Medication Administration Hassles Reported by Family Caregivers of Dependent Elderly Persons

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Background. Even under the new long-term care mantra for increased home- and community-based care options, attention to and an understanding of the ways that family caregivers are managing complex care for dependent elderly persons, for example, with medication administration, have been slow to materialize.

Methods. Twenty-three family caregivers completed semistructured, face-to-face interviews to capture the shared and idiosyncratic experiences of individuals responsible for all aspects of medication administration regimens for elderly, dependent family members. Data analysis consisted of content analysis of the verbatim interview transcripts. This article reports an emerging typology of caregiver medication administration hassles derived from the interviews.

Results. Based on 122 separate accounts, three categories of medication administration hassles were identified. The categories (with the percentage of all accounts represented by the category) include (i) scheduling logistics (29.5%), (ii) administration procedures (31.9%), and (iii) safety issues (38.6%).

Conclusions. Primary care providers must continually reevaluate and simplify medication regimens for dependent elderly persons in the care of family members, and the family caregivers must be given adequate training and access to ongoing information support systems to help them perform safe and effective medication administration responsibilities.

As the emphasis in long-term care continues to shift from institutional care to an array of home- and community-based options (1,2), family caregivers are being expected to share increasingly complex care for dependent elderly persons who are likely to be taking combinations of prescription and over-the-counter medications for multiple chronic conditions (1,3,4). Except for a relatively new body of literature on home care and pain management of hospice patients (5–9), there has been little substantive information about how lay family caregivers deal with these medication administration issues.

In fact, most studies of family caregiving have largely ignored the responsibility of daily medication administration for a dependent family member. Even when an effort is made to address the contributions of medication administration to stress, strain, or burden, existing measurement items do little more than associate global medication administration responsibility with heightened caregiver stress. Although a great deal of information is available about how older adults comply or adhere to their own medication regimens, health care providers are just beginning to understand that giving medications to and managing medication regimens for a dependent elderly person contribute substantially to caregivers’ stress (10).

This knowledge void was clear during recent secondary analysis of caregiver interviews undertaken for the purpose of organizing the problems, issues, and concerns described by family caregivers with medication administration responsibility. The research team ultimately labeled these items “caregiver medication administration hassles” because they were more consistent with minor irritations of daily living (11) rather than with any obvious deficiencies in the caregivers’ situations or abilities. In addition, the importance of identifying this or any other group of hassles is that over time, the accumulation of hassle-related stress is commonly believed to have a negative effect on both the caregiver and the outcomes of the caregiving situation (12). The identification and organization of an emerging typology of caregiver medication administration hassles are the focus of this article.

Methods Design

The data for this analysis were part of a larger study designed to learn more about the ways that family caregivers (i) gather information and educate themselves about administering medications and monitoring for adverse effects; (ii) make decisions about administering medications to a dependent family member (dosing, withholding, discontinuing); (iii) communicate their decisions to formal caregivers in their long-term care networks, including their physicians; and (iv) receive information about medication administration issues. Multiple methods of data collection were used in the study, including caregiver questionnaires and face-to-face, semistructured interviews designed to maximize an understanding of the shared and idiosyncratic experiences of the family caregivers. In addition, field notes were used to provide supplemental information about the long-term care settings and observations of the caregiving triads (adult day services staff, family caregivers, and care recipients). Thus, data and methodological triangulation (13) were included in the overall study design.
The caregiver questionnaire included information about past and current utilization patterns for long-term care programs and services, medication histories, caregivers’ satisfaction with the day services, caregivers’ perceived ability to manage the medication regimen of the care recipient, basic demographic information about the caregivers and care recipients, and caregiving histories. In addition, a 14-item medication administration checklist (see Appendix 1) was developed from a review of related medication compliance/adherence literature, the oncology literature previously cited, and family case studies provided by the two participating day care centers to the first author. This simple checklist provided the interviewer with a conversational springboard to personalize probes about medication problems, concerns, or feelings during the semistructured interviews. A set of generative questions was also used to keep the interviews focused on the research questions (see Appendix 2).

