic insult. Potential participants or families of participants are often approached by research staff immediately upon a life threatening diagnosis, such as a traumatic brain injury or brain tumor. This is generally an overwhelming time for participants and families as they are forced to come to terms with the diagnosis while simultaneously collaborating with physicians, medical staff, and insurance companies to develop a treatment plan. When approached by researchers, participation in a study is often viewed as an additional burden to an already stressful situation in which there may not be any personal benefits from participating. With these challenges in mind, the purpose of this study was to 1) determine factors that predicted whether or not participants would be recruited into three ongoing research studies involving persons with neurological conditions and 2) determine factors that influenced retention in two longitudinal neurological studies.

Background

Recruitment and retention of participants to participate in research studies is a process which evolves through the trial and error of recruitment strategies with varying success. Success in recruitment and retention is measured by the ability of the research team to overcome system and patient barriers to research with all patient populations, such as the implementation of the Health Insurance Portability and Accountability Act (HIPAA), which complicates the screening process and increases the amount of time spent identifying potential participants. Due to HIPAA regulations that prohibit the researcher from directly contacting an eligible patient to ensure the patient's privacy, health care providers are now responsible for identifying and contacting patients to obtain written consent to be approached by the researcher (Sullivan-Bolyai et al., 2007). This process adds additional burden to health care providers and clinic staff, who are often constrained by a busy clinic schedule and who may have little interest in the research project.

From the research prospective, it can be less than ideal to have the healthcare provider serving as the gatekeeper to potential research participants. If the healthcare provider has a limited understanding of the study, is not heavily invested in the project, or is working in a stressful and busy environment, referrals may be inconsistent and recruitment may be inaccurate and skewed, thus limiting the generalizability of study results (Aitken, Gallagher, & Madronio, 2003). In addition, health care providers' opinions of research in general may influence a potential participant's willingness to consent (Sullivan-Bolvai, et al., 2007). Overcoming this barrier requires the research team to establish a solid working relationship with the healthcare providers and clinic staff. This is a time consuming process that requires a great deal of effort and communication by both research and clinic staff. Compensation for the clinic staff and health care providers may be necessary, adding to the investments made by the research team (Sullivan-Bolvai, et al., 2007). For example, an analysis of recruitment of breast cancer survivors to a randomized clinical trial for osteoporosis prevention estimated that the cost of recruitment averaged $480.00 per participant when including the time the recruiter spent making connections with eligible participants and their families (Ott, Twiss, Waltman, Gross, & Lindsey, 2006).

Another barrier facing recruitment in general is making the research project visible, appealing, and worthwhile to patients and/or families who are eligible. Oftentimes, this is a process that

requires recruiters to spend a great deal of time seeking eligible participants and having face to face contact to establish rapport. Establishing a relationship with patients who are potential participants is a critical step in the recruitment process by which the researcher can convey that participants are the experts in their situation and vital to the study. As experts, participants feel they have substantive information to share that will enable positive changes in health care delivery for others in the future. As experts, participants are also more likely to feel empowered, rather than part of an experiment being manipulated in some way.

The previous sections have described barriers to medical research which can be found in various patient populations. Recruiting and retaining persons with neurological disorders for research studies presents additional challenges, including the abrupt onset of conditions and potential cognitive deficits that develop. Multiple neurological conditions have a sudden and traumatic onset (such as traumatic brain injury, the diagnosis of a brain tumor, or aneurysmal subarachnoid hemorrhage). The traumatic onset is a highly stressful and overwhelming time for both participants and families as they attempt to understand the implications of the diagnosis and are often unsure whether the patient will live to discharge. In addition, surgeries, treatments, and other medical procedures must be coordinated during this time, adding to the burden of the situation, and participation in a research study may not be a priority.

In a study of cancer pain in participants and their caregivers recruited through a palliative care clinic, refusal rates were high due to tension, depression and strain from diagnosis, and being faced with the demands of pain and pain management (Ransom, Azzarello, & McMillan, 2006). In an intervention study with family caregivers of participants with dementia, it was found that caregivers first needed to acknowledge their need for help and their inability to cope with the situation before they would consider participating in a research study. This step of acknowledgement was found to be very difficult for the majority of caregivers in the study (Murphy, et al., 2007). Recruitment strategies need to be structured in such a way that potential participants are approached within the window of eligibility while maintaining consideration of the emotional distress they may be undergoing (Murphy, et al., 2007).

