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Hospice experiences and approaches to support and assess family caregivers in managing medications for home hospice patients: A providers survey

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Abstract

Background—Hospice providers need to ensure that informal, unpaid caregivers can safely manage medications to alleviate pain and distressing symptoms in patients near the end of life.

Aim—This study characterizes hospice providers' self-reported experiences and approaches to helping caregivers' medication management for home hospice patients.

Design—Survey with mixed-method analysis.

Setting/Participants—Surveys were administered to a convenience sample of 98 hospice providers (74 nurses, 6 physicians, 11 social workers, 7 chaplains) from 5 Chicago-based agencies in the United States.

Results—Among respondents, 67% rated ensuring proper medication management as “most important” in hospice care delivery, and 33% reported frequently encountering caregivers with problems managing medications. To assess if caregivers had problems managing medications, two categories of approaches emerged from the data: prospective approaches and retrospective warning signs when a problem occurred (e.g. identifying medication nonadherence after observing a sudden patient health decline). Overall, 42% reported using at least one prospective approach, while 38% reported only retrospective signs. To help caregivers manage medications, three categories of approaches emerged: teaching to increase knowledge, supporting existing or simplifying medication management process, and counseling to overcome attitudinal barriers. Overall, 6% reported approaches from all three categories. About 28% frequently experienced difficulty teaching/supporting caregivers with medication management. As much as 47% believed that they would benefit “to a great extent” from additional resources to help caregivers.

Conclusions—Supporting caregivers in medication management is considered important, yet challenging, to hospice providers. Additional resources may be needed to help providers consistently and effectively teach, support, and assess caregivers' medication management.

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Keywords

Hospices; caregivers; medication adherence; terminal care; self-care

Introduction

Of 1.3 million Americans who receive hospice care (defined in the United States as palliative care for patients with an estimated 6 months or less to live),¹ nearly half do so in private residences. Despite regular home visits by hospice providers, most hands-on care is provided by informal, unpaid caregivers.^{2,3} Research on experiences of caregivers and how to address their unmet needs is an international priority in end-of-life care research.⁴ Proper medication management and administration are critical to alleviating patients' suffering.^{5,6} Caregivers must skillfully perform complex tasks, including organizing/tracking medications, working in teams with other caregivers, administering medications of different formulations and schedules, assessing symptoms and medication effects, and responding to patient needs.^{5,7} Hospice providers are critical teachers and supporters of these tasks.⁸ However, less than 60% of home hospice patients in the United States receive assistance in medication management from their hospice agencies, and their quality varies widely.⁹ Many caregivers feel underprepared for medication responsibilities.^{10,11} While research has been done both in the United States and internationally regarding the caregivers' needs in medication management, clinical approaches used to address these needs are not well studied.¹²

There are currently no clinical guidelines defining hospice clinical roles in supporting caregivers with medication management. In the United States, neither the National Consensus Project¹³ nor the National Patient Safety Goals¹⁴ provide detailed guidance on how providers should facilitate medication access or explain prescriptions. A lack of standardized tools and education in end-of-life care for health-care professionals also is a recognized problem in other countries.¹⁵ Hospice approaches to facilitating medication management are therefore left to individual agencies and providers, raising challenges to comparing, evaluating, and improving the quality of care. Prior research provides a conceptual understanding of key domains in aiding caregivers with medication-related tasks: establish trust, provide medication information, encourage self-confidence, offer medication assistance, and assess understanding and performance.¹⁶ However, it is uncertain how common these approaches are in practice.

Using a provider survey administered in Chicago and surrounding areas ("Chicagoland"), United States, this study will quantify self-reported hospice experiences and approaches to support and assess caregivers' medication management. Because such services are not recorded systematically, assessing self-reported data is the best initial step toward documenting this area. This study also will quantify the proportion of providers who encounter difficulty supporting caregivers in medication management and who are receptive to receiving additional resources. This study is necessary to inform future research to benchmark these practices and help design evidence-based interventions to equip caregivers for medication responsibilities. The long-term goal is to alleviate suffering in home hospice patients by improving medication management among caregivers.

