




Managing medications among individuals with mild cognitive impairment and dementia: Patient-caregiver perspectives

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Abstract

Background: With changing cognitive abilities, individuals with mild cognitive impairment (MCI) and dementia face challenges in successfully managing multidrug regimens. We sought to understand how individuals with MCI or dementia and their family caregivers manage multidrug regimens and better understand patient-to-caregiver transitions in medication management responsibilities.

Methods: We conducted qualitative interviews among patient-caregiver dyads. Eligibility included: patients with a diagnosis of MCI, mild or moderate dementia, managing ≥ 3 chronic conditions, ≥ 5 prescription medications, who also had a family caregiver ≥ 18 years old. Semi-structured interview guides, informed by the Medication Self-Management model, ascertained roles and responsibilities for medication management and patient-to-caregiver transitions in medication responsibilities.

Results: We interviewed 32 patient-caregiver dyads. Older adults and caregivers favored older adult autonomy in medication management, and individuals with MCI and mild dementia largely managed their medications independently using multiple strategies (e.g., establishing daily routines, using pillboxes). Among individuals with moderate dementia, caregivers assumed all

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medication-related responsibilities except when living separately. In those scenarios, caregivers set up organizers and made reminder calls, but did not observe family members taking medications. Patient-to-caregiver transitions in medication responsibilities frequently occurred after caregivers observed older adults making errors with medications. As caregivers sought to assume greater responsibilities with family members' medicines, they faced multiple barriers. Most barriers were dyadic; they affected both the older adult and the caregiver and/or the relationship. Some barriers were specific to caregivers; these included caregivers' competing responsibilities or inaccurate perceptions of dementia, while other barriers were related to the healthcare system.

Conclusions: To ease medication management transitions, balance must be sought between preservation of older adult autonomy and early family caregiver involvement. Clinicians should work to initiate conversations with family caregivers and individuals living with MCI or dementia about transitioning medication responsibilities as memory loss progresses, simplify regimens, and deprescribe, as appropriate.

KEYWORDS

caregiver, dementia, dyads, medication, mild cognitive impairment

INTRODUCTION

Alzheimer's disease and Alzheimer's disease-related dementias (AD/ADRD) affects 6.7 million Americans,¹ and are progressive diseases characterized by their debilitating impact on cognitive function and inability to independently perform activities of daily living. Relatedly, mild cognitive impairment (MCI), a prodromal phase of dementia, affects 22% of older adults² and involves changes in an individual's cognition resulting in some difficulty performing complex cognitive tasks,³ but individuals generally maintain independence in most daily activities. Prior to an MCI or dementia diagnosis, most older adults are living with, not just one, but multiple chronic conditions (MCC). Compared to those without dementia, individuals with dementia have greater comorbidity (average of three additional chronic conditions),⁴⁻⁶ and subsequent polypharmacy (average of eight total medications at one time).⁷ While the onset of MCI or dementia often results in modified goals of care, treatment plans continue to focus on the management of comorbid conditions to minimize symptom severity, maintain function, and quality of life. Therefore, adherence to treatment, and specifically prescribed medication regimens is critical to optimize both cognitive and physical health.

Adherence to medications resulting from MCC is challenging, as it requires individuals to engage in a series of complex cognitive tasks. For individuals to gain

Key points

- Individuals with mild cognitive impairment and dementia and family caregivers value older adult autonomy in medication management, up until safety is seriously questioned.
- Patient-to-caregiver transitions in medications responsibilities were reactive to patient-driven medication errors or other adverse events, and reported multiple barriers to successful transitions in responsibilities.
- Caregivers involved in medication management reported either acceptance or overwhelm related to family members' complex medication regimens.

Why does this paper matter?

There is a range of assistance that individuals with mild cognitive impairment and dementia receive with managing multidrug medication regimens, and clinicians should not assume caregivers are actively and consistently involved in these patients' medication management.

the benefits of drug therapy, they must: (1) decide to fill prescriptions in a timely manner, (2) understand how to properly use their medication, (3) organize and

consolidate multiple medications for an efficient daily schedule, (4) remember to take the correct dosage at the correct time, (5) monitor use and side effects, and (6) sustain the behavior over time.⁸ Many older adults are challenged with all of these tasks, especially as regimen complexity increases.^{9–20} However, research to date has not investigated how individuals living with MCI and dementia manage their entire medication regimen, and how these responsibilities transition from patient-to-caregiver as the disease progresses.^{21,22} As a result, we examined strategies employed by individuals living with MCI or dementia and their caregivers to manage multi-drug regimens, and explored patient-to-caregiver transitions in medication management responsibilities.

