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Perceived Barriers that Impede Provider Relations and Medication Delivery: Hospice Providers' Experiences in Nursing Homes and Private Homes

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Abstract

Objectives: Hospice providers often work with nursing home providers or with family caregivers to deliver medication services aimed at alleviating suffering in patients with life-limiting illnesses. From the perspective of hospice providers, this study explores barriers that may impede provider relations and medication delivery in nursing homes and private homes.

Methods: Semistructured, open-ended interviews were conducted in-person with a purposive sample of 22 hospice providers (14 registered nurses, 4 physicians, and 4 social workers) from 4 hospice programs in the greater Chicago metropolitan area.

Results: In general, registered nurses, doctors, and social workers discussed similar barriers in nursing homes and in private homes. According to hospice providers, nursing home providers and family caregivers exhibited comparable attitudinal barriers ("owning" their settings; "knowing what's best for the patient"; distrust toward hospice; and emotional state), and encountered similar site-readiness barriers (ill-defined hierarchy, poor communication, disagreements among care providers, and responsibility overload). Additionally, comparable alignment barriers (differences in care priority and in education/training) existed between hospice providers and care providers in nursing homes and private homes. Together, these barriers impeded care providers' communication with hospice providers and their readiness to accept hospice guidance. Overall, poor provider relations compromised the efficiency and quality of medication management, as well as potentially undermined the role of hospice providers.

Conclusion: From the perspectives of hospice providers, this study provides preliminary insight into barriers that multilevel interventions may need to address to improve provider relations and medication delivery in nursing homes and private homes.

Introduction

In the United States, hospice care, generally considered the gold standard of care for patients with life-limiting illnesses, can occur in inpatient facilities, nursing or private homes, and hospitals.[1] Hospice providers must coordinate with care providers at these locations (e.g., nursing home providers in nursing homes and family caregivers in private homes), forming hospice service delivery networks. These networks can operate under contractual agreements or informally by exchanging resources to realize a shared care plan that effectively provides comfort to end-of-life patients.[2]

Proper medication use to manage pain and distressing symptoms is an important component of hospice; however, studies consistently find pain persisting among hospice patients despite continual education in medication and symptom management.[3–5] Because work-related barriers (e.g., conflicts among care providers) can adversely impact health care processes in many settings,[6,7] we anticipate that poor provider relations may impede medication delivery and symptom management in hospice service delivery networks.

Using qualitative interviews, we have explored hospice providers' perceived barriers that impede their relations with care providers in nursing and private homes, and examine how poor provider relations may hinder medication management. This study aims to begin discussing medication delivery in hospice service networks with hospice providers who are uniquely positioned to describe their clinical experiences in both nursing and private homes.

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Methods

Institutional Review Board approval was obtained at the lead institution. We purposively selected 4 hospice organizations in the Chicago area according to ownership (3 not-for-profit, 1 for-profit) and daily census (1 with ≤100 patients, 1 with 100–200 patients, 2 with 200+ patients). In each organization, we purposively sampled at least 1 registered nurse, 1 physician, and 1 social worker with in-depth experience and current practice in delivering care in both nursing and private homes. In all, we interviewed 22 providers: 14 nurses, 4 physicians, and 4 social workers. Most were female (16), white (18), and with 1+ years at their hospice institution (17) and 3+ years hospice experience (13).[8]

Semistructured, open-ended interview guides with trigger questions asked how hospice providers worked with nursing home (NH) providers and family caregivers (FCGs; e.g., "Describe your experience working with NH providers [or FCGs] while treating hospice patients with medications."). Follow-up questions focused on hospice providers' experience with barriers and poor relations within the context of medication delivery (e.g., "What barriers do you encounter working with NH providers [or FCGs] while managing patients' medications and symptoms?"). Probe questions asked for elaboration and examples from clinical practice.

Interviews were conducted by lead investigator D.L. and research assistant L.H. from March to July 2008. Interview locations were chosen by subjects; all but two chose their offices. Interviews averaging 1 hour were audiorecorded and transcribed. Atlas.ti v-5.2 software was used to manage interview data. Topic and thematic codes were generated by D.L. and research assistant J.M.P. and reviewed with research assistant M.O. and coinvestigator C.B. to ensure analytical consistency of the data.[8–10] Similar emergent themes were grouped into common categories. Comparable to other qualitative studies,[11,12] our analysis of 22 subjects reached thematic saturation, the threshold after which no new significant themes emerged.

