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Towards Health Equity: Deaf Adults' Engagement in Social e-Health Activities and e-Communication with Health Care Providers

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Abstract

Deaf people face significant barriers with accessing health information, health care services, and communication with their health care provider and as a result, show poorer health outcomes compared to the general population. Studies on the general population found that those who use social network sites (SNS) for health-related activities were more likely to communicate with their health care provider via the Internet or email. For deaf individuals who use American Sign Language (ASL), using eHealth platforms to communicate with health care providers has the potential to navigate around communication barriers and create greater opportunity to discuss screening and treatment plans. Using national data from the HINTS-ASL survey, we explored whether engagement in social eHealth activities on SNS is linked to electronic communication with health care providers after controlling for deaf patient characteristics. Our sample for this study consisted of 515 deaf participants who reported using (social media/SNS) to read and share health information. Controlling for sociodemographic variables, participants who engaged in social eHealth activity were 3-fold more likely to communicate with their healthcare provider electronically. Using eHealth platforms for social health engagement demonstrates potential to reduce health inequality among deaf people.

Keywords

deaf; social networks; patient-provider communication; eHealth; sign language

Health communication researchers have recognized the crucial need to understand the social media users for health information in order to grasp the benefits and capitalize on the health promoting advantages of SNS platforms such as Facebook and Twitter (Korda & Itani, 2013; Chou, Hunt, Beckjord, Moser, & Hesse, 2009). Moorhead et al (2013) conducted a systematic literature review on SNSs for health-related purposes. Nearly 10,000 papers were included in this study. Six main benefits of using social media for health communication were identified: increase interaction with other users, increased availability, sharing, and tailored health info, increase accessibility and widening access, peer/social emotional

support, public health surveillance, potential to influence health policy. These factors are of critical importance, as research suggests an association with communication with health care providers (Gimeno Garcia, Hernandez Alvarez Buylla, Nicolas-Perez, & Quintero, 2014; Von Wagner, Good, Whitaker, & Wardle, 2011; Power, Miles, Von Wagner, Robb, & Wardle, 2009; Honda & Kagawa-Singer, 2006). Nevertheless, it is important to acknowledge the limitations of applying health-related findings from the general population to linguistic minority groups, particularly those who experience barriers with communication and health information access.

Many SNS-related health studies have not included early deafened people who use ASL, a cultural linguistic minority group that has been historically overlooked and underserved in health care research and services. As an attempt to address this gap, Kushalnagar and colleagues (2017) translated the National Cancer Institute's Health Information National Trends Survey was translated to ASL and included new culturally-relevant items. The HINTS-ASL is unique in gathering health information not only related to health communication, but also specific to deaf people's experiences such as watching ASL videos about health on the Internet. In a study of 713 deaf respondents who took HINTS-ASL survey, Kushalnagar and Kushalnagar (2018) defined health-related SNS use as sharing health information on a SNS platform, such as Facebook. They found that deaf participants who were younger or used both ASL and English were more likely to use SNS for health-related purposes than older deaf participants or those who preferred using only ASL. Further research is needed to examine whether these demographics (age and language) and engagement in social media activities for health-related purposes are also associated with online communication with health care providers.

HEALTH INFORMATION AND PATIENT-PROVIDER COMMUNICATION

Today, many eHealth platforms have established patient portals for electronic communication, such as reviewing test results through online medical record, emailing doctors, and sharing health information through smartphone health apps. Patient portals are designed to be a resource for managing and maintaining health care needs. Many portals have the option to communicate with one's health care provider through the internet or email. Growing research on eHealth activities within the general population has begun to illustrate an association between health-related social media use and patient-provider communication. Jackson, Chou, Coa, Oh, & Hesse (2016) investigated the relationship between health-related social media use, including reading and sharing health information, and participating in an online support group, and online communication with healthcare providers. Results found that those who engaged in social eHealth activities were more likely to communicate with their health care provider via the internet or email. This study painted an initial picture of utilizing multiple digital platforms for health engagement and e-communication with providers. Access to health information via SNS platforms along with emerging eHealth platforms, where one can directly communicate with their health care provider, demonstrate tremendous potential as an alternative gateway for health communication to occur.

The dynamics of healthcare delivery is ever evolving to increase accessibility to information, services, patient-provider communication, and patient empowerment. (Beckjord et al., 2007; Karpeh & Bryczkowski, 2017). The option to communicate with one's health care provider through the internet and/or email may be especially beneficial for deaf signers, where communication barriers in health care settings are significant and widespread. The potential for social eHealth activities to create long needed access to health information is an area that deserves attention from health researchers. Available e-communication channels have potential advantages that should be considered and explored for the deaf population.

