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Medication management activities performed by informal caregivers of older adults

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Abstract

Background—Medication management is commonly performed by informal caregivers, yet they are often unprepared and ill-equipped to manage complex medication regimens for their older adult care recipients. In order to develop interventions that will enhance the caregiver's ability to safely and confidently manage medications, it is critical to first understand caregiver challenges and unmet needs related to medication management.

Objectives—To explore how informal caregivers manage medications for their older adult care recipients by identifying the activities involved in medication management and the tools or strategies used to facilitate these activities.

Methods—Four focus groups with caregivers of older adults were conducted with 5 to 9 caregivers per group. Participants were asked to describe the medication management activities performed and the tools or strategies used to facilitate these activities. Focus groups were recorded, transcribed verbatim, and analyzed for themes using an inductive approach.

Results—Caregivers were commonly involved in 2 types of activities: direct activities requiring physical handling of medications such as obtaining medications, preparing pill boxes, and assisting with medication administration; and indirect activities that were more complex and required more of a cognitive effort by the caregiver, such as organizing and tracking medications, gathering information, and making treatment decisions. They utilized a variety of tools and strategies to support these medication management activities; however, these approaches often needed to be modified or personalized to meet the specific needs of their caregiving situation.

Conclusions—Informal caregivers play a vital role in ensuring safe and appropriate medication use by older adults. Medication management is complex and involves many activities that are supported through the use of a variety of tools and strategies that have been adapted and individualized to each specific caregiving scenario. Caregivers should be an important component of interventions that aim to improve medication use among older adults.

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Keywords

Medications; Caregiving; Medication management

Introduction

Nearly 1 in 5 adults in the United States provides unpaid assistance to an older adult relative or friend.^{1,2} The estimated economic value of this assistance is over \$470 billion, which is more than all federal and state Medicaid yearly spending, or about \$1,500 for every person in the United States.³ Although informal caregivers play a critical role in ensuring quality and safety, they are often unrecognized members of the health care team.^{4,5} They often assist older adult care recipients that typically have multiple chronic physical and cognitive conditions, resulting in complex medication regimens. Medication management is the most common task reported by informal caregivers that perform medical tasks, with 78% managing medications, including preparing pill boxes and administering intravenous fluids and injections.⁶ Over half of caregivers administer 5 or more different prescription medications a day, with close to 20% administering 10 or more.⁶

Medication management is a difficult and time-consuming task, and many caregivers feel unprepared and ill-equipped to manage their care recipient's complex medication regimens.^{4,6-8} Two-thirds of caregivers report problems with one or more medication management activity, including problems with medication supply, administration, making clinical judgements, and communicating with care recipients or health care providers.⁹ Medication management has been identified as a major challenge for many caregivers and can be overwhelming, particularly when changes in health or medications occur, such as when their care recipient is discharged from a hospital or other health care facility.^{4,10} Despite the importance of medication management, caregivers often receive little or no training to perform these tasks; the majority of family caregivers learn how to manage medications on their own, with nearly half never receiving training from any source.⁶ As such, older adult advocacy organizations such as AARP (formerly known as the American Association of Retired Persons) have called for further research to understand the tasks performed by caregivers and their needs for training and support.⁶

Although several studies have identified caregivers' difficulties and needs for assistance with medication management,^{6,9,11-13} previous studies have not provided a detailed description of caregivers' work with medications or the tools and strategies used to support this work. A firm understanding of these factors is necessary to identify specific factors contributing to caregiver difficulties with medications, and to inform the development of interventions that will enhance the caregiver's ability to safely and confidently manage medications. Therefore, the objective of this study was to explore how informal caregivers manage medications for their older adult care recipients by identifying the activities involved in medication management and the tools or strategies used to facilitate these activities.

Methods

Sample

A convenience sample of informal caregivers was recruited from one rural Wisconsin county using a multimodal approach. Individuals that were currently or had previously attended a caregiving class, support group, or caregiver meeting offered through the county's aging department were mailed a recruitment letter informing them of the opportunity to participate in a focus group. A recruitment advertisement was placed in the county's monthly aging newsletter, and in-person recruitment was performed at the county's annual caregiver conference. Finally, the director of the county's aging department assisted with the identification and personal referral of potentially eligible caregivers.

