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Trust and the ethics of chronic pain management in HIV

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Case Study

The American Nurses Association has designated 2015 as the *Year of Ethics*, and accordingly has published a revised code of nursing ethics (Willard, 2015). This code explicitly identifies promoting social justice and reducing health care disparities as ethical imperatives. These themes will resonate strongly with health care providers devoted to HIV care, given the disproportionate effects of HIV on predominantly minority, socioeconomically disadvantaged communities. One area in which HIV care providers must be particularly alert to the potential for health care disparities and injustice is chronic pain. It is increasingly recognized that chronic pain is a common and treatment-resistant part of the multi-morbidity faced by patients living with chronic HIV (Lee et al., 2009; Merlin et al., 2012; Miaskowski et al., 2011; Parker, Stein, & Jelsma, 2014). Outside the realm of HIV, disparities in pain management have been well established (Campbell et al., 2012), particularly for African Americans, a demographic group that is also disproportionately affected by HIV. For example, health care providers have been shown to underestimate the pain of African American patients (Staton et al., 2007), and to feel less empathy toward them (Drwecki, Moore, Ward, & Prkachin, 2011). Disparities in the receipt of analgesics have been documented across various settings including acute pain in the emergency room (Todd, Samaroo, & Hoffman, 1993; Todd, Deaton, D'Adamo, & Goe, 2000), chronic non-cancer pain in primary care and specialty practice (Chen et al., 2005; Ringwalt, Roberts, Gugelmann, & Skinner, 2014), and even in cancer pain where treatment guidelines are far more firmly established and less controversial (Cleeland et al., 1994; Cleeland, Gonin, Baez, Loehrer, & Pandya, 1997).

The extent to which HIV-infected patients experience injustice and disparities in chronic pain management is still unknown, and hindering the acquisition of this knowledge is the fact that just and equitable chronic pain management for HIV is difficult to define. A particularly controversial issue is whether chronic opioid analgesics are appropriate given the risks of misuse, including addiction and diversion. Clinical guidelines suggest that this risk might be mitigated by careful patient selection and monitoring, but what does this mean

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in the day-to-day practice of caring for HIV-infected patients with chronic pain? Studies outside the realm of HIV have identified risk factors for prescription opioid misuse including past drug or alcohol abuse (Ives et al., 2006; Michna et al., 2004; Schieffer et al., 2005), younger age (Edlund et al., 2010; Ives et al., 2006), male sex (Edlund, Steffick, Hudson, Harris, & Sullivan, 2007; Ives et al., 2006; Liebschutz et al., 2010), psychiatric comorbidity (Ives et al., 2006), lower education level (Wasan et al., 2007), family history of substance use (Liebschutz et al., 2010; Michna et al., 2004), and history of having been the victim of abuse (Wasan et al., 2007). The ethical difficulty a provider would face in putting these risk factors to practical use is immediately apparent. Choosing perhaps the most obvious example, it would clearly be unjust to exclude a patient from opioid pain treatment that might otherwise be indicated, because he or she had been the victim of violence. The ethical concern is increased further by the methodological limitations inherent in this literature due to the lack of verifiable outcomes (i.e., knowing with certainty what patients do with their medications). Furthermore we have shown that although prescription opiate misuse is fairly common in HIV-infected patients, factors such as prior substance use history and psychiatric disorders do not predict misuse, likely because these factors are so highly prevalent in HIV (Robinson-Papp, Elliott, Simpson, Morgello, & Manhattan HIV Brain Bank, 2012). As for monitoring, clinical guidelines recommend opioid contracts and urine toxicology screening, but there is no evidence that these measures improve outcomes, and they run the risk of being implemented in ways that might exacerbate injustice and disparities (Payne et al., 2010).

In attempting to ameliorate social injustice and health care disparities, it is important to understand the perspectives of the affected populations; however, there has been very little effort to document the patient perspective in the area of chronic pain in HIV (Merlin et al., 2014). We present herein narrative experiences of patients living with HIV infection and chronic pain as they relate to possible health care disparities or injustice. These experiences were obtained from transcripts of audiotaped focus groups attended by participants in a study of a non-pharmacologic intervention for chronic pain in HIV. The study was approved by our institutional review board, and was carried out in accordance with The Code of Ethics of the World Medical Association (Declaration of Helsinki) for experiments involving humans. All participants gave written informed consent. Inspired by these experiences and *The Year of Ethics*, we also propose a conceptual framework for chronic pain management in HIV based on ethical principles.

Case Studies

Case 1

A woman in her 50s with well-controlled HIV developed low back pain related to multilevel lumbar degenerative disc disease. Her medical history was significant for intravenous drug use in remission for more than 10 years, anxiety and depression, and multiple social stressors including the end of a long-term relationship. She was initially given acetaminophen with codeine by her primary care provider, but the medication was withdrawn because the provider believed she was “using.” The patient gave the following account of subsequent events:

I asked my doctor to send me to pain management because... she wouldn't give me the pill back... I was struggling back and forth, going to the clinic. And I'm telling them I can't bear the pain no more. So I started to buy it outside... Don't buy it on the street because it almost killed me. I went through the worst convulsions. My whole body went (through a glass)... door... I was knocked out for 2 days... I am so scared to even touch that pill again. I don't even want to see it no more. I'm going to do it right and go to pain management and see what they can provide for me. And that's it.

