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Influence of social and cultural capital on participation in clinical trials among African American elders in faith-based settings in Atlanta, Georgia

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An abstract of
a thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
in partial fulfillment of the requirements for the degree of
Master of Public Health
in Global Health
2018

Abstract

Influence of social and cultural capital on participation in clinical trials among African American elders in faith-based settings in Atlanta, Georgia

By Luis W. Salazar

Introduction: Under-representation of minorities particularly, elder African Americans in clinical trials (CT) remains to be a current issue in the United States (US) impeding adequate generalizability of results. Social Capital (SC) and Cultural Capital (CC) have been associated with improved health and good health outcomes. Faith-based settings (black churches) are points of gathering for elder African Americans where social support is high (SC and CC).

Goal: The purpose of the study is to understand to what extent SC and CC influence the decision-making process of participating in clinical trials among elder African Americans in faith-based settings.

Methods: Sample population consisted of 221 African American elders (over 50 years old) who attended church regularly. Secondary analysis of questionnaire-data collected after an educational session about health risks was given by the researchers at the faith-based setting. Periodic enrollment was made accessible to all participants during the study period. Three multiple logistic regression models were used to assess the relationship of outcomes with SC and CC predictors.

Results: 221 elder African Americans, mean age=64.0 (SD 7.7). 78.3% were female, 98.2% were African Americans. The outcomes where: 1. “Already being in contact with a CT” regressed with cultural capital predictors; 2. “Likelihood of contacting a CT” regressed with social capital predictors; and 3. “Likelihood of joining a CT” regressed with social capital predictors. Cultural capital predictors significantly associated with “Already being in contact with a CT”, were “*attended art, music or dance classes as a child*”, and “*like listening to music*”. SC predictors statistically associated with “Likelihood of **contacting** a CT” were “*frequently visiting friends*”; and SC predictors associated with “Likelihood of **joining** a CT” were “*Attended frequent public meetings”* and *“Voted in last presidential elections”.*

Conclusions: SC and CC influence the decision-making process that takes you from contacting to joining a CT, therefore, being a facilitator for participation in CTs.

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Acknowledgements

This project would not have been possible without the undoubtful guidance of my thesis advisor Dr. Paula Frew. Her generosity and willingness to help proved to be paramount in the successful completion of this project. To her, my eternal gratitude and admiration.

A special thanks to all investigators involved with the Dose of Hope intervention for aiding in the fruition of this project.

I am very grateful for the work and hours that Laura Randall dedicated to the review and coordination of the project and its timely progression.

To my family and friends, all my gratefulness for their support and unbelievable faith in me, especially to my dear and close friends, Irina and Amedee for carving time in their busy schedules to lend a helping hand.

Lastly, but not least, to my wife, whom along me endured the dire battle of fulfilling my master's degree journey. For her invaluable, and unconditional love and support, I will always be in your debt my sweet Emilia.

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Chapter 1: Introduction

Taking access to quality healthcare services in the United States (US) as an example of a health indicator or outcome, we see it remains to be elusive for many, even more so, for populations of certain racial and ethnic minorities. This exposes historically rooted inequalities which have recently become more evident with the last economic recession (Singh et al., 2017; Travers, Cohen, Dick, & Stone, 2017).

Marked under-representation/low participation of African Americans in clinical trials reveal these social inequalities for racial/ethnic minorities (Chen et al., 2017; Falasinnu, Chaichian, Bass, & Simard, 2018; Kurt, Kincaid, Curtis, et al., 2017; Moreno-John et al., 2004; Sheffet et al., 2018). Furthermore, the under-representation of elder African Americans in clinical trials is hindering us from generating appropriate evidence-based knowledge that can be adequately generalizable (Hutchins, Unger, Crowley, Coltman, & Albain, 1999; Stewart, Bertoni, Staten, Levine, & Gross, 2007). In addition, elder African Americans show poorer health status (Mouton, 1997), and are at greater risk for missed diagnoses, greater disabilities and higher death rates (Byrd, Fletcher, & Menifield, 2007).

Social capital and cultural capital have some influence in determining the health status of an individual or collective (Eriksson, 2011). In this sense, social capital may influence/predict/facilitate the participation of African Americans in clinical trials.

In lieu of the previous claims, the purpose of this research project is to understand to what extent social and cultural capital influence/predict/facilitate participation in clinical research among elder African Americans.

Our three primary objectives are:

i) To evaluate how *cultural capital* influences or predicts the participation of elder African Americans in clinical trials;

ii) To evaluate how *social capital* influences or predicts the likelihood of "contacting" a clinical research study by elder African Americans (in this case an Emory study); and

iii) To evaluate how *social capital* influences or predicts the likelihood of "joining" a clinical research study by elder African Americans (in this case an Emory study).

Accomplishing the latter, will let us better understand the role of social and cultural capital as influencers/predictors/facilitators for participation in clinical trials in minorities, helping the medical research consider these factors to tackle the need of adequate representation of minorities in future clinical trials and consider them when screening participants for recruitment. Furthermore, this may aid all of us, as a society to put our efforts in attempting to acquire high levels of social and cultural capital, hence giving these populations another door for access to quality healthcare and a better quality of life.

Finally, we offer some definitions for terms to be used throughout this research project for standardization purposes. Elder African Americans is defined as a self-reported African American, 50 years old and above. Social capital and cultural capital will be defined thoroughly in the next chapter.

