Willingness of African American Women to Participate in e-Health/m-Health Research

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Abstract

Introduction: *Due to high rates of technology adoption, African American women are well positioned to benefit from e-health/mobile health (m-health) interventions; yet, there are limited data on understanding their use of technology and willingness to participate in e-health/m-health research.* ***Materials and Methods:*** *A self-administered survey was completed by 589 African American women. Survey items measured sociodemographics, technology use and access, and willingness to participate in e-health/m-health research. Multinomial logistic regression examined associations among three age groups (18–29, 30–50, and 51+ years old) and technology access, as well as motivators and barriers to participating in e-health/m-health research.* ***Results:*** *Most participants were willing to receive text messages as part of a research study. Many reported using a health-related application in the past 30 days, with younger women more likely to do so than older women ($p < 0.0001$). Younger women were more likely than older women to be motivated for the greater good ($p < 0.01$) and for financial incentives ($p = 0.02$), whereas older women were more likely than younger women to be motivated if referred by a healthcare provider ($p = 0.02$). Younger women were more likely than older women to report concerns about data plans ($p < 0.01$ for all), whereas older women were more likely to report a lack of a smartphone ($p = 0.048$) and privacy concerns ($p < 0.001$).* ***Conclusions:*** *Culturally tailored e-health/m-health research using smartphones may be of interest to African American women who are interested in risk reduction and chronic disease self-management. Barriers such as smartphone data plans and privacy will need to be addressed.*

Key words: *behavioral health, e-health, mobile health, education*

Introduction

The use of emerging information and communication technologies to improve or enable health and healthcare (i.e., e-health) holds tremendous promise for preventing and treating chronic and acute diseases.[1,2] Despite the National Institutes of Health Revitalization Act of 1993 mandate for the inclusion of minorities in all federally funded research,[3] African Americans remain underrepresented in e-health research,[4,5] even though they have higher morbidity and mortality rates from chronic conditions such as diabetes, hypertension, heart disease, obesity, and some types of cancer.[6,7]

African Americans may be reluctant to participate in health research studies for a variety of sociocultural reasons, including institutional racism, discrimination by the healthcare system, mistrust of researchers, low physician referral rates, privacy concerns, and interference with work, family, and other responsibilities. They also may lack an understanding of the different types of research studies.[4,5,8] E-health research studies have the potential to minimize some of the common challenges that occur in community-based and clinical interventions, namely, low enrollment, attrition, ease of access, geographic proximity, time limitations, inconvenience, and sociocultural attitudes toward research. In addition, e-health studies may allow interventions to be delivered with high fidelity, low cost, anonymity, and minimal demands on patients, researchers, and clinical personnel.[5,9]

Nationally representative data from the Pew Research Center suggest that African Americans are in a unique position to be potential users of e-health technologies and participants in e-health and mobile health (m-health) research studies. African Americans have higher ownership of smartphones compared with the general population (70% versus 64%), and although they are less likely than whites to have home broadband Internet (49% versus 66%), they are adopting the Internet faster than the general population. In particular, they are more likely to own mobile phones compared with whites and are more likely than whites to use smartphones as their main source of Internet access.[10,11] Therefore, a huge opportunity exists to recruit and engage African Americans to participate in e-health and m-health

interventions that focus on risk reduction and chronic disease self-management.

Although many m-health interventions are still being evaluated for efficacy, current evidence suggests that m-health tools, especially those delivered via smartphones, can support behavior change by empowering, encouraging, and educating patients.[12,13] Studies show that African American women frequently use the Internet to search for health information, particularly dieting and nutrition information.[14] Thus, African American women are prime targets for e-health and m-health interventions, especially for risk reduction and disease self-management. The aims of this cross-sectional study were (1) to examine African American women's use of and access to technology, (2) to identify motivators and barriers to participating in e-health/m-health research, and (3) to determine if African American women's use, access, motivators, and barriers varied by age group.

Materials and Methods

SUBJECTS AND PROCEDURES

Data were collected from a convenience sample of 589 African American women during a 9-month period from April 2014 to January 2015 in north central Florida. Participants were asked to complete a self-administered questionnaire and received a $5 gift card for participating. Participants were recruited primarily from community events, churches, and beauty shops. The study received approval from the Institutional Review Board at the authors' institution.

