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Electronic health literacy of older Hispanics with diabetes

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Summary

Although the internet increases the availability of diabetes-related health information, health care consumers need to have different skills in order to obtain, interpret and evaluate such information. The eHealth literacy scale (eHEALS) was originally developed to assess consumers' perceived skills at using information technology for health. The objective of this study was to explore the experiences of older Hispanics' with type 2 diabetes in using the internet for diabetes management. This study was conducted in the USA among a convenience sample of older Hispanics with type 2 diabetes ($n = 20$) who attended a senior center in East Harlem, New York City. All participants first completed eHEALS and a demographic, diabetes-related, and smart phone use form either in English or Spanish and then participated in a focus group. Descriptive statistics and a univariate exploratory analysis were conducted to determine differences in electronic health literacy based on age or gender. In addition, qualitative data from the focus groups were analyzed. No significant differences were found based on age ($F = 0.76$, $p = 0.66$), but a t-test found significant differences based on gender ($t = -2.67$, df = 18, $p = 0.015$). During the qualitative data analysis, five themes were identified from the focus group responses. Although the participants had access to the internet, they were not using the technology to access diabetes-related health information. Given the small sample size in this study, the Spanish version of the instrument needs to be used in a larger sample and further psychometric testing.

Key words: diabetes, community based

INTRODUCTION

Diabetes is a major cause of morbidity and mortality and a growing public health concern. In 2012, Hispanics comprised 52.9 million (16.9%) of the total 313.9 million US population (U.S. Census Bureau, 2014a); and by 2013 there was a 2.2 million increase in the Hispanic population (U.S. Census Bureau, 2014b). Of the number of Hispanics in the USA in 2012, 12.8% had diabetes (Centers for Disease Control and Prevention [CDC], 2014). Since the Hispanic population is currently one of the fastest-growing ethnic minority groups in the USA

with documented critical levels of diabetes, it is logical to project that diabetes in the Hispanic population will persist as a growing public health concern.

Within New York City (NYC), 28.9% of the 2013 population is Hispanic (NYC Department of City Planning, 2014) and, East Harlem is one of the 10 Manhattan neighborhoods with large Hispanic populations (New York City Department of Health and Mental Hygiene, 2015), where more than half of that population (51%) identifies as Hispanic (Olson *et al.*, 2006). East Harlem residents are greatly affected by diabetes, with the highest diabetes

mortality and complications rate compared to other neighborhoods in NYC (Fox *et al.*, 2012).

Although there are many definitions of health literacy, the Affordable Care Act states that health literacy is the degree to which individuals have the skills and competencies needed to obtain, communicate, process, and understand basic health information and services needed in order to make appropriate health decisions (Wizemann and Institute of Medicine [IOM], 2011; Serensen *et al.*, 2012). Almost half (36%) of the adults in the USA have limited health literacy (i.e. below basic or the basic health literacy); and of those 36%, more than half (59%) are older adults (i.e. 65 years and older) (CDC, 2009). Studies show that those with diabetes and limited health literacy have worse health outcomes (Sarkar *et al.*, 2010), since they have less knowledge about their diabetes, difficulty in reading medication labels, and a poor understanding on ways to better management their health (White *et al.*, 2010).

Health literacy influences a person's ability to engage in self- management (Cornett, 2009) and the internet can be a resource for providing diabetes-related information for people to self-manage their diabetes more effectively (Powers *et al.*, 2008; Wilson, 2013). In the USA, 76% of all adults used the internet for health information (Harris Poll, 2010). But Levy *et al.* (Levy *et al.*, 2014) found that only 9.7% of older individuals with low health literacy regularly used the Internet for health information, compared with 31.9% of those with adequate health literacy.

The internet can be a useful tool to access information about diabetes and better manage the day-to-day challenges posed by living with this chronic illness. In order to develop effective interventions that capitalize on the information available on the internet, it is important to describe use patterns among older Hispanic with diabetes. The purpose of this descriptive study was to explore the experiences of older Hispanics' with type 2 diabetes in using the internet for diabetes management.

