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# Self-Management of Buprenorphine/Naloxone Among Online Discussion Board Users

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# Abstract

**Background**—Buprenorphine/naloxone is an effective medication used to treat opioid dependence. Patients in treatment and those using it illegally without prescriptions have discussed using buprenorphine/naloxone anonymously on Internet discussion boards. Their beliefs about self-treatment and efforts to self-treat are not well known.

**Objectives**—To identify facilitators of self-treatment by online buprenorphine/naloxone users.

**Methods**—A qualitative, retrospective study of discussion board postings from September 2010 to November 2012 analyzed 121 threads from 13 discussion boards using grounded theory.

**Results**—Facilitators of self-management themes that emerged included: (1) a ready supply of buprenorphine/naloxone from a variety of sources; (2) distrust of buprenorphine prescribers and pharmaceutical companies; (3) the declaration that buprenorphine/naloxone is a "bad-tasting" medicine; (4) the desire to adopt a different delivery method other than sublingually; and (5) a desire to become completely "substance-free." The sublingual film formulation appears to be an important facilitator in self-treatment because it can more easily be apportioned to extend the medication because of limited supply, cost, or to taper.

**Conclusions/Importance**—The findings indicate a range of self-management activities ranging from altering the amount taken to modifying the physical medication composition or changing the administration route; some of these behaviors constitute problematic extra-medical use. Contributors to discussion boards seem to trust each other more than they trust pharmacists and prescribing physicians. The shared knowledge and behaviors of this understudied online community are important to healthcare providers because of the previously unknown precautions and risks taken to self-treat.

#### Keywords

buprenorphine; naloxone; self-treatment; diversion; Internet; discussion board

#### **Declaration of Interest**

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# INTRODUCTION

Not enough is known about patients' desires and strategies to self-treat their opioid dependence and treatment preferences about buprenorphine/naloxone are not well understood (Daulouede et al., 2010). This study elaborates on the self-treatment for chronic illness strategies described by Morden, Jinks, & Ong, et al., (2012); the authors advocate for a more holistic understanding of self-treatment since patients use information to calculate their personal risk of harm in order to self-treat. Concerns about trust in the patient–provider relationship (Altice, Mostashari, & Friedland, 2001; Ostertag, Wright, Broadhead, & Altice, 2006, Miller, 2007), especially about a medication that could be abused,<sup>1</sup> may motivate individuals with opioid dependence to take matters into their own hands and adjust their regimens. Individuals who self-treat may not broach the topic with medical providers (if they have them), but Internet discussion boards provide opportunities to join virtual communities in an anonymous, supportive environment where they describe their self-treatment strategies and reasons for experimentation with their medications. This study uses online discussion boards about buprenorphine to illustrate values shared by this online group in their efforts to assert their autonomy regarding taking medications.

Buprenorphine, a partial opioid agonist and antagonist, is a medication used to treat opioid dependence and has similar outcomes to other effective opioid replacement therapies such as methadone (Amato et al., 2005; Mattick, Kimber, Breen, & Davoli, 2008). Compared to methadone, however, it has a markedly safer profile (Dasgupta et al., 2010), thereby allowing authorized physicians in the U.S. to prescribe it in primary care settings rather than in structured substance user treatment settings (Haddad, Zelenev, & Altice, 2013). As treatment with buprenorphine creates opportunities for more patient-centered care through home-based inductions (Sohler et al., 2010; Cunningham et al., 2011), patients' satisfaction with their treatment outcomes (Egan et al., 2011) paves the way for increased patient autonomy and attempts to self-treat their opioid dependence.

Prescription drug abuse is a growing problem in the United States (Bell, 2010). Since the U.S. Food and Drug Administration's approval of buprenorphine for treating opioid dependence in 2002, there have been concerns about buprenorphine diversion and abuse and recent reports of accidental ingestion by children (Stimmel, 2011). Increasing numbers of individuals testing positive for buprenorphine and other substances (Daniulaityte, Falck, & Carlson, 2012a) have heightened concerns, including suggestions of a growing epidemic of buprenorphine misuse (Wish et al., 2012). As a pharmaceutical strategy to prevent tampering and discourage misuse, buprenorphine in the United States was co-formulated with naloxone, a complex opioid receptor antagonist. If injected, the naloxone in the co-formulated medication, known by its brand name Suboxone<sup>®</sup>, becomes activated and induces withdrawal symptoms by overriding buprenorphine's opioid agonist effects (Stanos, Bruckenthal, & Barkin, 2012). The co-formulation of the two medications has been heralded as a serious improvement in the treatment of opioid dependence, especially as a medication

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<sup>&</sup>lt;sup>1</sup>The journal's style utilizes the category *substance abuse* as a diagnostic category. Substances are used or misused; living organisms are and can be *abused*. Editor's note.