The self-administered questionnaire was developed based on a review of the literature on e-health, m-health, and use of technology by African Americans. Additionally, items from previously validated instruments measuring barriers and motivators to participating in research, exposure to social media, use of digital devices, and e-health literacy were also included.[15–17] The final instrument consisted of 60 questions that measured select sociodemographic variables, general health literacy, willingness to participate in e-health research, and lifestyle and wellness data. Question types included "yes/no," "choose the answer that best suits you," and "choose all that apply." Participants were asked to choose "all that apply" from 7 possible locations where they accessed the Internet (Cronbach's alpha = 0.66), 14 motivators to participating (Cronbach's alpha = 0.81), and 12 barriers to participating (Cronbach's alpha = 0.76). The survey took approximately 15 min to complete.

Data were analyzed using Statistical Package for Social Science (SPSS) version 21.0 software (2012; SPSS Inc., Chicago, IL). Frequency tables were computed to check for completeness, range, and consistency. Descriptive statistics were computed to summarize the data, and means were calculated with standard deviations. Analyses included odds ratio (OR), independent-samples *t* test, and analysis of variance. *Post hoc* comparison was performed with the Tukey–Kramer HSD test. Multinomial logistic regression analyses examined the association among three age groups (18–29, 30–50, and 51 + years old) and (1) how the Internet was accessed, (2) motivators to participating, and (3) barriers to participating. The dependent variable was age group, with 18–29 year olds as the reference group. The amount of variation in the model was determined using the Cox and Snell R^2 and the Negelkerke R^2 statistics. Statistical significance was established at the $p < 0.05$ level for all tests.

Results

PARTICIPANTS

The women's mean age was 37.35 ± 14.73 years, and the age group distribution was as follows: 18–29 years old, 39%; 30–50 years old, 37%; and 51 + years old, 24%. Most participants were single (72%), employed (63%), born in the United States (89%), non-homeowners (71%), and did not have children under 18 years of age (59%). *Table 1* gives more demographic data. Mean body mass index was 29.90 ± 8.05 kg/m^2. Body mass index varied by age, with those 18–29 years of age having significantly lower body mass index (27.32 ± 8.00 kg/m^2) than those 30–50 years of age (31.90 ± 8.24 kg/m^2) and those 51 + years of age (31.12 ± 6.64 kg/m^2) ($p < 0.0001$). There were no significant differences in body mass index between the other groups.

MOBILE DEVICES AND INTERNET ACCESS

Most (83%) rated their computer skills between good and excellent and believed the Internet may be helpful in making health decisions (78%). Smartphones were owned by 82% of 18–29 year olds, 76% of 30–50 year olds, and 33% of those 51 + years old. Those who were 18–29 years old were five times more likely to own a smartphone than those 51 + years old ($p < 0.0001$, OR = 4.80) but were not more likely to own one than those 30–50 years old. Laptops were owned by 73% of 18–29 year olds, 70% of 30–50 year olds, and 63% of 51 + years old. There were no significant differences in laptop ownership among any of the age groups. Forty-percent owned a tablet computer. Tablets were owned by 35% of the 18–29 year olds, 46% of the 30–50 year olds, and 33% of those 51 + years old. Those 18–29 years old were as likely as those 51 + years old to own a tablet but significantly less likely to own one compared with those 30–50 years old ($p < 0.0001$, OR = 1.53).

Table 1. Sociodemographic Data for African American Women ($n = 589$)

CHARACTERISTIC	*N* (%)
Age group	
18–29 years	230 (39%)
30–50 years	218 (37%)
51+ years	139 (24%)
Parental status of child under 18 years of age	
Yes	242 (41%)
No	342 (59%)
Marital status	
Married	166 (28%)
Single	345 (72%)
Employment	
Employed	367 (63%)
Unemployed	163 (28%)
Retired	23 (4%)
Disabled, unable to work	33 (6%)
Born in the United States	
Yes	520 (89%)
No	67 (11%)
Highest education level	
Did not finish high school	55 (9%)
High school graduate	125 (22%)
Some college credits	147 (25%)
AA/AS degree	81 (14%)
BA/BS degree	91 (16%)
Graduate or professional degree	88 (14%)
Current college student	
Yes	165 (28%)
No	417 (71%)
Homeowner	
Yes	171 (29%)
No	417 (71%)

Percentages may not add up to 100% due to rounding.

