

Impact of a Hospice Emergency Kit for Veterans and Their Caregivers: A Prospective Cohort Study

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Abstract

Background: Although hospice emergency kits (HEKs) are provided by many home hospice agencies, little is known about their use, side effects, and perceived impact.

Objective: To evaluate HEK medication utilization, side effects, and impact as perceived by home hospice patients and their caregivers.

Methods: We conducted a prospective longitudinal cohort study. Participants included 43 veterans and their family/caregivers referred to community home hospices with a Veterans Affairs (VA)-provided HEK. Measurements included patient/family reports based on weekly telephone interviews, electronic medical record (EMR) review, and after-death caregiver interviews.

Results: The HEK was used by 27 of 43 patients/caregivers (62.8%). In 11 cases, they reported using the kit on more than one occasion. The most commonly used medications were morphine concentrate (30.2% of patients), lorazepam (20.9%), and levofloxacin (16.3%). In 15 cases (34.9%), the family thought the HEK may have helped the patient stay at home. Nineteen of the 43 patients made at least one visit to the emergency department (ED) and 22 were hospitalized. Most admissions through the ED were due to uncontrolled pain and/or gastrointestinal problems, such as nausea or bowel obstruction. In after-death interviews, opinions of the HEK were uniformly positive. Respondents described the HEK's usefulness and felt supported and empowered by its presence in the home. Minor side effects were reported in four cases.

Conclusions: Findings provide promising evidence that HEKs are a feasible and well-tolerated method for achieving timely relief of emergent symptoms in home hospice patients and possibly avoiding unwanted ED visits and hospitalizations.

Introduction

PATIENTS REFERRED TO HOME HOSPICE are terminally ill and generally experience a variety of symptoms as their condition progresses and their health declines. These symptoms include pain, dyspnea, nausea/vomiting, delirium, anxiety, infection with fever, fluid overload with peripheral edema and pulmonary congestion, and difficulty controlling secretions.¹ Symptoms may develop quickly and unexpectedly, often at night or on the weekend, when access to emergency or urgent assistance in the home is limited. Prompt relief of symptoms can

be facilitated by timely access to medications. However, even during normal working hours, up to 24 hours may elapse before physician-ordered and pharmacy-dispensed medications are delivered to the patient's home.

The logistics of care delivery are particularly challenging for emergencies occurring on weekends and holidays when delays in medication delivery can exacerbate the suffering that might have been ameliorated by prompt access to medications. Additionally, as patients enter the dying process, they may be unable to continue to take medications orally, necessitating alternative routes for continued administration.

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These include sublingual, rectal, topical, and, in some patients, parenteral routes, including subcutaneous or intravenous administration.

When not managed promptly, symptoms can lead to unnecessary suffering and unwanted visits to the emergency department (ED) or inpatient hospitalizations. Such transfers often do not reflect patient or family/caregiver preferences for location of care or death, and may not result in sufficient symptom control and psychosocial support for the patient and family/caregiver.² Timely attention to these crises has the potential to reduce suffering and avoid costly health care utilization.

To this end, in the 1990s some hospice programs began to station medications, such as sublingual morphine concentrate, with hospice nurses or in the homes of patients. This practice evolved into the development of home hospice emergency kits (HEKs) to enable more rapid response and relief of emergent symptoms during routine home hospice care, particularly during the active dying process. HEKs are a group of medications and supplies that are deposited in the patient's home for use by the patient or family/caregiver at the direction of the home hospice nurse or physician. The concept of a HEK appears to be a common-sense solution for a very predictable problem faced by most home hospice patients.^{3,4} However, the literature related to the utilization and impact of HEKs is currently sparse.⁵⁻¹³

One study has demonstrated that HEKs alone reduced the odds of ED visits by 67%, and the odds were reduced by 75% when there was a caregiver in the home.⁷ Surveys of hospice nurses and nurse managers indicate that medication kits are well received,^{8,9} help to avoid ED visits,^{10,11} save costs,¹¹ and increase patient/family satisfaction.¹¹ However, to our knowledge, no studies have examined patient- or caregiver-reported perspectives, including how and when the kits are utilized, and whether such use effects symptom relief, produces negative effects, or impacts patients/caregivers in a positive or negative way.

