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Successful Recruitment of Centenarians for Post-Mortem Brain Donation: Results from the Georgia Centenarian Study

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Abstract

Objective—Brain donation and neuropathological examination of brain tissues is the only way to obtain definitive diagnostic information on research subjects enrolled in aging studies. We investigated predictors of brain donation in a population-based study of centenarians in Phase III of the Georgia Centenarian Study (GCS).

Methods—Sixty-six individuals (mean age = 100.6 years, 91% female, 20% African American) were successfully recruited from the core sample of 244 individuals residing in 44 counties of Northeast Georgia to provide brain donation.

Results—Bivariate (t-tests, chi-square tests) and multivariate analyses (logistic regression) showed no significant differences between donors and non-donors across a wide range of demographic, religious, personality, cognitive and physical functioning characteristics.

Conclusions—We succeeded in recruiting a diverse, population-based sample of centenarians for brain donation. Our findings also suggest that barriers to brain donation reported in other studies may have less impact in these exceptional survivors.

INTRODUCTION

Postmortem brain donation is critical for the advancement of research in aging and neurodegenerative diseases. Yet relatively few studies to date have examined factors contributing to successful recruitment of brain donors, and most of these have involved convenience samples. Several studies have suggested that race or ethnicity is an important factor in successful recruitment of brain or other organ donors. DeJong and colleagues [1] reported significant race/ethnicity differences between organ donors and non-donors, with African American and Hispanic subjects being less likely than Caucasian subjects to agree to organ donation for transplant. Boulware and coworkers [2] reported similar reluctance among African Americans with regard to donation of cadaveric organs. Studies investigating the reasons behind the reluctance of African Americans to donate organs reported factors

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including distrust of the medical community, religious beliefs, and understanding of autopsy procedures as being important contributors [3].

Age has also been associated with consent to brain donation. Beardsall and colleagues [4] reported a high consent rate among individuals aged 75+. Kaye and coworkers reported a significantly higher consent rate among the oldest old (85+ years) participants compared with younger (65–85 years old) subjects in their study [5]. Although Stevens [6] reported no difference in the rate of agreement to donate with increasing age, the age distribution of the 194 respondents included in her study is not provided.

In this study, we report on the recruitment of brain donors within the context of the Georgia Centenarian Study (GCS) [7]. The GCS study was recruited from a population-based sample of centenarians from 44 counties in Northeast Georgia. Here we describe the procedures and success rate in recruitment for brain donation among this population-based sample. Specifically, we investigate the similarities and differences between brain donors and non-donors in a sample of 244 subjects, including approximately one-fifth African-Americans. Strategies for successful recruitment are also discussed.

MATERIALS AND METHODS

Participation

Study participants were drawn from the Georgia Centenarian Study, a population-based multidisciplinary study of centenarians and near-centenarians (aged 98+) conducted in 44 counties in Northeast Georgia (USA) from 2002 to 2005. The study included 244 centenarians from the estimated total eligible population of 1244. As such, this sample reflects nearly one-fifth (19.6%) of the entire population in this geographic area, with a recruitment rate of 62.7%. The sample also appears to largely represent the characteristics of centenarians residing in the community, personal care homes and skilled nursing facilities. Procedures and measures were approved by the University of Georgia's Institutional Review Board for Human Subjects, and have been described in detail elsewhere [7, 8].

Procedures

Data Acquisition—The comprehensive nature of the Georgia Centenarian Study required that a data collection team meet centenarians at their place of residence. In order to keep testing burden to a minimum, data collection was divided into four separate sessions, each of which could be completed within a two hour time frame. An additional component to the program project grant was funded after data collection was already under way. This component added information regarding resources and adaptations of centenarians, both directly from the centenarian and through a proxy according to a set of selection criteria. As a result of this later start date, data on personality traits are not available for all study participants.

Participants were informed of the opportunity to participate in the brain donation project when they consented to participate in the Georgia Centenarian Study. Those who did not indicate a preference about participating were contacted again in-person or by letter. Whenever possible, the brain donation coordinator, who was a registered nurse, went on interview sessions with other interviewers to meet participants and family members or caregivers. A brochure which explained the brain donation project was provided and the program briefly discussed. If it was not possible for the coordinator to make a face-to-face visit, the brochure was mailed to the participant upon completion of the four visits comprising the main portion of the Georgia Centenarian Study. The coordinator followed up with a phone call a few days after the brochure was provided. If a participant or family

indicated interest in participating in the study, a face-to-face visit was made to answer further questions, sign the consent form and review the procedure to follow at the time of death. Follow-up appointments were only made with those participants who indicated a possible interest in becoming brain donors. Some participants or family members required several months "to think it over," therefore periodic follow-up phone calls were made if the participants or caregivers indicated they needed more time to decide. A consistent procedure was followed for approaching participants about possible brain donation (Figure 1).