METHODS

Sample and procedure

We recruited patient-caregiver dyads from primary care, geriatric medicine, and memory care clinics in Chicago, Illinois. Patients were eligible if they (1) had a chart diagnosis of MCI, AD, vascular cognitive impairment dementia, dementia with Lewy bodies, frontotemporal dementia, or multiple etiologies dementia, (2) score of 10–25 on the Montreal Cognitive Assessment, (3) ≥ 60 years of age, (4) ≥ 3 cardiovascular, metabolic, psychiatric, and/or pulmonary chronic conditions documented in the EHR, (5) ≥ 5 daily prescription medications, (6) English speaking, (7) capacity to provide consent, and (8) identified a family member who acted as their primary caregiver. Caregivers were eligible if they were (1) the primary family caregiver of the patient for ≥ 6 months, (2) ≥ 18 years of age, and (3) English speaking. As this study focused on dyads, eligibility criteria also required both the older adult and their primary caregiver to agree to participate.

A list of patients meeting eligibility criteria was generated via the electronic medical records and a chart review was conducted to confirm eligibility criteria that could not be easily extracted. Stage of cognitive impairment was determined using a 2-step method following the Clinical Dementia Rating (CDR) Scale criteria. The CDR Dementia Staging Instrument is a 5-point scale used to characterize six domains of cognitive and functional performance applicable to dementia: memory, orientation, judgment and problem-solving, community affairs, home and hobbies, and personal care.^{23,24} We initially reviewed patients' most recent clinical notes and CDR scores. Following the research interview, the principal investigator (RO) and a cognitive neuroscientist and expert in dementia (ER) met to discuss the interaction with the

participant and finalize the stage of dementia (MCI, mild dementia, moderate dementia). We deployed purposive and quota sampling methods to enroll dyads that were racially and ethnically diverse, with older adults at varying stages of cognitive impairment. Research staff contacted potential participants by telephone and confirmed interest and eligibility. Individuals' living with MCI or dementia capacity to consent was confirmed by asking a series of yes/no questions regarding the study purpose and requirements for participating, and consent was subsequently obtained. Older adults and caregivers completed one-time individual interviews separately. To facilitate participation, interviews took place in settings that were easiest for the participants (e.g., in-person in a private clinic room, participant's home, virtually via zoom or telephone). The study was approved by the Institutional Review Board at Northwestern University.

The research team developed semi-structured interview guides (Supplementary Appendix S1) for older adults and caregivers. The interview guides included questions and probes to determine (1) roles and responsibilities for medication management, (2) how responsibilities transition from older adult to caregiver as the disease progresses, and (3) facilitators and barriers to effective medication management. Questions related to medication roles and responsibilities were informed by the Model of Medication Self-Management,⁸ which deconstructs medication-taking as a series of actions: deciding, filling, understanding, organizing, taking, monitoring, and sustaining medication use. Interviewers received in-depth training in qualitative interview techniques and best practices for working with individuals with cognitive impairment. Interviews lasted between 30 and 60 min, were audio-recorded, and transcribed by a transcription company. Interviewers also administered a brief demographic and health survey at the end of each interview and recorded participant responses using REDCap.^{25,26} Participants were compensated \$50 for their participation. All dyads were assigned an ID number; older adults were assigned a corresponding older adult ID (dyad ID +100), and caregivers were assigned a caregiver ID (dyad ID +200).

Analysis

A team of three coders (RO, DO, SF) reviewed the transcripts and utilized an iterative coding process guided by a quasi-inductive descriptive approach and the Framework Method.²⁷ First, coders read transcripts for familiarity and applied theoretical codes informed by the Model of Medication Self-Management, to categorize how patients and caregivers managed medications. Each coder

analyzed the first three dyad transcripts and met as a team to review the application of codes and fully resolve discrepancies. Following initial agreement, coders independently applied codes to the transcripts and met regularly to reconcile interpretive differences and update the working code book until all transcripts were coded. Next, as a form of data reduction, older adult and caregiver data were transferred into an Excel matrix: individual rows represented unique dyads and individual columns represented clinical and demographic data and the unique medication self-management codes. Upon completing the data transfer, coders reviewed medication management processes by stage of cognitive impairment (MCI, mild dementia, moderate dementia) and recorded overarching summaries in the Excel matrix; findings were compared across each stage.²⁷ Following the initial application of theoretical codes, coders applied analytical codes to all transcripts informed by emergent observations that captured dyadic aspects of medication management. Application of analytic codes followed the same process described above to ensure coding consensus. All qualitative coding was conducted using NVivo (QSR International), and descriptive statistics were calculated using STATA/SE software.

RESULTS

We identified 729 patients as potentially eligible, and after chart review 492 were deemed ineligible. Of the remaining individuals, we successfully contacted 146, screened 56, and determined 40 were eligible. Of those, 32 dyads (32 older adults, 32 caregivers) enrolled and completed the interview. Enrolled older adults had a mean age of 78 years and 62% were female; half identified as White, 31% as Black, and 13% as Latino. Older adults were managing an average of five chronic conditions and taking nine prescription medicines (range 5–20); 34% had MCI, 32% had mild dementia, and 34% had moderate dementia. Caregivers had a mean age of 66 years, 72% were female, and 59% were a spouse and 41% were an adult child. With regard to their own health, caregivers were managing an average of three chronic conditions and taking three prescription medicines (Table 1).