Sample
Because one of the goals of the original study was to explore how family caregivers made decisions and communicated with formal long-term care providers, caregivers were recruited from two adult day care centers in a large metropolitan city located in the southwestern United States. The two centers serve approximately 125 clients per day.

The assembled sample consisted of 23 caregivers of adult day care participants who (i) were over the age of 65; (ii) took medication daily; (iii) depended on the informal provider to manage and oversee their medication regimens; and (iv) attended adult day care at least 3 days a week for the 3 months preceding the interview (to ensure that the relationship with the formal day care provider was stable and mature). Because of the obvious confounding effects that frail or impaired caregivers can have on a caregiving situation, we chose to exclude caregivers who were dependent on others for personal assistance. A letter announcing the study and asking for participation was given to eligible caregivers at each center. Then, with the help of center staff, caregivers representing a variety of age groups, diverse caregiving dyads (spousal, adult child, and other caregiver dyads), and those known to the day services staff to be experiencing both positive and negative caregiving experiences were personally invited (by center staff) to participate in the study. All caregivers who gave permission to have their names forwarded to the project team as potential respondents participated in the study.

Caregiver respondents ranged in age from 33 to 77 years (mean = 60 years). Their care recipients were 66 to 94 years of age (mean = 81 years). The overwhelming majority of the caregiving dyads were spousal (48%) or parent–adult child arrangements (35%). One sibling caregiver, two daughters-in-law caring for mothers-in-law, and one granddaughter caring for a grandmother comprised the “unusual caregiving” category (17%). Consistent with the utilization rates of community-based, long-term care programs across the state, only one of the respondents was African American (4%) (14). Despite efforts to recruit male respondents, only one eligible male caregiver (4%) was interviewed for the study, which is probably a reflection of the current gendered nature of family caregiving responsibility (15). About two thirds of the respondents (61%) did not work outside the home. Caregivers had been in their roles between 7 and 188 months (mean = 54 months). The majority of the caregivers (83%) reported at least a high school education, and about one fifth reported having received college or graduate degrees.

Clients of the two participating centers generally come from middle income families and neighborhoods. Both centers offer a sliding-scale fee structure supported by the state’s Division on Aging, the United Way, and various scholarship programs, so almost all of the families interviewed received some financial assistance to pay for their dependent members’ day care services. One family was receiving assistance from the Department of Veterans’ Affairs. None of the participating families was receiving Medicaid-reimbursed day care at the time of the study.

Data Collection
At their request, slightly more than half of the respondents were interviewed at their respective adult day care centers. All other interviews took place in respondents’ homes. With the permission of the respondents, an oral consent to participate in the study was tape-recorded at the onset of the session and before the caregiver questionnaire was completed. A caregiver questionnaire was administered first and generally took about 10 minutes to complete. The interviewer then obtained the tape-recorded, semistructured interview. The entire data collection process took between 1 and 2.5 hours. All procedures were approved by a university institutional review board.

Analysis
Content analysis of the transcribed interviews was facilitated by HyperResearch, a software program for qualitative data analysis. The following steps were taken to enhance coding reliability. First, a set of referential codes—codes reflecting the topic of the text or things being expressed in the passage (16)—were developed by the first author from all transcripts. The second author used this list to code a random set of 40 pages drawn from all transcript pages. This process resulted in a 50.4% rate of agreement on the codes assigned to text. Next, the authors discussed the “hits” and “misses” in coding to eliminate confusing, overlapping, or unclear codes and to add new codes that were needed. The coded transcripts were then recoded via the procedures in the software program. Finally, a third reader, a graduate assistant who was working on various aspects of the project but who had not collected the data, was asked to read five complete, recoded transcripts selected at random from the entire set of study transcripts. She agreed with the revised referential coding scheme 100% of the time. Thus, the team had a high degree of confidence that excerpts about medication administration issues had been correctly identified.

