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Medication self-management: Considerations and decisions by older people living at home

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ABSTRACT

Background: Medication self-management is complicated for older people. Little is known about older persons' considerations and decisions concerning medication therapy at home.
Objective: (s): To explore how older people living at home self-manage their medication and what considerations and decisions underpin their medication self-management behavior.
Methods: Semi-structured interviews with consenting participants (living at home, aged ≥65, ≥5 different prescription medications daily) were recorded and transcribed with supporting photographs. Content was analyzed with a directed approach and presented according to three phases of medication self-management (initiation, execution, and discontinuation).
Results: Sixty people were interviewed. In the initiation phase, participants used different techniques to inform healthcare professionals and to fill and check prescriptions. Over-the-counter medication was seldom discussed, and potential interactions were unknown to the participants. Some participants decided to not start treatment after reading the patient information leaflets for fear of side effects. In the execution phase, participants had various methods for integrating the use of new and chronic medication in daily life. Usage problems were discussed with healthcare professionals, but side effects were not discussed, since the participants were not aware that the signs and symptoms of side effects could be medication-related. Furthermore, participants stored medication in various (sometimes incorrect) ways and devised their own systems for ordering and filling repeat prescriptions. In the discontinuation phase, some participants decided to stop or change doses by themselves (because of side effects, therapeutic effects, or a lack of effect). They also mentioned different considerations regarding medication disposal and disposed their medication (in)correctly, stored it for future use, or distributed it to others.
Conclusions: Participants' considerations and decisions led to the following: problems in organizing medication intake, inadequate discussion of medication-related information with healthcare professionals, and incorrect and undesirable medication storage and disposal. There is a need for medication self-management observation, monitoring, and assistance by healthcare professionals.

Introduction

Older people, aged 65 and over, often have comorbidities and are prescribed multiple drugs.[1,2] Medication therapy may improve health-related outcomes by slowing down or halting disease progression and by easing symptoms of disease. In primary care, medication therapy requires varies tasks of patients, informal caregivers, and healthcare professionals including general practitioners, their assistants, medical

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and nurse specialists, pharmacists, pharmacy assistants, and home care nurses. Patients and informal caregivers are required to ensure accurate medication taking, storing, and disposal and to discuss problems in the medication therapy with healthcare professionals. Healthcare professionals tasks include prescribing, dispensing, or delivering medication, educating patients, assisting patients in accurate medication self-management and administering, monitoring, and evaluating drug effectiveness and efficacy.[3–5]

The effectiveness of medication therapy depends on the efficacy of the therapy and on patients' ability to manage the medication therapy in daily life, either independently or with the help of informal caregivers or healthcare professionals.[6,7] Older people may experience problems in medication self-management because of several factors, such as the use of a large number of medicines with multiple dosing schedules each day; information from multiple healthcare professionals about medications in combination with other healthcare therapies, each with their own instructions; and personal factors (e.g., visual, physical, and cognitive impairments), all of which can result in unsafe situations.[8–12] Bailey et al. (2013) define patients' medication self-management as "the extent to which a patient takes medications as prescribed, including not only the correct dose, frequency and spacing, but also its continued, safe use over time."[7] Medication self-management starts when patients experience health problems for which a medicine is prescribed, and it ends with discontinuation of the medicine.[13,14] Three phases of medication self-management can be distinguished.[13] In the first phase, the initiation phase, a person receives a prescription for a new course of treatment and needs to fill the prescription at the pharmacy and start the treatment. In the second phase, the execution phase, people are expected to use the medications in a correct and timely manner, store medications as recommended, consult healthcare professionals in case of drug-related problems, and ensure a repeat prescription in time. This phase is a continuous process that begins after each repeat prescription and ends when the treatment is discontinued (Phase 3). Discontinuation can be a result of achieving therapeutic effects or side effects, and discontinued medication must be disposed of according to guidelines. From literature, older persons living at home are known to insufficiently manage several of their medication therapy tasks.[15–19] For example, a study by Vlieland et al. found that 130 out of 170 older persons did not store all drugs according to the recommendations.[17] Moreover, Wieczorkiewicz, Kassamali, and Danziger found that out of 445 interviewed adults, 59% disposed of medications in their household garbage, and 31% flushed medications down the toilet or sink.[16] Previous studies help in understanding how older people manage their medication therapy at home. However, little is known about the considerations they make and the decisions they take with regard to managing medication therapy at home. To gain a better understanding of this, the objective of this study is to explore how older people who live at home self-manage their medication and what considerations and decisions underpin their medication self-management behavior.