We reviewed how older adults and caregivers managed multidrug regimens by stage of cognitive impairment. A summary of medication management responsibilities by stage of cognitive impairment is presented in Figure 1, and detailed descriptions of how older adults and caregivers managed their medicines by different components of medication-taking are presented in

TABLE 1 Older adult and caregiver demographic and health characteristics.

Characteristics, n (%)	Older adult n = 32	Caregiver n = 32
Age, mean (SD)	78.2 (8.2)	66.4 (13.6)
Chronic conditions, mean (SD)	5.0 (2.1)	3.2 (1.8)
Prescription medicines, mean (SD)	9.3 (4.6)	3.1 (3.9)
Sex		
Female	20 (62.5)	23 (71.9)
Male	12 (37.5)	9 (28.1)
Race/ethnicity		
Black, not Hispanic	10 (31.3)	9 (28.1)
Hispanic	4 (12.5)	3 (9.4)
White, not Hispanic	17 (53.1)	18 (56.3)
Other	1 (3.1)	2 (6.3)
Education		
High school degree or less	9 (28.1)	2 (6.3)
Some college or technical school	9 (28.1)	3 (9.4)
College graduate	14 (43.8)	27 (84.4)
Relationship		
Spouse/partner	19 (59.4)	–
Child	13 (40.6)	–
Live with caregiver		
Yes	22 (68.7)	
No	10 (31.3)	
Cognitive impairment		
Mild cognitive impairment (MCI)	11 (34.4)	–
Mild dementia	10 (31.3)	–
Moderate dementia	11 (34.4)	–

Table 2. Thematic findings summarizing how older adults and caregivers managed multidrug regimens and how transitions occurred are detailed below.

Caregivers take more medication responsibilities with increasing cognitive impairment severity yet both older adults and caregivers favor older adult autonomy in medication self-management

Older adults and caregivers favored, and sought to maintain, older adult autonomy in medication management for as long as possible. The degree to which individuals

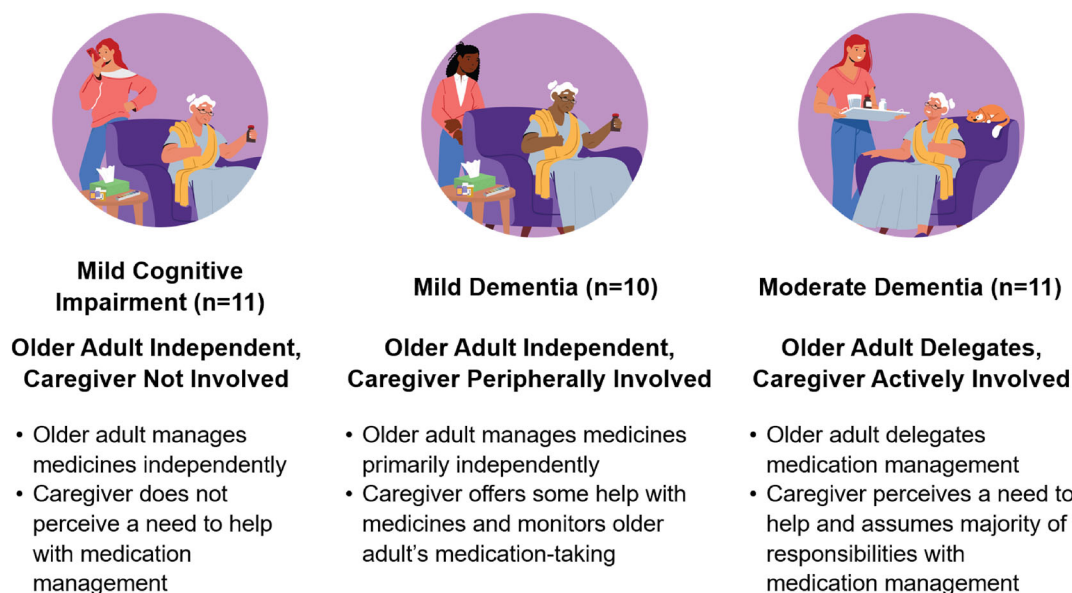


FIGURE 1 Summary of medication management responsibilities by severity of cognitive impairment.

TABLE 2 Medication management responsibility by severity of cognitive impairment.

