Maximizing the Impact of ePHIM in Low-Income, Multiethnic Populations

Alain Bertoni (PI), Thomas a. Arcury, Sara A. Quandt, David P. Miller, Iris Leng, Jennifer Talton, Celine Latulip, Doug A, Smith, Kathryn P. Melius

Wake Forest School of Medicine

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Shafa Al-Showk

Structured Abstract

Purpose: We examine Internet use and eHealth literacy among older adults (aged 55+ years) who were patients at clinics serving low-income populations. **Scope:** Participants included 200 minority and White adults who completed interviews based on a technology acceptance conceptual model. A total of 106 participants (53.0%) used the Internet; utilization was associated with personal characteristics (age, ethnicity, education, poverty), computer characteristics (number of e-devices, computer stress), social support (marital status), and health knowledge and attitudes (health literacy, medical decision making, health information sources), but not health status. Of the 106 participants who used the Internet, 52 (49.1%) had high eHealth literacy; eHealth literacy was associated with computer characteristics (number of e-devices, computer stress), and health knowledge and attitudes (medical decision making, health information sources). **Methods:** Qualitative interviews were completed with 36 low-income African American, American Indian, Latino, and white older adults, 16 caregivers, and 8 health care providers. 200 participants completed interviews based on technology use and acceptance. 10 of the 200 completed an additional qualitative interview regarding proxy access to patient portals. **Results**: In multivariate analysis, computer stress maintained a significant inverse association with eHealth literacy. Educational interventions to help older adults successfully use technology and improve eHealth literacy must be identified.

Purpose

The ability to access, manage, and understand personal health information enables individuals to become better health care consumers and to participate more fully with providers in making health care decisions. The development of electronic health records, with the availability of electronic patient portals for accessing personal health information, has provided the potential for electronic personal health information management (ePHIM). Great variability exists access to the internet, electronic media, electronic health records, and technology-based health (eHealth) information, with certain components of the US population experiencing significant access limitations or being completely unconnected. The goal of this project is to document the ability of low-income African American, Indian, Latino, and white older adults to use information technology applications for personal health information management and the factors which affect their use of this information technology.

This study has three specific aims:

1. It will document the ePHIM experience, knowledge, perceived needs, and perceived risks of low-income African American, American Indian, Latino, and white older adults living in rural and urban communities. A qualitative research design will be used for this aim. In-depth interviews conducted with 36 low-income African American, American Indian, Latino, and white <u>older adult patients</u> and 16 of <u>their caregivers</u> will delineate their health information technology experience, knowledge, and perceived needs and risks. Rural patients will be recruited from the community clinics in Community Partners HealthNet located in rural North Carolina communities. Urban patients will be recruited from a clinic associated with Wake Forest Baptist Medical Center in Winston-Salem. In-depth interviews will be completed with 20 rural and urban health care providers to obtain their perspectives on information technology and ePHIM for their patients. Finally, 8 in-depth interviews will be completed with information technology service providers, and those who support access to information technology, to delineate their understanding of community member needs.

2. **It will delineate the actual use of ePHIM by low-income African American, American Indian, Latino, and white older adults living in rural and urban communities.** A longitudinal research design will be used. The Community Partners HealthNet clinics and a Wake Forest Baptist Medical Center clinic each have ePHIM systems with patient portals. 200 patients will be recruited from these clinics and introduced to the ePHIM system using standard clinic procedures. These patients and 100 of their caregivers will be asked to complete baseline interviews focused on their knowledge and experience using ePHIM, and then followed for 12 months with interviews every 2 months and review of their EHRs to document use of ePHIM, changes in their knowledge of ePHIM, and any efforts they make to learn how to use ePHIM. As a secondary aim, the association of ePHIM use with the control of common chronic medical conditions will be investigated among these patients, by assessing blood pressure, cholesterol, and diabetes related data in the EHR.

3. **It will delineate differences in perception, belief and experience in using ePHIM between patients and caregivers who use versus those who do not use ePHIM.** A qualitative research design will be used for this aim. In-depth interviews 45 patients and 15 caregivers will explore the differences in ePHIM use. Ten health care providers will be interviewed about their perceptions and experience about patient use of ePHIM.