Methods

Study approach

A qualitative study design with semi-structured interviews was used. This study design was deemed the most suitable to answer the research aim. This study is reported according to the Standards for Reporting Qualitative Research to enhance the transparency of the study approach, execution, analysis, and reporting of research data.[20]

Context and sampling strategy

Participants were recruited through a community pharmacy and five home care organizations in the Netherlands. Home care in the Netherlands involves care delivered in patients' homes by nurses who provide short- and long-term care to monitor patients' health, assist in (instrumental) activities of daily living (ADL; e.g., bathing), educate, and/or assist in therapies (e.g., pharmacotherapy) tailored to each person's needs.[21,22]

Participants were eligible if they were registered as a patient at the community pharmacy or the home care organization and lived at home, were aged 65 or older, and used at least five different prescription medications daily. The following people were not invited to participate: those with suspected or diagnosed dementia; with an end-stage disease; with an inability to read, speak, or understand the Dutch language; and/or for whom home care professionals or informal caregivers managed the medication therapy entirely. A pharmacist at the community pharmacy and nurses of the home care organizations indicated which patients met the inclusion criteria. The pharmacist and home care nurses subsequently informed the researcher or research assistants (one medical student with a PharmD degree or 15 Bachelor of Nursing students respectively) about the patients who met the inclusion criteria. Thereafter, the researcher (NED) or a research assistant informed the patients about the study via telephone or face to face and invited them to participate. Each Bachelor of Nursing student was asked to interview two to five patients, which means that at least 30 interviews could be performed. This number of interviews was expected to provide ample theoretical data saturation. Patients received both oral and written information about the study protocol, and a week after the information was provided, patients were asked whether they consented to participate. All patients who consented to participate were interviewed, and the interview was subsequently planned. Written informed consent was obtained from all participants, and an informal caregiver could be present at the interview.

Data collection methods

Semi-structured interview guide

A semi-structured interview guide was constructed using a guide for a qualitative interview design.[23] The interview guide involved general instruction on the interview aim and procedure and questions in Dutch concerning (1) general participant characteristics and (2) participants' medication self-management behavior (Appendix A.docx). During the interviews, the interviewers could make notes and take photographs.

(1) General participant characteristics. General participant characteristics, such as gender, age, education level, and living situation, and information on assistance in medication self-management (assistance by other people) and the use of the multidose dispensing (MDD) system were collected. The MDD system involves disposable sachets in which medications are packaged according to the intended time of administration. In MDD systems, all solid medication intended for one dosing moment (e.g., capsules and tablets) is robot-packed in plastic disposable bags.[24] The bags are labeled with patient data, drug contents, and the date and time for intake.[25]

MDD systems are dispensed only for a short period of time (one week, two weeks or three weeks). Patients can collect the MDD system in the pharmacy or get it delivered in their homes. Patients do not have to order the MDD system each week or less frequent, because the pharmacy ensures that a repeat MDD system is available in the pharmacy in time or will be delivered to patient's home in time.

(2) Medication self-management behavior. Urquhart and Vrijens[14] and Van Geffen[13] described three separate phases for medication therapy, namely an initiation phase, an execution phase, and a discontinuation phase, which have been described in the introduction.[13,14] When applied for medication self-management, in each phase patients are required to perform several behaviors. The interviews have been based on these phases in order to report how participants self-manage the behaviors of each phase. The behaviors of the three phases are described next.

The initiation phase.

The initiation phase consists of the following behaviors:

I Informing a healthcare professional about medication-related information. This information involves the use of prescription and over-the-counter (OTC) medications and allergies;
II Filling a new prescription and checking the received medications. Filling a new prescription means that the patient will pick up the medication in the pharmacy or have the medication delivered at home;
III Starting a treatment.

The execution phase.
The execution phase consists of the following behaviors:

I Integrating the use of new and chronic medications in daily life. Integrating means a) becoming accustomed to a new medication in the current therapy and to changes in brands of medications and b) organizing the correct and timely use of medications. For the latter, the following behaviors were included: using the patient information leaflets, taking into account nutritional advice and expiration dates and handling practical problems;
II Organizing the storage of medications. This involves organizing the storage according to the recommendations and taking into account that young children could find the medications;
III Informing a healthcare professional about medication-related information. This information involves signs and symptoms of side effects and problems with the usage of medication;
IV Ensuring timely ordering and filling of repeat prescriptions and checking the received medications.