Methods

Study participants

Institutional Review Board approved this study (University of Illinois at Chicago Protocol #2010-0930). Study sites consisted of a convenience sample of five Chicagoland hospice

agencies (one for-profit, four not-for-profit). Agency I had an average daily census of 100 patients with one interdisciplinary team (IDT); Agency II had 100–200 patients with two IDTs; and Agencies III, IV, and V each had >200 patients (three IDTs, three IDTs, and five IDTs, respectively). Among 14 IDTs, we conducted self-administered, anonymous surveys with 12 teams at on-site meetings; two Agency V teams were not surveyed due to scheduling conflicts. We surveyed providers who were paid employees with clinical responsibilities (e.g. excluding volunteers and administrators). A research assistant was present to clarify survey items and ensure 100% response among attendees and no answer sharing. All team leaders reviewed and approved the survey beforehand and reported over 85% attendance at meetings when surveys were administered. Due to survey anonymity, absentees were not surveyed.

Surveys

Surveys containing closed- and open-ended items were constructed based largely on data from a previous interview-based study¹⁶ that provided an in-depth conceptual understanding of ways hospice providers (nurses, physicians, social workers, and chaplains) supported caregivers in medication management. We surveyed respondents of various hospice disciplines (nurse, physician, social worker, chaplain, others) to comprehensively explore their involvement with medication management. The survey asked respondents the length of time they had worked in hospice and at their current agency. On a visual analog scale (1 = least to 10 = most important), respondents rated the importance of ensuring proper medication management among caregivers for home hospice care. Respondents rated on a Likert scale (1 = very frequently, 2 = frequently, 3 = occasionally, 4 = rarely, 5 = very rarely, 6 = never) how often they encountered caregivers with problems managing medications.

Open-ended items asked the following: (1) *assessment approaches*: evidence respondents looked for to assess if a caregiver had medication management problems and (2) *teaching/support approaches*: “tricks of the trade” respondents found effective to teach or support caregivers in managing medications. To elicit details, we asked respondents to think about difficult cases and discuss approaches they found effective in practice.

On another Likert scale (1 = very frequently to 6 = never), respondents rated how often they had difficulty teaching/supporting caregivers in managing medications. Finally, respondents rated how much (1 = not at all, 2 = very little, 3 = somewhat, 4 = to a great extent) they would benefit from receiving additional resources to help caregivers in five key areas of medication management (published previously):^{5,7} (1) organize/track medications, (2) coordinate with other caregivers, (3) administer different medications, (4) recognize symptoms and drug effects, and (5) respond to patient needs and preferences.

Analysis

Categorical responses were summarized in frequency tables. Fisher's exact tests using SAS v. 9.2 were performed to assess variation by hospice agency, discipline, time worked in hospice, and time worked at the agency. For open-ended responses, research assistant B.T.J. initially read and labeled them with topic codes. Similar topic codes were grouped into common themes describing providers' approaches to assess, teach, or support caregivers in medication management. To minimize single-coder bias, codes were reviewed weekly with lead investigator DL; consensus was reached to resolve discrepant opinions and ensure analytical consistency. All topic codes and emergent themes were summarized by frequency distributions at the personal level.

Results

We surveyed 98 hospice providers (Table 1): 74 nurses, 6 physicians, 11 social workers, 7 chaplains, and 1 missing. Average time respondents had worked in the hospice field was 73.0 months (8 respondents missing) and at their agency was 57.8 months (14 respondents missing).

Importance and encountering caregivers with problems

Among respondents, 67% rated ensuring proper medication management among caregivers as “most important” (10 on 10-point scale) for home hospice delivery. Importance ratings varied significantly by agency ($p = 0.027$). Overall, 33% had frequently or very frequently encountered caregivers with problems in managing medications; these percentages varied by professional discipline ($p = 0.001$).