Strict eligibility criteria and family involvement in the enrollment process adds to the challenge in recruiting and retaining study participants in neurological research. Studies that require the consent of two individuals as a dyad (e.g., family caregiver research) is a more complicated process than recruiting an individual. Consent must be obtained from both members of the dyad, and recruitment efforts need to be expanded to address the needs of each individual. Members of the dyad may have different needs and may have conflicting reasons for wanting, or not wanting, to participate in the study. This requires additional personnel time invested to either provide further information or to mediate disagreements (Sadler et al., 2007). In addition, since either member of the dyad could serve as the point of contact, recruitment efforts may extend beyond the setting where patients are typically recruited, into community settings where family members can be more easily accessed (Sadler, et al., 2007), and may prolong the recruitment and follow up process.

Potential cognitive deficits in the participant add additional burdens when recruiting persons with neurological conditions. Recruiting participants with cognitive dysfunction requires a system that accurately screens, determines eligibility, and obtains consent by proxy which maintains the rights of the participant and is acceptable to governing institutional review boards. Studies which obtain consent by proxy add to the time and effort expended by research staff. Providing valid and informed consent requires participants to learn and retain new, technical information about the research design, which can be a difficult task for someone with cognitive dysfunction (Kim, & Appelbaum, 2006). If participants are unable to give consent at the time of approach, the usual practice is to approach a family member to obtain consent (Kim, & Appelbaum, 2006). This process of ‘proxy consent/patient assent’ adds to the time

and energy of the recruiter, who must locate a family member or trusted friend to provide consent, and who may not be in the same location as the participant at the time of the approach. The recruitment process is extended due to the required follow up necessary to obtain patient assent at a later time.

After participants are recruited, retention becomes crucial to obtaining valid and reliable data for analysis, yet retention of participants in medical research has proven to be particularly challenging. Research conducted on dyads of men diagnosed with prostate cancer and their wives suggests that attrition rates are highest between baseline and four months (10.3%) and among newly diagnosed participants who felt they were too busy or decided that the study was not beneficial to them in their current situation (Northhouse, et al., 2006). Longitudinal research studies are faced with the challenge of following up with patients months or years after initial contact has been made. This follow up process can be challenging if extensive contact information is not collected during the time of consent (Northhouse, et al., 2006).

Despite the barriers to recruitment and retention described in the previous section, participation in research is vital to advancing the science of healthcare. Little work has been done investigating recruitment and retention issues in neurological research. The purpose of this paper is to identify factors that affected recruitment and retention in three ongoing neurological research studies. Specifically, we sought to determine the impact of sociodemographic and clinical variables on recruitment and retention of persons with neurological disorders and their families.

Methods

For this analysis, data from three separate, ongoing research studies were used. Each study and its methods are described separately in the following sections.

Mind body interactions in neuro-oncology caregiving (Sherwood, PI; R01 CA 118711001) (heretofore referred to as “Family Caregiver”)

The purpose of this longitudinal study is to examine the biobehavioral interaction of disease and personal characteristics, psycho-behavioral and biologic responses, and overall physical health in family members who provide care to persons with a primary malignant brain tumor (PMBT). Both caregivers and care recipients (patients) are recruited for participation in this study. Potentially eligible participants are identified through either an urban outpatient neuro-surgery clinic at the time of pre-operative or post-operative appointments or through a neuro-oncology clinic at the time of the initial consult. Both caregiver and care recipient must agree to participate in the study, although if the care recipient withdraws from the study at a later timepoint, the caregiver is retained. Care recipient eligibility is determined through: 1) diagnosis of a primary malignant brain tumor within the past month (verified by surgical pathology), and 2) at least 21 years of age. Caregiver eligibility is based on the following criteria: 1) non-professional caregiver, 2) at least 21 years of age, 3) regular and reliable access to a telephone, 4) able to read and speak English, and 4) not be a primary caregiver for anyone else excluding children under the age of 21.

