

Intergenerational Influence of African American, Caribbean and Hispanic/Latino Adults Regarding Decision to Participate in Health-Related Research

Research on Aging
2024, Vol. 0(0) 1–12
© The Author(s) 2024
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/01640275241229411
journals.sagepub.com/home/roa



Trudy Gaillard¹ , Donna Z. Shambley-Ebron², Joan A. Vaccaro³ , Donna F. Neff⁴, Cynthia Morton Padovano⁵, Phildra Swagger⁶, Edgar Vieira⁷, and Fern Webb⁸

Abstract

Introduction: Identifying effective strategies to enroll African American, Caribbean, and Hispanic/Latino adults ≥ 65 years of age in health research is a public health priority. This study aimed to explore intergenerational influence (IGI) among these populations living throughout Florida. **Methods:** African American, Caribbean, and Hispanic/Latino adults ≥ 65 years of age and a trusted family member/friend between 25–64 years participated in virtual listening sessions (LS). Culturally matched facilitators used a semi-structured guide to lead LS that was recorded, transcribed, and uploaded into NVivo[®]. The constant comparative method was used for analysis. **Results:** 363 African American, Caribbean, and Hispanic/Latino participated in LS. Five (5) themes relate to IGI emerged: (1) parent-child relationships; (2) family caregiving/parental illness experiences; (3) historical research maltreatment; (4) transfer of cultural knowledge; and (5) future generations. **Discussion:** Our findings support that IGI can be leveraged to increase the participation of African American, Caribbean, and Hispanic/Latino older adults in health research.

Keywords

intergenerational influence, ethnically diverse adults, research decision making, listening sessions

African Americans, Caribbeans, and Hispanic/Latinos experience higher incidence, prevalence, morbidity, and mortality for chronic diseases and health conditions, such as diabetes, cardiovascular disease, certain cancers, and stroke when compared to non-Hispanic White Americans (Fenelon et al., 2017; Kamath et al., 2021; Marron et al., 2018). The underrepresentation of ethnically diverse populations in health research poses a significant challenge, given their disproportionate impact by chronic diseases (Javed et al., 2022). Inclusion of ethnically diverse individuals in studies is essential due to potential variations in treatment effectiveness across diverse groups, influenced by genetic and environmental factors. Moreover, addressing cultural nuances is crucial for developing healthcare strategies that are sensitive to the diverse needs of different ethnic groups. Research involving ethnically diverse populations is integral to understanding and mitigating health disparities linked to socioeconomic factors, unequal access to healthcare, and systemic injustices (Javed et al., 2022). Furthermore, it enhances the generalizability of research findings, ensuring they are applicable to a broader demographic. Actively involving ethnically diverse groups in research builds trust, encourages participation, and fosters collaborative partnerships. This

inclusivity is vital for shaping policies and practices that consider the specific needs of ethnically diverse populations and contributes to more equitable healthcare outcomes.

¹Nicole Wertheim College of Nursing and Health Science, Florida International University, Miami, FL, USA

²College of Nursing, University of Cincinnati, Cincinnati, OH, USA

³Department of Dietetics and Nutrition, Robert Stempel College of Public Health and Social Work, Florida International University, Miami, FL, USA

⁴College of Nursing, Academic Health Science Center, University of Central Florida, Orlando, FL, USA

⁵Department of Advertising, College of Journalism and Communications, University of Florida, Gainesville, FL, USA

⁶College of Nursing, Academic Health Science Center, University of Central Florida, Orlando, FL, USA

⁷Department of Physical Therapy, Nicole Wertheim College of Nursing and Health Science, Florida International University, Miami, FL, USA

⁸Department of Surgery, Center for Health Equity & Engagement Research (CHEER), University of Florida, Jacksonville, FL, USA

Corresponding Author:

Trudy Gaillard, Nicole Wertheim College of Nursing and Health Sciences Undergraduate Nursing, Florida International University - Modesto A Maidique Campus, 11200 SW 8th Street, AHC3, Room 240, Miami, FL 33199, USA.

Email: tgailar@fiu.edu

According to the United States Census Bureau, over 55 million adults were 65 years or older in 2022, representing 1 in 6 adults (Caplan Z, 2023, Accessed, May 1, 2023). These numbers are projected to rise to 77 million by 2035 (Census, U.S, 2018, Accessed, May 1, 2023). The State of Florida has one of the largest representation of adults aged ≥ 65 years (21.1%). Among 22 million Floridians ≥ 65 years old, approximately 3 million (17%) were African American, 4.9 million (27.1%) were Hispanic/Latino, and 3.7 million (20%) were Caribbean (U.S. Census Bureau QuickFacts: Florida, Accessed May 1, 2023; Migration Policy Institute, 2019). Thus, understanding perceptions and views towards health research participation is necessary to improve engagement of these ethnically diverse populations and is an important public health priority. Therefore, research engaging these diverse populations is of high significance given their high population representation in the State.

Several studies have documented challenges in the recruitment and retention of ethnically diverse populations into clinical research (Forsat et al., 2020; George et al., 2014; Luebbert & Perez, 2016). These impediments include the following: inadequate outreach and engagement, ineffective communication and messaging; and a widespread distrust of researchers and academic institutions within the community (Barrett et al., 2017; Brewster et al., 2019). These challenges are greater for older adults who often rely on trusted family members and friends for additional assistance, such as explaining and translating medical information (Bishop et al., 2018). In response to these challenges, several approaches were found to be effective in recruiting ethnically diverse older adults, such as, including high staff cultural proficiency, clear communication and messaging, and community relevance and involvement (Ejiogu, et al., 2011; Green et al., 2015; Ochs-Balcom, et al., 2015). In addition, several studies documented that older ethnically diverse adults often consult family members about health care treatment before making final decisions (Nyborg, et al., 2017; Ochs-Balcom, et al., 2015). However, few studies have examined the potential influence of younger trusted family members.

An important yet less explored potential recruitment and retention strategy is the role that younger adults can have on their older family members' decisions to participate in clinical research. One common assumption is that the older adult (i.e., parent) primarily influences the younger adult (i.e., child). However, marketing researchers provide evidence of an inverse relationship where the *younger* adult (i.e., child/family member) influences the *older* adult (i.e., parent). Swinyard and Sim (1987) reported that adult children have significant influence on their parents, and the influence depends on what is being discussed or decided as well as the age of the child. Polachek's (1989) seminal work found that in addition to an adult child influencing the parent, there was a reciprocal benefit for both the adult child and parent. However, this potential influence of younger adults

influencing older adults' decision to participate in clinical research has not been fully explored.

