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Patient Recommendations for Opioid Prescribing in the Context of HIV Care: Findings from a Set of Public Deliberations

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Abstract

It is widely acknowledged that the growing opioid epidemic and associated increase in overdose deaths necessitates a reexamination of processes and procedures related to opioid prescription for the treatment of chronic pain. However, the perspectives of patients, including those at highest risk for opioid-related harms, are largely missing from this reexamination. To partially address the gap in patient input, we conducted a pair of one-day public deliberations on opioid prescribing in the context of HIV care, as part of a larger study on opioid prescribing and patient-provider communication. Results included recommendations and perspectives from people living with HIV that detail how providers can best assess patient needs, communicate regarding opioid-related treatment and monitoring, and reduce the risk of misuse. Participants emphasized the importance of building trust with patients and taking an extensive patient history prior to making decisions about whether to initiate or end an opioid prescription. This trust—together with an understanding of the origin of a patient's pain, history of drug use and other therapies tried—was perceived as essential to effective monitoring and pain management, as well as promotion of positive health outcomes. Ensuring that such patient perspectives are incorporated into the operationalization of guidelines for safe opioid prescribing may help to improve outcomes and quality of care for people living with HIV.

Keywords

HIV/AIDS; opioid prescribing guidelines public deliberation; patient perspectives

Introduction

The rates of opioid addiction, overdose, and opioid-related death are at crisis levels (Centers for Disease Control and Prevention, 2018; Gomes, Tadrous, Mamdani, Paterson, & Juurlink, 2018; Kolodny et al., 2015; National Institute on Drug Abuse, 2018; Samet & Kertesz,

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2018), prompting a response that has included prescriber education, mandated use of state prescription drug monitoring programs, expanded access to naloxone (Kolodny et al., 2015), and expanded access to substance use education and treatment (Bernstein, 2018). Greater specificity and clearer guidelines related to opioid prescribing have been promulgated by several bodies (Lowenstein, Grande, & Delgado, 2018; Manchikanti et al., 2017), including the Centers for Disease Control and Prevention (CDC)(Dowell, Haegerich, & Chou, 2016; Kroenke et al., 2019).

The combination of approaches appears to have had some impact, and recent years have seen a leveling or reductions in opioid prescribing and in adverse outcomes from prescribed opioids (Bernstein, 2018; Dart et al., 2015; García et al., 2019). However, the sense of urgency and increased focus on limits to opioid prescribing have also led to difficulties with access for patients who might benefit from opioid treatment, increasing the likelihood of unrelieved pain (Kertesz & Gordon, 2018). In addition, non-consensual and/or overly rapid opioid tapering can lead to severe withdrawal, and to use of more risky non-prescribed and illegal opioids as a substitute for prescribed medications (Darnall et al., 2018; Kertesz & Gordon, 2018; Lowenstein et al., 2018; Samet & Kertesz, 2018). In fact, increases in overdose and deaths from non-prescribed opioids, including heroin and illegally manufactured fentanyl, have been concurrent with reductions in overdose and deaths from prescribed opioids (Bernstein, 2018; Centers for Disease Control and Prevention, 2018; Kertesz, 2017).

Opioid prescribing in the context of HIV care is particularly challenging. Chronic pain is common among people living with HIV (PLWH), with studies showing prevalence estimates of 39-85% (Bruce et al., 2017). Chronic pain is associated with poor mental health and functional limitations in PLWH, even in the absence of advanced disease; poor pain control has also been associated with poor treatment outcomes (Bruce et al., 2017; Merlin et al., 2018). However, “red flags” for opioid risks, such as prior substance abuse history and social instability, are also associated with HIV infection.(Centers for Disease Control and Prevention, 2019; El-Sadr, Mayer, Rabkin, & Hodder, 2019)

Policy and practice changes to address the opioid epidemic, such as those described above, have been informed by multiple stakeholders, including providers, public health professionals, and policy makers (Manchikanti et al., 2017; National Conference of State Legislators, 2018; Samet & Kertesz, 2018; US Department of Health and Human Services, n.d.). However, the perspectives of patients, including those at highest risk for opioid-related harms, are largely missing from the discussion. Ignoring the patient perspective is likely to lead to approaches that are inconsistent with patient needs, priorities and concerns (Woolf, Zimmerman, Haley, & Krist, 2016).