The purpose of this study was to fill the gap in the literature by evaluating the use, effectiveness, side effects, and other impacts of a HEK in the care of veterans in home hospice settings. We report patient and caregiver perceptions of a HEK, including their assessments of its timeliness for relieving common distressing symptoms that occur at end of life.

Methods

Overview

This study was a prospective longitudinal cohort study, in which patients referred to home hospice and their caregivers were contacted weekly regarding HEK utilization and its impact. After death, caregivers were interviewed by telephone to assess perceptions of the impact of the HEK. The study was approved by the Veterans Affairs (VA) Institutional Review Board, and all patients/caregivers provided informed consent.

Participants

Participants were a convenience sample of veterans from inpatient or outpatient settings referred to home hospice with a HEK between November 9, 2011 and August 27, 2012 and their caregivers. Potential patient/caregiver dyads were identified by the home hospice coordinator and invited to participate. Patients were not excluded due to diagnosis, prognosis, or prior abuse of alcohol or drugs.

The VA provides home hospice care by contracting with local hospice agencies through a national network of VA Hospice-Veteran Partnerships (HVP).¹⁴ The Birmingham VA Medical Center (VAMC) palliative care team works with more than 30 hospice care providers to offer referral to a community home hospice program to veterans with adequate home support. Selection of the private hospice agency is at the discretion of the veteran.

Agreements with local hospices were in place to guide veterans' care, including uniform standing orders that superseded the agency's standing orders. It is standard of care that all Birmingham VAMC veterans entering home hospice are offered a HEK.⁹ VA palliative care physicians, including one of the authors (AB), maintained oversight as the attending physicians of record and were on 24-hour call to assist with symptoms not controlled with the HEK, as well as problems outside the scope of the HEK. Hospice agencies delivered interdisciplinary care and provided medications related to the hospice diagnosis, with the exception of the VA HEK.

Hospice emergency kit

The HEK was designed to address common symptoms that emerge in the last days and hours of life, including pain,

TABLE 1. ITEMS INCLUDED IN THE HOSPICE EMERGENCY KIT

Medication	Dosing	Indication	Amount dispensed
Morphine concentrate solution	20mg/1 mL, Sig 0.25 to 1 mL SL q2 hour PRN	Pain or dyspnea	30 mL
Haloperidol	1 mg tabs, Sig 0.5 to 1 mg PO q2 hours (up to 3 doses)	Confusion or nausea/vomiting	10
Lorazepam	1 mg tabs, Sig 0.5 to 1 mg PO q6 hour PRN	Anxiety	10
Promethazine	25 mg tabs, Sig 1 PO q6 hours PRN	Nausea/vomiting	10
Furosemide	40 mg tabs, Sig 1 PO q8 hours PRN	Edema/pulmonary congestion	10
Scopolamine patches	Sig 1 patch topically q3 days PRN	Excessive secretions	5
Disposable oral swabs		Mouth care	One packet
Levofloxacin ^a	400 mg, Sig PO daily		10-day supply

^aAntibiotic may have varied depending on current formulary or patient allergies. PO, orally; PRN, as needed; q, time interval; Sig, dose; SL, sublingual.

dyspnea, confusion, nausea, vomiting, anxiety, edema, infections, and excessive secretions. The contents of the HEK were selected based on clinical experience and available data on drugs prescribed to hospice patients in the last week of life (Table 1).¹⁵

The HEK was ordered through an electronic outpatient pharmacy order set to ensure that the contents were standardized and the kit was complete. If a patient already was prescribed an opioid or some other medication in the kit, the prescribing provider was instructed to order the complete kit, so that patients who used up a prescribed medication had access to the medication in the kit until they could obtain a refill. A VA pharmacy consultation was added to ensure that the kit did not include inappropriate medications, and that substitutions were made if there were contraindications.

