

Selected Papers of #AoIR2020: The 21<sup>st</sup> Annual Conference of the Association of Internet Researchers Virtual Event / 27-31 October 2020

# FROM ONLINE ENGAGEMENT TO OFFLINE ACTIONS: UNDERSTANDING THE IMPACT OF CANCER (MIS)INFORMATION ENGAGEMENT AMONG LATINO FACEBOOK USERS

Yonaira M. Rivera Johns Hopkins Bloomberg School of Public Health

### Introduction

As social media continues to influence multiple facets of daily life, it is important to understand the role of these platforms in the uptake of prevention and screening behaviors among communities with high cancer burden.<sup>1</sup> In the U.S., Latinos experience high incidence rates for screenable cancers linked to preventable behaviors (breast, prostate, colorectal).<sup>2</sup> Given that U.S. Latinos are avid Facebook users,<sup>3</sup> this platform is an opportune tool to deliver evidence-based cancer prevention and screening information (CPSI) as a way to reduce cancer health disparities. However, there is a dearth in scholarship exploring how Latinos engage with and act upon cancer (mis)information encountered on social media, which is increasingly inundated with potentially detrimental health misinformation.<sup>4</sup> The Social Media Engagement Model<sup>5</sup> posits that engagement is influenced by multiple individual and contextual factors. For Latinos, these include cultural values (i.e. *familismo, personalismo, fatalismo*)<sup>6,7</sup> that may influence how they engage with multi-lingual CPSI shared by close friends and family on Facebook. Cultural values may also influence assessments of cancer information<sup>8</sup> and whether Latinos participate in cancer control and prevention efforts.<sup>9</sup>

This exploratory study sought to understand how and why U.S. Latinos engage with and act upon CPSI on Facebook. This topic is in clear alignment with the conference's theme, Life, and provides important insights on how information consumed through social media has the ability to impact decision making, health outcomes, and life offline.

Suggested Citation (APA): Rivera, Y. (2020, October). *From Online Engagement to Offline Actions: Understanding the Impact of Cancer (Mis)Information Engagement Among Latino Facebook Users*. Paper presented at AoIR 2020: The 21<sup>th</sup> Annual Conference of the Association of Internet Researchers. Virtual Event: AoIR. Retrieved from http://spir.aoir.org.

## Methods

A novel gualitatively-driven, mixed-methods approach was developed to elicit audio and screen data concurrently during one-on-one in-person encounters where participants accessed their social media profile, scrolled-through relevant content, and contextualized content engagement with the researcher.<sup>10</sup> During one-on-one, in-depth interviews (~2hr), participants (n=20) logged onto their Facebook account alongside the researcher, typed "cancer" in the search bar, and discussed cancer-related posts they engaged with during the past 12 months (sorted by "Most Recent" and posted by "Your Friends and Groups"). Engagement with CPSI (i.e. liking/commenting/sharing; clicking a link; reading an article; and/or watching a video) prompted questions regarding the reasons for engagement with the source of the post and/or post content, and if/how engagement triggered further action. When applicable, embedded videos/links were viewed and discussed. Computer screen and audio were recorded during the encounter. De-identified CPSI posts were analyzed via content analysis; posts were coded for message factors (i.e., post type, cancer topic, language, visual elements) and source factors (i.e., post source, Facebook poster) (kappa=0.89-1.0). A thematic analysis was conducted on interview transcripts to capture why participants engaged with CPSI and any subsequent actions.

### Results

Overall, 16 participants reported engaging with 66 posts containing CPSI in the previous 12 months (4.1 average posts). Participants mainly engaged with CPSI content by viewing/reading content (73%, n=48), rather than by liking/commenting/sharing (27%, n=18). Engagement was most common with prevention posts (76%, n=50), when posts included videos/images (91%, n=60), and when individuals had personal relationships to those posting information (72%, n=47). The majority of cancer prevention posts participants engaged with were about food/diet (53% or n=35).

Emerging themes specific to engagement with food/diet posts included a general interest in prevention/healthy eating, other salient chronic conditions, and sociopolitical issues. Additional reasons for engaging with any CPSI included personal experiences related to cancer, professional context, and curiosity. Regardless of the content, posts in Spanish and those with images/videos of cultural relevance and sensationalist titles consistently elicited more engagement. Interviews also revealed that a post's source oftentimes contributed to engagement due to perceived topic expertise or authority, the role of trust in interpersonal relationships, and alignment with cultural identity. Furthermore, there were multiple occasions where the source was the most important reason for engagement. Reasons for engagement with a particular post were not mutually exclusive.