	Mild cognitive impairment (n = 11)	Mild dementia (n = 10)	Moderate dementia (n = 11)
Decide	<ul style="list-style-type: none"> • Older adults make medication decisions 	<ul style="list-style-type: none"> • Older adults make most medication decisions • Caregivers are involved occasionally 	<ul style="list-style-type: none"> • Caregivers make medication decisions
Fill	<ul style="list-style-type: none"> • Older adults order refills • Older adults pick up medicines • Some older adults use delivery services 	<ul style="list-style-type: none"> • Some older adults order refills • Some caregivers monitor pill bottles to order refills • Caregivers pick up medicines 	<ul style="list-style-type: none"> • Caregivers order refills • Caregivers pick up medicines • Some caregivers use delivery services
Understand	<ul style="list-style-type: none"> • Older adults maintain lists of medicines • Caregivers are aware of medicines or rely on older adults' lists 	<ul style="list-style-type: none"> • Older adults maintain lists of medicines • Caregivers are aware of medicines and use lists 	<ul style="list-style-type: none"> • Older adults rely on caregivers to know medicines • Caregivers are aware of medications and maintain lists of medicines
Organize	<ul style="list-style-type: none"> • Most older adults use pill box organizers • Most older adults fill organizers themselves 	<ul style="list-style-type: none"> • Most older adults use pill box organizers • Most older adults fill organizers themselves 	<ul style="list-style-type: none"> • Most older adults use pill box organizers • Most caregivers fill organizers
Take	<ul style="list-style-type: none"> • Most older adults take medicines independently • Caregivers occasionally inquire if older adults took pills 	<ul style="list-style-type: none"> • Most older adults take medicines independently • Older adults rely on habit, routines, and alarms to remember to take medicines • Caregivers occasionally remind older adults to take medicines • Caregivers monitor pill boxes and occasionally observe errors 	<ul style="list-style-type: none"> • Older adults who do not live with a caregivers take medicines independently • Caregivers who live with the older adult hand older adults pills when it is time to take them
Monitor	<ul style="list-style-type: none"> • Older adults monitor for side effects • Some caregivers inquire if older adults take medicines 	<ul style="list-style-type: none"> • Older adults monitor for side effects • Caregivers monitor pillboxes • Caregivers try to become more involved if they observe errors 	<ul style="list-style-type: none"> • Caregivers monitor for side effects • Caregivers ensure older adults are taking medicines

TABLE 3 Dyad quotes by stage of cognitive impairment exemplifying level of caregiver assistance is informed by older adult capacity with continued preference for older adult autonomy.

	Older adult quotes	Caregiver quotes
Mild cognitive impairment	"My wife knows I take them. I don't miss them. There's no need [for her to help]" (#123, individual with MCI).	"I help him by going to pick them up [from the pharmacy] if necessary, but I don't help him take them. He's perfectly capable." (#223, wife of person with MCI).
Mild dementia	"I think I do pretty well. I don't have any problem. My daughter checks my bottles to be sure when they're running out and if I need anything, and she asks me if I'm taking them." (#130, individual with mild dementia).	"Even though she has memory issues, it seems like she takes charge of [her medicines] pretty well. I do follow-up behind her." (#230, daughter of person with mild dementia)
Moderate dementia	"My daughter has control of the pills. I have the medicine marked for four slots and it's for each day. It works out very well and I like to try to participate in things as much as I can. My job ends up being filling up the tray that has all the medicine by days and time. We always [fill the pill tray together] so the other person knows what we're doing." (#135, individual with moderate dementia)	"On the days where he is not having a good day and it's time for him to fill his multi-compartment medicine box, I sometimes feel like doing it myself, but I don't, because, my father has his ways and likes to do things, and people like to be as independent as they can. Sometimes it's a struggle for him to fill it, and he'll take a long time and appear very frustrated and confused. I catch myself like, okay, should I intervene more? I don't want him to get so upset." (#235, daughter of person with moderate dementia).

with MCI and dementia retained autonomy was informed by older adult and caregiver perceptions regarding older adult capacity to manage medications (Table 3). While in instances where caregivers were unavailable throughout the day, independence was by necessity.

Individuals with MCI were primarily independent in medication management and caregivers did not perceive a need to help. Caregivers sometimes helped family members with MCI obtain medications, but this was reported as occasional rather than a pattern. Individuals with mild dementia managed medicines largely independently, while caregivers offered some help and monitored family members' medication-taking behaviors. Most individuals with mild dementia relied on compensatory strategies to help them remember to take their medicines independently, including utilizing a pill box organizer, developing a routine, and using reminder alerts. Caregivers, on the other hand, tended to be more involved in helping family members obtain medication, such as routinely picking them up from the pharmacy, as most individuals with mild dementia no longer drove.

Individuals with moderate dementia mostly delegated medication management responsibilities to caregivers. Similarly, caregivers perceived a need to help and assumed the majority of responsibilities. Although caregivers were highly involved, many continued to express valuing family member autonomy in medication management as much as possible. Yet, many individuals with moderate dementia who did not live with a caregiver took their medicines independently. Caregivers organized

family members' medicines and implemented strategies to facilitate medication-taking, but ultimately these individuals were responsible for taking their medicines multiple times throughout the day. For example, one caregiver noted:

"She has two 30-day dispensers, one for morning and one for night. I load them in there and then it is set for a certain time and an alarm goes off and then it turns and dispenses that dosage of pills. Sometimes she doesn't hear the alarm. If she doesn't have her hearing aids in, I'll call her to see if she took her pills and I can hear the alarm going in the background." (#234, daughter of person with moderate dementia).