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that can be combined with other harm reduction strategies (Altice et al., 2006; Maremmani, 2008). Newer formulations of buprenorphine include a dissolvable film (Strain, Harrison, & Bigelow, 2011) and an implantable slow-release delivery system (Ling et al., 2010). Compared to the tablet formulation, the film would be impossible to crush, reconstitute, and inject (Stanos et al., 2012). The sublingual film's unit dose packaging also addressed the increased potential for childhood exposure with the sublingual tablet (Strain et al., 2011). On September 18, 2012, the pharmaceutical manufacturer of Suboxone<sup>®</sup> in the United States announced that it would discontinue the sublingual tablet and only distribute sublingual film, which resulted in considerable online discussion among individuals who use this medication, including what this change might mean for treatment and self-treatment.

The addition of naloxone to buprenorphine has reduced, but not eliminated diversion (Vicknasingam, Mazlan, Schottenfeld, & Chawarski, 2010), but not all extramedical buprenorphine use is intended to divert the medication. When opioid-dependent persons do not have legal access to buprenorphine through a licensed physician, they may obtain it illegally but use it in ways that are consistent with treatment (Bazazi, Yokell, Fu, Rich, & Zaller, 2011). A study of opioid-dependent treatment seekers found that illicit use of buprenorphine is associated with a desire for self-treatment of opioid dependence, pain, and depression, rather than a desire to achieve euphoria (Schuman-Olivier et al., 2010). These findings are consistent with another study of buprenorphine injectors, which found that nearly 50% of participants had injected buprenorphine, but only a minority (12.67%) did so to experience euphoria. The majority, however, had self-treatment of their dependence as their goal (Moratti, Kashanpour, Lombardelli, & Maisto, 2010) and injection was associated with younger age groups. Thus, the motivations for taking buprenorphine may differ from motivations to take illegal drugs.

Many of patients' conversations about self-treatment happen between themselves as online discussions (Boyer, Babu, Macalino & Compton, 2007) apart from the traditional medical system. Discussion boards are an important space where individuals with common experiences contribute and learn, share advice and create virtual communities based on their affinity; contributors ("authors") can anonymously share intimate details about their lives in a public space and use the Internet as a resource for healthcare information (Baker, Wagner, Singer, & Bundorf, 2003). Discussion boards have been shown to be important sources of social support and perceived empathy (Nambisan, 2011) for people with specific illnesses such as cancer (Schultz, Stava, Beck, & Vassilopoulou-Sellin, 2003; Kenen, Shapiro, Friedman, & Coyne, 2007), breast cancer (Wen, McTavish, Kreps, Wise, & Gustafson, 2011), arthritis (Hadert & Rodham 2008), depression (Barney, Griffiths, & Banfield, 2011), people who self-injure (Johnson, Zastawny, & Kulpa, 2010), or are at risk for suicide (Eichenberg, 2008). An analysis of 41 online health message boards (Orizio, Schulz, Gasparotti, Caimi, & Gelatti, 2010) revealed that they are a significant source of patient empowerment yet they are also a resource for self-treatment. Discussion board authors have an outlet to describe beliefs and behaviors that they might never openly discuss with their family, friends, or health providers for fear of rebuke or legal action. Researchers have analyzed online descriptions of ecstasy (MDMA) use (Murguía, Tackett-Gibson, & Lessem, 2007) and online opioid addiction narratives (Jodlowski, Sharf, Nguyen, Haidet, & Woodard, 2007). Little research, however, has reported on buprenorphine drug preferences

from an online source. The purpose of this retrospective study was to understand how individuals who use buprenorphine/naloxone congregate as an online community to share their self-treatment and drug delivery preferences by anonymously posting to online asynchronous discussion boards for self-management of their opioid dependence.

# METHODS

Methods for collecting and analyzing data from online discussion boards vary because the use of research using online discussion boards and other Internet communities depends on the perception of how "public" or "private" (Eysenbach & Till, 2001) the community is. The use of discussion boards for research purposes is not without serious privacy and informed consent considerations because of the complex relationship between the online format, the individuals who create its text, the text generated, and the researchers. Some researchers have actively participated on discussion boards with drug users (Barratt & Lenton 2010); for this study, the posts were collected and analyzed retrospectively to eliminate any influences on interactions between authors and researchers.

