Exploring Factors that Influence Informal Caregiving in Medication Management for Home Hospice Patients

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Abstract

Objective: To explore factors that influence how informal caregivers manage medications as part of caring for hospice patients.

Methods: Semistructured, open-ended interviews were conducted with 23 informal caregivers and 22 hospice providers from 4 hospice programs in the Chicago metropolitan areas. Qualitative analysis was conducted consistent with the grounded theory approach.

Results: In general, informal caregivers and hospice providers identified similar key factors that facilitated or impeded caregivers' process in managing medications. Caregivers' life experience and self-confidence were considered assets that facilitated medication management. Limitations impeding the process included caregivers' negative emotional states, cognitive and physical impairments, low literacy, other competing responsibilities, as well as patients' negative emotional states and complex medication needs. Furthermore, the social context of medication management emerged as a salient theme: caregivers' good interpersonal relations with patients facilitated medication management, whereas poor communication/relations among caregivers within a support network impeded the process. While both study groups discussed the positive attributes of good caregiver-patient relations and support from multiple caregivers, hospice providers were cautious about the potential adverse influence of close relations with patients on caregivers' decision making about medications and discussed poor communication/relations among informal and privately hired caregivers that often resulted from family conflicts and/or a lack of long-standing leadership.

Conclusion: Our findings suggest additional intervention points, beyond knowledge and skill building, that could be addressed to support caregivers in executing medication responsibilities at home for hospice patients.

Introduction

INFORMAL (OR UNPAID) CAREGIVERS become increasingly important as they take on expanded roles in coordinating and delivering care, especially to seriously ill older adults receiving home hospice services. Although hospice providers visit regularly, caregivers such as family and friends provide most of the around-the-clock, hands-on care.^{1,2} Over 80% of caregivers of hospice patients report managing and administering medications to relieve patients' pain and other distressing symptoms.^{3,4} Hospice medication regimens often

include potent medications with narrow therapeutic ranges and serious adverse side effects, requiring careful monitoring and skillful management by caregivers. Evidence indicates that caregivers feel insufficiently supported in performing medication-related duties and adhering to hospice prescription instructions.^{5,6}

Most literature on informal caregiving focuses on general caregiving responsibilities and coping skills in reducing burden and stress.^{7,8} One study conceptualizes medication management for dependent older adults as a "caregiving hassle" from a stress-coping perspective.⁹ Few studies examine

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caregivers' knowledge/skill needs specific to hospice medication management or explore factors that influence the medication management process as a caregiving responsibility. In an earlier report,¹⁰ we identified core knowledge/skill areas that caregivers need to effectively manage medications for hospice patients. Core areas include management skills such as the ability to store, organize, and discard medications, and technical skills such as the ability to recognize symptoms and administer different types of medications. Overall, medication management requires high-level, proactive skills that combine general knowledge of symptomatology and pharmacology with specific understanding of a patient's preferences and needs.¹¹ Although identifying core knowledge/skills can contribute to the content of future educational curricula for caregivers, other factors may influence the process in which caregivers manage and administer medications for hospice patients.

For this study, we conducted analysis to explore patient- and caregiver-related factors, other than core knowledge/skills (i.e., patient- and caregiver-related factors) that may facilitate or impede caregivers' execution of medication duties at home. Although not intended to identify every influence on the medication management process, this study will begin this conceptualization from the perspectives of caregivers and hospice providers. Our findings will inform hospice providers of additional intervention points, beyond teaching core knowledge/skills, to help caregivers properly manage medications and avoid medication-related errors, thereby alleviating distressing symptoms in hospice patients.

