Dear Dr. Marcin Chwistek,

We would like to express grave concern about the AAHPM Quarterly Winter 2020 Let’s Think About It Again case discussion on offering chemotherapy to a 45-year-old male with substance use disorder (SUD) who was recently diagnosed with extensive-stage small cell lung cancer.

Persons with SUD consistently experience barriers to appropriate care because of persistent healthcare stigma and poor understanding of the chronic disease that is addiction. Dr. Fulp’s counterpoint serves to only promote misconceptions about people who use drugs, does not reflect evidence-based addiction care, and furthers systemic bias that exacerbates long-standing disparities and punitive approaches to caring for individuals with SUD.

To demonstrate our view, we will focus on the following errors in the case: (1) lack of recognition of addiction as a treatable chronic disease, (2) missed opportunity to offer life-saving therapies through shared decision making, (3) absence of the application of trauma-informed care principles and 4) lost opportunity for harm reduction.

1. Dr. Fulp describes the individual continued heroin use akin to “lifestyle modifications,” implying that addiction is a choice. This view is in direct conflict with the American Society of Addiction Medicine definition of addiction as a “treatable, chronic medical disease …[where] prevention efforts and treatment approaches are generally as successful as those for other chronic diseases.” SUD is not a lifestyle choice- it is a chronic disease influenced by genetics and environment, where intermittent use of heroin signals periods of increased disease activity requiring more robust healthcare support – not a personal choice or moral failing. Overdose should thus be seen as a notable exacerbation of disease and an opportunity for engaging the patient in life-saving treatment.

2. Dr. Fulp’s piece also emphasized shared decision making but does not consider the patients’ goals and values regarding their substance use, or the fact that irrational and compulsive behaviors are often the outward manifestation of brain function compromised by active SUD. “Not taking Suboxone and managing his heroin use on his own” is not a goals and values discussion. As PC clinicians we regularly probe further to understand the rationale behind patients’ decisions- one could imagine that his recent homelessness and cancer diagnosis are significant stressors that may be triggering further substance use.

SUDs are diseases that deserve equal attention in their own right. In other disease states, when patients make decisions that we do not feel are in their best interest, we explore these decisions in a non-judgmental fashion and use communication techniques such as motivational interviewing and open-ended questions to orchestrate goal-concurrent care. Shared decision making in a patient with cancer and SUD warrants attention to each illness to optimize length and quality of life. In shared decision-making discussions clinicians elicit worries and also offer access to information to make choices that align with goals. Tools are available through the Substance Abuse and Mental Health Service Administration (SAMHSA) website that may have helped this patient better understand treatment options that fit his needs, and could also have helped providers with clinical/specialty mentorship in his care. Lastly, the patient’s interest in pursuing chemotherapy suggests a clear interest in life-prolonging treatment, which should not be undermined by the seeming appearance of decisions not to engage in SUD treatment. Patients with SUD often require multiple engagements with treatment before achieving remission, and may take several approaches, as active disease itself clouds the brain’s ability to make controlled, prudent choices around substance use.

3. Psychological trauma is incredibly common in a person with SUD and individuals should be provided with trauma-informed care that recognizes that medical treatment (including treatment of a life-threatening illness and substance use disorder) may be anxiety-producing resulting in avoidance of medical care. For some individuals, cancer serves as a traumatic event leading to symptoms typical in post-traumatic stress disorder. Individuals with substance use disorders are also more likely to experience housing or food instability, lack of social support, domestic and sexual violence, or involvement with the carceral system in the United States, putting them at further risk of experiencing traumatic events. Recognizing potential barriers to treatment and sources of suffering is core to providing both trauma informed care and palliative care. As PC clinicians we must respond with empathy and cultivate a safe environment—not one that denies standard medical care (which Dr. Fulp
acknowledges “seems cruel”). Understandably, the patient declining medication for addiction treatment at the same time at the first oncology visit may not reflect his/her long-term choices. Discussion of treatment options should be reviewed at each visit and integrated into standard practice to reduce barriers. Similarly, before confiscating the patient’s access to chemotherapy and deepening disparities in this patient’s care based on heroin use, a thorough differential for declining the Suboxone referral should be explored – did the patient have prior lack of effect with Suboxone for OUD, is Suboxone too expensive, would he rather engage in methadone maintenance treatment, is he worried Suboxone will not adequately treat underlying pain, etc.? Integrated treatment models that combine medication addiction treatment and life-saving treatment (such as endocarditis) have shown promising results.

4. There is a missed opportunity for a discussion of harm reduction and meeting the patient where he/she is in their illness. The case acknowledges a recent opioid overdose, at which point the authors should have sought to understand what led to the overdose and consider ways of preventing an overdose in the future such as offering naloxone, assessing current use, or recommending never-use-alone resources. According to the National Survey on Drug Use and Health, well over half of people who misuse opioids (prescription drug and heroin) report doing so to treat pain. The assumption that the patient was “self-titrating” heroin which led to an overdose fails to consider the many factors that can result in an overdose – some of which, like pain or anxiety due to a new cancer diagnosis – are especially well-suited to engagement with specialty PC care. Having a SUD does not equate to an inability to take medication as prescribed and this conclusion is dangerous. While undoubtedly this patient’s ongoing heroin use is harmful to his health and will complicate his oncology care, allowing him to die rapidly of his treatable (albeit not curable) cancer constitutes a far greater harm to him.

In summary, as palliative care clinicians with experience in addiction care through additional training, research, and clinical practice, we request that this piece be redacted. We understand the purpose of this series is to generate dialogue and that the point/counterpoint format can be used to share opposing views. We believe this counterpoint actively dehumanizes some of our most vulnerable patients and is harmful to our professional community and patients. It normalizes anti-patient stigma, only further gives voice to stigma, perpetuates outdated understandings of addiction, and validates harmful care in patients with serious illness and concurrent SUD. As all of us can attest to, providing care to individuals with SUD and serious illness can be challenging, but is also some of the most rewarding professional work we do.

Sincerely,
Katie Fitzgerald Jones MSN, Hospice & Palliative Care Nurse Practitioner VA Boston Healthcare System and Boston College School of Nursing

Janet Ho, MPH, MD Palliative and Addiction Medicine Physician University of California San Francisco

Zachary Sager, MD Psychiatrist and Hospice & Palliative Medicine Physician VA Boston Healthcare System

Drew Rosielle, MD Internal Medicine and Hospice and Palliative Care Physician University of Minnesota Medical Center

Jessica Merlin, MD, Ph.D., MBA Addiction Medicine, Infectious Disease, and Palliative Medicine Physician University of Pittsburg School of Medicine