ATTITUDES AND EXPERIENCES OF PALLIATIVE CARE PROVIDERS TOWARD PATIENTS WITH SUBSTANCE USE DISORDER

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Abstract

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As the U.S. population ages and older adults use substances at unprecedented rates, more patients with substance use disorder (SUD) will require medical care for serious illnesses. Despite shifting demographics and population care needs, there is a paucity of research on palliative care for patients with SUD. The limited literature at the intersection of palliative care and patients with SUD focuses on the challenges of safely prescribing to patients, excluding any other elements of care for this patient population. The current study is the first to explore the attitudes and experiences of palliative care providers of different disciplines toward patients with SUD. This research utilized an exploratory, qualitative methodology with semi-structured interviews with 14 interprofessional palliative care providers. Several salient themes emerged following a thematic analysis of interviews: the distinct roles and values of palliative care, the perception of patients with SUD as complex with complex care needs, awareness of stigma and desire to reduce impacts on patients, the multivariate factors that influence the development of SUD, and a spectrum of care strategies and identified training needs. The results of this study establish there are other relevant considerations for palliative care patients with SUD in addition to safe prescribing. Due to the lack of a comprehensive approach for palliative care patients with SUD, this study supports the need for further resources and training opportunities for providers. Patients with SUD also experience systemic marginalization, pointing to a need for greater structural shifts to reduce barriers to adequate care.

Keywords: palliative care, substance use disorder, serious illness

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Section One: Introduction

Defining Substance Use Disorder

Exploring the intersection of patients with substance use disorder (SUD) and palliative care requires that we define the diagnostic criteria of SUD within the medical model. The language used in the healthcare context and this paper reflects the language used in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) and International Classification of Diseases (ICD-11). The medical model utilizes standard diagnoses bestowed by healthcare providers according to the DSM-5 or ICD-11, and insurance reimbursement of treatment is conditional on a particular diagnosis. However, it is necessary to acknowledge the shortcomings of language and care provision within the context of the medical model. The dominant medical model posits that disease is a result of biological abnormalities that should be addressed or corrected, using a frame of deficit and fixing to pathologize patients without accounting for systemic factors on individual and community health (Brinkman et al., 2023; Wade & Halligan, 2004). Despite significant limitations, harmful impacts on historically marginalized groups (Washington et al., 2006), and the emergence of other models, the medical model is still pervasive in American systems, particularly within the context of managed care (Brinkman et al., 2023). This study is embedded within the American healthcare system and will therefore utilize the language of that system, with an awareness of its limitations and disadvantages.

The DSM-5 defines the essential feature of a SUD as a “cluster of cognitive, behavioral, and physiological symptoms indicating that the individual continues using the substance despite significant substance-related problems,” (American Psychiatric Association, 2013a). The DSM-5 groups substance-related problems into 11 criteria, which can be categorized into four categories: impaired control, social impairment, risky use, and physical dependence. SUD can be classified as mild, moderate, or severe depending on how many criterion items are met.

The World Health Organization (WHO) and the American Psychiatric Association made efforts to “harmonize” the DSM-5 and the 11th revision of the ICD (First et al., 2021). Whereas the DSM-5 defines a single SUD category, the ICD-11 delineates three disorders based on the pattern of use: episode of harmful substance, harmful pattern of substance use, and substance dependence (First et al., 2021). Despite their differences in the classification of SUDs, the DSM-5 provides instructions on utilizing a corresponding or compatible ICD code since the DSM does not have its own insurance billing codes (APA 2013b).

Notably, the ICD-11 and DSM-5 differ on the category of “dependence.” The DSM-5 replaced the substance abuse and substance dependence categories with the overarching category of substance use disorder (American Psychiatric Association, 2013a). The DSM-5 notes that the presence of physical dependence has been “easily confused with the term addiction,” even though tolerance and withdrawal are “very normal responses to prescribed medications that affect the central nervous system,” (American Psychiatric Association, 2013a). The DSM-5 highlights the omission of “addiction” as a diagnostic category despite widespread colloquial use, even among some clinicians. The APA acknowledges that addiction is not a clearly defined term and has a “potentially negative connotation,” (2013a). The APA’s allusion to stigma highlights the importance of precise terminology when describing substance use.

Substance Use and Stigma

People who use substances (PWUS) are often viewed with stigma which results in negative outcomes. Two factors influence stigma: cause and controllability (Kelly et al., 2015). Stigma decreases when people are perceived to have less responsibility and less control over a problem. PWUS are perceived to have caused a problem and unwilling to control it, deeming them “morally flawed,” (Fong et al., 2021; Gowan, 2010). Stigma results in harmful outcomes in healthcare and policy development and enforcement for PWUS (McGinty & White, 2022). Stigma does not impact all substance users in the same way – stigma and negative outcomes can be deflated or exacerbated based on the substance used and the identity of the user (Committee on the Science of Changing Behavioral Health Social Norms et al., 2016). For example, Black substance users are significantly more likely to be incarcerated for drug-related offenses than white substance users (Rosenberg et al, 2017). The National Institute on Drug Abuse (NIDA) highlighted that the criminalization of substance use provides a “social sanctioning of stigma,” which justifies further negative perceptions of PWUS and the consequences of “social rejection,” such as incarceration and withdrawal of care and resources (NIDA, 2023).

PWUS report experiencing high levels of stigma in medical settings. A systematic review found that healthcare providers hold negative attitudes regarding PWUS, resulting in shorter visits, lower empathy, and reduced personal engagement (van Boekel et al., 2013). PWUS report that stigma results in reduced self-efficacy and ability to communicate health concerns to providers (Clements, 2015; Fong, 2021). Due to stigma, there is less willingness to treat PWUS (Peckover & Chidlaw, 2007). PWUS also report delaying or avoiding care due to stigma, but when they access care, they are further disparaged for “causing” health conditions related to substance use (Fong, 2021). One study interviewed a patient who explained,

> I’d be afraid to go [to a specific hospital] if I could not breathe with my asthma. They’ll think it was something else, I do not know, and I’d probably die, so … I think they suspect that people are drug seeking right? And then they do not bother seeing if you are okay (Chan Carusone et al., 2019).

This quote illustrates how stigma in the medical system can permeate the healthcare experiences of PWUS.

Due to the negative impacts of stigma, it is important within this study and for providers at large to use non-stigmatizing language, even when language surrounding substance use is complex, changing, and dependent on in-group identities. Research details the importance of using non-stigmatizing language to reduce the impact of bias in professional settings (Healy et a., 2022), however, it is important to note that people in active substance use or in recovery may use self-identifying labels that professionals are encouraged to avoid such as “addict,” “alcoholic,” or “junkie” (Dingle et al., 2015). Michael Botticelli, director of the White House Office of National Drug Control Policy from 2014-2017, explains, “When you’re a member of a community, you have certain liberties in terms of what you call yourself, and those liberties are not extended, necessarily, to other people,” (Facher, 2022). Mindful of the fluidity of language around substance use, this project will refer to people who use alcohol or drugs as people who use substances (PWUS). Other terminology (such as substance abuse, addiction, or alcoholism) may be utilized when describing literature and research results to echo the source material.