REVIEW OF THE LITERATURE

Life in the 21st century relies heavily on the use of technology-based sources of information and communication. Online health information allows consumers' to access information and resources to make decisions regarding health and disease management (Fox and Jones, 2009). Historically, trends on internet usage among different ethnic groups showed that Hispanics were not taking advantage of the resources the internet had to offer (Rainie, 2010). Although the Pew Research Center (Lopez *et al.*, 2013) reported that there was a 14% increase of internet usage among Hispanics from 2009 to 2012, other studies found that Hispanics use the internet to seek health information less than Non-Hispanic Blacks and Whites (Livingston, 2011; Laz and Berenson, 2013). A study showed that although Hispanics seek health information less than other ethnic groups, Hispanics reported that health information retrieved from the internet improved their understanding of medical conditions and treatment, and confidence to talk to doctors about their health concerns (Pena-Purcell, 2008). Differences between ethnic groups use of the internet to seek health information varies.

In order to search for internet use of diabetes-related information among Hispanics, a PUBMED database search of articles published between January 2004 and January 2015 was conducted. The first search using the keywords *Hispanics* and *electronic health literacy* yielded six articles which were all on adolescents or young adults (i.e. 18–31 years of age). A second search using the keywords *Hispanics, internet* and *diabetes* identified 25 articles. Of the 25 articles, only two discussed internet usage or examined an internet-based diabetes self-management program for Hispanics. The first study showed that Hispanics use of the internet increased their diabetes knowledge (Zhao, 2014); while the second study reported that an internet-based diabetes self-management intervention showed positive changes in behaviors (e.g. medication adherence), particular physiological values (e.g. hemoglobin A1c), and psychosocial (e.g. problem-solving) outcomes among Hispanics (Glasgow *et al.*, 2013).

The lack of published articles on older Hispanics with diabetes that explore the experiences of older Hispanics' with type 2 diabetes in using the internet for diabetes and diabetes-related information points to the need for such studies and is an essential preliminary step to developing culturally appropriate effective internet-based diabetes interventions.

METHODS

Design

A convergent mixed methods design was used (Creswell, 2013). Descriptive quantitative data about electronic health literacy used the 10 item E-Health Literacy Scale (e-HEALS) which measures perceived skill and confidence in using the internet for gathering and acquiring health-related information (Norman and Skinner, 2006). Qualitative data was gathered through focus groups that further explored how electronic health literacy impacts on accessing diabetes and diabetes-related health information by older Hispanics with diabetes. Prior to beginning the data collection, this research was approved by the Institutional Review Board of the City University of New York.

Setting/recruitment

Recruitment took place at a publicly funded Senior Center in East Harlem. The Senior Center regularly services about 100 older adults (men and women), who are 60 years of age and older, and reside in East Harlem. Recruitment flyers were posted throughout the Senior Center and the Director of the Center made daily announcements before the mid-day meal to maximize ways to reach all members of the Senior Center, make them aware of the study, and potentially increase the number of interested individuals. To ensure eligibility, each interested participant was individually screened by a Research Assistant (RA) who was Hispanic, bilingual and fluent in reading, writing and speaking both English and Spanish. The RA screened the interested participant via telephone to ensure eligibility, based on the inclusion and exclusion criteria; the study was explained and interested persons were asked their preferred language (English or Spanish) in order to plan for a focus group and to have the instrument packet (i.e. eHEALS, short demographic, diabetes-related, and smart phone use forms) in that language. Interested participants were given an appointment and the RA called each participant the day, to remind them of the appointment.

Sample

A convenience sample of 20 Hispanic adults with Type 2 diabetes was recruited from an East Harlem Senior Center. Inclusion criteria included: (i) residing in East Harlem; (ii) able to access the internet; (iii) aged 60 or older; (iv) either English or Spanish speaking; and (v) diagnosed with type 2 diabetes. Exclusion criteria included: (i) participating in another study; and (ii) diagnosed with a cognitive dysfunction. All who were interested participants and fit the eligibility criteria participated in the study, resulting in 20 participants.

