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The Impact of Misinformation and Health Literacy on HIV Prevention and Service Usage

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Abstract

There are an increasing number of online resources people can use to gain access to information, including for health-related issues, such as for HIV prevention. Trend data show that the way individuals obtain news and information has changed from years past. Health literacy, therefore, is an important skill to ensure adequate understanding of the data available about HIV in the media and online. Unfortunately, the proliferation of misinformation is ubiquitous and may have deleterious effects on individual health behavior, and consequently, the public's health. This commentary focuses on sources of online misinformation as it relates to HIV and how misinformation impacts seeking health services.

Keywords

COVID-19; health seeking behaviors; HIV; pre-exposure prophylaxis; social media

The digital age has ushered in unprecedented access to massive amounts of information, bringing significant changes to the way the public consumes information, as well as challenges in response to these changes. According to the Pew Research Center, one consequence of the explosion of the digital era was the propagation and spread of misinformation, from COVID-19 to politics (Mitchell et al., 2020). The rise of social media in disseminating information has led to curated content that may not have the same journalistic standard as traditional media and therefore can spread inaccurate, false, malicious information, or propaganda. According to UNESCO (2018), misinformation is information that is misleading but not created with mal intent. This is altogether

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All authors on this paper meet the four criteria for authorship as identified by the International Committee of Medical Journal Editors (ICMJE); all authors have contributed to the conception and design of the study, drafted or have been involved in revising this manuscript, reviewed the final version of this manuscript before submission, and agree to be accountable for all aspects of the work. The specific contributions of each author is as follows: Conceptualization: Garrett, Young; Funding acquisition: Young; Writing – Garrett, Young.

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different than disinformation, which is false information created to purposefully create harm. Misinformation regarding COVID-19 was prevalent and appeared in various forms of media. The majority of misinformation about COVID-19 appeared on social media (88%), followed by television (9%), news outlets (8%), and other websites (7%) (Brennen et al., 2020). Often times, facts were misconstrued (59%) instead of fabricated (38%). Consequently, exposure to misinformation led to a reduced perception of needing additional information, which leads to information avoidance and heuristic processing and less systematic processing of COVID-19 information (Kim et al., 2020). Despite its ubiquity, only about 30% of Americans have expressed confidence in their ability to check the accuracy of information regarding COVID-19 (Gottfried, 2020). Misinformation regarding the United States presidential election was similarly widespread.

This commentary will focus on the impact of misinformation on the use of HIV services, including misinformation related to the safety, efficacy, and use of pre-exposure prophylaxis (PrEP); use of supplements; and HIV-related stigma. Those at risk for or living with HIV may be susceptible to misinformation for a variety of reasons. For instance, one study examined the perception of individuals living with HIV with limited income resources and history of substance use about their health seeking behavior online (Nokes et al., 2018). Findings showed that study participants had low electronic health literacy and, though they were interested in seeking information online, low confidence in their ability to distinguish a credible source, with some preferring to speak with health providers instead.

Misinformation and stigma continue to marginalize vulnerable populations, which may lead to negative health outcomes. For example, among Black men who have sex with men, perceived stigma was expressed as a barrier to PrEP uptake, along with medical mistrust and concerns about medication side effects (Cahill et al., 2017). In 2018, 21% of all new HIV diagnosis were among youth, with 92% among young gay and bisexual men (Centers for Disease Control and Prevention, 2020). A survey of millennials and Generation Z found that stigma surrounding HIV impacted the emotional, mental, and sexual health among those living with HIV (Salman et al., 2016). Misinformation about treatment adherence was also high in this group with a third believing that medication can be ceased if they feel better.