Interested caregivers were administered a screening questionnaire to determine whether they qualified to participate and to assist with focus group assignment. Eligible caregivers were those currently providing unpaid assistance to an older adult friend or relative aged 65 years or older with their medications. There were no requirements as far as level or duration of caregiver medication involvement, which was done deliberately in order to fully explore the range of medication-related activities performed. At the end of the focus group, an exit questionnaire was administered, which contained demographic information about the caregiver and their care recipient. Participants were paid \$50 for their participation and complementary respite care was available to facilitate caregiver participation in the focus groups. This project was reviewed and granted exempt status by the UW-Madison Health Sciences Minimal Risk institutional review board.

Study Design

Focus groups were chosen as the data collection method for this research in order to discuss medication management in depth.¹⁴ A diverse group of caregivers with a variety of experiences was recruited to enrich these conversations and to allow for deeper probing in order to describe the breadth and depth of caregiver involvement in medication-related activities.¹⁵ This approach allowed for participants to learn from one another, to allow their thoughts to trigger new ones, and to use the interactions between group participants to generate insights on the issues faced when managing medications for their care recipient. Focus groups also allowed for group activities centered on identifying commonly encountered challenges faced by caregivers when managing medications for someone else, and to brainstorm potential solutions to address these challenges. The focus groups were moderated by an experienced focus group facilitator from the University of Wisconsin Survey Center and attended by the principal investigator [KA Look], who took notes during the groups and occasionally asked clarifying questions. A total of 4 focus groups were conducted in 3 locations in different parts of the county during November and December of 2015. The sessions lasted between 90 and 120 minutes, with time at the beginning of each session to establish rapport.

A questioning route¹⁵ was developed and administered at all focus groups using the Patient Work System model as a guiding framework.¹⁶ First, participants were asked to describe the typical activities or tasks that they performed daily to assist someone with their medications.

Next, they described the ways in which they helped someone take their medications as directed and the methods or tools that they used in the process. Participants were also asked how they adjusted their activities or tasks when a change in medications or a change in health (e.g., hospitalization or worsening dementia) occurred. Group activities included brainstorming a list of problems the caregivers had encountered while assisting their care recipients with medications, and discussing actual or potential solutions to these problems. Lastly, caregivers were asked to reflect on how where they lived affected the assistance they provided with medications. This paper focuses on the medication management activities performed and the tools or strategies used to facilitate these activities.

Analysis

All 4 focus groups were digitally recorded with the permission of the participants. Verbatim transcripts of the audio recordings were prepared to facilitate thematic analysis, and all interview transcripts were checked against audio recordings for accuracy. Data analysis proceeded in several steps, including getting familiar with the data, generating initial codes, identifying recurrent patterns, defining and naming themes, and reviewing themes.¹⁷ Both researchers read the scripts independently several times to familiarize themselves with the entire transcript. The researchers then independently coded the transcripts using an inductive approach.¹⁸ Each response of the focus group participants was given a label such as “caregiver assists with medication injections” or “caregiver assesses meds for accuracy”. Following independent coding, the researchers met and compared codes, and discrepancies were discussed until agreement was reached. Codes that were similar or related were grouped together to form themes and subthemes using an iterative process, and representative quotes for each theme were identified from the transcripts. Coding was performed using the data analysis software NVivo 10.

Results

A total of 29 caregivers participated in the study (Table 1). Caregiver age ranged from 42 to 85 years, while care recipient age ranged from 65 to 106 years. The length of time the caregiver had assisted the care recipient with their medications ranged from 2 months to 12 years. The majority of caregivers assisted a spouse (n=14), or parent or parent-in-law (n=11). About one-third of the caregivers assisted an individual with dementia. Approximately 80% of the caregivers managed 5 or more medications and 31% managed 10 or more.

The first part of this section describes the medication-related activities performed by caregivers. The second part provides a description of the tools and strategies caregivers used to support these activities. Each section contains representative caregiver quotes from the focus groups, along with the speaker’s gender and the care recipient’s relationship to the speaker. Table 2 provides a summary of the care activities, tools, and strategies that were identified related to informal caregiver medication management.

Medication Management Activities Performed by Caregivers

Medication management ranged from more direct care activities to more indirect activities such as organization and monitoring. The extent of caregiver involvement in managing medications varied due to a variety of factors, such as the care recipient's physical or mental health (e.g., dementia), the caregiver's living situation (i.e., living with or separately from the care recipient), and the number of other caregivers providing assistance.