Methods

Institutional Review Board approval was obtained at the lead institution. We purposively selected four Chicago-based hospice organizations based on ownership (one for-profit, three not-for-profit) and daily census (one ≤ 100 patients, one 100–200 patients, two 200+ patients). We worked with clinical managers at each organization to recruit a convenience sample of caregivers and hospice providers. Caregivers had to be at least 18 years old, English-speaking, and assisting an elderly hospice patient (aged 60+) with at least 1 hospice-prescribed medication. Hospice providers had to have at least 1 year of hospice clinical experience.¹⁰

We interviewed 45 participants: 23 caregivers and 22 hospice providers. The 23 caregivers included 10 daughters, 4 wives, 2 husbands, 2 partners, 2 sisters, and 3 others. Most were between 51 and 70 years old ($n = 13$); white ($n = 11$) or African American ($n = 9$); and not college educated ($n = 12$). One quarter ($n = 6$) reported annual household income $\leq \$20,000$ and almost half ($n = 10$) reported income $\geq \$50,000$. All but one had helped a patient enrolled in hospice for ≥ 1 month and most ($n = 17$) had managed the patient's medications for 1+ years. Caregivers were helping patients with cancer ($n = 8$), dementia ($n = 8$), congestive heart failure ($n = 3$), and other primary hospice diagnoses ($n = 4$). Of the 22 hospice providers, 14 were registered nurses, 4 physicians, and 4 social workers. Most providers were female ($n = 16$), white ($n = 18$) or Asian American ($n = 3$), and had 3+ years hospice experience ($n = 13$).¹⁰

Based on review of caregiving studies and health care clinical/research experience among study investigators,¹⁰ we developed semistructured, open-ended interview guides to

address caregivers' medication responsibilities ("How do you care for [the patient] with his/her medications?") and explore factors that facilitated ("Who helps you organize and give [the patient's] medications? How is it easier for you?") and impeded medication management ("Describe a situation when you had trouble organizing or giving medications. What was difficult about it?"). A similar interview guide was developed asking hospice providers to share their observations of caregivers' experience with medication management. Probe questions asked for elaboration.

Interviews were conducted by lead investigator D.L. and research assistant L.H. from March to August 2008. Interviews with caregivers occurred at their private residences. All but two hospice provider interviews occurred at their offices. Interviews averaged 1 hour and were audio-recorded and transcribed. Using Atlas.ti v-5.2 software, D.L. and L.H. generated topic and thematic codes using an iterative process of data review consistent with the grounded theory approach. Weekly meetings were held to ensure analytical consistency.^{12,13} Co-occurrences of emergent themes were examined and categorized together to illustrate their complex interconnections. For example, participants discussed the presence of caregiving support networks as facilitators to medication management but also raised concerns regarding negative interpersonal relations as impediments. While both were coded as separate themes, they also received a broader code of "social context" of medication management.

Results

Overall, caregivers and hospice providers identified similar factors that facilitated or impeded medication management (Table 1). Caregivers' life experience and self-confidence were assets facilitating medication management. Caregivers' negative emotional states, cognitive and physical impairments, low literacy, competing responsibilities, as well as patients' negative emotional states and complex medication needs were limitations that impeded the process. Caregivers emphasized life experience and patients' negative emotional state, while hospice providers focused on the influence of caregivers' low literacy. Furthermore, the social context of medication management emerged as a salient theme: caregivers' good interpersonal relations with patients facilitated medication management, whereas poor communication/relations among caregivers in a support network impeded the process. While caregivers and hospice providers described the positive aspects of good caregiver-patient relations and support from multiple caregivers, hospice providers noted the potential adverse impact of close relations with patients on caregivers' judgment about medications and discussed poor communication/relations among caregivers resulting from family conflicts and lack of long-standing leadership.

We observed some intragroup variations among caregivers and hospice providers. For example, older caregivers (e.g., spouses/partners) discussed cognitive and physical impairments as impediments to medication management more often than younger caregivers (e.g., offspring). Social workers emphasized emotional and relationship factors, while physicians discussed the significance of caregivers' self-confidence. Due to small sample size, we describe key findings broadly by caregivers and hospice providers to reflect participants' perspectives, but present quotes according to caregiver's

TABLE 1. FACTORS THAT MAY FACILITATE OR IMPEDE FAMILY CAREGIVING IN MEDICATION MANAGEMENT FOR HOME HOSPICE PATIENTS, ACCORDING TO PARTICIPANT GROUPS THAT EMPHASIZED THE FACTORS