The discontinuation phase.
The discontinuation phase consists of the following behaviors:

I Consulting a healthcare professional to discuss the need to discontinue medications;
II Organizing the disposal of leftover and expired medications.

Considerations (e.g., meanings, beliefs, emotions, and experiences) and decisions (e.g., the use of aides) for each behavior were questioned. For each behavior, an open introduction question was followed by open follow-up questions. CGMS, MJS, and ERH commented on the draft interview guide, and the researcher (NED) subsequently piloted the interview questions in three interviews to check the clarity of the questions for participants and to make final revisions if needed. The interviews were performed at the beginning of April 2018 at the participants' homes. Participants understood the questions, no adjustments were needed. The interview data from these interviews were included in the data analyses. Prior to the interviews, the participants were asked to obtain a medication list from the pharmacy. During the interview, a check was performed to determine whether the medication intake corresponded to the correct and timely intake as described on the medication list. The pharmacist's medication list was considered to provide the actual information on patients' medication use. The interviewers made notes of remarkable situations (e.g., inaccurate intake of medications and the use of medications that had passed the expiration date), and there was no strict order in which the questions were asked.

Table 1
General participant characteristics ($n = 60$).

	N (%)
Gender, female	44 (73.3)
Age, [median; IQR], years	[86.5; 78–89]
Education	
Low[a]	13 (21.6)
Medium[b]	31 (51.6)
High[c]	16 (26.6)
Living situation	
Living alone	37 (61.7)
Living with partner or other family member	23 (38.3)
Number of prescriptions [median; IQR]	[8; 6–11]
Assistance in medication self-management	
None	31 (51.6)
Informal care (family or other)/home care	29 (48.3)
Use of multidose dispensing system, yes	37 (61.7)

[a] Primary education.
[b] Lower and upper secondary education and vocational education.
[c] Bachelor's degree or higher.

Photographs

Photographs were taken to collect visual information on behaviors and tools (e.g., tools for the organization of the correct and timely intake, such as reminders or dosing systems, and storage locations) to support the interview data. Furthermore, interviewers were not allowed to photograph individuals, and personal data were either not photographed or blurred in the photos.

Data collection process

Data were collected between April and December 2018 by the research assistants and the researcher. The interviews were held in Dutch. The Bachelor of Nursing students held the interviews as part of an assignment from the nursing education program, and the researcher trained the students (in 1.5 h) in interview techniques prior to the data collection and provided them with examples of behaviors that could be photographed to increase the inter-interviewer reliability. Furthermore, information on medication self-management and considerations and decisions were audiotaped. The notes of remarkable situations, the photographs, and the general participant characteristics were saved in the digital survey software LimeSurvey (version 3.0).

Data analysis

General participant characteristics

Descriptive statistics were used to describe general participants' characteristics in number and percentages (for gender, education level, living situation, assistance in medication self-management, and use of MDD) and in medians and interquartile ranges (IQRs; for age and number of prescription medications in use). The participants' general characteristics were imported into statistical software SPSS (version 25.0, Armonk, NY, IBM Corp.).

Participants' medication self-management

Data were analyzed using a content analysis with a directed approach.[26] Interview transcripts, notes, and photographs were analyzed by two independent persons (a PhD student [NED] and a research assistant [MS, fourth year Bachelor of Nursing student]). If they had difficulties with interpreting the interview data and the photographs, they reached the interviewers to ask for clarity. Data analysis was supported by ATLAS.ti software for coding and analysis (version 8.0, Scientific Software Development GmbH, Berlin, Germany). First, the two researchers read the transcripts and notes in their entirety and viewed the photographs to gain an overall picture with regard to the research objective. Thereafter, the transcripts and notes were reread, and the photographs were re-viewed in more detail. Meaningful paragraphs (i.e., paragraphs that reflect information regarding medication self-management) from the transcripts, notes, and photographs were coded by both researchers and discussed afterwards until consensus was reached. For disagreements in the coding, the researchers discussed differences in the codes and could rephrase or rewrite codes to reach consensus. Codes reflect a) participants' considerations (e.g., meanings, beliefs, emotions, and experiences) or decisions to manage the therapy or b) remarkable behaviors observed by the interviewer of the predefined medication-self management behaviors, as described in data collection methods. Hereafter, the

researchers brought the codes of each interview under the main phases of medication self-management. Finally, a description of behaviors, including citations and photographs that represent a result of a behavior, was created. The interviewers notes and the names of medications and characteristics of participants (i.e., gender and age) were added to some descriptions. The researchers (NED; CGMS; MJS; LS; ERH) translated the interviewers' notes, the names of medications, citations, and information from photographs to English.