Neurosurgery and neuro-oncology clinic schedules are obtained at the beginning of each week by personnel with approved access to these lists. All incoming patients who have consented to be part of a research registry are screened by a study recruiter through an electronic medical record database to determine preliminary eligibility. All potentially eligible participants are approached during their clinic visit by research staff and, and if necessary, additional screening is conducted by the study recruiter through communication with the participant, neurosurgeon, or clinic staff.

The recruiter is responsible for explaining the study and obtaining informed consent to potential participants. This generally takes place in the examination room of the clinic at the beginning of the participant's appointment. The study is explained in detail, and once consent is obtained, a member of the research team contacts the dyad at an arranged time to schedule a data collection visit which takes place either in the participant's home or at an agreed upon location.

The care recipient's role in the study includes 4, 30-minute, face to face interviews with research staff at diagnosis, 4, 8, and 12 months following diagnosis. The care recipient is reimbursed $25 for the completion of each interview. Participation of the caregiver includes data collection at the same time as the care recipient and starts with the completion of a 60-90 minute telephone interview. The caregiver is also given a blood pressure monitor and asked to record the readings for three consecutive days and is asked to wear an energy expenditure armband for three days. Finally, a blood sample is collected from the caregiver. The caregiver is reimbursed $75 for their participation.

Retention strategies have been implemented by research staff to maintain contact with dyads between time-points. Thank-you letters from the principal investigator are sent to both care recipient and caregiver at the completion of each time point. Greeting cards are sent to care recipient and caregiver at the mid-point between time-points to check in with participants and remind them that they will soon be contacted to schedule their next visit. In addition, holiday cards are sent to all enrolled participants and signed by the research team. Research staff contacts the dyad by telephone one month prior to the due date for the next follow up visit to ensure that the participants will be reached within the appropriate time frame.

The role of 20-Hete on Vasospasm Induced Ischemia after SAH (Hoffman, PI; R01 NR004339-06) (Heretofore referred to as “20-Hete”)

The purpose of this study is to identify early warnings signs of decreased cerebral blood flow following aneurysmal subarachnoid hemorrhage (aSAH). Potentially eligible participants are recruited through the neurovascular intensive care unit of a large, urban trauma center at the time of onset of the hemorrhage. To be considered eligible, patient must be 21-75 with a Hunt and Hess grade of 3 or higher and/or Fisher score of 2 or greater. Patients with preexisting neurological disease or SAH from other causes such as trauma or AVM's are excluded.

Potentially eligible participants are screened by nursing staff. A recruiter who works closely with the nursing staff is on call 24 hours a day, and recruitment takes place every day of the year including weekends and holidays. The consent process is typically carried out between the recruiter and the family of the participant, due to the condition of the participant at the time of consent. Biological specimens (blood, urine, and cerebrospinal fluid) are obtained twice a day from the first to the fourteenth day following the onset of the hemorrhage, or until the participant is discharged from the hospital. Transcranial Doppler ultrasound examinations are conducted each morning.

Participants are contacted at 3 and 12 months following the time of insult to complete data collection at their home or an agreed upon location. During the follow up visits, a complete neuropsychological battery in addition to functional and psychological measures are administered. Follow up telephone calls are made at 6, 24, 36, 48 and 60 months from the time of the hemorrhage during which information regarding functional status is obtained.

Neurological Surgery Research Registry (Kassam, PI) (Heretofore referred to as “Research Registry”)

The purpose of the Neurological Surgery Research Registry is to collect past, current, and future medical record information of patients utilizing the department of neurosurgery.

Participants are recruited through the neurosurgery clinic. Participation in the research registry requires the participant to grant researchers the permission to contact the participants if they become eligible to be involved in a research study being conducted by their physician or collaborating physicians and researchers associated with the department. Participant consent also gives researchers permission to access medical records which are entered into a database to determine eligibility for future or ongoing studies.

Any participant who schedules an appointment in the clinic is approached by research personnel with the opportunity to participate. Research staff members greet potential participants at the time they arrive and check-in at the clinic. The purpose of the research registry is explained to the participant along with the details of participant involvement. Participants are then presented with a consent form to read through, sign, and return to the recruiter before they complete their clinic visit. The recruiter is available in person to answer any questions or concerns that the participant may have.

