



The Opioid Crisis and Hospice Care: Exploring Key Partner Experiences

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Key Findings

- There are a variety of ways in which hospice providers' and patients' experiences of hospice care have been impacted by the opioid crisis.
- These impacts indicate a need for effective strategies to mitigate opioid misuse and diversion in hospice, including for caregivers providing home-based care.
- There is also a clear and pressing need for effective policies and practices that ensure leftover opioids are safely disposed of after a patient death.
- Study insights can guide education and support for hospice providers related to new and changing laws and help inform strategies for maintaining safe and effective hospice care during public health emergencies.

Introduction

In 2020, approximately 1.72 million Medicare beneficiaries received hospice services in the United States.¹ Hospice care aims to maximize comfort and quality of life for dying patients, and effective care often involves giving opioids at higher doses than for treating other types of pain, such as pain related to sickle cell disease or cancer.^{2,3} Over the last decade, many groups—including the medical community, public health, regulatory agencies, and policymakers—have reexamined the use of opioids as treatment, and policymakers have enacted more conservative opioid guidelines and policies to address misuse. As a result, barriers to access have increased, and providers have decreased opioid prescribing for chronic pain.^{4–6}

Few studies explore how these developments have shaped hospice care in the United States.⁷ Researchers have used surveys to understand opioid access, diversion, and disposal; care for patients and families with substance use disorder; and prescribing trends. These investigations show that hospices have experienced medication shortages, varied drug diversion and disposal policies, barriers to opioid disposal after patient death, and decreased opioid prescribing on discharge to hospice care.^{8–15} One study interviewed hospice care clinicians to explore the epidemic's impact on prescribing practices and found limited opioid access, as well as undertreatment, stigma, illicit use, and fear among patients.¹⁶

Exploring Hospice Care During the Opioid Crisis

Our study expands on these findings by exploring hospice partners' experiences of the opioid crisis and prioritizing their perceptions of the most salient issues shaping hospice care. These insights can inform education to keep providers current with new and changing laws and guide strategies to maintain safe and effective hospice care during public health emergencies.

Methods

From April through June 2019, we conducted semistructured phone interviews (60 minutes) and in-person focus groups (90 minutes) to explore how the opioid crisis and related public policy changes may shape hospice care. Study procedures were approved by the RTI International Institutional Review Board. Data from this study are stored on a Health Insurance Portability and Accountability Act–compliant share drive on a password-protected computer to ensure confidentiality.

Sample and Recruitment

We conducted interviews with hospice partners from across the United States, including administrators and executives from hospice agencies and representatives from provider associations. Focus groups were conducted with clinical hospice team members from a large hospice provider in North Carolina.

Participants were recruited through convenience and snowball sampling. We contacted hospital, hospice agency, and provider association administrators for lists of direct

care staff who might be interested in study participation. We then sent emails to identified staff with a study description and invitation to participate, asking respondents to suggest additional participants.

Data Collection

After obtaining verbal informed consent, one team member conducted the interview or focus group, while another member took detailed notes. Table 1 summarizes topics discussed during interviews and focus groups. Discussions were audio recorded with participant permission. Recordings were transcribed, and transcripts were verified for accuracy before analysis.

Analysis

We used NVivo 11 (QSR International Inc., Burlington, MA) to organize transcripts and deductively developed an initial coding scheme using the Project Lazarus Model.¹⁷ Data were coded using the coding scheme and additional codes that emerged from the data. Two team members separately coded transcripts and discussed and resolved any discrepancies. Coders achieved satisfactory interrater reliability levels after separately coding three transcripts: Cohen's kappa of 0.74 and percent agreement of 96 percent.^{18,19} The team searched coded data for patterns and organized codes into candidate themes.

Table 1. Topics discussed in interviews and focus groups

Topics	Interviews	Focus Groups
Impact of opioid crisis on patients, caregivers, and providers	X	X
Changes to hospice care due to the opioid crisis, if any	X	X
Impact of opioid crisis on hospice care for patients receiving medication-assisted therapy (MAT) for opioid use disorder	X	X
Challenges faced by hospice providers due to the opioid crisis	X	X
Impact of federal and state opioid-related policies on providers	X	
Care delivery changes made because of the opioid crisis, if any	X	
Opioid monitoring interventions (e.g., pill counts, lockboxes, diversion risk assessments) used by the hospice		X
Naloxone for home-based patients receiving opioids		X
Impact of the opioid crisis on symptom management, access to opioids, and the relationship among hospice providers, patients, and caregivers		X

Results

Twelve participants engaged in eight interviews, and nine hospice staff participated in two focus groups (Table 2).

