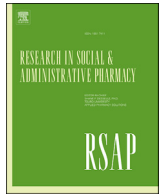




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Medication management activities performed by informal caregivers of older adults

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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 5–9 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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1. 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 \$1500 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,

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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.

2. Methods

2.1. 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.

2.2. 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 (K. A. 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 min, 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.

2.3. 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.

3. 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

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