Using data from a national sample of deaf SNS users, we explore whether engagement in health-related SNS use is linked to electronic communication with health care providers after controlling for deaf patient characteristics. We end with a discussion and recommendations to increase patient-provider communication via eHealth platforms for this medically underserved population.

Methods

The Health Information National Trends Survey (HINTS) was implemented to collect ongoing nationally representative data about the American public's use of cancer-related information (Nelson et al., 2004). This survey is currently available in English and Spanish through the HINTS website (<http://hints.cancer.gov>) and has been translated into multiple spoken languages. With permission from the HINTS team at the National Cancer Institute, questions from "Using the Internet to Find Information" and "Looking for Health Information" sections were translated to ASL and presented in a video format for use with deaf adults (Kushalnagar, Harris, Paludneviciene, & Hoglind, 2017). The question and response option list are visible on the screen, to increase better understanding and recall of the targeted behavior. Each participant had an option to replay the question/responses and enlarge text as needed.

The items used in this study were included in two separate survey administration cycles: October 2015-March 2016 and June 2017-December 2017. While a formal measure of computer literacy was not included in the HINTS-ASL survey where we drew secondary data from, we limited the analyses to those who answered "yes" to the question: "*Do you ever go online to access the Internet or World Wide Web, or to send and receive email?*" Respondents who did not use the Internet for any reason were excluded from analyses related to engagement in social media activities for health and e-communication with health care providers.

HINTS-ASL Predictors: Engagement in Social Media Activities for Health

To assess deaf people's engagement in social media activities related to health, two items were drawn from HINTS-ASL: 1) "In the last 12 months, have you used the Internet to participate in an online support group for people with a similar health or medical issue?" and 2) "In the past 12 months, have you used the Internet to visit a "social networking" site, such as "Facebook," DeafTV, or ASL vlog to read and share about medical topics?"

HINTS-ASL Outcome: Electronic Communication with Health Care Provider or Staff

Two items were used to assess deaf people's communication with health care providers or staff through the Internet such as email or secure messaging: 1) "In the past 12 months, have you used your online medical record to securely message your health care provider and staff (e.g. email)?" and 2) "In the past 12 months, have you used a computer, smartphone, or other electronic means to use email or the Internet to communicate with a doctor or a doctor's office?".

HINTS-ASL Covariates: Deaf-Specific and Health-Related Characteristics

Along with sociodemographic variables (e.g. age, education, gender), we controlled for the following deaf-specific and health-related characteristics: 1) *What is your preferred language?* 2) *How do you communicate with your doctor, nurse, or health professional that you see the most?* 3) *Not including psychiatrists and other mental health professionals, is there a particular doctor, nurse, or other health professional that you see most often?* For chronic diseases, participants were asked if they were told by their doctors if they had specific medical conditions such as diabetes and cancer. If a participant reported having more than one chronic disease diagnosis, then this participant is considered to have a comorbidity.

Study Procedures

After the university's Institutional Review Board approved the study procedures for the HINTS-ASL study, the research staff began recruitment through national channels, targeting deaf community members who use ASL. Given the nature of this low-incidence and hard-to-reach population, a purposive strategic, respondent-driven sampling method was used to ensure adequate inclusion of deaf signers across the USA, including Hawaii and Alaska, with respect to key demographic characteristics such as age, education, race/ethnicity, and sexual identity. Recruitment methods included snowball sampling through personal networks, flyers, and advertisements on deaf-centered organizations' websites and e-newsletters. We included those who self-report using ASL as their primary language and excluded those who are 17 years old or younger as well as those who have unilateral hearing loss. We enrolled those who provided their signed consent. Each participant received a \$25 gift card as gratuity or participating in the study. The online survey took approximately one hour to complete. No names or identifying information were included in this survey.

Statistical Analysis Plan

Descriptive statistics such as cross-tabulation and percentage procedures were used to describe the sample. Binary logistic regression analysis was used to examine the relationship between the engagement in health-related social media activities and communicating with healthcare providers or staff online, after controlling for sociodemographic and deaf patient-related characteristics. Age, having a regular provider, and education variables were previously reported to be associated with electronic communication (e.g. Internet or email) with healthcare providers (Jackson et al., 2016). These, along with communication modality

used with health care providers, language preference, and comorbidity, were entered in the logistic regression model. The statistical program SPSS 25.0 was used for all analyses.