Chapter 2: Literature review

As stated in the previous chapter, under-representation of racial and ethnic minorities in medical research is a current concern in medicine and public health. We must research different aspects of this issue to, eventually, result in medical research with adequate minority representation similar to their representation in the general population. The aspect focused in this literature review is the potential influence/prediction/facilitation that social and cultural capital may have on participation in clinical research among our study participants.

In doing so, we will discuss the following themes: Social and Cultural Capital; Social/Cultural capital, health and African Americans; Health disparities, clinical trials and African Americans; and lastly Faith-based organizations, Social/Cultural Capital and African Americans.

Social and Cultural Capital

Social Capital was being studied but not published until the 1990s when articles began to appear in our common scientific paper databases (Kawachi, Subramanian, & Kim, 2008). Currently, more have been appearing and database searches show articles in the low thousands as we do this literature review.

Among some of the first proponents of a definition for social capital, Pierre Bourdieu, French sociologist was the first to propose that social capital was *"the aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance or recognition"* (Bourdieu, 1986).

A second important author is James S Coleman who proposed a definition of social capital according to its function as "*a variety of entities with two elements in common: they all consist of*

some aspect of social structures, and they facilitate certain action of actors - whether persons or corporate actors - within the structure" (Coleman, 1988).

According to Alejandro Portes, a Princeton sociologist, many other definitions arose at the time (early 1990s) but there was a growing consensus in the literature that *social capital stands for the ability of actors to secure benefits by virtue of membership in social networks or other social structures*. He further makes some distinctions of different forms of capital to further clarify where social capital can be found, and affirms, *whereas economic capital is in people's bank accounts, and human capital is in their heads, social capital is inherent in the structure of their relationships* (Portes, 1998).

Roughly at the same time, Robert Putnam, an American political scientist, tries to parallel social capital to the level of "civicness" in communities and proposes that social capital means "*features of social organizations, such as networks, norms, and trust, that facilitate action and cooperation for mutual benefit*" (Putnam) and further defines it in another one of his books "*Bowling Alone: The collapse and revival of American community*" as "*the connections among individuals-social networks and the norms of reciprocity and trustworthiness that arise from them*" (Putnam, 2001).

Social capital has different forms according to a network perspective (bonding, bridging and linking): **Bonding social capital**, refers to strong ties <u>within a network</u> that strengthen common identities and is a source of support among members; it is like the sociological "superglue" that maintains these connections (family, friends, neighbors or ethnic fraternal organizations). **Bridging social capital** refers to weaker ties that link people from <u>different networks</u> together and are sources of information and resources; it's like the "WD-40" of society keeping

everything smoothly running along as a lubricant (civil rights movement or youth service groups) (Putnam, 2001). **Linking social capital**, are vertical ties, not horizontal as bridging, between people that interact through different formal or institutionalized power or authority in the society (bankers at a conference, etc.) (Szreter & Woolcock, 2004); and according to the social structure perspective (structural and cognitive): **Structural social capital** refers to the structure or composition of the network, the roles undertaken and the activities they perform. **Cognitive social capital** refers to the shared social norms, and values of trust, solidarity, and reciprocity (Eriksson, 2011).

Cultural capital on the other hand, is considered by Bourdieu as a type of capital. In his "*Forms of capital*" he states three types of capital: economic capital, social capital and cultural capital. He considers cultural capital to be essentially referred to the collection of elements such as skills, education, postures, material possessions, credentials, etc., that one may acquire through a lifetime and considers it to have three forms: the embodied state, seen in the form of long-lasting dispositions of the mind and body and presupposes it takes time to acquire (such as our own culture, or our cultural dialect or accent, or simply as being able to read); the objectified state in the form of cultural goods (collections of art, music instruments, cars, etc.); and the institutionalized state in the form of educational qualifications (credentials such as a higher education degree) (Bourdieu, 1986).

For the sake of this research project and clarity, we will convene the cultural capital definition from Bourdieu, and in a similar fashion, we will convene the social capital definition from Putnam, which refers to the connections among individuals-social networks and the norms of reciprocity and trustworthiness that arise from them (Putnam, 2001).

Social/Cultural capital, health, and African Americans

Social/Cultural capital and health

Since its conception, social capital has been linked with favorable outcomes and one of those outcomes is good health. In this case, our focus is to uncover evidence that links social capital and good health in general but in a more specific way with the African American population.

According to Berkman and Glass, by being part of a social network, individuals may acquire benefits such as health through certain pathways such as provision of social support, social influence (influence of peers on health behaviors), social engagement and attachment and access to resources and material goods (such as job opportunities, access to health services) (Berkman, Glass, Brissette, & Seeman, 2000). This last pathway may function as a way to acquire a skill (job), hence higher cultural capital, as well as social capital.

Eriksson's PhD dissertation on social capital and health-implications for health promotion, discusses the associations between social capital and health through individual or collective pathways that are similar to how Berkman and Glass describe by using the social influence pathway and positively influencing health behaviors and also maybe helping in the access to health services (Eriksson, 2011).