Substance Use Disorders in the United States

According to the 2021 National Survey on Drug Use and Health, 46.3 million people over the age of 12 met DSM-5 criteria for SUD (SAMHSA, 2022). Of those people, 48% met criteria for an alcohol use disorder, 36% met criteria for a drug use disorder, and 16% met criteria for both alcohol and drug use disorder. SUD can result in significant costs to social, health, and economic systems (Lo, 2022) and contribute to a significant loss of life. Over the last twenty years, drug overdose deaths have increased fivefold (Spencer et al., 2022). The U.S. reached a grim milestone in 2021—the first time over 100,000 deaths by overdose were recorded in a single year. There are several factors contributing to the spike in overdose deaths, including the economic, social, and psychological risks of the global COVID-19 pandemic, which intensified substance use as well as reduced access to social and formalized supports (Ornell et al., 2020). Significant media attention has been dedicated to the "opioid epidemic," particularly as use shifts towards illicitly manufactured synthetic opioids like fentanyl and its analogues (Welhausen, 2022; Han, 2019). However, in 2021, there was also an increase in deaths related to psychostimulants (including methamphetamine) and cocaine (Spencer et al., 2022). Stimulant "overdoses" do not result in acute respiratory depression like an opioid overdose but have acute and chronic impacts on the cardiovascular and cerebrovascular systems that can be fatal (Harding et al., 2022). Despite statistics presenting substances used in isolation, many people who use substances are considered "polysubstance users," meaning they may use multiple substances on the same occasion or different drugs in different occasions (Crummy et al., 2020). Despite media focus on illicit substances, legal substances can also have significant impacts on individuals and communities – one recent study found alcohol to have the highest overall "harm score" of substances across domains of harm to self and others (Nutt et al., 2010).

Shifting Demographics in the U.S.

Alongside substance use trends, there is also an increase in older adults using substances. From 2020 to 2021, adults 65 and older experienced the largest proportional increase in drug overdose deaths, a 28% increase (Spencer et al., 2022). The number of adults 55 and over entering SUD treatment facilities increased by 203.7% from 2000 to 2017, compared to a 13.0%

increase for younger adults (Na et al., 2022). This trend is a departure from previous patterns since older adults historically do not have high rates of substance use (Han & Moore, 2018). The Baby Boomer generation reports higher substance use than any other previous generation and had more exposure to substances from a younger age, a risk factor for SUD later in life (Chhatre et al., 2017; Na et al., 2022). The proportion of older adults in the U.S. is steadily increasing – by 2030, all members of the Baby Boomer generation will be over 65 and older adults will make up 21% of the population (Vespa, 2018). As a population with higher rates of substance use continues to age, Han & Moore (2018) predict that the number of older adults engaging in "unhealthy substance use" is expected to "increase substantially to levels never seen before." Changing demographics and rates of substance use in older adults point to shifting demands in the healthcare system to meet the unique needs of this population.

Palliative Care

The Center to Advance Palliative Care (CAPC) defines palliative care as "specialized medical care for people with serious illness," (2022). Palliative care focuses on symptom relief, pain management, and attending to stress that accompanies life with a serious illness –with an emphasis on the quality of life for patients and their families. Unlike hospice, palliative care is not constrained to end-of-life care. Hospice services are only accessible to patients with a terminal diagnosis of 6 months or less, whereas palliative care is accessible to patients with serious, chronic, and lifelong illnesses (Hughes & Smith, 2014). Patients receiving palliative care may also receive parallel curative treatment, although there may be? some lack of clarity if curative treatment refers to eradication of disease or life-prolonging treatment (Center to Advance Palliative Care, 2014; Gaertner et al., 2014).

There are a variety of ways palliative care delivery models. The Joint Commission Advanced Certification for Palliative Care defines the core interdisciplinary palliative care team as a physician, registered nurse or advanced practice nurse, social worker, and chaplain (Rogers & Dumavosky, 2017). The interdisciplinary team works in collaboration with the patient and their healthcare team members to address physical, psychosocial, and spiritual needs. Palliative care is often povided in the inpatient setting, but as care has moved "upstream" for patients with serious illness, there has been significant growth in the number of outpatient programs (Merlin et al., 2019). Palliative care teams may directly oversee a patient's care or serve as a consult for the patient's primary team (Hughes & Smith, 2014).

Patients who receive palliative care report improved satisfaction and their families report increased self-efficacy (Hughes & Smith, 2014; Gelfman et al., 2008). Patients receiving palliative care have also reported improved symptom management (Alesi et al., 2011) and increased awareness of and attention given to end-of-life choices, such as place of death (Hughes & Smith, 2014). Palliative care also reduces 30-day hospital readmission rates (Cassel et al., 2018) and utilization of the emergency room (Scibetta et al., 2016) and ICU (Khandelwal et al., 2015). Due to these positive benefits for patients and health systems, palliative care has developed rapidly in the last two decades. In 2000, 24.5% of hospitals with 50 or more beds had a palliative care program which increased to 83.4% by 2020. The increase in palliative care utilization also corresponds with an aging population and an increase in the number of people living with a serious and chronic illness. (Hughes & Smith, 2014).

Prevalence of Substance Use Disorders in Palliative Care

Despite the changing rates in substance use among older adults, the increase in people living with serious illness, and the increased utilization in palliative care, there is limited research documenting the prevalence of patients with SUD in palliative care. A 1995 study on frequency of alcohol use disorder in patients with terminal patients found that up to 25% of them had a SUD (Bruera et al., 1995). However, the study sample consisted of 200 patients recruited in 1989 and 1992 and may not be representative of current rates of SUD in palliative care given demographic shifts, substance use rates, and the significant growth of palliative care in the last two decades. A 2012 survey of hospice and palliative care fellows across the country found that 77.2% of them had treated a patient with a SUD in the last two weeks (Childers & Arnold). A 2019 survey of 169 ambulatory palliative care providers found that providers experience “nearly ubiquitous” instances of “opioid misuse behaviors” which may be indicative of a SUD (Merlin at al., 2019).

Section Two: Literature Review

Opioids

There are limited resources for palliative care providers working with patients with a SUD with much of the literature focusing on concerns surrounding safe prescribing of opioids for pain management in the palliative context. The CDC Clinical Practice Guideline for Prescribing Opioids for Pain (Dowell et al., 2022) does not include recommendations for palliative care and there are no standardized guidelines for prescribing to palliative patients with an SUD (Chua et al., 2021). Providers must balance the desire to adequately address pain with a variety of concerns regarding opiates, such as undertreatment of pain, opioid misuse, opioid use disorder, diversion, and overdose or death. This is evident in the “Substance Abuse” curriculum sponsored by the Palliative Care Network of Wisconsin (PCNW) - one of the few accessible resources for providers at the intersection of SUD and palliative care - in which six out of the nine fact sheets related to substance use center opioids and pain management (PCNW, 2019).