While the Family Caregiver and 20-Hete projects focus on specific populations, the Research Registry recruits a wide range of participants and cases. All three projects were approved by the institutional review board.

For the recruitment analysis, limited variables were used as potential predictors to avoid violation of HIPAA regulations. Sex, age, and race were gathered from participant and potential participant interviews (with permission). For analysis concerning retention, age, marital status, and level of education were collected from participant interviews and used as potential predictors. In addition, for the Family Care study, the following variables were explored to determine their impact on retention: caregivers' relationship to the care recipient (obtained from participant interviews), care recipients' tumor type (obtained from the pathology report), and care recipients' neuropsychological function and symptom severity.

Neuropsychological function in the care recipient was measured by the Cognistat (Kiernan et al., 1987). Participants answer questions and perform tasks that indicate ability in the following cognitive domains: level of consciousness, attention, language, constructional ability, memory, calculations, and reasoning. Scores are generated for each domain via algorithm (average ability=0, mild impairment=1, moderate impairment=2, and severe impairment=3); an overall score is calculated by summing the scores for each domain; higher scores indicate higher levels of neurological dysfunction. This measure has demonstrated validity when compared to the Mini Mental Status Examination and clinician examinations in both geriatric patients and patients with brain tumors (Roper, 1996; Schwamm et al., 1987).

Symptom severity was measured using the Given Symptom Assessment Tool (Given et al., 2002), modified to reflect the typical side effects of cranial radiation and common neuro-oncology chemotherapeutic agents. The participant is asked to rate the severity of symptoms during the past 2 weeks on a scale of 0 (not present) to 10 (as severe as it possibly could be). A total symptom severity score is computed by adding severity scores for individual items, higher scores indicating greater symptom severity. This self-report tool has been validated with over 500 patients undergoing chemotherapy and/or radiation for a diagnosis of cancer (Given et al., 1993; Given et al., 1998).

Statistical Analysis

To address the first aim of the study, independent sample T-Tests, Chi-Square tests for Dichotomized/Categorical variables, and Mann-Whitney *U* Tests for nonparametric continuous variables were used to compare those who consented with those who did not on key variables (sex, age, and race).

Similar analyses were used to compare participants who were retained and attrited in the two longitudinal studies (Family Care and 20-hete). There have been no participants who agreed to be a part of the Research Registry and then attrited at a later timepoint. For that reason, no retention analysis was done on this group. For Family Care participants, care recipient's neuropsychological function, symptom severity scores, tumor type, as well as caregivers' age, relationship to the care recipient, marital status, and level of education were explored to identify differences between participants who were retained from baseline to four months versus those who were not retained. For 20-hete participants' age, marital status, and level of education were explored to identify differences between participants who were retained from baseline to 3 months.

Results

The Family Caregiver Studies recruitment analysis included 59 participants; 40 participants were retained at the 4 month follow up visit. The majority of caregivers were female, Caucasian, and in their mid 50's (see Table 1). The overall recruitment rate was 67.8%, and retention was 82.5%. The 20-hete recruitment analysis included 496 participants; 422 were retained at 3 months. This sample was also primarily Caucasian, and the average age of participants was in the mid 50's. The overall recruitment rate was 85.1%, and the overall retention rate was 89.6%. The Research Registry analysis included 1019 participants, and only focused on recruitment.

Recruitment

Of the Family Caregiver study participants, no significant differences were found between recruited participants and participants who were not recruited based on caregiver age, race, sex, level of education, relation to the care recipient, or marital status or based on care recipient's cognitive status, symptom severity scores or tumor type. Similarly, when participants recruited for the 20-Hete study were examined, no significant differences were found based on age, race, sex, or level of education. Regarding the Research Registry participants, there were no significant differences in recruitment based on gender or race. Age however, did have an effect on recruitment (Table 2). Participants who were under 30 years of age were more likely to agree to participate than those in their 60's (OR = 3.2; 95% CI 1.05 to 10.0), those in their 70's (OR = 4.1; 95% CI 1.3 to 12.5), and those 80 or over (OR = 6.9; 95% CI 1.8 to 25.0).