To partially address the gap in patient input, we conducted a pair of one-day public deliberations on opioid prescribing in the context of HIV care, as part of a larger study on opioid prescribing and patient-provider communication. Public deliberation is a method of community engagement that includes a significant educational component, as well as small and large group discussions, with the goal of eliciting specific recommendations to be acted upon by the deliberation sponsor (Abelson et al., 2003; Carmen et al., 2013; Scherer, Weiss,

Kamler, Realmuto, & Gold, 2016). Public deliberation has been used in multiple health care contexts (Street, Duszynski, Krawczyk, & Braunack-mayer, 2014), and is particularly well-suited to issues that are value-laden, without clear technical solutions (Scherer et al., 2016). Topics have included prioritization of programs for chronic disease prevention (Gold, Realmuto, Scherer, Kamler, & Weiss, 2018) and reducing use of ineffective health care practices (The Center for Healthcare Decisions, 2016).

The specific objective of the deliberation described in this paper was operationalization of the CDC Guidelines for Opioid Prescribing (Dowell et al., 2016) within the context of HIV care, and development and refinement of communication strategies to facilitate provider use of and adherence to the CDC Guidelines. Public deliberation was selected as the methodology for addressing this topic because of the multiple competing priorities and concerns, including alleviation of chronic pain, patient-provider trust, management of HIV disease, risks of overdose, and the health and safety of the community at large. Appropriate consideration of these issues required extended discussion, as well as background information that may not be readily available to the general public.

Methods

We convened two one-day public deliberations in New York City (NYC) with 43 PLWH. The curriculum for the public deliberations was developed by the authors and included:

- Didactic presentations by healthcare providers that included information on opioids, the opioid epidemic, chronic pain and its treatment, and physician-patient communication;
- Small and large group discussion, with targeted questions and case studies describing example patients for participants to respond to;
- Priority setting activities, providing participants with opportunities to explain and vote on their recommendations.

Participants were recruited through listservs for PLWH and community-based organizations that serve HIV+ populations. They were initially surveyed by phone to determine eligibility (age 18 or older, HIV+, and receiving medical care outside the sponsoring healthcare institution) and to gather basic demographic and health-related information. In addition, all participants completed a pre- and post-survey at the start and end of the deliberation. Both surveys included questions on physician trust, chronic pain and its treatment, and perspectives on the opioid epidemic and opioid prescribing. The pre-survey included questions on current pain and prescribed opioid use; the post-survey included questions on the event itself, including satisfaction and perceived impact. Notes were taken throughout the two days and discussions were audio-recorded, professionally transcribed, and coded for pre-identified and emerging themes using Nvivo version 11 (Melbourne, Australia).

Results

Participants: Characteristics and Perspectives on Care

As shown in Table 1, just over half (53%) were female; 72% were African-American and 26% were Latino. Approximately one-fifth (21%) reported some college or vocational school, 16% had a college degree, and 2% (1 person) had a Master's Degree or higher. All participants were PLWH; over half were diagnosed with HIV 20+ years ago (see Table 2). Seventy percent experienced chronic pain, currently or in the past and approximately one-quarter (23%) were currently taking prescribed opioid for chronic pain. Approximately two-thirds (67%) had an undetectable viral load. The same number reported having had a problem with drugs or alcohol.

Table 3 describes participant perspectives on medical care, treatment of pain, and opioids, as reported in surveys completed at the start of the public deliberation. Close to 90% agreed or strongly agreed that "*Chronic pain is a big problem for HIV+ people*" and 63% agreed or strongly agreed that "*Patients are less likely to abuse or misuse prescription opioids if they have a good relationship with their doctors.*" During the deliberation, many described their own experiences living with HIV and living with pain, as well as experiences with—and a distrust of—the health care system.

Because, she would tell me, "No, you can't be on nothing." But, why would you –? But, I'm doing good. My labs and everything are fine. Why would you deny me the medication, something that'll make me feel better? And she was like, "Oh, because, I know once you get addicted –" And right away, when you walk in there, we are judged right off the bat. They don't – we're not getting a chance to explain what's going on.

I don't care what you [the doctor] tell[s] me. It doesn't matter. You're not in pain, you're not suffering, you don't have panic attacks in the train, you don't have panic attacks on a bus. You don't go through it. So, you can't tell me anything.

Participant recommendations for opioid prescribing

Participants were asked to provide recommendations on topics related to opioid prescribing in an HIV care context. Presented below are their responses, including specific language where available, focusing on three key areas: (1) provider decision-making regarding opioid prescribing; (2) patient-provider communication; and (3) processes for reducing risk.

Provider decision-making—Consistent with the curriculum and questions posed to participants, discussions around opioid prescribing focused primarily on decision making in the context of a substance use history and/or seeming non-adherence to medical recommendations. According to participants, provider decisions about whether to initiate or continue an opioid prescription for PLWH cannot be made using a one-size-fits-all approach. Rather, physicians should engage in an open conversation with patients, to build needed trust and to avoid assumptions about patient risk based on stereotypes—including those related to race and ethnicity—and stigmatized behavior.