Assessment approaches

From open-ended responses, two types of assessments to determine whether caregivers had problems managing medications emerged (Table 2): retrospective warning signs and prospective provider assessments. Retrospective signs were indicators that respondents observed when a medication management problem had already occurred or had potential to occur during the caregiving process (e.g. counting and reconciling pills in pillboxes to assess potential nonadherence). Prospective assessments were initiated by respondents before a potential medication management problem could occur (e.g. assessing caregivers' understanding before a caregiving task started). Overall, 42% reported using *at least one* prospective assessment and 38% reported *only* retrospective signs (32% reported both). About 20% (17 nurses, 2 chaplains, 1 social worker) provided no assessment approaches.

Retrospective signs—Overall, 70% of respondents reported using at least one retrospective sign to assess caregiver problems with medication management. The most commonly reported warning sign (51%) was sudden decline in patient health, particularly increased pain, distress, and symptom severity, thereby inferring that a caregiver may have experienced problems managing medications. About 45% retrospectively assessed discrepancies in caregiving during home visits. For example, respondents counted pills in pillboxes and examined caregivers' medication logs/diaries to determine whether medications were administered properly. A physician wrote, “Number of pills left in the bottles compared to when it was filled should make sense ...” Some respondents referred to this as medication reconciliation to “reveal if too much/little meds given.” Other retrospective signs included caregivers' recapping problems that they had encountered with medication management between providers' home visits and caregivers making telephone calls to triage nurses or 911 during caregiving episodes.

Prospective assessments—Overall, 42% of respondents reported using one or more prospective assessments to determine whether a caregiver had medication management problems. The most common (29%) was assessing caregivers' emotional states: confusion and stress, fear and misconceptions about hospice medications, and poor attitudes toward the end of life (e.g. denial and defensiveness). Respondents primarily relied on nonverbal cues to discern if these suggested problems with managing medications.

About 16% proactively asked caregivers questions to assess information deficiencies regarding medications. For example, respondents asked caregivers questions after providing them with facts; a nurse wrote, “Ask what they'd give for particular symptoms.” Another approach asked whether caregivers had questions that needed clarification. Caregivers also

were asked to re-demonstrate new procedures, such as administering liquid medicines or applying medicated patches.

Additional prospective assessments included examining caregiving context, such as disorganized medication storage and poor coordination among multiple caregivers. Several providers assessed caregivers' predispositions, for example, language/cultural or educational backgrounds, as potential barriers to understanding medication instructions that might lead to future medication management problems.

Teaching/support approaches

Three categories of “tricks of the trade” emerged from the data on approaches to support caregivers in medication management (Table 3): teach to increase knowledge, support medication management process, and counsel to overcome attitudinal barriers. Teaching approaches aimed at improving caregivers' knowledge of correct ways to administer and manage medications. Supporting medication management process included facilitating existing processes and modifying/simplifying them to alleviate caregiver burden. Counseling approaches aimed at helping overcome attitudinal barriers (e.g. anxiety in performing medication-related tasks or fear of administering stigmatized medications such as opioids or antianxiety medications).

Overall, 50% reported using *only one* category of teaching/support approaches (19% taught to increase knowledge, 14% supported medication management process, and 17% counseled to overcome attitudinal barriers). About 32% reported *two of the three* categories of approaches, and 6% reported approaches in *all three* categories. About 12% (8 nurses, 2 social workers, 1 physician, 1 chaplain) reported no teaching/support approaches.

Teach—Overall, 54% reported one or more teaching approaches aimed at increasing caregivers' medication knowledge. The most common (37%) was supplementing with ad hoc, nonstandardized materials, ranging from listing medications with administration instructions to drawing charts and diagrams. One nurse wrote, “Poster-board taped with pills and labels for liquids so they can be visualized.”

About 23% repeated medication information and had caregivers repeat it back; 10% demonstrated a medication administration procedure and had caregivers return-demonstrate. Teaching approaches included simplifying terms so that caregivers did not have to memorize medical words. One respondent noted soliciting instructions from physicians.