Intergenerational influence (IGI) is defined as the "influence of one generation on another in terms of the transfer of skills, attitudes, preferences, values, and behaviors (Shah & Mittal, 1997). This concept encompasses both health communication (Baiocchi-Wagner & Talley, 2013) and family communication (Koerner & Fitzpatrick, 2002), and focuses on cognitive and interpersonal relationships between parents and adult children. IGI is present whenever advice is sought either from the older adult by the adult child or from the adult child by the older adult. The authors posited that the beliefs of a family member or trusted friend can serve as motivation for an individual to engage in a health behavior and or research participation. Consequently, intergenerational communication plays a pivotal role in information exchange, particularly within many ethnically diverse older communities. For example, research has shown that older adults often rely on younger family members for decisions regarding healthcare (Nyborg et al., 2017). Despite the significance of intergenerational communication, there is a scarcity of research on how IGI can be leveraged for *younger adults to involve older adults in the clinical research process*. Attempting to recruit ethnically diverse older adults, without engaging another family member may risk alienating the family, potentially fostering distrust in research. Thus, the objective of this study was to investigate the potential role of trusted younger adult family member and/or friend in influencing the health care and health research decision-making of ethnically diverse older adults regarding research participation. To achieve this goal, the following questions were posed:

- 1) "Whose views do you value?"
- 2) "Who influences your health care decision-making?"
- 3) "Who influences your decisions regarding health research participation?"

Conceptual Framework

The current study integrated intergenerational influence (IGI) into the *Theory of Reasoned Action* (TRA) which posits an individual's attitudes, beliefs, and behaviors can influence others through the processes of (a) compliance, (b) identification, and (c) internalization (Shah and Mittal, 1997; Ajzen, 1991; Ajzen & Fishbein, 1980) (Figure 1). The original TRA consisted of four (4) major constructions: beliefs, attitudes, intentions, and behaviors. This model assumes that behaviors are under volitional control and that the intention to perform a behavior is influenced by the perceived expectations of benefits of changing behavior, beliefs regarding the behavior, and expectations of how others view the behavior (Ajzen & Fishbein, 1980). In the present study, we amalgamated the constructs of the IGI and TRA to

guide the formation of our study (Figure 1). We postulated that beliefs can be transferred between family members, thereby motivating, or encouraging research participation among ethnically diverse older adults. Our conceptual framework, incorporating IGI and TRA holds significant potential to enhance our understanding of the perspectives of older ethnically diverse African American, Caribbean, and Hispanic/Latino individuals regarding the value of younger family members/friends and their capacity to potentially influence health care decision making and participation in health research.

Methods

Study Team

We employed a qualitative descriptive approach using focus groups following the methodology outlined by Doyle et al., (2020). Our interdisciplinary study team was multi-institutional, with locations in North (Jacksonville area), Central (Orlando and Tampa area) and South (Miami, Ft. Lauderdale area). These regions represent the tri-institutional representation of study team members. Team members had expertise in qualitative and quantitative methods.

We purposely recruited bilingual facilitators and note takers (Spanish and Creole). Each facilitator and note taker completed three (3) hours of training covering study goals, conducting of listening sessions, and how to manage difficult participant behaviors. Notetakers met with participants prior to sessions to explain the Zoom platform, assisted facilitators during sessions, addressed technical issues, and monitored Zoom sessions.

Participants, Recruitment, and Setting

Participants were recruited in dyads of older adult (>65 years) and a younger (25–64 years) trusted family member or friend who was identified as a person to whom health information was shared. Participants self-identified as African American, Caribbean, and Hispanic/Latino. There was a total of 363 participants, 179 older adults (>65 years) and 184 younger adults (25–64 years), 94 males and 269 females (Table 1 and Table 2). Informed consent approved by the Florida International University Institutional Review Board (IRB Protocol Approval #IRB-20-0119) was obtained from all participants. Recruitment occurred between August 2021 and December 2022 through community partners, social and mass media, and by word of mouth, and within professional, social, and personal networks.

The term “focus groups” was replaced with “listening sessions” based on recommendation of the Florida Statewide Aging Governance Engagement (FL-SAGE) Council, our community advisory council, and to reflect the current qualitative terminology (Adrion et al., 2022). FL-SAGE consisted of ethnically diverse community residents, faith-based community members, community-based organizations serving older adults, and community partners from each respective university representing North, Central and South Florida. The FL-SAGE members contributed to the study’s development from its inception, including recruitment. A total of 134 listening sessions were conducted throughout North, Central and South Florida (Table 3). Each participant completed two listening sessions, one with their peer group and one as dyads. Session lasted 60–90 minutes with 4–10 participants per session.

All listening sessions occurred via Zoom, were recorded, and transcribed verbatim into English. Spanish and Creole

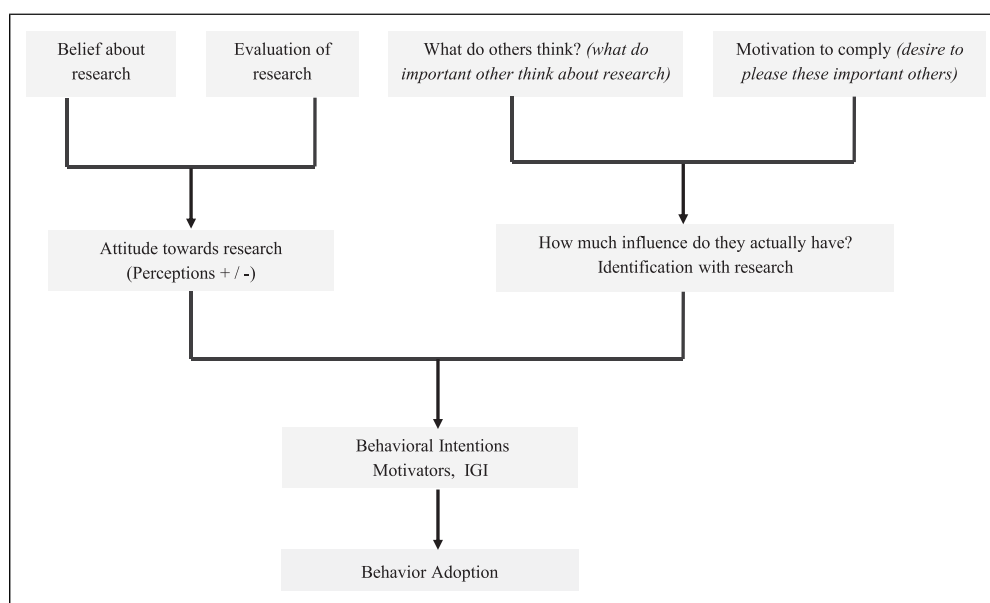


Figure 1. Theory of reasoned action and intergenerational influence.

Table 1. Number of Participants by Ethnicity/Race and by Region.