In the next stage of analysis pertaining specifically to this article, transcript excerpts with referential codes for medication administration issues were reviewed until all accounts of medication hassles were identified and labeled. The hassle codes were then assigned to mutually exclusive hassle domains.
**Results**

Medication Conditions and Medication Use

In brief, the most commonly mentioned active medical conditions of the care recipients reported by their caregivers are consistent with chronic conditions found by researchers who have studied similar older adult populations receiving adult day services (17,18). In descending order, these conditions were Alzheimer’s disease/dementia (52%), stroke (30%), arthritis (26%), heart disease (26%), hypertension (26%), sensory deficits (17%), depression (13%), diabetes (13%), and seizure disorders (13%). Respondents listed on average three active medical conditions for their care recipients.

Caregivers were managing between 1 and 14 medications on a daily basis. Over-the-counter medications were also given to the care recipients by all of the caregivers for analgesia, nutritional supplementation, treatment of cold or allergy symptoms, and constipation. A complete description of the caregiver questionnaire data can be obtained from the first author.

Caregiver Medication Administration Hassles

A total of 122 accounts of medication administration hassles were mentioned by the caregivers. An excerpt was coded as a separate account if the remarks described a different situation or set of circumstances than the one previously mentioned. For example, a caregiver may have reported two different situations in which he or she had to decide when to hold, increase, or decrease a dose or discontinue a medication. Unless the excerpt was a continuation of a previous discussion, it was coded as a new account. The 122 accounts of medication administration hassles were subsequently categorized into three domains: (i) scheduling logistics, (ii) administration procedures, and (iii) safety issues. These domains with the hassles placed within each domain comprise the typology presented in Table 1. Also reported in Table 1 are the number of caregiver accounts for each hassle, the percentage of the total number of accounts represented by each hassle, and the number of caregivers affected by each hassle. Caregivers gave 1 to 19 separate medication hassle accounts during their interviews.

Scheduling logistics.—Every caregiver reported having to deal with scheduling logistics of some type on an ongoing basis. The most common hassle in this category—working administration schedules into caregiving routines—was usually handled by planning medication schedules around meal and bedtime routines. This approach worked best for those caregivers who had predictable schedules. Caregivers who continued to work or who had other family/caregiving responsibilities reported more missed doses, regardless of the medication administration schedules they tried to keep.

Other problems discussed by the caregivers included constantly trying to give certain medications on time and scheduling up to 14 medications throughout the day. In those cases in which both the caregiver and the care recipient took medications, schedules were usually rearranged so that both individuals took some or all of their medications at the same time.

One of the more thought-provoking hassles in the scheduling logistics category was keeping multiple prescriptions filled. The five caregivers who reported this hassle either had large numbers of medications or very expensive medications to purchase. Because these caregivers used different sources for refilling prescriptions (pharmacies, mail order plans, and office samples) and relied on different mechanisms for reimbursement (e.g., private insurance and Veterans Administration benefits), they had to create elaborate strategies for keeping an adequate supply of multiple prescriptions. A 69-year-old caregiver who was caring for her 70-year-old, retired military spouse gave this account of the hassle:

Many of our medications [the air base] will provide. But then there are several that they don’t provide and I have to get them elsewhere. So I constantly forget when to get more medicine for him, when to get more medicine for me, when to call the other place.

Administration procedures.—Hassles associated with administration procedures seemed worse among caregivers who were responsible for cognitively impaired elders. Most of the stress with these types of hassles seemed to stem from the fact that caregivers placed a high premium on conflict-free caregiving time, and giving medications on a “bad” day was sure to precipitate or heighten caregiving conflict.

