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## RESEARCH

# The association between family caregivers' involvement in managing older adults' medications and caregivers' information-seeking behavior

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## ABSTRACT

**Objectives:** 1) To explore the association between family caregivers' involvement in managing care recipients' medications and their information-seeking behavior related to caregiving; and 2) to examine the sources used by caregivers when seeking information.

**Methods:** A retrospective analysis of cross-sectional data from 2 national studies, the 2011 National Health and Aging Trends Study (NHATS) and its supplement, the National Study of Caregiving (NSOC), was conducted. A nationally representative sample of community-dwelling adults ( $\geq 65$  years of age) completed NHATS interviews, and a sample of their family caregivers participated in NSOC. Caregiver involvement in medication management was assessed with the use of 2 items asking caregivers if they helped keep track of care recipients' medications or helped with injecting medications. Information seeking was assessed with the use of an item asking caregivers if they ever looked for caregiving-related information.

**Results:** Out of 1367 caregivers interviewed, 54% reported helping to keep track of care recipients' medications and 8.7% assisting with injecting medications. Approximately 10.2% ( $n = 149$ ) of caregivers reported seeking information to help them care for their care recipients. Caregivers sought information primarily on their own either through online resources or asking friends or relatives (73.3%). Sixty-four percent also sought information from medical providers or social workers. Adult children of caregivers were more likely to seek information for their older adult parents, based on bivariate analysis ( $P < 0.01$ ). In multivariable-adjusted models, caregivers who helped to keep track of medications had 2.30 (95% confidence interval [CI] 1.18 to 4.51) times higher odds of seeking information to help them to provide care for their care recipients. Caregivers helping with injecting medications were less likely to seek information (odds ratio 0.32, 95% CI 0.14 to 0.76).

**Conclusion:** Specific caregiver responsibilities, such as assisting with medication management activities, are associated with caregivers' information-seeking behavior related to care recipients' health. Health care providers, including pharmacists, can play an important role in helping caregivers to identify proper resources for information and in educating them about medication management.

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An estimated 14.3% of U.S. adults, or about 34.2 million individuals, serve as family or informal caregivers for adults 50 years of age or older.<sup>1</sup> Family caregivers remain the main source of long-term care support for older adults,<sup>2,3</sup> and the economic value of informal caregiving has been estimated to be \$450 billion.<sup>3</sup> With the aging of the U.S. population and the burden of chronic disease on older adults,<sup>4</sup> family caregivers are increasingly responsible for older adults' care coordination and play key roles in the management of care recipients' health and well-being, including medication management.<sup>5-7</sup>

**Key Points****Background:**

- Family caregivers play key roles in the management of care recipients' health and well-being, including medication management.
- Caregivers report a wide range of information and support needs for their responsibilities, but few studies have examined caregivers' information-seeking behavior and its relationship to caregiving responsibilities, such as medication management.
- A better understanding of the relationship between family caregivers' involvement in medication management and their information-seeking behavior can inform pharmacy practice and research on the importance of integrating caregivers in the patient care process.

**Findings:**

- More than one-half of caregivers (54.2%) helped older adults to keep track of their medication regimens, and 8.7% helped with injecting medications. In addition, 10.2% reported seeking information to help them in providing care to their care recipients.
- Caregivers who helped care recipients with keeping track of their medications were significantly more likely to seek information. This suggests that managing medication regimens might be one of several triggers that prompts caregivers to look for information related to their caregiving responsibilities.
- Health care providers, including pharmacists, can play a more proactive role in engaging and educating caregivers during counseling sessions and inquiring about caregivers' potential information needs.

In the caregiving literature, medication management has been formerly categorized as a high-level instrumental activity of daily living (IADL)<sup>8</sup> or as a medically related task.<sup>9,10</sup> Medication management encompasses more than medication adherence,<sup>11</sup> and caregivers' involvement in medication management may include multiple activities, such as ordering and picking up medications, keeping track of medications to ensure that the correct medication is taken at the right time, and administering medications.<sup>10,12–14</sup> Reinhard et al. reported that among caregivers who manage medications, 61% considered it to be a hard task.<sup>10</sup> Medication management by caregivers may have a significant impact on care recipients' disease management and health outcomes, and this multifaceted responsibility can also lead to increased caregiver burden or stress.<sup>13,15</sup> Access to reliable and credible information is an important factor that can influence caregivers' ability to manage chronic conditions and medications. Yet caregivers report receiving little support or training to assist with responsibilities, including medication management.<sup>5,16</sup> Only 16% of family caregivers for adults ( $\geq 50$  years of age) have obtained any formal caregiver training,<sup>17</sup> 15% reported receiving training from a pharmacist, and 24% of caregivers

stated that they want more training with medication management.<sup>10</sup>

Several studies have examined caregivers' information and support needs,<sup>10,18,19</sup> but there has been less emphasis on caregivers' information-seeking behavior when providing care for a family member or friend. Studies examining information seeking are mainly focused on caregivers' use of technology or online sources to find information or assist with care recipients' care.<sup>20–22</sup> However, it is unclear how specific caregiving responsibilities, such as caregivers' involvement in managing older adults' medications, are related to information seeking. Based on the health communication literature, information seeking is defined as a behavior to fulfill a perceived need for information and characterized based on individuals' triggers to seek information, the sources used, and the type of information sought.<sup>23</sup> Informational and skill-based needs may serve as triggers for caregivers to seek information or training to help them in providing care.<sup>23</sup> For example, concerns related to medication administration, including lack of education regarding medication-specific issues,<sup>14,16</sup> may create situations that prompt caregivers to seek information to fulfill their informational needs. Examination of the relationship between caregivers' involvement in medication management and their information-seeking behavior may enhance the understanding of caregivers' experiences with managing care recipients' health and can be useful in informing pharmacy practice and research.

**Objectives**

The purpose of the present study was to explore the association between family caregivers' involvement in the management of older adults' medications and their experience in seeking caregiving-related information. An additional objective was to examine the sources of information that caregivers used when they looked for information.

**Methods***Study population*

Caregiver and care recipient data from Round One of the National Health and Aging Trends Study (NHATS) and its supplement, the National Study of Caregiving (NSOC), were utilized for this retrospective cross-sectional study. NHATS and NSOC are sponsored by the US National Institute on Aging (grant no. U01AG032947) and were conducted by Johns Hopkins University Bloomberg School of Public Health in 2011.<sup>24</sup> NHATS was designed to follow a nationally representative cohort of Medicare beneficiaries ( $\geq 65$  years of age) on an annual basis, and the Medicare enrollment database served as the sampling frame for NHATS.<sup>24</sup> Participants had to be: a) 65 years of age or older as of September 30, 2010, b) with no date of death, and c) residing in 1 of the 655 sampled zip clusters previously determined by NHATS investigators. NHATS Round One participants were selected with the use of a stratified 3-stage sampling design. A total of 8245 Medicare beneficiaries were enrolled in Round One.<sup>25</sup>

NSOC is composed of a nationally representative sample of 2007 family caregivers (out of 4935 eligible caregivers) of NHATS Round One study participants. NHATS participants

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