Direct Medication Management Activities—Direct medication management activities were those requiring physical handling of medications, and included ordering and picking up medications, splitting or cutting pills, preparing pill boxes, and assisting with medication administration (e.g., eye drops, injections). Caregiver involvement in these activities varied depending on the care recipient's physical and cognitive health, where caregivers assisting relatively healthy or independent individuals provided assistance with as few as one of these activities, whereas caregivers assisting individuals with dementia usually took responsibility for all of these activities. Caregivers were also responsible for assisting the care recipient with the use of devices, including teaching them how to use the device and ensuring proper use of the device. The caregivers reported assisting their care recipients with inhalers, nebulizers, nasal sprays, blood pressure machines, diabetic test strips, and anticoagulation monitoring.

4006: I assist with a nebulizer, because she used to be really good with it, but with her dementia, right now, she'll like, you know— [makes motions as though removing nebulizer] —be moving it, and not having it where she's supposed to have it on her face [laughs]. And you got to sit there with her, and literally, you know, "Ma, you got to keep it on there until it's gone," so. (Female, Parent)

Indirect Medication Management Activities—Indirect medication management activities were more complex and required more of a cognitive effort on the part of caregivers. These activities required caregivers to organize and keep track of medications, gather medication-related information, and interact with the health care system. Some caregivers had to use their best judgement to make treatment decisions that were clinical in nature, such as changing medication doses or monitoring the care recipient's health.

Caregivers were often the ones primarily responsible for organizing medications and ensuring that they were being taken as prescribed. The difficulty of this task varied depending on the care recipient's health; for some this was a relatively easy task, such as checking once a week to ensure a pill box was empty. For others it was more difficult, such as when dementia was present and care recipients were unable to take their medications independently or resisted taking them. This required caregivers to perform multiple checks to ensure that medications were being taken appropriately.

3002: And then I fill her bottles and check to make sure she takes it. I don't do that as well as I should, to check that she takes them, because she misses them quite often, uh, because I just forget to check. But I try to check regularly to make sure she takes them, because she doesn't take them if I don't keep reminding her. And then after I do remind her, I still have to check that she took them, because she

sometimes has them in her hand and lays them down on the cupboard, or just doesn't— Her mind goes someplace else, too, just like mine does, only it's a little worse. (Male, Spouse)

Caregivers also played an important role in gathering medication information. At times this was done on behalf of the care recipient, but more often it was for the caregiver's own reference. This information was commonly obtained from providers, pharmacies, prescription printouts, online, or library books. Caregivers collected information about potential side effects and drug interactions, and used this information to monitor the care recipient's condition, coordinate care with health care providers, and ensure the care recipient's safety.

Some indirect activities were centered on interactions with various members of the health care system, which included doctors, nurses, pharmacies, health care facilities (e.g., hospitals, clinics, etc.), and insurance companies. These interactions involved scheduling and attending appointments, documenting and ensuring care recipient understanding of provider instructions, working with providers and pharmacies to coordinate medication refills, and working with insurance companies to ensure coverage for medications.

1005: And I have called [the insurance company] and balled them out, I said, she can't take anything else, she's allergic and I start naming all the drugs in her allergies and then, eventually, they will cover it, but otherwise, the pharmacy wanted to charge us fourteen hundred dollars for the little tiny bottle and, you know, that just gets crazy, "Oh, we prefer covering something else." I said, I don't really care what you prefer, because this is the only thing she can use. (Female, Parent)

Medication changes were typically precipitated by a change in health status (e.g., due to a gradual decline in physical or mental health, or an acute event such as a rehabilitation visit or hospitalization). When such changes occurred, the caregivers made adjustments in order to accommodate the change into their care management. For example, they reported changing their level of involvement with medications by taking on new responsibilities, or changing the ways in which they provided assistance. When a change occurred, caregivers were responsible for reorganizing medications, switching out changed medications, managing dose changes, and removing discontinued medications. Because several caregivers had to keep track of frequent changes to the medication regimen, they expressed concerns about disposing of discontinued or old medications, as they might have a need for them in the future (e.g. a medication dosage is changed back to a dose they already have).

3004: You adjust first with your pharmacy and then the extra pills, you just...put them away and put tape on them, because maybe 6 weeks down the road they found out that [Medicine X] with 25 was too much or not enough, so you might come back with a stronger or less, and then why throw that away until...it expires. (Female, Spouse)

Monitoring-related activities were some of the most cognitively complex and demanding medication-related activities performed by caregivers, but were also viewed as some of the most important. They required caregivers to assess the care recipient's current situation and

make a clinical judgement regarding the care recipient's medication regimen. Some caregivers took on more of a provider role in assessing medications for accuracy, adjusting medication doses, and ensuring the safety of the medication regimen. In some cases, these adjustments were made solely by the caregiver based on the health of the care recipient; in others, it was a joint effort between the caregiver and the care recipient.