Retention

Our second research question involved determining potential predictors of retention across time in two neurological research studies. In the Family Care study, there was a trend (p=0.06) for retained participants to be younger (mean age 50.45, SD=12.0) than those who attrited (mean age 65.00; SD=10.0). Significant differences in retention were also found based on the care recipient's neuropsychological status and the caregiver's level of education. Dyads where the care recipient had higher scores on the Neurobehavioral Cognitive Exam (indicating higher levels of cognitive function) were significantly (p=0.03) more likely to be retained than those whose care recipient had lower neuropsychological function (Table 3. Participants who did not complete high school were more likely to attrit than those who completed high school or above (p=0.03). No significant differences in retention were found based on caregiver sex, marital status, relationship to the care recipient, or care recipient symptom severity scores (Table 3). Regarding the second longitudinal study (20-hete), no significant differences in retention were found based on age, gender, or race (Table 3).

Discussion

While challenges exist in recruiting participants to participate in longitudinal neurological research studies, findings indicate that participants and their families are willing to be an active

part of the research process. Our data support that both participants with neurological disorders as well as their caregivers agree to participate in studies even in times of crisis. Additionally, these participants were found to willingly maintain long term participation in research studies, even months and years after the initial diagnosis.

Recruitment

Of the sociodemographic variables that were analyzed (age, sex, race), none were found to be significant predictors of who would agree to participate in research studies. Of those that did show marginal significance, the results were not consistent across the studies. Neither age, gender, or race were significant predictors of recruitment in the Family Caregiver and 20-Hete studies, in addition to level of education, relation to the care recipient, and marital status, which were explored in the Family Caregiver study and also found to be non-significant. Age, however, was found to be a predictor of recruitment for the Research Registry. It may be that age is not a determinant for agreeing to participate in a specific study, but that older persons are less trusting of having their “name on a list” for potential recruitment.

The actual timing of the approach in relation to the initial insult or diagnosis may impact willingness to participate. We anticipated that recruitment rates would be lower for studies which consent persons at the point of diagnosis (the Family Caregiver and 20-Hete studies). This time frame is generally not ideal for families to sit down with research staff to discuss research opportunities. The consenting process usually begins with education and building rapport with the patient and family, and can last up to two hours to establish the relationship and communication that team's desire in care and outcome of the patient (Tansey, Matte, Needham, & Herridge, 2007). If approached too soon after receiving a poor prognosis, a patient or the patient's family may still be too overwhelmed to engage in these discussions or fully grasp the significance or importance of the research project. One of the most common reasons for refusal in the Family Caregiver study is overwhelm and stress. Even if the patient is willing to participate, family members often are in the process of embracing a traumatic, life-changing diagnosis, and they are not willing to volunteer their time or energies to an additional commitment. Krupp et al. found that patients undergoing neurosurgical procedures that were approached preoperatively filtered or blocked information provided during the consent process as a result of the emotionally stressful situation at hand (Krupp, Spanehl, Laubach, & Seifert, 2000). Our data do not support this hypothesis, as our recruitment rates were equivalent among studies.

No differences were found among participants recruited for the 20-Hete study based on age or gender, or race. African American participants had a slightly higher consent rate than Caucasian participants. This contrasts the trend for African Americans to be more hesitant to agree to participate in research (Dancy, Wilbur, Talashek, Bonner, & Barnes-Boyd, 2004). Research has suggested a general distrust of academic or healthcare institutions exists within the African American community. (Dancy, et al., 2004, Thompson, Neighbors, & Munday, 1996) Currently, skepticism of research may also exist from the perception that discriminatory healthcare practices continue to result in unequal or inadequate access to health care for African Americans (Dancy, et al., 2004). The high consent-rate of African American participants reported here is encouraging. This may be an indication that general perceptions of medical research may be changing within the African American community. A more racially diverse sample is integral to the validity of study findings, as well as the ability to generalize findings across different populations.

