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The role of misinformation and stigma in opioid treatment uptake

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Abstract

Deaths due to opioid overdose continue to rise in the United States. Despite availability of effective treatment for opioid use disorder, uptake is low among those who misuse opioids. This paper explores the role of misconception, stigma, and misinformation in influencing decisions to initiate medications for opioid use disorder among patients and providers. Misinformation about opioids has been prevalent among future healthcare providers and first responders as well as pharmaceutical companies, which may have implications for treatment. Among individuals with opioid use disorder, treatment uptake and adherence have been negatively affected by misconceptions about treatment efficacy and side effects, as well as stigma. We discuss the role of social media, education, and the community, in mitigating misinformation and addressing misconceptions about opioids and treatment options.

Keywords

misconception; misinformation; opioid use disorder; stigma; treatment

Background

The opioid crisis that plagues the United States has affected thousands of lives. Deaths due to overdose of opioids (prescription and illicit) increased six-fold since 1999, with nearly 70,000 deaths in 2020 (Baumgartner & Radley, 2021). Treatment options for opioid misuse and opioid use disorder (OUD) include methadone, buprenorphine, and extended-release naltrexone (XR-NX). Although proven effective, both prescription and uptake of treatment are low due to a variety of reasons including stigma; lack of access (Scorsone et al., 2020),

financial, geographic, and logistical barriers (Sharma et al., 2017); misconceptions, such as medications for treatment being a substitute of one drug for another (Scorsone et al., 2020; Volkow & McLellan, 2016); as well as other misinformation surrounding opioid misuse and treatment options.

This viewpoint will examine misconceptions about opioids and treatment options, the role that misinformation plays in perpetuating inaccurate information to the greater public and subsequent misconceptions about opioids, and future directions for combating misinformation.

A background history on misconceptions and perspectives about opioid use and treatment

The combination of various factors, including different waves of the opioid epidemic (i.e., from a first phase of prescription opioid use and misuse, to heroin use, to fentanyl use), and patient and provider misconceptions about opioid use and medications for opioid use disorder (MOUD), have contributed to low rates of MOUD use and misinformation about MOUD. The role of pharmaceutical companies in spreading misinformation about the addiction potential of opioids contributed to the initial rise in the first phase of prescribing opioids for pain management (Ayoo et al., 2020). This had long-lasting negative consequences that persisted beyond misuse of and addiction to prescription opioids, and which predated high rates of overdose due to heroin and synthetic opioids such as fentanyl. As providers and patients began to see the real harms of opioid use, including medical and legal consequences, there was a sudden reduction in opioid prescribing among providers (Ayoo et al., 2020; Bohnert et al., 2018; Suffoletto et al., 2018). This in turn, led to patients seeking opioids through other means, leading to the current state of the opioid crisis (Ayoo et al., 2020).

Provider knowledge and attitudes about treatment

Stigma by health professionals towards patients with OUD is prevalent. Investigators have found that negative attitudes about patients with substance use disorders, including opioid use, has resulted in strained patient-provider collaborative relationships, shorter visits, and a task-oriented approach to treatment (van Boekel et al., 2013). Furthermore, many physicians have become more reluctant to prescribe opioids, especially when there are stricter rules for prescribing opioids (Owens, 2019). Aside from the now known harms of opioid use, such as addiction and death, physicians may also worry about being fined or losing their license for "over-prescribing." There are also administrative burdens to prescribing opioids including needing a waiver, however, much of these administrative burdens have been lessening as the waiver process becomes less cumbersome. Studies examining knowledge and attitudes of future providers also show that misinformation has been prevalent among incoming medical and pharmacy students (Moses et al., 2020). Relatedly, incoming pharmacy students have expressed mixed attitudes and knowledge about the role of naloxone on treating an overdose (Mahon et al., 2018). For example, Moses et al, 2020 found that approximately half of the students thought that naloxone distribution should be unrestricted, but many were uncertain whether naloxone receipt would deter individuals from seeking treatment or increase opioid

use. Without being able to study research on the effect of naloxone on treatment seeking, there is a risk that providers carry and spread misinformation about naloxone.