The HEK was dispensed in a sealed bag with an information sheet that itemized the contents, described the symptoms for which each medication is indicated, and instructed the patient/caregiver on the proper storage and use of the kit (i.e., place bag in the refrigerator; open and use only at the direction of the home hospice nurse). The HEK was delivered in its entirety during hospital discharge or by mail. The instructions were reviewed and clarified by the nurse coordinator during the hospice referral process.

Measurement

Outcomes were assessed using data from weekly telephone interviews, electronic medical record (EMR) review, and after-death interviews. Interviews were conducted by non-clinical research staff who did not have the knowledge or expertise to provide medical guidance or advice. Participants were advised to contact the hospice nurse with any clinical questions or concerns.

Weekly telephone interviews. Participants were contacted weekly by telephone to assess symptoms and whether or not the symptoms were treated with items from the HEK. When the HEK had been used, a structured questionnaire was employed to obtain details about how the HEK was used and the respondent’s perceptions of its effectiveness and timeliness for relieving symptoms. The inquiry included questions regarding the specific items used from the kit, the number of times it was used, and whether the hospice nurse was contacted about HEK use. It also explored whether the patient/caregiver experienced anxiety about using the kit and other negative physical or emotional effects associated with HEK use.

Medical record review. When patients/families reported going to the ED or hospital, the EMR was reviewed to assess the relationship of the admission to poorly controlled symptoms. When the patient died or was otherwise discharged from the home hospice program, the EMR was reviewed for additional documentation of HEK use, negative effects of HEK use, and hospitalizations or ED visits.

After-death telephone interviews. Between 1 and 3 months after the death of the hospice patient, the caregiver was invited to participate in a telephone interview to further assess their perceptions of the impact of the HEK. The after-death interview included closed-ended and open-ended

questions. It addressed location of death, preferences for location of death, family member attitudes about the HEK, and impact of the HEK on patients and family members, including empowerment to keep the patient home as well as emergence of negative effects. Open-ended questions included, “As a caregiver, what did you think about the kit?”; “How did the presence of the kit in the home make you feel?”; and “In your opinion, what could we do to improve the kit?”

Analysis

The primary statistical methods were descriptive, including measures of central tendency and dispersion. Responses to open-ended questions underwent content analysis.

Results

Characteristics of participants

Seventy patients were screened for the study; 25 declined and 45 enrolled. Two died before hospital discharge, leaving 43 patients discharged to hospice with a HEK. The characteristics of these 43 patients are presented in Table 2. Patients ranged in age from 53 years to 95 years (mean, 69.8 years). All but one were male; 55.8% self-identified as white or Caucasian, and 44.2% as African American or black. The median time from hospice referral to time of death was 42.0 days (range, 1–516 days). The majority of deaths occurred in the home (58.1%). Other locations of death were inpatient palliative care unit (27.9%) and nursing home (4.7%). At the end of the study, four medically stable patients (9.3%) who had been discharged from hospice were still alive.

TABLE 2. PATIENT CHARACTERISTICS (N=43)

Age (years)	
Mean ± SD	69.8 ± 11.2
Range	53–95
Race (n, %)	
Black	19 (44.2)
White	24 (55.8)
Gender (n, %)	
Male	42 (97.7)
Female	1 (2.3)
Hospice diagnosis (n, %)	
Cancer	29 (67.4)
Dementia	2 (4.7)
Lung disease	3 (7.0)
Heart disease	5 (11.6)
Kidney disease	1 (2.3)
Liver disease	1 (2.3)
Brain (stroke, neurological)	2 (4.7)
Location of death (n, %)	
Home	25 (58.1)
Inpatient palliative care unit	12 (27.9)
Nursing home	2 (4.7)
Discharged from hospice	4 (9.3)
Days between hospice referral and death (consider categories)	
Median	42.0
Mean ± SD	98.0 ± 112.2
Range	1–516

SD, standard deviation.