Many articles have found evidence of associations on how social capital influences health outcomes (Arezzo & Giudici, 2017; Berkman et al., 2000; Eriksson, 2011; Flor et al., 2018; Helliwell & Putnam, 2004; Rocco, Fumagalli, & Suhrcke, 2014; Vassilev et al., 2011; Yamada et al., 2018) . Some examples include good outcomes in diabetic patients (Flor et al., 2018; Yamada et al., 2018), cardiovascular disease patients (Choi et al., 2014; Palafox et al., 2017), cancer patients (Choi et al., 2014; Shelton et al., 2016), mental health patients (Han et al., 2018; Zhou et al., 2018) to name a few conditions. They all find a positive association with the good health

outcome (not having the condition) or a negative association with characteristic symptoms of each health condition.

Social/Cultural Capital and African Americans

Regarding African Americans and their association on how social capital may lead to better health, lets discuss some examples. Ransome et al, found evidence that US states that have higher levels of social trust had lower late Human Immunodeficiency Virus (HIV) diagnosis rates in African Americans, henceforth, social trust may promote timely HIV testing which in turn may facilitate earlier HIV diagnosis (Ransome et al., 2017). Cheney et al, concluded that interventions designed to increase connection and support (social capital) to African Americans by non-drug using families and friends may reduce the substance abuse in low income and resource poor communities (Cheney, Booth, Borders, & Curran, 2016). If we go further to evaluate the elder African Americans and the role of social capital in their health outcomes we find, for instance, when trying to recommend elder African American men to get screened for prostate cancer due to having a higher prevalence and cancer-related mortality, social capital was associated with a 3 to 3.5 greater likelihood of having a Prostatic-Specific Antigen (PSA) testing (Dean et al., 2015); or when recommending elder African American women for breast cancer screening with routine mammography, similar results are found associated with social capital (Gibbons & Schiaffino, 2016).

As we can gather, social capital has much evidence of playing a preponderant role in influencing better health outcomes in elder African Americans.

Health disparities, clinical trials, and African Americans

Health disparities and African Americans

Considerable health disparities remain in the US more than ever, despite the implementation of the Healthy People 2020 (US Department of Health and Human Services, 2010) program which is in charge of improving the health of all and reducing health disparities. From worst to best health, African Americans and American Indians have the worst health, followed by Latinos and Asians, while Whites are at the other end of the spectrum having the best health (Braveman, 2012).

Proof of this, is a study regarding surveillance of health status in minority communities that indicates residents of most of the minority communities in the US, persist to have lower socioeconomic status (SES), greater barriers to access to quality health care, and greater risks for and burden of disease compared to the general population living in the same metropolitan area, county or state (Liao et al., 2011). Another study has found evidence that African Americans have more disparities in almost every aspect of health ranging from specific low vaccination coverage for Influenza and pneumococcal disease (Hughes, Saiyed, & Chen, 2018), or decreased mental health visit access compared to non-Latino Whites (Jones et al., 2018), to higher cervical cancer and related-mortality (Yoo et al., 2017), to cite some examples.

But elder African Americans (over 65 years of age) are even in worse situations than the average age African American, just as an example one study shows that the cardiometabolic risk health of older blacks worsens as they age compared to that of Whites and Hispanics (Mitchell, Ailshire, & Crimmins, 2018). As we can see, health disparities are broadly distributed among African Americans' experience with health.

Clinical trials and African Americans

Clinical trials also show the same disparities in participation numbers for all racial/ethnic groups, especially for African Americans as we describe below but may be another avenue for African Americans to access to quality healthcare.

In general, clinical trials' purpose is to advance our knowledge base in medicine and public health by providing the strongest evidence-based information. Under-representation of African Americans in them also reveal more disparities compared to other racial/ethnics groups (Chen et al., 2017; Falasinnu et al., 2018; Kurt, Kincaid, Curtis, et al., 2017; Moreno-John et al., 2004; Sheffet et al., 2018), and is also true for elder African Americans as well (Hutchins et al., 1999; Kwiatkowski, Coe, Bailar, & Swanson, 2013; Stewart et al., 2007)A systematic review of racial/ethnic minorities in cancer treatment and prevention clinical trials, that included clinical trials from 1990 to 2010, found the following participation: 82,9% were White, 6.2% were African American, 3.3% were Asian, 2.2% were Hispanic, and 0.1% were Native American (Kwiatkowski et al., 2013).

Factors that may be behind the under-representation of African Americans in clinical trials were assessed and found to be statistically significant for not participating in clinical trials; some of the reasons found were "how well the research study was explained to me" or "the risk of unknown side effects" (Kurt et al., 2016). Another study found that African Americans' motivation to participate declined with more education as well as with more income (Kurt, Kincaid, Semler, et al., 2017).

Faith-based organizations, Social/Cultural capital and African Americans

Putnam stated that faith-based organizations or churches are a good source of bonding social capital where people see each other repeatedly and periodically (attending mass each week, bible

study, or volunteering) (Putnam, 2001). More specifically, faith-based organizations are a good source of religious social capital which is defined as "*the social resources available to individuals and groups through their social connections with a religious community*" (Joanna Maselko, Hughes, & Cheney, 2011). As discussed before, there are well established links between social/cultural capital and health.