Support process—Among respondents, 47% reported using one or more approaches to support caregivers' medication management processes. The most common was facilitating existing processes (42%). For example, respondents would set up and pre-fill pillboxes with different medications and separate regularly scheduled from as-needed medications. Another approach was helping caregivers organize medications and monitor their effects by offering techniques to record medications. A nurse wrote, “Help keep a log of meds given, time received, frequency.”

Several respondents (9%) reported modifying/simplifying medication management processes, including simplifying prescriptions (e.g. changing from as-needed to regularly scheduled) and modifying instructions (e.g. crushing pills) to improve medication adherence. Another approach to simplifying processes was assigning medication management to one caregiver to avoid confusion.

Counsel—About 31% reported counseling to address attitudinal barriers to managing medications. For example, caregivers might be apprehensive about administering

stigmatized medications, particularly opioids, to patients. Respondents would address any fear/myths and reassure caregivers about benefits. Several respondents suggested “trial runs” of medications and offered to change regimens if they were ineffective. Two providers reported using negative messaging to convince caregivers to adhere to instructions by describing the potential adverse impact of poor medication management. A nurse wrote, “Review the worst scenario that could happen if [caregivers] do not comply with meds.”

Difficulty supporting caregivers and benefiting from resources

Overall, 28% reported very frequent/frequent difficulty with teaching/supporting caregivers in managing medications (Table 1), significantly varying by discipline ($p = 0.012$). Additionally, 47% reported that they would benefit “to a great extent” from resources to help caregivers coordinate with others, 41% in organizing medications, 40% in administering medications, 46% in recognizing symptoms, and 37% in responding to patient needs (Table 4). Respondents with fewer months working in hospice tended to perceive greater benefits from resources on administering medications ($p = 0.025$) and recognizing symptoms ($p < 0.001$).

Discussion

Hospice literature on supporting caregivers has largely focused on coping with stress/grief and overcoming attitudinal barriers to pain management.^{6,16–21} Evidence-based interventions have primarily addressed caregiver grief/coping²² and administering pain medications, particularly opioids.²³ There remains a lack of knowledge regarding hospice providers' experiences and approaches in assessing and helping informal caregivers in medication management. Based on our survey of a convenience sample of 98 hospice providers in Chicagoland, two out of three providers consider ensuring proper medication management among the most important aspects of home hospice care delivery. While one-third of providers frequently encounter caregivers with medication management problems, over one-quarter frequently experience difficulty teaching/supporting caregivers' medication manager roles. Sizable proportions of providers believe that they would benefit from additional resources to help caregivers perform medication management duties. Furthermore, this study identifies self-reported assessment, teaching, and support approaches that will provide important insights for developing interventions to better facilitate caregivers in managing medications. These findings will also help standardize reporting to promote benchmarking and improve comparability of hospice practice internationally.²⁴ Standardized palliative care curricula and quality improvement programs have been implemented in Australia with promising results.²⁵

Over one-third of providers surveyed report only retrospective warning signs to identify potential medication management problems. Retrospective signs, especially sudden patient health decline, are suboptimal indicators because medication management problems have occurred or have potential to occur. Although prospective approaches may be preferred because providers can detect potential medication-related problems beforehand, this study finds that prospective approaches are neither described consistently across providers nor executed with evidence-based clinical tools (e.g. no standard instruments to systematically assess caregivers' knowledge/understanding). Consequently, there is uncertainty regarding the reliability and validity of using only currently available prospective approaches to assess medication management problems. Arguably, at present, employing retrospective and prospective assessments may be interpreted as comprehensive *out of necessity* to detect potential problems before and after adverse events. More evidence-based research is needed to evaluate the effectiveness and efficiencies of these assessment approaches.