Literature at the intersection of opioid prescribing and palliative care primarily focuses on symptom assessment and management, patient risk screening, and controlled substances prescribing practices (Groninger & Knapik, 2019). Patients reporting lost or stolen prescriptions, urine screens that show non-prescribed substances, or requests for early refills are considered "concerning signs" of nonmedical opioid use (Sager & Childers, 2019). Nonmedical use encompasses taking medication for symptoms other than prescribed (such as insomnia or anxiety) or for the experience opioids produce. There are several published opioid risk screen tools for cancer patients in palliative care (Wells-Di Gregorio, 2022) but literature is lacking regarding the care plans that follow screening tools.

The literature that describes opioid prescribing strategies when working with palliative care patients with SUD are discordant. Sager and Childers (2019) provide a conversation guide for prescribing clinicians to use when discussing concerns about nonmedical use for opioids, highlighting a "stance of nonabandonment" when approaching this topic with patients. Sager and Childers describe utilizing a "benefit-to-harm framework" and the necessity of providers setting clear limits with patients when opioids will not be prescribed. Literature recognizes that opioid prescribing practices are dependent on prognosis, noting that patients with a short prognosis may have a benefit from opioids that outweigh the risks (Sager & Childers, 2019; Morrison et al. 2022). One study acknowledges patients with a longer prognosis who are actively using substances should be tapered from opioids (Sager & Childers, 2019), which conflicts with a recent consensus-based study that found that it inappropriate to taper opioids for patients with concurrent methamphetamine or cocaine use (Morrison et al., 2022). Instead, the consensus-based study recommended continuance of opioid therapy and additional monitoring of the patient, possibly transitioning patients to buprenorphine/naloxone to mitigate the risk of simulant contamination. In the literature that does address safe prescribing for patients with SUD, there is some conflict regarding direct practice strategies.

Alcohol

There is literature describing the particular care needs of patients with “alcohol dependence.” Like literature focused on opioids in the palliative care context, there are several validated assessment tools available to identify risk or presence of alcohol use disorder. Patients with alcohol use disorder are at an increased risk for chronic pain which can make pain management more difficult (MacCormac, 2017). Patients with alcohol use disorder are also more likely to experience psychiatric comorbidities, (Castillo-Carniglia et al., 2019) social isolation (MacCormac, 2017) and financial barriers (Podymow et al., 2006) and may require greater psychosocial and financial support. If patients pursue alcohol abstinence, it is recommended they detox in an inpatient setting so their complex medical needs can be monitored and addressed. There are medications available to treat alcohol use disorder, but lorazepam, acamprosate, and naltrexone are contraindicated in patients with serious liver disease which is significant because a patient’s liver disease may be secondary to alcohol use (MacCormac, 2017). Patients may pursue controlled alcohol use, but this can pose a particular barrier if they require admission to a hospital or long-term care facility who not provide controlled use. Acute alcohol withdrawal is a concern in the palliative context, because withdrawal causes patients to suffer and the symptoms can be fatal (Band et al., 2015). A recent systemic review notes, “There is currently no consensus on the management of alcohol dependence in the palliative care setting,” (MacCormac, 2017).

Stimulants

Literature on palliative care patients with stimulant use disorder is extremely limited. Morrison et al. (2022) described consensus-based opinions for opioid therapy in patients who also use cocaine or methamphetamine but remained focused on opioid pain management. Some providers in the study reported transitioning their patients to buprenorphine/naloxone for pain control, but only due to concern of stimulant contamination with opioids. However, it is necessary to note that stimulant use, even absent opioid contamination, has specific impacts on disease progression and organ systems. Use of amphetamine and crack cocaine expediate HIV and HCV disease progression, leading to increased rates of AIDS-related cancers and infections (McNeil et al., 2012). Methamphetamine can be toxic for the cardiovascular, pulmonary, neurological, and hepatic systems, and patients are at risk for "compound multimorbidity." Researchers acknowledge the need for integrated interventions to be able to address the specific needs of patients who use this substance class (Han & Palamar, 2021).

Psychosocial Domain

In addition to pain and symptom management, CAPC highlights palliative care's role in addressing stress related to serious illness to improve quality life for the patient and family (CAPAC, 2022). Palliative care social workers and chaplains are both uniquely positioned to address stress in the psychosocial and spiritual realm, however, there is limited research defining both roles in caring for patients with SUD and much of it focuses directly on end-of-life support. The James Cancer Hospital palliative care team and the Lifespan Cancer Institute describe the utilization of behavioral health professionals and spiritual care workers while working with patients with SUD, but they do not specify the role of these providers, or the specific strategies utilized to support patients (Nickels et al., 2022; Wells-Di Gregorio et al., 2022). Beyond the recommendation of referring patients to 12-step recovery programs, there is no literature defining the role of palliative care chaplains in care for patients with SUD (Groninger & Knapik, 2019). Significantly, this approach does account for patients not pursuing abstinence from substance use or being precluded from participation in 12-step programs due to non-Christian orientations (Donovan et al., 2013).

The primary identified tasks of palliative care social workers include addressing psychosocial concerns of patient and family, coordinating advanced care planning, and providing bereavement support to loved ones (Brandsen, 2005). Psychosocial concerns of patients with SUD may also include support with a coexisting mental health disorder – commonly referred to as a co-occurring disorder. A 2017 study on the 2018-2014 NIDA National Survey on Drug Use and Health found that 37.9% of all people living with a substance use disorder also live with mental illness (Han et al., 2017). Research on patients living with HIV and SUD emphasizes grief and bereavement counseling, which can be delivered through various modalities (Durvasula & Miller, 2014). Identified interventions include abstinence-based substance use counseling, twelve-step programs, and art therapy (Lau et al., 2022)