3007: She's on actually 2 water pills. I have to track the salt that is naturally in food...somebody, somehow thought that a sea salt was naturally— a natural salt, that it wouldn't affect them...My mother gained 10 pounds of water weight because of it. She almost had congestive heart failure because of it. And she had to increase her, you know, water pills, because of the sodium in the food...And we got to watch it. I mean, if she goes over, she increases her, um, water pills. If she goes under we got to decrease her water pills. (Female, Parent)

4004: He's also completely illiterate, um, but we have taught him, between I and my husband, to take his blood pressure. He records his blood pressure, he knows his parameters for his heart medication or his blood pressure medication, so that if it's below— if his systolic is— his diastolic is below 50, then he knows not to take that medication. So, he keeps the running tally. (Female, Uncle)

Another important role of the caregiver was to monitor the care recipient for side effects, and to follow up with providers to modify the medications when necessary. They also applied their knowledge of the medications to screen the medication regimen for actual or potential interactions, such as drug-drug interactions, drug-food interactions, or problems with medication allergies. Caregivers often noticed side effects or other health problems before they were detected by the providers, and in some cases helped influence treatment decisions.

1005: Be aware of what they could be, right away. So that, if something comes up, you're going to recognize it. And then make sure that you contact the doctor right away. Or if it's something that you know that there's a real problem. Stop it and call them and say, uh, this problem came up. We had to stop it. Because my mom was on a blood pressure pill and it made her heart rate so low, that if we wouldn't have stopped that pill, her heart would have quit...I said, "She's— this just isn't right." And they determined that, yes, her heart would have quit if we wouldn't have quit that particular medication. (Female, Parent)

Tools and Strategies Used by Caregivers to Support Medication Management Activities

Caregivers utilized a variety of tools and strategies to support medication management activities. To differentiate between tools and strategies, tools were defined as tangible objects and strategies as processes that caregivers used to help them manage medications for their care recipient. However, the two were often used in combination to enable the caregivers to meet the needs of their particular caregiving situation.

Tools—Caregivers utilized a variety of tools to organize medications or remind the care recipient to take their doses. Commonly used tools included pill boxes and other containers such as cups or dishes; medication lists; checklists, calendars, and other reminder tools such as notes or alarm clocks.

Pill Boxes and Other Containers—Pill boxes were the most common tool used by caregivers while managing medications. They were utilized as an adherence aid for the care recipient as well as an organizational tool for the caregiver. They were also utilized by the caregiver as a way to quickly tell if the care recipient had missed any doses. In situations where the care recipient retained sufficient independence, the caregiver typically prepared the pill box but the care recipient took the medications on their own. In situations where the care recipient was unable to take their medications without supervision, such as when dementia was present, the pill box was for the exclusive use of the caregiver. Most pill boxes were prepared by the caregiver or by the care recipient under the caregiver's supervision; occasionally, the pill box was prepared by a pharmacy.

1003: He doesn't need— He does it himself. I just have it in the pill containers, they're all marked, you know marked "morning" and then he takes it at 10, 2, 6 and bedtime. (Female, Spouse)

3004: My medication for my husband that has Alzheimer's, it's all pre-done at the druggist, already. So, I know in the morning he gets X amount, and in the evening he gets X amount...And it makes my work a lot easier, seeing that I have the pharmacist do that all already. (Female, Spouse)

The caregivers expressed numerous complaints about certain pill box features and the lack of options available to them. Common complaints included the slots being too small, not enough time slots available (e.g., 3 or 4 time slots per day such as morning, afternoon, and evening), difficulty getting the pills out of the slots, and difficulty with locking mechanisms. Features that were identified as being helpful included large pill compartments, the ability to remove the lid when putting medications in the pill box, and the ability to detach a single day when traveling.

2005: But anything now that I see, you know, for us they're probably a reasonable size, but for her, she can't. Her fingers just don't work. (Female, Parent)

4004: Well, there is [a benefit to the removal of the individual day's box from the frame] for me, because, [laughs] that's what I keep my own medication set-up in, and so then, when I grab for the day, if I'm going to be gone all day then I have them with me. (Female, Uncle)

4006: See, and when I take my mom out, the same thing, I can just take that day's with me. (Female, Parent)

The pill boxes were commonly modified by caregivers to address these limitations and meet their individual needs. This included writing information on the box, color coding the slots to indicate the time of day each dose was to be taken, or taping shut the times where no medications needed to be taken.