During conversation about the brain donation program, the nurse coordinator focused upon her role in educating participants about the project, and did not attempt to influence their decision or convince them to participate.

Once a participant consented to brain donation, the coordinator followed up with a phone call every six to eight weeks to communicate with participants and caregivers. Participants were tested at six month intervals using the CERAD battery [9] and the Clinical Dementia Rating. A brief neurological exam was performed and any changes in health were noted.

Measures

Donor Status—Of the 244 individuals in the Core GCS Sample, 66 individuals (27.0%) agreed to participate, 145 individuals (59.4%) declined to participate, 8 individuals (3.3%) had already agreed to donate their body for scientific purposes, and 25 individuals (10.2%) refused additional information about brain donation.

Demographic Characteristics—Demographic variables included age in years, sex, years of formal education, living arrangement (recorded for analyses as community-or facility-dwelling), religious affiliation, importance of religion, and residence in a metropolitan area.

Personality Traits—Personality traits were assessed using NEO Personality Inventory-Revised [10] as reported by proxies, a reliable and valid measurement approach to reduce testing burden on the centenarians [11]. Personality factors included Neuroticism, Extraversion, Openness to Experience, Agreeableness, and Conscientiousness.

Cognitive Status—Cognitive status was evaluated using the Mini-Mental Status Examination (MMSE) [12], and the Global Deterioration Rating Scale (GDRS) [13, 14].

Functional Status—Both basic (BADLs) and instrumental (IADLs) activities of daily living were assessed using the Older Americans Resources and Services scales [15]. BADLs ranged from 0 to 14, with higher scores indicating better physical functioning. IADLs ranged from 0 to 15, with higher scores indicating better physical functioning.

RESULTS AND DISCUSSION

Bivariate Analysis

Descriptive statistics for all study variables are presented by donor status in Table 1.

Differences were tested for categorical variables by Fisher's exact tests, and for continuous variables using independent group's t-tests. No adjustments to p-values were made for multiple tests. As can be seen, there were no bivariate differences on any study variables between individuals who agreed to participate in the brain donation study compared with individuals who declined to participate. Thus, the participating subsample of brain donors

appears to reflect the characteristics of the larger population-based sample quite well, even without adjusting p-values for multiple testing.

Multivariate Analysis

A multivariate logistic regression model predicting donor status is presented in Table 2.

As can be seen, neither the omnibus test ($\chi^2(17) = 18.66$, $p = .348$) nor individual likelihood ratio tests were significant at $\alpha = .05$ for any study variable. There was a trend toward significance for the Global Deterioration Rating Scale in the direction of nondonors having greater cognitive impairment, with donors and nondonors differing by less than half of a category on the GDRS. Thus the multivariate model adds support to the representative nature of the donor subsample.

Discussion

The 31% participation rate for brain donation (66 of 212 approached) in the Georgia Centenarian study indicates that it is possible to successfully recruit a sample of organ donors in this population. There were no differences in characteristics among the centenarians who did or did not choose to participate. It can be extrapolated that the success of the project was due to the recruitment strategies used by the project coordinator. Because nursing consistently rates as one of the most ethical professions, perhaps this instilled a high level of trust in the information being given by the project coordinator. Recruitment strategies included: face-to-face meetings whenever possible; giving ample time for decision making; emphasizing respect for the participant's decision; providing honest, accurate information to aid in making the decision; explaining the importance of brain donation and the implications for medical research; and having a friendly and open attitude toward older people. The literature suggests that providing written information which explains autopsy and the importance of organ donation can be helpful; thus, we distributed brochures on brain donation when approaching subjects about the project, cf. [16].

In addition to the age and health status of the participants, caregiver age and health must also be taken into consideration. The children and/or caregivers of centenarians are usually elderly with personal health problems and physical disabilities of their own. This can result in difficult or poor communication, inability to schedule appointments for follow up and in one instance, lack of follow up for brain donation at the time of death. It is recommended that ongoing, frequent contact and a regular review of the procedures to be followed at the time of death is done with caregivers. In the present study, two autopsies were missed because of the inability to make ongoing contact with caregivers. In one instance, the caregiver was elderly and had health problems which contributed to the procedure not being followed at the time of death. In the other instance, the caregiver lived a long distance from the participant and was not available to the project coordinator by phone on an ongoing basis. The reasons centenarians provided for agreeing or refusing to donate their brains support those previously published [6, 16–18]. In some instances, participants and their families were unable to articulate their reasons for refusing to donate. Of those agreeing to donate, the predominant reason was a sense of altruism, including to help learn more about AD because they knew someone affected by AD; wanting to make a contribution; not needing the brain after death; having an interest in research and science; being cremated; and being aware of brain donation after death. Those refusing to donate gave reasons which included: the participant or family did not like the idea; they did not want to be disfigured; it would upset the participant to mention or think about it; the procedure was too extreme; they did not believe or participate in organ donation; belief that the brain belongs to God; feeling conflicted about what was the right decision for them; and needing to have the brain intact after death.