Region	African American		Caribbean		Hispanic/Latino		Total
	Younger adult	Older adult	Younger adult	Older adult	Younger adult	Older adult	
North	34	35	11	8	16	10	114
Central	22	22	8	8	14	14	88
South	9	9	8	8	33	33	159
TOTAL	65	66	56	56	63	57	363

Table 2. Total Number of Participants by Gender (Male/Female) and Region.

Region	African American				Caribbean				Hispanic/Latino			
	Younger adult		Older adult		Younger adult		Older adult		Younger adult		Older adult	
	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female
North	14	21	10	25	4	7	2	6	1	15	5	4
Central	1	21	0	22	0	8	0	8	2	12	2	12
South	3	6	1	8	10	27	16	24	11	22	12	21
TOTAL	18	48	11	55	14	42	18	38	14	49	19	37

Table 3. Total Number of Listening Sessions by Ethnicity/Race and Region.

Region	African American			Caribbean			Hispanic/Latino			Total
	Younger	Older	Combined	Younger	Older	Combined	Younger	Older	Combined	
North	6	6	8	3	4	4	2	2	3	38
Central	5	5	5	3	3	3	5	5	5	39
South	3	3	3	7	7	7	9	8	10	57
Total										134

Note. Regions. Participants self-identified their region of residence; North (Jacksonville area), Central (Orlando and Tampa area) and South (Miami, Ft. Lauderdale area). Regions were justified by participants address. These regions represents the tri-institutional representation of study team members.

sessions were transcribed by fluent speakers and verified by bilingual study team members.

Data Analysis and Integrity

All listening sessions were uploaded into NVivo[®], a web-based tool for qualitative data management and analysis (NVivo.com, version 12). Transcripts were independently analyzed by author 1 and 2 using the constant comparative method (Glaser, 1965). The following general steps included (1) familiarization of transcripts and noting initial ideas, (2) scrutinizing data with open coding to applied to individual meaning units, (3) reading and grouping codes to form categories and concepts, (4) constant comparisons within and between transcripts to identify patterns, and (5) inductively abstracting codes into higher level codes until broad themes representing intergenerational influence (IGI) were developed. Investigators met several times to discuss the themes until thematic congruence was achieved.

Findings

We actively involved ethnically diverse older adults and their trusted younger family member and/or friend in discussions about health research to gain deeper insights into their decision-making processes. From these engagements, five (5) broad themes emerged related to intergenerational influence (IGI): (1) parent-child relationships; (2) family care giving and parental illness experiences; (3) historical research maltreatment; (4) transfer of cultural knowledge; and (5) importance for future generations. These themes provide a comprehensive understanding of the various factors encompassed by IGI in the context of health research decision making of ethnically diverse older adults and their trusted family member and/or friend (Figure 2).

Theme 1: Parent-Child Relationships

We found that all participants from African American, Caribbean, and Hispanic/Latino groups consulted with their

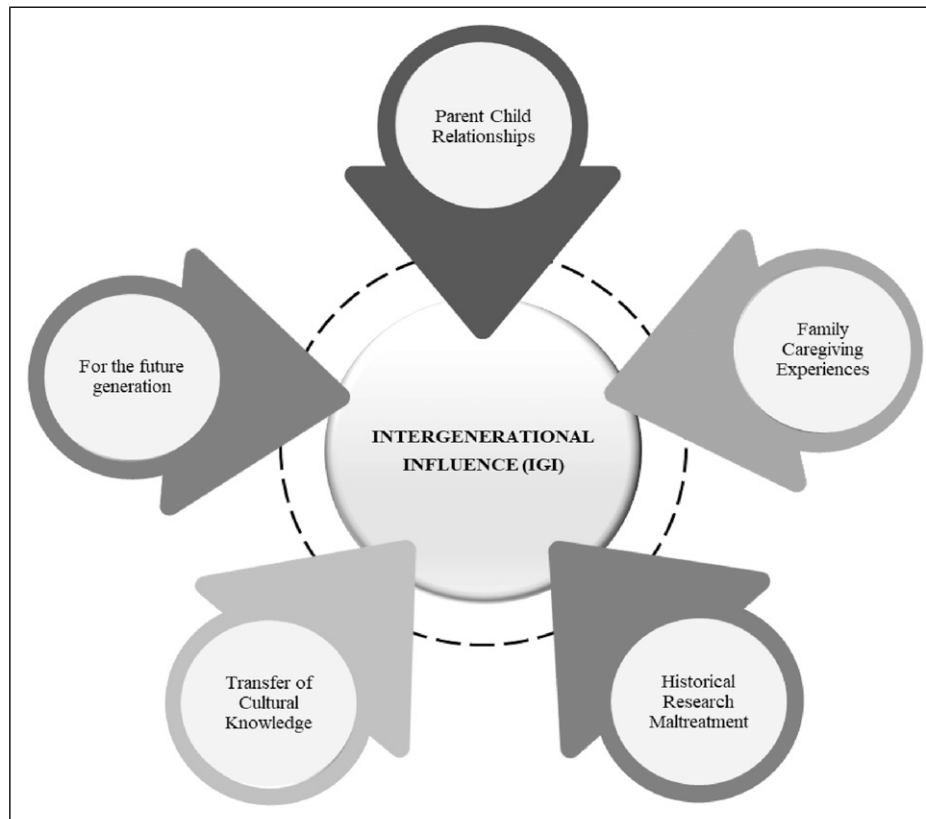


Figure 2. Intergenerational influences on culturally diverse adults.

younger trusted family member and/or friend regarding decisions to participate in health research. However, most older adult participants stated they made their final decisions independently. Many ethnically diverse older adults frequently sought advice about health issues, concerns and potential research participation from various family members or friends, but most often from their adult children. They reported relying on daughters more often than sons, especially if they had a daughter who was a health care professional. In addition, older adults verbalized sharing health concerns and research participation with spouses, their health care providers and trusted family members who were in the health care field. Younger adults reported being more independent in their decision making and relied on self, spouse, and contemporaries more so than older adults. However, some younger participants still sought advice from their mothers demonstrating an interdependence and intergenerational communication among generations regarding health care decision making.