Patient perception about MOUD

Misconceptions about MOUD, such as myths about the negative health effects of methadone and that it is a "life sentence," have created barriers to seeking treatment for patients (Cioe et al., 2020). For example, many patients believe that methadone will rot your teeth or make you gain weight (Velasquez et al., 2019). Misconceptions like these may reduce patients' willingness to try the medications. Those already on methadone, especially patients with other comorbidities, may stop treatment because they believe methadone is the cause of their weight gain or dental problems.

Importantly, MOUD misconceptions are not limited to methadone. Interview data from persons who misused opioids revealed inaccurate beliefs about buprenorphine such as its potency over heroin or other opioids that rendered it more difficult to taper off compared to other opioids. Additionally, peer networks have strong potential to spread accurate or false information, as individuals are increasingly likely to shape their attitudes and behaviors around their peers and others in the social networks (Evans et al., 2020; Young et al., 2018, 2020; Young & Heinzerling, 2017). However, misinformation among peer networks about buprenorphine have perpetuated stigma which prevented people from maintaining long-term treatment (Allen & Harocopos, 2016). In an unpublished study (under review), our team found that individuals with OUD would rather receive OUD-related information from their peers than from a health provider. Although still unpublished, this highlights the potential importance of ensuring influential peers have accurate information about opioids and treatment to reduce the spread of misinformation.

The potential role of media and social media in spreading opioid misinformation

Health-related misinformation on social media spans various conditions and behaviors, from infectious diseases to cancer to smoking (Wang et al., 2019). One type of opioid-related misinformation that has spread on social media relates to the overdose risk of casual fentanyl dermal exposure. One study found that reports from mainstream media about the health risk of casual contact with fentanyl went "viral" on social media and was shared hundreds of thousands of times (Beletsky et al., 2020) despite expert findings that risks were low (American College of Medical Toxicology & American Academy of Clinical Toxicology, 2017) . Consequently, some emergency responders believed that they would overdose through dermal exposure to fentanyl and expressed concern for their safety as they attended to cases of fentanyl overdose (Winograd et al., 2020). The fear of workplace injury is a valid threat for first responders who deal with substance use emergencies. However, fentanyl panic, for which no evidence exists and have been debunked by clinicians, may cause further stigmatization of individuals who misuse opioids and potentially delay assistance and treatment to those in precarious situations.

Effects of misconception and misinformation on stigma

Misinformation, which further perpetuates stigma, can negatively impact treatment-prescribing among providers and treatment-seeking among patients. There are several main types of stigma that may hinder patients from receiving appropriate care (Table 1). One type is structural stigma, which includes administrative barriers that prevent easy prescribing of MOUD, however, these are getting less burdensome for providers with recent changes. These barriers may stigmatize patients by making it burdensome to provide treatment to them (Atkins et al., 2020; Sokolow, 2020).

Another type is public stigma, including stigmatized perceptions of people who use opioids as being "drug addicts."Public stigma may lead to discrimination by the public, health care providers, and family and friends (Tsai et al., 2019). Self-stigma, another type of stigma, can occur when patients devalue themselves because of their addiction. This can lead to feelings of guilt and other psychological distress, as well as disengagement from treatment (Bozinoff et al., 2018; Tsai et al., 2019). Finally, there is stigma towards the treatment medications themselves. For example, patients may think that medications are ineffective or more harmful, which can stigmatized the medications themselves (Tsai et al., 2019). All this stigma taken together, perpetuated by misinformation and misconceptions, may further the cycle of stigma and reduce treatment initiation and sustainment.

Challenges and future directions

Although misinformation on social media can help perpetuate stigma and misconceptions, social media can also be a helpful source of information for individuals who misuse opioids, their family, and friends. Several studies mining social media content, posts, and comments found that users shared opioid resources and personal experiences on various platforms. A study of YouTube videos found that most videos were from credible sources such as news media or health professionals, followed by consumers (Johnson et al., 2019; Kernan et al., 2020). Similarly, Reddit posts were typically from users linked to reliable resources (Park & Conway, 2018) who contributed their first-hand experience with MOUD and alternatives (Chancellor et al., 2019).