Data collection

Data was collected by the principal investigator (PI) and RA. Both were Hispanic, bilingual and fluent in reading, writing and speaking both English and Spanish and had conducted research with this sample previously.

Each participant completed the informed consent form including giving permission to audiotape the focus group; and completed the instrument packet consisting of the eHealth Literacy Scale (eHEALS) and a short demographic, diabetes-related, and smart phone use form which were available in both English and Spanish. After all participants completed the packet, the qualitative phase proceeded. Based on the participants preferred language of either English or Spanish, 14 completed the instrument packet in English and 6 in Spanish. After all participants

completed the packet, the forms were collected and the focus groups proceeded.

A total of two focus groups were conducted in the preferred language (English or Spanish), with each group having 10 participants and lasting approximately 90 min. Both focus groups were conducted in English since it was the preferred language of the participants. Given that the PI and RA were bilingual and had experience conducting focus groups, the PI conducted the focus groups and the RA moderated (i.e. ensured topics were covered and kept track of the time) the groups. During the focus groups, place cards with initials and a Roman numeral was used to identify each individual and maintain anonymity. Each participant received $15 compensation upon completing the study.

Instruments

The eHealth Literacy Scale

The 10-item eHEALS is a 5-point Likert scale, which is a valid and reliable tool developed by Norman and Skinner (Norman and Skinner, 2006), that provides self-reported information on the knowledge, comfort and perceived skills of an individual in using the internet for health information (Norman, 2011). Higher scores are consistent with higher electronic health literacy.

The instrument is available in English, Japanese (Mitsutake *et al.*, 2012), Chinese (Koo *et al.*, 2012) and Dutch (van der Vaart *et al.*, 2011) but not in Spanish. It has been validated for use with older adults (Xie, 2011; Chung and Nahm, 2015). Since no Spanish version of eHEALS could be located the instrument was translated to Spanish by a professional translation service, called ANP transcriptions (ANP transcriptions, 2014), in preparation for participants who preferred to complete it in Spanish. One linguist translated the instrument from English to Spanish and a second one verified the Spanish translation. Hence, the 10-item eHEALS was available in English and Spanish for participants.

Focus group questions

Fourteen focus group guide questions (Table 1) were used which were drawn from the 10 items of the eHEALS. These questions focused on internet usage in accessing health-related information in accessing diabetes resources and diabetes-related information.

Demographic (i.e. age, gender, country of origin), diabetes-related information, and smart phone use to access the internet data were also collected (Table 2).

Data analysis

Descriptive statistics were conducted on the eHEALS data using SPSS software version 21. The focus groups were

Table 1: Focus group questions

You will be asked questions about your use of the internet as a source of health-related information about your diabetes.

1. In the last week, have you used the internet for health or diabetes information?
2. In the last month, have you used the internet for health or diabetes information?
3. In what ways do you use the internet for health or diabetes information?
4. In what ways have you found the internet useful or not useful?
5. When accessing the internet for health or diabetes information, what makes it important or not important?
6. Give three examples of what you have used the internet for, in accessing health or diabetes information?
7. What diabetes resources are available on the internet?
8. Where would you find information in the internet on diabetes?
9. In the last week, have you used the internet to answer a question you have had about diabetes?
10. In the last month, have you used the internet to answer a question you have had about diabetes?
11. In what ways have you used information on diabetes you have found on the internet?
12. Do you feel confident in using the internet to access information on diabetes? Why or why not?
    (a) What needs to be done in order for you to feel more confident?
13. From the internet, have you used diabetes information in making a health decision?
14. What would you do if you find diabetes information accessed via the internet you do not understand because it is complicated information?