It [is] about building a rapport, getting to know each other, and having some history to guide you. Knowing the history of the patient from the doctor's part is a good thing, and respecting the patient enough to say, "We have to talk about this. We're part of this together, so let's work together."

It's important that doctors don't look at different layers or add on layers of stigma to the judgment, on how they judge. So, the layer of HIV and AIDS status, race or appearance, drug history. That should be not a part of their decision.

An extensive patient history was considered to be essential for opioid prescribing decisions, including information on drug use (past and present), mental health, and the etiology and severity of pain. Participants were aware that providers notice levels of patient engagement and adherence to medical recommendations and consider these factors when making treatment decisions. They, therefore, wanted physicians to fully understand issues that contributed to healthcare behaviors and the potential for behavioral change.

A doctor should be taking a full assessment. Based on that full assessment, talking to other doctors based on what the person's issues are. If the person has mental illness, if the person has chronic pain, if the person has HIV, those specialists ... he should get advice from them to figure out what is the best move for this patient, in particular.

I'm the person that I miss doctor's appointments. I do. Some days [it] is good for me, and some days it isn't. ...I did, I missed two appointments and the social worker's calling my house. "Oh, I need to see you." Okay, fine. So, when I get there I tell her, I said, "Listen, first and foremost, it's thirty-five years [with HIV]." It's not easy. And for people who are not positive, they really don't understand what we go through being positive.

Even if I'm mentally unstable, crazy, whatever you wanna call me, I'm still in pain. So, that doesn't eliminate the fact that you're in pain, and opioids could help you, and maybe even become more stable.

Patient-provider communication—Participants recommended that decisions related to opioid prescription and management should be communicated honestly and transparently. For example, when carrying out drug screens and other standard assessments, providers should explain the rationale for their actions, noting that they are following guidelines rather than targeting specific patients based on their individual characteristics. Recommended language included:

- "Recently there's been a lot of concern about opioid addiction, and I see that you only take one. So, I don't think that this has anything to do with you, but I just need to do it because this is what's on paper. We wanna make sure that everything is the way it's supposed to be."
- "Across the board, this is something that everyone has to do. We appreciate that you're taking the time to do that."
- "We need to do this for your best interest, to get a sense of where you're at."

- “This is routine. Everyone that takes an opioid must do this, this is a controlled substance.”

According to deliberation participants, maintaining such an honest and open dialogue can promote trust and facilitate improved care; it is also more likely to lead to effective monitoring of patients’ opioid use.

[The patient] may have some preconceived notions: “Okay, well, I don’t trust this doctor. If I take a urine test, they’re gonna wind up reporting me; they’re gonna tell the cops, they’re gonna get me arrested, whatever.” Explain to the patient, “This is for this, and this only. We value honesty, and so I’m gonna be honest with you, and I’m gonna say this is only for us to know what’s going on with your body.”

One thing with a patient-provider relationship, you don’t want to hold back from what you really feel. If it’s to help that patient, you gotta just be honest about what the dos and don’ts are. What can happen, what can’t happen. If you don’t discuss those things, then the person won’t know, and the person won’t take the time to keep themselves aware about it.

Reducing Risk—Participants clearly recognized the risks of opioid use. As noted previously, many had substance use histories; they knew from experience the dangers of addiction and the challenges to breaking a drug habit, once established. Recommended actions to reduce patient risk included patient education on the dangers associated with opioid misuse and safe storage practices. They also recognized the value and importance of monitoring prescribed opioids.

It’s a thin line between empathy and with trying to save your life. You understand? So, my approach, be it true or false, is “Good morning, [patient name], how are you, blah-blah-blah. You know, I had a patient similar to you who was going through the same thing. She was one of my best patients and I lost her, and I don’t want that for you, you understand?”

“Let’s talk about these new meds now that you’re about to take. How do you feel about them?” And then after seeing how they feel about them – “Well, how would you feel about carrying these every day? Do you have a safe place to keep them? What are some issues that might come up in your home that might make you feel like you can’t keep it in that particular place? Where else can you keep it?”

You can’t take a controlled substance and not expect somebody to want to monitor you on how you’re doing with it. You can’t just take a controlled substance and think that somebody’s just gonna say, “Here, go ahead.”