However the patient was also concerned that pain management would not trust her because of her past history, even though she had "learned her lesson." She also expressed fear that her depression would prevent her from attending her appointments regularly and result in her being unable to obtain the medication she felt that she needed.

Case 2

A woman in her 40s with AIDS had chronic debilitating pain in the lower extremities related to osteonecrosis. She had no known history of substance abuse and acquired HIV through sexual transmission. She was prescribed high dose extended release morphine. She gives the following account of her pain:

Surgery is not an option, so the only thing they could do is physical therapy and painkillers. And now... they're not giving out the narcotics like they used to. So I am going through physical therapy, going through stretches, just to keep me motivated, keep me mobile. Because I don't want to be depending on somebody... When I'm at the last week of the month and I don't have my painkillers because they're not giving them like they're supposed to, I hate that week. Because my kids – it's hard for me to take care of them... (I don't want) them to take care of me... (My primary care provider) sends me all over the place but they say they can't help me, they can't help me... what I want is too high of a dosage.

Case 3

A man in his 40s with well-controlled HIV experienced pain related to spinal stenosis and neuropathy. He was prescribed a pain management regimen by his primary care provider that included gabapentin, codeine, a muscle relaxant, and a non-steroidal anti-inflammatory. He gave the following account of his pain management experience:

I used to get 90 pills. Now I get 60. How am I going to take care of the same amount of pain with 30 less pills? ...So they are less likely to hand out narcotics as they were before. They try to refer you to alternative treatment... Well, the physical therapy works pretty good... To a degree. If my back goes out, I'm gonna' need a lot more than physical therapy... I'm not dealing with the pain management program anymore... because the doctor put me on methadone... and I had to sign a contract... that I couldn't get pain medication from anybody else, anywhere else. And they dropped me from it because my (primary care) doctor was writing me a prescription for Percocet. So they dropped me from the pain management. And

abrupt stoppage of narcotics like that; not good. I curled up on the couch for 2 weeks in a ball.

Discussion

A balance must be struck between relief of suffering for the individual and the potential harm that prescription opioids might cause to that individual and his or her community. Lately this balance seems to have tipped in the direction of limiting the potential harm, with clinical guidelines for opioid pain prescription focused on patient selection, opioid contracts, and urine toxicology (Alford, 2013). The narrative accounts above illustrate how these practices, and the overall greater restraint in opioid prescribing have been perceived by some HIV-infected patients as arbitrary, not intended for their benefit, and leading to loss of independence, attempts to obtain opioids from other sources, and suffering in the form of anxiety and significant physical harm. It is unknown whether injustice or disparity played a role in the case patients' clinical outcomes, or whether more liberal prescribing would have been beneficial to them, but clearly there is room for improvement in the management of their pain.

A theme present in all three narratives was disruption of trust. This is worrisome because trust is one of the foundational principles of medical ethics. As described by Rhodes, many of the familiar principles of medical ethics, such as justice and respect for autonomy, could be boiled down to a simple dictum that physicians should, "seek trust and deserve it," that is the trust of both the patient and society (Rhodes, 2001). This simple statement could form the basis of a conceptual framework for chronic pain management in HIV based on ethical principles. If "seek trust and deserve it," were the guiding principle, an interaction with a patient would be judged by the standard of whether it was trust affirming. In this trust-affirming approach, the first priority would be to convey sincere concern for the patient's wellbeing, including treating pain and avoiding harm (such as addiction). Practices with the potential to disrupt trust would be regarded with skepticism, and would only be implemented if it were very important to do so and also possible to do so with sensitivity and care. For example, if for regulatory or patient safety reasons it were necessary to implement opioid agreements and urine toxicology screens, care would be taken to do so in a trust-affirming manner. Opioid agreements would be used as an informed consent process to better involve patients in their own care. Urine toxicology screening would be performed in the spirit of trying to keep the patient safe from addiction. The principle of seeking and deserving the trust of society would serve as a balancing factor. For example, if the health care provider truly suspected malingering and diversion of prescription opiates, then the requirement to seek and deserve the trust of society would dictate that the prescription be discontinued. In addition to ethics, there are also very practical reasons to preserve trust. In HIV, trust in the health care provider is associated with adherence to antiretroviral therapy (Golin et al., 2002; Schneider, Kaplan, Greenfield, Li, & Wilson, 2004). In chronic pain, a trusting, therapeutic patient-provider relationship is considered crucial for successful outcomes (Frantsve & Kerns, 2007; Matthias et al., 2010).

In summary, the *Year of Ethics* provides an opportunity for practitioners committed to the care of HIV-infected patients to focus on strategies for ethical chronic pain management.

We believe that the principle of trust can be used to guide this endeavor and will help to fulfill the challenge presented by the American Nurses Association to promote justice and work to eliminate health care disparities.

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