The data from this study are significant because they will document the problems limiting the use of ePHIM. The study is innovative in its use of qualitative and longitudinal data to document the actual use of ePHIM in a low-income, multiethnic cohort of older adults and their caregivers. The results of this study are important for designing ePHIM software and ePHIM educational programs.

Scope

Older adults often have multiple chronic conditions and are major users of health care.[1] Supporting the health self-management for older adults with multiple chronic conditions is a central component of improving the overall health of this population.[2] However, several barriers compromise individuals' self-management of chronic conditions, such as lack of financial resources, poor access to medical resources, complexity of social support, and confusion due to contradictory information provided by multiple health care providers[2] (Liddy et al., 2014). New electronic technology provides opportunities to help older adults address these limitations and improve their self-management of chronic conditions.

Although electronic technology has become nearly ubiquitous, older adults, particularly those age 75 years and older, still lag behind younger persons in its adoption, especially with regard to the Internet.[3] Commonly cited reasons for older adults' lack of electronic technology uptake include attitude, awareness, inappropriate design, cost, lack of self-efficacy, and a general lack of interest. [4]

The term "eHealth" refers to electronic technology applications in the health domain, in particular opportunities for health care provided via the Internet. [5] The Internet can be a resource to individuals seeking knowledge about health conditions and their treatments; therefore, it is not surprising that the Internet is considered a tool for transforming the health care industry. [5] The Internet has extensive readily available information, but the reliability and accuracy of that information is difficult to assess [6] This is problematic as most online health seekers believe all or most information they find on the Internet and do not assess the sources of the website they visit. [7,8]

eHealth literacy is "the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem" (Norman & Skinner, 2006b, p. e9). [9]Research examining the levels of eHealth literacy among older adults and factors associated with eHealth literacy levels is limited. Choi and Dinitto [10] examined factors associated with eHealth literacy among adults aged 60 years and older receiving home-delivered meals in central Texas, and found only 17% of adults age 60 years and older used the Internet. In addition, they found that affordability was the primary barrier to Internet use with the number of older adults who had discontinued Internet use due to costs equal to the number who were currently using it. [10] Furthermore, eHealth literacy was negatively associated with age; those of older ages had lower perceived eHealth self-efficacy. [10]

It is necessary to assess patients' eHealth literacy and identify its determining factors to ensure they can use available eHealth resources effectively. [11]However, little research has examined the eHealth literacy of older adults, and the factors associated with eHealth literacy levels. This information is particularly important to address eHealth among the members of low-income and minority older adults who have had limited access to technology. [12]The eHealth Literacy Scale (eHEALS) is one of a few existing validated scales assessing eHealth literacy [9,11] It includes eight items scored on a 5-point Likert-type scale and was developed to assess individuals' perceptions about their skills using information technology to learn about health issues and evaluate the "fit" between eHealth programs and users.

Davis's technology acceptance model (TAM) [13] and the person-environmental interaction model (Lawton) [14] together provide a conceptual framework for understanding technology adoption and proficiency among older adults.[15-20] Computer characteristics (including whether a person owns or uses electronic devices and stress in using these devices), social support, general health knowledge and attitudes, and health status shape eHealth technology adoption and proficiency, in conjunction with such personal characteristics as age, gender, ethnicity, education, employment, and poverty, influence the degree to which older adults utilize personal health technology and their perception of its usability and usefulness. [21] The Internet is an important (perhaps necessary) means to utilize personal health technology, and eHealth literacy is an important indicator of effective personal health technology utilization.

This analysis examines the eHealth literacy levels of low-income and minority older adults and the factors associated with levels by addressing two aims. Among older adults (aged 55 years and older) who are patients at clinics serving low-income populations, the first aim is to determine Internet use, and to identify computer characteristics, social support, general health knowledge and attitudes, health status, and personal characteristics associated with Internet use. Among the older adults who use the Internet, the second aim is to identify the levels of eHealth literacy using the eHEALS scale, and to identify computer and Internet characteristics, social support, general health knowledge and attitudes, health status, and personal characteristics associated with eHealth literacy level.