Despite diverse self-reported teaching/support approaches to facilitate medication management, only 6% of the providers report using approaches in all the categories: teaching, supporting, and counseling caregivers (half report only one category). Furthermore, teaching/support approaches do not appear to be standardized among hospice providers. For example, ad hoc materials to supplement teaching range from handwritten schedules to pictures of medications and actual samples taped onto poster boards. These self-reported behaviors may underestimate or overestimate actual practices (e.g. providers forget a practice or report a practice they never employed). In part, this may be attributed to differences in hospice disciplines (e.g. social workers/chaplains emphasize counseling, nurses emphasize teaching/supporting, and physicians emphasize simplifying prescription instructions).¹⁶ Nonetheless, these findings may reflect the current lack of consensus guidelines or agency protocols on comprehensive, standard ways to aid caregivers in managing medications. Additionally, because teaching/support approaches may depend on clinical needs, these findings may reflect providers' clinical experiences that may not require all types of approaches to effectively facilitate medication management. Future research will need to consider clinical needs and whether they are effectively addressed by providers' teaching/support approaches. Hospice providers should be equipped to help caregivers with various kinds of approaches, which should be implemented consistently and effectively to avoid potential disparity in supporting caregivers.

The identified “tricks of the trade” provide important preliminary insights for future interventions, including in-service training curricula and evidence-based tools to support practice. However, some approaches need further investigation to evaluate their effectiveness and appropriateness. For example, while most use positive messaging, few providers report using negative messaging to counsel caregivers (e.g. discussing potential adverse effects if medications are administered incorrectly), which can increase anxiety among already-stressed caregivers facing end-of-life concerns. Furthermore, because we find that perceived medication management importance varies by hospice agency, organizational culture may need to be considered when intervening to improve medication management practices in different institutions. Variations across countries also will need to be considered and interventions may need to be adapted appropriately. As evidence on best practices accumulates, agency protocols and consensus recommendations on facilitating medication management may need to be updated.

This study has limitations. Because we used data collected from a small, nonprobabilistic sample of hospice providers in a single geographic area, our findings cannot be generalized and will need to be replicated in a larger, representative sample and in other countries. Many of our results may be specific to the United States; for example, in Australia, it is recommended that pharmacists fill pillboxes, rather than nurses. Additionally, there is item nonresponse in our data, rendering some percentages conservative. Although our sample is multidisciplinary, our findings reflect those surveyed; most of whom are hospice nurses. Surveying patients and caregivers may offer insight into the additional approaches that consumers perceive as effective. Finally, despite a research assistant's effort to minimize distractions and inconsistencies in survey administration, responses might have been influenced by survey conditions and time constraints.

Hospice providers play an important role in supporting caregivers' various responsibilities, including medication management. Our study provides evidence that ensuring proper and safe medication management among caregivers is considered important, yet challenging, for many providers to facilitate and many caregivers to execute. Additionally, many hospice providers, especially those with little working experience, believe that receiving additional resources would tremendously benefit them in helping caregivers perform medication-related tasks. These findings provide evidence of the need for developing new interventions

to help caregivers better manage medications. The “tricks of the trade” identified in this study can inform future development of such interventions that ultimately would improve quality of home hospice care worldwide to increase competence and confidence among caregivers and provide comfort and relief to the hospice patients.

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Table 1

Hospice providers' medication management importance rating, frequency encountering caregivers with medication management problems, and frequency having difficulty in teaching/assisting caregivers in managing medications.