Finally, study results indicated that older participants are less likely to participate in a research registry. Though participation in the registry allows physicians associated with the neurosurgery clinic to have access to patient medical information, and is not released to the public, older participants were generally more apprehensive about their willingness to

participate. This is consistent with the literature, which attributes that the inflexibility and mistrust of older adults leads to difficulty recruiting this population into clinical research (Dancy, et al., 2004) While research staff members typically describe the nature of the registry in detail with each potential participant, one possible solution could be to have the participant's primary health-care provider encourage participation, which has been found to be an effective method for recruiting elderly participants (Adams, Silverman, Musa, & Peele, 1997).

It is possible that characteristics of the individual doing the recruiting may impact a potential subject's willingness to participate in a research study. Age, gender, and ethnicity of the recruiter may encourage or discourage participation, depending on the potential participant's beliefs and experiences. In addition to recruiter characteristics, when subjects are recruited in the clinical or hospital setting, the attitude of the health care provider may impact their willingness to participate (Sullivan-Bolyai, et al., 2007). Participants may be more likely to consent to a study if they have an established, trusting relationship with the recruiter. These factors were not explored in this analysis. Future analyses should consider the impact these characteristics may have on recruitment.

Retention

No significance was found to affect retention in the Family Caregiver Study based on caregiver sex, marital status, relationship to the care recipient, or in care recipient symptom severity. Caregiver age was found to be marginally significant in retention. The mean age for attrited caregivers was 15 years higher than the mean of retained caregivers. This finding is surprising, if taking into account the possibility that younger caregivers have been reported to be faced with more competing demands than older caregivers. Smith, et al (2008), found that family caregivers of stroke survivors reported different experiences and personal needs based on their age, and that younger caregivers were more likely to be unhappy with the health care system than older caregivers (Smith, Gignoac, Richardson, & Cameron, 2008). Younger caregivers may be active in the workforce, and may still have children in the home to care for in addition to the care recipient. Conversely, older caregivers may not be in the same state of physical health as their younger counterparts, and may view the study as an additional burden. While not examined in this analysis, there is the potential that older caregivers are providing care to older care recipients, who may also respond less favorably to treatment options, and may influence the caregiver's willingness to continue participation.

Caregiver education was also found to be significant in retention efforts. Caregivers who were retained at the four month time point had on average, five more years of formal education than attrited caregivers. It is possible that caregivers who had more years of education have (or had) higher paying professions with better quality health insurance and paid time off. This may have alleviated some of the strain and burden of providing care, and allowed the higher educated caregivers the time and energy necessary to continue participating in the study. In addition, individuals who have more years of education may have a better understanding and appreciation of the research process, potentially motivating them to remain enrolled in the study until its' completion. For those with less years of formal education, participation in a study may become burdensome, and if no direct benefits from enrollment are recognized, attrition may result.

Care recipient Neurobehavoral Cognitive Status Exam (NCSE) scores were found to be marginally significant to retention. The NCSE score consists of the sum of scores from multiple domains which test different areas of cognitive functioning. It could be hypothesized that care recipients who perform better on the NCSE exhibit more normal levels of cognitive functioning, or are responding more favorably to treatment. No significant differences were found in retention in the 20-hete study based on the participant's level of education or gender.

Participants in neurological research are a diverse group of people. Both men and women of all ages and races have been found to be qualified candidates to participate in the three studies included in this analysis. It is important for researchers to know their target population prior to beginning active recruitment before optimal results in recruitment can be expected. Based on the results of the three studies included in this analysis, it appears that recruitment and retention is slightly affected by the age of the participant targeted, with younger participants being more willing to participate. This finding is a necessary addition to the literature on neurological research, and should be explored more thoroughly. It should also be taken into account that participants who performed better on the Cognitive Behavioral Status Exam in addition to those participants who were more highly educated also had higher retention rates.

The identification of variables that put specific subsets at risk for refusal or attrition in longitudinal studies is crucial for the advancement of neurological research. This is a necessary step when seeking to learn about the group targeted for research. Once variables have been identified that put participants at high risk for attrition (males, older participants, and caregivers of participants with neuropsychological dysfunction), recruitment and retention efforts should be altered to cater to those specific populations.