TABLE 3. SEVERE OR DISTRESSING SYMPTOMS EXPERIENCED IN THE LAST 7 DAYS AND SYMPTOMS FOR WHICH THE HEK WAS MOST COMMONLY USED AS REPORTED IN WEEKLY TELEPHONE CALLS (N=43)

Symptom	Severe or distressing Symptom experienced N=43		Symptoms for which the HEK was most commonly used N=43	
	N	% ^a	N	% ^a
Pain	19	44.2	12	27.9
Nausea/vomiting	10	23.3	5	11.6
Weakness	10	23.3	1	2.3
Swelling	9	20.9	6	14.0
Anxiety	8	18.6	7	16.3
Constipation/diarrhea	8	18.6	1	2.3
Dyspnea	7	16.3	2	4.7
Signs of infection	7	16.3	7	16.3
Confusion	6	14.0	5	11.6
Anorexia	4	9.3	0	0.0
Depression	3	7.0	2	4.7
Secretions	2	4.7	2	4.7
Shaking	1	2.3	1	2.3
Insomnia	1	2.3	1	2.3
Irritation	1	2.3	1	2.3
Not sure/don't know	1	2.3	1	2.3

^aThe numbers of cases reporting each symptom adds to more than 100%, because each patient could have used the kit more than once and for more than one symptom.

Patient/Caregiver reports: Symptoms, HEK use, and impact

During the weekly phone calls, patients and caregivers reported a number of severe or distressing symptoms (Table 3), the most common of which were pain (19 patients, 44.2%), nausea/vomiting (10 patients, 23.3%), weakness (10 patients, 23.3%), and swelling (9 patients, 20.9%). Use of items in the HEK was reported in 21 cases (48.8%; Table 4). The symptoms for which the HEK was most often used were pain (12 cases; 27.9%), anxiety (7 cases; 16.3%), signs of infection (7 cases; 16.3%), and swelling (6 cases; 14.0%; Table 3). The most commonly used items were morphine concentrate (reported in 30.2% of the 43 cases), lorazepam (20.9%), levofloxacin (16.3%), and promethazine (14.0%; Table 4).

All 21 patient/caregiver dyads who used the HEK reported speaking with the hospice nurse about using the kit. Sixteen of the 21 dyads reported that the medication in the HEK was helpful in controlling/relieving the patient's symptoms, and 15 respondents reported that the treatment from the HEK helped the patient remain at home. In four cases the participant indicated feeling anxious or afraid regarding medication use. In 11 cases, caregivers reported that the kit was used on more than one occasion, resulting in 59 incidents of HEK use. Among the 59 incidents of HEK use, 28 (47.5%) were associated with symptom relief in less than one hour.

Medical record review: Emergency department visits and hospitalizations

Of the 43 cases, 19 patients made at least one visit to the ED and 22 were hospitalized (Table 5). Most of the admis-

sions through the ED were due to chest pain, bowel obstruction, abdominal pain, or nausea/diarrhea. The most common reasons for direct admission to the inpatient palliative care unit were palliative procedures (e.g., transfusions), respite, or desire for death to occur in the VAMC inpatient palliative care unit instead of at home.

After-death telephone interviews

Twenty-two caregivers could not be contacted, 2 declined, and 19 agreed to participate in the after-death interview. The majority of respondents (63.2%) reported that the patient died at home, and in most cases, the location of death was consistent with the veteran's preference (78.9%; Table 6).

When asked, "As a caregiver, what did you think about the kit?" responses were uniformly positive. Words and phrases used to describe caregivers' opinions included: "really good," "good to have," "glad it was here," "very helpful," "excellent idea," "definitely a good idea," "glad it was here," "great comfort," and "We slept better knowing we had it." Some respondents focused on the emotional impact, noting that it "made us feel better" or "feel more comfortable" or that it was "emotionally helpful to the patient." Others focused on its utility: "We needed it at that moment," "very useful when we needed the morphine," and "convenient to have and very helpful in controlling his problems and symptoms." Some were reluctant initially: "When I first got it, I didn't know how useful it would be. But as time went on I saw how useful it was to have it at the house." Others did not use the kit but noted: "Glad to have it...in case we needed it." There were no negative comments.

