

A Registry of Adult African American Twins: The Carolina African American Twin Study of Aging

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Twin studies have seldom addressed ethnicity as one of the possible factors that create unique combinations of genetic and environmental influences. The major objective of the Carolina African American Twin Study of Aging is to identify the proportion of the genetic and environmental sources of individual variation in measures of health and behavioral factors in a sample of adult African Americans. Drawn from birth records from the State of North Carolina, this in-person study used public records to identify a cohort of twins between 22 and 92 years of age ($X = 49.82$ yrs, $SD = 14.62$), 39.7% of which were men. Members of non-intact twin pairs and siblings were also recruited to explore alternative models to the classic twin design. To date, the project has contributed to knowledge about blood pressure, forced expiratory volume, chronic illness, body mass index, and waist-hip ratio memory, personality, social, and demographic factors, mortality, and mental health.

■ **Keywords:** African Americans, health disparities, non-intact twin pairs, North Carolina, minority, aging

Nearly 25 years ago, quantitative genetics became a questionable domain of research in response to Arthur Jensen's 1969 paper that addressed perceived genetic differences in IQ between racial groups. There was outrage by scientists and lay people at the idea that one racial/ethnic group was 'genetically inferior' to another. This research had reverberations on science at two levels. First, doing quantitative genetic studies involving people of color was considered taboo or politically incorrect by all but a few researchers (see Sandra Scarr's work for examples of exceptions: Scarr, 1981, 1988; Scarr & Weinberg, 1976). Second, this research had an effect on scientific studies done on minorities in all fields of inquiry. Scientists tended to avoid conducting racially comparative research for fear of showing that minorities did not perform as well as Whites on tests designed for Whites. This concern over finding deficits in the performance of minorities in cross-cultural studies became an impediment to the accumulation of knowledge about minorities. More recently, there has been a similar response to Hernstein and Murray's book *The Bell Curve* (Hernstein & Murry, 1994). This book revisits the issue of differences between racial/ethnic groups in intellectual ability. Quantitative genetic methodologies, however, are not designed to directly test, nor are they based on assumptions of genetic differences between racial or ethnic populations. Over- or misinterpreting the results from quantitative genetic studies

does not advance science and could be potentially harmful for increasing the knowledge about minorities. Quantitative or behavioral genetic methodology has been considered by some to be a vehicle used to further racist agendas by some researchers. This arguably has been true for some research in this area. Research methodologies themselves are not racist, but the researcher behind the data can be. In fact, behavioral genetic methodologies are not designed to test assumptions of inequality among racial or ethnic populations. These methods should be used for what they were designed as important descriptive tools to understand causal influences on individual differences within a population, but not between population groups. These methods allow scientists to identify proportions of variation due to genetic and environmental influences on an observed variable or phenotypes, including behaviors. As scientists are beginning to convincingly argue that within-race studies must be performed prior to conducting cross-cultural studies (Burton et al., 1992; Whitfield et al., 1999, 2008), researchers can benefit by being open to the potential usefulness and power

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that behavioral genetic techniques have for answering questions about minority populations (Whitfield & Brandon, 2000).

The composition of the United States is quickly becoming more demographically diverse, particularly in the number of people of color and age (Macera et al., 2000). To begin to address the gap in knowledge about genetic and environmental influences in African Americans, the Carolina African American Twin Study of Aging (CAATSA) was developed with funding from the National Institute on Aging (Grant #RO1-AG13662). This project draws on the studies done in Sweden (Swedish Adoption and Twin Study of Aging (SATSA)) and from the work done by McGue and colleagues in Minnesota. The major objective of CAATSA was to identify a cohort of adult twins for the purposes of estimating the proportion of genetic and environmental sources of individual variation in measures of health (e.g., blood pressure, forced expiratory volume, chronic illness, body mass index, and waist-hip ratio) and psycho-social variables (memory, personality, social, and demographic factors, and mental health) and the co-variation among these measures. The work will provide important information concerning the health status, health behaviors, and psychological measures of aging among African American twins.