There is a large literature that links regular church attendance to better health outcomes. Some of those studies have shown that regular religious service attendance is associated with lower mortality and less consistently correlated with lower physical and psychological morbidity (Hummer, Rogers, Nam, & Ellison, 1999; J. Maselko, Gilman, & Buka, 2009; J. Maselko & Kubzansky, 2006). In addition, data analyzed from the National Health Interview Survey-Multiple cause of death, people who never attend regular religious services have 1.87 times more risk of death from different causes compared to people who attend more than once a week; even though the magnitudes of risk differ by cause of death, the association's direction is consistent through all causes (Hummer et al., 1999). All these studies are based on having high social support, influence or capital.

Elder African Americans who are frequent church attendants have a great relationship and high participatory involvement with their faith-based institutions (Taylor, Chatters, & Jackson, 2007), hence theoretically may have some benefit through mechanisms such as increase access to social networks and support (social capital), encourage better health behaviors, promote coping mechanisms and even encourage volunteering. Religious social capital may be a strong social determinant of health because the ties in an average religious community are stronger than the ties in an average neighborhood or community (Joanna Maselko et al., 2011).

Chapter 3: Methods

Introduction

To evaluate the extent to which social and cultural capital influence the attitudes towards participating in medical research and clinical trials, our research project pulled from primary evidence captured by the "*Delivering a Dose of Hope*" (DoH) intervention.

"Delivering a Dose of Hope"

DoH's goal was to influence the attitudes of church-going, elder black/African Americans (over 50 years of age) regarding medical research and clinical trials. The faith-based settings were utilized as a channel to reach the study population. Their main objective was to examine the effect of an educational intervention in future clinical trial enrollment. For this, the study population was followed longitudinally for 24 months, time at which any enrollment of intervention participants in ongoing clinical trials was measured (main outcome).

DoH implemented three educational workshops in faith-based settings (churches) about health disparities, clinical research and health risks. The control groups received basic health information for elders, instead of the educational workshops. Data was collected from surveys administered at different points in the study (at baseline, at three-months, and at six-months) for both, the intervention and control groups. Along the study period, both groups received periodical newsletters and were contacted directly (via phone and email), regarding ongoing research projects which were actively recruiting participants.

Population and sample

The rationale behind the selection of faith-based settings (churches) is rooted in the prospect of being a channel to directly access the African American study population. The faith-based organizations (churches) included three different Christian denominations: Baptist, Seventh-Day Adventist (SDA), and African Methodist Episcopal (AME). Six of these churches were randomly selected from a sampling frame of 20 faith-based organizations that were required to have ≥ 30% of African Americans ≥ 50 years of age, and that were located within the 22 counties of the Atlanta-metro area.

There were two hundred and twenty-one (n=221) participants. Inclusion criteria were: black/African American, ages ≥ 50 years, active member of one of the churches selected, and a resident of the Atlanta-metro area. Exclusion criteria: moving within the next 12 months, previous participation in a clinical trial or faith-based intervention, or unable to attend all three intervention education workshops. Of the total of 221 participants, 112 were assigned to the intervention group and 109 to the control groups. Using pair-matched randomization, three churches were randomly selected to the intervention group and the matched pairs were assigned to the control group.

Research design

The DoH developed the longitudinal mixed-methods study intervention with a Community Based Participatory Research approach, and used a cluster randomized controlled trial design to implement the intervention. In addition, to the survey data collected 10 participants from both, the control and intervention groups were chosen to participate in qualitative interviews regarding their perceptions of the DoH study and perceptions of health concerns and barriers to health

education and clinical trials within their communities. The 10 participants were compensated for the interviews, in addition to the survey compensation.

Procedures

The DoH intervention was conducted by Emory Faculty and staff, and pastors and health ministry leaders from the assigned churches. The Emory team visited each church jointly with other study staff to establish relationships prior to implementation. To obtain the sampling frame of churches, the DoH used ethnographic observation and key informant interviews.

Months prior to the baseline start, implementation started with training of pastors and ministry leaders regarding the conduction of the educational workshops, which were offered at baseline, at three months, and at six months. Surveys were administered and completed by participants at each of these timepoints. After 24 months of follow-up other clinical trial variables were collected. All study activities took place in the sanctuary or a meeting room at each of the churches that would accommodate the number of participants and that were convenient, familiar and comfortable for the participants. Our specific research project was based on the secondary analysis of the six-month surveys.

Instruments

Data collection was performed through survey administration at 3 different timepoints: at baseline, at three months, and at six months, after each educational workshop. The baseline survey had 134 items with demographic questions and some other measurable domains; the three-month survey had 137 items and the six-month survey had 192 items.

All sociodemographic characteristics were measured at baseline and the three-month surveys. They included, church denomination, gender, age, marital status, educational attainment, employment, annual household income, and medical insurance policy.

The primary outcome of regarding having already been in contact with a medical research study was measured with answer choice of Yes and No. The secondary outcomes of likelihood of contacting a medical research study, and the likelihood of joining a medical research study were measured on a scale from 0 (definitely not) to 10 (definitely).

Cultural capital was measured at the six-month survey through a series of 15 questions regarding recreation and entertainment experiences. Thirteen of these questions had an answer scale ranging through never, seldom, sometimes, often and always. The 14th question had an answer scale through none, 1 to 10, 11 to 30, 31 to 50 and more than 50. And the 15th question had an answer scale ranging through not at all, barely, moderately well, well and very well.

Social capital was measured through a series of 7 questions regarding community involvement and social networks. Questions 1 to 3, had an answer scale ranging from strongly agree (1) to strongly disagree (5). Questions 4 to 6, had an answer scale ranging through 25% or less of my free time, 50 percent of my free time to 75% or more of my free time. Lastly, question 7 was a Yes/No answer.