Ethics

This research was not subject to the Dutch Medical Research Involving Human Subjects Act. The institutional review board of the Utrecht Pharmacy Practice network for Education and Research reviewed the study (UPF1802), which was conducted in compliance with its requirements and the World Medical Association's Declaration of Helsinki.[28]

Results

In total, 69 people were invited to participate in this study, and 60 of them were interviewed: 48 people were interviewed by 15 Bachelor of Nursing students (students conducted on average 3.3 interviews [SD 1]), five people were interviewed by the medical student, and seven people were interviewed by the researcher. Furthermore, nine people declined participation because of deteriorated health conditions, holiday plans, or hospital admissions with an additional stay in a nursing home. The 60 participants had a median age of 86.5 (IQR 78–89) and a median number of eight prescriptions (IQR 6–11), and 73.3% were female (Table 1). Moreover, an informal caregiver was present in three interviews.

Participants' medication self-management with considerations and decisions

This section describes how older people manage the behaviors per phase (initiation, execution, and discontinuation) followed by their considerations and decisions regarding the behaviors.

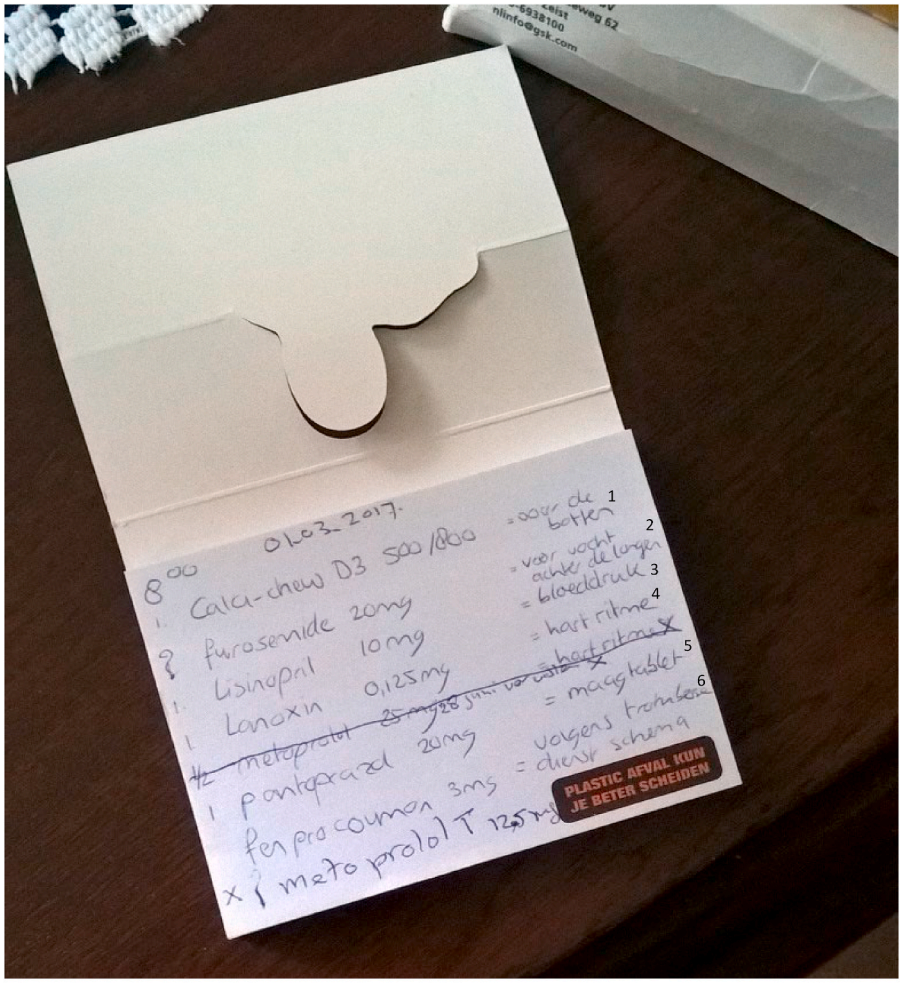
The initiation phase

I Informing a healthcare professional about medication-related information

Participants used different methods to inform healthcare professionals about current medication use. They stated that they used self-made (written or digital) medication lists (Fig. 1; Fig. 2) or a medication passport, empty plastic pouches of the MDD system, and/or photographs of those plastic pouches on their mobile phone.