This research focused on online discussion boards that specifically compared buprenorphine/ naloxone tablet and film formulations. An Internet search using the Google search engine was used to identify suitable discussion boards using the following search terms: buprenorphine, naloxone, Suboxone, sublingual, strip, film, pill, tab, and tablet. We excluded online media such as blog postings and user reviews of buprenorphine/naloxone at drug websites because blogs and user reviews do not always facilitate two-way discussions. Of the 17 message boards found, 13 included content that specifically included: (1) preference for the formulation; (2) "extramedical" use (Larance, Degenhardt, Lintzeris, Winstock, & Mattick, 2011); and (3) self-management. These 13 discussion boards with appropriate threads, postings organized around a single topic initiated by an author, were identified: Bluelight, CafePharma, Drug Forum, Addiction Treatment Watchdog, Drugs.com, Suboxone, the Light at the End of the Tunnel, MD Junction, Med Help, All Nurses.com, Pharmer, Prescription Drug-Info, Totse, Suboxone Zone, and Zoklet. Overall, 121 threads from when the film was first marketed in 2010 to November 2012, were collected as HTML pages and inputted into the qualitative software NVivo. Discussion board authors who submitted postings to discussion boards compared the buprenorphine tablet to the film using the following factors: preference of medication delivery method, dislike and fear of change, efficacy, cost, and ease of misuse. The text content of the threads was analyzed using grounded theory (Denzin & Lincoln, 2003), which involves open coding and axial coding (Walker & Myrick, 2006) to generate category headings from the posts to understand how the preference of drug formulation is mediated by one's desire to self-manage treatment. In the open coding approach, the text of the discussion board posts is reviewed and organized so that a codebook of repeated categories is developed, with notes as guideposts for understanding what the discussion board authors are discussing—from their perspective.

The discussion boards identified for this study are public and can be viewed by anyone. Administrators for some discussion boards provide rules on how to be a contributor that maintains personal safety for oneself, other users, and to ensure the continued existence of the board. Authors take care to shield their own identities. We added additional measures by

not using their usernames and paraphrasing their posts for profanity, length, content, and use of specialized online vocabulary. Retrospective review of the online discussion boards was undertaken after approval by Yale University School of Medicine's Human Investigation Committee, which declared it exempt from institutional review board oversight, invoking federal regulation 45 CFR 46.101(b)(4) because the online postings are publicly available and the identities of the authors cannot be traced.

# RESULTS

While most authors rarely stated that they are practicing self-management of their care, their questions, concerns, and advice demonstrate that they advocated for self-management of buprenorphine/naloxone regardless of whether they are active participants in a treatment program or obtaining the medication without a prescription.

"I recently took myself off pain meds (opiates) altogether. I'm tired of dependency. However about once a week I take a Suboxone strip when I get cravings. I took a half a strip today . . . and found out we have a random drug test at work tomorrow . . . . Will it appear in a lab drug screening for work 24–36 hours after taking? If yes how can I appear clean for test?"

"I am transitioning from methadone to Suboxone today. I want to wait as long as possible [to take the first buprenorphine/naloxone film] and take as little as necessary . . . Where can I get advice on the Internet? Chat rooms? I am very eager to stop all opiate related meds. If I wanted to stop very soon and quick what are my options? I have a new doctor but I don't feel like I can burden him with all the questions I have."

Many posts, however rejected self-treatment:

"It is not the drugs that define us as addicts. It is our behavior. What you are still doing is self-medicating. You need to get a schedule or a plan with the Suboxone. If you are trying to avoid the withdrawal with it then you are on dangerous ground. I know I keep repeating myself but I still think you need to talk with your doctor and get honest."

"I don't see you following any plan. Either the doctor is contradicting himself or you didn't hear him right. Not all Suboxone doctors are in it to help people. Some are in it for the quick buck and I really hope your doctor isn't one of them. Anyway, I still feel that taking it willy-nilly is dangerous. YOU being in control like this is dangerous. Addiction is so much a mental game–far more than physical and that is what people don't get. There is where my concern is. And it has nothing to do with taking a higher dose because it won't make you feel good. That is one good thing about it."

The above quotations exemplify a spirit of autonomy and some pushback about treatment options especially because they are tired of feeling dependent on opioids. Without records of their treatment plans, it is impossible to determine if the authors are taking their doses as directed, but it is evident that some of the authors are managing their treatment on their own. The authors discuss adjusting the dosage by breaking the pills and strips into pieces.

Based on the discussion board postings, the following themes emerge as facilitators of selfmanagement: (1) a ready supply of buprenorphine/naloxone from a variety of sources; (2) distrust of buprenorphine prescribers and pharmaceutical companies; (3) the declaration that buprenorphine/naloxone is a "bad-tasting" medicine; (4) the desire to adopt a different delivery method other than sublingually, such as intravenously or insufficient, to maximize buprenorphine absorption and/or receive some euphoria; and (5) a desire to become completely "substance-free" (i.e., not dependent on any medication or illicit drug).

#### Ready Supply of Buprenorphine/naloxone from a Variety of Sources

The majority of the authors do not state how they obtain buprenorphine/naloxone, but the literature demonstrates that buprenorphine/naloxone has a following among people who do not have prescriptions for it. For people not in therapy, purchasing from a drug dealer, or acquiring medications through transactions or gifts from friends are viable options. The majority of authors claimed to have prescriptions, but on a board specifically designed for people in recovery (and their families), a woman learned where her relative was buying her buprenorphine/naloxone: "I asked her where she got it. Are you ready for this? The same [expletive] who she gets pills from."

"It's no harder for a dealer on a street corner to swap a few films for a bunch of cash than a few tablets. The film's glossy wrappers make the handshake even slicker."