One way for health professionals to combat opioid misinformation on social media is to engage with the public on social media(Garett & Young, In Press). Health professionals and medical scientist are experts and considered trustworthy sources of information by the public (Swire-Thompson & Lazer, 2020). They may therefore play an integral role in combating misinformation online. Additionally, they can help to correct posts and comments to address misinformation in public forums. One important area of future research and potential intervention to address is further exploring whether patients would prefer to receive information from scientists and health providers versus peers and others who post information online. These research questions have important implications for combating misinformation, improving patient-provider communication, and increasing treatment acceptance.

As more health consumers obtain information online (National Cancer Institute, 2019), increased literacy to discern between factual and misleading information would assist in making educated decisions about one's health (Garett & Young, 2021). One study found that low-income people living with HIV had low confidence in distinguishing credible sources online (Nokes et al., 2018). The ability to detect misinformation can be crucial when making choices that can impact quality of life, withdrawal symptoms, and treatment options. It can also correct inaccurately held opinions by providers and emergency responders who provide treatment and may curtail any bias or stigma.

Online health literacy is a complex process requiring trust and good communication. Partnering with fact-checking organizations and technology companies might help to reduce the spread of misinformation. Small companies/startups exploring these approaches will be limited by the expertise available to them, allowing them to benefit from health professionals who could work with them (Swire-Thompson & Lazer, 2020; Wojtowicz, 2020). Public health campaigns would benefit from being more tailored and focused in their outreach attempts to their target audience (Wojtowicz, 2020). Some audiences, for example, may be part of online information silos where they only receive information from their social networks; finding ways to break through those siloes and reach these audiences will be essential. Finally, campaigns that help teach critical thinking or online health literacy can be useful for both patients and providers (Swire-Thompson & Lazer, 2020; Wojtowicz, 2020)

Outside of the online environment, building a trusting and collaborative relationship between patients and providers is essential. More education for providers could be given at schools and during training years. Patients might have opportunities for education at clinics and public spaces in the community, such as libraries. Online advertisements might be used to help inform patients about treatments and other health promotion areas (Garett et al., n.d.). New treatment alternatives, such as XR-NX may help to reduce stigma and increase uptake, and the process for prescribing these treatments is becoming easier for providers. Besides the FDA-approved treatments for OUD, the provision of life saving medication such as naloxone to prevent fatal overdose may also rely on providers knowing and understanding the effects of naloxone and distributing them to patients in the emergency department, pharmacy, clinics, or public settings. Finally, education for the general public, again in public areas like libraries, can help build support for treatment programs. Taken together, these education and community initiatives can help combat misinformation and start to break down stigma.

Conclusion

Opioid-related misconception and misinformation is a complex problem. The deeply-held inaccurate and false beliefs by both patients and providers can lead to stigma and serve as barriers to receiving appropriate treatment. Building trust among providers, patients, and community members will be important in destigmatizing opioid use disorder treatment. Engagement by providers online and increasing electronic health literacy by patients may diminish the spread of misinformation. Education and community initiatives can also help normalize treatment of opioid use disorder.

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Table 1.

Types of Stigma

Type of Stigma	Examples	Consequences
Structural Stigma	Administrative burdens and other barriers to prescribing like needing a waiver	Patients with substance use disorder can become stigmatized as they are seen as burdensome. It can also lead to a lack of providers being willing to provide treatment.
Public Stigma	Seeing patients as drug seekers or the public believing opioid users are the cause of their problems	Isolates those who have opioid use disorder and leads to discrimination and lack of support for treatment programs. Patients may be less likely to start or continue treatment.
Self-stigma	Feeling guilty about using medications and perceiving one's self has a moral weakness	Reduced engagement with care. Psychological distress and poorer health outcomes.
Stigma to Treatment Medications	Belief that treatment is ineffective or that medications will cause more harm than good.	Patients are hesitant to start treatment or continue treatment.