Engagement often led to varying levels of action. Online actions included informationseeking or sharing on other platforms (e.g., WhatsApp). Offline actions included discussing content with family members or changing health behaviors. However, not all decisions were evidence-based (e.g., consuming popular "cancer-curing" foods) and some were potentially harmful (e.g., canceling mammogram after engaging with misinformation from a culturally-relevant source).

#### Implications

Findings illuminate the salient role that cultural values and other cultural connectors (e.g., language and country of origin) play in how message factors and source factors influence engagement with CPSI among Latinos. Consistent with literature highlighting the importance of tailoring content to Latino populations,<sup>8,9</sup> participants oftentimes engaged with visually appealing posts that contained features that provided connections to cultural identity. However, rarely did these posts come from verifiable health organizations. Rather, most engaged with CPSI from potentially unreliable sources that contained sensationalist titles and claimed cancer cures linked to foods popular in Latin American countries; these posts were mainly shared by Facebook friends. Importantly, participants discussed the relevance of the offline relationships they shared with these individuals, which many times contributed to why they engaged with CPSI. Personalismo and familismo are strong cultural values that tie notions of trust to core interpersonal and familial relationships in the Latino community;<sup>6</sup> the presence of these values appeared to reinforce messages being shared and consumed on social media, regardless of their accuracy. Cultural values also appeared to have an impact on how some Latinos chose to act upon CPSI: several participants reported discussing CPSI with other family members offline, while others discussed ways in which fatalistic view of cancer acted as a barrier to cancer control and prevention efforts.<sup>7,9</sup>

Findings highlight the complex and interrelated ways in which cultural values, source factors and message factors contribute to engagement with health content on social media. They also provide important insights to how social media can both promote or hinder health outcomes, at times leading individuals to bypass evidence-based procedures. These are important contributions for current debates on how to best curtail the effects of health misinformation on social media platforms. Specific interdisciplinary recommendations to address these issues include developing interventions to counteract/correct misinformation, improving digital health literacy, and establishing transnational, interdisciplinary research collaborations.

#### References

- 1. Chou WYS, Oh A, Klein WM. Addressing health-related misinformation on social media. *JAMA*. 2018;320(23):2417-2418.
- 2. American Cancer Society. Cancer Facts & Figures for Hispanics/Latinos 2018-2020. Atlanta: American Cancer Society;2018.
- 3. Smith A, Anderson M. Social media use in 2018. Pew Research Center. <u>https://www.pewinternet.org/2018/03/01/social-media-use-in-2018/</u>. Published 2018.
- 4. Teoh, F. The most popular health articles of 2018, a scientific credibility review. Health Feedback. <u>https://healthfeedback.org/the-most-popular-health-articles-of-2018-a-scientific-credibility-review/.</u> Published 2019.

- 5. McCay-Peet L, Quan-Haase A. A model of social media engagement: User profiles, gratifications, and experiences. In O'Brien H, Lalmas M, eds. *Why Engagement Matters.* Heidelberg: Springer;2016:199-217.
- 6. Ayon C, Aisenberg E. Negotiating cultural values and expectations within the public child welfare system: A look at familismo and personalismo. *Child Fam Soc Work*. 2010;*15*(3):335-344.
- 7. Yañez B, McGinty HL, Buitrago D, Ramirez AG, Penedo FJ, et al. Cancer outcomes in Hispanics/Latinos in the United States: An integrative review and conceptual model of determinants of health. *J Lat Psychol*. 2016;4(2):114.
- Murphy ST, Frank LB, Chatterjee JS, Moran MB, Zhao N, Amezola de Herrera P, Baezconde-Garbanati LA. Comparing the Relative Efficacy of Narrative vs Nonnarrative Health Messages in Reducing Health Disparities Using a Randomized Trial. *AJPH*. 2015;105(10):2117-2123.
- 9. Erwin DO, Treviño M, Saad-Harfouche FG, Rodriguez EM, Gage E, Jandorf L. Contextualizing diversity and culture within cancer control interventions for Latinas: changing interventions, not cultures. *Soc Sci Med*. 2010;71(4):693-701.
- 10. Rivera YM, Moran MB, Smith K. (2019, July). Beneath the tip of the iceberg: A qualitative approach to capturing engagement with cancer information on Facebook. Oral presentation at the International Association of Media and Communication Research 2019 Annual Conference: Communication, Technology and Human Dignity: Disputed Rights, Contested Truths. Madrid, Spain.