Palliative Care Provider Experience

Palliative care providers report varying levels of confidence when working with this particular patient population, but literature primarily focuses on providers with prescribing authority. A 2019 national survey of palliative care physicians and nurse practitioners found that they were least confident in their ability to “manage addiction” and prescribe naloxone. Providers reported higher confidence in tracking measures, such as utilizing urine testing and using prescription monitoring programs. In that survey, only 27% reported they had addiction training (Merlin et al., 2019), which is consistent with other palliative provider surveys exploring SUD education (Childers & Arnold, 2012). A 2011 qualitative study found that medical and social service providers identified patient non-disclosure of use and lack of training as a barrier to care for unhoused patients with SUDs (McNeil & Guirguis-Younger, 2012). The interviewees observed that there was “seldom” overlap between SUD training and end-of-life care, which they believed to be harmful to their patients. Childers & Arnold (2012) surveyed hospice and palliative care fellows and found the majority of fellows “receive little training in this area and have low perceived competency.” Only 21.1% of the fellows were satisfied with their ability to treat pain in patients with SUDs. Prescribing providers report feeling “uncomfortable” providing care related to a SUD without consulting addiction medicine providers and some providers feel like it is not their role to address SUD at all (Jones et al., 2021). However, the authors of the study argue that palliative care providers should develop clinical skills to meet the needs of patients with SUD, highlighting the “abundant” shared values between palliative care and principles of SUD treatment. They assert within the context of palliative care, it is appropriate to relieve the impacts of SUD which contribute to higher levels of mortality and increased suffering (Jones et al., 2021). Providers recognize these patients require a “high level of skill” (Childers & Arnold, 2019) and mainstream palliative care models are not built to meet the needs of patients with SUDs (Buchman et al., 2022). Since literature at the intersection of palliative care and SUD is so limited, it is unclear what factors, elements, or attitudes providers consider in treatment of these patients. The purpose of this study is to identify factors, elements, and attitudes that influence interprofessional palliative care providers caring for patients with SUD.

Section Three: Methodology

Study Design

This study investigates provider attitudes and experiences with patients with SUD to identify salient factors that influence patient care, using an exploratory design with a qualitative approach. The present study received approval from the University of Washington Institutional Review Board, study ID STUDY00016617.

Recruitment and Criteria

Providers were recruited using convenience snowball sampling through professional contacts of primary investigator and committee members. Prospective participants were recruited via an email graphic with study participation criteria. To participate in the study, providers were required to be a palliative care provider in the state of Washington and provided care for a patient with SUD. Participants completed informed consent and a basic demographic survey using the secure web application REDCap.

Participants

The term "provider" is used to describe providers of all discipline types unless otherwise specified. The sample size consisted of fourteen providers: five advanced registered nurse practitioners (ARNPs), four medical doctors (MDs), three social workers, one nurse, and one chaplain. Two providers identified as male, twelve identified as female. One provider identified as Asian, two as multiracial, and eleven as white. Participants' ages ranged from 29-66 (mean 44.4). On average, participants practiced palliative care for 5.6 years.

Measures and Data Collection

Providers completed a semi-structured interview exploring several domains: understanding of SUD, education related to SUD, and method of addressing SUD with patients (Appendix A). Participants were interviewed via phone or Zoom. All interviews were recorded, verbal consent was obtained prior to recording.

Analysis

Interviews were listened to and transcribed. Interviews transcripts were coded using ATLAS.ti, a qualitative data analysis software. Coding was conducted through an iterative process, utilizing hand-coding and ATLAS.ti. Codes were also reviewed for methodological and substantive accuracy with two experts in the field. This study employed a thematic analysis of interviews to identify salient attitudes and experiences of palliative care providers when working with patients with SUD.

Section Four: Results

The purpose of this study was to explore attitudes and experiences of palliative care providers regarding patients with SUD. Five emergent themes were identified following analysis of interviews of fourteen interprofessional providers: (1) the distinct role and values of palliative care, (2) patients with SUD identified by providers as complex with complex needs (3) awareness of and desire to reduce impacts of stigma for patients with SUD, (4) acknowledgement of wide spectrum of factors contributing to the development of SUD, and (5) specturm of seategies for this patient population and identified training needs. See Table 1 for further illustration of themes and subthemes.

Table 1

Themes and Subthemes of Semi-Structured Interviews

Themes	Subthemes
Distinct Roles and Values of Palliative Care	• Individualized patient care • Collaborative, values-based communication • Recognition of patient and provider goal disparities • Palliative care distinct from rest of medical system • Inherently interdisciplinary
Patient Identified as Complex with Complex Needs	• Concern for safe prescribing • SUD as a barrier to participation in care • Barriers in continuity of care • Co-existing systemic vulnerabilities • Difficulties in communication • Impact on support system • Care dependent on variable prognosis
Awareness of Stigma and Desire to Reduce Impacts on Patients	• Recognition of stigma in the healthcare system for patients with SUD • Desire to be a non-stigmatizing provider • Actions taken to address stigma
Multivariate Factors Contributing to SUD Development	• Trauma • Environment • Mental health • Genetics • Interacting Factors
Spectrum of Strategies and Identified Training Needs	• A spectrum of approaches for patients with SUD • Identified training needs

Distinct Role and Values of Palliative Care

Providers highlighted the distinct role of palliative care within the context of the larger healthcare ecosystem and values and how those values guide care for patients with SUD. Palliative care was defined as patient-specific and driven by patient values. Communication in the palliative context was defined as exploratory, collaborative, and in alignment with elicited patient values. This theme also highlighted the importance of treating the patient holistically, fostered through intentional rapport and relationship building. Providers also acknowledged the difference between the values of palliative care versus the larger healthcare system, recognizing that palliative care has a particular capacity to create more in-depth connections with their patients and families. Providers described their awareness of goal discrepancies between themselves and patients, highlighting palliative care's unique prioritization of the patient's values and goals. One ARNP reported,

> My goals will probably never be a priority to them. So what can I do to improve their life...and understanding that that it may never align with mine. Our goals - you may not live as long as I would like you to live because you're choosing differently, and I can't change that. And that's really hard. Like your choices may end your life sooner. But I'm gonna try and keep you as healthy as possible for as long as possible.

Providers explicitly mentioned the interdisciplinary, team-based approach of palliative care. Providers continuously referred to consulting with team members and utilizing each member's skill set when making decisions or recommendations. Providers described an environment where all team members were oriented towards these palliative-specific values. This study also pointed to the particular capacity of the social worker on the palliative care team when working with patients with SUD. Social workers were described as helpful resources to reduce or address communication barriers, one of this study's identified factors that contribute to patient complexity. Social workers also have the capacity to support the patient's friends, family, and loved ones – relationships that providers in this study acknowledged can be significantly impacted by a SUD.

Patient Identified as Complex with Complex Needs

Providers perceived patients with SUD as complex and requiring more intensive care. Patient complexity was defined by several factors: (1) need for safe prescribing, (2) SUD impacting a patient's ability to participate in care, (3) barriers in continuity of care, (4) coexisting systemic vulnerabilities (5), communication difficulty, (6) impact on patient social support system, and (7) a care plan highly dependent on prognosis, and the impact of substance use on prognosis. Providers described the complications of safe prescribing of opiates for pain management. Patients with SUD could have a higher tolerance for opioids, request opioids for non-acute, physical pain, or simultaneously be using community-acquired opioids (such as heroin or fentanyl). One provider MD explained the difficulty of prescribing to patients with SUD,

> When you're working in a palliative context, you're always weighing with the patient and oftentimes in totally complex situations, consulting with your colleagues to figure out, well what's the medium here to make sure that you're getting good symptom control, while also doing safe prescribing.

