PALLIATIVE CARE

Palliative Care of the Terminally Ill Drug Addict

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ABSTRACT

Palliative care with terminally ill drug addicts is a major challenge for medical professionals to face. With growing problems of prescription drug abuse in this country, the problem is only going to continue to grow and be faced more often. To date, very little has been done focusing on this special population of end-of-life care patients. This review article attempts to explore the terminology and definitions for identifying addiction in the terminally ill as well as exploring management options for healthcare professionals. As with other opioid treated pain patients, relying on terms such as “physiological dependence” and “tolerance” is inappropriate for use in this population, who are likely to have been on opioids for extended periods of time requiring dose escalation for progressive disease. Thus, these terms have little utility for identifying problem patients. Rather, understanding the context of the drug abuse as it reflects on the concepts of use despite harm and the damage inflicted to the physical, psychological, or social make-up of the patient is necessary. Recommendations include careful monitoring and assessment of patients, utilizing multidisciplinary team approaches, encouraging participation in recovery programs, and utilization of pill counts and urine toxicology screenings as necessary. Implications for the field are discussed.

INTRODUCTION

Since substance abuse is increasingly widespread in the population at large, patients with terminal illness who have utilized illicit drugs are being encountered more frequently, leaving medical professionals with many questions regarding how to handle these patients (1, 2). Illicit drug use, actual or suspected misuse of prescribed medication, or actual substance use disorders are among the most serious difficulties in the clinical setting. However, the management of substance abuse in terminally ill patients is crucial for several reasons. For one, treating addiction helps foster adherence to medical therapy and safety during treatment. Also, adverse interactions between illicit drugs and medications prescribed as part of the patient’s treatment can be dangerous. Human growth and development are important aspects of a good death. Aspects of “recovery” (i.e., responsibility, making amends) are central to growth at the end of life and not unlike tasks common to all dying patients. Finally, continuous substance abuse may alienate or weaken an already tenuous social support network that is crucial for alleviating the chronic stressors associated with advanced disease and its treatment (3).

The following case example highlights an approach that was successful for just this type of patient. While not all cases will resolve in this fashion, it is a fitting guide to the approaches discussed throughout the rest of this article.

CASE EXAMPLE

The patient was a 39-year-old man with pancreatic cancer who was referred to the palliative care program shortly after it was decided he was not a candidate for surgical resection and he had opted to forego chemotherapy and radiation therapy. The
patient had presented with advanced disease and a 40 pound weight loss. He had been suffering with abdominal pain for months, but was self-treating with sustained release oxycodone that he had been abusing and dealing for the last several years. The patient had a very limited life expectancy when first evaluated and he was not open to considering other opioids or celiac plexus nerve blocks. He stated that he just wanted to be comfortable enough to play with his 3 year-old daughter until he died. The patient always required high doses of medication for comfort (800 mg sustained release oxycodone twice per day) and did agree eventually to also take adjuvant analgesics and corticosteroids. He had remarkably good pain and symptom management until his death, even deer hunting 2 weeks before he died.

The provision of supportive care would have been impossible without the structure provided by hospice nurses who: delivered one day’s worth of medicine at a time; turned up randomly for pill counts at the patient’s home; collected urine for toxicology screens; and otherwise coordinated tremendous levels of family support from those family members who had been assessed and deemed not involved with illicit drug use and sales. The patient made amends with family and developed the capacity for trust with his treatment team. These were markers of tremendous growth for him at the end of life and were a source of great pride for him.

INCIDENCE OF SUBSTANCE USE DISORDERS

Substance use disorders are a consistent phenomenon in the United States, with estimated base rates of 6–15 percent (2, 6). Due to these issues and despite the fact that national guidelines exist for the treatment of pain disorders such as cancer, pain continues to be undertreated, even at the end of life (7–9). In one advanced disease type, cancer, it has been reported that approximately 40–50 percent of patients with metastatic disease and 90 percent of patients with terminal cancer or other advanced diseases experience unrelieved pain (7–9). Furthermore, inadequate treatment of pain is a greater possibility if the patient is a member of an ethnic minority, female, elderly, a child, or a substance abuser (5, 10–15). A history of substance abuse is a tremendous risk factor for undertreatment, for example in HIV treatment (16).