Several board authors described helping their friends by sharing their medications:

"A friend of mine from the same clinic I go to decided to get on them and he gave me one."

"I have been able to try the films because I have traded a few tabs for films with someone I know who is also on sub–I know, I know, I guess technically that's a type of diversion–but we both have legit scripts and we traded evenly–1 tab for 1 film."

Although the discussion boards prohibit using postings to purchase medications, authors hint at the system of exchange outside of the medical community where drug dealers sell opioids and opioid replacement therapy and sympathetic friends who understand dependence share their medications with others.

#### **Distrust of Buprenorphine Providers and Pharmaceutical Companies**

For discussion board authors receiving treatment from a certified buprenorphine/naloxone prescriber, finding a supportive doctor willing to work with them on developing an appropriate treatment plan was of utmost importance, and authors encouraged others to seek other doctors when they suspected the doctor did not trust them. One author described feeling penalized for being honest with medical professionals:

"If you tell your doctor or the pharmacist that you think the crumbled film strips are weaker than they are supposed to be, they will both tell you that is impossible and they will think you are trying to scam them. They might not come out and say it, Brown and Altice

but that is what they will think. I made the mistake of doing that and it really ended up hurting me in the long run. (Even though I was being honest, it didn't matter.)"

Authors expressed distrust about the financial motivations of doctors and pharmaceutical corporations:

"It's [referring to buprenorphine/naloxone] more expensive and they can do tablets and now films I am guessing because the patent ran out . . . it's all about money."

"In no way am I looking for a higher dose if anything I want less I have been on them for so long that I would like to wean down at some point, I find that it might be quite difficult with the new films, I would like to switch back but unfortunately I don't think that is going to happen! Where I am going now they are all about the films, it's like a big group thing and they are set in their ways and don't like to work with you as far as I can see. They treat everybody the same, the heroin addict just barely seeking treatment like they do the people who have been clean for years and never miss a pill count and have clean urine!"

Authors described difficulty maintaining an open and judgment-free rapport with their medical professionals, and the timing of the buprenorphine/naloxone pill's discontinuation further widens the rift.

### Declaration that Buprenorphine/naloxone is a "Bad-tasting" Medicine

When discussion board authors compared the buprenorphine/naloxone tablet to the film, a significant factor was the taste. While neither form of the drug tasted good according to the authors, opinions differed about which tasted better. As one author wrote:

"Personally, I hate the taste of the films, and I gave myself weeks to get used to them before I went back to the tablets."

From a different author: "Not to mention the Suboxone film [in my opinion] is one of the nastiest substances I've ever had the displeasure of ingesting. Tastes like diet soda (which I loathe) and has the same nasty chemicals listed as ingredients. How can they get away with that, and worse leave us with no alternatives! It's so sickening that I actually tried alternate routes of delivery (guess which one, and it's probably not your first or second guess . . . lol) and I was only on it for 2 days."

Taste is used as a rationale for using buprenorphine formulations on areas of the body other than sublingually, which represents suspicious behavior.

#### Desire to Adopt a Different Delivery Method Other than Sublingually

Besides taste, discussion board authors discussed additional motivators of trying for taking buprenorphine/naloxone other than sublingually, as directed, to maximize absorption or to achieve euphoria. Two examples from two different authors:

"Now if your addict is gonna shoot it or snort it or sell it then they don't really want to be clean do they? Not for everyone but if it helped one addict live it is a path. Addicts will find any drugs to abuse so you can't really make the argument they are dying from it, under proper care it has saved many life." "I try to taper myself every week to less and less Suboxone nasally. I try to take smaller and smaller lines as the week progresses, but when Friday rolls around, I use my bundle . . . Is this really necessary? I don't know, I'm sorry. I'm just looking for answers. I feel out of control, not knowing everything I want to know about this thing I have to shove up my nose daily."

These quotations indicate a range of self-management activities ranging from altering the amount taken to modifying the physical medicine to changing the route of administration. There is often confrontational dialogue between authors because some authors disapprove of the improvisation exhibited by other authors in how they take their medications. The suggestion is that authors who use buprenorphine in ways that are not medically sanctioned are not self-treating their opioid dependence, but instead diverting the medication, an action that risks "ruining it for everyone else" through policy changes and heavier restrictions on how the medication is prescribed.

#### **Desire to Be Completely Substance-Free**

Some of the authors who self-manage their buprenorphine/naloxone intake do so in order to be substance-free:

"I am tapering immediately. I am too old and life is too short. Drugs have taken far too much from me . . . I will not let the drugs, meds or doctors tell me what to do. I'm ready for out and they seem to want to keep hold of you."

"I just called my doctor and he said no. Everyone says no. I feel like a bad little kid who doesn't want to take his drug. 'uh cawnt hav ma puddin if uh don't eat my sub.' I will try googling "pleasant withdrawal experiences". I am not joking either. oh to answer the other questions, thanks for asking . . . I don't know what I want. it has changed every day. Today I know I want OFF ALL MEDS."