Results

According to hospice providers, three sets of barriers adversely influenced hospice providers' relations with NH providers and FCGs (Table 1): attitudinal barriers ("owning" the setting, "knowing what's best for the patient," distrust toward hospice, emotional state); site-readiness barriers (ill-defined hierarchy/poor communication, disagreements among care providers, responsibility overload); and alignment barriers (differences in care priority and in education/training). These barriers impeded NH providers' and FCGs' communication and coordination with hospice providers and their readiness to follow hospice recommendations. By and large, poor provider relations (i.e., poor communication and coordination among care providers, and resisting hospice instructions) compromised the quality of medication management at the settings of care, and undermined hospice providers' clinical role. Generally, hospice providers reported similar barriers regardless of profession. We observe minimal intragroup variations by hospice provider or organization types. We summarize findings broadly by hospice providers but present quotes according to professional groups.

Attitudinal barriers

"Owning" the setting. Hospice providers said many NH providers consulted them regularly on pain management; however, some NH providers guarded their facilities as "their turf." This perceived ownership drove NH providers to heed hospice recommendations sporadically, if at all. One hospice nurse said, "I have several [NH nurses] who won't take our recommendations . . . . They find us to be an intrusion in their facilities. . . . They think we're stepping on their toes."

Perceived ownership existed in private homes, which hospice providers said FCGs viewed as "sacred." One nurse said, "Families invite me into their home that [they viewed as] an intimate space . . . . Finding that balance between respecting their authority and professionally caring for the patient is a challenge." Concern about professional boundaries was complicated when privately-hired caregivers were present. One social worker said, "This [hired caregiver] refused to administer any pain medications. I told the family, 'I can't control her because I don't employ her . . . you do.' I can't just take over." Hospice providers discussed how perceived ownership influenced FCGs' willingness to accept assistance with medications. One nurse said, "Some family members don't want to lose control in their home . . . . They don't want help with ordering medications or setting up pill boxes." Refusing hospice assistance was especially concerning when medication safety was jeopardized. One nurse recalled, "Some [caregivers] have pill bottles all over the place . . . . Some pills are lying outside . . . . Some are expired. It's a real safety issue."

"Knowing what's best for the patient." Hospice providers realized that they delivered care in settings with preexisting caregiver–patient relationships. Hospice providers believed that some NH providers assumed they knew more about the patient and discounted hospice providers' expertise. One nurse said, "When I go [to the NH], this patient tells me that he's having all this pain. When I ask the nurse to give him more medications, she says, 'Oh, that's just him . . . . He's always like that.' The nurse did nothing . . . . One day the patient started cradling in pain . . . . I yelled at the nurses for his pain medications."

While some NH providers appeared complacent and inattentive about patients' care, hospice providers observed that some FCGs were overprotective and resisted instructions. One hospice nurse explained, "Some families have taken care of [the patient] for years . . . . They don't want to lose that control [especially with medications] . . . . When I explain different medications to them, they'd say, 'I know him . . . he doesn't need that drug. I'm not giving it to him.' "

Distrust toward hospice. Hospice providers believed that building NH providers' trust in their expertise helped ensure proper execution of instructions. One nurse explained, "I've been working at [this NH] for 6 years . . . many nurses there know me. Even if they're concerned about [pain medications], they trust my judgment . . . . Some let me administer drugs to my patients in their NHs." Hospice providers said that without trust some NHs were less cooperative about sharing patient records with them.

Hospice providers said FCGs distrusted hospice because of prior experiences. One nurse noted, "I had several families who were very hostile because they had bad experiences with the medical establishment. They saw me as a representative of

Table 1. Barriers Impeding Provider Relations and Hospice Medication Delivery with Examples in Nursing Homes and Private Homes

Barriers	*Examples in nursing homes*	*Examples in private homes*
1. Attitudinal Barriers		
	Nursing Home Providers . . .	***Family Caregivers*** . . .
"Owning" the setting	Guarded their nursing home as their "turf" and saw hospice providers as "an intrusion"	Viewed their home as a "sacred" space and resisted hospice guidance, raising concerns about medication safety
"Knowing what's best for the patient"	Thought they knew patients' needs but seemed complacent about their care, dismissing hospice's clinical advice	Were overprotective of the patient's care and did not want to lose control of medications
Distrust toward hospice	Had professional distrust toward hospice and did not cooperate with hospice providers during visits	Had distrust toward hospice due to prior negative experience with health care and did not involve hospice in family meetings
Emotional state	Feared giving opioids and therefore did not adhere to hospice prescribing instructions	Feared being viewed as incompetent and avoided asking questions
		Were overwhelmed with grief, which impaired learning and caregiving
2. Site-Readiness Barriers		
	Nursing Homes . . .	***Private Homes*** . . .
Ill-Defined Hierarchy/Poor Communication	Had hierarchy but poor communications existed, making coordination with hospice difficult	Had poorly-defined hierarchy with no primary caregiver in charge, making communication with hospice confusing
Disagreements among Care Providers	Had a lack of teamwork among nursing home providers, resulting in hospice orders being overturned	Had poor cohesion among family caregivers, which often resulted from deep-seated conflict
Responsibility Overload	Had high patient load that limited communication opportunities and hindered around-the-clock monitoring of patient	Had responsibility overload among family caregivers that increased burn-out and hampered communication
3. Alignment Barriers		
	Nursing Home Providers . . .	***Family Caregivers*** . . .
Differences in care priority	Did not prioritize pain management, contradicting hospice priority in comfort care	Gave less than necessary dosage of pain medicines by favoring alertness with patient
Differences in education/training	Did not possess basic pain management skills that hospice providers expected of them	Questioned hospice clinical advice when they used unreliable sources to self-educate