	Agency					Discipline ^a					Months in hospice ^b					Months at agency ^c				
	Site I	Site II	Site III	Site IV	Site V	p value	RN	MD	SW	CH	p value	Mean	SD	p value	Mean	SD	p value	Mean	SD	p value
	n = 98, %	n = 9, %	n = 33, %	n = 25, %	n = 12, %		n = 74, %	n = 6, %	n = 11, %	n = 7, %		73.0	75.1		57.8	16.0				
Importance rating						0.027					0.300			0.421						
10	67	58	78	48	83		69	83	36	86		71.9	66.3		55.2	83.6				
9	10	21	0	8	8		10	0	18	14		86.9	98.0		84.8	43.8				
8	19	21	11	40	0		18	17	45	0		73.2	99.0		57.4	90.2				
7	2	0	11	0	8		3	0	0	0		84.0	50.9		54.0	8.5				
Missing	1	0	0	4	0		0	0	0	0		3.0	N/A		3.0	N/A				
Encounter caregivers with problems						0.704					<0.001			0.354						0.261
Frequently/very frequently	33	26	56	36	25		36	33	9	29		102.8	87.8		53.4	69.3				
Occasionally	50	53	44	52	42		53	17	82	0		59.4	62.2		68.0	98.3				
Rarely/very rarely/never	11	16	0	4	25		7	33	9	43		48.7	47.6		42.7	42.0				
Missing	6	5	0	8	8		4	17	0	29		66.5	101.6		36.8	36.4				
Have difficulty teaching/assisting caregivers						0.635					0.012			0.647						0.544
Frequently/very frequently	28	32	44	32	17		30	33	9	29		96.7	93.7		68.1	101.8				
Occasionally	52	47	44	52	50		55	50	64	0		67.9	66.1		47.4	60.9				
Rarely/very rarely/never	15	16	11	8	33		11	17	18	57		56.5	68.6		48.2	49.2				
Missing	5	5	0	8	0		4	0	9	14		42.2	33.5		115.8	145.5				

RN: registered nurse; MD: physician; SW: social worker; CH: chaplain; SD: standard deviation.

Statistical significance at $p < 0.050$

^a1 respondent had missing data in professional discipline.

^b8 respondents had missing data on months worked in hospice.

^c14 respondents had missing data on months at current agency.

Table 2

Hospice assessment approaches to determine whether caregivers have problems with managing medications.

Assessment approaches	% ^a , (N = 98)	Illustrative quotes
<i>Retrospective warning signs</i>	70	
<i>Patient health decline</i>	51	
Patient assessment	51	"I witness a patient in pain or distress and find that the caregiver does not recognize the need for breakthrough meds"
<i>Discrepancies in caregiving process</i>	45	
Pillbox/log check	28	"Number of pills left in the bottles compared to when it was filled should make sense with the instructions. If there are more or less than expected then it's a sign the caregiver is having problems"
Nonadherence	16	"Are they following administration of medications as prescribed?"
Infrequent need to reorder medications	4	"Timing of need for refills"
<i>Caregiver recapping problems</i>	18	
Caregiver discuss problems encountered	18	"[Caregiver] told me they gave a medication for a symptom but it was the wrong medicine"
<i>Calls during caregiving process</i>	12	
Frequent calls to helpline	12	"When they call the triage nurse and ask the same questions over and over again"
Calls to 911	1	"Are they calling 911?"
<i>Prospective provider assessments</i>	42	
<i>Examine caregiver emotional state</i>	29	
Confusion and stress	19	"If [caregiver] looks exhausted, struggling emotionally."
Fear and misconceptions	6	"Fear of killing the patient ... making death quicker ... and not wanting to over-sedate the patient. Some worried about addiction."
Poor attitudes toward end of life	5	"Unrealistic expectations—denial regarding prognosis"
<i>Determine information deficiency</i>	16	
Ask caregiver to answer questions	9	"See if caregivers can verbalize their understanding of a medication after telling them what the drug is for."
Ask if caregiver has questions	4	"Ask how caregivers are doing ... if anything they don't understand."
Ask caregiver to demonstrate	4	"How [caregiver] demonstrates back a procedure after teaching"
<i>Examine caregiving context</i>	9	
Poor organization of meds	6	"Unable to keep medicines organized ... not storing them well"
Poor coordination among caregivers	3	"Too many cooks in the kitchen"
<i>Assess caregiver predisposition</i>	6	
Language/cultural backgrounds	3	"Communication issues such as English as a second language"
Low-education/knowledge backgrounds	2	"Their knowledge base"
Functional limitations	1	"Assess ability of caregiver to open bottles or draw up liquid meds"

^aPercentages do not add up to 100% or subtotals because respondents provided responses in multiple categories; therefore, responses were not mutually exclusive.