Participants Statements

- *“I usually share all of my information with my children because they’re the ones that carry me to the doctor anyway. So, I don’t go to the doctor alone.” Older African American*

- *“Okay, I basically didn’t have much of a choice because my daughter works in the health field and she said, “Mom, you have to take it, you have to.” (Referring to the COVID-19 vaccine). Older Hispanic/Latino*
- *“Well, my daughter, I would rely heavily on my daughter’s opinion and her assistance in making the correct decisions.” Older Caribbean*
- *“Because I think the girls are more attentive. They’re more likely to be, I guess you’d say, more into your business than we (men) would be.” Older African American*
- *“I’ve talked to my children about it, my daughters. I’ve talked to them about the different things that I have been a part of and some of the studies that I’ve been in and questionnaires and things of that nature, just so they understand where I am.” Older Hispanic/Latino*

Theme 2: Family Caregiving and Parental Illness Experiences

In the current study, participants >65 years told stories about caring for their elderly parents, in-laws, or other family members. Thus, family caregiving, defined as a relative who provides emotional, financial, nursing, social, homemaking or

other services daily in the care recipient's homes, many without pay, was common (Allen et al., 2019). Although younger participants shared that their older family member or friends did not readily discuss healthcare issues with them, they did report that their parents' and caregivers' experiences shaped their viewpoints on research participation and the need for research. Participants with experiences of caring for their older family members, especially with dementia, influenced their older members and increased the likelihood of research participation.

Participant Statements

- *"Alzheimer's...because my mom is suffering from it at this moment, and it's very scary thinking I might have to go through what she's going through." Younger Hispanic/Latino*
- *"She was a vibrant evangelist at the church, and she moved in around 2011. Slowly but surely....as the years went by, she started declining ...and as of 2years ago, she was really in a childlike state. So, the research definitely needs to go further and deeper to find the root cause of dementia and Alzheimer's." Older African American*
- *"I think it's important to do aging studies because I know Alzheimer's runs in my family. My great grandmother has it, but then my grandmother participated in an Alzheimer's study and her quality of life was better because of it." Younger African American*
- *"I lost my dad to Alzheimer's. I think that I never knew there were so many people who were exposed to this until it hits home...or it affects you personally." Older Hispanic/Latino*

Theme 3: Historical Research Maltreatment

In the current study, both older and younger adults had been influenced by generational knowledge passed down related to historical mistreatment of ethnically diverse populations in unethical research. They indicated that knowledge of historical maltreatment from prior generations led many to distrust health-related research and continues to influence their decisions regarding research participation. For example, many older ethnically diverse populations referenced the injustices experienced by African Americans in the well-known Tuskegee experiment, in which Black men were deliberately left untreated for syphilis to determine the long-term effects of the disease (Katz et al., 2008; Washington, 2007). A Hispanic younger adult spoke of sterilization of young Hispanic women from Puerto Rico. Yet others spoke of not being invited to participate in health research by health care providers or injustices seen in the distribution and administration of the COVID-19 vaccination during the pandemic that made them fearful and hesitant of receiving the vaccination. A final aspect of research participation was

trust. Many participants stated they would trust research if the providers conducting research were from the same ethnicity and or they were recruited by individuals who "looked like them".

Participant Statements

- *"You know, because when you speak about research to the Black community, you get that rejection right away because of what happened in the past." Older African American*
- *"...and we cannot deny the Tuskegee Institute's (sic) incidents, most minorities are hesitant to participate in any type of research..." Older African American*
- *"You go and think about the Tuskegee experiment. That is still engraved in the Black and Brown community's minds..." Older African American*
- *"...because I feel like there's such distrust with when you hear the word research, especially with an older population...maybe 70 plus? Because, I mean, we've all experienced things, but when you think of history, they experienced a lot. ...Last year when the subject of vaccines came up...and I think the first correlation was the Tuskegee experiment." Older Hispanic/Latino*
- *"Even myself, I was hesitant to get the vaccination because I knew about the Tuskegee trials and I knew about that doctor, I think they were calling him the doctor of gynecology when he was experimenting on Black women without any anesthesia." Older Hispanic/Latino*
- *"To me, trust is very, very important. That's extremely important as to how well you trust whoever is doing the research and experimenting on us Black folks like they did in the past. And you know, we definitely have to trust the individuals...and not just experimenting on us and put in something that they want to see what effects it is going to have..." Older Caribbean*
- *"We just don't trust people...but we just typically don't trust the larger medical population because of what they've done in the past." Older Caribbean*

Theme 4: Transfer of Cultural Knowledge

Study participants spoke about how culture impacted their perspectives on health care and participation in health care research. These findings exemplify intergenerational cultural transmission, which refers to the transmission of cultural ideas (e.g., values, beliefs, knowledge, practices) from one generation to the next generation (Tam, 2015). Many participants spoke of cultural taboos, especially those relating to mental illness, thus acknowledging the impact of culture on her beliefs and practices. The fear of stigmatization was a common theme that led to many not sharing with others and suffering in silence. The notion of mental illness seen as a point of

weakness was stated in many of the older African American and Caribbean groups. Not wanting to have others “in their business” was also a theme when discussing health concerns and illnesses. In addition, the belief in traditional medicine and practices was mentioned as a reason for not wanting to participate in research by many from the Caribbean, especially older adults from Haiti.

Participant Statements

- “It’s not something that we talked about or discussed with anybody. You go through it on your own. You don’t ask anyone to help because you don’t want anybody to know you’re going through that.” Younger Caribbean
- “One of the things with West Indians do is that when they have a sickness or they’re sick, they don’t want anybody to know. A lot of them hide it; they don’t want to talk about it...and then by the time they find out or they go for help, it’s late.” Younger Caribbean
- “So yes, we don’t trust too much of the medical profession. I mean, that’s been my experience.” Older African American
- “Also, another point with that, in African American and Caribbean cultures, mental health is almost seen as some type of weakness. You’re suffering from depression, and it’s frowned upon. And a lot of people are suffering from it, and they can’t get the help because they feel like they can’t reach out to someone and ask for that help. It’s almost like a shameful position to be in.” Younger African American
- “I think a lot of it is cultural. Folks don’t want anybody in their business. When I say ‘folks’, I’m talking about our people.” Older African American
- “We stick to a lot of old medicine, the way we were brought up in the Caribbean, we still do a lot of that...we still stick with a lot of the old ways, the way we grew up.” Younger Caribbean

Theme 5: for the Future Generations

An overwhelmingly common theme was that older adults chose to participate in research that they believed would benefit “future generations.” This altruism for the “generations to come” was a strong motivator for participating in research studies for both older and younger adults regardless of ethnicity. Overall, participants indicated a willingness to participate in research if they believed that their participation would help improve the lives of future generations, that is their children, grandchildren, their community and finally society as a whole.

Participant Statements

- “I do believe it’s so important that we get involved in that and inform our Black culture to get more involved.