Method

To identify a cohort of African American twins that could be recruited for in-person assessments, we used data from the Black Elderly Twin Study conducted by Miles and colleagues (Miles, 1997). Based on their estimates of twins that could be identified from Medicare records and an algorithm of social security numbers and birthdates, North Carolina was one of the top five states yielding African American twins over the age of 65 years. North Carolina also is one of the states that allow the review of birth records by researchers.

Design

We reviewed 1990 census data for all counties in North Carolina to establish the ethnic distribution of African Americans who were within our target age range. We also searched vital statistics by county from 1920, 1930, 1940, 1950, 1960, and 1970 to examine the ethnic distribution of births by county. We combined the statistics for living births in each county for each of the years and rank ordered the counties according to birth rates. The counties were then rank ordered according to 1990 census data for the population 25 years of age and older. While there are 100 counties in the state of North Carolina, we were able to identify 23 counties that represented over 50% of the population over the age of 25 years and were the same counties that represented over 50% of the births that occurred in the state. This is not to imply that those born in those counties stayed in those counties for life. There is evidence of migration to the north

in the 1920s and 1930s and back migration to the south in the 1970s (Longino & Smith, 1991).

Once the sample counties were identified, the CAATSA staff traveled to offices of Vital Records or Register of Deeds for each county and hand copied the birth records of twins. The information recorded included date of birth, gender, name, number of living siblings, and name, address, and occupation of parents. This process yielded 14,852 twin records. These records were transferred from the handwritten forms to an electronic format and we then began the task of attempting to locate twins.

Before searching for twins, we eliminated individuals in our registry who would not be available for contact. Initially, we eliminated 1,573 records from our search because they were stillborn at the time of delivery (stillbirths). In addition, we identified 1,253 birth records that noted the twin died sometime between birth and the time of the search (noting death on the birth record is a policy of some but not all the counties searched). To find other twins who passed away since birth, we used the Social Security Death Index (SSDI) on the World Wide Web. We searched from 1913 to 1932 on SSDI to identify deceased subjects that would be eligible to draw social security prior to 1998 (at the time, the most recent update for SSDI was 1997). This search identified 717 individuals as deceased. Once we eliminated twins via these sources, 11,309 records remained for further investigation.

To locate twins we employed two methods. The first method involved finding possible addresses and phone numbers for twins using the white pages from telephone books and Internet web sites. Then the names and addresses were used to access credit service on perspective subjects. This procedure was performed using a credit reporting service called DAC. We used this particular service because no credit information was provided and inquiries did not adversely affect potential subjects' credit reports. These reports contained the subject's name, current and prior addresses, and occasionally the year of birth. Matches between credit information and birth information were marked as a 'hit' and were used in the recruitment process. There were two types of misses: (1) each subject's address was entered into DAC and the verification attempt produced a record for a different individual based on their date of birth, and (2) no record was available for access. Records designated as misses were not used in the recruitment process.

The second method for locating twins involved searching voter registration records. Voter registries were obtained from the counties of interest. The registries were in both paper and electronic form. The paper copies of voter registries were searched by hand for matches to our birth registry. For the counties with electronic records, we used the Version 6.12 of the Statistical Analysis System (SAS) program for Windows to compare birth dates and first names listed in the voter registries to a concatenated file of birth information from all of the counties.

In addition to deaths, we were not able to find information on 2,499 twins using our search methods. A total of 8,810 twin records were successfully searched yielding contact information. The 2,499 twins whom we did not find information on were not necessarily lost for recruitment because they can sometimes be found by referral if the other member of the pair has been contacted. Using the combination of DAC and voter registries minus deaths reported using SSDI and deaths reported on birth records, we have collected information on 59.3% of the individuals in the registry.

From preliminary examination of the registry, we observed that on average about 3.1% of the African American births were members of a twin pair between 1920 and 1950. Closer examination revealed that while there was a declining trend in the percentage of twin births across these years, there was actually an increase in the raw number of twin births. The declining percentage in twin births was a result of an increase in the rate of births among the general population exceeding the rate of increase in the number of twin births during 1940–1950.