<i>Factors identified by participants</i>	<i>Type of factor</i>	<i>Participant group(s) that emphasized the factor</i>
A) Caregivers' assets		
Life experience/background knowledge that caregivers may draw upon	Facilitator	Caregivers
High self-confidence may help caregivers make decisive actions/overcome fear	Facilitator	Caregivers/hospice providers
B) Caregivers' limitations		
Negative emotional states—grief and fatigue—may impair decision making	Impediment	Caregivers/hospice providers
Cognitive/physical impairments may challenge performance	Impediment	Caregivers/hospice providers
Low literacy may impede learning and understanding of prescription instructions	Impediment	Hospice providers
C) Caregivers' competing responsibilities		
Employment, housekeeping, and other dependents may compete with caregiving	Impediment	Caregivers/hospice providers
D) Patient-driven demands		
Negative emotional state may lead to patient's refusal of medications	Impediment	Caregivers
Complex medication needs may entail more complicated instructions to follow	Impediment	Caregivers/hospice providers
E) Social context of medication management		
<i>Interpersonal relations with patients</i>		
Good communication may help patients accept medication assistance	Facilitator	Caregivers/hospice providers
Close relations may cloud caregivers' judgment to prioritize patients' comfort	Impediment	Hospice providers
<i>Caregivers' support networks</i>		
Multiple caregivers' support may help relieve primary caregivers' responsibilities	Facilitator	Caregivers/hospice providers
Poor communication/relations among caregivers—family conflicts and lack of leadership—may impede the process	Impediment	Hospice providers

relationship to the patient (e.g., daughter, wife) or provider's profession (social worker, nurse or doctor).

Caregivers' assets

Caregivers highlighted life experiences, such as employment background, as assets that facilitated medication management. Unlike core knowledge/skills specific to medication management that hospice providers would teach, life experience encompassed broader, background knowledge that caregivers acquired in other life events and that they drew upon while managing medications. For example, a husband displayed a binder of logs documenting his wife's medication regimens, saying, "Being an engineer, I'm very precise about what I do... like tracking all of [my wife's] medications and symptoms." A daughter taking care of her mother said, "I used to be a teacher... and don't operate well in confusion... I teach everyone in the house how to give medications to my mom."

Caregivers and hospice providers discussed how caregivers' high self-confidence empowered them to take more decisive actions and overcome their fear of making medication errors. A nurse recalled caregivers saying, "Show me the morphine. I know how it works... I'm not afraid of it." Conversely, low self-confidence impeded caregivers' performance in managing medications even if they had prior caregiving experience. A daughter said, "I've been taking care of

my mom and my own kids... but I froze when [my mom] moved into my place [after hospice enrollment]... I started doubting myself with her medications."

Caregivers' limitations

Caregivers and hospice providers discussed caregivers' negative emotional states, including grief and fatigue, as limitations to managing medications. A nurse said, "I had a patient whose husband was so paralyzed by grief... he had to relinquish his caregiving responsibilities so he could be the husband again." Fatigue impeded caregivers' ability to make thoughtful decisions and increased the chance of medication errors including skipping or giving incorrect dosages. A daughter admitted, "I averaged 4 hours of sleep... Last night, I dozed off, jumped up, and realized I forgot to give Mama her medications."

Both study groups mentioned cognitive and physical impairments impeding caregivers, especially older spouses/partners, in managing medications. A wife noted, "Even if [the nurse] explained the information, I'd forget it later." A nurse added, "Liquid medicine is especially hard to give if [the caregiver] has poor eyesight and can't see the tick marks on the droppers or the number of drops going under the tongue."

Only hospice providers discussed low literacy (e.g., poor reading and math skills) and limited English proficiency as

challenges to caregivers' ability to communicate with hospice and learn prescription instructions. A nurse explained, "A patient's wife who was managing the medications didn't speak English. I had an interpreter... But even in her language, I didn't know how well she understood what I said and whether she'd give the medications according to my instructions."