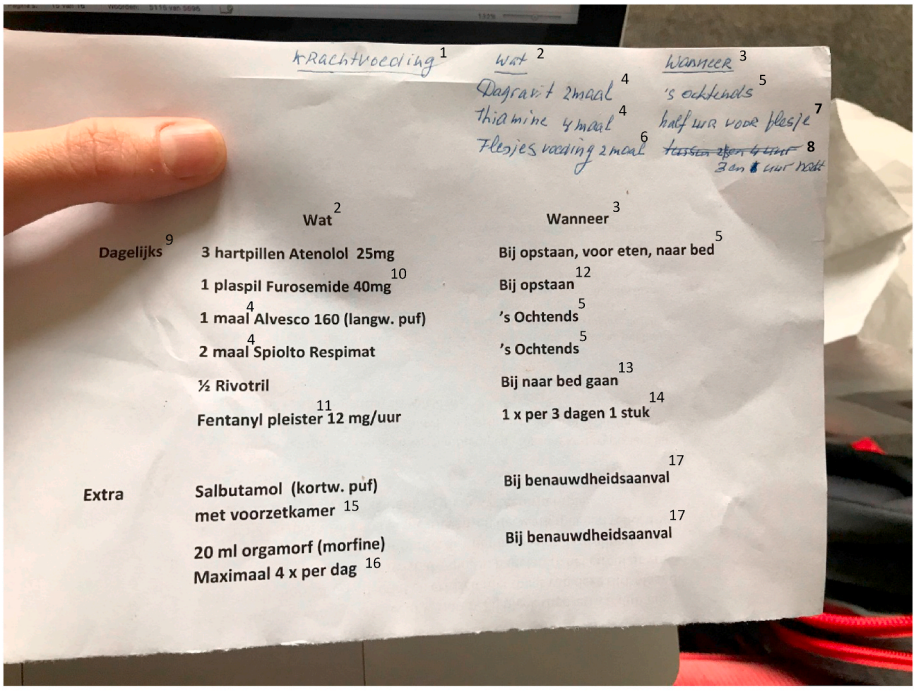
"I don't have a printed medication list, but I have photos of the plastic pouches [of the MDD system] in my mobile phone. I always have my mobile phone and thus information of my medications. When I go to a physician, I show him the photo." - **Participant 7 (female, 73 years**).

Some participants did not bring information about their current



[1] For the bones; [2] For fluid behind the lungs; [3] Blood pressure; [4] Heart rhythm; [5] Stomach tablet; [6] According to thrombosis schedule.

Fig. 1. Self-made medication list - **Participant 17 (Female, 91 years).**



[1] Powerfood; [2] What; [3] When; [4] 2maal/4maal = Two/four times; [5] In the morning; [6] Two times bottle with oral nutritional supplement; [7] Half an hour before taking the bottle; [8] Unclear to translate; [9] Daily; [10] One pill for urination Furosemide 40 mg; [11] Fentanyl plaster; [12] When getting up; [13] When going to bed; [14] Once per 3 days 1 plaster; [15] Salbutamol (short-term bronchodilators) with aerochamber; [16] 20 ml orgamorf (morfine) Maximum of 4 times per day; [17] For sudden breathlessness

Fig. 2. Self-made medication list - **Participant 25 (Female, 84 years).**

medication use to a healthcare professional. Their reasons for not doing so are, for example, believing that professionals have access to accurate information about their current medication in the digital patient file.

> "I don't bring a medication list with me to the physician, because all information about my medication is in their computer." - **Participant 30 (female, 91 years)**

Some participants stated that their self-made medication lists were several years old and contained information on prescription medication, but had no information about OTC medication or allergies. Most of the lists were also not up to date.

Many participants did not inform healthcare professionals about other relevant information, such as OTC medication use or allergies. In the case of OTC medication, participants were not aware of potential interactions between OTC medication and prescription medication.

> "I didn't know there could be interactions between my medications of my physicians and the OTC medications. I do not ask the pharmacist or the seller of OTC medications if it is safe for me to use it." - **Participant 1 (male, 93 years)**

> "I use OTC medication occasionally. My body won't get used to it, so no, there could not be any interaction between OTC medication and prescribed medication." - **Participant 54 (female, 66 years)**

II Filling a new prescription and checking the received medications

Participants stated that they filled a new prescription immediately in the pharmacy by themselves or with the help of an informal caregiver or home care professional, or the pharmacy delivered the medication to their home. Participants asked other persons to fill prescriptions when they were unable to go the pharmacy themselves due to immobility. The following reasons were mentioned for allowing medication to be delivered to participants homes: participants were not able to go to a pharmacy due to physical conditions (e.g., immobility or shortage of breath); they experienced the frequent pick-up moments in the pharmacy as annoying; or they had to wait in the pharmacy for a long time before they received the medications, and that was experienced as intensive.