Subject Recruitment

In previous research studies, successful recruitment of African Americans has required attention to cultural issues. In the few published articles that address subject recruitment in the African American population, no perfect strategy for successful recruitment into research studies has been proposed (Picot et al., 1996; Prohaska & Walcott-McQuigg, 1996; Young et al., 1996). Much of the difficulty in recruitment has arisen from memories of prior research that was both unethical and poorly designed, such as the Tuskegee Experiment (Bowman, 1991; Gamble, 1993). Although there are safeguards in place to protect subjects in human experimentation, these measures have not erased the fear among many African Americans that they will be abused for the sake of medical research (Gamble 1993). This fear of medical research has contributed to the low participation rates and subsequent under-representation of African Americans in clinical trials (King, 1992; Sevansson, 1989; Smith, 1991). However, successful recruitment of African Americans into research has been done and is possible.

The procedures and methods used in the CAATSA were drawn from previous research experiences with African American seniors and from other aging twin studies (e.g., The Swedish Adoption/Twin Study of Aging; the Minnesota Twin Study of Adult Development and Aging) (McGue et al., 1993; Pedersen et al., 1991). To recruit subjects for our research project, we first mailed a letter explaining our study. Two weeks after letters were sent, we would call potential subjects. Using this procedure individuals who are not twins were also found.

For those contacts who were twins, we were able to conduct interviews with 82% of those contacts. This rate is

fairly high given the age of the sample and, we believe, due to the recruitment approach taken. The average number of days from the time we contact a twin until we actually interviewed the subject is 19.81 days ($SD = 26.36$). However, approximately 50% of the interviews were conducted within 1 week of the recruitment call. There were a few interviews conducted over a month after the initial recruitment call because there was an illness or delays on the subject's part.

Participants

We began our recruitment on 1 March 1999 and we exhausted the searches of our twin registry and closed our testing site at the University of North Carolina at Chapel Hill's Center for Developmental Science on 14 June 2003. The final sample of the original CAATSA resulted in 706 interviews with 286 pairs of twins, 31 pairs of siblings and 72 surviving members of non-intact twin pairs. Of the intact twin pairs, there were 101 monozygotic twins and 121 were dizygotic and 64 were opposite sex twin pairs. Zygosity was established using a physical similarity questionnaire. This questionnaire has largely been derived from Nichols and Bilbro's (1966) research that used physical similarity criteria to predict with 93% accuracy diagnoses based on genetic markers from blood. Zygosity was confirmed in one of the subsequent analyses of DNA (Whitfield et al., 2009).

Due to the impact of poor health outcomes that drive health disparities observed between African Americans and Whites, we contacted a number of potential participants who were the surviving member of a twin pair. We deviated from the classic twin model that includes only members of intact twin pairs and recruited these surviving members of non-intact twin pairs. For 31 of these twins, we were able to also recruit a sibling to participate in the interview. For an additional 72, we were not able to either recruit a member of the family due to no living relatives being available for testing, living nearby, or still living. The sample consisted of 39.7% men and had an average age of 49.82 years ($SD = 14.62$) and an average educational level of 12.88 years ($SD = 3.4$). The gender and education distribution matches with state population estimates for the age range of the sample. The average income was between \$1,200–1,300 (income was defined by \$100 categories). The families of these participants tended to be large by today's standards, but quite common for those born in the middle part of the last century. The average number of siblings of our participants was 5.85 ($SD = 3.70$) and the average number of children our participants had was 2.35 ($SD = 2.15$). The sample required travel totaling over 100,000 miles to complete the study. There were some pairs that had members living in different states (North Carolina and another) while others that lived in the same county and even the same household.

Interestingly, we only had one incident in which our study came into question by children of one of our older participants. The question was not about the validity of doing studies or twins or genetic research, but concern that

we might be somehow abusing or attempting to fraud an older adult. Once we were able to speak to the children of the participant, we were allowed to proceed. Family is an important component of African American life in the South. Social networks between families are extensive. Some of the twins we contacted knew from other twins who lived in the same area and had grown up together that we might be calling upon them to participate. We also found anecdotally that while there was strong belief in the transmission of physical and behavioral traits between parents to children, there was little or no attribution by many to the role genes might play in the transmission of these traits, nor that did the similarity of twins arises from genes per se.

What Have We Learned?