# CONCLUSION/IMPORTANCE

Discussion boards are important venues to view opinions and experiences about substance user treatment and a novel way to access the culture of drug user treatment. Authors simultaneously incorporate multiple sources of information to make decisions about their health: physicians, Internet websites, and other discussion board authors' experiences. The result is a diversity of accurate and inaccurate information, a mixture of opinions, myth, and factual medical and pharmaceutical information. A discussion board specifically on buprenorphine provides opportunities for users to ask questions to other users about how to use it to curb craving and treat dependence, how to self-treat and taper the medication, or how to misuse it. For individuals who obtain buprenorphine through a non-physician supplier (i.e., extra-medical users), discussion boards are one of few ways to find information on the drug they have purchased.

#### How the Tablet Hinders and the Film Facilitates Self-management

Studies of illegal opioid consumers (Daniulaityte, Falck, Wang, & Carlson, 2009; Daniulaityte, Falck, & Carlson, 2012b) show that pharmaceutical medications are legitimized as being "from a doctor," therefore perceived to be of lower risk than other illicit

drugs that may be co-formulated with a myriad of potentially dangerous excipients. Buprenorphine/naloxone produced by the manufacturer flows through different channels doctors, dealers, and friends—to the people who want it. The film, according to discussion board authors, facilitates tapering because of its easy ability to be cut in half or smaller sections, and the authors assumed that the medication was evenly distributed throughout the film, which makes cutting and tapering "the great thing" about them. The film appears to be an important facilitator in self-treatment because it can be more easily cut into pieces to extend the medication because of limited supply, cost, or to taper. Although the film was devised to reduce diversion, this formulation may indeed contribute unwittingly to it and facilitate self-regulation, thus requiring prescribing physicians to build trust with their patients and to combat diversion.

#### A Social Norm that Promotes Autonomy

The discussion board posts establish a social norm where authors believe they should trust each other more than they can trust pharmacists and prescribing physicians. This research represents a look at medicine from the "bottom-up" (Orizio et al., 2010) by elaborating on differences in the medical and nonmedical ways of obtaining and using a medication, which sets up an opposition between users and medical professionals who, if they were fully aware of how their patients move the boundaries of "as directed," would consider many of their activities diversion. The authors craft their online identities in opposition to the medical system and pharmaceutical industry. Authors believe they are spending too much money on their medications and worry that they are being overmedicated and kept in therapy so that doctors and corporations can profit. Their knowledge is based in common experiences of being inducted onto buprenorphine/naloxone, adhering to the medication, identifying which formulation they prefer, and adjusting the medication's physical properties and even describing in explicit detail how to do so. Many authors are in their first days of a new buprenorphine/naloxone regimen looking for advice and reassurance, and the authors are welcoming. The speculations encourage authors to be proactive and decide when to disregard medical advice or make up their own treatment plans. The information presented on these boards, while it may not necessarily be medically accurate or recommended, represents real-world discussions about this medication that the medical and pharmaceutical community may not be fully aware.

The desire to be free from all medications and illegal drugs is a worthwhile goal, but the discussion board authors seem to want to achieve it as quickly as possible. Authors' impatience with their treatment regimes is an apparent motivator for tapering themselves off their medications using their own means. The taste of the medication is mentioned as a hindrance to taking it as directed, but it is also a rationalization for misusing it. Online descriptions of using the medication nasally, by injection, or rectally indicate subversive behaviors that betray authors' earnest commitment to therapy. Admittedly, some authors who describe these behaviors are trying to reach euphoria, but some of the authors who do this are prescribed buprenorphine/naloxone and receiving treatment. Providers should find ways to ask if their patients are taking the medication as directed without jeopardizing their trust. The findings of this study should be verified by pharmacists and then with interviews

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and surveys of buprenorphine/naloxone users, which could lead to novel interventions to discourage individuals at risk for harm.

Physicians should reinforce that a substance use disorder is a chronic condition that requires a network of support and is mitigated by internal and external factors such as stable housing, mental health diagnosis and treatment, violence, and criminal justice involvement (Dennis & Scott, 2007). Another reason for wanting to take less medication for opioid dependence is to be able to use illegal drugs; this behavior is rarely mentioned outright by the authors because it is stigmatized. Some authors accuse each other, especially when they mention polydrug use or query the boards to find out how to taper their medications enough to stabilize themselves so that they can use other drugs.

#### Study Limitations

Though important themes emerged in this analysis, this study has several limitations. First, the anonymous structure of the discussion boards prevents the collection of demographic information. The discussion board users may be comprised of a group of more affluent, less visible drug users who are not the stereotypical opioid-dependent person in treatment since they write eloquent, grammatically correct posts. Second, unless the individual posting states how medication was obtained, it is nearly impossible to determine which individuals are in treatment and which are not. Understandably, some users would not want to disclose this information for fear of punishment if the postings would ever be traced back to them. Despite this concern, the users who do choose to post to a discussion board are remarkably candid and a reader should assume the veracity of the postings unless something in the postings suggest otherwise. Last, the analysis can only use text from authors who contribute; those who read the postings but never contribute remain silent.