We need to know so that our children and our children’s children will be able to move forward and survive these different diseases and things.” Older African American

- “Well, the reason why I wanted to participate in certain research is because I love my children and my grandchildren, and I wanted to be able to, you know, just be able to help them somewhat.” Older Hispanic/Latino
- “As an elder, is it going to be something twenty years from now that is going to help my grands?” Older African American
- “If the research is going to be for the better of my sisters and brothers, I’m all for it.” Older African American
- “I would not be opposed to anybody, including myself being a part of that type of research if it’s going to have a great impact on not only our community, the Black community or the minority community or this nation as well. If it’s going to have a big impact, I would definitely wholeheartedly be interested.” Older African American

Discussion

The purpose of this study was to explore if intergenerational influence (IGI) can be used as a strategy to recruit ethnically diverse older adults to participate in clinical research and to understand their perspectives towards research decision making. Our findings revealed that IGI is a complex construct that involves relationships between older and younger adults around the transfer of knowledge, beliefs and practices, and culture across generations. Most importantly, ethnically diverse older adults consulted younger family members as well as other trusted adults before deciding to participate in research, however they made the final decisions by themselves.

Intergenerational Influence

The parent-child relationship was very important in health care decision-making as well as in decisions to participate in health-related research, mostly for the older adults but also for their adult children. Literature has suggested that adult parent-child relationships are important sources of support for both parents and adult children (Kim & Kim, 2018). Hugo and colleagues (2017) describe how aging adults provided emotional and practical support to their adult children who were experiencing life problems and these same children were a source of emotional support and advice for the older adults, indicating a reciprocally beneficial relationship. These findings are consistent with our results of reciprocal relationships, as well as vital sources of support, information, and advice especially for the older adults, and to a lesser extent for their adult children. Ethnically diverse older adults in our study discussed health care issues and decisions regarding research participation with their adult children, especially those in healthcare professions. A recent study, by our group reported

evidence that younger adults of several populations have been influential in the lives of older adults and their health care decisions (Vaccaro et al., 2021). However, many older adults in our study stated that they made their decisions independently after consulting their children, especially their daughters. There was evidence of reciprocity and interdependency as some younger adults indicated that they still relied on their parents for health and health care advice. We can surmise that these mutually supportive intergenerational relationships between older adults and their adult children can be leveraged to create opportunities for discussions about research participation.

In this study, both older and younger adults of all ethnicities were very aware of the unethical research and maltreatment of ethnically diverse populations, especially African Americans, in the U.S. The knowledge of this unethical experimentation has been passed down over time to contribute to a sustained distrust and fear of research participation. Several participants in our study used the term “human guinea pigs” and did not trust researchers to treat them fairly in research studies (Washington, 2007).

A study by Ojikkutu and colleagues (2022) reported that the Tuskegee experiment; coercive sterilization in the early 20th century impacting Black, Indigenous, and Latinx women, and unnecessary gynecological procedures performed at immigration detention centers were the most frequently cited historical and more recent event that continues to perpetuate distrust among people of color. Congruent with the findings of this study, they suggest that this medical distrust is an adaptive, learned, and protective response that has been transmitted culturally. This generational transmission of mistrust continues to influence their health care decisions including potential participation in research. However, many of our participants verbalized that these topics should be discussed before suggesting persons participate in research.

Closely related to IGI is the transfer of knowledge and attitudes that promote distrust is the transmission of cultural knowledge. Participants shared aspects about their beliefs and practices that were passed down to them about health and health care. These beliefs and practices most often resulted into reluctance to seek medical care; the use of natural and complementary medicines for prevention and treatment of illness; and health issues that were cultural taboos. A study exploring the use of complementary and alternative medicines for prostate cancer in a sample of 575 African Americans, and Caribbean immigrants found that 61% of African American, 90% of Caribbean, and 72% of African immigrants used complementary and alternative therapies for both health promotion and treatment for illness (Malika et al., 2022). Likewise, Brown and colleagues (2022) found widespread use of cultural remedies and a heavy reliance on elders and grandparents about the use of various treatments among Jamaicans with type 2 diabetes in South Florida. We found the used of cultural remedies and alternate medicines among our

study populations. These cultural beliefs are relevant in that each may influence whether ethnically diverse older adults would participate in health-related research because of their reliance on cultural remedies in lieu of formal medical treatments and their reluctance to acknowledge and seek health care for certain health conditions.

In the current study, altruism most often was focused on a desire to reduce risks and prevent illness in their children and grandchildren and to eradicate the conditions that disproportionately impact communities of color, such as Alzheimer’s Disease. Altruism has been documented often as a source of motivation for individuals to participate in research. In one study that investigated motivations for participation in community-centered research found that altruistic motivations were often held and indicated a sense of connection to a common humanity (Carrera et al., 2018). Thus, many of our participants indicated that they would participate in research for the benefit of future generations, particularly their own children, grandchildren, others in their ethnocultural communities, and society.

Strengths and Limitations

To our knowledge, no studies to date have qualitatively explored if IGI can be used as a strategy to recruit ethnically diverse older adults to participate in research and to understand their decision-making process regarding research participation. In addition, the benefit of including family members in the research process has been discussed (Barrett et al., 2017); especially those involving genetics (Bishop et al., 2018) and Alzheimer’s Disease (Lines & Wiener, 2014). As such, a strength of our study lies in its contribution and the expansion to this body of literature applicable to IGI. The various recruitment strategies employed add to the breadth of experiences of our diverse population, in turn, enhance the transferability of the findings.

There are several additional strengths in our study. First, we asked the same questions among older and younger participations, across all ethnically diverse groups (African American, Caribbean, Hispanic/Latino). We then brought the dyads together to discuss the concept of influence. Secondly, another strength is that participating dyads were recruited from North, Central and South Florida regions, theoretically resulting in a great array of experiences from African American, Caribbean, Hispanic/Latino adults living throughout Florida. This is important because the state of Florida has one of the highest populations of ethnically diverse older adults. Finally, we asked older adults to select a younger, trusted family/member and/or friend whom they discussed health issues with, thus, we want to include trusted individuals into discussion about health research participation. Many of our participants believed this was an additional strength of the study. This issue is important because the younger adult family members will be those whom we potentially recruit into further studies of aging.

There are also several limitations noted with the current study. Our population sampling approach may have resulted in persons participating who already have a more positive perspective of research. Our study was conducted during the height of the COVID-19 pandemic and required participation online via Zoom which may have resulted in socially and politically astute participants, who were more technically savvy. We sought to overcome this barrier by providing training on how to use Zoom via computer and mobile devices before participation in the study. In addition, we may have eliminated other older adults who did not identify a trusted family/member of friend that could participate in the listening session, thus our findings may only be applicable to persons having a trusted familiar or social network.