Publication of negative findings is important [19]. The success of this project indicates that recruited and non-recruited participants did not differ across a wide range of demographic, religious, personality, cognitive and physical functioning characteristics, consistent with their representativeness of the parent sample. Results suggest that an extremely diverse and highly representative sample of centenarians can be successfully recruited for brain donation. Currently the project has collected 53 brains post mortem (5 brains were missed, and another 8 centenarians are still living) from a population based sample of centenarians, which highlights the uniqueness of this study.

Conclusion

Brain donation is extremely valuable in diagnosing neurological diseases that occur in old age and understanding neuropsychological function in this population. Organ donation for the older adult population and their families can be a difficult decision. The 31% participation rate for brain donation in this study provides evidence that it is possible to successfully recruit participants from this age group without regard to race, gender, or religious variables. With the growing aging population and advances in medical research, it is increasingly important to understand the difficulties that may be encountered when discussing organ donation, how to approach the subject and which recruitment strategies may be most successful with older adults, including the oldest old.

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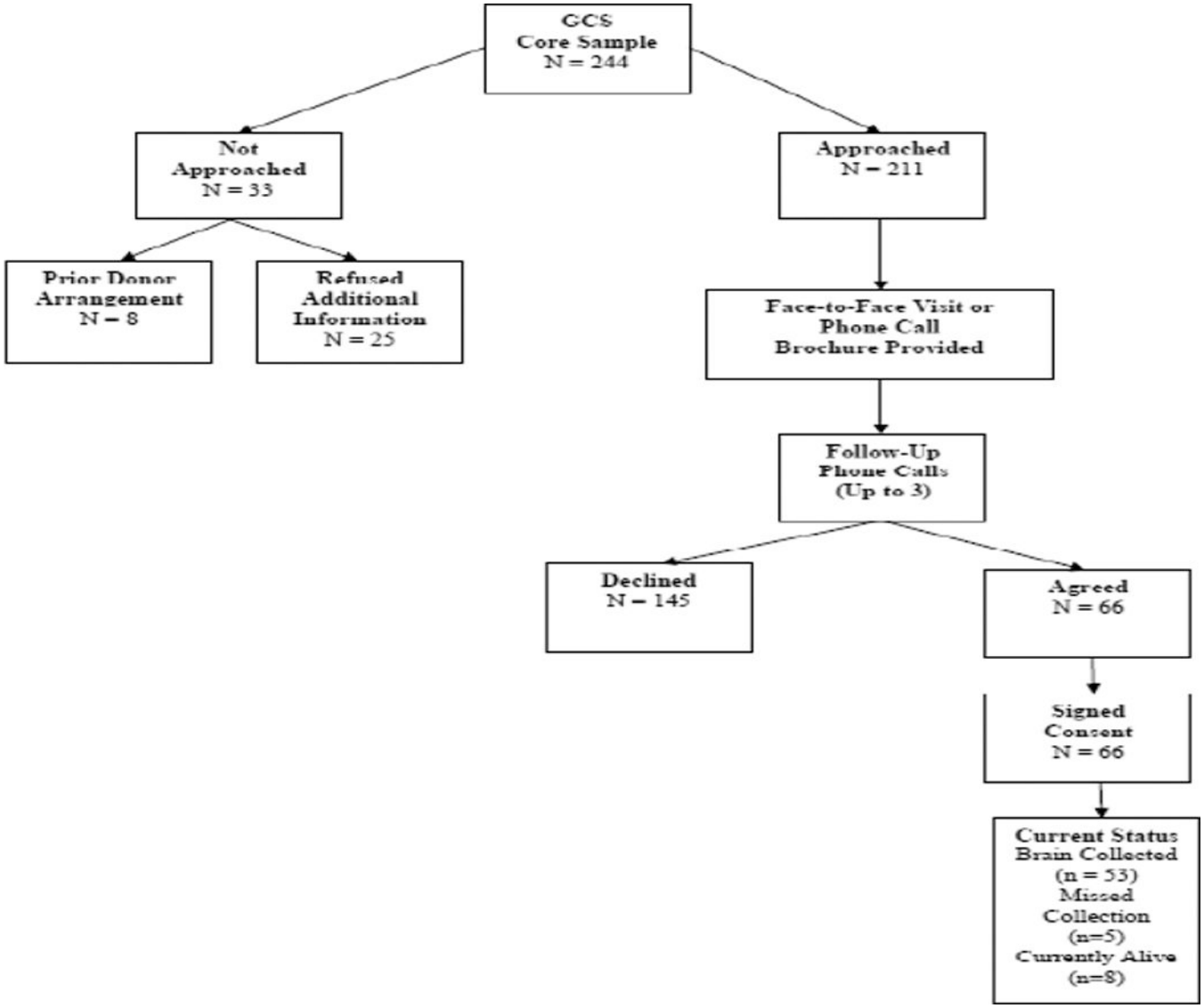