that." This distrust impeded hospice providers from effectively coordinating patient care with FCGs. One social worker said, "Coordinating a family meeting is hard for some because they don't trust medical people . . . . They don't want us to get involved."

Emotional state. Hospice providers observed that many NH providers and FCGs feared opioids and resisted hospice instructions. One hospice nurse said, "[NH nurses] are health care professionals but many are scared of giving morphine and causing a patient's demise." FCGs were described as being afraid to "get the patient addicted," "make the patient all drugged up," or "kill the patient with morphine." Hospice providers believed that some FCGs feared opioids due to social factors including religion and race/ethnicity. One social worker said, "For [some groups], they don't want morphine in their home because they have family members with substance abuse problems."

Hospice providers observed various coping behaviors in FCGs from being emotionally distant to being overwhelmed with grief. One nurse recalled, "[A husband] was so paralyzed by grief . . . he just left his wife's medications in their packaging." These FCGs had difficulties learning about medication management or following instructions. A nurse said, "It's hard to teach them and know how much information they retain when they're grieving." Hospice providers discussed how some FCGs were embarrassed to ask questions or report mistakes. One nurse recalled a FCG saying: "Oh that [amount of drug] was what I really gave to [the patient], but I didn't tell you . . . . I was afraid you'd think I was giving too much."

Site-readiness barriers

Ill-defined hierarchy/poor communication. Hospice providers described how hierarchies at NHs and private homes affected communication and shared decision-making. NH physicians had the ultimate prescribing authority, with nurses implementing treatment plans. NH providers who disagreed with hospice care plans could disregard hospice recommendations. One nurse stated, "The [NH] doctor has to

agree with what we ordered . . . . If we think the patient is in pain but the doctor doesn't think so, the patient won't get the order." Despite established hierarchies, poor communication existed among NH providers. One nurse explained, "We may teach one set of [NH] nurses one day . . . then during the weekend, an entirely different crew works with the patients . . . . Our instructions don't get passed on."

The hierarchy in private homes varied from one FCG performing all medication-related tasks to multiple FCGs. Hospice providers described confusing interactions with FCGs when families did not designate a primary caregiver. One nurse said, "Some families have different people helping . . . . I don't know whom I should talk to to give instructions." Miscommunication also compromised medication safety. One nurse recalled, "This husband came home and gave [the patient] the medications. His wife came home later, and without knowing, administered the same medications again . . . [the patient] was double-dosed." Problems existed in families with hired caregivers but without strong family leadership. One nurse reported, "[This hired caregiver] said to me, 'It's time for his medications . . . but I don't give drugs.' I told the family but they did nothing . . . . I ended up visiting the patient every day to administer his medications." This created inefficiencies for hospice providers.

Disagreements among care providers. Hospice providers found that the lack of teamwork among care providers impeded medication delivery. A few hospice providers recalled situations in which hospice and NH providers agreed on medication orders only to have them overturned by another NH nurse. One hospice nurse recalled a director of nursing being disagreeable and argumentative with other NH providers, stating, "Our [hospice] doctor worked with a [NH] nurse to put in an order for the patient. We find out later that the director of nursing was being difficult and stopped the order without consulting us." Hospice providers said they had to return to NHs more often to monitor and ensure their patients' comfort.

Hospice providers observed that FCGs' disagreements often resulted from deep-seated conflicts. One social worker explained, "When I walk into someone's home . . . there might be ulterior motives and resentment among siblings." Such conflicts impeded FCGs' adherence because family members question every decision they make. A nurse said, "They end up not giving the medication or giving less medication than needed."