As alluded to above, participants recommended alternative therapies and collaboration or coordination with other providers in decision-making about opioid prescribing. Additionally, participants noted the importance of referrals to, and insurance coverage for, other providers and services, including pain specialists, physical therapists, and mental health providers. The link between mental health and chronic pain was commonly noted, as was concern about interactions resulting from treatment of the two conditions.

We're all positive. We've all got a team and a group of nurses, doctors and all that. I think it's important for them to know who you are and where you come from and what it's about. Before I even have a conversation with [the patient] about stopping [her opioid prescription], maybe I need to talk to her therapist, like, "When's the last time you've seen her?" Maybe I need to talk to the psychologist, "When's the last time you gave her pills?"

The medications they had me on was flaring up these depressions and anxiety and all this other stuff. They didn't take the time to see that it was affecting me in that way.

If left without adequate treatment options, participants described seeking out illicit drugs to cope with severe pain—clearly increasing risk to their health and safety.

When every avenue has been exhausted, what do you do? Just suffer? No, go to the street.

You're the doctor and you make me [as the patient] feel uncomfortable, I'm gonna walk out and I'm going down the block and cop from [name] and get some pills – for two for three dollars.

Discussion

It is widely acknowledged that the growing opioid epidemic and associated increase in overdose deaths necessitates a reexamination of existing processes and procedures related to opioid prescription for the treatment of chronic pain (Kolodny et al., 2015; Lowenstein et al., 2018). To this end, the CDC Guidelines aim to provide a roadmap for provider decision-making to reduce the risks associated with opioid use. This research captures important recommendations and perspectives directly from PLWH to facilitate operationalization of the CDC Guidelines, as well as support provider decision-making and communication about opioids. Specifically, recommendations detail how providers can best assess patient needs, communicate regarding opioid-related treatment and monitoring, and reduce the risk of misuse.

Participants emphasized the importance of building trust with patients and taking an extensive patient history prior to making decisions about whether to initiate or end an opioid prescription. This trust—together with an understanding of the origin of a patient's pain, history of drug use and other therapies tried—were perceived as essential to effective monitoring and pain management, as well as promotion of positive health outcomes. The findings are consistent with positive associations between trust and health outcomes identified in previous research (Lee & Lin, 2009; Street Jr., Makoul, Arora, & Epstein, 2009) and indicate that patients themselves are reactive to the quality of the patient-provider relationship in their own pain management behavior. For example, they may be more likely to adhere to the provider's treatment plan if they trust the provider (Lee & Lin, 2009). Notably, research examining provider perspectives on decision-making related to chronic pain and opioid use concluded that providers also feel that positive relationships between patients and providers are essential for good pain management and care (Matthias et al., 2010).

According to participants in the public deliberation reported on here, an essential component of patient-provider trust in the context of pain management for PLWH is the quality of provider communication related to opioids. For example, providing contextual explanations and rationales for actions taken to monitor opioid use is important to patient acceptance of the monitoring and decision-making processes. The transparency inherent in this communication approach (e.g., a provider says they must perform a routine drug test because it is their policy for all patients) reassures patients that providers are making decisions based on clinical knowledge and best practice recommendations rather than personal biases—promoting trust between patient and provider and supporting better quality of care. (Cockroft et al., 2019; Lee & Lin, 2009)

Participant recommendations related to reducing the risk of opioid misuse were broader than patient-provider trust and communication. For example, they recommended referrals to alternative therapies prior to prescribing opioids, coordinating care across a team of service providers, and careful attention to the connections between pain and mental health. These approaches have been identified and promoted in the literature on treating chronic pain, (Cahana et al., 2013; Kroenke et al., 2019; Mcgeary, Mcgeary, & Robert, 2014) with some documented success reducing the use of opioids. (Carey, Nolan, Kerns, Ho, & Frank, 2018) Furthermore, the final two recommendations are consistent with practices promoted in recent healthcare reform efforts, which may indicate ample opportunity for uptake in the future. (Kocher, Emanuel, & Deparle, 2010)

This research has several limitations. Because public deliberation is time and resource intensive, the number of participants is small. Additionally, recruitment was carried out through a network of organizations working with PLWH; most participants were connected to these organizations and were not necessarily representative of the larger population of PLWH. Finally, this research was carried out in NYC, an urban area with unique characteristics related to its large size and historical significance as an early epicenter of the global AIDS crisis. Those who participated may have specific experiences and perceptions that are influenced by this social context.

Despite these limitations, this work is unusual in its focus on recommendations for opioid prescribing from the perspectives of PLWH. Many PLWH have personal experience with chronic pain and substance use. However, their voices have largely been absent from the literature—and the policy making—related to opioid prescribing and the opioid epidemic. Considering the complexities and risks related to opioid prescribing for chronic pain among PLWH, this work provides practical insights to increase providers' sensitivity to their patients' needs and perspectives, advance their ability to follow the CDC Guidelines, and ultimately improve the quality of care they deliver.