3005: And we have it marked, you know, "3" and "7" so, you know, she knows that one, and then there's the supper one, and then there's the bedtime one, so. (Female, Parent)

Caregivers also utilized a wide variety of cups, glasses, plates, and dishes to give medications to their care recipient. The caregivers filled these items with the medications to

be taken at that particular time and would directly hand them to the care recipient or leave them to be taken at a later time. The care recipients often associated these items with the medications that needed to be taken.

2004: Well, I, um, in the morning when I get up, set up 2 pills for my husband that he's supposed to take before breakfast. Then after breakfast I dose out his pills, morning and evening, for 2 weeks at a time. We do that every other Saturday and then after breakfast I always put his pills in a little, 3-ounce cup. And he is to the point where he recognizes that if it's a 3-ounce cup sitting there, he should take it. (Female, Spouse)

Medication Lists—Medication lists were another commonly used tool, and were most commonly created by the caregivers themselves. Some caregivers reported receiving a medication list from a health care provider or facility, while only one participant said they had received a list from their pharmacy. Caregivers usually carried these lists on them at all times, and used them to coordinate care with health care providers or facilities, pharmacies, emergency medical services, and other caregivers.

The medication lists contained a wide variety of information about the care recipient and their medications, and were often tailored to each caregiving situation. Common information in the lists included drug names and strengths, indications, allergies, when each drug was to be taken, contact information for health care providers, and caregiver contact information. This information was most commonly documented in a written format such as paper, index cards, or a notebook, although one caregiver kept a digital copy on their cell phone.

3001: So it's like, it's always on me in case I need to access, you know. Say she goes to the doctor, "What's she on for pills?" You know, it's an emergency. "I'll tell you what she's on. I've got it right here on my cell phone, on my notes." So that really helps. And instead of like, keeping a piece of paper, going, OK, now where did I put the piece of paper which I usually keep? (Female, Parent)

Checklists, Calendars, and Other Reminders—Checklists or calendars were sometimes used by caregivers to help them remember when certain medications were to be taken. Depending on the situation, these tools were used by either the caregiver or the care recipients themselves.

1001: I took a calendar and I put down the pills and then when he had to take them and how much he had to take them, because it was like, a half a tablet for 4 days and then a full tablet for another 4 days and they kept going like that, so I got that all written down, so I can look at the calendar to see how much he's supposed to be getting on that day. (Female, Spouse)

3005: When my mother came home from the hospital...my sister and I made a checklist. You know, Monday, Tuesday, Wednesday, Thursday, Friday, Saturday, Sunday. 7 o'clock, you do this. 8 o'clock, you do this. 9 o'clock, you do this. You know, we even had "Rest." You know, "Eat lunch." "Eat breakfast." ...And then when she did it, she checked it off. (Female, Parent)

Reminder notes were another tool used by caregivers. Notes were often strategically placed in locations where the patient would encounter them in their daily routine, such as in the bathroom or kitchen. However, some caregivers reported problems with care recipients being frustrated by the notes or ignoring them, which required the caregivers to develop ways to draw attention to the notes, such as varying their color or size.

2003: So I wrote notes and I have it hanging on the, um, mirror in the bathroom for his morning, um, things and then I put a note on the, um, kitchen table for his night time medications... (Female, Spouse)

2005: Yes. I find that I can write her, you know, just like you normally would, and maybe 70 percent of the time that's OK. But if it's something that I know she absolutely hasn't been, and I can't seem to get it across, then I go for the giant-size. (Female, Parent)

Some caregivers also utilized alarms to indicate when a medication needed to be taken, which included the use of cell phone alarms or traditional alarm clocks. In most cases the alarms were used to remind the caregiver when to give the care recipient their medications. In a few situations where the care recipient lived separately from the caregiver or was able to take their medications independently, the alarm was used as a reminder for the care recipient. However, one caregiver indicated that her husband had refused to use an alarm.

3007: And then, when she takes them, we set it up so she has 2 alarm clocks. One clock in the morning and one at night, so she remembers to take her pills. You know, so. (Female, Parent)

Strategies—Caregivers utilized a variety of strategies to assist with medication management, and often used them in combination with tools. Although similarities were observed in the types of strategies that were used by various caregivers, in many instances they were adapted to best fit the needs of their particular caregiving situation. For example, verbal reminders were one of the most commonly used strategies to ensure a care recipient took their medications. However, depending on the caregiving situation and the health status of the patient, these reminders took different forms. For example, caregivers often had to repeat themselves when the care recipient had memory issues.