Results

Sample Description

Of more than 1,700 accrued to the survey between October 2015 and April 2018, a total of 515 participants answered all questions required for this study. Table 1 displays an unweighted summary of the demographic data for this national sample. This sample was somewhat equally distributed across 4 regions of U.S. and included 31% respondents who self-identified as people of color. About half of the sample engaged in social media activities for health, with a majority being female. Education was significant, with slightly more people in this group having a college degree (57%) than those who do not engage in social media activities for health (47%).

The eHealth engaged and nonengaged groups were similar for insurance, regular provider, comorbidity, and communication modality used with their doctors. Those who engaged in social media activities for health had greater family history of cancer (75%) but less personal history of cancer (14%) compared to those who were not engaged in social eHealth activities. Significant differences emerged for having friends or family to talk to about health, with greater endorsement in those who engaged in social eHealth activities (87%) than those who did not engage in social eHealth activities (79%).

Engagement in Social Media Activities for Health and Email Communication with Healthcare Providers or Staff

Binary logistic regression was performed to examine the effect of engagement in health-related social media activities on the likelihood of using online communication with health care providers or staff, after controlling for sociodemographic and deaf patient-related characteristics. The logistic regression model was statistically significant, $X^2(10) = 56.68$, $p < .001$. Comorbidity [OR= 1.64; 95% CI: 1.07-2.52] and higher education [OR=1.83; 95% CI: 1.23-2.70] significantly contributed to this model. After controlling for sociodemographic and deaf patient characteristics, engagement in eHealth social activities was significantly associated with online communication with health care providers or staff [OR=2.81; 95% CI: 1.86-4.23]. Those who reported using SNS to share about medical topics or participate in an online support group for people with a similar health or medical issue were 3-fold more likely to communicate with their health care provider online compared to deaf adults who did not engage in eHealth social activities. Online communication with healthcare providers or staff did not differ across age, race, gender, communication modality used with healthcare provider, or having a regular provider.

Discussion

This study provides a greater understanding of the association between U.S. deaf adult social media users engagement in social media eHealth activity and e-communication with healthcare providers. Our findings identify a trend among deaf adults in utilizing multiple digital platforms for health-related purposes. Those who reported using social media for

eHealth activities were 3-fold more likely to communicate with their health care provider or staff through online platforms. This did not vary across race, gender, age, language preference, or communication modality with health care provider, indicating comparable trend and prevalence of eHealth engagement. This finding from our sample of deaf adults' contrasts with previous research on the general population which found that those who were between the age of 34-44 years old were more likely to communicate with healthcare providers online than other age groups (Jackson et al., 2016). In addition, deaf people who had comorbid medical conditions or college education had higher engagement in e-communication with their providers than those who did not have comorbidity or college degree. The increased likelihood to electronically communicate with healthcare providers or staff was also observed regardless of whether they used a third-party interpreter or communicated directly with providers at in-person visits.

Our findings emphasize the importance of developing or improving strategies to leverage the internet, SNSs, and eHealth platforms for deaf consumers, especially those who already use the Internet. Research has shown that social eHealth platforms activities has potential to facilitate patient engagement, health promotion, early detection screening, earlier intervention, and management of health conditions compared to conventional outpatient structured health care (Neuhauser & Kreps, 2010). The surging popularity of SNS offers an accessible venue to share, post, and discuss health related issues with a network of like peers. Having accessible ASL health videos on SNSs may help fill gaps for important health information not received from health care providers. With the option to access videos, whether on its own or to supplement health information in text, SNSs provide unique benefits for special populations, including those with low literacy (Feng & Xie, 2015). For deaf individuals, widespread use of video technology and popular SNSs is beginning to open the doors for discussing and sharing health information in their primary language, ASL. These popular, frequently visited sites have the ability to bridge social capital among users and potential to foster critical health literacy in deaf users.

Critical health literacy (CHL) is an important dimension of health literacy described as the ability to apply knowledge of health information to make proactive, health-promoting decisions and actions at the individual and community level. A recent study examined the roles of discussion with family and friends about health in critical health literacy among deaf college students (Kushalnagar, Ryan, Smith, & Kushalnagar, 2017). The study findings revealed that greater frequency of health-related discussions with friends, but not family, was significantly associated with better CHL score. Possessing health information knowledge and CHIL skills can function as a catalyst towards taking action to improve the health of oneself, peers, and community. This underscores the substantial role of health communication with like-peers in boosting health knowledge, actions, and promotion at the individual and community level. Contacting healthcare providers through emails or secure messaging as an alternate route for accessible communication may reduce such barriers and create opportunities to discuss available options and participate in the decision-making process.

