UNDERSTANDING THE DIGITAL HEALTH KNOWLEDGE ECOSYSTEM: ANALYZING THE MARKETING AND COMMUNICATION PRACTICES OF PATIENT INFLUENCERS, PHARMACEUTICAL AND TELEHEALTH COMPANIES

Milana Leskovac
Queen's University, Canada

Introduction

In the past several years, the so-called 'miracle drugs' Ozempic and Wegovy—initially developed for managing type-2 diabetes and weight-loss, respectively—gained significant attention on social media, leading to a widespread shortage in 2022 (Han et al. 2024; Mahase 2024; Suran 2023). This shortage was driven via social media by influencers and prominent figures who promoted using these drugs primarily for weight loss, rather than their intended medical purposes of treating diabetes and obesity (Shmerling 2023). This trend quickly morphed the medications from disease/illness solutions to 'lifestyle' drugs. As a result, people who genuinely required Ozempic for managing type-2 diabetes were affected by the shortage (Han et al. 2024). This shortage also prompted many concerns among academics and the media regarding off-label prescriptions, use without proper consultation, new compounding pharmacy formulations, the adverse side-effects of overuse, etc. (Billingsley and Woodcock 2024; Han et al. 2024).

Within this context, new entanglements are emerging among actors with conflicting interests—including patient influencers, telehealth and pharmaceutical companies—who play a role in constructing narratives around medications and their use, and health more broadly. These actors are involved in the assembly of health knowledge through product promotion and social media communication raising crucial issues of how trust is multiply mediated and health/medical knowledge is constructed and distributed. This paper investigates the roles of different creators (influencers and companies), specifically focusing on how they communicate and the types of content that gain online attention to better understand how they shape cultural trends, like the virality of medications, but more importantly, how they contribute to our knowledge around health and medicine.

The Actors

Social media influencers employ unique strategies of self-branding to create and maintain a credible, reliable, and authentic persona for their followers (Maares et al. 2019; Leaver et al. 2020). This work of self-branding results in user trust of influencer content (Scolere et al. 2018), making their own brand and authenticity prime tools that other company brands (such as pharmaceutical and telehealth companies) can then leverage to help promote their products on social media (Stoldt et al. 2019). Patient influencers are a specific type of influencer, compared to the commonly studied fashion, food, travel, and beauty influencers (Maares et al. 2019), as they face stricter marketing regulations, must balance sharing personal experiences with sharing the latest science, and often have stronger emotional connections with their followers (Willis et al. 2023).

Pharmaceutical companies, who have long struggled with brand reputation, have begun leveraging influencers' online presence, accessing their 'very specific audiences that may be primed for health messaging' (Willis and Delbaere 2022). In doing so, they mediate public trust, increasing the 'invisible hands' (Sismondo 2018) through which they shape the political economies of medical knowledge. Finally, along with prescribing and distributing medications, telehealth companies engage in social media marketing *and* have been known to partner with influencers to promote pharmaceutical products (Castronuovo 2023). However, currently the extent to the involvement and influence of these actors is unknown. To this end, the differences in the information and knowledge distributed through these marketing strategies by the above-mentioned actors as well as the extent of commercial influence concerning sponsored/non-sponsored videos, company/influencer videos, etc. remains unclear. Examining these uncertainties is crucial for developing a comprehensive understanding of the formation and dynamics of the ecosystem of health/medical knowledge online.

Theoretical Framework & Methods

In this paper, I employ two theoretical approaches to analyze this issue. First, STS frameworks enable an understanding of the roles that institutions (such as pharmaceutical companies) play in constructing knowledge through social practices (such as social media marketing) (Jasanoff 2004). These frameworks are mobilized to examine how digital media today, and its' actors, influence the production, circulation and distribution of knowledge, focusing on key concepts such as expertise, trust, epistemic democratization and competition, 'civic epistemologies', etc. (Law 1992; Latour 1999; Marres 2018; Jasanoff 2022). Second, digital media, through their materiality and omnipresence, mediate the construction of knowledge in ways that are both embodied and relational, therefore, theories of digital mediatization are utilized here as well. The focus here is on how digital media increasingly shapes social life, utilizing the concept of *entanglements* (adapted from Barad 1996) which theorizes the increasingly complex ways that people and data are interwoven, and how meaning and knowledge become established in mediated domains (Hepp and Couldry 2023). This interdisciplinary framework enables an understanding of how the complex web of pharmaceutical marketing actors contributes to the construction of health and medical knowledge online.

This paper presents preliminary findings from the first of three phases of my ongoing doctoral research. The first phase has been designed to contextualize and investigate this topic, employing a content analysis of patient influencer Instagram and TikTok videos to understand what they post and how this varies. The primary focus here is to uncover what is communicated in videos and by whom. For example, researchers have noted differences in branded and unbranded (or 'help seeking') advertising campaigns, the latter of which 'focuses on disease and health education as well as medication compliance' (Rollins et al. 2011). Notably, direct-to-consumer marketing is only legal in the United States and New Zealand (Mor et al. 2024; Leonardo Alves et al. 2017); however, unbranded 'awareness campaigns' are used to circumvent this marketing barrier, as it is a grey area in pharmaceutical regulation (Leonardo Alves et al. 2017: 4). In addition, 'reminder ads' and 'help seeking ads' are permitted, for example in Canada (Government of Canada 2020), therefore increasing the ways in which pharmaceutical marketing can enter our everyday social media use.

By investigating these approaches and their differences, I uncover some of the ways in which different actors mobilize their expertise, credibility, and authenticity (to differing degrees), to produce and circulate health/medical knowledge. These findings focus on *what is communicated* (health/medical knowledge)*, by whom* (patient influencers, and telehealth and pharmaceutical companies by way of sponsorship)*, and *how* (i.e., through branded marketing or unbranded awareness campaigns). Revealing differences between health communication among these actors contributes to prior research on public health knowledge and science communication (Willis et al. 2023) online, focusing on expertise (i.e., *practical patient knowledge* (Pols 2014)), trust, assembly and source of knowledge. Additionally, it reveals what role other actors—for example, social media management agencies (SMMAs) and social media platforms—may play in this knowledge ecosystem.

Ultimately, the ecosystem of health and medical knowledge online is uniquely assembled due to factors such as strict governmental and social media regulations—many of which are not always followed (Klara et al. 2018), for a variety of reasons—as well as its significant impact on people's behaviour and well-being. This complexity highlights the distinctive challenges within this domain, but also provides a valuable framework for understanding broader knowledge and information ecosystems online, offering insights that may extend to other forms of knowledge as well.

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