4005: And then I say, "OK, now [name], this is your medicine. Now, today you're going to take this many." You have to do it verbally, and then, tomorrow, you know, every day repeat, repeat, repeat, because, "You're taking it for this, and it's going to be less," and, you know, things like that. (Female, Friend)

However, not all care recipients responded positively to verbal reminders. In such situations, caregivers expressed a need to find ways to remind the care recipient without offending or upsetting them. The caregivers mentioned the desire to discuss medications with the care recipient and remind them without lecturing. Some resorted to the excuse that "the doctor said so" while others tried to find creative ways to provide indirect reminders.

3007: We have to find ways of reminding him, without it making it sound like we're reminding him of doing it...He's a very proud man and if you make it sound like you're reminding him, he's like, "I don't need to be reminded! I'm a grown

man!” ...I kind of go, “Hey Mom, you need to take your pills” while he’s in the house, you know... Yeah, so we kind of indirectly bring it up, you know, kind of thing, and we find ways around to bring up pills somehow in the conversation when I know he hasn’t taken them. So, you know, sometimes it works, sometimes it doesn’t. (Female, Parent)

Caregivers felt that in order to get the care recipient to take their medications, it was vital for them to be built into the care recipient’s normal daily routine. One way this was accomplished was by strategically placing medications in spots where the care recipient would see them while going about their usual daily activities. However, while this strategy often helped the care recipient remember to take their medications, its effectiveness was limited in situations where the care recipient had memory issues.

3005: She’s into her little routine. She wakes up, she takes her pill, she makes her bed, she weighs herself, and then she has breakfast, and then she takes her other pill. So it’s in the morning. That’s the worst one, because she’s got more pills than 3 of them that need to be taken before she eats. (Female, Parent)

2009: So I set his night pills right in front of the microwave and his morning pills where he sits to eat breakfast, and sometimes he still gets them mixed up. (Female, Spouse)

At times, strategies were used in combination with one another. Long-term medication organization was commonly discussed as a way to reduce the day-to-day burden of medication management, with caregivers organizing medications up to 4 weeks at a time. One way to facilitate this process was another strategy: using multiple containers. For example, some caregivers utilized 2 pill boxes, where one box was with the care recipient to take their medications for the week while the other was with the caregiver to be prepared when they had the time.

2007: You have the 7 days, you have the four slots. I get these prescriptions filled once a month. I lay out all these boxes, open them all up, take those little lids off... And I go through this list alphabetically and fill all the boxes for one pill at a time. You know, one medication at a time...Go to the next medication, put that in, according to the number of pills she’s supposed to have and the day that, or the time that they’re supposed to be. Let me tell you, purchasing that extra medication box is worth it...because I have one day where I’m spending over an hour filling out all those pills in those boxes, instead of once a week or whatever. (Female, Parent)

Despite the use of these strategies, the caregivers noted that mistakes or issues frequently occurred when care recipients took their medications. This included taking the wrong medication or taking a medication at the wrong time of day, taking another person’s medication, or taking multiple doses of a medication because they forgot they had already taken it. To prevent their care recipients from making these mistakes, caregivers often restricted access to medications, particularly in situations where the care recipient had dementia or memory problems. This included restricting the quantity of medication available

to the care recipient to one day at a time, locking up medications in the home or storing them at the caregiver's home, or simply storing them out of the patient's sight.

4005: Because there are times you get there, "Oh, I see, like, you didn't take your medicine." "Oh, yes I did," but no. But then she says, "You know I got goofed up, so I think I took—" Sometimes they take the other day, you know? And then you're like, "OK, did you really take it, or not?" So, that's kind of a challenge that way too, but— (Female, Friend)

4006: See, and the reason I like our pillbox is because now that she's getting worse I just have the one day out, and we have that sitting on the cupboard. Everything else is put away where she cannot find it anymore [laughs]. (Female, Parent)

The caregivers also expressed difficulty telling medications apart, particularly when multiple medications had the same color and/or shape, or when a medication changed appearance such as when a different generic medication was received. They used a variety of strategies to keep track of and quickly differentiate between medications. For example, caregivers often wrote the drug indication somewhere on the pill bottle, or labeled the drug strength or time of day on the pill bottle or pill box. Caregivers also developed ways to draw attention to certain medications, such as those that were given at infrequent intervals.