When asked specifically "How did the presence of the kit in the home make you feel?" several respondents described feeling "supported," "confident," or "comforted." Some described a feeling of empowerment to help their loved one: "It made me feel like I could take care of him better" and "I felt very empowered and comfortable about it." The only negative emotion was described by a single respondent who noted anxiety initially: "I was scared at first, but once I used it, it became routine and no problem to use it."

Regarding respondents' opinions about what could be done to improve the kit, most caregivers ($n=17$) had nothing to offer. Only 2 of the 19 respondents offered a suggestion, which involved clearer written labeling of each medication, including specific uses. In the words of one caregiver, "You could write the labels on the bottle telling you what each is for. The flyer was helpful, but I went out and bought labels to use that made it a lot easier!"

Composite HEK utilization and safety

In addition to the 21 cases of HEK use reported in the weekly telephone calls, another 3 cases of HEK use were found in the medical record review. An additional 3 cases were subsequently revealed in the after-death interviews. Thus, considering all three sources of information, the weekly telephone calls, medical record review, and after-death interviews, a total of 27 participants/caregivers (62.8%) reported using the HEK on at least one occasion.

Five incidents of side effects of HEK use were reported: dizziness ($n=1$), drowsiness/sleepiness ($n=2$), disorientation/aggressiveness ($n=1$), and headache ($n=1$). The patients' medical records did not contain any notes documenting loss or

TABLE 4. UTILIZATION AND IMPACT OF THE HEK AS REPORTED IN WEEKLY TELEPHONE CALLS (N=43)

	N	% of total sample	% of users
HEK used a least once (n=43)	21	48.8	–
Number of uses (range=0–8; n=43)			
None	22	51.2	–
1 use	10	23.3	47.6
2 uses	2	4.7	9.5
3 uses	2	4.7	9.5
4 uses	2	4.7	9.5
5 uses	2	4.7	9.5
6 uses	1	2.3	4.8
7 uses	1	2.3	4.8
8 uses	1	2.3	4.8
Items used (n=43) ^a			
Morphine concentrate	13	30.2	61.9
Lorazepam	9	20.9	42.9
Antibiotic	7	16.3	33.3
Promethazine	6	14.0	28.6
Haloperidol	4	9.3	19.0
Furosemide	4	9.3	19.0
Scopolamine patch	2	4.7	9.5
Unknown/unable to recall	4	9.3	19.0
Did you speak with your hospice nurse about using HEK? (n=43)			
Yes (at least once)	21	48.8	100.0
No (never)	0	0.0	0.0
N/A (no HEK use reported)	22	51.2	–
Did the nurse help manage symptoms by: (n=43)			
Phone only	2	4.7	9.5
Home visit only	6	14.0	28.6
Both phone and home visit	13	30.2	61.9
N/A (no HEK use reported)	22	51.2	–
Was the medication in the HEK helpful in controlling/relieving the symptoms/problem you were having? (n=43)			
Yes (at least once)	16	37.2	76.2
No (never)	3	7.0	14.3
Unsure	2	4.7	9.5
N/A (no HEK use reported)	22	51.2	–
Did the patient consider going to the ED/hospital when symptoms were not well controlled? (n=43)			
Yes (at least once)	13	30.2	61.9
No (never)	8	18.6	38.1
N/A (no HEK use reported)	22	51.2	–
Did the treatment from the HEK help patient stay at home? (n=43)			
Yes (at least once)	15	34.9	71.4
No (never)	1	2.3	4.8
Unsure	5	11.6	23.8
N/A (no HEK use reported)	22	51.2	–
Did you feel anxious or afraid regarding using any of the medications from the HEK? (n=43)			
Yes (at least once)	4	9.3	19.0
No (never)	17	39.5	81.0
N/A (no HEK use reported)	22	51.2	–
Did the patient experience any negative effects from using any of the medications from the HEK? (n=43)			
Yes (at least once)	4	9.3	19.0
No (never)	17	39.5	81.0
N/A (no HEK use reported)	22	51.2	–
	N		% of incidents
How long did the patient have the troubling symptoms before using the HEK? (n=59 incidents)			
≤ 1 hour	21		35.6
≤ 1 day	8		13.6
> 1 day	10		16.9
N/A (regular medication)	9		15.3
Not sure/not descriptive	11		18.6
How long did it take for the medication in the HEK to help relieve the troubling symptoms? (n=59 incidents)			
≤ 1 hour	28		47.5
> 1 hour to < 1 day	4		6.8
> 1 day	3		5.1
No relief	5		8.5
Not able to specify	19		32.2

^aThe numbers of cases add to more than 100% because each patient could have used more than one medication. ED, emergency department.