From these discussions, participants identified several key impacts of the opioid crisis that have shaped the experience of hospice care for staff, patients, and caregivers. Table 3 outlines these impacts with illustrative quotations.

New Public Policies Governing Opioid Prescribing and Disposal

Participants described burden in complying with new guidelines for opioid prescribing and disposal. In part, requirements—such as when, how, and who should dispose of leftover opioids—were difficult to reconcile across state and federal levels or federal agencies. Participants also described legislation that disproportionately challenged hospice care. For example, one Michigan law required that providers review an automated prescription report before prescribing opioids

Table 2. Participant sample

	Interviews (N = 8)	Focus Groups (N = 2)
Total number of participants	12	9
Job title/association		
Nurse		5
Social worker		2
Chaplain		2
Hospice provider association staff	4	
Hospice agency leadership (e.g., president, medical director, chief medical officer, hospice director)	8	

Table 3. Key factors, quotations illustrating influence of opioid crisis on hospice care

Factors shaping care	Quotations
New public policies governing opioid prescribing and disposal	<p><i>We have a lot of providers that are a bit confused about what they can do, what they can't do ... the new legislation on a state level ... and on the federal level, and how does that impact their capacity to prescribe, what kind of limits does it put on them[?]</i></p> <p><i>Many initial prescriptions are limited to either three or seven days. When it's clear that somebody's got weeks to live ... it's more cost effective to send out a prescription for two weeks than to send out a prescription every three days.</i></p> <p><i>When hospice ends it's because the patient has died. Now you have a variety of pills and sometimes other forms of medication in this house. The hospice nurse has a role to play, which frankly is muddy, and [varies] state to state, and is a huge mess. If you want a massive problem to take on, here's one. Who disposes, and how do they dispose of it right[?]</i></p>
Pushback and fear among patients, caregivers, and providers related to prescribing and using opioids	<p><i>... patients definitely are suffering for those whose family members are reluctant to give that opioid or even for the patients themselves that are reluctant to take it.</i></p> <p><i>[The pharmacists] are very fearful about dispensing medications and... So they'll ask for extra steps, even when they're not legally required. There's a hospice exemption in California where they can dispense without a hard copy of the prescription to patients who have a terminal, a one year or less life expectancy. But many of the pharmacies won't follow that exemption procedure.</i></p>
The need to adopt additional misuse prevention and control activities	<p><i>You know, I just know that that is now part of routine hospice care, the placement and the practice of that medication within that home, and that has to be taught in awareness from not only the hospice nurse, but the hospice social worker; and now, in patient assessments, you've got to begin to approach that assessment of not just looking at the client, but look at the whole family and the environment that that medication is in.</i></p> <p><i>And now there are disposal containers that you can have in the home; you know, open a bag, put the medication in there, shake it up; the chemical compounds in the bag destroy the medication, and then you throw the bag away. Obviously, for a hospice, that's an additional expense.</i></p>

exceeding a 3-day supply.* One participant explained that this requirement may be manageable in settings where opioid use is less frequent, but it is extremely burdensome for a hospice where 400 reports may be reviewed weekly. Another policy required face-to-face consults with physicians for prescriptions; for hospice models that rely on nurses to visit “*debilitated, homebound, and bedbound*” patients and report to physicians, this policy delays patient access to needed medications.

Participants added that small hospices may face additional burden because they lack resources to track, manage, and influence rapid regulatory changes (“*sometimes those bills or rules slip through without anyone realizing it [or] offering input*”). Also, large, multistate hospice groups must balance “*overlying principles for the company*” with varied rules across states.

Pushback and Fear Among Patients, Caregivers, and Providers Related to Opioids

Participants explained that due to the visibility of the opioid crisis, more patients and caregivers were reluctant to use prescribed opioids as treatment. For caregivers, there is stress from responsibility to manage opioid treatments and prevent diversion in the home. For patients and caregivers, there is fear about theft, safety, overdosing, and being seen as an addict, “*junkie*,” or weak. Participants added that patients and caregivers also worry that having opioids in the home can lead to addiction. Collectively, these fears were believed to increase patient suffering at the end of life by reducing willingness to administer and take prescribed opioids.