Patient-to-caregiver transitions in medication responsibilities were reactive to patient errors

There were two primary catalysts for transitions in medication management responsibilities among individuals with mild or moderate dementia. In the first instance, caregivers observed reduced family member cognitive capacity (i.e., memory, attention, executive function) either in general or specific to medications. In some cases, cognitive decline was concerning for potential future errors whereas in others, caregivers observed

family members making repeated errors such as missing doses without noticing. In the second instance, older adults experienced an adverse health event (i.e., hospitalization, uncontrolled chronic conditions). One example of this transition was highlighted by one individual with mild dementia who stated: “We recently had to change [my levothyroxine], it was my responsibility since it needed to be taken so early. When I got up, he would say, ‘Did you take your pill?’ I’m like, ‘Yes, I think so.’ Coming to find out, last week my thyroid level was 20.45, which was way out of whack so then he counted the pills, went back to when we got them, and that’s when he [started helping].” (#119, individual with mild dementia). Only one dyad stated they had a proactive conversation regarding future transitions in responsibilities.

Caregivers reported multiple barriers to successful patient-to-caregiver transitions in responsibilities

As caregivers to individuals with mild or moderate dementia sought to take a greater responsibility in the family members’ medicines, they often faced a range of barriers (Table 4). Some barriers were specific to caregivers; these included caregivers’ competing responsibilities or inaccurate perceptions of individuals with dementia (e.g., individuals intentionally nonadhere to regimens). Most barriers, however, were dyadic; they affected both the older adult and the caregiver and/or the relationship. Examples include living arrangements, relationship dynamics, and older adult preferences such as privacy. Other barriers were related to the healthcare system, including the challenges of navigating complex prescription medication regimes and communication channels within medical systems. Notably, caregivers who identified as adult children of the individual with MCI or dementia reported the greatest number of barriers.

Caregivers reported either acceptance or overwhelm related to family members’ complex medication regimens

Caregiver feelings toward their responsibilities with complex medication regimens ranged from either: (1) acceptance with complexity, or (2) overwhelm. For example, one caregiver detailed a complicated daily medication schedule in which he gave his wife medicine five times a day, including waking early in the morning to allow her to take her levothyroxine on an empty stomach, but also

stated “That’s one of the least intrusive things I have to deal with, so that’s not a big deal. Sometimes I can get a little frazzled, but for the most part, it’s nothing.” (#236, husband of individual with moderate dementia). Conversely, other caregivers, while attentive and continuously managing their family member’s medication, endorsed significant feelings of overwhelm.

“I feel overwhelmed constantly. Especially for somebody that’s not a nurse or a doctor. I feel like I need medication. I went through all physical symptoms of a sick person because the stress of giving so many medications to one human being was just that overwhelming.” (#203, daughter of individual with moderate dementia)

DISCUSSION

In our study of individuals with MCI or dementia and their family caregivers on the management of complex medication regimens, participants had a strong preference for older adult autonomy. Among individuals with MCI or mild dementia, many caregivers were by their own report only peripherally involved in medication management activities, mostly by intermittent monitoring of family member’s behavior. In contrast, among individuals with moderate dementia, caregivers described a more active role, while still expressing a desire to preserve autonomy whenever possible. These findings on autonomy align with other research among individuals with and without dementia.^{28,29} Considering there are multiple steps involved in taking a single medication successfully,⁸ and older adults in our sample were taking between 5 and 20 medications, it was noteworthy the degree of independence individuals with mild dementia maintained. Further, many individuals with moderate dementia were responsible for taking their medicines at the correct times throughout the day when they did not live with their caregiver, or the caregiver was at work. For those individuals, caregivers instituted creative organizational strategies to facilitate this behavior (including a combination of pill boxes, alarms, and reminder calls); nevertheless, they could not ensure their family member fully complied with their regimens. Particularly for individuals taking medication as many as four times per day or more, there are many opportunities for errors.

Individuals in our sample were managing an average of nine daily medications, some of which had added layers of complexity, including multiple dosages per day, a need to take medications at specific times, or to ensure a certain amount of time has passed from food intake or

TABLE 4 Barriers to greater caregiver involvement with medication management.