Women reported accessing the Internet from a variety of locations: smartphones (74%), home broadband connections (72%), work computers/network (59%), libraries (38%), someone else's home (28%), restaurant WiFi (28%), and community centers (10%). A multinomial regression model predicting access to the Internet by age group was significant [$\chi^2(14) = 68.58$, $p < 0.001$]. Women 18–29 years old were two times more likely than those 51 + years old to access the Internet from smartphones ($\beta = -0.86$, $p < 0.001$, OR = 0.42) and libraries ($\beta = -0.90$, $p < 0.001$, OR = 0.41), and they were three times more likely than those 30–50 years old to access the Internet from someone else's home ($\beta = -1.07$, $p < 0.0001$, OR = 0.30).

WILLINGNESS TO PARTICIPATE IN E-HEALTH/M-HEALTH RESEARCH

Most (63%) reported they had never participated in a research intervention study, yet most (69%) were willing to receive health education text messages as part of a research study. Forty-five percent reported using a nutrition, health, or fitness application (app) in the past 30 days, with those 18–29 years old almost three times more likely to do so than those 51 + years old ($p < 0.000$, OR = 2.93). There were no significant differences in using an app between those 18–29 years old and those 30–50 years old. Overall, women reported willingness to participate in e-health/m-health research interventions that used smart watches and wristband monitors (64%), smartphone/tablet computer apps (59%), Web sites to log data (47%), and online support/counseling (33%). Women 18–29 years old were almost seven times more willing to use an app than those 51 + years old ($p < 0.001$, OR = 6.71) and two times more willing to do so than those 30–50 years old ($p = 0.002$, OR = 2.00).

MOTIVATION TO PARTICIPATE

Potential motivators for participating in e-health/m-health research included interest in topic (61%), becoming more educated about the topic (51%), contribution to the greater good (50%), being diagnosed with a disease (42%), financial incentives (39%), disease management (38%), research having a positive impact on their life (36%), free medication/check-up (34%), making a difference in minority communities (32%), free cell phone/data plan (30%), encouragement by friends/family members (25%), referral by healthcare provider (21%), gain technical/computer skills (21%), and having minority researchers on the team (18%).

The multinomial regression model predicting motivators by age group (*Table 2*) was significant [$\chi^2(28) = 58.60$, $p < 0.001$]. Women 18–29 years old were almost two times more likely

Table 2. Multinominal Logistic Regression of Motivators to Participating in e-Health Research Studies and Age Group Among African American Women ($n=589$)