Managing variable doses of medications, including efforts to make up missed doses, were also common hassles in this domain. Many of the care recipients’ medications had instructions to reduce the dose to half or hold the dose altogether under certain circumstances. Making the decision at night or on weekends and holidays and then verifying it

<table>
<thead>
<tr>
<th>Hassle Item by Domains</th>
<th>Hassle</th>
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<tbody>
<tr>
<td><strong>Domain 1: scheduling logistics (29.5% of accounts)</strong></td>
<td></td>
</tr>
<tr>
<td>Working administration schedules into care routines</td>
<td>13.1 (16)</td>
</tr>
<tr>
<td>Scheduling multiple medications throughout the day</td>
<td>5.7 (7)</td>
</tr>
<tr>
<td>Giving medications on time</td>
<td>4.1 (5)</td>
</tr>
<tr>
<td>Keeping medication prescriptions filled</td>
<td>4.1 (5)</td>
</tr>
<tr>
<td>Coordinating personal medication schedules with those of the care recipient</td>
<td>2.5 (3)</td>
</tr>
<tr>
<td><strong>Domain 2: administration procedures (32.0% of accounts)</strong></td>
<td></td>
</tr>
<tr>
<td>Giving medication to a confused/uncooperative person</td>
<td>16.4 (20)</td>
</tr>
<tr>
<td>Knowing when to hold, alter, or discontinue a medication</td>
<td>9.8 (12)</td>
</tr>
<tr>
<td>Knowing how to make up missed doses</td>
<td>4.1 (5)</td>
</tr>
<tr>
<td>Learning how to administer a painful, embarrassing, or noxious medication</td>
<td>1.6 (2)</td>
</tr>
<tr>
<td><strong>Domain 3: safety issues (38.5% of accounts)</strong></td>
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<tr>
<td>Recognizing adverse or toxic effects</td>
<td>13.1 (16)</td>
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<tr>
<td>Knowing how to recognize an emergency</td>
<td>10.7 (13)</td>
</tr>
<tr>
<td>Staying constantly vigilant for problems</td>
<td>8.2 (10)</td>
</tr>
<tr>
<td>Knowing how to give medications safely</td>
<td>4.1 (5)</td>
</tr>
<tr>
<td>Knowing how to react if an emergency occurs</td>
<td>2.5 (3)</td>
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</tbody>
</table>

Note: n = 122 accounts of medication administration hassles.

**Table 1. An Emerging Typology of Caregiver Medication Administration Hassles**
with the physician’s office at the next convenient or accessible time was a subpart of this hassle, because waiting for verification also had to be factored into the caregiver’s day.

Administering painful, embarrassing, or noxious medications also appeared in this hassles domain. Although it was not a commonly reported hassle, when it occurred, the accounts were compelling. A 50-year-old daughter-in-law who was the primary caregiver for her 81-year-old mother-in-law described in a pained voice the process of administering vaginal suppositories that had been ordered by the doctor. She said:

That has been a nightmare, and there has been no help in helping me know how to do that without causing her so much stress. But, I wish somebody would give caregivers a hint on what to do on like when we have to give [a vaginal suppository], because my mother-in-law’s very modest. She does not like, to this day, to be undressed in front of me, still, even though, you know, we . . . I take her to the bathroom every time she goes. And to give it [the suppository] to her . . . it was horrible. It was . . . the first time I gave it to her; I felt like that I was raping.

Safety issues.— Daily hassles classified as safety issues were the most frequently mentioned hassles and ranged from the need to monitor for adverse or toxic effects to concerns about recognizing emergency situations and knowing how to respond appropriately. Caregivers described the need to be constantly vigilant in monitoring their care recipients’ conditions. Their stories portrayed realistic understanding that part of their responsibilities as primary caregivers was to watch for adverse reactions from individuals who were no longer capable of reporting problems themselves and whose adverse reactions may begin in very subtle ways. One spousal caregiver said, “It’s like watching children.”

Accounts about the need for caregivers to remain constantly vigilant for problems were made by caregivers who seemed to have learned through experience to take nothing for granted. In one account, a physician wrote a refill prescription for double the strength of the previous prescription. Neither the physician nor the pharmacist mentioned verification also had to be factored into the caregiver’s day.