Barriers	Illustrative quotes
Caregiver	
Other commitments (work, family)	"I also have a lot of other things going on. I'm a single mom. I'm finishing a double master's program and I work two part-time jobs. I don't have as much time as I wish I did to be able to go there more often and check her medicines." (#232, daughter of person with mild dementia)
Overestimation of patient's abilities	"He gets lazy, trust and believe, he gets lazy. Like I said, [his medicines are] right there. How can you not take it? But every now and then, he does forget." (#204, wife of person with moderate dementia)
Dyadic	
Not living together	"She lives by herself. I live close, but not with her. Her cognitive abilities and the decline that's happening there, I think, makes it very difficult for me to know what happens. If I get there and there's still pills in the box, I don't know if she thought she had to refill them or if she actually didn't take them." (#232, daughter of person with mild dementia)
Cemented parent-child Relationship	"She's not managing that too well. We tried and she's just not budging on taking her medicines, like she should. In the last year, she's sent me more pushback. She thinks I'm overstepping because I'm telling her what to do, and she's the parent and I'm the child." (#2271, daughter of person with mild dementia)
Conflict in the relationship	"Me and my mom weren't speaking for about a year. She made me so angry." (#221, daughter of person with mild dementia) "She doesn't have a lot of patience anyway. She's goodhearted and everything like that, but her patience is shortened, and then my system works for me. I'm rather organized with my medication." (#121, individual with mild dementia)
Patient anosognosia regarding cognitive decline	"You need to be prepared that you will encounter some resistance to the assistance [you provide], because they're in denial about the extent of their condition until they realize how extensive it is and what it impacts, including taking medication or remembering medication that you might encounter some resistance" (#216, wife of person with MCI) "She has dementia. She doesn't believe she does. She thinks it's a false thing because she does remember things. It just comes and goes. She won't use her pill box. My siblings have tried to get her to use pill box, just different things so you know what you're doing, because you're going to make mistakes." (#209, daughter of person with MCI)
Preference for patient independence	"He likes to be independent so I've let him do as much as he can. He fills his weekly pill containers himself." (#228, wife of person with mild dementia)
Heightened sense of privacy regarding medications	"She's a pretty private person, and I think medication falls under that category of privacy. I think for her, it's a different sort of vulnerability with, 'I take this medication so I can do X, Y, Z or to be in homeostasis.' With age, the loss of strength and mobility is something to be expected and accommodated. There's not, as much trepidation or shame or fear of loss of privacy around that" (#220, daughter of person with MCI)
Healthcare	
Multi-daily drug dosing	"I have Alexa reminding him. Half the time, I'm not sure if he pays attention to that because it's every day at 12:30 it goes off to take his midday medicine. If I'm talking to him, I'll remind him, but I can't talk to him three times a day every day." (#207, daughter of person with moderate dementia)
Dementia diagnosis not communicated to caregiver	"Before, I knew it, but I didn't want to accept it. Because all the time no one ever said the word dementia so, of course, I wasn't saying the word dementia. I was taking her to the doctors, no one ever said dementia. It wasn't on the summary sheet, so when [dementia] appeared on that summary sheet, that's what caused a paradigm shift." (#221, daughter of person with mild dementia)

Abbreviation: MCI, mild cognitive impairment.

other medications. Older adults and caregivers with more complex regimens either accepted this reality or reported significant feelings of overwhelm. Related research by

Traviss and colleagues has focused on medication administration hassles, or minor irritants in medication administration, and found positive associations between

medication hassles and regimen complexity.³⁰ Furthermore, in their sample, caregivers to individuals with medium levels of cognitive capacity reported the highest levels of medication hassles, compared with those with high and low levels of cognitive capacity. These caregivers share several similarities as our peripherally involved caregivers who were experiencing tension between preservation of family member independence and caregiver involvement, leading to continuously monitoring older adults' medication-taking behaviors. Over time, medication administration hassles can accumulate to cause significant strain and burden for the caregiver.³⁰ It may be beneficial for clinicians to ask probing questions (e.g., "Walk me through how you take your medicines") instead of inquiring about the frequency ("How many times do you take your medicines?"), to better understand how patients and caregivers are organizing their medication schedules. By performing a medication review in this manner, clinicians may be able to clarify any misconceptions and simplify regimens. These discussions should occur regularly, as this is a progressive disease and as individuals with dementia are commonly diagnosed with new comorbidities³¹ and prescribed new medications.³² Clinicians should consider simplifying regimens or to deprescribe, if possible.

Patient-to-caregiver transitions in medication responsibilities did not occur proactively; rather, they were reactive to patient-driven medication errors or other adverse events. This problem-response strategy has been replicated in other studies that describe transitions occurring once errors were observed.³³ A delayed approach rather than proactive planning could be related to a tendency for caregivers to focus predominantly on dementia rather than all health conditions. Due to a paucity of education around dementia, caregivers may not recognize that poor management of other chronic conditions could affect their family member's cognition and overall well-being.³⁴ For example, estimates suggest that half of all potentially avoidable hospitalizations among individuals with dementia are due to poorly controlled chronic conditions.³⁵ These findings have important implications for clinicians, who should consider initiating conversations with caregivers and patients about medication assistance for their entire medication regimen early. Although these conversations can be challenging, studies have demonstrated patient and caregiver preferences for communication in dementia care.³⁶

We identified multiple barriers family caregivers faced when seeking to take a greater role in medication responsibilities for the older adult. Notably, adult children reported more barriers to involvement with family member's medication. With longer life expectancies and

changes to family structures, more individuals are entering older age without a partner, and will likely require assistance from their children. However, as individuals are also having fewer children, caregiving responsibilities will be assumed by fewer people who also have their own children and careers to attend to.³⁷ An additional barrier described by caregivers was patient anosognosia, or the inability to recognize one's own cognitive decline, which resulted in feelings of frustration or anger among caregivers. Spousal and parent-child relationships have long histories, which inform how the dyads work together in the present context. With the onset of cognitive impairment and dementia, there can be a need to shift how communication occurs. A team-based care approach that includes allied health professionals with experience in dementia such as psychologists, counselors, or social workers may be one way to facilitate these discussions and ease transitions.³⁸