Competing responsibilities

Both study groups mentioned competing responsibilities including employment, housekeeping, and other dependents as impediments to managing medications. A daughter said, "When I have to clean after my son or do housework, I can't keep a constant watch of my mom or give her medications always on time." A social worker noted, "Some [caregivers] take time off from work and dedicate themselves to the patient 24/7... Others have to work part-time or work from home on top of taking care of the patient." Some hospice providers said they made more frequent home visits to help caregivers with competing responsibilities.

Patient-driven demands

Caregivers emphasized how patients' negative emotional states challenged their ability to administer medications because patients became more resistant toward taking medications. A daughter explained her need to understand her dad's emotions: "Sometimes my dad said hurtful things to me but he might be upset with the world... It's hard for him to accept his current state and relinquish independence... He refused his medications to take back control over his life." Caregivers and hospice providers discussed how complex medication regimens and patient health needs increased caregiving demands. For example, patients exhibiting frequent symptom changes required multiple "as needed" medications at the onset and thus vigilant monitoring by caregivers. Patients with difficulty swallowing were prescribed liquid medicines or medicated patches with complex instructions that caregivers needed to learn from hospice providers.

Social Context

Relations with patients. Caregivers discussed how they effectively managed medications by interacting with the patient with greater patience. A neighbor explained, "A lot of patience... If [the patient] refuses his medications, I wait, take a breath, and try later... asking him what's wrong." Some hospice providers described how caregivers neglected the patient's emotions and comfort by being emotionally disengaged and preoccupying themselves with the mechanical aspects of managing medications. A nurse said, "I tell [a caregiver] that her husband needs her to sit with him, hold his hand, and ask how he was feeling... but she's busy running around organizing [medications]."

Caregivers and hospice providers described how maintaining good relations and communication helped patients accept assistance. A daughter said, "I keep telling my mom that she took care of us when we were little... now it's my turn to help her." Good relations with patients helped caregivers better understand and manage patients' health needs despite complex medication responsibilities. A daughter explained, "I

can read my mom and know her tolerance level... It's easier knowing what [amount is] too much to give her."

While strong caregiver-patient relations facilitated medication management, hospice providers expressed concerns that close relations clouded some caregivers' judgment concerning the best care for the patient. Hospice providers cautioned that some caregivers resisted treatment plans, particularly those involving medications that induced drowsiness, because of their own preferences rather than the patients' comfort needs. One nurse noted, "Sometimes it's the patient but sometimes it's [the caregiver] who doesn't want opioids... They want more awake time with [the patient]... but I see her whole face screaming pain."

Support networks. Both study groups spoke about how having support from multiple caregivers facilitated medication management by providing respite for the primary caregiver. A wife said, "My friends and my daughters come over on the weekends to help me... like giving [my husband] his medications." While most informal caregivers valued the help of multiple caregivers, hospice providers noted the impeding influence of negative interpersonal relations on medication management. Poor cohesion among family caregivers often resulted from deep-seated conflicts. A social worker said, "When [a caregiver] disputing with other family members, they question each other's motives... they think she isn't giving adequate care... or she's sedating the patient to kill him faster." Hospice providers often assessed family dynamics and facilitated conflict resolution among family members.

When privately hired caregivers, often nonmedically trained personal care assistants, are involved, hospice providers discussed the need for hired caregivers to understand hospice philosophy and treatment plans. A nurse said, "Some [hired caregivers] aren't onboard with hospice... and won't give opioids... I have to educate them and the families together." Poor communication between informal and privately hired caregivers further impeded the medication management process. HP particularly emphasized that many informal caregivers assumed trust in their hired caregivers and did not take a leadership role to manage medications. A nurse recalled, "I told a family that [the hired caregiver] blatantly refused to give any pain medications when they weren't there... but [the family] didn't intervene... perhaps they never had to or they just assumed she knows what she's doing."

Discussion

Our findings indicate that merely increasing caregivers' knowledge and skills may not guarantee successful execution of medication responsibilities if other factors impede the process. Interviews with caregivers and hospice providers suggest that there are key patient- and caregiver-related factors that may influence how caregivers manage medications for home hospice patients. Among the identified facilitators and impediments to optimal medication management, the social context of medication management emerges as a salient theme. In particular, hospice providers recognize that poor interpersonal relations among multiple caregivers may adversely influence medication management and that privately hired caregivers complicate these relational and communication dynamics.