We recruited participants from urban and rural clinics that primarily serve low-income patients and patients from minority communities. The urban clinic was the Outpatient Department (OPD) of the Wake Forest Baptist Health Internal Medicine residency program, located in Winston-Salem, North Carolina (NC). OPD serves ethnically diverse, low-income, predominantly Medicare and Medicaid patients. Two members of Community Partners HealthNet were the rural clinics. Community Partners HealthNet is a Health Center Controlled Network (established in 1999) to implement practice management systems for community health centers. Greene County Health Care, Inc., and West Caldwell Health Council, Inc., serve the rural areas of

Greene and Caldwell Counties, NC, respectively. Greene County Health Care, Inc., has six clinic locations. West Caldwell Health Council, Inc., has two clinic locations.

In-depth interviews were conducted with 36 low-income African American, American Indian, Latino, and white older adults and 16 of their care givers to delineate their health information technology experience, knowledge, and perceived needs and risks. Rural patients were recruited from the community clinics in Community Partners HealthNet located in rural North Carolina communities. Urban patients were recruited from a clinic associated with Wake Forest Baptist Medical Center in Winston-Salem. In-depth interviews were completed with 20 rural and urban health care providers to obtain their perspectives on information technology and ePHIM for their patients. Finally, 8 in-depth interviews were completed with information technology service providers, and those who support access to information technology, to delineate their understanding of community member needs. These qualitative interviews informed the development of interview guides for the quantitative, and central, component of this project.

Quantitative participants included community-dwelling adults aged 55 years and older, who were being treated for a chronic disease (diabetes, hypertension, dyslipidemia, or cardiovascular disease), who spoke English or Spanish, and were in sufficiently good health to give informed consent and complete an interview. The sample included those 55 years and older because familiarity with and use of electronic media varies greatly by age among older adults starting at age 55 years. We recruited a majority of participants using a three-step process. First, with the assistance of clinic staff and physicians, we generated lists of patients who met the inclusion criteria. Second, we randomly selected potential participants from these lists and sent letters introducing and describing the study. Third, we made follow-up phone calls to describe the study and to schedule interviews with those who were sent the letters. In addition, we recruited Spanish-speaking participants as they came to one set of rural clinics. The clinics often do not have accurate telephone information for these participants due to the frequency with which they change telephone service. We approached individuals fitting the inclusion criteria described the study and scheduled interviews for a later date. The study protocol was approved by the investigators' Institutional Review Board, and all participants provided signed informed consent.

Participants included 200 minority (African American, Latino, American Indian, Asian) and White older adult patients who completed baseline interviews. Data collectors attempted telephone contacts with 628 patients who were sent a letter or who were contacted in a clinic. Of the 628 attempted telephone contacts, 110 had a nonworking telephone number, 111 could not be contacted by telephone, 13 were deceased, and 394 were contacted for a contact rate of 62.7%. Of the 394 who were contacted, 194 refused to participate, for a refusal rate of 49.2%, and 200 participants were successfully enrolled and completed interviews, for an overall participation rate of 31.8%. Those who refused to participate were equally divided among women and men. However, more White (42.2%) than African American (22.1%), Latino (0%), American Indian (0%), or Asian (0%) patients refused to participate, and more urban clinic (65.9%) than rural clinic (28.8%) patients refused to participate.

Methods

This project is based on a partnership of Wake Forest Baptist Health and Community Partners HealthNet with the common goal of documenting the ability of low-income African American, American Indian, Latino, and white older adults living in rural and urban communities to use information technology applications for ePHIM. Community Partners HealthNet includes 15 clinics that serve an ethnically diverse, low-income rural population across North Carolina.

Wake Forest Baptist Health operates the Outpatient Department Clinic which services an ethnically diverse, low-income population within the city of Winston-Salem, North Carolina. The Community Partners HealthNet members use MicroMD® for electronic health record; MicroMD® has introduced the Updox patient portal for ePHIM. Wake Forest Baptist Health members use WakeOne, an EpicCare EMR for electronic health record; this system includes a patient portal for ePHIM.

This research project has three major components, reflecting the three specific aims. The first component (Project Years 1 & 2) entails a qualitative research design that will document the ePHIM information, health information technology and personal health information management experience, knowledge, perceived needs, and perceived risks of low-income African American, American Indian, Latino, and white older adults. This qualitative component will include the perspectives of older adult patients, their primary health caregivers, their health care providers, and IT providers in their communities. The second project component (Project Years 2-5) will measure actual use of the patient portal by older adults and their caregivers, and delineate the factors associated with the use of the patient portal. The third project component (Project Year 4 - 5) will use a qualitative design to delineate the differences in perception, belief and experience between patients and caregivers who use versus those who do not use the patient portal. This qualitative component will include the perspectives of older adult patients, their primary health caregivers, and their health care providers. Through the systematic analysis of these textual data from older adult patients, their caregivers, and those who provide care for these patients, and through longitudinal measures of ePHIM use by older adult patients and their caregivers, this project will document levels of ePHIM use, and factors affecting ePHIM use.