Participants also described reluctance among some providers to prescribe opioids, including “*actual cases [of] physicians being looked at by their state boards of medicine*,” and “*a lot of rumors*” about physicians being increasingly monitored related to opioids. In these cases, providers may choose “*self-preservation*” and avoid prescribing opioids altogether to prevent a licensing board investigation. These challenges extended to pharmacists, who were described by participants as keeping fewer amounts and varieties of opioid medications in stock. One participant described contacting five different pharmacies to find one that carried the opioids they needed. And even though hospice organizations are permitted by exemption to fax prescriptions for narcotic substances, some pharmacists were reportedly unaware of or unwilling to honor amended rules. Participants explained that these challenges delayed hospice patients’ access to needed medications.

Increased Need for Misuse Prevention and Control Activities

In response to the opioid crisis, participants described performing more diversion control activities including assessing families for diversion risk and using lockboxes, pill counts, patient/family contracts, and diversion plans. Participants also discussed disabling patient pharmacy profiles immediately after death so family members could not continue to fill prescriptions.

Participants added that some hospices are required to provide, or are voluntarily providing, households with naloxone to prevent overdose from opioids. Participants had mixed responses to this approach because it could send a confusing message to families that opioids are dangerous. Further, they posited that a caregiver could administer naloxone because they conflate a loved one’s active death from disease with death from overdose, resulting in their loved one dying in pain. Other providers believed that naloxone in the home was a necessary safety intervention, especially in cases of heightened diversion risk.

Since the beginning of the opioid crisis, participants also interacted more with patients and caregivers with a history of addiction or those who were receiving medication-assisted treatment (MAT). One participant explained that hospice care is “*exponentially [more] difficult when someone in that community has an addiction issue*,” and that not all hospices may be prepared to effectively treat these patients. Some participants averred that caring for people with addiction was not new while others argued that hospices need more guidance, including how to adjust MAT patients’ medications without triggering pain or causing harm.

Limitations

Study findings are based on a small sample, and clinical participants engaged in focus groups represented only one hospice organization in North Carolina. The selection of the overall study sample, however, was intentionally diverse and included respondents in a variety of hospice care roles across the United States.

The study also relied on self-reported data on potentially sensitive topics, which may have encouraged participants to share what they believed were more socially desirable perceptions.

* Public Act 248 of 2017: Beginning June 1, 2018, before prescribing or dispensing to a patient a controlled substance in a quantity that exceeds a 3-day supply, a licensed prescriber shall obtain and review a Michigan Automated Prescription System (MAPS) report concerning that patient.

Discussion and Conclusion

This study exploring the influence of the opioid crisis on hospice care supported results of prior research that found patients had limited access to drugs; varied policies governed opioid use; barriers existed for proper disposal of drugs after patient death; and patients experienced undertreatment, stigma, and fear.

Our results expand on these findings to reveal how hospice partners have been challenged to keep up with and inform new opioid policies, which can create requirements that disproportionately burden hospice providers and delay patients' access to needed medications. We also show how the publicity of the opioid crisis and concerns about misuse and diversion have increased demand for diversion control activities and have affected patients', caregivers', and providers' willingness to engage with opioids, even when critical to symptom management or directed by law.

These findings suggest a need for research about effective strategies to mitigate opioid misuse and diversion in hospice, including for caregivers providing home-based care. Study results also reveal a clear and pressing need for effective policies and practices that ensure leftover opioids are safely disposed of after a patient death. And fear and pushback among providers when prescribing or dispensing opioids indicate the importance of new strategies to enhance opioid stewardship in clinical settings. These strategies may involve implementing opioid stewardship programs with full-time opioid stewardship pharmacists employed in inpatient and outpatient settings.²⁰

Participants' emphasis on the challenge of interpreting and keeping up with rapidly changing opioid policies indicates the need for greater education and clarity for hospice providers on new and potentially conflicting laws. This future research education includes exploring how recent bills to improve the treatment of substance abuse disorder, under the 2023 Consolidated Appropriations Act,[†] may shape hospice care. Hospice providers may also benefit from advocacy support to ensure that policies addressing opioids allow for differences in hospice care, including exemptions for opioid prescribing restrictions and clear requirements for hospice opioid dispensing.

[†] The Consolidated Appropriations Act includes three bills to greatly improve treatment for substance use disorder: (1) Medication Access and Training Expansion (MATE) Act (H.R. 2067/S.2235); (2) Mainstreaming Addiction Treatment (MAT) Act (H.R. 1384/S. 445); (3) Collaboration in an Orderly and Cohesive Manner Act (H.R. 5218).

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