Figure 1.
Participant Flowchart

Table 1

Descriptive Statistics for Study Variables by Donor Status

	Non-Donors			Donors			
Variable	**n**	**M/%**	**SD**	**n**	**M/%**	**SD**	**p**
Age (Years)	145	100.7	2.1	66	100.6	2.1	0.828
Female	145	82.1%		66	90.6%		0.146
Black	145	22.1%		66	19.7%		0.856
Education (Years)	143	10.5	3.6	63	10.4	4.0	0.826
Living Arrangement	144			66			0.267
Private Home Alone		3.5%			4.6%		
Assisted Living Facility		18.8%			27.3%		
Skilled Nursing Facility		44.4%			36.4%		
Independent Living Facility		5.6%			7.6%		
Home with Full-Time Formal Caregivers		5.6%			0.0%		
Acute Care Hospital		0.7%			1.5%		
Private Home with Family		21.5%			22.7%		
Religion	144			65			0.070
Protestant		93.1%			84.6%		
Catholic		4.2%			12.3%		
Jewish		2.1%			1.5%		
Other		0.7%			1.5%		
Importance of Religion	141			62			0.492
Very Important		83.7%			82.3%		
Somewhat Important		12.1%			9.7%		
Not Too Important		4.3%			8.1%		
Neuroticism[a]	102	50.4	8.8	58	48.6	8.1	0.195
Extraversion[a]	102	45.6	9.1	58	44.6	9.9	0.527
Openness to Experience[a]	102	42.0	7.5	58	40.7	8.4	0.319
Agreeableness[a]	102	47.1	10.0	58	47.0	8.6	0.969
Conscientiousness[a]	102	44.2	10.2	58	45.0	9.7	0.612

	Non-Donors			Donors			
Variable	**n**	**M/%**	**SD**	**n**	**M/%**	**SD**	**p**
MMSE	145	15.8	8.4	66	17.0	9.5	0.343
Metropolitan Residence	145	80.0%		66	83.3%		0.705
GDRS	140	4.2	1.5	65	3.6	1.9	0.154
Facility Residence	145	62.1%		66	65.2%		0.759
PADLs	117	9.3	3.4	55	9.0	3.6	0.566
IADLs	121	11.1	3.2	56	12.0	2.4	0.061
Geriatric Depression Scale 15	120	6.6	1.6	54	6.7	1.8	0.904

[a]The GCS contained different studies that were not based on completely overlapping samples. Thus personality is available for a subset (65.6%) of the Core GCS Sample. Other frequencies vary due to modest amounts of missing data.

Table 2

Predictor	b	SE(b)	LR χ^2	p
Age (Years)	−0.053	0.112	0.23	0.633
Female	0.459	0.524	0.78	0.376
Black	0.305	0.529	0.33	0.565
Education (Years)	0.032	0.055	0.33	0.564
Importance of Religion	0.449	0.450	1.02	0.312
Neuroticism	−0.026	0.031	0.73	0.391
Extraversion	0.017	0.028	0.35	0.554
Openness to Experience	−0.037	0.028	1.83	0.176
Agreeableness	−0.013	0.025	0.28	0.600
Conscientiousness	−0.011	0.024	0.21	0.648
MMSE	−0.009	0.051	0.03	0.861
Metropolitan Residence	0.664	0.484	1.94	0.164
GDRS	−0.412	0.227	3.40	0.065
Facility Residence	0.297	0.424	0.50	0.482
PADLs	−0.090	0.069	1.79	0.181
IADLs	0.124	0.089	2.01	0.156
Geriatric Depression Scale 15	0.160	0.121	1.76	0.184
Intercept	6.250	11.851		
Likelihood Ratio $\chi^2(17)$			18.66	0.348