Data analysis

For data analysis we had access to the six-month follow-up survey data and were completed by using SAS statistical software version 9.4 (SAS Institute Inc., Cary, NC, USA). To assess the effect of different predictors on the 3 outcomes we ran logistic regression models.

All sociodemographic characteristics were measured at baseline and the three-month surveys.

Ethical considerations

The study staff were CITI certified in Social and Behavioral Research. This project was approved by the Institutional Review Board of Emory University. An additional request was completed and approved to add myself to the study staff and be able to perform the corresponding data analysis for my project. Consent forms were given to the participants to read and were explained verbally to participants by study staff. Once all questions were answered and a verbal acceptance was given by the participant, the consent forms were signed. Surveys were locked and secured in a file cabinet at the Emory Hope Vaccine Clinic. Data was deidentified with a participant identification number and entered into IBM SPSS Statistics software, version 21 and stored on the secure Emory drive. Surveys will be stored for the required 5 years and immediately destroyed. Data was transferred to SAS software for statistical analysis.

Chapter 4: Results

Study participants

A total of 221 participants in the sample started the study at baseline. The sociodemographic characteristics of the study participants at baseline are shown on Table 1. Age was divided in 6 categories ranging from 50 to 80+ year olds: 50-59 year olds (10.4%); 55-59 year olds (17.6%); 60-64 year olds (26.2%); 65-69 year olds (22.6%); 70-79 year olds (18.6%); and the 80+ year olds (3.2%). The average age of the study participants was 64.0 (SD 7.7). The majority of study participants identified as female (79.3%), while men accounted for the remainder. In terms of race, most identified as African American/Black (217, 98.2%). In terms of ethnicity, non-Hispanics were slightly shy of 80%. Most of the participants had a technical associates degree or higher which accounted for 64.2% of the study population. Almost half of the participants (110, 49.8%) had an annual household income of less than $40,000. Most of the participants were unemployed or retired (148, 67.0%). Regarding, marital status, 46.2% were married or had a domestic partner, 26.7% were divorced or separated; 10.9% were single or never married, and 15.8% were widowed.

Multivariate Logistic Models

We ran some multiple logistic regression models to assess the relationship between the 3 outcomes and different predictors regarding cultural and social capital. All logistic models ran were using the six-month timepoint data. A covariance matrix was run to assess multicollinearity. None of the Pearson Correlation coefficients (r) between the variables assessed exhibited an r above 0.02, therefore indicating the absence of multicollinearity.

Table 1. Sociodemographic Characteristics of the Study Population

Item	Frequency	Percent (%)
Age (missing n=3) [Mean 64.0, SD 7.7]		
50 to 54	23	10.4
55 to 59	39	17.6
60 to 64	58	26.2
65 to 69	50	22.6
70 to 79	41	18.6
80 or greater	7	3.2
Gender		
Female	173	78.3
Male	48	21.7
Race		
African American/Black	217	98.2
Multiracial/Multicultural	4	1.8
Ethnicity (missing n=45)		
Non-Hispanic	175	79.2
Hispanic/Latino/Chicano	1	0.5
Highest Level of Education		
K-8 grade	3	1.4
9-11 grade	10	4.5
High School Grad/GED	66	29.9
Technical/Vocational/Associates	66	29.9
Bachelor's Degree	37	16.7
Master's Degree	33	14.9
Doctorate	6	2.7
Household Income (missing n=23)		
Less than $20,000	61	27.6
$20,001 - $40,000	49	22.2
$40,001 - $60,000	36	16.3
$60,001 - $80,000	20	9.0
$80,001 - $100,000	19	8.6
More than $100,001	13	5.9
Employment (missing n=8)		
Employed – Full Time	43	19.5
Employed – Part Time	18	8.1
Unemployed	37	16.7
Other (Retired n=85, 44.4%)	115	52.0
Relationship Status		
Single/Never Married	24	10.9
Married/Domestic Partner	102	46.2
Divorced/Separated	59	26.7
Widowed	35	15.8
Other	1	0.5

**Total sample (N=221)*

Model 1: Being in contact with Emory about a medical research study

The overall model was significant (p=0.0316). The model was run to assess the relationship between "Being in contact with Emory about a medical research study" and the 17 predictors for cultural capital (Table 2). Two of our factors showed to be significantly associated to "Being in contact with Emory regarding medical research": 1. individuals who "*Attended art, music or dance classes outside school as a child*" (OR=1.346, CI=1.028,1.762), and 2. individuals who "*like listening to music*" (OR=0.890, CI=0.260, 0.811). The majority of the predictors were not significant and included but not limited to "*Do you buy books or newspapers*" (OR=0.740, CI=0.474, 1.156), "*In your lifetime have you been to the theatre*" (OR=1.292, CI=0.793, 2.103), or "*Can you read music score"* (OR=1.087, CI=0.668, 1.771).

Model 2: Likelihood of contacting a medical research study

Logistic ordinal regression analysis was run for this model to assess the relationship between "Likelihood of contacting a medical research study" and 7 predictors for social capital (Table 3). The overall model was not significant (p=0.257), therefore, no association was found for this outcome. The predictor" *Spending a lot of time visiting friends*" (OR=1.457, CI=1.061, 2.000) showed to be significant while controlling for the other 6 social capital predictors.