TABLE 5. EMERGENCY DEPARTMENT VISITS AND HOSPITALIZATIONS BASED ON MEDICAL RECORD REVIEW

<i>Emergency department visits (n=43)</i>	N	%
0	24	55.8
1	12	27.9
2	6	14.0
7	1	2.3
Hospitalizations (n=43)		
0	21	48.8
1	16	37.2
2	4	9.3
3	1	2.3
5	1	2.3
Reasons for admissions from ED (19 admissions in 14 patients)		
Bowel obstruction, abdominal pain, nausea/diarrhea	6	31.6
Chest pain	5	26.3
Palliative transfusions	2	10.5
Aspiration	2	10.5
Hypersomnolence, increased weakness	2	10.5
Fall with injury	1	5.3
Urinary tract infection	1	5.3
Reasons for direct admissions (n=13 admissions in 12 patients)		
Respite, VAMC inpatient palliative care unit was preferred location of care or death	5	38.5
Palliative transfusion, thoracentesis, paracentesis	4	30.8
Bed sores not manageable at home	1	7.7
Patient found unresponsive	1	7.7
Pain crisis	1	7.7
No caregiver available	1	7.7

VAMC, Veterans Affairs Medical Center.

diversion of the HEK. In after-death interviews, all respondents reported that the HEK was never lost or diverted for use.

Discussion

This study found that among patients discharged to home hospice with a HEK, over half of the patients/caregivers used the kit to control emergent symptoms, and half of those reported using the kit more than once, indicating the feasibility of HEK use. All the medications were utilized to control a variety of symptoms. The majority of participants reported that the HEK provided timely symptom control and helped the patient to remain at home. Although 51% of patients were hospitalized at some point, many were direct admissions to the inpatient palliative care unit for palliative procedures, caregiver respite, or preference for the unit as location of death. These findings validate the feasibility of stationing medications in the home and support the effectiveness of HEKs. Based on reported usage, it seems reasonable to conclude that the kit used in this study contains appropriate medications. The composition of the kit is further supported by a recent study examining the most commonly prescribed medications in a population of hospice patients.¹⁶

Previous studies have not examined the perceptions of patients and caregivers. However, our results are concordant with prior studies examining the perspectives of hospice nurses. These studies demonstrate that nurses believed HEKs were helpful most of the time,⁹ helped avoid ED visits and/or hospitalization,⁹⁻¹¹ and increased patient and family satisfaction.¹¹

The most commonly used medications were morphine concentrate, lorazepam, levofloxacin, and promethazine for nausea and vomiting. The remaining medications, haloperidol, furosemide, and scopolamine were used in fewer cases. The inclusion in the kit of an oral antibiotic with similar efficacy to the parenteral formulation has the potential not only to relieve symptoms of infection, but also to reassure patients and caregivers that treatment for infection in the home is comparable to treatment in an ED or inpatient facility. A possible concern related to including an antibiotic in the kit is the potential development of resistant bacterial infections due to inappropriate use. Based on review of the EMR, this did not appear to be an issue in this small cohort, but it should be examined in future investigations.

The safety of the HEK medications is supported by the minimal incidents (five) of reported side effects, four of which were related to dizziness or sedation, which could be an expected side effect of many of the medications in the kit. These side effects appear to have been mild, self-limiting, and not associated with a need to seek medical care outside the home.

This study also examined the impact on caregivers of having a HEK in the home. The issue of medication management is salient for home hospice caregivers, particularly as it pertains to organizing medications, coordinating medication administration, and assuring patient adherence to medication orders.¹⁷ Patients and families/caregivers may feel burdened by the presence of the HEK and anxious about correctly handling potent and potentially dangerous medication, such as morphine concentrate, while providing care for their terminally ill family member.^{18,19} However, in this study, only 9.3% of patients/families reported feeling anxious or afraid about using the medications.