AGE GROUP, MOTIVATOR	β (SE)	WALD	ODDS RATIO	P
30–50 years old				
Interest in topic	−0.58 (0.24)	5.96	0.56	0.02[a]
Get more educated about topic	0.03 (0.23)	0.02	1.03	0.90
Contribute to greater good	−0.17 (0.22)	0.60	0.84	0.44
Diagnosis with disease	0.31 (0.25)	1.49	1.36	0.22
Financial incentives	−0.13 (0.24)	0.28	0.88	0.60
Managing disease/condition	−0.15 (0.26)	0.34	0.86	0.56
Positive impact on life	−0.57 (0.24)	5.74	0.57	0.02[a]
Free medication/check-up	−0.32 (0.24)	1.73	0.73	0.19
Research helps minorities	−0.08 (0.26)	0.00	0.99	0.98
Free cell phone/data plan	−0.34 (0.25)	1.88	0.70	0.17
Encouraged by friends/family	−0.18 (0.25)	0.53	0.84	0.47
Referral from a health professional	−0.87 (0.30)	8.50	2.38	0.01[a]
Gain technical/computer skills	0.06 (0.27)	0.05	1.06	0.90
Minority researchers on team	−0.10 (0.31)	0.11	1.11	0.74
51+years old				
Interest in topic	0.49 (0.27)	3.36	0.61	0.07
Get more educated about topic	−0.14 (0.27)	0.29	0.87	0.59
Contribute to greater good	−0.63 (0.25)	6.11	0.53	0.01[a]
Diagnosis with disease	0.42 (0.29)	2.05	1.52	0.15
Financial incentives	−0.64 (0.28)	5.26	0.53	0.02[a]
Managing disease/condition	−0.08 (0.30)	0.07	0.93	0.80
Positive impact on life	−0.24 (0.27)	0.82	0.78	0.37
Free medication/check-up	−0.39 (0.28)	1.87	0.68	0.17
Research helps minorities	−0.08 (0.30)	0.07	1.08	0.80
Free cell phone/data plan	−0.51 (0.30)	2.97	0.60	0.09
Encouraged by friends/family	−0.07 (0.28)	0.06	0.93	0.81
Referral from a health professional	0.80 (0.34)	5.48	2.22	0.02[a]
Gain technical/computer skills	0.38 (0.30)	1.60	1.47	0.21
Minority researchers on team	0.42 (0.34)	1.47	1.51	0.23

The reference group is 18–29 years old. Model fit: –2 Log Likelihood = 922.821, $\chi^2(28) = 58.601$, $p = 0.001$ (significant difference); pseudo R^2 by Cox and Snell = 0.095 and by Negelkerke = 0.108; hit ratio, 84.7%.

[a] $p < 0.05$ indicates a significant difference.

SE, standard error.

than those 51+years old to be motivated to contribute to the greater good ($\beta = -0.63$, $p < 0.01$, OR = 0.53) and for financial incentives ($\beta = -0.64$, $p = 0.02$, OR = 0.53). However they were two times less likely than those 51+years old to be motivated by referral from a healthcare provider ($\beta = 0.80$, $p = 0.02$, OR = 2.22). Those 18–29 years old were almost two times more likely than those 30–50 years old to be motivated because of interest in the topic ($\beta = -0.58$, $p = 0.02$, OR = 0.56) and almost two times more likely to be motivated if the research impacted minority communities ($\beta = -0.57$, $p = 0.02$, OR = 0.57). However, they were two times less likely than those 30–50 years old to be motivated by referral from a healthcare provider ($\beta = 0.87$, $p < 0.01$, OR = 2.38).

BARRIERS TO PARTICIPATION

Potential barriers to participating in e-health/m-health research included no interest in research (60%), no interest in the topic (44%), privacy concerns (34%), mistrust of researchers (30%), being too busy (18%), research does not target minorities (16%), no financial incentives offered (15%), a lack of minority researchers (14%), lack of computer or smartphone (11%), no reliable Internet access (11%), concerns about smartphone data plans (10%), and research has no real value (6%).

The multinomial regression model predicting barriers by age group (*Table 3*) was significant [$\chi^2(24) = 78.65$, $p < 0.001$]. Women 18–29 years old were almost four times more likely than those 51+years old to report concerns about their smartphone data plan ($\beta = -1.38$, $p < 0.01$, OR = 0.25), two times more likely to report lack of interest in the topic ($\beta = -0.78$, $p < 0.01$, OR = 0.46), and two times more likely to report being too busy ($\beta = -0.64$, $p < 0.01$, OR = 0.53). However, they were two times less likely than those 51+years old to report not having a computer or smartphone ($\beta = 0.81$, $p = 0.048$, OR = 2.24) and two times less likely to report privacy concerns ($\beta = 0.89$, $p < 0.001$, OR = 2.42). Those 18–29 years old were

Table 3. Multinominal Logistic Regression of Barriers to Participating in e-Health Research Studies and Age Group Among African American Women ($n = 589$)