Implications

In the current study, we employed a qualitative descriptive approach to increase our understanding of IGI, decision-making processes regarding research participation and the significance of trusted family members or friends in shaping these decisions among ethnically diverse older adults. We believe that the findings of our qualitative descriptive study can inform future interventions as they directly capture the perspectives of both older and younger ethnically diverse adults regarding decision for health research participation (Sullivan-Bolyai et al., 2005). Several key implications arise from our current study. First, emphasizing the reciprocal decision-making process between older and younger ethnically diverse adults is critical in the development of recruitment and retention strategies. Inclusions of family members emerged as a significant factor for all ethnically diverse groups in our study. Second, regardless of age, awareness of historical maltreatment of “Black and Brown” populations in research was evident among all ethnically diverse groups. Addressing this historical context during recruitment is paramount. Third, consistent with other studies, our research underscored the importance of involving the target population in all stages of the research process, particularly in recruitment and retention. Participants expressed a desire to see more representation of individuals who resembled them throughout the study, emphasizing the cultural sensitivity required in selecting trusted spokespersons for the research process. Lastly, integrating trusted younger family members and friends into discussions about health research participation of their older family member emerged as an innovative strategy that could enhance the recruitment and retention of ethnically diverse older adults in clinical research studies.

Conclusion

This qualitative descriptive study contributes to the literature by providing insight into the potential utility of IGI as a strategy to recruit ethnically diverse older adults into health research. With the population of adults aged 65 years and older

continuously expanding, there is a pressing need for research that includes this demographic. However, achieving greater representation of ethnically diverse older adults, including African American, Caribbean, Hispanic/Latino individuals in clinical research is crucial to developing effective treatments that are both ethnically and culturally appropriate. To address this need, novel and innovative strategies are required to attract ethnically diverse older adults to participate in clinical research. Recognizing the impact of IGI on research participation of ethnically diverse older adults is a one strategy that can be incorporated. The insights gained from this study have the potential to be instrumental in developing new and more effective recruitment, enrollment, and retention strategies tailored to older ethnically diverse adults participating in clinical research studies.

Acknowledgments

The authors thank Dawn Gardier for her help with formatting Figures and Tables.

Declaration of Conflicting Interests


The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Research reported in this publication was supported by the National Institute on Aging of the National Institutes of Health under Award Number R24AG067951. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. Prior to issuing a press release concerning the outcome of this research, please notify the NIH awarding IC in advance to allow for coordination.

ORCID iDs

Trudy Gaillard  <https://orcid.org/0000-0002-7925-1480>

Joan A. Vaccaro  <https://orcid.org/0000-0002-8322-3466>

References

- Ajzen, I. (1991). The theory of planned behavior. *Organizational Behavior and Human Decision Processes*, 50(2), 179–211. [https://doi.org/10.1016/0749-5978\(91\)90020-T](https://doi.org/10.1016/0749-5978(91)90020-T)
- Ajzen, I., & Fishbein, M. (1980). *Understanding attitudes and predicting social behavior*. Prentice-Hall.
- Allen, A. P., Buckley, M. M., Cryan, J. F., Ní Chorcóirín, A., Dinan, T. G., Kearney, P. M., O’Caoimh, R., Calnan, M., Clarke, G., & Molloy, D. W. (2019). Informal caregiving for dementia patients: The contribution of patient characteristics and behaviours to caregiver burden. *Age and Ageing*, 49(1), 52–56. <https://doi.org/10.1093/ageing/afz128>
- Ardoin, N., Gould, R. K., Wojcik, D., Wyman Roth, N., & Biggar, M. (2022). Community listening sessions: An approach for

- facilitating collective reflection on environmental learning and behavior in everyday life. *Ecosystems and People*, 18(1), 469–477. <https://doi.org/10.1080/26395916.2022.2101531>
- Baiocchi-Wagner, E. A., & Talley, A. E. (2013). The role of family communication in individual health attitudes and behaviors concerning diet and physical activity. *Health Communication*, 28(2), 193–205. <https://doi.org/10.1080/10410236.2012.674911>
- Barrett, N. J., Ingraham, K. L., Vann Hawkins, T., & Moorman, P. G. (2017). Engaging African Americans in research: The recruiter's perspective. *Ethnicity and Disease*, 27(4), 453–462. <https://doi.org/10.18865/ed.27.4.453>
- Bishop, M. R., Shah, A., Shively, M., Huskey, A. L. W., Omeler, S. M., Bilgili, E. P., Jackson, E., Daniell, K., Stallworth, E., Spina, S., Shepp, K., Bergstresser, S., Davis, A., Dean, H., Gibson, J., Johnson, B., & Merner, N. D. (2018). Establishment of the Alabama Hereditary Cancer Cohort - strategies for the inclusion of underrepresented populations in cancer genetics research. *Molecular Genetics and Genomic Medicine*, 6(5), 766–778. <https://doi.org/10.1002/mgg3.443>
- Brewster, P., Barnes, L., Haan, M., Johnson, J. K., Manly, J. J., Nápoles, A. M., Whitmer, R. A., Carvajal-Carmona, L., Early, D., Farias, S., Mayeda, E. R., Melrose, R., Meyer, O., Zeki Al Hazzouri, A., Hinton, L., & Mungas, D. (2019). Progress and future challenges in aging and diversity research in the United States. *Alzheimer's and Dementia: The Journal of the Alzheimer's Association*, 15(7), 995–1003. <https://doi.org/10.1016/j.jalz.2018.07.221>
- Brown, R., Hain, D. J., & Hanisko, L. C. (2022). Culture and self-care: Practices in Jamaican adults with diabetes mellitus residing in South Florida. *Nephrology Nursing Journal*, 49(4), 359–365. <https://doi.org/10.37526/1526744X.2022.49.4.359>
- Caplan, Z. May 25, (2023). *U.S. Older Population Grew From 2010 to 2020 at Fastest Rate Since 1880 to 1890*. <https://www.census.gov/library/stories/2023/05/2020-census-united-states-older-population-grew.html> Accessed May 1, 2023
- Carrera, J. S., Brown, P., Brody, J. G., & Morello-Frosch, R. (2018). Research altruism as motivation for participation in community-centered environmental health research. *Social Science & Medicine*, 196, 175–181. <https://doi.org/10.1016/j.socscimed.2017.11.028>
- Census, US, March 13, (2018). Older People Projected to Outnumber Children for First Time in U.S. History. Press Release Number CB18-41. Accessed, May 1, 2023. <https://www.census.gov/newsroom/press-releases/2018/cb18-41-population-projections.html#>
- Doyle, L., McCabe, C., Keogh, B., Brady, A., & McCann, M. (2020). An overview of the qualitative descriptive design within nursing research. *Journal of Research in Nursing*, 25(5), 443–455. <https://doi.org/10.1177/1744987119880234>
- Ejiogu, N., Norbeck, J. H., Mason, M. A., Cromwell, B. C., Zonderman, A. B., & Evans, M. K. (2011). Recruitment and retention strategies for minority or poor clinical research participants: Lessons from the healthy aging in neighborhoods of diversity across the life span study. *The Gerontologist*, 51(Suppl 1), S33–S45. <https://doi.org/10.1093/geront/gnr027>
- Fenelon, A., Chinn, J. J., & Anderson, R. N. (2017). A comprehensive analysis of the mortality experience of hispanic subgroups in the United States: Variation by age, country of origin, and nativity. *SSM - Population Health*, 3, 245–254. <https://doi.org/10.1016/j.ssmph.2017.01.011>
- Forsat, N. D., Palmowski, A., Palmowski, Y., Boers, M., & Buttgerit, F. (2020). Recruitment and retention of older people in clinical research: A systematic literature review. *Journal of the American Geriatrics Society*, 68(12), 2955–2963. <https://doi.org/10.1111/jgs.16875>
- George, S., Duran, N., & Norris, K. (2014). A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. *American Journal of Public Health*, 104(2), e16–e31. <https://doi.org/10.2105/AJPH.2013.301706>
- Glaser, B. J. (1965). The constant comparative method of qualitative analysis. *Social Problems*, 12(4), 436–445. <https://doi.org/10.2307/798843>
- Green, M. A., Michaels, M., Blakeney, N., Odulana, A. A., Isler, M. R., Richmond, A., Long, D. G., Robinson, W. S., Taylor, Y. J., & Corbie-Smith, G. (2015). Evaluating a community-partnered cancer clinical trials pilot intervention with African American communities. *Journal of Cancer Education: The Official Journal of the American Association for Cancer Education*, 30(1), 158–166. <https://doi.org/10.1007/s13187-014-0764-1>
- Javed, Z., Haisum Maqsood, M., Yahya, T., Amin, Z., Acquah, I., Valero-Elizondo, J., Andrieni, J., Dubey, P., Jackson, R. K., Daffin, M. A., Cainzos-Achirica, M., Hyder, A. A., & Nasir, K. (2022). Race, racism, and cardiovascular health: Applying a social determinants of health framework to racial/ethnic disparities in cardiovascular disease. *Circulation. Cardiovascular Quality and Outcomes*, 15(1), Article e007917. <https://doi.org/10.1161/CIRCOUTCOMES.121.007917>
- Kamath, S. D., Torrejon, N., Wei, W., Tullio, K., Nair, K. G., Liska, D., Krishnamurthi, S. S., & Khorana, A. A. (2021). Racial disparities negatively impact outcomes in early-onset colorectal cancer independent of socioeconomic status. *Cancer Medicine*, 10(21), 7542–7550. <https://doi.org/10.1002/cam4.4276>
- Katz, R. V., Green, B. L., Kressin, N. R., Kegeles, S. S., Wang, M. Q., James, S. A., Russell-Claudio, S. C., & McCallum, J. M. (2008). The legacy of the tuskegee syphilis study: Assessing its impact on willingness to participate in biomedical studies. *Journal of Health Care for the Poor and Underserved*, 19(4), 1168–1180. <https://doi.org/10.1353/hpu.0.0067>
- Kim, K., & Kim, Y. (2018). Parent-child relations and their importance for older adults. *Oxford research encyclopedia of psychology*. Oxford University Press. <https://doi.org/10.1093/acrefore/9780190236557.013.392>
- Koerner, A. F., & Fitzpatrick, M. A. (2002). Toward a theory of family communication. *Communication Theory*, 12(1), 70–91. <https://doi.org/10.1111/j.1468-2885.2002.tb00260.x>