We recognize several limitations in our study. We did not include deaf individuals who became deaf later in life or solely use English as their main communication method.

Furthermore, our sample of deaf signers did not include those who did not use the Internet, therefore this finding cannot be generalized to deaf individuals who do not use the Internet. Strengths of this study include a national, diverse sample of deaf signers across the United States and use of a fully accessible health survey in ASL and English that includes questions related to eHealth usage. Rather than focusing on the deficits and limitations of deaf individuals, this study capitalizes on the benefits of community cohesion connected to using accessible eHealth platforms for social support as well as communicating with healthcare professionals. Findings from this study bring us closer to realizing the potential of using eHealth platforms as one of many methods to achieve health equity for deaf people.

As Gibbons et al. (2011) discussed “the potential to connect underserved and underrepresented populations to important health information resources and to build social support for those affected by health care issues” (p. 78) through eHealth platforms. For the deaf population, eHealth platforms show promising potential for navigating around barriers to health information access and health communication participation. To reduce inequalities in health-care systems and outcomes, future research should investigate how eHealth technology can be utilized as a gateway to in-depth resources and evidence-based interventions for deaf individuals. Furthermore, subsequent research should examine eHealth behaviors across chronic health conditions, such as cancer, diabetes, or heart disease, and their contribution to screening participation or shared decision making about treatments. A better understanding of the gaps in eHealth usage and management of health care is needed in order to appropriately tailor health interventions according to the specific needs and stressors of a condition. Accessible, online communication with healthcare providers provides greater opportunity for deaf individuals to discuss preventative cancer screening and treatment adherence with their doctor and therefore increases health care management and better health outcomes.

References

- Beckjord EB, Rutten LJF, Squiers L, Arora NK, Volckmann L, Moser RP, & Hesse BW (2007). Use of the internet to communicate with health care providers in the United States: estimates from the 2003 and 2005 Health Information National Trends Surveys (HINTS). *Journal of Medical Internet Research*, 9(3).
- Chou WYS, Hunt YM, Beckjord EB, Moser RP, & Hesse BW (2009). Social media use in the United States: implications for health communication. *Journal of Medical Internet Research*, 11(4).
- Feng Y, & Xie W (2015). Digital divide 2.0: the role of social networking sites in seeking health information online from a longitudinal perspective. *Journal of Health Communication*, 20(1), 60–68.
- Gibbons MC, Fleisher L, Slamon RE, Bass S, Kandadai V, & Beck JR (2011). Exploring the potential of Web 2.0 to address health disparities. *Journal of Health Communication*, 16(sup1), 77–89. [PubMed: 21843097]
- Gimeno Garcia AZ, Hernandez Alvarez Buylla N, Nicolas-Perez D, & Quintero E (2014). Public awareness of colorectal cancer screening: knowledge, attitudes, and interventions for increasing screening uptake. *ISRN Oncology*, 2014.
- Honda K, & Kagawa-Singer M (2006). Cognitive mediators linking social support networks to colorectal cancer screening adherence. *Journal of Behavioral Medicine*, 29(5), 449. [PubMed: 16958004]

- Jackson DN, Chou W-YS, Coa KI, Oh A, & Hesse B (2016). Implications of social media use on health information technology engagement: Data from HINTS 4 cycle 3. *Translational Behavioral Medicine*, 6(4), 566–576. <http://doi.org/10.1007/s13142-016-0437-1> [PubMed: 27628436]
- Karpeh MS, & Bryczkowski S (2017). Digital communications and social media use in surgery: how to maximize communication in the digital age. *Innovative Surgical Sciences*, 2, 153–7.
- Korda H, & Itani Z (2013). Harnessing social media for health promotion and behavior change. *Health Promotion Practice*, 14(1), 15–23. [PubMed: 21558472]
- Kushalnagar P, Harris R, Paludneviene R, & Hoglind T (2017). Protocol for cultural adaptation and linguistic validation of Health Information National Trends Survey in American Sign Language (HINTS-ASL). *Journal of Medical Internet Research Protocols*. doi:10.2196/jmir.8067
- Kushalnagar P & Kushalnagar R (2018). Health Information Seeking among Deaf Adults: Findings from the 2017 Health Information National Trends Survey in American Sign Language (HINTS-ASL). *Emerald Studies in Media and Communication_e-Health: Current Evidence, Promises, Perils, and Future Directions*.
- Kushalnagar P, Smith S, Hopper M, Ryan C, Rinkevich M, & Kushalnagar R (2016). Making cancer health text on the Internet easier to read for deaf people who use American Sign Language. *Journal of Cancer Education*. 1–7.
- Moorhead SA, Hazlett DE, Harrison L, Carroll JK, Irwin A, & Hoving C (2013). A new dimension of health care: systematic review of the uses, benefits, and limitations of social media for health communication. *Journal of Medical Internet Research*, 15(4).
- Nelson D, Kreps G, Hesse B, Croyle R, Willis G, Arora N, ... & Alden S. (2004). The health information national trends survey (HINTS): development, design, and dissemination. *Journal of Health Communication*, 9(5), 443–460. [PubMed: 15513791]
- Neuhauser L, & Kreps GL (2010). eHealth communication and behavior change: promise and performance. *Social Semiotics*, 20(1), 9–27.
- Power E, Miles A, Von Wagner C, Robb K, & Wardle J (2009). Uptake of colorectal cancer screening: system, provider and individual factors and strategies to improve participation. *Future Oncology*, 5(9), 1371–1388. [PubMed: 19903066]
- Von Wagner C, Good A, Whitaker KL, & Wardle J (2011). Psychosocial determinants of socioeconomic inequalities in cancer screening participation: a conceptual framework. *Epidemiologic Reviews*, 33(1), 135–147. [PubMed: 21586673]