We were with our son and he was gonna stay at home, he wasn’t feeling very good. But [her granddaughter] wanted to go shopping and so, I thought, gee, this would be a good chance for me to just go away for a while and let somebody else have him. So [her son] said, ‘Yeah, we’ll watch him for you.’ And so we left and we were gone over lunch. We left about 11:00 and came back about 2, 2:30. And he hadn’t had lunch. Because . . . nobody fixed lunch. Finally the kids got a little hungry and they just went to the refrigerator and helped themselves. Well, [her husband] won’t do that in somebody else’s home . . . So that’s when we went through this bit about what is going on here.

Following this account, the caregiver went on to express multiple caregiving needs that she associated with this situation, including the need for periods of respite time with her family and dependable back-up care. She worried about what would happen to her husband if she became ill. Her story about this hypoglycemic episode underscored the complex relationship between medication administration demands and caregiver stress.

Discussion

Additional work is under way to refine the hassles typology and develop a new measurement tool that will quantify the intensity of medication administration hassles for family caregivers. This measurement could be useful for better understanding the added stress associated with medication administration responsibility. However, in this article, we focus our discussion on the implications of these hassles as we currently know them and on the ways (i) that primary care providers of dependent elderly persons prescribe medications that will be managed by a family caregiver, (ii) that family caregivers are prepared to assume medication administration responsibility, and (iii) that health and human service organizations choose to support family caregivers over the long term.

Prescribing Practice

These initial findings suggest that physicians and other primary care providers must be sensitive to the need for continual reevaluation and simplification of medication regimens for dependent elderly persons in family care situations. At a minimum, family caregivers should be encouraged and empowered to ask if (i) a medication is still indicated, (ii) the provider is seeing evidence of therapeutic value or the desired outcome of the medication, and/or (iii) the medication continues to be appropriate as the elderly person’s condition changes.

Preparing Family Caregivers

Litwak’s Model of Complementary Care (19) and other similar works describing the separate and shared functions
of formal and informal providers of care to dependent elderly persons clearly articulate the need for mutual respect and shared decision making. If, as current public policy suggests, shared long-term care responsibility will continue to flourish in the future, there must be higher expectations and accountability on the part of the formal network to prepare family caregivers to assume complex care responsibility such as medication administration. Caregivers understand the need to be educated about recognizing the “classic” adverse drug effects printed in the literature and to understand the myriad atypical presentations they may see over the long term as functioning declines and conditions change. Access to this level of education is sorely needed.

Ongoing Support for Caregivers

A striking feature of the caregivers’ narratives was that medication administration hassles were largely events that caregivers did not discuss on a regular basis with their professional providers (physicians or adult day care staff) unless there was a need for specific health- or medication-related information. Of course in most cases, the information they needed had less to do with being provided an answer to a straightforward question and more to do with developing critical thinking skills that would enable them to handle myriad behavioral problems and the ever-changing nature of long-term caregiving. Unfortunately, as others have noted (20), there are few organizations that have been willing to provide this level of intentional, systematic support for caregivers on an ongoing basis. The advent of quality indicator report cards of individuals, service agencies, and managed care organizations who receive reimbursement for the care of dependent family members remaining in family care may provide the necessary stimulus for changes in attitudes and practice (21).

Need for Additional Research

Even with changes in practice, it is probably unrealistic to propose that the unpredictable world of long-term caregiving is ever going to be hassle free. This is especially true when family caregivers are expected to design medication administration procedures for cognitively impaired or otherwise dependent care recipients, develop and follow medication administration schedules, monitor for numerous adverse effects of potentially lethal combinations of drugs, and make decisions regarding whether to give or withhold, or increase or decrease, a medication dose. Clearly, a broad array of daily irritants awaits family caregivers who provide medication management for dependent family members. Therefore, many important areas of research on the topic remain.