## IMPORTANCE

To our knowledge, this is the first analysis of buprenorphine/naloxone discussion boards to glean important insights into the use and misuse of a proven medication-assisted therapy used to treat opioid dependence. This study raises new questions about where people find medical information and how they use it. It advances our thinking about the variety of ways a single medication is used for self-treatment, and the medical community has only some of this information. Such anonymous modalities might be considered in the future with involvement of professionals who can provide guidance for individuals who might not otherwise be willing to jeopardize their relationship with their prescribing clinician.

The number of people using buprenorphine/naloxone is likely underestimated, as some people who write on discussion boards do not obtain the medication from the authorized pathways of physicians and pharmacies but want to take it correctly. Therefore, the discussion board acts as one of few venues to ask advice about the medication and its effects. It is human nature to look for others who share an affinity, and authors who are in treatment are often looking for support from people like them. The discussion board model could be further incorporated into group therapy to create an outlet for patients to communicate with each other. Providers can build trust with patients and maintain a safe space for talking about problems with their dependence and treatment. Providers can also

build steps for increasing patient autonomy into the framework of their therapy regimen so that patients and providers are allies instead of adversaries.

# **Biographies**



**Shan-Estelle Brown**, Ph.D., is a Postdoctoral Research Associate in the Department of Internal Medicine—AIDS Program at Yale University School of Medicine. Educated at Yale University, Old Dominion University, she earned her doctorate in anthropology at the University of Connecticut. She is an applied medical anthropologist looking at the relationship between inequality and poor health outcomes. More specifically, she researches the relationship between medical technologies and people, individuals' perceptions of risk and well-being, and structural facilitators and barriers to access to healthcare. Her current research investigates acceptability of drugs for opioid substitution therapy to understand users' preferred method of medication delivery and what factors influence these preferences.



**Frederick L.** Altice, MD, is a Professor of Medicine at Yale University School of Medicine in New Haven, Connecticut. He is the Director of Clinical and Community Research of the Yale University AIDS Program for the School of Medicine, where he also directs the Community Health Care Van and the HIV in Prisons Program. Dr. Altice's research interests are focused on the interface between infectious diseases and substance abuse. As a clinical epidemiologist, health services and intervention researcher, he has created novel programs for the treatment of HIV, HCV, and tuberculosis in vulnerable populations, including injection drug users and prison inmates. Specifically, he has been an international leader in research related to adherence to antiretroviral therapy, particularly among HIV+ drug users, has made considerable in roads into novel approaches using directly administered antiretroviral therapy and other structural interventions to facilitate adherence both nationally and internationally. Dr. Altice has been at the forefront of integrating buprenorphine and methadone treatment into managing co-morbid conditions, including the management of HIV, HCV, TB, and mental illness.

# GLOSSARY

#### Buprenorphine/naloxone

A medication prescribed to treat opioid dependence.

#### **Discussion board**

An online site where people with similar interests can post messages and engage in conversations with each other.

#### **Extra-medical**

Drug use that is either without a prescription (i.e., obtained from outside the formal medical system), or not as directed by a doctor, without excluding the possibility that the user may have medically driven reasons for using the medication (Larance et al., 2011).

#### Post

A message posted to a discussion board.

#### Self-management

a system of actions taken by people with addiction problems who feel self-empowered to abstain from drugs.

#### Social norms

the informal rules that develop between members of a group or society that govern appropriate behavior.

#### Thread

A single topic on a discussion board consisting of an initial post and all asynchronous replies to that post.

#### References

- Altice FL, Mostashari F, Friedland GH. Trust and the acceptance of and adherence to antiretroviral therapy. Journal of Acquired Immune Deficiency Syndromes. 2001; 28(1):47–58. [PubMed: 11579277]
- Altice FL, Sullivan LE, Smith-Rohrberg D, Basu S, Stancliff S, Eldred L. The potential role of buprenorphine in the treatment of opioid dependence in HIV-Infected individuals and in HIV Infection Prevention. Clinical Infectious Diseases. 2006; 43(Suppl 4):S178–S183. [PubMed: 17109304]
- Amato L, Davoli M, Perucci CA, Ferri M, Faggiano F, Mattick RP. An overview of systematic reviews of the effectiveness of opiate maintenance therapies: Availableevidence to inform clinical practice and research. Journal of Substance Abuse Treatment. 2005; 28(4):321–329. [PubMed: 15925266]
- Baker L, Wagner TH, Singer S, Bundorf M. Use of the internet and e-mail for health care information: Results from a national survey. JAMA: The Journal of The American Medical Association. 2003; 289(18):2400–2406. [PubMed: 12746364]
- Barney LJ, Griffiths KM, Banfield MA. Explicit and implicit information needs of people with depression: A qualitative investigation of problems reported on an online depression support forum. Bmc Psychiatry. 2011; 11(88)doi: 10.1186/1471-244X-11-88
- Barratt MJ, Lenton S. Beyond recruitment? Participatory online research with people who use drugs. International Journal of Internet Research Ethics. 2010; 3:69–86.