AGE GROUP, BARRIERS	β (SE)	WALD	ODDS RATIO	P
30–50 years old				
No interest in research	−0.48 (0.21)	5.27	0.62	0.02[a]
No interest in topic	−0.28 (0.21)	1.76	0.76	0.18
Concerns about privacy	0.24 (0.24)	1.00	1.27	0.32
Mistrust of researchers	−0.32 (0.24)	1.86	0.72	0.17
Too busy	−0.60 (0.21)	8.25	0.55	<0.01[a]
Research does not target minorities	−0.23 (0.32)	0.52	0.79	0.47
No financial incentives	−0.11 (0.28)	0.15	0.90	0.70
No minority researchers	0.04 (0.34)	0.01	1.04	0.90
No computer or smartphone	0.44 (0.38)	0.77	1.40	0.38
Concerns about data plan	−0.12 (0.34)	0.13	0.89	0.72
Research has no value	1.14 (0.47)	5.75	3.11	0.02[a]
No reliable Internet access	−0.28 (0.37)	0.57	0.76	0.45
51+years old				
No interest in research	−0.16 (0.24)	0.45	0.85	0.50
No interest in topic	−0.78 (0.26)	9.23	0.46	<0.01[a]
Concerns about privacy	0.89 (0.26)	11.50	2.42	<0.001[a]
Mistrust of researchers	−0.35 (0.28)	1.64	0.70	0.20
Too busy	−0.64 (0.24)	7.02	0.53	<0.01[a]
Research does not target minorities	0.04 (0.36)	0.01	1.04	0.91
No financial incentives	−0.64 (0.37)	2.98	0.53	0.08
No minority researchers	0.37 (0.38)	0.94	1.44	0.33
No computer or smartphone	0.81 (0.41)	3.92	2.38	0.048[a]
Concerns about data plan	−1.38 (0.52)	7.00	0.25	<0.01[a]
Research has no value	0.96 (0.54)	3.13	2.60	0.08
No reliable Internet access	−0.09 (0.41)	0.05	0.91	0.82

The reference group is 18–29 years old. Model fit: −2 Log Likelihood = 606.415, $\chi^2(24) = 78.653$, $p = 0.000$ (significant difference); pseudo R^2 by Cox and Snell = 0.125 and by Negelkerke = 0.142; hit ratio, 76.0%.

[a]$P < 0.05$ indicates a significant difference.

SE, standard error.

almost two times more likely than those 30–50 years old to report lack of interest in the topic ($\beta = -0.48$, $p < 0.02$, OR = 0.62) and almost two times as likely to report being too busy ($\beta = -0.60$, $p < 0.01$, OR = 0.55). However, they were three times less likely than those 30–50 years old to believe that research has no value ($\beta = 1.14$, $p = 0.02$, OR = 3.11).

Discussion

This study fills a gap in research that seeks to understand motivators and barriers to e-health/m-health research among African American women. The women in the present study believed that the Internet was helpful for making health decisions, rated their computer skills between good and excellent, and expressed a willingness to participate in e-health/m-health research.

MOBILE DEVICES AND INTERNET ACCESS

The women owned a variety of mobile devices, including smartphones, laptops, and tablets. The prevalence of smartphone ownership in this sample was slightly higher than the national average (73% versus 64%) and slightly higher, but comparable, to a national sample of African Americans (73% versus 70%).[10] As with the national findings, younger women were more likely to own smartphones than older women.[10] Smartphones serve as an essential communication channel to the world of online health information and services, and the latest generations of smartphones have tremendous ability to empower African American women, especially younger ones, to use them for personal health and wellness, self-management of diseases, access to health services and information for themselves and other family members, and participation in community and clinical research.[18,19]

Most women used their smartphones to access the Internet. The study did not investigate if smartphones were the women's only access to high-speed Internet. Nationally, 10% of all Americans and 13% of Americans with incomes below $30,000 use smartphones as their only access to the Internet.[10] Researchers who are solely interested in conducting m-health research via smartphones need to consider the different mobile carriers in the geographical area, the signal strength, the type of plan carried by participants (e.g., unlimited data plans versus limited data plans), the cost of data plans, and other

financial constraints. Furthermore, low-income households may have only one smartphone due to the high cost of a group or family plan.[10] Thus, researchers may want to consider providing participants with a smartphone dedicated for research purposes or upgrading the participants' current plan to an unlimited data plan.