For example, research is needed that points to the specific ways in which formal providers can most effectively adjust their behavior and practice for new generations of family caregivers who will be asked to provide levels of care that were unthinkable a decade ago. Because family caregivers give medications to dependent family members of all ages, the identification and exploration of intergenerational themes may also be important. Research into family caregivers’ abilities to understand instructions, give correct dosages, and monitor for adverse effects frequently appears in the pediatric care literature (22–25). Intergenerational approaches may facilitate the identification of cross-cutting themes that could add substantial conceptual rigor to this area of research. In addition, extension of the present analysis to include caregivers who are themselves experiencing decline in functioning and caregiving dyads who are being sustained by Medicaid-funded programs and services is needed.

In conclusion, this analysis of long-term family caregivers’ medication administration experiences brings into focus a set of medication administration hassles that have been heretofore widely dispersed and largely invisible in the medication compliance/adherence and family caregiving literature. Although the typology will continue to undergo refinement with additional research, the current work should provide a springboard for examining current practice patterns and planning further research on the topic.

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Appendix 1: Medication Administration Checklist

(Instructions to respondents: below is a list of some of the problems, concerns, and feelings that caregivers encounter when they have responsibility for giving medications to a dependent older family member. Please put a check beside all items that apply to your situation.)

- knowing when to hold a dose
- knowing when to increase or decrease a dose
- knowing when to give something ordered “as needed”
- recognizing adverse or toxic effects of the drugs
- having someone who can answer questions about the medications as they arise
- finding general information about the medication action and effects
- giving medication on time
- giving medication when care recipient is confused or uncooperative
- being comfortable talking to the doctor about new medications
- understanding the information that is given to me about the medications and how they should be administered

Appendix 2: Generative Questions Used for the Interview Sessions

Tell me what a typical day is like for you and your care recipient. At what times during the day do you give medication? How did you arrive at this schedule (e.g., help of the physician, nurse, or other professional)?

- Have you read or how did you learn when and how to give these medications?
- What is the most difficult part of arranging for, giving, and monitoring the effects of your care recipient’s medications?
- What side effects do you look for, if any? How did you learn about these side effects?

Sometimes it is necessary to make a decision to hold a dose, increase or decrease a dose, or discontinue a medication. Do you consult someone when you make those decisions? Has your physician or other primary care provider given you some general guidelines for making those types of decisions?

- Is your care recipient currently taking any medication that requires variable doses? If yes, tell me about your experiences with this medication, what you look for before deciding on a dose, and when you know to call your physician, a nurse, a pharmacist, or other provider for advice.

When you increase, decrease, or withhold a medication, or decide to give a dose ordered “as needed,” do you communicate that information to the day care staff? Do you think they need to know that information, even if they aren’t the ones giving the medication?

- Sometimes it is necessary to make a decision to hold a dose, increase or decrease a dose, or discontinue a medication. Do you consult someone when you make those decisions? Has your physician or other primary care provider given you some general guidelines for making those types of decisions?

- Is your care recipient currently taking any medication that requires variable doses? If yes, tell me about your experiences with this medication, what you look for before deciding on a dose, and when you know to call your physician, a nurse, a pharmacist, or other provider for advice.

We all have different ways that we prefer to receive information and educational material. What works best for you? Who or what is your primary source of information about medication side effects, dosing, and contraindications?

- (If respondent gives over-the-counter medications, he/she was asked the following:) How do you make decisions about giving over-the-counter medications to your care recipient? Have you discussed these remedies with your physician, pharmacist, nurse, or other professional provider?

- (If respondent uses herbs or home remedies, he/she was asked the following:) Tell me about the folk or home remedies you listed on your caregiver questionnaire. Which ones work and which ones do you use just to satisfy your care recipient’s requests? Have you discussed these remedies with your physician, pharmacist, nurse, or other professional provider?

- Have you ever had a medication emergency with your care recipient? Tell me about it. Could it have been avoided or prevented? Did you tell the day care staff about it?