Responsibility overload. Hospice providers highlighted responsibility overload as a factor limiting communication between hospice and care providers (e.g., conducting care plans or resolving disagreements). One nurse said, "We get attitudes [from NH providers] . . . they'd say, 'Don't you see I'm busy?' The nurses are doing a med pass for 40 patients at once . . . . They have to keep moving." Another nurse commented, "Our NH patients can have several prn drugs ordered every 1 to 2 hours. It's hard to get a nurse to assess the patient every 1 to 2 hours to see if the patient needs the drugs." One doctor added, "In NHs, we end up changing the medications to regularly scheduled rather than as-needed so that [the medications] get administered."

Hospice providers described how FCGs had to balance other responsibilities including self-care, house chores, and employment outside the home. A nurse said, "When I talk to family members, many seem like they understand me . . . . But they have so many responsibilities that I wonder if they forget what they're supposed to do or remember what I've said." Hospice providers expressed concerns about caregiver burn-out.

Alignment barriers

Differences in care priority. Although hospice providers prioritized comfort care as their guide for clinical decision-making, they found that some NH providers and FCGs did not prioritize pain management. In NHs, the priority was generally on restoring patients' physical functioning. One nurse said, "[NH providers] don't seem to worry that the patient's in pain . . . . They worry about drug addiction when the patients theoretically have less than 6 months to live."

Hospice providers said FCGs struggled balancing between comfort-inducing effects of pain medications and their sedative side effects. Many FCGs preferred under-dosing because they prioritized patient alertness. One nurse said, "Sometimes it's the patient but sometimes it's [the caregiver] who doesn't want opioids because the patient gets knocked out. They want more awake time with each other . . . . But I see [the patient's] whole face is screaming pain."

Differences in education/training. Hospice providers believed that conflicting opinions about treatments were attributable to education/training differences between hospice and care providers. Hospice providers expected NH providers to possess basic pain management skills. One nurse said, "[NH providers] are professionally trained but they don't know some of these medications . . . they don't understand how they're used for different symptoms . . . like sedatives for restlessness."

Hospice providers said that it was reasonable to teach nonprofessional FCGs about medication and symptom management. However, problems occurred when FCGs found unreliable information that opposed hospice instructions. One nurse reported, "When [caregivers] search the Internet, they get sensationalized news about rare occurrences. . . . They start questioning what we do in hospice." Hospice providers spoke about challenges in instructing FCGs with limited English proficiency or health literacy. One nurse said, "It's not easy to gauge what they understand and explain things in simpler terms."

Discussion

To our knowledge, this study is the first to describe hospice providers' relations with both NH providers and FCGs. According to our sample, even though NH providers are professionally trained and FCGs are generally lay persons, attitudinal barriers such as perceived ownership and fear of opioids adversely affect medication delivery in nursing and private homes. Additionally, while NHs are highly regulated settings and private homes are places of residence, providers in both settings face similar site-readiness barriers including poor communication and responsibility overload that impede collaboration with hospice providers.

Hospice providers face misaligned care priorities when working with NH providers and FCGs. While hospice providers prioritize comfort care, NH providers emphasize re-

storative care perhaps as a result of regulatory pressure to maintain patients' physical functioning.[13] In private homes, FCGs may question the value of hospice care in maintaining the patient's quality of life. They may struggle between providing enough pain medications and minimizing adverse side effects. Their priority to maintain patient alertness may compete with hospice orders to meet the patient's palliative needs.

Collectively, attitudinal, site-readiness, and alignment barriers contribute to poor provider relations in both NHs and private homes. According to hospice providers, poor provider relations and communications may compromise the efficiency and quality of symptom management, and potentially jeopardize medication safety. When hospice instructions are overturned or ignored, the raison-d'être of hospice providers in NHs and private homes may be obviated. The undermining of care providers' role has been documented in other settings.[6,7]

Overload and understaffing are well-documented NH problems.[14,15] This study suggests that site-readiness barriers may curtail opportunities for care planning and conflict resolutions not only among NH providers, but also between hospice and NH providers. In private homes, time and financial constraints are recognized caregiver strains.[16] Coupling these factors with poorly delineated hierarchy may cause further confusion between hospice providers and FCGs.

Additional research should determine which barriers exert the greatest impediment on provider relations in hospice service delivery networks. From hospice providers' perspective, this study suggests that multilevel interventions may need to extend beyond individual-level education in medication management for NH providers and FCGs. Team-building efforts with hospice and other care providers may be needed to improve shared decision-making, build trust, and address "ownership" concerns. Resources may help alleviate workload of NH providers and FCGs, and establish effective communication protocols. Group workshops on care coordination may help address disagreements and misalignment of care priorities among providers. Distinction between NH providers as professional peers and FCGs as clients of hospice may influence the development of interventions. For example, training and reorganization can be mandated in NHs, but interventions for FCGs may need to be reinforced as part of standard care.