Table 3

Hospice “tricks of the trade” for teaching or supporting caregivers in managing medications.

Teaching/support approaches	% ^a (N = 98)	Illustrative quotes
<i>Teach to increase knowledge</i>	54	
Supplement with ad hoc materials	37	“Write a list of medications that includes times, symptom controlled, dose”
Repeat information/have caregiver repeat back information	23	“Repetition, repetition, repetition ... Ask caregiver to repeat their understanding of the medication plan”
Demonstrate procedure/have caregiver demonstrate back	10	“Demonstrate, have [caregivers] return demo”
Simplify terms	10	“Instead of using names of meds—refer each drug by size and shape for each pill “Use analogies so caregivers can better understand the importance of adhering medications to prescriptions (e.g., only feeding a baby when [he/she] cries is like only giving pain meds when it gets really bad. If you feed a baby regularly, [he/she] won't cry from hunger. → If you give pain meds regularly, [the patient] won't feel the pain as much)”
Use analogies	3	
Ask physician to explain	1	“Ask physician to explain”
<i>Support medication management process</i>	47	
<i>Facilitate existing process</i>	42	
Provide/pre-fill pillboxes or pre-fill syringes	24	“Give out medication boxes, which RN fills” And, “Draw up liquid morphine and lorazepam in syringes and label them for caregivers who have difficulty in vision, coordination or are just overwhelmed”
Help keep medication logs/diaries	20	“Help keep a med list with time to administer, dose to give, symptoms present when PRN dose used, etc.”
Help organize meds	4	“Color coding bottles; separate scheduled vs. PRN meds”
Telephone to follow up/remind	3	“Have triage RN call to remind [caregiver] to give medication”
<i>Modify/simplify process</i>	9	
Simplify prescription	5	“Simplify medication regimen (i.e. use fentanyl patch if the family is not reliable with pain med administration)”
Modify administration instructions	2	“Some patients don't want to take meds. I would advise caregivers to crunch the meds in applesauce or ice cream”
Assign medication manager role to a single caregiver	2	“Assign 1 family member to be responsible for meds”
<i>Counsel to overcome attitudinal barriers</i>	31	
Focus on potential or actual health benefits of medications	11	“Assured [caregivers] about the positive outcomes of pain and comfort management” And, “When the patient is comfortable or not in a state of crisis, I make sure the family notices it and can see that due to treatments the patient's comfortable”
Encourage caregiver	9	“Encourage, say that they can make a difference in making the patient feel more comfortable”
Address fear/myths about medications, especially pain/anxiety drugs	8	“Discuss benefits of pain medications, dispelling myths”
Share common stories of other caregivers/patients	6	“Share stories of my experiences with other patients”
Reassure hospice presence	4	“Address fears about ‘bothering’ nurse with concerns. Call if any signs of pain/discomfort when caregivers don't know what to do”
Suggest a trial and then reassess	3	“Suggest that we can try it, change can always be done”
Remind caregivers about patient's goals of care/preferences	3	“Remind caregivers about past discussions they had with the patients about the desires for comfort at the end of life”
Explain adverse impact of poor medication management	2	“Review the worst scenario that could happen if [caregivers] do not comply with meds”

^aPercentages do not add up to 100% or subtotals because respondents provided responses in multiple categories; therefore, responses were not mutually exclusive.

Table 4
Perceived benefits that hospice providers expected from additional resources to better help caregivers manage medications.