Most of the participants stated that they checked the correctness of the received medications. They had several reasons for checking the correctness; for example, they once received the wrong medication and want to be sure that they receive the correct medications, or they received medication of other brands and wanted to be sure that the medication was correct.

> "Once, I received the wrong medication by the pharmacy; since then, I always check the correctness." - **Participant 51 (female, 87 years)**

Some participants did not check the correctness. They stated that they believed they received the correct medications.

> "No, I don't check the medications [interviewer: 'No, you don't check the correctness?']. No, the pharmacy sends the medications and then well I assume that the medications are correct." - **Participant 54 (female, 66 years)**

III Starting a treatment

Most participants stated that they started a treatment after they filled the prescription. Participants who did not start a new treatment decided not to start because after reading the potential side effects in the patient information leaflet, they feared experiencing side effects.

> "… Miconazol (vaginal) cream, no I won't use it. I have read the patient information leaflet and I am scared to get side effects." - **Participant 17 (female, 91 years)**

A few participants started the use of medications from their stockpile that was intended for other health problems. They did not consult a

healthcare professional to discuss the appropriateness of the medication for the health problem. They believed that taking these drugs would not cause any problems when using other prescribed drugs at the same time.

The execution phase

I Integrating the use of new and chronic medications in daily life and organizing the correct and timely use of medications

Becoming accustomed to a new medication in the current therapy

Some participants stated that they needed reminders to become accustomed to taking new medication at the right time. A participant used written reminders (Fig. 3) that informed her about the date on which a new treatment had to be started and about the intake moments of chronic medication.

Becoming accustomed to changes in brands of medications

Many participants experienced changes in the brand of medication as annoying and confusing. Changes also resulted in confusion about organizing the correct intake. Besides, participants mentioned feelings of uncertainty about the therapeutic effects of the new brands and were worried about experiencing side effects.

> "So I always check the colors of the pills before I take the pills. I use eight pills, six white pills, a pink one and a yellow one. But that pill, the color has been changed, the pill was yellow but now it is white. I get confused because 'my system'* tells me to take six white pills each day." - **Participant 44 (female, 79 years)**

> *i.e., medication they should use according to what they can remember.

Using the patient information leaflets

Some participants stored and used the patient information leaflets. In some circumstances, they used the leaflets, for example, when they receive a new medication or when they experience problems.

> "I use the leaflet not that much. Since a while I easily get hematoma on my legs. For this, I check the leaflet to find out if it is a side effect of my medication." - **Participant 5 (Female, 72 years)**

The majority of participants did not store or use the patient information leaflet. They mentioned the following reasons: they found it unnecessary to have a leaflet; they already know the information on the leaflets; the leaflets contain too much information; participants had a negative feeling by reading the information; or they were not able to read the information.

> "I don't read the leaflets. I find it unnecessary. When I have a problem, for example a side effect, then I go to the general practitioner." - **Participant 30 (Female, 91 years)**

> "I can't read the text; the letters are too small. My daughter in law reads aloud the leaflets for me." - **Participant 14 (Female, 90 years**).

Organizing the correct and timely use of medications

Some of the participants mentioned that they know how to take the medication correctly and at what time because this information is in their "system." Many participants used (self-made) tools, including medication lists (Fig. 1; Fig. 2), week boxes, or storage boxes (Fig. 4) which helped them to take medication in the correct way and correct time. Furthermore, several participants mentioned that they regularly forgot to take their medication at the right moment. Some of them mentioned that they believed they should not take the medications once the intake moment had passed.