Timeline and Project Administration

Project Tasks	Year 1				Year 2				Year 3				Year 4				Year 5			
Community Participation	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x	x
Specific Aim 1: Document ePHIM experience of older adult patients																				
Finalize in-depth interview guide	x																			
Conduct in-depth interviews		x	x																	
Analysis and reporting results		x	x	x	x	x	x	x												
Specific Aims 2 : Delineate actual use of ePHIM																				

Project Tasks	Year 1				Year 2				Year 3				Year 4				Year 5			
Finalize questionnaires			x	x	x	x														
Select sample							x	x	x	x										
Data collection							x	x	x	x	x	x	x	x						
Analysis and reporting results													x	x	x	x	x	x	x	x
Specific Aim 3: Delineate differences between those who use and do not use ePHIM																				
Finalize in-depth interview guide													x	x						
Conduct in-depth interviews															x	x				
Analysis and reporting results															x	x	x	x	x	x

Results

About one quarter (27.5%) of participants were aged 55 to 59 years, with 31.5% aged 60 to 64 years, 26.0% aged 65 to 69 years, and 15.0% were aged 70 years or older. More participants were female (58.0%) than male (42.0%). Most (60.0%) were minority, 35.0% had greater than a high school education, and 80.0% were not employed. Most (83.3%) had household incomes at 200% of poverty or less.

More than one quarter (28.0%) of participants did not own an e-device, with 47.5% owning two or more. Most participants (69.5%) used the Internet less than once each day, and 75.9% experienced stress when using a computer. Fewer than half (42.0%) were married, but 62.0% had a care provider. Thirty-five percent lived alone.

Almost three quarters (72.0%) had inadequate general health literacy, and 56.9% preferred to rely on the doctor's knowledge when making medical decisions. The mean of health information sources used by the participants was 3 ($SD = 1.7$). The mean for the MCS was 50.2 ($SD = 12.3$), and for the PCS was 37.6 ($SD = 12.2$). The mean for the Modified Charlson Index was 5.9 ($SD = 2.7$).

Factors Associated With Internet Use

A little more than half (53%) of the participants used the Internet. A greater percentage of those less than age 65 years (65.5% of those aged 55-59 years, and 61.9% of those aged 60-64

years) used the Internet than those aged 65 years or older (42.3% of those aged 65-69 years, 30% of those aged 70 years and older). Internet use did not differ by gender. A greater percentage of White participants (67.5%) than minority participants (43.3%) used the Internet; comparison of African American and Latino participants showed no statistically significant difference (results not shown). Those with greater than a high school education (75.7%) were more likely to use the Internet than those with high school education or less (40.8%). Employment was not related to Internet use. Those with an income greater than 200% of poverty (75.0%) were more likely to use the Internet than those with a lower income (50.6%).

Computer characteristics were associated with Internet use. Those with two or more e-devices in their homes were much more likely to use the Internet (82.1%) than those with one (25.5%) or no home e-devices (1.8%). Those experiencing any stress while using a computer (41.1%) were less likely to use the Internet than those who experienced no stress (91.7%). A greater percentage of those who were married (64.3%) used the Internet than those who were not married (44.8%). Having a care partner and household structure was not related to Internet use.

Fewer of those with inadequate general health literacy (42.6%) than those with adequate general health literacy (83.0%) used the Internet. Those who preferred to rely on their doctor's knowledge for medical decision making (42.9%) were less likely to use the Internet than those who did not prefer to rely on their doctor's knowledge (68.2%). Those who used the Internet had an average of 3.4 (SD = 1.5) health information sources; those who did not use the Internet used an average of 2.6 (SD = 1.7) health information sources. Health status, as measured by the SF-12 MCS subscale and PCS subscale, and the Charlson Index, was not associated with Internet use.