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Table 1

Participant Demographics (n=43)

	n	%
Gender		
Female	23	53.5%
Male	20	46.5%
Age		
18-34	9	20.9%
35-49	9	20.9%
50-59	13	30.2%
60-74	12	27.9%
Race/Ethnicity*		
White	2	4.7%
Black	34	79.1%
Hispanic/Latino	9	20.9%
Asian	0	0.0%
American Indian/ Alaskan Native	2	4.7%
Other	4	9.3%
Education		
< HS grad	9	20.9%
HS graduate or GED	16	37.2%
Some college or vocational school	9	20.9%
College degree (2 or 4 yrs)	7	16.3%
Master's Degree +	1	2.3%
Missing	1	2.3%
Employment		
Full time	3	7.0%
Part time	9	20.9%
Retired	4	9.3%
Unemployed	13	30.2%
Unable to work	10	23.3%
Other	4	9.3%

Table 2

Health-Related Characteristics (n=43)

	n	%
Time since HIV diagnosis		
< 10 years	5	11.6%
10 - 19 years	10	23.3%
20 - 29 years	18	41.9%
30+ years	4	9.3%
Missing	6	14.0%
Chronic pain		
Current chronic pain	20	46.5%
Had chronic pain in past, not current	10	23.3%
Never had chronic pain	13	30.2%
Prescribed opioids for chronic pain		
Currently taking prescribed opioids	10	23.3%
Taken prescribed opioids in past	9	20.9%
Never taken prescribed opioids	10	23.3%
Not applicable (never had chronic pain)	13	30.2%
Don't know	1	2.3%
Currently taking medicine for HIV		
No	2	4.7%
Yes	41	95.3%
Undetectable viral load		
No	14	32.6%
yes	29	67.4%
don't know	4	9.3%
Prefer not to answer	13	30.2%
Ever had a problem with drugs or alcohol		
No	14	32.6%
Yes	29	67.4%

Table 3

Perceptions of Care, Pain and Opioid Use (n=43)

		Total Pre Survey	
		N = 43	
		n	(%)
I trust my doctor.			
	Strongly agree	17	(39.5%)
	Agree	24	(55.8%)
	Disagree	1	(2.3%)
	Strongly disagree	1	(2.3%)
Chronic pain is a big problem for HIV+ people.			
	Strongly agree	16	(37.2%)
	Agree	22	(51.2%)
	Disagree	5	(11.6%)
	Strongly disagree	0	(0.0%)
HIV+ people with chronic pain are treated fairly by doctors.			
	Strongly agree	5	(11.6%)
	Agree	19	(44.2%)
	Disagree	15	(34.9%)
	Strongly disagree	4	(9.3%)
I am worried about the opioid epidemic.			
	Strongly agree	20	(46.5%)
	Agree	15	(34.9%)
	Disagree	5	(11.6%)
	Strongly disagree	3	(7.0%)
Opioid painkillers really help some HIV+ people with chronic pain.			
	Strongly agree	13	(30.2%)
	Agree	22	(51.2%)
	Disagree	8	(18.6%)
	Strongly disagree	0	(0.0%)
If a friend of mine was prescribed opioid painkillers, I would worry about them getting addicted.			
	Strongly agree	16	(37.2%)
	Agree	17	(39.5%)
	Disagree	9	(20.9%)
	Strongly disagree	1	(2.3%)
Doctors should think only about the good of the patient when deciding whether to prescribe opioid painkillers.			
	Strongly agree	21	(48.8%)
	Agree	12	(27.9%)
	Disagree	8	(18.6%)
	Strongly disagree	2	(4.7%)
Doctors who prescribe opioid painkillers need to think about the impact on the larger community, not just their patients.			

		Total Pre Survey	
		N = 43	
		n	(%)
Strongly agree		15	(34.9%)
Agree		16	(37.2%)
Disagree		11	(25.6%)
Strongly disagree		1	(2.3%)
Patients are less likely to abuse or misuse prescription opioids if they have a good relationship with their doctors.			
Strongly agree		13	(30.2%)
Agree		14	(32.6%)
Disagree		14	(32.6%)
Strongly disagree		2	(4.7%)
Doctors should not prescribe opioid painkillers to patients who have a history of substance abuse.			
Strongly agree		17	(39.5%)
Agree		11	(25.6%)
Disagree		9	(20.9%)
Strongly disagree		6	(14.0%)
Missing		0	(0.0%)