3005: Mom had a little rash on her face, and then she had a rash on her body. Well, 2 kinds of cream. A lower percent of medication for the face. A different one for the body. "Use as directed." Well, I have to write that on the box, "For body." "For face." (Female, Parent)

Discussion

Informal caregivers play a vital role in ensuring the care recipient takes their medications as prescribed, and should be an important component of interventions that aim to improve medication adherence among older adults.^{19–21} Medication management is complex and involves many physical and cognitive activities for caregivers. Many caregivers performed monitoring-related activities which often require them to make clinical judgements regarding the care recipient's medication regimen, which is particularly important when dementia is present.⁸ As such, it is vital that caregivers receive adequate education, training, support for medication management.

However, despite repeated calls for improving medication management training and support over 2 decades,^{11,22,23} most caregivers continue to receive little or no formal training related to medications.⁶ The majority of medication-related training for caregivers is provided by a doctor or nurse in an outpatient community setting; only 15% of caregivers reported receiving training from a pharmacist.⁶ There is a growing recognition that caregivers need to be involved in transitions of care that often involve multiple medication changes, which provides opportunities for pharmacists to provide caregivers with medication-related education and training.²⁴ However, these transitions involve many changes that are often overwhelming for patients and caregivers, and caregivers commonly report receiving inadequate training in these situations.²⁵ Pharmacists are uniquely positioned to prevent medication errors and resolve insurance issues that may lead to medication adherence

problems during transitions of care.²⁶ However, opportunities for pharmacists to provide medication-related education and support to informal caregivers remain largely unexplored.

Caregivers utilized a variety of tools and strategies to assist with medication management, but often needed to adapt these tools to meet their individual caring situation. Medication taking was often incorporated into the care recipient's daily routine or reinforced by providing locational cues, although the success of these approaches may vary based on the cognitive health of the care recipient.²⁷ Often times the tools and strategies were used in combination with one another, but required trial and error to find the approaches that best met their needs. This implies that a "one size fits all" approach cannot adequately support caregivers in their role as medication managers; rather, personalized interventions are required to address the subtle nuances of each caregiving situation.²⁸ Changes to the care recipient's medications or health status may also lead to disruptions and require changes to the way medications are managed, suggesting that ongoing support for caregivers may be required.²⁷

The caregivers viewed alarms, pill boxes, and other containers as important tools for managing medications, which have been shown to be positively associated with medication adherence.²⁹ In addition to using pill boxes as a reminder tool for the care recipient, they were also used to aid caregivers with the organization and distribution of medications. Still, many caregivers complained about certain pill box features and the lack of options available to them. A simple and low-cost way to support caregivers could be to help match caregivers with pill boxes that help meet their individual caregiving needs.

Caregivers also expressed confusion regarding the medications their care recipient was taking and how to appropriately organize the drug regimen. They often created lists, notes, checklists, calendars, and other reminders to help them organize and keep track of different medications and when they need to be taken. However, these tools were often created without the input or support of providers or pharmacies. This could be addressed by providing caregivers with updated medication lists at each clinic visit, during transitions in care, or when visiting the pharmacy, and may be particularly helpful when medication changes occur. However, it is vital that the content and formatting of this information is presented in a way that is understandable and meaningful to caregivers and care recipients.^{30,31} Although medication list aids for caregivers have been developed by several organizations including the Agency for Healthcare Research and Quality and the US Department of Veterans Affairs,^{32,33} these lists have not been assessed for caregiver understanding and are not widely utilized in the community setting.

Caregivers may also benefit from involvement in programs designed to educate or inform them about their care recipient's medication regimen. This could include providing support to caregivers efforts when gathering medication-related information, or through more involved pharmacy services such as comprehensive medication reviews or medication therapy management. Such programs have been shown to help simplify drug regimens, reduce the likelihood of medication-related problems and drug discrepancies at care transitions, and improve medication safety.^{34,35} In addition, caregivers that report higher

difficulties with medication-related information are more likely to perceive such services to be helpful and are more willing to use them.³⁶

Despite their importance, caregivers are often untrained and ill-prepared to perform these medication-related activities.^{4,6,7} They can be difficult for caregivers because they are time consuming, can lead to burden, anxiety, or stress, and care recipients may be uncooperative.^{4,6,7,9,22} The caregivers in this study reported that medication mistakes commonly occurred despite the medication management systems they had developed. In addition, caregivers may inadvertently put the care recipient at risk for adverse events through activities such as saving expired or changed medications.