This study is not without limitations. Our sample was comprised of English-speaking individuals in one urban city, and we required a chart diagnosis of mild cognitive impairment or dementia. Receiving a timely diagnosis requires significant work on the part of patients and family members, and we are limited in our sample to individuals who did obtain a diagnosis. There are also documented racial disparities in receipt of a diagnosis,^{39,40} and although we purposefully sampled for racially diverse participants, those in our study may not be fully representative of individuals experiencing cognitive decline. Furthermore, we required older adults to have a family caregiver to participate, and did not capture the experience of individuals who did not have a caregiver. Additionally, our focus was on medication-taking behaviors, once patients were prescribed medications, and did not consider upstream factors related to receipt of medications.⁴¹ Lastly, we are relying on self-report of medication responsibilities and abilities and did not directly observe behaviors.

CONCLUSION

In conclusion, individuals with MCI and mild dementia manage their medications independently, often until a mistake is observed and caregivers subsequently assume medication-related responsibilities. Among individuals with moderate dementia, caregivers manage the majority of medication responsibilities, but many cannot directly observe intake. As a trusted third party, clinicians can initiate conversations about transitioning medication duties from older adults with dementia to family caregivers as their memory loss progresses. Clinicians can

also work to simplify regimens, and deprescribe where appropriate.

AUTHOR CONTRIBUTIONS

RO contributed to the conception and design of the study. RO, DO contributed to the data acquisition. RO, AR, AP, DO, SF, ER, DM, LL, MW contributed to the data analysis and interpretation. All authors provided critical revision for intellectual content and final approval of the manuscript.

CONFLICT OF INTEREST STATEMENT

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SPONSOR'S ROLE

The sponsor played no role in the design, methods, subject recruitment, data collections, analysis, and preparation of this manuscript.

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REFERENCES

1. Alzheimer's Association. Alzheimer's Disease Facts and Figures. 2023.
2. Manly JJ, Jones RN, Langa KM, et al. Estimating the prevalence of dementia and mild cognitive impairment in the US: the 2016 health and retirement study harmonized cognitive assessment protocol project. *JAMA Neurol.* 2022;79(12):1242-1249.
3. Albert MS, DeKosky ST, Dickson D, et al. The diagnosis of mild cognitive impairment due to Alzheimer's disease: recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Focus.* 2013;11(1):96-106.
4. Schubert CC, Boustani M, Callahan CM, et al. Comorbidity profile of dementia patients in primary care: are they sicker? *J Am Geriatr Soc.* 2006;54(1):104-109.
5. Doraiswamy PM, Leon J, Cummings JL, Marin D, Neumann PJ. Prevalence and impact of medical comorbidity in Alzheimer's disease. *J Gerontol A Biol Sci Med Sci.* 2002;57(3):M173-M177.
6. Bauer K, Schwarzkopf L, Graessel E, Holle R. A claims data-based comparison of comorbidity in individuals with and without dementia. *BMC Geriatr.* 2014;14:10.
7. Growdon ME, Gan S, Yaffe K, Steinman MA. Polypharmacy among older adults with dementia compared with those without dementia in the United States. *J Am Geriatr Soc.* 2021; 69(9):2464-2475.
8. Bailey SC, Oramasionwu CU, Wolf MS. Rethinking adherence: a health literacy-informed model of medication self-management. *J Health Commun.* 2013;18(Suppl 1):20-30.
9. Wolf MS, Curtis LM, Waite K, et al. Helping patients simplify and safely use complex prescription regimens. *Arch Intern Med.* 2011;171(4):300-305.
10. Davis TC, Wolf MS, Bass PF 3rd, et al. Literacy and misunderstanding prescription drug labels. *Ann Intern Med.* 2006; 145(12):887-894.
11. Wolf MS, Davis TC, Tilson HH, Bass PF 3rd, Parker RM. Misunderstanding of prescription drug warning labels among patients with low literacy. *Am J Health-Syst Pharm.* 2006; 63(11):1048-1055.
12. Farber HJ, Capra AM, Finkelstein JA, et al. Misunderstanding of asthma controller medications: association with nonadherence. *J Asthma.* 2003;40(1):17-25.
13. Lindquist LA, Lindquist LM, Zickuhr L, Friesema E, Wolf MS. Unnecessary complexity of home medication regimens among seniors. *Patient Educ Couns.* 2014;96(1):93-97.
14. Bailey SC, Opsasnick LA, Curtis LM, et al. Longitudinal investigation of older Adults' ability to self-manage complex drug regimens. *J Am Ger Soc.* 2020;68(3):569-575.
15. O'Connor R, Muellers K, Arvanitis M, et al. Effects of health literacy and cognitive abilities on COPD self-management behaviors: a prospective cohort study. *Respir Med.* 2019;160:105630.
16. O'Connor R, Wolf MS, Smith SG, et al. Health literacy, cognitive function, proper use, and adherence to inhaled asthma controller medications among older adults with asthma. *Chest.* 2015; 147(5):1307-1315.
17. Gellad WF, Grenard JL, Marcum ZA. A systematic review of barriers to medication adherence in the elderly: looking beyond cost and regimen complexity. *Am J Geriatr Pharmacother.* 2011;9(1):11-23. doi:10.1016/j.amjopharm.2011.02.004
18. Gellad WF, Haas JS, Safran DG. Race/ethnicity and nonadherence to prescription medications among seniors: results of a national study. *J Gen Intern Med.* 2007;22(11):1572-1578.