Although few studies have been conducted to evaluate the epidemiology of substance abuse in patients with advanced illness, substance use disorders appear to be identified relatively rarely within the tertiary care population with cancer and other advanced diseases. Findings of a review of consultations performed by the Psychiatry Services at Memorial Sloan-Kettering Cancer Center revealed that requests for management of issues related to substance abuse comprised only 3 percent of all consultations (17, 18).

While the incidence of substance use disorders appears to be lower in patients with terminal illness than that of society at large, this may not represent the true prevalence in the advanced illness spectrum overall. Institutional biases or a tendency for patients’ underreporting in tertiary care hospitals may be reflective of the relatively low prevalence of substance abuse among advanced patients. Social forces may also inhibit patients’ reporting of drug use behavior. Many drug abusers are of lower socioeconomic standing and feel alienated from the health care system, and therefore may not seek care in tertiary care centers. Furthermore, those who are treated in these centers may not acknowledge drug abuse for fear of stigmatization (4, 17, 18). Physicians and nurses are well documented to poorly identify and diagnose substance abuse (19).

APPROPRIATE DEFINITION OF ADDICTION IN THE TERMINALLY ILL

An appropriate definition of addiction in the terminally ill would exemplify that it is a chronic disorder characterized by “the compulsive use of a substance resulting in physical, psychological, or social harm to the user and continued use despite the harm” (20). Although this definition is not without fault, it emphasizes that addiction is essentially a psychological and behavioral syndrome (17, 18). Alternately, the definition proposed by American Pain Society (APS), American Association of Pain Management (AAPM), and American Society of Addiction Medicine (ASAM) states that addiction is “a primary, chronic, neurobiologic disease, with genetic, psychosocial, and environmental factors influencing its development and manifestations . . . characterized by behaviors that include one or more of the following: impaired control over drug use, compulsive use, continued use despite harm, and craving.” (21).

A differential diagnosis also should be considered if questionable behaviors occur during pain treatment. A true addiction (substance dependence) is only one of many possible interpretations. A diagnosis of pseudoaddiction should be taken into account if the patient is reporting distress associated with unrelieved symptoms (22). Pseudoaddiction is an iatrogenic syndrome wherein patients “act out” when distressed and can be confused with drug-seeking. The behavior is thought to resolve with improved pain relief. Impulsive drug use may also be indicative of another psychiatric disorder, diagnosis of which may have therapeutic implications. For example, patients with personality disorders are often impulsive and may require psychotherapy and limit-setting to deal with these behaviors. On occasion, aberrant drug-related behaviors appear to be causally related to mild encephalopathy, with perplexity concerning the appropriate therapeutic regimen. Simple regimens, such as once daily or every three day dosing of medications, plus the possible addition of neuroleptics may improve compliance. On rare occasions questionable behaviors imply criminal intent. These diagnoses are not mutually exclusive (17, 18).

Varied and repeated observations over a period of time may be necessary in order to categorize questionable behaviors properly. Perceptive psychiatric assessment is crucial and may require evaluation by consultants who can elucidate the complex interactions among personality factors, non addiction-related psychiatric illness, addiction, and abuse. Some patients may be self-medicating symptoms of anxiety or depression, insomnia, or problems of adjustment (such as boredom due to decreased
ability to engage in usual activities and hobbies). Yet others may have character pathology that may be the more prominent determinant of drug-taking behavior. Patients with borderline personality disorders, for example, may utilize prescription medications in an impulsive manner that regulates inner tension; express anger at physicians, friends or family; or improves chronic emptiness of boredom (23). Psychiatric assessment is vitally important for both the population without a prior history of substance abuse and the population of known substance abusers who have a high incidence of psychiatric comorbidity (24). Treating depression, anxiety, personality disorders, and encephalopathies appropriately may stabilize drug-taking behaviors.

RISKS IN PATIENTS WITH CURRENT OR REMOTE HISTORIES OF DRUG ABUSE

There is a lack of information regarding the risks during or subsequent to the therapeutic administration of potentially abusable drugs to terminally ill patients with a current or remote history of abuse or addiction (18). The possibility of successful long-term opioid therapy in patients with cancer or chronic nonmalignant pain has been indicated by anecdotal reports, particularly if the abuse or addiction is remote (25–27). Due to shortened exposure, limited social contacts, and physical energy, the treatment of the terminally ill patient with a history of addiction is less risky and controversial than treatment in other clinical contexts.