- Bazazi AR, Yokell M, Fu JJ, Rich JD, Zaller ND. Illicit use of Buprenorphine/Naloxone among injecting and noninjecting Opioid users. Journal of Addiction Medicine. 2011; 5(3):175–180. [PubMed: 21844833]
- Bell J. The Global Diversion of Pharmaceutical Drugs. Addiction. 2010; 105(9):1531–1537. [PubMed: 20626373]
- Boyer EW, Babu KM, Macalino GE, Compton W. Self-treatment of opioid withdrawal with a dietary supplement, Kratom. The American Journal on Addictions. 2007; 16(5):352–356. [PubMed: 17882605]
- Cunningham CO, Giovanniello A, Li X, Kunins HV, Roose RJ, Sohler NL. A comparison of buprenorphine induction strategies: Patient-centered home-based inductions versus standard-ofcare office-based inductions. Journal of Substance Abuse Treatment. 2011; 40(4):349–356. [PubMed: 21310583]
- Daniulaityte R, Falck R, Carlson RG. Illicit use of buprenorphine in a community sample of young adult non-medical users of pharmaceutical opioids. Drug and Alcohol Dependence. 2012a; 122(3): 201–207. [PubMed: 22036303]
- Daniulaityte R, Falck R, Carlson RG. "I'm not afraid of those ones just 'cause they've been prescribed": Perceptions of risk among illicit users of pharmaceutical opioids. International Journal of Drug Policy. 2012b; 23(5):374–384. [PubMed: 22417823]
- Daniulaityte R, Falck RS, Wang J, Carlson RG. Illicit use of pharmaceutical opioids among young polydrug users in Ohio. Addictive Behaviors. 2009; 34(8):649–653. [PubMed: 19398164]
- Dasgupta N, Bailey EJ, Cicero T, Inciardi J, Parrino M, Rosenblum A, ... Dart RC. Post-marketing Surveillance of Methadone and Buprenorphine in the United States. Pain Medicine. 2010; 11(7): 1078–1091. [PubMed: 20545875]
- Daulouede JP, Caer Y, Galland P, Villeger P, Brunelle E, Bachellier J, ... Courty P. Preference for buprenorphine/naloxone and buprenorphine among patients receiving buprenorphine maintenance therapy in France: A prospective, multicenter study. Journal of Substance Abuse Treatment. 2010; 38(1):83–89. [PubMed: 19800758]
- Dennis M, Scott CK. Managing addiction as a chronic condition. Addiction Science & Clinical Practice. 2007; 4(1):45–55. [PubMed: 18292710]
- Denzin, NK., Lincoln, YS. Strategies of qualitative inquiry. New Delhi: SAGE Publications; 2003.
- Egan JE, Netherland J, Gass J, Finkelstein R, Weiss L. Collaborative f. t. B. Patient perspectives on Buprenorphine/Naloxone Treatment in the context of HIV care. JAIDS Journal of Acquired Immune Deficiency Syndromes. 2011; 56:S46–S53. DOI: 10.1097/QAI.1090b1013e3182097561 [PubMed: 21317594]
- Eichenberg C. Internet message boards for suicidal people: A typology of users. Cyberpsychology & Behavior. 2008; 11(1):107–113. [PubMed: 18275323]
- Eysenbach G, Till JE. Ethical issues in qualitative research on internet communities. British Medical Journal. 2001; 323(7321):1103–1105. [PubMed: 11701577]
- Haddad MS, Zelenev A, Altice FL. Integrating buprenorphine maintenance therapy into federally qualified health centers: Real-world substance abuse treatment outcomes. Drug Alcohol Dependence. 2013; 131(1–2):127–135. [PubMed: 23332439]
- Hadert A, Rodham K. The invisible reality of arthritis: A qualitative analysis of an online message board. Musculoskeletal Care. 2008; 6(3):181–196. [PubMed: 18570188]
- Jodlowski D, Sharf BF, Nguyen LC, Haidet P, Woodard LD. 'Screwed for life': Examining identification and division in addiction narratives. Communication & Medicine. 2007; 4(1):15–26. [PubMed: 17714040]
- Johnson G, Zastawny S, Kulpa A. E-message boards for those who self-injure: Implications for Ehealth. International Journal of Mental Health and Addiction. 2010; 8(4):566–569.
- Kenen RH, Shapiro PJ, Friedman S, Coyne JC. Peer-support in coping with medical uncertainty: discussion of oophorectomy and hormone replacement therapy on a web-based message board. Psycho-Oncology. 2007; 16(8):763–771. [PubMed: 17230435]
- Larance B, Degenhardt L, Lintzeris N, Winstock A, Mattick R. Definitions related to the use of pharmaceutical opioids: Extramedical use, diversion, non-adherence and aberrant medicationrelated behaviours. Drug and Alcohol Review. 2011; 30(3):236–245. [PubMed: 21545553]