Future research should focus on the development and implementation of strategies used to improve recruitment and retention of participants in neurological research studies. First, studies should be designed to understand the reasons that people with neurological insult both agree and refuse to participate in research studies. Once these are identified, various methods for improving recruitment and retention can be evaluated (e.g., payments, newsletters, other types of incentives). Specifically, studies should explore methods and that are effective in recruiting and retaining older populations of participants. Studies that have been conducted on patients with Alzeheimer's disease should be referenced, and strategies found to be successful in recruitment and retention should be employed. Some recommendations that have been made by families of patients with Alzheimer's disease to increase retention in research include providing feedback about the patient's evaluations at each data collection timepoint, increasing public awareness of research opportunities, and sending newsletters to families to help them stay informed on research findings and study updates (Connell, Shaw, Holmes, & Foster, 2001). In addition, strategies that have been used to address barriers in recruitment and retention in dementia research should also be explored, including increased communication, becoming familiar with the community and recruitment sites before beginning recruitment, being flexible with recruitment approaches, and being aware of cultural differences in participants (Dilworth-Anderson, Thaker, & Burke, 2005). Work should also continue to focus on strategies that improve the retention of participants who have cognitive deficits or who have a limited number of years of formal education.

Acknowledgments

Mind body interactions in neuro-oncology caregiving (Sherwood, PI; R01 CA 118711001) The role of 20-Hete on Vasospasm Induced Ischemia after SAH (Hoffman, PI; R01 NR004339-06)

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Table 1

Sociodemographic characteristics of participants in three neurological research studies

Characteristic	Family Care Studies (N=59)		Research Registry (N=1019)		20 Hete (N=496)	
	Recruited	Not recruited	Recruited	Not recruited	Recruited	Not recruited
	M(SD) N(%)	M(SD) N(%)	M(SD) N(%)	M(SD) N(%)	M(SD) N(%)	M(SD) N(%)
Overall	40 (67.8%)	19 (32.2%)	933 (91.6%)	86 (8.4%)	422 (85.1%)	74 (14.9%)
Age	52.10 (12.92)	53.87 (11.43)	See table 3		53.12(11.66)	54.05(13.81)
Sex						
Male	7 (17.9%)	5 (26.3%)	350 (38.5%)	30 (34.9%)	117 (27.7%)	18 (24.3%)
Female	33 (82.5%)	14 (73.7%)	559 (61.5)	56 (65.1%)	305 (72.3%)	56 (75.7%)
Race						
White	38 (95.0%)	19 (100.0%)	735 (86.8%)	78(90.7%)	378 (89.6%)	62 (83.8%)
NonWhite	2 (5.0%)	0 (0.0%)	112 (13.2%)	8 (9.3%)	44 (10.4%)	12 (16.2)

Data for level of education, marital status, and Caregiver/Care Recipient characteristics were not collected for non-recruited participants.

Table 2
Odds ratio analysis of the impact of age on recruitment in the Research Registry

Age Groups	Recruited	Not recruited	Odds Ratio	95% CI
18 to 29	82 (10.1%)	4 (4.7%)	1.0	--
30 to 39	125 (15.4%)	9 (10.5%)	0.678	0.20-2.27
40 to 49	172 (21.2%)	17 (19.8%)	0.494	0.16-1.51
50 to 59	204 (25.2%)	13 (15.1%)	0.765	0.24-2.42
60 to 69	128 (15.8%)	20 (23.3%)	0.312	0.10-0.95**
70 to 79	79 (9.7%)	16 (18.6%)	0.241	0.08-0.75**
80 and over	21 (2.6%)	7 (8.1%)	0.146	0.04-0.55**

* $p<0.10$,

** $p<0.05$

Table 3

Comparison of sociodemographic and clinical characteristics among those who attrited and were retained in two longitudinal neurological research studies