Benefit from resources	Agency					Discipline ^a				Months in hospice ^b				Months at agency ^c			
	Agency					Discipline ^a				Months in hospice ^b				Months at agency ^c			
	Site I	Site II	Site III	Site IV	Site V	RN	MD	SW	CH	Mean	SD	p value	Mean	SD	p value	Mean	p value
<i>N</i> = 98, %	<i>n</i> = 19, %	<i>n</i> = 9, %	<i>n</i> = 33, %	<i>n</i> = 25, %	<i>n</i> = 12, %	<i>n</i> = 74, %	<i>n</i> = 6, %	<i>n</i> = 11, %	<i>n</i> = 7, %								
<i>Teamwork</i>										0.249		0.960			0.562		0.720
To a great extent	47	53	67	56	17	47	50	45	43	52.4	50.8		57.3	97.8			
Somewhat	42	42	22	36	58	42	50	55	14	82.2	74.7		60.5	65.4			
Very little	4	0	0	4	8	5	0	0	0	192.0	155.2		51.0	60.2			
Not at all	2	5	11	0	0	3	0	0	0	72.0	67.9		30.0	8.5			
Missing	5	0	0	4	17	3	0	0	43	94.8	104.0		59.2	42.7			
<i>Organization</i>										0.158		0.392			0.056		0.639
To a great extent	41	42	89	36	40	46	33	27	14	61.5	55.7		58.0	92.2			
Somewhat	41	37	11	52	50	41	50	55	14	58.3	46.0		50.8	68.5			
Very little	9	11	0	6	8	8	17	18	0	162.8	151.1		76.0	98.6			
Not at all	3	5	0	4	8	3	0	0	14	138.0	88.4		110.0	108.1			
Missing	6	5	0	6	17	3	0	0	57	79.5	100.3		49.8	44.6			
<i>Medication knowledge</i>										0.642		0.110			0.025		0.957
To a great extent	40	42	44	36	52	43	33	45	0	67.7	80.3		53.2	86.2			
Somewhat	43	37	44	52	50	46	50	45	0	75.9	72.8		70.0	89.9			
Very little	8	5	11	6	17	7	17	9	14	77.4	65.6		33.3	21.8			
Not at all	2	5	0	4	0	1	0	0	14	90.0	42.4		48.0	17.0			
Missing	7	11	0	6	17	3	0	0	71	75.0	92.3		47.9	41.0			
<i>Symptom knowledge</i>										0.290		0.799			<0.001		0.427
To a great extent	46	42	56	42	64	46	50	55	29	50.7	75.1		37.1	61.5			
Somewhat	43	42	44	42	75	45	33	36	43	87.8	60.8		76.4	92.6			
Very little	5	11	0	6	4	4	17	9	0	104.6	106.1		133.3	123.0			
Not at all	2	5	0	3	0	3	0	0	0	150.0	42.4		21.0	21.2			
Missing	4	0	0	6	8	3	0	0	29	93.0	120.0		48.5	40.8			
<i>Personhood</i>										0.541		0.609			0.849		0.777

Benefit from resources	Agency		Discipline ^a					Months in hospice ^b				Months at agency ^c			
	Site I		Site II	Site III	Site IV	Site V	p value	RN	MD	SW	CH	p value	Mean	SD	p value
	n = 98, 19, %	n = 42, %	n = 56, %	n = 33, %	n = 25, %	n = 12, %		n = 74, %	n = 6, %	n = 11, %	n = 7, %		73.0	75.1	57.8 16.0
To a great extent	37	42	56	36	36	17		39	50	18	29		62.3	89.6	49.9 94.6
Somewhat	52	42	33	55	56	67		51	33	73	43		74.1	55.9	57.2 66.4
Very little	6	11	11	3	4	8		5	17	9	0		104.0	91.9	141.0 111.9
Not at all	1	5	0	0	0	0		1	0	0	0		120.0	78.5	36.0 87.8
Missing	4	0	0	6	4	8		3	0	0	29		93.0	120.0	48.5 40.8

RN: registered nurse; MD: physician; SW: social worker; CH: chaplain; SD: standard deviation.

Statistical significance at $p < 0.050$

^a 1 respondent had missing data in professional discipline.

^b 8 respondents had missing data on months worked in hospice.

^c 14 respondents had missing data on months worked at the current agency.