- Ling W, Casadonte P, Bigelow G, Kampman KM, Patkar A, Bailey GL, ... Beebe KL. Buprenorphine implants for treatment of opioid dependence: A randomized controlled trial. Journal of the American Medical Association. 2010; 304(14):1576–1583. [PubMed: 20940383]
- Maremmani I. When a new drug promotes the integration of treatment modalities: Suboxone and harm reduction. Heroin Addiction and Related Clinical Problems. 2008; 10(3):5–11.
- Mattick RP, Kimber J, Breen C, Davoli M. Buprenorphine maintenance versus placebo or methadone maintenance for opioid dependence. Cochrane Database System Review. 2008; 16(2):CD002207.
- Miller J. The other side of trust in health care: Prescribing drugs with the potential for abuse. Bioethics. 2007; 21(1):51–60. [PubMed: 17845502]
- Moratti E, Kashanpour H, Lombardelli T, Maisto M. Intravenous misuse of Buprenorphine characteristics and extent among patients undergoing drug maintenance therapy. Clinical Drug Investigation. 2010; 30:3–11.
- Morden A, Jinks C, Ong BN. Rethinking 'risk' and self-management for chronic illness. Social Theory & Health. 2012; 10:78–99. [PubMed: 23226974]
- Murguía, E., Tackett-Gibson, M., Lessem, A. Real Drugs in a Virtual World: Drug Discourse and Community Online. Lanham, MD: Lexington Books; 2007.
- Nambisan P. Information seeking and social support in online health communities: impact on patients' perceived empathy. Journal of the American Medical Informatics Association. 2011; 18(3):298– 304. [PubMed: 21486888]
- Orizio G, Schulz P, Gasparotti C, Caimi L, Gelatti U. The World of e-patients: A content analysis of online social networks focusing on diseases. Telemedicine Journal and E-Health. 2010; 16(10): 1060–1066. [PubMed: 21070131]
- Ostertag S, Wright BRE, Broadhead RS, Altice FL. Trust and other characteristics associated with health care utilization by injection drug users. Journal of Drug Issues. 2006; 36(4):953–974.
- Schultz PN, Stava C, Beck ML, Vassilopoulou-Sellin R. Internet message board use by patients with cancer and their families. Clinical Journal of Oncology Nursing. 2003; 7(6):663–667. [PubMed: 14705483]
- Schuman-Olivier Z, Albanese M, Nelson SE, Roland L, Puopolo F, Klinker L, ... Shaffer HJ. Selftreatment: Illicit buprenorphine use by opioid-dependent treatment seekers. Journal of Substance Abuse Treatment. 2010; 39(1):41–50. [PubMed: 20434868]
- Sohler NL, Li X, Kunins HV, Sacajiu G, Giovanniello A, Whitley S, ... Cunningham CO. Homeversus office-based buprenorphine inductions for opioid-dependent patients. Journal of Substance Abuse Treatment. 2010; 38(2):153–159. [PubMed: 19801178]
- Stanos SP, Bruckenthal P, Barkin RL. Strategies to reduce the tampering and subsequent abuse of longacting opioids: Potential risks and benefits of formulations with physical or pharmacologic deterrents to tampering. Mayo Clinic Proceedings. 2012; 87(7):683–694. [PubMed: 22766088]
- Stimmel B. Buprenorphine in the treatment of Heroin Addiction: Déjà Vu all over again. Journal of Addictive Diseases. 2011; 31(1):1–2.
- Strain EC, Harrison JA, Bigelow GE. Induction of opioid-dependent individuals onto buprenorphine and buprenorphine/naloxone soluble-films. Clinical Pharmacology & Theraputics. 2011; 89(3): 443–449.
- Vicknasingam B, Mazlan M, Schottenfeld RS, Chawarski MC. Injection of buprenorphine and buprenorphine/naloxone tablets in Malaysia. Drug and Alcohol Dependence. 2010; 111(1–2):44– 49. [PubMed: 20478668]
- Walker D, Myrick F. Grounded theory: An exploration of process and procedure. Qualitative Health Research. 2006; 16(4):547–559. [PubMed: 16513996]
- Wen KY, McTavish F, Kreps G, Wise M, Gustafson D. From diagnosis to death: A case study of coping with breast cancer as seen through online discussion group messages. Journal of Computer-Mediated Communication. 2011; 16(2):331–361. [PubMed: 23055657]
- Wish ED, Artigiani E, Billing A, Hauser W, Hemberg J, Shiplet M, ... DuPont RL. The Emerging Buprenorphine Epidemic in the United States. Journal of Addictive Diseases. 2012; 31(1):3–7. [PubMed: 22356664]