Providers described the importance of safe prescribing for themselves and their patients. Patient safety encompassed physical and psychological safety – which can be threatened by accidental or intentional overdose, either through opiates or a combination of prescribed opiates, community-acquired opiates, benzodiazepines, or alcohol. Provider safety, on the other hand, encompassed not only patient safety, but broader considerations such as: desire to treat acute pain opposed to chronic pain, concern about medication diversion, maintenance of the provider's medical license, aversion to "enabling" a SUD, and personal moral distress. Providers also described some role confusion with other members of the healthcare team who prescribe medications for opioid use disorder (MOUD, like methadone and buprenorphine). Patients may be required to receive MOUD from a MOUD clinic while pain management medication prescribed by palliative care providers, causing role confusion and increasing the risk for discordant patient care. One physician recalled the predicament of prescribing methadone to a past patient without being a part of an opioid treatment program,

> So what is the patient's goal? What is the best way to support him and the family in this situation? And that's the driver to me. And you're trying to stay safe and maintain my license...I had a patient who I probably met when she was ten…and later it turns out she's an injection drug user. She has HIV. She was dying of complications of AIDS and was going to be on methadone. I was going to prescribe the methadone for her and prescribe it for pain. But it's dicey because methadone for opioid use disorder is once a day. And if the indication is opiate use disorder, you have to be part of a federally certified program, and I'm not. Or you can say, oh, wink wink, I'm doing it for pain. It's two or three times a day. And that's a very dicey situation. My supervising physician at the time really leaned into that with me and said, you're going to lose your license if you prescribe this person methadone. What are you doing? But just another example of, well, how do you parse it out? … But just another example of she needed her symptoms managed. She was very open that she had opiate use disorder. What do you do with that?

Providers also described SUD negatively impacting a patient's ability to participate in a care plan. A SUD could limit a patient's ability to participate in care provided within the highly structured medical system: patients may have difficulty keeping track of dates and times or balancing competing needs that result in missed appointments. Providers also described concern regarding patients' level of presence during appointments and the ability to have goals of care conversations if the patient is intoxicated. The impacts of a SUD may also interfere with a patient's ability to meet their self-defined care goals. If a patient expresses a desire to see their grandchildren get married but their substance use is rapidly impacting the trajectory of their disease, they may not be able to achieve their goal. Barriers to continuity of care were also identified for patients with SUD. Discharge planning can be complicated, particularly if family relationships are strained to the point that patients cannot discharge to their care and skilled nursing facilities and adult family homes decline referrals for patients with SUD. Inpatient providers are described the difficulty in finding an outpatient provider willing and available to assume care of patients with SUD. Providers acknowledged that patients with SUD were also more likely to experience systemic marginalization, which could be a factor in reduced continuity of care capacity. Providers identified various social determinants of health impacting patients with SUD: poverty, racism, access to housing, and access to transportation. An ARNP reflected on the tension between meeting system metrics and awareness of patient contexts,

> ...they are truly, just purely trying to survive and they don't know where housing is gonna come next month. They don't know where their food is going to come next month. They barely have money to get to your appointment. They're taking the bus.

Providers also described communication concerns with patients, particularly if there was a perception of the patient’s actions not corresponding with stated goals. Providers also acknowledged that patients may not have access to a robust support system due to relational harms related to SUD, leading to reduced informal care. A social worker described an experience with a past patient,

> ...and then you have the person that's alone. Because you know, we had a gentleman for 30 years of drinking and his whole -he got divorced. He lost his kids. One of his daughters was never got back involved with him, and the other daughter was like, ‘Okay, he has cancer. I will help him as much as I can, but I have to have some good boundaries with him because he is actively drinking and has never acknowledged this is an issue.’

Providers also described concern when a patient’s support system is entirely comprised of other individuals in active substance use. They described action steps taken to ensure that patients could not receive community-acquired substances in the hospital, such as ensuring that security accompanied their support person into the patient’s hospital room. Palliative care providers, particularly prescribing providers, consistently highlighted that their treatment approach is dependent on the patient’s prognosis. However, disease trajectory and prognosis can be complicated by the physical impacts of a SUD. One provider described the prognosis of a patient with heart failure, ,

> And they’re probably going to die very soon if they don’t stop meth, and even it may have gone to where their heart can’t repair, but their prognosis matters based off of their meth use.

Awareness of Stigma and Desire to Reduce Impacts

Providers expressed awareness of and desire to mitigate or reduce the negative impacts of stigma on patients with SUD. Providers identified negative stereotypes about patients with SUD adversely affecting patients in the denial of care or provision of substandard care from other providers in the healthcare system. An ARNP observed,

> There's often this feeling of they're at odds. They’re at odds with the medical team - not their fault. But the medical team is just as much at odds with them, you know, like there's like nobody's gelling. Everyone's mad at each other.

Providers were particularly aware of the importance of using non-stigmatizing language when describing these patients. Providers expressed a desire to be perceived as non-stigmatizing, emphasizing their desire that patients feel comfortable and not judged by them:

> I think it's something I always feel like it comes awkwardly out of my mouth because it's like, is it substance abuse? Is it substance use disorder? Is it alcohol use disorder? Drug user disorder? But I'm always trying to say the right thing and be sensitive about it because it is something I have zero rights to judge whatsoever about.

Providers discussed some strategies they took to address stigma within the medical system – modeling reflection on their own biases, challenging non-patient centered language, and providing education to peers.

Multivariate Factors Contributing to SUD Development

Providers identified various factors that can contribute to a SUD. Providers paid particular attention to the impact of childhood trauma on SUD development, referencing the CDC-Kaiser Permanente 1998 Adverse Childhood Experiences (ACE) Study (Felitti et al., 1998). Providers described individual-level traumatic events patients experienced, such as interpersonal violence, verbal abuse, and sexual violence – all events captured in an ACE score. Providers conceptualized substance use as a coping or self-soothing strategy from trauma or other negative life experiences. One physician reflected on the impact of trauma on her patients,

> I think I hear a lot of folks with stories and childhood trauma. And so you know, feeling like they didn't have kind of a solid place to go to with a parent figure, or sibling, or something where they felt kind of psychologically safe. And so I think that that's a piece of it, but sort of physical, psychological, sexual trauma. And then I think also that there seems to be like – what do you call it...like sort of a hopelessness kind of piece or something. Where if you're in a situation where you do have access to, I don't know, after school activities, to a job, to mentors, to that sort of thing that that you have these ways to have comfort and to sort of self-regulate or something that probably kind of crowd out the space that substances might have.

Other contributing factors included the presence of diagnosed or undiagnosed mental health conditions. Providers also recognized intergenerational elements that contribute to a SUD such as genetic predisposition and family or community environment. Providers also expressed awareness that there is often not a singular factor that can lead to the development of an SUD. One provider explained the multifactor nature of SUD development,

> I think that people have substance use disorders for myriad of reasons. I don't think there's just - it's because of this, it's because of this. There's a lot of different things that can lead someone to have a substance use disorder.