Caregiver involvement in medication management varied considerably, ranging from participation in one medication-related activity up to complete responsibility for all aspects of an individual's care. One issue of concern is that much of the caregiving literature focuses on caregivers of individuals with dementia due to the complex nature of their care; however, nationally only about a quarter of caregivers assist an individual with dementia.² It should be noted that caregivers in this study expressed difficulties with medication management even in relatively basic caregiving situations. Thus, while there is understandably a need to support caregivers caring for individuals with complex health conditions, it is important that the needs of other caregivers are not overlooked. Future research will explore the factors that influence the caregiver's involvement in medication management and the ways in which these activities are carried out.

Finally, it is also important to recognize that medication management activities are viewed by caregivers as being just one piece of the overall caregiving picture, and are often integrated into other caregiving activities. This has important implications for the development and implementation of interventions to support medication management by caregivers, as caregivers may have difficulty recognizing a need for training related to medication management or viewing medication-related activities separately from their other responsibilities.

Limitations

This study has several limitations that should be acknowledged. Sample size was small with only 29 caregivers in 4 focus groups within one rural county. Subjects were selected for convenience and focus groups were not continued until saturation was achieved. In addition, due to the use of a convenience sampling approach, an accurate response rate could not be determined³⁷; however, consistent with prior research utilizing community partners the majority of participants were recruited via personal referral and recruitment rates were very high among eligible individuals that were personally approached by the community partner.^{38,39} Differences between caregivers, including generational differences, living situation, and care recipient health status were not addressed. As a result, caution should be used in generalizing the findings to a wider population of caregivers, as the participants may be more engaged or interested in medication management than non-participants. Compared to the national caregiving population, our sample had older caregivers and care recipients, more females, a higher prevalence of care recipient dementia, and managed a higher number of medications.^{2,6} However, these differences may be a reflection of differences between

caregivers and care recipients located in rural, suburban, and urban areas.⁴⁰ In addition, a diverse group of caregivers with a variety of experiences was recruited in order to capture a range of caregiver experiences; however, care recipients with specific physical and mental health conditions may require specific medication management activities. The medication management needs associated with specific illnesses or conditions were not addressed in this study.

Conclusions

Caregivers play a vital role in ensuring safe and appropriate medication use by older adults. However, medication management is complex and involves many physical and cognitive activities. These activities are supported through the use of a variety of tools and strategies that have been adapted and individualized to each specific caregiving scenario. The development of programs to provide education, training, and support for caregivers is vital to assist them in these tasks, but also need to be individualized to meet the needs of both the caregiver and care recipient. Pharmacists are uniquely positioned to provide medication-related education and support to caregivers, yet these opportunities remain largely unexplored.

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- Care recipient health status determined caregiver involvement with medications
- Monitoring activities were more complex and required more cognitive effort
- Some caregiver take on provider-like roles to adjust medication regimens
- Tools and strategies often need to be modified to meet caregiver needs
- Caregivers experienced difficulties even in relatively basic caregiving situations

Table 1

Participant Demographics (N = 29)

Caregiver age (mean)	67 years (range: 42 – 85 years)
Care recipient age (mean)	83 years (range: 65 – 106 years)
Gender	
Male	5
Female	24
Care Recipient Dementia diagnosis	
Yes	10
No	19
Caregiving duration (mean)	4.8 years (range: 2 months – 12 years)
Care Recipient Relationship to caregiver	
Spouse	14
Parent or parent-in-law	11
Other	4
Number of medications managed	
1–4	6
5–9	14
10	9

Table 2

Summary of Care Activities, Tools, and Strategies

Category	Definition	Examples
Direct Activities	Involves physical handling of medications	Ordering and picking up medications; splitting or cutting pills; preparing pill boxes; assisting with medication administration
Indirect Activities	Cognitive activities related to organizing and monitoring of medications	Organizing medications; ensuring medications are taken as prescribed; gathering medication information; interacting with members of the health care system; making treatment decisions; monitoring for adverse events or side effects
Tools	Tangible objects used to support medication management	Pill boxes and other containers; medication lists; checklists, calendars, and other reminders
Strategies	Processes used to support medication management	Verbal reminders; incorporating medications into daily routine; long-term medication organization; using multiple containers; restricting care recipient access to medications; labeling pill boxes, bottles, and other containers