Although the rate of home broadband access (72%) was below the Healthy People 2010 goal of 83%,[6] the gap in home broadband access continues to narrow in African American households. In 2009, 65% of white households and 46% of African American households had broadband service, but by 2010 the number for African American households increased to 56%.[16] One of the aims of the National Broadband Plan is to increase universal access to health information and improve healthcare outcomes.[20] This will significantly close the gap between the "haves" and "have-nots" and provide great opportunities for e-health/m-health research.

MOTIVATION FOR PARTICIPATING

The reasons that motivate African Americans to participate in research clinical trials appear to be researched less frequently than the barriers to participating. The findings in this study are consistent with other findings that indicate that many African Americans are willing to participate in research studies.[21] Women reported they would be primarily motivated to participate in e-health/m-health research if they were interested in the topic, if they had an opportunity to become more educated about the topic, and to contribute to the greater good. Those who are diagnosed with a disease or at high risk for developing a disease may be especially motivated if the research allows them to better understand the disease, empowers them to self-manage the disease, and adds to their overall quality of life. The study also suggests that physicians and other healthcare providers can play a vital role in referring these individuals to e-health/m-health clinical trials and interventions, especially with older women. E-health/m-health researchers must consider if they will provide obvious incentives such as free cell phones, smart watches, digital activity trackers, and unlimited data plans. However, participants may be also motivated to participate if they will gain technical and computer skills.

BARRIERS TO PARTICIPATING

The barriers to participating in e-health/m-health research in the present study were similar to those identified in other types of research studies and clinical interventions. Most women did not have an interest in participating in any type of research. They also expressed mistrust of researchers and concerns about the security and privacy of personal information. These barriers are commonly identified in the literature and are probably tied to the fear and mistrust of the healthcare system, knowledge of the Tuskegee syphilis study, and conspiratorial beliefs that they will be intentionally harmed.[22–24] These issues may be compounded if there are no African American researchers on the team and if the research team has no ties to the local community.[25,26] Furthermore, e-health/m-health researchers must acknowledge the fact that consumers live in an age where there is frequent media coverage of breach of patient data, hacking of computers, and other issues of living in a digital world. The current research suggests that e-health/m-health researchers should also address privacy concerns and lack of a smartphone ownership with older women, as well as address concerns about data plans with younger women.

LIMITATIONS

This study used a convenience sample, which limits generalizability of the findings to African American women in the local geographic area and the general population of African American women. In addition, the results cannot show a causal relationship between age group and willingness to participate in e-health/m-health research. Despite these limitations, the results have some practical applications to researchers who want to target African American women for e-health and m-health research.

Conclusions and Implications

The rapid growth of mobile devices such as smartphones among African Americans, low-income individuals, and other underserved populations has influenced a new paradigm that is transforming healthcare delivery, patient education, community-based research, and clinical interventions. This study adds to the literature by providing in-depth information on the willingness of African American women to participate in e-health/m-health research.

First, there is a high level of ownership of smartphones, which means that they may be receptive to participating in e-health and m-health research. Second, African Americans who are targeted for e-health and m-health research may have a variety of ways to access the Internet and participate in the research (e.g., smartphones, home computers/networks, and work computers/networks). Access to the Internet will increase more rapidly if the aims of the National Broadband Plan are achieved. Third, researchers must consider what type of financial incentives they will provide to participants, including smartphones or upgrades to mobile plans. Fourth, researchers must clearly explain the nature of the research, address privacy and data concerns, and explain how the

participants' electronic footprints will be handled. They also must consider how these issues will be addressed in institutional review board protocols. Fifth, there is a need to increase the number of African American researchers in academia, engage African American physicians in referring patients, and connect meaningfully with the community outside of the research realm. Sixth, e-health/m-health research may need to be tailored to age group. Older women are not averse to participating in these types of research but may need training in e-health literacy and using smartphone apps, smart watches, and other Web-based technology. Culturally tailored e-health and m-health research may be of particular value to African American women who are interested in the topic and want to contribute to the greater good but who may still have significant privacy concerns and mistrust of researchers.

Disclosure Statement

No competing financial interests exist.

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