Table 2: Sample characteristics including demographics, diabetes-related, and smart-phone related responses

Demographic characteristics		
Age	74 years (SD = 5.59)	Range: 68–86 years
Country of origin	Puerto Rico	70% ($n = 14$)
	Mexico	15% ($n = 03$)
	Dominican Republic	05% ($n = 01$)
	Other Hispanic country	10% ($n = 02$)
Primary or preferred language	Spanish	80% ($n = 16$)
	English	20% ($n = 4$)
Diabetes-related characteristics		
Length of time diagnosed with diabetes	16.7 years (SD = 6.79)	Range: 2–31 years
Take medications for diabetes	Yes	65% ($n = 13$)
	No	35% ($n = 07$)
Smart phone related characteristics		
Number of years with cell phone that accesses the internet	2.95 (SD = 1.47)	Range: 1–5 years
Total number of calls made and received daily on cell phone	3.15 (SD = 1.42)	Range: 1–5 calls
Comfort level in making/receiving calls on cell phone	Very/somewhat comfortable	55% ($n = 11$)
	Not comfortable/uncomfortable	25% ($n = 05$)
	Very/somewhat uncomfortable	20% ($n = 04$)
Total number of texts made and received daily on cell phone	0.05 (SD = .827)	Range: 0–3 texts
Concerns with privacy of texting	Very concerned	40% ($n = 08$)
	Somewhat concerned	35% ($n = 07$)
	Slightly concerned	10% ($n = 02$)
	Not concerned	15% ($n = 03$)

audiotaped and transcribed verbatim by a professional transcribing company (i.e. ANP Transcriptions). Content analysis was used for subjective text of the focus groups, by systematically coding text into categories and identifying themes (Krippendorff, 2012). Each focus group transcript was read repeatedly to achieve immersion of the data and until data saturation was achieved. Based on the text of the transcripts, notations were made on significant topics and were identified. As reoccurring concepts were identified based on the responses, codes began

to emerge and were grouped into similar categories. The themes were identified from the text at which time the significance of the text was recorded. Both authors independently read the transcripts and identified themes; they subsequently met to discuss and refine the identified themes and reach consensus.

RESULTS

The sample was equally divided between men and women; the average participant was 74 years; born in Puerto Rico; preferred to speak in Spanish; lived with diabetes an average of 17 years and took medications to manage their diabetes. Since access to the internet could be an issue, respondents were asked if they had a smart phone with internet access and the average participant had a smart phone for 3 years; made or received 3 calls daily; texted less than once daily; and 75% were either very or somewhat concerned with privacy and texting. See Table 2 for further details.

The mean score on e-Heals was computed as 22.35 (SD = 12.96) with a range from 8 to 40; respondents reported the most difficulty with knowing how to use the Internet to answer questions about their health (Table 3). Cronbach's alpha was computed for this sample and was 0.989. Table 3 shows the 10 items on e-Heals along with responses, item means and standard deviations for this sample.

Differences in electronic health literacy based on age and gender were calculated. No significant differences were found based on age ($F = 0.76$, $p = 0.66$) but an independent sample t-test found highly significant differences based on gender ($t = -2.67$, $df = 18$, $p = 0.015$); men were significantly lower than those of women (means = 13.85 (9.69) and 25.77 (10.22) respectively).

Five themes were identified from the responses provided during the focus group specifically: Useful information source; Family and friends help; Complex and confusing; Type words and get information; and Improved self-management.

The internet is a useful source for health-related information

Useful information source

Reasons identified by thirteen (10 female and three male) of the focus group participants for using the internet for diabetes-related information were, 'I used it because I was given a new medication'; 'I use it when I have time to look up health information'; 'The internet is useful to me; sometimes it answers my questions because I am able to get information about my diabetes or anything