Sources of Misinformation and Its Influence

News

The way society consumes news has drastically changed over the years. As stated by a Pew Research Center report (Stocking et al., 2020), 26% of Americans sought news on YouTube, where both traditional media outlets (i.e., news organization, CNN, Fox News) and independent channels (i.e., no clear affiliation) were viewed. Content analysis from the report showed that channels without clear affiliations covered conspiracy theories more frequently than media outlets. This becomes problematic as access to accurate information is paramount in all forms of decision making, including decision making related to health (Carrieri et al., 2019; Chen et al., 2018). This is especially the case in HIV where medications are available to prevent the transmission of the virus. Although some news outlets provided factual information that was vetted by an editor, there were times when the comments section contained misinformation from readers. For example, a post on a popular

site reported on an experimental HIV vaccine study that contained quotes and information from credible sources such as the National Institute of Allergy and Infectious Diseases and Centers for Disease Control and Prevention (Furr, 2020). However, upon reading further in the comments section, several commenters espoused misinformation. The article had 209 comments and was shared on Facebook 797 times. Though efforts are made by writers and editors to present factual information in published articles, nevertheless, misinformation may spread due to comments on the article that may not have been subject to the same editorial review.

In addition to accessibility of information, recognizing and processing health information also play a role in health behavior, which is an essential component of health literacy (Institute of Medicine, 2004). Unfortunately, the capacity to distinguish accurate information about HIV from misinformation in the news is challenged by limited health literacy. The Pew Research Center (Mitchell et al., 2018) conducted a study about the ability of adults to distinguish between factual and opinion news statements correctly. Findings showed that approximately a quarter of American adults correctly classified factual statements as true (26%) or got most or all of the statements wrong (28%). Similar to the United States, misinformation about HIV and treatment persist in other countries, sometimes with news media and the government contributing to false statements and conspiracy theories, and a portion of the medical community supporting it (Ayres, 2020). In turn, this concerted effort has influenced those at risk in terms of seeking health care and getting screened due to fears of stigma and finding out the results of the test. Mainstream media have also been found to perpetuate stigma about PrEP, which in turn has affected PrEP uptake (Card et al., 2019). Table 1 shows sample text messaging about PrEP across online platforms, from online news media to social media. Aside from headline titles, page content and comments also contained misinformation (data not shown).

Impact of Misinformation from Websites

In addition to news media outlets, misinformation also persists on other websites and can affect HIV-related attitudes and behaviors. Research has indicated that individuals who sought medical information online were apt to change their medical decision (Chen et al., 2018; Yigzaw et al., 2020), and that the credibility of the source of information influenced medical decision making (Chen et al., 2018). For instance, people living with HIV who took supplements had significantly greater use of the internet to seek health and medical information compared to those who did not take supplements, and they also were more likely to believe and trust information about HIV cures that was unfounded (Kalichman et al., 2012). For those with low electronic health literacy, the wherewithal or confidence to differentiate between factual and erroneous messaging may be challenging, resulting in negative health behaviors and outcomes.

Social Media

Health literacy, whether online or off, plays a key role in distinguishing misinformation, especially when false information can spread quickly or go viral. For instance, one study examined young adults exposed to YouTube videos with misinformation about the health effects of tobacco products and found that the videos led to a more positive attitude

about the featured tobacco products (Albarracin et al., 2018). Additionally, consequences of health misinformation obtained on social media can have an impact on health seeking behavior, information knowledge, self-management, and relationships with health care providers (Smaldone et al., 2020). Concerns about health misinformation obtained on social media may negatively impact communication and relationships with health professionals, information knowledge, self-management, and participation/health engagement. The power of social media and its influencers on health, can have a massive influence on people's attitudes and behaviors, including HIV-related behaviors (Young, 2012; Young et al., 2020). A study examining "fake news" found that 40% of the most shared links contained false health information, which was shared more than 450,000 times (Waszak et al., 2018). Facebook advertisements of lawsuits against manufacturers of PrEP claimed that drugs, such as Truvada, caused serious side effects. Despite pleas from LGBTQ advocacy groups that the advertisements presented false medical information and created harm by perpetuating misleading information, Facebook did not remove the advertisements, citing the advertisements did not violate their policy (Romm, 2019). Consequently, these advertisements resulted in a decreased likelihood that those at risk would start PrEP or continue taking PrEP, as well as created doubt about the overall safety of PrEP (Groves et al., 2021). A sexual health charity had a similar experience when they informed Facebook of advertisements promoting herbs that can cure HIV (Rodger, 2020). They requested the platform delete the advertisements due to their potentially harmful effects. Facebook deleted the advertisement from the charity's page but left the advertisements visible on other pages that were frequented by those affected by HIV. Misinformation about HIV on social media stems from misleading advertisements to opinions by users who publish posts and comments. For example, , similar to other platforms, conversations about health topics on Twitter are influenced by current world events that can result in positive, negative, and misinformed tweets (Cai et al., 2020). Efforts to curtail HIV misinformation on social media (Young, 2012) may be implemented which may have potential to mitigate its pervasiveness.