19. Marcum ZA, Gellad WF. Medication adherence to multidrug regimens. *Clin Geriatr Med*. 2012;28(2):287-300.
20. Hughes CM. Medication non-adherence in the elderly: how big is the problem? *Drugs Aging*. 2004;21(12):793-811.
21. El-Saifi N, Moyle W, Jones C, Tuffaha H. Medication adherence in older patients with dementia: a systematic literature review. *J Pharm Pract*. 2018;31(3):322-334.
22. Smith D, Lovell J, Weller C, et al. A systematic review of medication non-adherence in persons with dementia or cognitive impairment. *PLoS One*. 2017;12(2):e0170651.
23. Morris JC. The clinical dementia rating (CDR): current version and scoring rules. *Neurology*. 1993;43(11):2412-2414.
24. Hughes CP, Berg L, Danziger WL, Coben LA, Martin RL. A new clinical scale for the staging of dementia. *Br J Psychiatry*. 1982;140:566-572. (In eng).
25. Harris PA, Taylor R, Minor BL, et al. The REDCap consortium: building an international community of software platform partners. *J Biomed Inform*. 2019;95:103208.
26. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform*. 2009;42(2):377-381.
27. Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol*. 2013;13(1):117.
28. O'Connor R, Eifler M, Russell AM, et al. Caregiver involvement in managing medications among older adults with multiple chronic conditions. *J Am Geriatr Soc*. 2021;69(10):2916-2922.
29. Pohontsch NJ, Loffler A, Luck T, et al. Informal caregivers' perspectives on health of and (potentially inappropriate) medication for (relatively) independent oldest-old people - a qualitative interview study. *BMC Geriatr*. 2018;18(1):169.
30. Travis SS, McAuley WJ, Dmochowski J, Bernard MA, Kao HF, Greene R. Factors associated with medication hassles experienced by family caregivers of older adults. *Patient Educ Couns*. 2007;66(1):51-57.
31. Choi H, Langa KM, Norton EC, Cho TC, Connell CM. Changes in care use and financial status associated with dementia in older adults. *JAMA Intern Med*. 2023;183(12):1315-1323.
32. Anderson TS, Ayanian JZ, Curto VE, et al. Changes in the use of long-term medications following incident dementia diagnosis. *JAMA Intern Med*. 2023;183(10):1098-1108.
33. While C, Duane F, Beanland C, Koch S. Medication management: the perspectives of people with dementia and family carers. *Dementia*. 2013;12(6):734-750.
34. Lam A, Ploeg J, Carroll SL, Duggleby W, McAiney C, Julian P. Transition experiences of caregivers of older adults with dementia and multiple chronic conditions: an interpretive description study. *SAGE Open Nurs*. 2020;6:2377960820934290.
35. Lin PJ, Fillit HM, Cohen JT, Neumann PJ. Potentially avoidable hospitalizations among Medicare beneficiaries with Alzheimer's disease and related disorders. *Alzheimers Dement*. 2013;9(1):30-38.
36. Griffin JM, Riffin C, Havyer RD, et al. Integrating family caregivers of people with Alzheimer's disease and dementias into clinical appointments: identifying potential best practices. *J Appl Gerontol*. 2020;39(11):1184-1194.
37. Pillemer K, Czaja SJ, Reid MC. Caring for chronically ill older adults: a view over the last 75 years. *J Gerontol B Psychol Sci Soc Sci*. 2020;75(10):2165-2169.
38. Hirschman KB, Hodgson NA. Evidence-based interventions for transitions in Care for Individuals Living with Dementia. *Gerontologist*. 2018;58(suppl_1):S129-S140.
39. Davis MA, Lee KA, Harris M, et al. Time to dementia diagnosis by race: a retrospective cohort study. *J Am Geriatr Soc*. 2022;70(11):3250-3259.
40. Tsoy E, Kiekhoefer RE, Guterman EL, et al. Assessment of racial/ethnic disparities in timeliness and comprehensiveness of dementia diagnosis in California. *JAMA Neurol*. 2021;78(6):657-665.
41. Essien UR, Dusetzina SB, Gellad WF. A policy prescription for reducing health disparities-achieving Pharmacoequity. *JAMA*. 2021;326(18):1793-1794.

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

Supplementary Appendix S1. Interview Guide.

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