Table 3: Experiences using internet for health information

	Not useful at all / Not important at all / Strongly disagree	Not useful / Not important / Disagree	Unsure / Undecided	Useful / Important / Agree	Very useful / Very important / Strongly Agree	Item mean (SD)
1. How useful do you feel the Internet is in helping you in making decisions about your health?	30% (n = 6)	15% (n = 3)	10% (n = 2)	20% (n = 4)	25% (n = 5)	2.95 (1.63)
2. How important is it for you to be able to access health resources on the Internet?	30% (n = 6)	15% (n = 3)	10% (n = 2)	25% (n = 5)	20% (n = 4)	2.90 (1.58)
3. I know what health resources are available on the Internet.	35% (n = 7)	10% (n = 2)	5% (n = 1)	30% (n = 6)	20% (n = 4)	2.90 (1.65)
4. I know where to find helpful health resources on the Internet.	40% (n = 8)	5% (n = 1)	5% (n = 1)	30% (n = 6)	20% (n = 4)	2.85 (1.69)
5. I know how to find helpful health resources on the Internet.	40% (n = 8)	5% (n = 1)	5% (n = 1)	20% (n = 4)	30% (n = 6)	2.95 (1.79)
6. I know how to use the Internet to answer my questions about health.	40% (n = 8)	5% (n = 1)	25% (n = 5)	25% (n = 5)	5% (n = 1)	2.50 (1.39)
7. I know how to use the health information I find on the Internet to help me.	45% (n = 9)	5% (n = 1)	5% (n = 1)	25% (n = 5)	20% (n = 4)	2.70 (1.71)
8. I have the skills I need to evaluate the health resources I find on the Internet.	40% (n = 8)	5% (n = 1)	5% (n = 1)	25% (n = 5)	25% (n = 5)	2.90 (1.74)
9. I can tell high quality health resources from low quality health resources on the Internet.	45% (n = 9)	5% (n = 1)	5% (n = 1)	30% (n = 6)	15% (n = 3)	2.65 (1.66)
10. I feel confident in using information from the Internet to make health decisions.	40% (n = 8)	5% (n = 1)	5% (n = 1)	25% (n = 5)	25% (n = 5)	2.90 (1.74)

else'; 'For me, it gives me more information than I know'; 'I have used it to know the side-effects of my medications'; 'I use the internet for information about insulin and testing your sugar'; 'I used it to know more about my disease of diabetes'; 'You know what I do, I compare the information my doctor tells me with what the computer tells me'. They found the internet useful for looking up new and current medications and its side-effects, overall health and diabetes information, and in providing additional information.

Go to family/friends for help to access information
Family and friends help

When asked about whether or not the participants had help when accessing diabetes-related information from the internet, eight (seven male and one female) participants indicated, 'either my daughter or son go into the internet for me ad looks things up when I have questions about diabetes'; 'Some information is confusing and complicated so I ask my family and friends'; 'I don't know where, I see my wife just types diabetes and gets information'; 'I ask my wife to read it and then to tell me'; 'I don't know how to use the internet, I see my wife just types diabetes and gets information and she looks for me'; 'my son looks in the internet for me'. Almost half of the total 20 focus group participants depended on either a son/daughter or spouse to help them with accessing and interpreting diabetes-related information from the internet.

Health-related information can be very complicated and confusing
Complex and confusing

Of the 13 participants (six female and seven male) who responded to using and not using the internet to access diabetes-related information because, 'The words in the internet [sic] I can't understand. The words they use are too hard, they give information like the only people going on the internet are doctors'; 'it is hard to know what is true or not true'; 'the information is too complicated for me'; 'the internet needs to use easier words that I could understand'; 'I don't use the internet too much so I'm not too bright'; 'I know that the internet is used to get information but it is confusing'; 'it does not give me too much information since it is confusing and hard to understand'; 'there is a lot of information and I don't know what the information means'; 'the internet has all of the information but has a lot of places to search, I don't know what to do'; 'Most of the information I don't understand and that is the main reason I don't use the internet more'. More than half of the 20 focus group participants felt the internet was overwhelming, confusing

and complex preventing them from using it for diabetes-related information.

Try different methods to verify internet-based information
Type words and get information

Of the participants five (all female) mentioned that the methods used to verify diabetes-related information from the internet included, 'sometimes I go into each of the things that come up in the first and second page and whatever is repeated must be right'; 'I speak to my friends who have diabetes and we talk about information we learn'; 'I can't explain where because I like them, you know, just type words and get information' 'I go into different links'; 'I go into all of the sites that pop-up and whatever information I read over and over again that is the same that feel is true [sic]'; 'I ask my friends who have diabetes about it and we talk about information we learn from the internet'. All of the respondents used different internet methods to access and verify diabetes-related information.