Impact of COVID-19 on Internet Health Information Seeking

The COVID-19 pandemic has impacted daily life in unprecedented ways, including related to HIV services (Young & Schneider, 2020). In-person information seeking through health practitioners has been thwarted due to the pandemic because of less frequent clinic visits for HIV services. Health care consumers who are using virtual visits more and plan on continuing to use them are more likely to share data during a crisis compared to before the pandemic, and also plan to use digital tools to track their health (Betts et al., 2020). Not only are more people relying on others beyond the medical profession for their health information, the information they receive may not be accurate or may be completely false. The pandemic will likely have a long-standing effect on the increased use of online HIV and health services, thus making it important for clinicians, researchers, and policymakers to quickly navigate and identify the large amounts of health misinformation online.

Conclusion

The spread of misinformation can have dire consequence for individuals at risk for HIV or living with HIV. As a precaution, individuals in search of health information online should

take several steps to evaluate the credibility of health information websites. It is equally imperative that health advocates reach out to the public in meaningful ways on digital platforms to provide credible information. Additionally, social media platforms need to monitor their content to minimize misinformation that can pose great harm to public health and safety. Similar to the misinformation posted about COVID-19, social media companies need to tackle inaccurate and false information about HIV. Policymakers also have a role in mitigating the spread of misinformation through actions that would fund educational programs and campaigns to increase health literacy, minimize stigma, and combat harmful myths about HIV, as well as passing legislation to educate online behavior, and minimize misinformation and disinformation.

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Key Considerations

- Misinformation may impact attitudes about HIV prevention and treatment which may influence health behaviors that can potentially affect clinical outcomes
- Clinicians should address health literacy during visits to counter HIV misinformation patients may encounter online
- HIV social media public health campaigns should address misinformation and offer guidance on recognizing credible sources of health information

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Table 1.

Sample Text of Posts About PrEP by Platform.

| Platform | Source | Engagement | Sample text ^a |
|--------------|--|--------------------------|--|
| News | Newspunch.com , February 11, 2016 | 0 comments | <i>(Headline) Big Pharma Knowingly Gave HIV To Thousands Of Children</i> |
| Website | Americasfreedomfighters.com , n.d. ^b | 0 comments 851 shares | <i>(Title) BREAKING: Chicago Hospital EXPERIMENTS On TEENS...Now They Have HIV Forever</i> |
| Social Media | Facebook, May 20, 2014 | 2 likes 5 comments | <i>Well you are a truvada whore but not in the sense this article implies. You're "whoring" yourself to big pharma. You just want to create an environment where everyone is medicated and barebacking. It's so transparent.</i> |
| | Twitter, February 7, 2019 | 1 like 1 comment | <i>PrEP promotes unsafe sex among people at risk. Men who take it are colloquially called "Truvada Whores;" bareback boys without an ounce of decency.</i> |
| | Reddit, March 25, 2016 | 6 comments | <i>Do you want drug resistant strains of HIV - one already exists, a man was infected while on Truvada - because that's how you get them.</i> |

^aQuotes from individuals have been modified to protect individuals from being identified by or linked to this report.

^bn.d.=no date

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