Hospice providers recognize the need to assess and support caregiver medication management in the home, especially in the areas of safety and adherence to medication protocols.²⁰ Comments from patients/caregivers indicated that although some had trepidations initially about using the kit, their concerns dissipated when the nurse provided support with education, training, or coaching. Further, caregivers who did not use the HEK commented that they felt supported knowing it was there. There is growing interest in identifying strategies for reducing home hospice caregiver burden, providing emotional support, and promoting self-efficacy in the area of medication management.²¹ The consistent provision of HEKs may contribute to such initiatives.

Another important issue involves potentially unintended harmful consequences stemming from patient or caregiver unsupervised use of the kit. However, in all cases of HEK use, the patient/caregiver reported that they contacted the home hospice nurse about using the kit. The nurse, in turn, followed up with a home visit in the majority of cases.

The strengths of the study include its prospective, longitudinal design, which enabled monitoring of HEK utilization over time and detecting multiple uses. Also, unlike previous

TABLE 6. AFTER-DEATH INTERVIEW RESPONSES (N= 19)

	N (%)
Where did the patient die?	
At home	12 (63.2)
At the VAMC inpatient palliative care unit	6 (31.6)
At another location	1 (5.3)
Was the location of death consistent with your patient’s preferences?	
Yes	15 (78.9)
No	1 (5.3)
Don’t know	3 (15.8)
Was the location of death consistent with family member/caregiver preferences?	
Yes	16 (84.2)
No	0 (0.0)
Don’t know	3 (15.8)
On a scale from 0 (no influence at all) to 10 (extreme influence), how much did having the hospice emergency kit influence how you felt about keeping the patient at home? (Mean, SD)	7.1 (3.6)
On a scale from 0 (no pressure at all) to 10 (extreme pressure), how much pressure did you feel to keep the patient at home because of hospice/the kit? (Mean, SD)	0.3 (0.7)
On a scale from 0 (not empowered at all) to 10 (highly empowered), how empowered did you feel to keep the patient at home because of hospice/the kit? (Mean, SD)	7.9 (2.7)
How often was it helpful to have the kit in the home?	
Always	9 (47.4)
Usually	1 (5.3)
Sometimes	4 (21.1)
Never	0 (0.0)
Missing	5 (26.3)
How easy or difficult was the kit to use?	
Very easy	9 (47.4)
Fairly easy	5 (26.3)
Not easy, fairly difficult, very difficult	0 (0.0)
Missing	5 (26.3)
Did you ever lose the kit?	
Yes	0 (0.0)
No	19 (100.0)
Were any of the medications in the kit used by anyone other than the patient?	
Yes	0 (0.0)
No	19 (100.0)
Is there anything you didn’t know about the kit or the medication that you wish someone had told you?	
Yes	0 (0.0)
No	19 (100.0)

VAMC, Veterans Affairs Medical Center; SD, standard deviation.

studies that report only on the opinions of hospice nurses or nurse managers, this study captured the perspective of the patient and caregivers. This is also a limitation because patient and caregiver report may be vulnerable to response bias, including an unwillingness to report diversion if it were present. Although the interviewers were careful not to provide therapeutic interaction, it is possible that families experienced a sense of social support from the regular telephone calls. Other limitations are the absence of a control group, the lack of data on other medications provided by the hospice agency, and the role of one of the authors (AB) in the rotation for on-call support to hospice nurses, possibly influencing HEK use.

In conclusion, this study provides promising evidence that HEKs are a well-tolerated and feasible method for achieving timely symptom relief for patients in home hospice and possibly avoiding unwanted ED visits and hospitalizations. Additionally, HEKs may ease emotional stress among family

caregivers. Further investigation is needed to examine the extent to which HEKs improve quality of end-of-life care and enhance medication management for family caregivers of home hospice patients.

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Author Disclosure Statement

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