- Lines, L. M., & Wiener, J. M. (2014). Racial and ethnic disparities in alzheimer's disease: A literature review. In *US department of health and human services, assistant secretary for planning and evaluation, office of disability, aging and long-term care policy*. Assistant Secretary for Planning and Evaluation (ASPE). Secretary of the Department of Health and Human Service. https://aspe.hhs.gov/sites/default/files/migrated_legacy_files/138596/RacEthDis.pdf.
- Luebbert, R., & Perez, A. (2016). Barriers to clinical research participation among African Americans. *Journal of Transcultural Nursing: Official Journal of the Transcultural Nursing Society*, 27(5), 456–463. <https://doi.org/10.1177/1043659615575578>
- Malika, N., Roberts, L., Casiano, C., & Montgomery, S. (2022). Use of complementary and alternative medicine for prostate cancer among African Americans, African immigrants and caribbean immigrants. *Journal of Community Health*, 47(2), 284–291. <https://doi.org/10.1007/s10900-021-01046-4>
- Marron, M. M., Ives, D. G., Boudreau, R. M., Harris, T. B., & Newman, A. B. (2018). Racial differences in cause-specific mortality between community-dwelling older black and white adults. *Journal of the American Geriatrics Society*, 66(10), 1980–1986. <https://doi.org/10.1111/jgs.15534>
- Migration Policy Institute from the United Nations, Department of Economic and Social Affairs. *Trends in international migrant stock: Migrants by destination and origin (united nations database, POP/DB/MIG/Stock/Rev.2017)* (Accessed 1 June 2023).
- Nyborg, I., Danbolt, L. J., & Kirkevold, M. (2017). User participation is a family matter: A multiple case study of the experiences of older, hospitalised people and their relatives. *Journal of Clinical Nursing*, 26(23–24), 4353–4363. <https://doi.org/10.1111/jocn.13765>
- Ochs-Balcom, H. M., Jandorf, L., Wang, Y., Johnson, D., Meadows Ray, V., Willis, M. J., & Erwin, D. O. (2015). "It takes a village": Multilevel approaches to recruit African Americans and their families for genetic research. *Journal of community genetics*, 6(1), 39–45. <https://doi.org/10.1007/s12687-014-0199-8>
- Ojikkutu, B., Bogart, L. M., & Dong, L. (2022). Mistrust, empowerment, and structural change: Lessons we should be learning from COVID-19. *American Journal of Public Health*, 112(3), 401–404. <https://doi.org/10.2105/ajph.2021.306604>
- Polachek, D., & Polachek, W. (1989). An indirect test of children's influence on efficiencies in parental consumer behavior. *Journal of Consumer Affairs*, 23(1), 91–110. <https://doi.org/10.1111/j.1745-6606.1989.tb00237.x>
- Shah, R. H., & Mittal, B. (1997). Toward a theory of intergenerational influence in consumer behavior: An exploratory essay. *Advances in Consumer Research*, 24, 56–60. <https://www.acrwebsite.org/volumes/8008/volumes/v24/NA-24>.
- Sullivan-Bolyai, S., Bova, C., & Harper, D. (2005). Developing and refining interventions in persons with health disparities: The use of qualitative description. *Nursing Outlook*, 53(3), 127–133. <https://doi.org/10.1016/j.outlook.2005.03.005>
- Swinyard, W., & Sim, C. (1987). Perception of children's influence on family decision processes. *Journal of Consumer Marketing* 1987, 4(1), 25–38. <https://doi.org/10.1108/eb008186>
- Tam, K. P. (2015). Understanding intergenerational cultural transmission through the role of perceived norms. *Journal of Cross-Cultural Psychology*, 46(10), 1260–1266. <https://doi.org/10.1177/0022022115600074>
- U.S. Census Bureau. *QuickFacts* (Accessed 1 May 2023).
- Vaccaro, J. A., Gaillard, T. R., & Marsilli, R. L. (2021). Review and implications of intergenerational communication and social support in chronic disease care and participation in health research of low-income, minority older adults in the United States. *Frontiers in Public Health*, 9, 769731. <https://doi.org/10.3389/fpubh.2021.769731>.
- Washington, H. A. (2007). *Medical apartheid: The dark history of medical experimentation on black Americans from colonial times to the present*. Doubleday Books.

