

Social Media, Technology Access, and Oncology- Where Do Patients Seek and Share Health Information?: A Survey Study

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Abstract

Social media in healthcare has many benefits, including the dissemination of health information,¹ health promotion, and recruitment of clinical study participants.² The COVID-19 pandemic has highlighted the benefits of the Internet and social media as tools through which individuals can exchange health information. While little is known about oncology patient preferences for social media platforms, particularly among minority populations, some studies have shown its use to be linked to the alleviation of patient stress and loneliness, increased feelings of self-efficacy and control of care, and efficient delivery of health information from health practitioners.³ The aim of this study is to assess cancer patient access to and use of social media platforms and technology. Between March 2021 to June 2021, we administered a 16-item survey adapted from the National Cancer Institute's (NCI) Health Information National Trends Survey (HINTS)⁴ to patients scheduled for a visit in the oncology department at the Outpatient Care Center (OCC) at UI Health. The survey was delivered by e-mail and administered in person. Respondents were asked to identify all sources used to learn about their diagnosis, their preferred information source, social media usage and preferences, and demographics. We used Chi-square to assess associations between categorical variables. This study was approved by the Office for the Protection of Research Subjects (OPRS) at the University of Illinois at Chicago. Demographics of our sample can be found in Table 1. Respondents use several forms of information sources. The top three include: their doctor or healthcare provider (89.3%), Internet search engine (71%), and brochures and pamphlets (40.7%). However, when directed to choose just one source, 67.4% chose their doctor or health care provider, while 21.8% chose Internet search engine. The majority of respondents use a smartphone with Internet (77.2%), a home desktop or laptop with Internet (62.5%), or a tablet with Internet (61.2%). However, approximately one-quarter of respondents indicated that they use a mobile phone without Internet or a data plan.

In exploring social media use and preferences, we found the majority of respondents have a social media platform (64.7%). Having a social media platform was associated with age ($X^2=18.7$, $p<.001$) and sex (Fisher's $p=.001$). The top 5 social media platforms used by respondents include: Facebook (61.9%), YouTube (48.9%), Instagram (28.9%), Snapchat (15.3%), and Twitter (14.6%). While respondents primarily used Facebook (22.5%), YouTube (21.5%), and Instagram (8.1%), to receive health information, few actually share health information with a medical professional (5.5%) and if they did, they primarily use Facebook (48.7%). Understanding how patients exchange health information is important to ensure access to accurate information and promote engagement with the healthcare team. We found that despite having social media platforms, our patient population does not predominantly use it as an avenue to engage with their healthcare providers, but rather to find health related information. Recent trends from the HINTS survey show an increased use of social media to exchange health information with healthcare providers.⁵ As social media engagement is linked to positive patient outcomes, employing social media interventions can help us improve the illness experience of oncology patients. While both cancer care providers and patients are increasingly using social media as a learning and sharing tool⁶, the exact information-seeking behavior of cancer patients has yet to be fully examined. In the current climate where medical misinformation is rampant on the Internet, healthcare workers should find innovative ways to disseminate evidence-based patient facing information utilizing the platforms most accessed by oncology patients. Our study highlights the need to further explore communication preferences to inform the development of tailored communication strategies to support oncology patients and their families.

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Social Media, Technology Access, and Oncology- Where Do Patients Seek and Share Health Information?: A Survey Study

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Introduction

Social media in healthcare has many benefits, including the dissemination of health information[1] and health promotion[2]. The COVID-19 pandemic has highlighted the benefits of the Internet and social media as tools through which individuals can exchange health information. While little is known about oncology patient preferences for social media platforms, particularly among minority populations and those in low SES communities, some studies have shown its use is linked to alleviation of patient stress and loneliness, increased feelings of self-efficacy and control of care, and efficient delivery of health

information from health practitioners[3]. The aim of this study is to assess where patients from marginalized communities receive a majority of their healthcare information by surveying patients in a cancer clinic. This study was conducted at the University of Illinois Chicago (UIC). UIC is a public hospital that mainly serves patients from under-resourced communities.

Methods

Between March 2021 to June 2021, we administered a 16-item survey[Appendix A] adapted from the National Cancer Institute's Health Information National Trends Survey (HINTS)[4] to patients scheduled for an oncology visit at the Outpatient Care Center at UI Health. The survey was administered to 145 patients via email and 161 patients in person. Respondents were asked to identify sources used to self-educate about their diagnosis, their preferred information source, social media usage and preferences, and demographics. We used Chi-square to assess associations between categorical variables.

Ethical Considerations

This study was approved by the Institutional Review Board at UIC and was found to meet the criteria for exemption as defined in the U. S. Department of Health and Human Services Regulations for the Protection of Human Subjects [(45 CFR 46.104(d))].

Results

Demographics of our sample can be found in Table 1. Respondents routinely access several forms of health information sources. The top three include: their doctor or healthcare provider (89.3%), Internet search engine (71%), and brochures and pamphlets (40.7%). However, when directed to choose just one source, 67.4% chose their doctor or health care provider, while 21.8% chose Internet search engine. The majority of respondents use a smartphone with Internet (77.2%), a home desktop or laptop with

Internet (62.5%), or a tablet with Internet (61.2%). However, approximately one-quarter of respondents indicated that they use a mobile phone without Internet or a data plan.