This study has limitations. The design focused on perceived barriers to provider relations in hospice medication delivery. Several facilitators, however, were discussed. For example, building trust with NH providers helped a hospice nurse gain better access to her patients' records and permission to administer medications to her patients in NHs. Soliciting facilitators from respondents could have yielded additional insights and intervention recommendations. Furthermore, this study was based on qualitative data from a purposive sample of 22 experienced hospice providers, reflecting the perspectives of individuals in our study. Because our findings reflect only hospice providers' views, alternative explanations should be considered. For example, hospice providers perceived that some NH providers were complacent and being difficult, and some FCGs were overprotective about patients' care. Such perceptions of other providers' motivations cannot be validated. Our findings need further investigation in samples that include other care providers and geographic locations. While most hospice care and NH regulations on medication delivery are federally imposed, local factors such as market competition may influence care practices and provider relations in different locations. NH providers and FCGs may identify barriers absent from this study (e.g., conflicts within hospice teams).

Understanding how service delivery networks function will become increasingly important as the health care industry becomes more specialized and long-term care shifts toward private homes. While service delivery networks may theoretically provide more effective and efficient health services than other service models, this exploratory study provides insight from hospice providers' perspective on barriers that may impede provider relations and medication delivery. Our findings will inform future research to develop more effective interventions to improve hospice medication management in both nursing and private homes.

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Author Disclosure Statement

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References

1. Brass DJ, Galaskiewicz J, Greve HR, Wenpin T: Taking stock of networks and organizations: A multilevel perspective. Acad Manage J 2004;47:795–817.
2. Huerta TR, Casebeer A, Vanderplaat M: Using networks to enhance health services delivery: Perspectives, paradoxes and propositions. Healthc Pap 2006;7:10–26.
3. Buchanan RJ, Choi M, Wang S, Huang C: Analyses of nursing home residents in hospice care using the minimum data set. Palliat Med 2002;16:465–480.
4. Deandrea S, Montanari M, Moja L, Apolone G: Prevalence of undertreatment in cancer pain: A review of published literature. Ann Oncol 2008;19:1985–1991.
5. Teno JM, Clarridge BR, Casey V, Welch LC, Wetle T, Shield R, Mor V: Family perspectives on end-of-life care at the last place of care. JAMA 2004;291:88–93.
6. Bostick JE, Rantz MJ, Flesner MK, Riggs CJ: Systematic review of studies of staffing and quality in nursing homes. J Am Med Dir Assoc 2006;7:366–376.
7. Lau DT, Banaszak-Holl J, Nigam A: Perception and use of guidelines and interprofessional dynamics: Assessing their

roles in guideline adherence in delivering medications in nursing homes. Qual Manag Health Care 2007;16:135–145.
8. Lau DT, Kasper JD, Hauser JM, Berdes C, Chang CH, Berman RL, Masin-Peters J, Paice J, Emanuel L: Family caregiver skills in medication management for hospice patients: A qualitative study to define a construct. J Gerontol B Psychol Sci Soc Sci 2009;64:799–807.
9. Glaser BG, Strauss AL: *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago: Aldine, 1967.
10. Miles MB, Huberman AM: *Qualitative Data Analysis*: *An Expanded Sourcebook*, 2nd ed. Thousand Oaks: Sage, 1994.
11. Guest G, Bunce A, Johnson L: How many interviews are enough? An experiment with data saturation and variability. Field Methods 2006;18:59–82.
12. Weller SC, Romney AK: *Systematic Data Collection*, Volume 10. Newbury Park: Sage, 1988.
13. Hodgson NA, Lehning AJ: Palliative care in nursing homes: A comparison of high- and low-level providers. Int J Palliat Nurs 2008;14:38–44.
14. Miller SC, Mor V: The opportunity for collaborative care provision: The presence of nursing home/hospice collaborations in the U.S. states. J Pain Symptom Manage 2004;28: 537–547.
15. Parker-Oliver D: Hospice experience and perceptions in nursing homes. J Palliat Med 2002;5:713–720.
16. Raina P, O'Donnell M, Schwellnus H, Rosenbaum P, King G, Brehaut J, Russell D, Swinton M, King S, Wong M, Walter SD, Wood E: Caregiving process and caregiver burden: Conceptual models to guide research and practice. BMC Pediatr 2004;4:1.

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