Table 1:*Sociodemographic of Deaf Adults Social eHealth Engagement (N=515)*

	Overall N=515	Engaged N=258		Not Engaged n=257		<i>t</i>
	%	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	
Age		42	16	49	19	-5.23**
BMI		28	6	28	6	NS
		n	%	n	%	
Gender						NS
Male	43.5%	111	43%	113	44%	
Female	56.5%	147	57%	144	56%	
Non-binary						
Missing		0				
Race/Ethnicity						NS
White	68.9%	170	65.9%	185	72%	
Black	10.7%	29	11.2%	26	10.1%	
Hispanic	12.8%	37	14.3%	29	11.3%	
Other	7.6%	22	8.5%	17	6.6%	
Missing						
Education						.022*
12 years or completed high school	48.2%	111	43%	137	53.3%	
College graduate	51.8%	147	57%	120	46.7%	
Missing						
Health insurance						NS
Yes	97.1%	249	96.5%	251	97.7%	
No/Not sure	2.9%	9	3.5%	6	2.3%	
Missing						
Regular provider						NS
Yes	60.8%	161	62.4%	152	59.1%	
No	39.2%	97	37.6%	105	40.9%	
Missing						
Communication with doctor						NS
ASL ^a	63.7%	167	64.7%	161	62.6%	
English ^b	36.3%	91	35.3%	96	37.4%	
Missing						
Comorbidity						NS
No	55.7%	146	56.6%	141	54.9%	
Yes	44.3%	112	43.4%	116	45.1%	
Missing						
Family History of Cancer						7.696*
No	22.4%	45	17.6%	70	27.2%	

	Overall N=515	Engaged N=258		Not Engaged n=257		
	%	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>t</i>
Yes	69.2%	191	74.6%	164	63.8%	
Not sure	8.4%	20	7.8%	23	8.9%	
Missing		2				
Personal History of Cancer						4.281 *
No	82.5%	220	85.9%	203	79%	
Yes	17.5%	36	14.1%	54	21%	
Missing		2				
Have friends or family to talk to about health						5.783 **
Yes	83.7%	226	87.6%	205	79.8%	
No	16.3%	32	12.4%	52	20.2%	
Missing						

^a direct or through an interpreter

^b written or oral

* $p < .05$

** $p < .001$.

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Table 2.

Logistic Regression for Electronic Communication with Healthcare Providers or Staff.

Variable	Log Reg Adj OR	95% CI for Log Reg (Lower)	95% CI for Log Reg (Upper)
Age	1.003	.991	1.016
Race ^a	.786	.504	1.225
Education ^b	1.826**	1.234	2.704
Sex ^c	1.067	.719	1.582
Preferred language ^d	1.596	1.077	2.365
Communication with provider ^e	.976	.651	1.463
Comorbidity ^g	1.648*	1.074	2.528
Regular provider	1.362	.913	2.032
Engagement in health-related social activities on the Internet or SNS	2.805***	1.861	4.229

^aWhite is the reference group^bMale is the reference group^cHigh school degree is the reference group^dSign language is the reference group^eSpoken/Lipreading/Writing is the reference group*
 $P < .05$ **
 $P < .01$ ***
 $P < .001$