We found the majority of respondents accessed social media in the past year (64.7%). Utilizing social media was associated with age ($X^2=18.7$, $P<.001$) and sex (Fisher's $P=.001$). While respondents primarily used Facebook (22.5%), YouTube (21.5%), and Instagram (8.1%), to receive health information, few share health information with a medical professional (5.5%) and if they did, they primarily use Facebook (48.7%).

Discussion

Understanding how patients exchange health information is important to ensure access to accurate information and promote engagement with the healthcare team. We found that a majority of our patients utilize social media to find health-related information. However, there continues to be an internet access disparity that can limit patients' ability to improve their own health literacy. As social media engagement is linked to positive patient outcomes, employing social media interventions can help us improve oncology patients' illness experience. While both oncology providers and patients are increasingly using social media as a learning and sharing tool[5], the exact information-seeking behavior of cancer patients has yet to be fully examined, especially in disadvantaged populations. In the current climate of rampant online medical misinformation, healthcare workers should find innovative ways to disseminate evidence-based patient-facing information utilizing the platforms most accessed by oncology patients. Our study highlights the need to further explore communication preferences to help develop tailored communication strategies to support underserved patients and their families.

Limitations

Our study has various limitations. This study was a single clinic, single institution study with a relatively small sample size. Additionally, our patient population was older, which could have influenced preferred social media platforms.

Data Availability

The data sets generated during and/or analyzed during this study are available from the corresponding author on reasonable request.

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Table 1. Respondent Demographics

	E-mail N (%) N= 145	In-Person N (%) N=161	Statistic	P-value
Age (mean +/- sd)	60.1 +/-13.4	55.3 +/- 15.2	T(304)=2.9	P=.004
Gender			Fisher's	P=.05
Male	40 (27.6)	48 (29.8)		
Female	105 (72.4)	107 (66.5)		
Not reported	0	6 (3.7)		
Race			Fisher's	P=.26
White	49 (33.8)	50 (31.2)		
Black or African-American	75 (51.7)	85 (52.8)		
Asian	4 (2.8)	6 (3.7)		
Mixed Race or Bi-racial	0	5 (3.1)		
Not reported	17 (11.7)	15 (9.3)		
Ethnicity			Fisher's	P<.001
Hispanic or Latino	18 (12.4)	26 (16.2)		
Not Hispanic or Latino	125 (86.2)	98 (60.9)		
Not reported	2 (1.4)	37 (22.9)		
Primary care			X ² =6.2	P=.10
Has a primary care provider but has not seen them for over a year	19 (13.1)	22 (13.7)		
Has a primary care provider not at UI Health seen in the past year	36 (24.8)	50 (31.1)		
Has a primary care provider at UI Health seen in the past year	84 (57.9)	74 (45.9)		
Does not have a primary care provider	6 (4.1)	15 (9.3)		
Work Status			Fisher's	P=.17
In full-time paid work or full-time education	31 (21.4)	30 (18.6)		
In part-time paid work or part-time education	10 (6.9)	9 (5.6)		
Full-time career/homemaker	3 (2.1)	2 (1.2)		
Unemployed	40 (27.6)	21 (13.0)		
Retired	61 (42.1)	54 (33.5)		
Current living situation			Fisher's	P=.14
Alone	36 (24.8)	46 (28.6)		
With my spouse or partner	56 (38.6)	44 (27.3)		
With my non-adult children	12 (8.3)	12 (7.5)		
With family or friends	40 (27.6)	59 (36.7)		
Homeless	1 (0.7)	0		

Table 1. Respondent Demographics cont.

	E-mail N (%) N= 145	In-Person N (%) N=161	Statistic	P-value
Education			Fisher's	<i>P</i> <.001
Less than high school	5 (3.5)	19 (11.8)		
High school diploma or equivalent	26 (17.9)	48 (29.6)		
Some college but no degree	32 (22.1)	30 (18.6)		
Associate's degree or Trade School	15 (10.3)	23 (14.3)		
Bachelor's degree	37 (25.5)	26 (16.1)		
Graduate degree (Master's, MD, JD, PhD)	30 (20.7)	15 (9.3)		
Annual income			$\chi^2=7.8$	<i>P</i> =.05
<\$15,000	14 (9.7)	31 (19.1)		
<\$15,000 to \$30,000	18 (12.4)	23 (14.2)		
>\$30,000	57 (39.3)	44 (27.2)		
I wish not to answer	56 (38.6)	64 (39.5)		
Comfort with income			$\chi^2=0.55$	<i>P</i> =.91
Living Comfortably on present income	54 (37.2)	56 (35.8)		
Getting by on present income	58 (40.0)	63 (38.9)		
Finding it difficulty on present income	26 (17.9)	32 (19.8)		
Finding it very difficult	7 (4.8)	11 (6.8)		

Supplementary Files

Revised Manuscript with Track Changes.

URL: <http://asset.jmir.pub/assets/46f4a2d8abd561096154e90d278206c2.docx>

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Multimedia Appendixes

Social Media Survey.

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