The CAATSA was designed to examine the proportion of genetic and environmental influences on health in a sample of adult African American twins. Preliminary (prior to the close of recruitment) analysis of data from the CAATSA suggests that the disparities in blood pressure experienced by African Americans do influence the mortality of older twins. Whitfield et al. (2003) found that after controlling demographic variables, only blood pressures differed between members of intact twin pairs and surviving members of non-intact twin pairs. It appears that including only intact African American twin pairs may represent a bias in estimating sources of individual variability for some examinations of health and possibly other psychosocial variables.

We also conducted preliminary analyses to examine if there were age differences in genetic and environmental influences on blood pressure (Brandon et al., 2003). We found that among the older twins, heritabilities were .52 for systolic blood pressure (SBP), .36 for diastolic blood pressure (DBP), .14 for pulse pressure (PP). However, for younger twins, heritabilities were .44 for SBP, .27 for DBP, but with no genetic influence on PP. The results indicate that genetic factors are a significant source of variance in hemodynamic indexes and also suggest that, with advancing age, genetic factors play an increasing role in determining blood pressure and pulse pressure in this population. Conversely, it could be that environmental factors become less important with increasing age.

One of the unique approaches that we have used our data on health and aging in African Americans is to use the data as individuals. For a number of the publications that have resulted from our study, we conducted analyses that simply selected one of the members of the twin pairs at random to create a sub-sample of African American adults. For others, we wanted to use the entire data set, but the independence of observations assumption was not upheld, making standard regression procedures inappropriate. Therefore, to account for twin-pair dependency both in the outcome and covariates, a multilevel model approach was employed using xtreg, xtlogit, and ologit with a cluster option (STATA Inc., College Station, TX). This multilevel approach assumed that

each participant was nested within a twin pair and allowed for a varying degree of co-variation among twins depending on their twin status (i.e., monozygotic, dizygotic, same-sex dizygotic, or sibling; e.g., Szanton et al., 2010). These are just a sampling of the papers from the study.

Conclusion and Future Directions

The CAATSA has served as a useful tool in studying individual variability in aging and health among African Americans. The project has had good success with data analyses, resulting in 22 publications and over 30 presentations. The study is now over 10 years old, but there are still a number of analyses ongoing including one on gene environmental interactions on blood pressure. While we have been productive, there are still several missed opportunities yet to be explored in the data. For example, we have a small number of sibling pairs in our study that have never been utilized in any formal analyses of mortality. We have used the members of non-intact twin pairs in our analysis of mortality. Which provided important insights about special issues when using African American samples.

Another non-traditional analysis that we have not pursued is to examine the variability in the amount of contact our twins have with each other to estimate shared environment as opposed to the standard formula used in twin analyses. As adults, we assume it is less than when twins were children, but a confirmation of this assumption and perhaps even an assessment of how much contact used in an analysis of shared environment might provide some interesting information about contextual impact on phenotypes and genetic and environmental estimates. We also have DNA that is currently being used in analyses of obesity and the results will be included with two other data collections of non-twin samples, which will offer interesting insights about obesity in African Americans. The CAATSA continues to offer unique insights about individual variability in the health and aging of African Americans and continues to be one of the only in-person studies of adult African American twins. We have begun to re-interview the oldest twins in the cohort focusing on cognitive functioning. There are long-term plans to revisit the twins who participated in the first interview and refresh the cohort with younger twins who were born between 1975 and 1987.