Since it is commonly accepted that the likelihood of aberrant drug-related behavior occurring during treatment for medical illness will be greater for those with a remote or current history of substance abuse, it is reasonable to consider the possibility of abuse behaviors occurring when choosing opioids. For example, while no empirical evidence exists to support that the use of short-acting drugs or the parenteral route is more likely to cause questionable drug-related behaviors than other therapeutic strategies in low risk patients, it may be prudent to avoid such therapies in patients with histories of drug abuse who do show a marked preference for faster onset drugs (18). A basic set of principles pertaining to prescribing controlled substances to this patient population is presented in Table 1.

Table 1. Basic principles for prescribing controlled substances to patients with advanced illness and issues of addiction

<table>
<thead>
<tr>
<th>Principle</th>
<th>Description</th>
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<tbody>
<tr>
<td>Choose an opioid based on around-the-clock dosing</td>
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<tr>
<td>Choose long-acting agents when possible</td>
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<tr>
<td>As much as possible, limit or eliminate the use of short-acting or &quot;breakthrough&quot; doses</td>
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<tr>
<td>Use non opioid adjuvants when possible and monitor for compliance with those medications</td>
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<tr>
<td>Use nondrug adjuvants whenever possible (i.e., relaxation techniques, distraction, biofeedback, TNS, communication about thoughts and feelings of pain)</td>
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<tr>
<td>If necessary, limit the amount of medication given at any one time (i.e., write prescriptions for a few days’ worth or a weeks’ worth of medication at a time)</td>
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<tr>
<td>Utilize pill counts and urine toxicology screens as necessary</td>
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</tr>
<tr>
<td>If compliance is suspect or poor, refer to an addictions specialist</td>
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The following guidelines can be beneficial whether the patient is actively abusing drugs or has a history of substance abuse. The principles outlined assist clinicians in establishing structure, control and monitoring of addiction-related behaviors which may be helpful and necessary at times in all pain treatment (30).

General guidelines

Recommendations for the long-term administration of potentially abusable drugs, such as opioids, to patients with a history of substance abuse are based exclusively on clinical experience and consensus from pain experts (as opposed to randomized controlled clinical trials). Research is needed to ascertain the most effective strategies and to empirically identify patient subgroups who may be most responsive to different approaches. The following guidelines broadly reflect the types of interventions that might be considered in this clinical context (17, 30).

I. Multidisciplinary approach

Pain and symptom management is often complicated by various medical, psychosocial, and administrative issues in the population of advanced patients with a substance use disorder. Labor intensive and conflictual, management of these patients can be draining for solo practitioners. The most effective team may include a physician with expertise in pain/palliative care, nurses, social workers, and when possible, a mental health care provider, preferably with expertise in the area of addiction medicine (17, 30). The mental health professional can manage the multiple comorbidities associated with addiction, help assess the patient’s behavior with medications, address addiction, and help manage the team’s countertransference reactions to the patient.

II. Assessment of substance use history

In an effort to not offend, threaten, or anger patients, clinicians many times avoid asking patients about drug abuse. Often, there is the expectation that patients will not answer truthfully. However, obtaining a detailed history of duration, frequency, and desired effect of drug use is vital. Adopting a nonjudgmental
position and communicating in an empathetic and truthful manner is the best strategy when taking patients’ substance abuse histories (4, 17, 18). Clinicians need to use judgment when charting these findings to help make the patient feel safe but also so as not to prejudice other professionals against the patient.

In anticipating defensiveness on the part of the patient, it can be helpful for clinicians to mention that patients often misrepresent their drug use for logical reasons, such as stigmatization, mistrust of the interviewer, or concerns regarding fears of undertreatment. It is also wise for clinicians to explain that an effort to keep the patient as comfortable as possible, by preventing withdrawal states and prescribing sufficient medication for pain and symptom control, an accurate account of drug use is necessary (4, 30, 31).