A Spectrum of Strategies and Identified Training Needs

Providers described a spectrum of strategies when working with patients with SUD, reflecting the variable educational and training backgrounds regarding this patient population. Providers discussed the spectrum strategies when working with these patients: some providers described encouraging abstinence from substance use or reduction of use. One ARNP described how their clinic approaches palliative care for patients with SUD,

> We take it from an individual basis, and we do like pretty much a risk analysis between our team and be like, what can we do to feel safe in this? Because we have to feel safe as well. We would feel terrible, knowing that we expedited someone's leaving this earth from our medications. But there has to be some kind of active participation to reduce their usage, and that goes with like alcohol, too. And so there has to be active pursuing of reducing that, whether that be with substance abuse treatment. Whether that be you know, you have to continue with your counseling. We try to develop that plan with them, and it's just really close follow up.

Other providers describe a harm reduction approach. A provider who endorsed a harm reduction orientation explained how they conceptualize it in practice:

> A lot of clinics would say, well, if you're using, we're not gonna see you or we're not, you know, like they would just kind of cut people off right? So I think a lot of it is like, how are you meeting people where they're at? We're not just gonna cut off services. We're not going to stop seeing you. We might set other kind of boundaries, you know. We might set other kind of limits that are safety-directed, or that sort of thing.

Across the spectrum of orientations towards substance use, providers described an array of practice strategies when working with patients with SUD. Some providers described the implementation of management plans to reduce substance use, which involved increased coordination with behavioral health providers, more visits with medical providers, shorter prescribing intervals, MOUD, and promotion of naloxone. Providers also described the need for patients to complete narcotics contracts or behavioral contracts regarding substance use. Some providers described monitoring strategies for patients such as lock boxes for medication, pill counts, and the regular use of urine analysis.

The spectrum orientations and practice strategies correspond with the varied education and training levels reported by providers. Some providers reported receiving general education specific to SUD but identified some knowledge gaps and a desire for additional training focusing on the actual practice of working with this patient population. Providers who described training specific to SUD noted they had pursued it on their own, mentioning resources such as SAMHSA, topical books, or podcasts. One ARNP explained,

> It was not offered in my curriculum. It's not offered as part of, like my team. We do journal clubs, so we have like a methadone article, and we had, like a week or two ago, a research article how on oncologists felt prescribing opioids for patients who were at risk of opioid misuse. And so we have conversations around it for sure. I think we're all thinking about it, but it's not like systematically part of our training.

Providers articulated a desire for more educational resources at the intersection of palliative care and substance use disorders, particularly in training that accounts for the highly contextual and individualized care for these patients. A physician described a hope for meaningful training in this practice area:

> I mean I think you could imagine that there would be more role play, more drill-based practice of like, if you've got this patient, have this interaction, what would you actually do? No, I'm gonna go to an hour talk, and I'm gonna listen. And then when I'm actually out into practice, I don't actually know what I'm doing. So I think that there's a huge training need and a huge education for high quality kind of actually like simulation-based training in this area.

Section Five: Discussion

This study set out to explore interprofessional palliative care provider attitudes and experiences regarding patients with SUD. Providers in this study described salient elements in palliative care for patients with SUD that have been unattended to in existing literature. Results affirm the value of an interdisciplinary team and suggest that social workers have a unique capacity to support patients with SUD receiving palliative care. Providers identified patients as complex, but patient complexity was often illustrative of systemic gaps or marginalization. Providers described their observation of significant trauma exposure in patients with SUD but did not identify trauma-specific interventions. The trauma-informed care model could be integrated into palliative care for patients with SUD, but there are clear tensions between the stated values of palliative care that account for trauma and risk management surrounding safe prescribing. Palliative care providers described assorted strategies when working with patients with SUD, establishing a clear need for accessible guidelines at the intersection of palliative care and SUD.

Interdisciplinary Nature of Palliative Care

Providers emphasized the interdisciplinary nature of palliative care when describing experiences and orientations in care of patients with SUD. Much of the literature on patients with SUD in the palliative realm focuses on professions with prescriptive authority (Merlin et al., 2019; Jones et al., 2021; Childers & Arnold, 2019; Sager & Childers, 2019). This is the first qualitative study to include multiple disciplines on the palliative care team, affirming the utility of professionals without prescriptive authority on the palliative care team such as nurses, social workers, and chaplains. Despite only certain members of the palliative care team working with prescriptive authority, providers described working environments in which various disciplines participated in creating and supporting the patient’s treatment plan. Providers described other members of the team as resources of practice knowledge, indicating they often sought each other's advice or expertise when working with patients with SUD.

The role of the social worker described in this study aligns with existing research delineating specific social work tasks on a palliative care team (Brandsen, 2005). Social workers may also be uniquely equipped to support patients with SUD because their professional orientation inherently recognizes the presence of individual, community, and systemic factors of SUD. Since social workers utilize a “person-in-environment” approach that recognizes patients and their loved ones embedded within a greater social context. In this study, providers noted the impact of systemic factors on patients with substance use disorder, such as poverty, geographic location, access to housing, and race. A person-in-environment framework incorporates these systemic factors into the understanding of SUD as a condition encompassing physical, psychological, and environmental factors. Social work may contribute to a more comprehensive understanding of the cause and controllability in SUDs. Accounting for the influence of systemic factors in cause and controllability can reduce the level at which the patient is stigmatized and seen “to blame” for a SUD. Social workers are then able to model this orientation in interactions with other members of their team, aiming to reduce the impact of stigma on patients with SUD.

Role of Trauma and Practice Implications

In this study, providers were explicit in describing the link they observed between SUD and trauma experiences, expressing awareness that the patient has a higher likelihood of active trauma or trauma history. While providers in this study described interpersonal forms of trauma, systemic factors providers identified as impacting patients with SUD can also be traumatic. Trauma is defined by the presence of physical or emotional harm, the overwhelming of an individual’s ability to cope, and adverse impacts on well-being and functioning (Husum & Edvardsen, 2011). For example, people experiencing homelessness can experience individual-level traumatic events, but the experience of homelessness, in and of itself, can be traumatic (Winn et al., 2011). Poverty is also a form of trauma – as it causes harm, overburdens an individual’s coping mechanisms, and has significantly harmful impacts on functioning (Husum & Edvardsen, 2011). This study indicates that palliative care providers perceive patients with SUD to have higher exposures to trauma. However, their perception of trauma is heavily influenced by the ACE score and did not account for the systems-level trauma that patients experience. Again, this points to the role of social work and a “person-in-environment” lens to provide support for both the patient and team members, since social workers’ professional orientation facilitates a more robust analysis of trauma that encompass individual and systemic-level factors. Social workers should be equipped to resist overpathologizing behavior and to recognize the “complex nexus between poverty, oppression, and trauma,” (Levenson, 2017). In addition to utilizing an ecological approach, social workers are also trained in competency-based approaches to address systemic barriers impeding patients from accessing care (Ross & de Saxe Zerden, 2020).