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References

- Bowman, P. J. (1991). Race, class and ethics in research: Belmont principles to functional relevance. In R. L. Jones (Ed.), *Black Psychology* (3rd ed., pp. 747–766). Berkeley, CA: Cobb & Henry Publishers.
- Brandon, D. T., Whitfield, K. E., Sollers, J. J. III, Wiggins, S. A., West, S. G., Vogler, G. P., . . . Thayer, J. F. (2003). Genetic and environmental influences on blood pressure and pulse pressure among adult African Americans. *Ethnicity and Disease, 13*(2), 193–199.
- Burton, L. M., Dilworth-Anderson, P., & Bengtson, V. L. (1992). Creating new ways of thinking about diversity and aging: Theoretical challenges for the twenty-first century. *Generations, 15*(4), 67–72.
- Gamble, V. N. (1993). A legacy of distrust: African Americans and medical research. *American Journal of Preventive Medicine, 9*(Suppl 6), 35–38.
- Hernstein, R. J., & Murray, C. (1994). *The bell curve: Intelligence and class structure in American life*. New York: Free Press.
- King, P. A. (1992). The dangers of difference. *Hastings Center Report, 22*(6), 35.
- Longino, C. F., & Smith, K. J. (1991). Black retirement migration in the United States. *Journals of Gerontology, 46*, S125–S132.
- Macara, C. A., Armstead, C. A., & Anderson, N. B. (2000). Sociocultural influences on health. In A. Baum, T. Revenson & J. Singer (Eds.), *Handbook of Health Psychology* (pp. 427–440). Mahwah, NJ: Erlbaum.
- McGue, M., Hirsch, B., & Lykken, D. T. (1993). Age and the self-perception of ability: A twin study analysis. *Psychology of Aging, 8*, 72–80.
- Miles, T. P. (1997). Population-based, genetically informative sample for studies of physical frailty and aging: The Black Elderly Twin Study. *Human Biology, 69*, 107–120.
- Nichols, R. C., & Bilbro, W. C. (1966). The diagnosis of twin zygosity. *Acta Genetica et Statistica Medica, 16*, 265–275.
- Pedersen, N. L., McClearn, G. E., Plomin, R., Nesselroade, J. R., Berg, S., & DeFaire, U. (1991). The Swedish Adoption/Twin Study of Aging: An update. *Acta Geneticae Medicae et Gemellologiae: Twin Research, 40*(1), 7–20.
- Picot, S. F., Stuckey, J. C., Humphrey, S. W., Smyth, K. A., & Whitehouse, P. J. (1996). Cultural assessments of the recruitment and retention of African Americans into Alzheimer's disease research. *Journal of Aging and Ethnicity, 1*, 5–18.
- Prohaska, T. R., & Walcott-McQuigg, J. (1996). Recruitment of older African Americans: A focus group approach. *Journal of Aging and Ethnicity, 1*, 33–40.
- Scarr, S. (1981). *Race, Social Class and Individual Differences in IQ*. Hillsdale, NJ: Erlbaum.
- Scarr, S. (1988). Race and gender as psychological variables: Social and ethical issues. *American Psychologist, 43*, 56–59.
- Scarr, S., & Weinberg, R. A. (1976). IQ test performance of black children adopted by white families. *American Psychologist, 31*, 726–739.
- Sevensson, C. (1989). Representation of American Blacks in clinical trials of new drugs. *Journal of American Medical Association, 261*, 263–265.
- Smith, M. D. (1991). Zidovudine: Does it work for everyone? (Editorial). *Journal of American Medical Association, 266*, 2750–2751.
- Szanton, S. L., Thorpe, R. J., & Whitfield, K. E. (2010). Life-course financial strain and health in African-Americans. *Social Science and Medicine, 71*, 259–265.
- Whitfield, K. E., Allaire, J., Belue, R., & Edwards, C. L. (2008). Are comparisons the answer to understanding behavioral aspects of aging in racial and ethnic groups? *Journals of Gerontology: Psychological Sciences, 63B*(5), P301–P308.
- Whitfield, K. E., & Baker, T. A. (1999). Individual differences in aging among African Americans. *International Journal of Aging and Human Development, 48*, 73–79.
- Whitfield, K. E., & Brandon, D. (2000). Individual differences, ethnicity, and aging: What can gero-genetic studies contribute? *African American Research Perspectives, 6*(2), 115–122.
- Whitfield, K. E., Brandon, D. T., Wiggins, S. A., Vogler, G., & McClearn, G. (2003). Does intact pair status matter in the study of African American twins?: The Carolina African American Twin Study of Aging. *Experimental Aging Research, 29*, 1–17.
- Whitfield, K. E., Yao, X., Vogler, G. P., Hayward, M. D., Boomer, K., & Vandenberg, D. J. (2009). Analysis of candidate genes and hypertension in African American adults. *Journal of Ethnicity and Disease, 19*, 18–22.
- Young, R. F., Edevie, S., Young, J. H., & Peters, J. (1996). Issues of recruitment and retention in Alzheimer's research among African American and White Americans. *Journal of Aging and Ethnicity, 1*, 19–26.