The utilization of a careful, graduated style interview can be beneficial in slowly introducing the assessment of drug abuse. This approach begins with broad and general inquires regarding the role of drugs in the patient’s life, such as caffeine and nicotine, and gradually proceeds to more specific questions regarding illicit drugs. This interview style also can assist in discerning any coexisting psychiatric disorders, which can significantly contribute to aberrant drug-taking behavior. Once identified, treatment of comorbid psychiatric disorders can greatly enhance management strategies and decrease the risk of relapse (4, 30).

III. Set realistic goals for therapy

The rate of recurrence for drug abuse and addiction is high outside of the context of terminal illness. For example, nearly 80 percent of patients relapse within one year (32). The stress associated with advanced illness and the easy availability of centrally acting drugs increases this risk. Therefore, total prevention of relapse may be impossible in this type of setting. Gaining an understanding that compliance and abstinence are not realistic goals may decrease conflicts with staff members in terms of management goals. Instead, the goals might be perceived as the creation of a structure for therapy that includes ample social/emotional support and limit-setting to control the harm done by relapse (4, 30).

There may be some subgroups of patients who are unable to comply with the requirements of oncology therapy due to severe substance use disorders and comorbid psychiatric diagnoses. In these instances, clinicians must modify limits on various occasions and endeavor to develop a greater variety and intensity of supports. This may necessitate frequent team meetings and consultations with other clinicians. However, pertinent expectations must be clarified and therapy that is not successful should be modified (4, 30).

IV. Evaluate and treat comorbid psychiatric disorders

Extremely high comorbidity of personality disorders, depression, and anxiety disorders exist in alcoholics and other patients with substance abuse histories (24). The treatment of depression and anxiety can increase patient comfort and decrease the risk of relapse or aberrant drug taking (4, 30).

V. Consider the therapeutic impact of tolerance

Patients who are active substance abusers may be tolerant to drugs administered for therapy, which will make pain management more difficult. The magnitude of this tolerance is never known. Therefore, it is best to begin with a conservative dose of therapeutic drug and then rapidly titrate the dose with frequent reassessments until the patient is comfortable (18, 27). While this advice is useful for all patients, it is a crucial step that must be followed with these challenging patients.

VI. Apply pharmacological principles to treating pain

Widely accepted guidelines for pain management, based on cancer populations, must be utilized to optimize long-term opioid therapy (33, 34). These guidelines stress the importance of patient self-report as the base for dosing, individualization of therapy to identify a favorable equilibrium between efficacy and side effects, and the value of monitoring over time (30). They also are strongly indicative of the concurrent treatment of side effects as the basis for enhancing the balance between both analgesia and adverse effects (31).

Individualization of the dose without regard to the ultimate number of milligrams required, which is the most important guideline for long-term opioid therapy, can be difficult in populations with substance abuse histories (30). Although it may be appropriate to use care in prescribing potentially abusable drugs to these populations, deciding to forego the guideline of dose individualization without regard to absolute dose will increase the risk of undertreatment (35). Aberrant drug-related behaviors may develop in response to unrelieved pain. Although these behaviors might be best understood as pseudoaddiction, the incidence of such behaviors should be followed by prudence in prescribing (30). Pseudoaddiction can lead to true out of control use in patients with a history of substance abuse in our clinical experience.

Another common misconception is the utilization of methadone. Clinicians who manage patients with substance abuse histories must comprehend the pharmacology of methadone due to its dual role as a treatment for opioid addiction and as an analgesic (36, 37). Methadone impedes withdrawal for significantly longer periods than it relieves pain. That is, abstinence can be prevented and opioid cravings lessened with a single dose; while most patients appear to require a minimum of 3 doses daily to obtain sustained analgesia. Although patients who are receiving methadone maintenance for treatment for opioid addiction can be administered methadone as an analgesic beyond the guidelines of the addiction treatment program, this usually necessitates a substantial modification in therapy including dose escalation and multiple daily doses (4, 30, 38). There are also major misconceptions about the need for special licenses, which is needed to use methadone to treat addiction, but not to use methadone to treat pain.
VII. Recognizing specific drug abuse behaviors