Model 3: Likelihood of joining a medical research study

Logistic ordinal regression analysis was also run for this model to assess the relationship between "Likelihood of joining a medical research study" and 7 predictors for social capital (Table 4). The overall model was significant (p=0.0147). Two predictors showed to be significantly associated to "Likelihood of joining a medical research study":1. individuals who

"*attended any meeting on town or school affairs in last year*" (OR=0.367, CI=0.167, 0.809), and

2. "*Voting in last presidential election*" (OR=5.729, CI=1.540, 21.314).

Table 2. Logistic Regression "Being in contact with Emory regarding medical research" (Model 1)

	Coefficient Estimate	Standard error	Significance (p value)	Point estimate	95% Confidence Interval	
As a child, did you attend art, music, or dance classes outside your regular school?	0.297	0.137	*0.030	1.346	1.028	1.762
Do you read books for pleasure?	-0.150	0.251	0.549	0.860	0.525	1.409
Do you read newspapers or visit news websites?	-0.068	0.233	0.769	0.934	0.591	1.475
Do you watch documentaries on TV?	0.279	0.245	0.255	1.323	0.817	2.142
Do you buy books or newspapers?	-0.301	0.227	0.185	0.740	0.474	1.156
Do you go to the library?	-0.117	0.185	0.527	0.890	0.619	1.279
Do you like listening to music?	-0.777	0.289	*0.007	0.460	0.260	0.811
Do you play a music instrument?	-0.384	0.243	0.115	0.681	0.422	1.098
Do you listen to Jazz?	-0.593	0.349	0.090	0.553	0.278	1.097
Do you listen to Blues/R&B	0.654	0.353	0.063	1.924	0.963	3.844
Do you listen to Classical/chamber/opera	0.172	0.248	0.486	1.189	0.730	1.934
In your lifetime have you been to music concerts, orchestra performance, or opera?	-0.213	0.233	0.361	0.808	0.511	1.278
In your lifetime have you visited museums (art, science, history), exhibitions, or historic places?	0.411	0.315	0.191	1.509	0.813	2.801
In your lifetime, have you been to theatre?	0.256	0.248	0.303	1.292	0.793	2.103
Do you paint, draw, or do crafts in your free time?	0.157	0.172	0.362	1.170	0.835	1.640
Do you own any books?	-0.352	0.181	0.051	0.703	0.493	1.003
Can you read music score?	0.083	0.248	0.736	1.087	0.668	1.771

**Significant p-values **Variables 1 through 15: (1=Never to 5=Always) Variable 16: (1=None to 5=more than 50), Variable 17: (1=Not at all to 5=Very well). ***Missing data (deleted from analysis) =39.*

Table 3. Ordinal Regression of "Likelihood of contacting a medical research study" (Model 2)

	Coefficient Estimate	Standard error	Significance (p value)	Point estimate	95% Confidence Interval	
I spend a lot of time visiting friends	0.376	0.161	*0.020	1.457	1.061	2.000
Most people can be trusted	-0.387	0.381	0.309	0.679	0.322	1.433
Most people are honest	0.257	0.366	0.483	1.293	0.630	2.654
How often you attended any public meeting on town or school affairs in the last year?	-0.065	0.591	0.912	0.937	0.294	2.984
The number of times you volunteered in the last year.	-0.195	0.324	0.546	0.822	0.435	1.553
The number of times you entertained others at your home in the last year.	-0.273	0.338	0.418	0.761	0.392	1.476
Did you vote in the last presidential election?	1.303	0.848	0.124	3.683	0.698	19.419

**Significant p-values **Variables 1 through 3: (1=Strongly agree to 5=Strongly disagree) Variable 4 through 6: (1=25% or less of free time to 3=75% or more of free time), Variable 7: (1=Yes and 0=No). ***Missing data (deleted from analysis) =81.*

Table 4. Ordinal Regression of "Likelihood of Joining a medical research study" (Model 3)

	Coefficient Estimate	Standard error	Significance (p value)	Point estimate	95% Confidence Interval	
I spend a lot of time visiting friends	0.026	0.134	0.843	1.027	0.789	1.336
Most people can be trusted	0.440	0.290	0.129	1.553	0.879	2.746
Most people are honest	-0.534	0.280	0.056	0.586	0.338	1.016
How often you attended any public meeting on town or school affairs in the last year?	-1.002	0.403	*0.012	0.367	0.167	0.809
The number of times you volunteered in the last year.	-0.154	0.258	0.548	0.857	0.516	1.421
The number of times you entertained others at your home in the last year.	-0.105	0.251	0.675	0.900	0.549	1.474
Did you vote in the last presidential election?	1.745	0.670	*0.009	5.729	1.540	21.314

**Significant p-values **Variables 1 through 3: (1=Strongly agree to 5=Strongly disagree) Variable 4 through 6: (1=25% or less of free time to 3=75% or more of free time), Variable 7: (1=Yes and 0=No). ***Missing data (deleted from analysis) =25.*

Chapter 5: Discussion

The overall purpose of this project was to determine to what extent social and cultural capital had a role or influence in the likelihood of "contacting", "joining", or "being in a medical research study" among elder African Americans in faith-based settings (churches).