The findings in this study build on the existing literature linking trauma exposure and higher likelihood of SUD (Khoury et al., 2010), supporting the use of a patient care approach that accounts for trauma in the palliative care setting. Trauma-informed care (TIC) is an emerging framework to service delivery that recognizes the impact of trauma on physical, emotional, cognitive, and behavioral symptoms in systems of care (Blanch, 2012; Leitch 2017). TIC prescribes a set of basic principles: safety, trust, choice, collaboration, and empowerment. These principles can be utilized to avoid re-traumatization and promote a sense of safety, power, and self-worth (Blanch, 2012). Despite providers' awareness of the relationship between trauma and SUD, there was little mention of how patient trauma modified patient care. TIC in the palliative context could be integrated to maximize safety, trust, choice, collaboration, and empowerment, but it is necessary to recognize limitations of TIC implementation in the current healthcare system. The medical system is a high-barrier, hierarchal ecosystem that traditionally emphasizes adherence to provider-defined treatment plans and has caused historical and active harm to marginalized communities. Patients moving through this ecosystem may experience unavoidable retraumatization and palliative care providers are position to recognize the harms of the medical system, acknowledge harm to patients, partner with patients to disrupt harmful practices, and promote healing and empowerment whenever possible.

Even though providers did not explicitly articulate the integration of trauma-informed interventions in the palliative care setting, there is significant overlap in the distinct values identified by providers and TIC. One of the principles of TIC is empowerment and choice - recognizing someone's individuality, their experiences, and inherent wisdom. Providers described the integration of palliative care values that echo this principle, such as their emphasis on providing care specific to the individual, led by the patient's own values and goals. Providers also discussed the importance of collaborating with patients when discussing treatment goals, aligning with the TIC value of collaboration and mutuality. Providers acknowledged that a relationship defined by mutual decision-making meant that the patient's articulated goals might not align with the provider's goals for the patient. The acknowledgment of this disparity and disinclination to prioritize the provider's goals indicates a willingness of providers to cede decision-making power to the patient.

Despite the acknowledgement of goal disparity between patient and provider, there was a limit in how far providers are willing and able to cede decision-making power. Providers verbalized prioritizing patient goals, but when discussing safe prescribing, providers described more unilateral decision-making processes. Some of these unilateral processes included required behavioral or medication contracts, urine analysis, and the reduction or cessation of opiates. For example, behavioral management or controlled substance contracts are generally focused on the roles and responsibilities of the patient, not the provider. They also describe the punitive measures that will be taken should a patient violate the terms of the contract. The evidence supporting contract efficacy on reducing undesirable behavior is weak suggesting instead that contracts build a culture of mistrust and reinforce the power of providers over patients (Payne & Twilman, 2014). In unilateral decision-making practices, there is more emphasis on the provider's authoritative role, because providers must weigh safety for the patient and safety for themselves when prescribing opiates. This aligns with a TIC system, which ensures physical and psychological safety for service providers and service consumers. However, providers also described factors related to safe prescribing that moved beyond the realm of their personal safety and into system risk management. Understandably, providers are invested in maintaining their license and not risking harm to others. However, prioritizing provider risk management happens at the expense of patient self-determination and collaborative decision-making that is one of the distinct features of palliative care. Sara Doud, a social worker who works with unsheltered queer and trans youth, explains why the continuous prioritization of reducing provider risk makes it impossible to prioritize patient/consumer autonomy. Doud emphasizes, “Liability laws and other bureaucracy make the practice of honor what people want to do with their bodies nearly impossible. We’d get fired, license revoked, maybe even arrested,” (Hassan, p. 28). The tension between patient and provider safety points to larger difficulties of integrating a trauma-informed approach into the medical system, a hierarchical structure not structured empower patient autonomy and choice (Heller et al., 2004).

Patient Complexity Linked to Systemic Marginalization

Palliative care providers consistently described the complexity in treating patients with SUD. If patient complexity is defined as “one for whom clinical decision-making and required care processes are not routine or standard” (Weiss, 2007), patients with SUD certainly meet criteria, since their care does involve deviation from the norm. For example, providers described the impact of SUD on prognoses, which can make planning for future care more difficult, since the course of disease will fluctuate because of SUD. Providers in this study and in published literature described shifting to a more lenient approach regarding opioid prescribing when the patient is close to death (Sager & Childers, 2019; Morrison et al. 2022), although there is no specific timeframe in the literature that establishes when providers should change orientations, which was echoed by providers in this study. SUD makes prognoses less predictable, since the rate of use and type of substance used will impact the rate and trajectory of the disease and increase the likelihood of sudden death because of substance use. Therefore, it is even more difficult to predict when a prescribing orientation will change from more restrictive to less restrictive to provide comfort and pain relief as patients are actively dying.

Notably, some of the complexity described by providers in this study was not indicative of an inherently complex patient, but a result of marginalization in the medical system and unmet social needs of patients with SUD. Providers described specific instances that attribute perceived patient complexity as a result of systemic gaps, particularly regarding discharge from an inpatient setting and continuity of care. Patients experiencing homelessness may be difficult to discharge from the inpatient setting, but this is not due to their inherent complexity as patients – it is a result of appropriate disposition options. Shelters are not always safe or desirable disposition plans for patients for a variety of reasons (Donley & Wright, 2012) nor are they necessarily equipped to provide care for patients with complex medical needs, even with a medical respite program (Hadenfeldt et al., 2023). Patients with a SUD also experience significantly higher referral failures to SNFs, AFHs, or hospice placements. (Waters et al., 2022; Kimmel et al., 2020). Unfortunately, both providers and patients are navigating a care system that is not build to meet the needs of palliative care patients with SUD. Kirschner (2020) emphasizes, “The onus should not be on the individual clinician to fix the problem [of complexity], nor should the patient be blamed. These are structural problems that require structural solutions.” Impediments in continuity of care are not necessarily due to any fault of the patient or provider but illuminate structural gaps that must be addressed in larger systems of care.