In an effort to monitor the development of aberrant drug-taking behaviors, all patients who are prescribed potentially abusable drugs must be evaluated over time and have their behavior monitored. This is particularly true for those patients with a remote or current history of drug abuse including alcohol abuse. Should a high level of concern exist regarding such behaviors, frequent visits and regular assessments of significant others who can contribute information regarding the patient’s drug use may be required. It also may be necessary to have patients who have been actively abusing drugs in the recent past to submit urine specimens for regular screening of illicit or licit but unprescribed drugs to promote early recognition of aberrant drug-related behaviors. In informing the patient of this approach, it should be explained as a method of monitoring that can reassure the clinician and provide a foundation for aggressive symptom-oriented treatment, thus enhancing the therapeutic alliance with the patient (4, 30). It is important that providers understand false positives on urine screens as well.

VIII. Use written agreements

Utilizing written agreements that clearly state the roles of the team members and the rules and expectations for the patient is helpful when structuring outpatient treatment. While using the patient’s behaviors as the basis for the level of restrictions, graded agreements should be enforced that clearly state the consequences of aberrant drug use (4, 30, 40). This is crucial with terminally ill patients in whose care it may not be as appropriate to threaten dismissal from care. This template can be modified and structured to fit individual practices and clinics, but is a good general indication of the responsibilities of the patient as well as the provider. However, there are no definitive studies showing benefit at this time.

IX. Guidelines for prescribing

Patients who are actively abusing should be seen more often, perhaps as often as weekly, in order to build a good rapport with staff and afford evaluation of symptom control and addiction-related concerns. Frequent home or nursing visits allow the opportunity of prescribing small quantities of drugs, which may decrease the temptation to divert and provide a motive for not missing appointments (4, 30). All patients with a history of abuse and addiction should be monitored closely in this fashion.

Procedures for prescription loss or replacement should be explicitly explained to the patient with the stipulation that no renewals will be given if appointments are missed or if home supplies are hard to account for. The patient should also be informed that any dose changes require prior communication with the clinician. Also, clinicians who are covering for the primary care provider must be advised of the guidelines that have been established for each patient with a substance abuse history to avoid conflict and disruption of the treatment plan (30, 41).

X. Use 12-step programs

The clinician should consider referring the patient to a 12-step program with the stipulation that attendance be documented for ongoing prescription purposes. The clinician may wish to contact the patient’s sponsor in an effort to disclose the patient’s illness and that medication is required in the treatment of the illness. This contact will also assist in decreasing the risk of the stigmatization of the patient as being non-compliant with the ideals of the 12-step program (4, 30). Even with an “ombudsman,” there can be risks of 12-step program use. They may not support the liberal use of opioids and may misunderstand side effects despite the patient’s terminal status.

XI. Urine toxicology screens

Periodic urine toxicology screens should be performed for most patients with a history of illicit drugs to encourage compliance and detect the concurrent use of illicit substances. This practice, as well as how positive screens will be managed, should be clearly explained to the patient at the beginning of outpatient therapy. A response to a positive screen generally involves increasing the guidelines for continued treatment, such as more frequent visits and smaller quantities of prescribed drugs (4, 30, 42).

XII. Family sessions and meetings

The clinician, in an effort to increase support and function, should involve family members and friends in the treatment plan. These meetings will not only afford the clinician and other team members to become familiar with the family, but also assist the team in identifying family members who are using illicit drugs. Referral of these identified family members to drug treatment can be offered and portrayed as a manner of gathering support for the patient. Prompting family members to make changes in honor of the patient and to support them with specific referrals has been useful in our clinical experience. The patient should also be prepared to cope with family members or friends who may attempt to buy or sell the patient’s medications. These meetings will also assist the team in identifying dependable individuals who can serve as a source of strength and support for the patient during treatment (4, 43). Lockboxes in the home can be used, with the patient and perhaps one caregiver knowing the combination.

CONCLUSION

Treating terminally ill patients who have both chronic pain and a substance use disorder is both complicated and challenging, since each can significantly complicate the other. Utilizing a treatment plan that involves a team approach which recognizes and responds to these complex needs is the optimum strategy to facilitate treatment. While pain management may continue to be challenging even when all treatment plan procedures are implemented, the health care teams’ goal should be the highest level of pain management for all patients with substance use disorders.
REFERENCES