It is our theory that these three outcomes (assessed in each logistic model) are part of a "behavioral continuum" in which social and cultural capital exert their effect or influence towards the end goal of participating in a medical research study.

Findings

As an overview, findings from our three models suggest that some of the social and cultural capital factors were significantly related to our outcomes, while most of them were not related to any of our outcomes in the stated behavioral continuum.

Our first overall logistic model was significant (p=0.0316) and suggested that two factors, individuals who "*Attended art, music or dance classes outside school as a child*", and individuals who "*like listening to music*" were significantly related to "*Being in contact with Emory about a medical research study*". In essence, those elderly African Americans who like listening to music and have attended art, music or dance classes as a child are more inclined to contact Emory about participation in a medical research study. The fact that the relationship lay in factors that have to do with appreciation of the arts, and more strongly for music that was probably acquired during the individual's lifetime, suggests there was an acquisition of cultural capital (cultural assets) (Bourdieu, 1986). These musical attributes are associated with improved health (Ola Ekholm, Knud Juel, & Lars Ole Bonde, 2016; O. Ekholm, K. Juel, & L. O. Bonde, 2016), therefore, drawing individuals to situations and behaviors that may help them advance along our behavioral

continuum, where health has high value and it is considered an essential part of a fruitful and healthy lifestyle. The fact that music (spiritual gospel music) is very important in African American faith-based institutions and that music in general is such a social activity, those who are drawn to participating in medical research may be more socially aware or engaged in social justice issues than those who are not. This may suggest that there is an understanding or insight that being involved in medical research may be a channel to maintaining or acquiring access to healthcare, and in turn, a better health status; or even having an empathetic nexus to the notion of "the greater good" and benefit for humanity as a whole. In view of this, these cultural capital factors may become proxies for social engagement, and furthermore, the black church may be the right environment with the appropriate characteristics of social capital, to target the African American population for recruiting participants in future medical research.

The rest of the cultural capital factors (15 of them) in this model, were not significantly related to "*Being in contact with Emory about a medical research study*". It was our expectation that more of the cultural capital factors may be influencers or facilitators of participation in medical research, particularly factors related to similar musical engagement, such as the *types of music they listen to, particularly jazz, or blues/R&B* and others concerned with books such as with *book ownership*. Taking the latter as an example, those who were passionate for literature may be well-read and more motivated to be socially responsible, thus more inclined towards the cause of participating in medical research. One probable reason of the non-significance of all these factors, may be due to our small sample size. Perhaps with a larger sample size these factors may become significant and related to our outcome.

The two factors related to our outcome in this model, suggest that music has an important involvement in having a high social capital level, high enough to influence the decision of already participating in a medical research study.

Our second overall logistic model that assessed the relationship between the "*Likelihood of contacting a medical research study"* and social capital factors, although found to be overall non-significant (p=0.787), it seems important to draw attention to one of the factors that was significantly associated to the outcome while controlling for the other 6 factors for social capital. This significant factor "*I spend a lot of time visiting friends*", is important and worthy of mentioning because it is a direct measure of socialization, telling us about the connectedness of those individuals to their immediate acquaintances and the social trust amongst those relationships that would eventually lead these individuals to an improved health status, as we mentioned before regarding the association between social capital and improved health (Arezzo & Giudici, 2017; Berkman et al., 2000; Eriksson, 2011; Flor et al., 2018; Helliwell & Putnam, 2004; Rocco et al., 2014; Vassilev et al., 2011; Yamada et al., 2018) . It is also worthy of discussing because the opposing situation of lacking friends to visit or having some degree of social isolation, especially in the elderly, can impact their health such as having higher mortality risks (Smith, Jackson, Kobayashi, & Steptoe, 2018), worse cardiovascular and mental health outcomes (Leigh-Hunt et al., 2017), etc.

This social capital factor shows how important socialization, therefore, having a high social capital level may be to influence the decision of considering contacting a medical research study to participate in.

Our third overall logistic model that assessed the relationship between the "*Likelihood of joining a medical research study*" and social capital factors was found to be significant overall

(p=0.0147). Two factors for social capital, "*Frequency of attending public meetings about town or school affairs in the last year*" and "*Voting in the last presidential election*" where found to be significant. Those elder African Americans who exhibit stronger social capital behaviors such as voting in the last presidential elections and those who frequently attend public meetings, are more socially involved and are more likely to consider joining medical research studies. Behind these two forms of civic duty and social engagement, lies a possible feeling about how honest or trustworthy others may be, therefore, having a certain proclivity to join these types of medical research in an attempt to pursue that "greater good" we talked about earlier. Putnam professed social capital being this sense of "civicness" (Putnam, 2001) that drives individuals to participate in activities related to these forms of civic activism, which at the same time entail a high value of trust in the processes of our political life.

Some of the other factors (5 of them) not associated to this third model's outcome (joining medical research) are still good measures of social capital and were expected to be significant as well. Perhaps due to the fact that social trust may somehow be lower for African Americans, regarding these other non-significant factors ("*how honest people are"* or *"can most be trusted"*). This may have its origins in the general mistrust of the African Americans in the medical community in general (Tuskegee, Henrietta Lacks, etc) (Mays, 2012; Njoku, 2013).

The two social capital factors significant in this model have this "civicness" or civic mindedness nuance within them, therefore, is proof of the important influence of social capital in the decision-making process of joining a medical research study.