Factors Associated With eHealth Literacy

Among the 106 participants who used the Internet, eHealth literacy scores had a range of 8 to 40, and an overall mean of 28.4 (SD = 7.1). Fifty-two participants (49.1%) had high eHealth literacy, and 54 (50.9%) had low eHealth literacy. Having high eHealth literacy did not differ in terms of personal characteristics among older adults who use the Internet. However, having high eHealth literacy was associated with computer characteristics. A greater percentage of those with two or more e-devices in their homes (46.7%) had high eHealth literacy than those with one e-device (33.3%) or no e-device (0). More of those experiencing no stress while using a computer (68.2%) had high eHealth literacy, compared with those who experienced any stress (36.1%). None of the social support measures were associated with high eHealth literacy.

Fewer of those who preferred to rely on their doctor's knowledge for medical decision making (38.3%) had high eHealth literacy than those who did not prefer to rely on their doctor's knowledge (58.6%). Those with high eHealth literacy used an average of 3.8 (SD = 1.45) health information sources; those who did not have high eHealth literacy used an average of 3.0 (SD = 1.5) health information sources. Health status, as measured by the SF-12 MCS subscale and PCS subscale, and the Charlson Index, were not associated with high eHealth literacy.

A multivariate model of the measures with a statistically significant bivariate association with high eHealth literacy shows that no computer stress was the one measure that remained significantly associated. The odds ratio of no computer stress with high eHealth literacy was 3.05, with a 95% confidence interval of [1.13, 8.23], and a p value of .03. In addition, the number of health information sources had a marginal positive association with having a high eHealth literacy score. The odds ratio of health information sources with high eHealth literacy was 1.41,

with a 95% confidence interval of [1.00, 1.99], and a *p* value of .053. A second multivariate model in which all measures with a *p* value < .20 in the bivariate analyses was also calculated (results not shown). This second model did not differ from the first; only no computer stress was significantly associated with having high eHealth literacy, and the association of number of health information sources remained marginally associated with high eHealth literacy.

Increasing older adult Internet use can improve access to health information and improve health self-management.[4,22] It is essential that older adults have the eHealth literacy to understand and determine the veracity of information that they find through Internet and other digital sources.[9] Determining personal characteristics that are associated with limited Internet use and eHealth literacy among older adults is important to understanding their prevalence, but these personal characteristics do not provide leverage points to improve use or literacy. Our conceptually based analysis[16] indicates that improving computer skills and limiting computer stress may be the keys to improving older adults' eHealth use and understanding. Cotten argues that we must identify ways to help older adults successfully use technologies, but that current design impedes this use.[23] At the same time, in their review of eHealth literacy intervention, Watkins and Xie conclude that existing interventions are neither theory based nor use high-quality research design.[24] Future research and intervention must continue to delineate leverage points for improving technology use and eHealth literacy among older adults, and conceptually based interventions that use these leverage points should be developed and tested.

We conducted additional semi-structured interviews with 10 participants with chronic illness. We asked them about their relationship with their caregivers, their use of their patient portal, their caregiver's use of the portal, and their perceptions about the benefits and risks of their caregiver's use of the portals. We also asked them about their comfort level with caregivers having access to information about a hypothetical diagnosis of a stigmatized condition. Two investigators conducted a thematic analysis of the qualitative data.

All patients identified caregivers. Some had given caregivers access to their portals, in all cases by sharing log-in credentials, rather than by setting up an official proxy account. Patients generally saw benefits in their caregivers having access to the information and functions provided by the portal. Patients generally reported that they would be uncomfortable with caregivers learning of stigmatized conditions and also with caregivers (except spouses) accessing financial billing information.

This research should be evaluated within its limitations. The sample was drawn from patients receiving care at three sets of clinics (one urban, two rural), and the participation rate is limited. These factors limit the generalizability of the results. At the same time, this survey did recruit a large, multiethnic, low-income sample that included both rural and urban patients. The measure of eHealth literacy, the eHEALS, is a validated scale that is becoming widely used.[9,25]

List of Publications

Arcury TA, Sandberg JC, Melius KP, Quandt SA, Leng X, Latulipe C, Miller DP Jr, Smith DA, Bertoni AG. Older Adult Internet Use and eHealth Literacy.. J Appl Gerontol. 2018 Oct 24:733464818807468. doi: 10.1177/0733464818807468.

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