Information has improved health-related behaviors
Improved self-management

Six (three female and three male) respondents identified that diabetes-related information accessed from the internet improved their behaviors by, 'I haven't but my wife has because she cooks more vegetables and serves less food'; 'Now I eat less and try to eat better'; 'Now I understand diabetes more'; 'I try to now walk more than I use to and eat healthier'; 'I try to eat more fruits and vegetables'; 'I have used the information to ask the doctor questions'; 'The information lets me understand why I feel pain in my feet'; 'it has helped me to learn more about diabetes and why I should check my sugars'; 'I check information on my pills and know I need to take them every day like the doctor told me'. Few participants found the internet assisted them in improving their health-related behaviors.

DISCUSSION

Due to the small, convenience sample, descriptive data should be interpreted tentatively. The average electronic health literacy score in this small sample was lower than in the samples of the Dutch or Japanese studies. The electronic health literacy of men in this sample is strikingly low (13.85) which requires further exploration in a larger sample. During the focus group discussion, men often mentioned deferring to their wives or children to access and provide them with internet-based diabetes information, in order for them to self-manage their diabetes. It is not

clear if these gender role differences are unique to older Hispanic men due to cultural or educational or computer-literacy issues or perhaps a combination of all of those factors.

Although the participants said that Spanish was their preferred language, all agreed to participate in a focus group conducted in English and 70% used the English version of the instrument packet although the Spanish version was available. Older adults may lack the skills and knowledge necessary to use online health resources, in addition to possibly having a disability and chronic disease or a handicap which can make using technology difficult (Watkins and Xie, 2014). Text- based health messages are being offered as a strategy to increase self-management (Egbert and Nanna, 2009). But this sample did not text and so any intervention will first require that participants are taught how to use the technology and provided ongoing support until they are competent in the skill. As with any tool, the internet is only effective when used correctly and when technology-related barriers are addressed in a manner that is culturally competent and congruent with the skill levels of the participants.

Strengths

This study offers insights about the digital divide and highlights possible gender differences in this population. The Spanish version of eHEALS is available for use in a larger sample which will also allow for psychometric testing of the instrument in the Spanish language. Participants reported that they had the technology that allowed access to the internet but, especially men, were not using it for health-related information about their diabetes.

Limitations

There were several limitations to this study. First, using the Spanish version of the eHEALS with a population that may have low health literacy in general associated with older age and ethnicity limits the data only to this group and is not generalizable to other groups with different levels of health literacy. Second, the eHEALS measures health consumers' *perceived* skills and comfort with using the internet for health-related information and does not measure their computer skills. In addition, since the data is based on a person's perception, there is a potential for an individual to under- or over-estimate their actual knowledge and/or skills of the internet. Despite these limitations, the eHEALS provided the context of self-reported perceptions of the information and the focus groups provide descriptive data of the real experiences of older Hispanics in using the internet for diabetes management, which served to explain some of the e-HEALS findings, especially related to gender differences.

CONCLUSION

Sheng and Simpson (Sheng and Simpson, 2013) argue that education and trainings that increase seniors' eHealth literacy levels provide an actionable intervention mechanism; screening with a language congruent form of e-HEALS is a beginning step in developing those interventions. While a growing eHealth field has chartered a new course for tailored interventions (Lewis, 2015), it is essential to ensure that technology-use does not worsen prevailing health inequalities. This study provided valuable insight about how older Hispanics' with type 2 diabetes do not use the internet to access diabetes-related information. Consumer-oriented eHealth tools engage consumers in managing their health care and meeting their information needs (Chan and Kaufman, 2011). As the population ages, the prevalence of diabetes can be expected to increase. Interventions need to be developed that engage older, chronically ill, linguistically isolated populations in using the information available on the internet for self-management.

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