Some limitations of our study have to do with the fact that we used a cross-sectional timepoint data collection via questionnaires that may lead to issues of reliability of data (self-reporting) and which is a source of recall bias. Answering issues exploring health conditions, other social

constructs (social and cultural capital indicators and its scaling) may be difficult to understand or grasp.

Regarding participants' selection from a subset of the African American population in churches may have limited our generalizability. Also, considering the small number of our sample may have limited the power of our study, thus, limiting the ability to have stronger and more significant models.

Conclusions

In terms of cultural capital, appreciation for the arts (art, music, dance) and specifically appreciating music in African American elders who attend church services, seem to be influencers or facilitating factors related to already participating in medical research studies. These factors may act as proxies of cultural capital

In terms of social capital, socialization factors measured by "*frequency of visiting friends*", in African American elders that attend church, seems to be related or influence the decision-making process of "contacting" medical research studies;

In terms of social capital, social and civic involvedness factors measured by "*frequently attending public meetings*" and "*voting in elections*", in African American elders who attend church services seem to be related or influence the decision-making process of "joining" medical research studies.

Going back to the behavioral continuum we presented earlier, we see how social and cultural capital factors are shaping the behavioral intentions, your willingness, your attitudes, and even your decision to move along the behavioral continuum towards joining medical research studies.

Chapter 6: Implications and Recommendations

Our study has successfully proven that social and cultural capital may have high value in the elder African American population in terms of participation in medical research studies. Although not confirmed, other minorities may have similar characteristics and may also benefit of strategies where social and cultural capital are center key.

Future medical research studies should target faith-based settings or other settings where factors (the ones we have identified) such as appreciation of arts, music, connectedness to friends, and civic mindedness views are predominant because these may be acting as proxies for high level social and cultural capital individuals/environments. It is crucial for researchers to know these factors well because the individuals or environments that have these factors may be fertile ground for recruitment in medical research studies.

Obviously, by doing so, we will obtain high participation of minorities, hence, improve the current generalizability issues and appropriateness of the knowledge produced from medical research studies. Despite this, further research is granted to identify more possible social and cultural capital proxies and settings that may aid to increase participation in medical research studies.

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Appendices

Appendix A: Outcomes Instrument

A. Likelihood of Participation *Please fill in the blank space or check the box next to the response that best expresses your assessment of the items below.*

A6. Are you already in contact with Emory about being in a medical research study?

[ ] Yes, *skip to question A8*

[ ] No

[ ] Don't recall

A7. On a scale from 1 (definitely not) to 10 (definitely so), rank your likelihood of *contacting* Emory about being in a medical research study in the next 6 months:

1 2 3 4 5 6 7 8 9 10

A8. Have you joined a medical research study since the first Dose of Hope session?

[ ] Yes *Specify which one:*_____

[ ] No

[ ] Don't recall

A9. On a scale from 1 (definitely not) to 10 (definitely so), rank your likelihood of *joining* a medical research study within the next 6 months:

1 2 3 4 5 6 7 8 9 10

Appendix B: Cultural Capital Instrument

J1-J15. Recreation and Entertainment experiences. Please place an x in the appropriate box for each question, to indicate how much you agree with each statement.

Item	**Rating**				
	1 Never	**2** Seldom	**3** Sometimes	**4** Often	**5** Always
1. As a child, did you attend art, music, or dance classes outside your regular school?					
2. Do you read books for pleasure?					
3. Do you read newspapers or visit news websites?					
4. Do you watch documentaries on TV?					
5. Do you buy books or newspapers?					
6. Do you go to the library?					
7. Do you like listening to music?					
8. Do you play music instrument?					
9. Do you listen to any of the following genres of music? a. Jazz b. Blues/R&B c. Classical/chamber/opera					
10. In your lifetime, have you been to music concerts, orchestra performance, or opera?					
11. In your lifetime, have you visited museums (art, science, history), exhibitions, or historic places?					
12. In your lifetime, have you been to theatre?					
13. Do you paint, draw, or do crafts in your free time?					
14. Do you own any books?	**None**	**1 to 10**	**11 to 30**	**31 to 50**	**More than 50**
15. Can you read music score?	**Not at all**	**Barely**	**Modera-tely well**	**Well**	**Very well**

Appendix C: Social Capital Instrument

P4-P6. Community Involvement and Social Networks. Please place an X next to the response that best reflects your participation in community activities. Please mark how well you agree with each of the following statements:

	1 Strongly Agree	**2** Agree	**3** Neutral/No Opinion	**4** Disagree	**5** Strongly Disagree
I spend a lot of time visiting friends					
Most people can be trusted					
Most people are honest					

P7. Please estimate how often you attended any public meeting on town or school affairs in last year

___25 percent or less of my free time (less than 2 days a week)

___50 percent of my free time (3-4 days a week)

___75 or more of my free time (5-7 days a week)

P8. Please estimate the number of times you volunteered in last year

___25 percent or less of my free time (less than 2 days a week)

___50 percent of my free time (3-4 days a week)

___75 or more of my free time (5-7 days a week)

P9. Please estimate the number of times you entertained others at your home in last year

___25 percent or less of my free time (less than 2 days a week)

___50 percent of my free time (3-4 days a week)

___75 or more of my free time (5-7 days a week)

P10. Did you vote in the last presidential election?

___Yes

___No

___Not Sure/Don't Recall