> "… sometimes I fall asleep during the day. So, I have medications for 12 o'clock, but when I sleep at that time and wake up at let's say 12.30 o'clock, it is too late to take it. Someone told me to not take the medications when the intake moment has passed, so I don't take the pills." - **Participant 6 (female, 83 years)**

The 83-year-old female mentioned that she stored the medication that she has not taken in a bag, which she presented. It contained

[1] 8 o'clock, 2 pills Acetaminophen; [2] From September the 4th one pill of the Acetaminophen at 12 o'clock, September the 18th at 12 o'clock no Acetaminophen; [3] Medicines at 17 o'clock, September the 18th at 17 o'clock two pills of the Acetaminophen, October the 7th at 17 o'clock; [4] Before sleeping

Fig. 3. Written reminders - **Participant 44 (Female, 79 years).**

[1] Two per day; [2] One per day

Fig. 4. Medication stockpile and daily medication stored in a box - **Participant 27 (Female, 73 years).**

medications for approximately about a one-year period, including: 12 tablets atorvastatine, 20 mg; 120 tablets of acetaminophen, 1000 mg; eight tablets of acetaminophen, 500 mg; 146 tablets of baclofen, 10 mg; 25 tablets of metoprolol, 25 mg; 15 tablets of nortrilen, 10 mg; 24 tablets of enalapril maleate, 5 mg; 16 tablets of nifedipine, 30 mg; 25 tablets of pantoprazole, 2 mg; 26 tablets of clopidogrel, 75 mg; 23 tablets of cholecalciferol, 800 IE; three tablets of amitriptyline, 10 mg; and three unrecognized tablets. – ***Interviewer's note***.

Taking into account nutritional advice and expiration dates

Some participants stated that they did not check the nutritional advice for taking the medications correctly, because they did not know the advice.

"I don't know the rules, I stir all pills* in a glass of water and when they are mixed, I drink the water." - **Participant 6 (female, 83 years)**

*The medications for Intake Moment 1, included baclofen, cholecalciferol, clopidogrel, enalapril maleate, acetaminophen, and nortrilen; for Intake Moment 2, baclofen and acetaminophen; for Intake Moment 3, baclofen; and for Intake Moment 4, atorvastatin and acetaminophen **- Interviewer's note.**

"I never take expiration dates into account, and I did not know that the dates are described on the medication packages." - **Participant 27 (Female, 73 years)**

A few participants checked the expiration date of medications before using them and wrote that date on the packages or in their agenda, or they asked the home care professional to do it if they cannot read the expiration date themselves because they found the size of the text to small. Most participants did not check the expiration date because they do not know that packages contains an expiration date; or they believed that medicines' expiration dates are always in the far future, so they do not have to check them. Some participants have used medications (e.g., insulin and cetomacrogol cream) that have passed the expiration date, without being aware of it.

"The participant (11, Male 91 years) uses a Novo Rapid pen that has passed the expired date by four weeks." - **Interviewer's note**

Handling practical problems

Several participants stated that they experienced practical difficulties, including opening bottles and plastic packages of the MDD system and splitting those packages. In these situations, the participants asked for the help of a partner or home care professional, or they used tools such as used kitchen aids or their teeth.

"I use a knife to tear the foil of the blister." - ***Participant 11 (male, 91 years)***

"Opening the pouches of the MDD system is difficult. I use my teeth to open it." - ***Participant 56 (female, 81 years)***

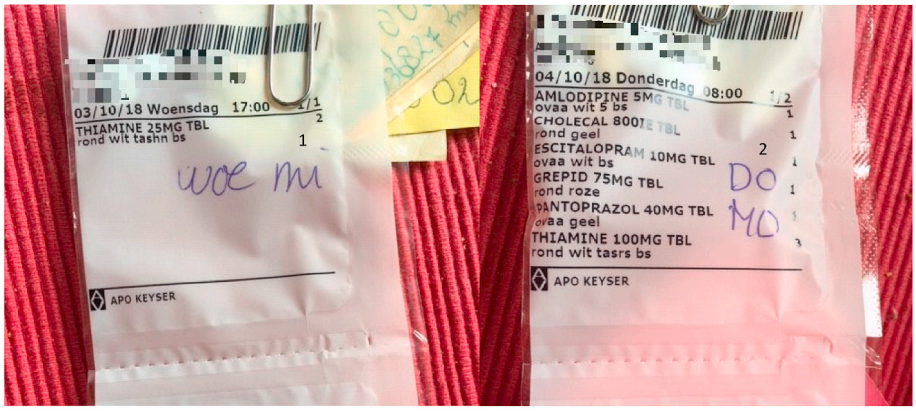
Some solutions are used for specific circumstances such as eye problems, pain due to physical problems, or memory difficulties. For eye problems, some participants wrote the day of intake in larger letters on the plastic packages because of difficulties reading the printed text on the plastic pouches (Fig. 5) or they zoomed in on photos of the medication packages to be able to read the letters.