Spectrum of Strategies

Providers described an array of orientations and strategies when providing palliative care for patients with SUD, from utilizing interventions or referrals to promote abstinence to harm reduction strategies. There were mixed responses on how, or even if, providers should address a SUD in palliative care, corresponding with a recent survey of palliative care physicians (Merlin et al., 2019). There was no clear consensus on the best way to meet the needs of these patients, which is remarkable given their identified complexity. However, the lack of consensus reflects the highly varied level of SUD-focused education and training received by providers and the general lack of resources at the intersection of palliative care and SUD. Providers described needing to personally seek out SUD-specialized knowledge or training, but there was an identified lack of available SUD resources specific to the palliative care context. There are no evidence-based practices providers can incorporate into practice (Dowell et al., 2022; Chua et al., 2021; MacCormac, 2017). Again, literature focuses on concerns regarding the safe prescription of opioids, but the literature available describes conflicting approaches regarding prescribing (Sagers & Childers, 2019; Morrison et al., 2022). Given the identified complexity of patients with SUD and the importance of providing non-stigmatizing care to this patient population, resources should be readily available for interprofessional providers to integrate into palliative care for patients with SUD that address prescribing, trauma-informed interventions, support system dynamics, communication, and systemic marginalization. Otherwise, providers are left to patch together care strategies from other sources that may not entirely translate into palliative care.

Limitations

The present study contains several limitations. Participants in this project were recruited via snowball sampling and many of the providers were embedded in a metropolitan hospital system, so there is a possibility results are impacted by sampling bias. Providers may have access to specialty referrals such as addiction medicine or have access to more community programs to support patients with SUD. Results may not be as generalizable to providers practicing in a rural setting or in less-resourced areas. However, regardless of practice location, there is a consistent lack of resources for palliative care providers to integrate into care for patients with SUD. This is the first known qualitative study of interprofessional providers and can therefore serve as a foundation to guide future, regional-specific inquiry.

Further Research, Practice and Policy Implications

Future Research

Given the emphasis of patient-driven care in the palliative context, the lack of patient voice and experience in the literature is troublesome. Future research should explore the prevalence of patients with SUD receiving palliative care as well as any barriers to referral and engagement in palliative care. There is currently only one study exploring patient experience at the intersection of palliative care and SUD conducted in the Netherlands - significantly different healthcare landscape than the U.S. (Ebeanu, 2020). Particularly within the context of identified palliative care values and TIC, it is imperative that patient experiences and needs are explored in future research.

Future research should expound on the integration of TIC in palliative care. Existing literature on the integration of trauma-informed practices into the palliative context describe treating trauma with therapeutic modalities such as trauma-focused cognitive behavioral therapy or eye movement desensitization and reprocessing (EMDR). However, this limits interventions to specialized behavioral health providers, which patients may not have access to – nor does TIC require that patients directly receive treatment for trauma symptoms (Blanch, 2012). Future research can identify TIC practices that all members of an interprofessional palliative care team can execute.

It is essential to create and evaluate accessible resource guides for interdisciplinary palliative care teams to utilize in care for patients with SUD. Patient voice should be present in practice guides and developed in partnership with patient stakeholders. Given the highly contextual and individualized nature of palliative care patients, it may not serve palliative care providers to have a highly structured, standardized care guide for patients with SUD. Practice guidance resources that identify principles and general guidelines for patients with SUD would be more appropriate for palliative care providers, offering fundamental parameters for care while also leaving space for - and even encouraging creativity and flexibility in individualized patient care. Guidelines should include a roadmap providers and patients can use based on patient's self-defined palliative care goals, goals regarding substance use, and patient context. Future interdisciplinary training can then focus on the implementation of practice guidelines and skill-building in various case-based scenarios.

Practice Implications

The distinct values of palliative care identified in this study align with the tenets of harm reduction, indicating its utility and suitability in palliative care practice. Harm reduction was named by some providers as one of the many care strategies in this study and recent research is beginning to explore the integration of harm reduction principles into the palliative care context (Nickels et al., 2022; Wells-Di Gregorio et al., 2022). However, harm reduction was conceptualized as strategy to manage or control substance use – which corresponds with a fundamental misunderstanding of harm reduction in healthcare literature, which posits "best outcomes are achieved not by total abstinence but by gaining partial control over harmful drug behaviors, or at least making them less lethal," (Rzetelny & Passik, 2022). It is crucial for practice to acknowledge that harm reduction does not elevate abstinence or even reduction of substance use over continued use, which conflicts with some provider approaches in this study and behavioral management plans described in recent literature. Integrating a harm reduction approach and allowing patients to make informed choices about their own substance use patterns embodies the values of palliative care. Harm reductionist palliative care should be non-judgmental, non-coercive, and define success as quality of life and the well-being of the individual - instead of defining success through abstinence or management.

Policy Recommendations

There are significant limitations to current harm reduction interventions on the individual level of patient care in the context of U.S. healthcare. For example, referrals to safe consumption sites are virtually impossible in most areas of the country, since there's only sanctioned safe consumption site in the U.S. in New York City. The Department of Justice is "evaluating" the utility of supervised consumption sites in other cities in conversation with state and local authorities (Peltz & Balsamo, 2022) – the department's support could bolster organizations working to establish local sites. Safe consumptions sites not only reduce healthcare costs through preventative measures (Finke & Chan, 2022), but they can also reduce barriers to healthcare access for patients with SUD and increase engagement with palliative care supports (McNeil et al., 2013).

There are also emerging "safe supply" programs in Canada that provide patients with SUD pharmaceutical substances to reduce the risk of death by contamination. These programs are controversial and have received significant criticism - a 2022 Stanford-Lancet commission report discouraged the implementation of take-home, safe supply programs in the U.S., (Humphreys et al., 2022); echoing the aversion to safe supply in substance use literature (Carroll, 2020; Lembke, 2020). However, early findings from Canadian programs demonstrate reduced overdose risk, reduced emergency room visits, and increased access to medical and social care (Canadian Drugs and Substances Strategy, 2023) - which would benefit both palliative care patients with SUD and other PWUS. Significant systemic and policy changes are needed to implement community-wide harm reduction interventions that could benefit palliative care patients with SUD.

Conclusion

In this study, several themes emerged that palliative care providers identified when working with patients with SUD. The findings of this study are the first qualitative study that explores multiple disciplines within the palliative are team. Existing literature focuses on prescribing and has limited the discourse around palliative care patients with SUD to the prescribing professions. This study provides a more comprehensive depiction of interdisciplinary provider experiences embedded in a team. Providers described the significance of unique palliative care values when working with patients with SUD, but there was no consensus on the best way to integrate these values into a comprehensive care approach for patients perceived as complex. This study establishes a clear need for practice guidelines for palliative care patients with SUD. The study also demonstrates the utility for training opportunities for providers to build and develop skills when working with patients with SUD and adopting a harm reduction approach in the palliative setting. As demographics in the U.S. shift, it is crucial to develop the practice knowledge and systemic capacity to meet the needs of palliative care patients facing serious illness who have SUDs.

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Appendix A

Semi-Structured Interview Questions

What is your understanding of substance use disorders?

What factors impact the development of a substance use disorder?

What education or training do you have specific to substance use disorder care?

How do you address substance use disorder with patients?

How prepared do you feel addressing substance use disorder with patients?

How does a substance use disorder impact the delivery of palliative care?