This study contributes to existing literature on caregiving^{8,9,14} by highlighting influential factors that may be more relevant to medication management than general caregiving. For example, adequate literacy level may be particularly important in medication management for caregivers to read medication labels and follow prescription instructions. Compared to the general elderly population,⁹ medication management for hospice patients may be more emotionally stressful and caregivers may need more assistance to positively cope with their grief and fatigue. Because opioids and other medications with serious side effects are often prescribed "as needed," caregivers may need to be more vigilant about assessing the patient and continually monitoring medication effects. Furthermore, while interpersonal conflicts may impede overall caregiving processes, positive relations among multiple caregivers may be especially pertinent to medication management. For example, due to the stigma associated with opioids (e.g., hastening death), many caregivers may have difficulty in collectively agreeing on their use. Hospice providers' efforts to educate all caregivers, promote open communications, and build consensus around treatment plans may be particularly important for successful hospice medication management at home.

This study also highlights important topics rarely discussed in caregiving research, including communication between informal and privately hired caregivers. Many informal caregivers in this study valued privately hired caregivers while hospice providers cautioned that privately hired caregivers often lacked an understanding of hospice philosophy and refused to administer hospice medications (perhaps in part due to liability concerns) without notifying family members. Hospice providers may need to educate informal caregivers about the repercussions of these disagreements, discuss the importance of their leadership in the medication management process, and create tools to facilitate communication among all caregivers.

Some of our key findings are consistent with prior theoretical and empirical studies, and have important practice implications. Compatible with social learning theory,^{15,16} caregivers with high self-confidence are more likely to engage in active learning and medication management because they feel certain of their capabilities. Educational efforts by hospice providers may need to be coupled with encouragement and assessments of caregivers' self-confidence.

Similar to prior research on general caregiving responsibilities,⁸ cognitive and physical impairments and competing responsibilities of caregivers are influential factors. Simplifying medications, for example by decreasing medication regimen complexity¹⁷ and using pill management systems,¹⁸ can help avoid medication non-adherence and errors. Hospice providers may need to provide more direct assistance (e.g., set up pill-boxes or pre-fill droppers for liquid medicines) and help caregivers positively cope with demands and alleviate role strain.¹⁹

Comparable to other studies on caregiver-patient relations,^{20,21} caregivers in this study discussed how strong caregiver-patient relations helped caregivers assess patients' needs and helped patients accept assistance. However, some hospice providers observed that caregivers with strong relations to patients struggled with balancing medication benefits and adverse side effects (e.g., minimizing pain versus maximizing alertness). Hospice providers may need to sensitively

guide caregivers to make informed decisions with the patient's best interests in mind.

This qualitative study has several limitations. Using a nonprobabilistic sample limits the generalizability of these findings. While this study highlights factors that may influence medication management from the perspectives of caregivers and hospice providers, other factors including system-level factors and provider characteristics should be investigated. The current study did not match hospice providers and caregivers who cared for the same patient, which limited its ability to further explicate the social context of medication management. Finally, our study sample primarily includes caregivers with substantial medication management experience, and is restricted to English-speaking individuals in Chicago. Although most caregivers in our sample were not college educated, it was hospice providers only who discussed issues related to language/literacy barriers based on their clinical experience. Despite diversity in caregivers' race/ethnicity and gender, minimal differences in medication management were observed perhaps due to sample selection bias. Larger studies with less experienced caregivers and different geographic locations would enhance our understanding of factors that impact medication management.

Findings of this study should be useful to researchers and practitioners who are concerned with improving home hospice medication services. By understanding the context in which caregivers manage medications for home hospice patients, hospice providers can better identify intervention points to improve the medication management process. The implications of these findings may increase in relevance as more elderly patients choose to age and die in their own homes, relying on caregivers for medication assistance.

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