Author Biographies

Trudy Gaillard is a Tenured Associate Professor and the Dr. Vanessa Von Wertheim Endowed Chair in Chronic Disease Prevention and Care at Florida International University. Her contribution to nursing research has 3 primary interrelating health disparities emphasis; 1) glucose metabolism and insulin sensitivity of African Americans at high risk for type 2 diabetes, 2) cardiometabolic syndrome, 3) and healthy aging. She has published over 70 peer reviewed manuscripts in these areas. She has received funding from the National Institute on Aging (Award #R24AG067951) that explores intergenerational influences as a strategy to recruiting ethnically diverse older adults to participate in clinical research. There are several abstracts accepted for posters and oral presentation by this group. 1) Voices of Our Elders: Attitudes, Beliefs, and Perspectives About Research in Minority Older Adults; GSA, 2022; and 2) Recruitment and Retention of Culturally Diverse Older Adults into Aging Research: Understanding the Complexities of Intergenerational Influence. 37th Annual Conference of the Southern Nursing Research Society, 2023.

Donna Z. Shambley-Ebron is an Associate Professor, Emerita, at the University of Cincinnati College of Nursing. Her research focus has been on achieving health equity through community-based research. Most recently her research involved culturally tailoring evidence-based interventions for HIV prevention in Black girls. She is a fellow of the Transcultural Nursing Society Scholars. Dr. Shambley-Ebron now works as a graduate educator and consultant in research and program development. Selected publications include: Burlew, K., **Shambley-Ebron, D.**, Lannaway, D., McCuistian, C., Sherman, L., Steele, L. (2018). *Community-based cultural adaptation for HIV prevention in African American girls*. Collaborations in Public Health Research and Rites of Passage: Cultural Paths for HIV/AIDS Prevention in African American Girls in A.J. Lemelle et al. (eds.), Handbook of African American Health: Social and Behavioral Interventions, Springer Science+Business Media, LLC 2011

Joan A. Vaccaro is an adjunct professor in the Department of Dietetics and Nutrition, at Florida International University. Her main research interests involve health and health behaviors of ethnically diverse adults. Recent publications as first author with colleagues include: "Intergenerational perceptions of health and health research among African American, Caribbean, and Hispanic/Latinx American older and younger adults", in *Journal of Healthcare Administration*, (2023). "Review and implications of intergenerational communication and social support in chronic disease care and participation in health research of low income, minority older adults in the United States" in, *Frontiers in Public Health-Aging and Public Health* (2021) and "Barriers to participating in diabetes care behaviors in hard-to-reach older Hispanics" in *Nursing & Primary Care* (2021).

Donna F. Neff is Professor at the College of Nursing, University of Central Florida. Her former clinical and research experience led to her research trajectory: the pursuit of understanding determinants of elderly health outcomes and identifying leverage points for improving the systems and community in which they receive care. Funded by NIA, Dr. Neff (co-PI) and the other investigators oversaw outreach to agencies that serve groups of older adults from minority populations and direct contact with potential participants in settings such as day programs, churches, and exercise programs geared toward older adults. Her recent publications with authors of this paper include Community engagement strategies for population health research with culturally diverse adults in *Journal of Medicine, Surgery and Public Health*; Intergenerational perceptions of health and health research among African American, Caribbean, and Hispanic/Latinx American older and younger adults. *Journal of Healthcare Administration*.

Cynthia Morton Padovano is a professor of Advertising in the College of Journalism and Communications at the University of Florida. Her research focuses on the processes for, and the elements of, message strategy, with specific attention to the persuasion outcomes, message content and 3) message effects. Recent publications include "Advertising in the times of COVID: A tight-loose analysis of pandemic-related TV commercials" in *Journal of Current Issues and Research in Advertising* (2022), with colleagues, and "What women want: Improving patient health agency through sexual health advertising" in the *International Journal of Pharmaceutical and Healthcare Marketing* (2021), with colleagues.

Phildra Swagger is President/CEO of Academy of Certified Coaches. She began her career as a classroom teacher and served as a principal, district administrator, university instructor, and charter school founder over a career that spans 30 years. Dr. Swagger believes everyone should live their best life and serves as a transformational life coach, executive leadership coach and creative business strategist. In 2006, she founded Combined Expertise, Inc. a Coaching Collaborative and after retiring as Vice President of a national non-profit organization, she expanded her coaching services to establish the Academy of Certified Coaches. Dr. Swagger enjoys working in the community and has collaborated with the team to successfully execute the current project. She is the first author of "Intergenerational Influence on Healthcare Decision-Making Among Older African Americans" presented at the 37th Annual Conference of the Southern Nursing Research Society, 2023.

Edgar Vieira is the interim associate dean of research for the Nicole Wertheim College of Nursing and Health Sciences and an associate professor in the Department of Physical Therapy at Florida International University. He is the Editor in Chief of the journal "Physical & Occupational Therapy in Geriatrics". His main expertise is in risk assessments and prevention of aging-related mobility impairments, frailty and falls. Dr. Vieira has a BSs and an MSc in physical therapy and a PhD in rehabilitation science. His research program aims to help older adults to stay functionally independent by optimizing mobility, preventing frailty, falls and related injuries.

Fern Webb is an associate professor at the University of Florida (UF) in the Department of Surgery, and co-director for the (UF) Center for Health Equity and Engagement Research (CHEER; <https://med.jax.ufl.edu/center-health-equity-engagement-research/>). As a social behavioral and community-engaged researcher, Dr. Webb's translational research studies have included, but are not limited to, examining a myriad of conditions like diabetes, hypertension, obesity, telemedicine, infectious diseases, and population health among underserved populations. She also researches the most effective ways to recruit and enroll racially and ethnically diverse older adults into health-related research studies on cancer, behavioral interventions, and chronic health conditions. She currently serves as co-Principal Investigator on the NIA-funded Florida Statewide Registry of Aging Studies (PI: Gaillard, FIU), a statewide study designed to explore intergenerational influence among Black, Caribbean, and Hispanic/Latinx older adults living in Florida, of which results are presented in this manuscript.