Characteristic	Family Care Studies (N=40)		20 Hete (N=422)	
	Retained	Attrited	Retained	Attrited [a]
	M(SD) N(%)	M(SD) N(%)	M(SD) N(%)	M(SD) N(%)
Overall	33 (82.5%)	7 (17.5%)	378 (89.6%)	21 (5.0%)
Age	50.45 (12.63)	61.17 (11.48)*	53.14 (11.67)	50.10 (11.87)
Sex				
Male	5 (15.2%)	2 (28.6%)	104 (27.5%)	6 (28.6%)
Female	28 (84.8%)	5 (71.4%)	274 (72.5%)	15 (71.4%)
Race				
White	32 (97.0%)	6 (85.7%)	342 (90.5%)	16 (76.2%)
NonWhite	1 (3.0%)	1 (14.3%)	36 (9.5%)	5 (23.8%)
Level of Education				
Less than HS	1 (3.2%)	2 (66.7%)**	12 (9.9%)	0 (0.0%)[b]
Completed HS	5 (16.1%)	0 (0.0%)	64 (52.9%)	4 (80.0%)
Some College	11 (35.5%)	1 (33.3%)	32 (26.4%)	1 (20.0%)
Completed College	5 (16.1%)	0 (0.0%)	6 (5.0%)	0 (0.0%)
College and above	9 (29.0%)	0 (0.0%)	7 (5.8%)	0 (0.0%)
Marital Status				
Single	--	--	18 (14.2%)	1 (20.0%) [c]
Currently married	27 (81.8%)	4 (100.0%)	84 (66.1%)	3 (60.0%)
Living with someone	2 (6.1%)	0 (0.0%)	--	--
Widowed	1 (3.0%)	0 (0.0%)	10 (7.9%)	0 (0.0%)
Separated	1 (3.0%)	0 (0.0%)	--	--
Divorced	2 (6.1%)	0 (0.0%)	15 (11.8%)	1 (20.0%)
Relationship to Care Recipient				
Spouse	20 (60.6%)	4 (57.1%)		
Non-spouse	13 (39.4%)	3 (42.9%)		
Care Recipient Tumor Type				
Astrocytoma I-III	7 (21.8%)	0 (0.0%)		
Glioblastoma	19 (59.4%)	4 (80.0%)		

Characteristic	Family Care Studies (N=40)		20 Hete (N=422)	
	Retained	Attrited	Retained	Attrited [a]
	M(SD) N(%)	M(SD) N(%)	M(SD) N(%)	M(SD) N(%)
Oligodendroglioma	2 (6.2%)	0 (0.0%)		
Other	4 (12.5%)	1 (20.0%)		
Care Recipient Tumor Type				
Astrocytoma I-IV	26 (81.2%)	4 (80.0%)		
Other	6 (18.8%)	1 (20.0%)		
Orientation	11.75 (0.62)	11.50 (1.00)		
Digit Repetition	6.81 (1.80)	8.00 (0.00)**		
Comprehension	5.77 (0.50)	5.50 (0.58)		
Repetition	11.61 (1.23)	12.00 (0.00)		
Naming	7.87 (0.34)	7.75 (0.50)		
Constructional Ability	4.94 (1.69)	4.00 (1.63)		
Memory	8.16 (3.15)	5.50 (3.11)		
Calculations	3.80 (0.55)	3.50 (1.00)		
Reasoning	6.77 (1.83)	5.50 (1.73)		
Judgment	5.13 (1.07)	5.00 (1.73)		
Sum Score	72.89 (5.43)	65.67 (1.53)**		
Nausea & Vomiting	0.45 (1.25)	0.80 (1.79)		
Decreased appetite	1.15 (2.24)	1.40 (3.13)		
Disturbed sleep	3.82 (3.47)	1.80 (1.79)		
Fatigue	3.94 (3.25)	3.00 (4.12)		
Constipation	1.88 (3.15)	0.00 (0.00)		
Diarrhea	0.58 (1.82)	0.00 (0.00)		
Hair loss	1.03 (2.54)	0.00 (0.00)		
Weakness	2.48 (2.94)	1.80 (3.03)		
Pain	1.19 (2.18)	2.60 (3.58)		
Fever	0.13 (0.49)	0.60 (1.34)		
Symptom Sum	16.25 (14.15)	12.00 (12.59)		

Data for Research Registry is not shown since retainment data is identical to recruitment data.

[a] Out of total of 496, since 23 patients died.

[b] 2 patients died

[c] 1 patient died

* p<0.10,

** $p<0.05$