"I have difficulties with reading the small letters of the text on the packages, so I make a photo of the package with the tablet and then I use the photo to zoom in on the letters. Then I can read the text and know which medication I have to take at a specific time." - **Participant 24 (male, 69 years)**

Due to physical problems, participants had difficulties preparing the medication intake for a certain period. Therefore, they had several solutions, such as tools (e.g., kitchen aids) or the assistance of home care professionals or relatives.

"I have problems with opening packages every day because of my arthrosis in both my hands. I found a way to handle this situation. I decided to prepare the intake for a whole week on one day a week. Then the pain is just once per week. The pills are there [in front of the packages - Fig. 6]." - **Participant 26 (Male, 83 years)**

"I have Lambert-Eaton myastheen syndrome. I have muscle weakness in my hands and fingers. I can't open the packages or push pills out of the blisters. I asked the home care professional to do this four times a day". - **Participant 52 (Female, 69 years)**



[1] Wednesday afternoon; [2] Thursday morning

Fig. 5. Day and moment of intake (in abbreviations) written on the plastic MDD package - **Participant 43 (Female, 82 years)**.

Fig. 6. The prepared medication intake for a week - **Participant 26 (Male, 83 years).**

For memory problems, some participants used reminders (e.g., notes or placing medication besides the water tap or toothbrush) or the help of a relative or home care professional.

"I place the pills beside the toothbrush. It reminds me every morning and evening to take the pills." - **Participant 13 (Female, 82 years)**

II Organizing the storage of medications

Locations for storing daily medications

Participants stored their daily medications in several places in their home that remind them about the intake moments (e.g., next to the water tap, on a bedside table, kitchen table, or the couch, in the windowsill, kitchen cupboard, or bathroom next to tooth brushes or make-up) (Figs. 7 and 8).

Locations for storing medications for later use

The medications for later use were stored on other places than the daily medications (e.g., shelves of the bedroom table, clothing closets, and basements) to keep a tidy house. Participants stated that they used locations that are easy to remember and access.

Some medications in the stockpile contained expired or leftover medications.

Fig. 7. Medications stored alongside food in a kitchen cupboard - **Participant 52 (Female, 69 years).**

"I store the medication for later use in the wardrobe in the bedroom; the medication that I have to take each day are in the bedside table and in the kitchen." - **Participant 19 (Female, 90 years)**.

Storage recommendations

Several participants stated that they did not take the storage recommendations into account (Fig. 9), because they were not aware of the recommendations.

"I don't know where I have to store the medications: I don't know anything about rules. I store all pills of my wife, so the MDD system (including furosemide, metoformine, sotalol, spironolactone, and enalapril maleate, [interviewer's note]) and the other medications (tiotrus tiotropium, [interviewer's note]), in the fridge. For me it is a logical place, so I store all the medications in the same place." - **Informal caregiver of Participant 8**.

Several participants mentioned that they regularly have grandchildren in their home, and a few of them mentioned that they locked away the medication stockpile to prevent the children from accessing the medications. Most of the participants who live with other people who also use medications, stored their medications separately.

III Informing a healthcare professional about medication-related information

Several participants mentioned potential signs and symptoms of side effects, but they did not discussed these with a healthcare professional. Most of them mentioned that they were not aware that the side effects could be medication-related. They believed, for example, that their body was accustomed to the medications, so side effects could no longer occur, or they believed that signs and symptoms were a result of the aging process instead of medications.

"Well I use the medications for a very long period, I believe that when I use medications for a long period, my body is used to it and therefore it is not possible to get a side effect." - **Participant 58 (female, 88 years**).

When participants had home care and experienced usage problems, they discussed it with a home care professional and asked for help.

IV Ensuring timely ordering and filling of repeat prescriptions, and checking received medications

Many participants (who did not use an MDD) used several tools to ensure a repeat prescription (e.g., automatic repeat prescription principles, order repeat medications via telephone or an online service, or emails), and some participants tracked their medication stockpile via self-made stockpile lists (Fig. 10). These options are experienced as pleasant and easy to perform. Furthermore, participants stated that they used these options because then they do not have to go to the pharmacy, which for most persons is not possible due to physical conditions.

Furthermore, participants employ different methods to check the

Fig. 8. Medication stored on a kitchen table - **Participant 33 (Male, 90 years)**.

received medications (e.g., using a [self-made] medication list, counting the number of packages, or checking what they should use according to their "system").

The discontinuation phase

I Consulting a healthcare professional to discuss the need to discontinue medications

A few participants stated that they decided by themselves to stop or to change a dose. For example, participants stated they the stopped or changed their doses of thiamine, furosemide, and statins. There reasons for discontinuing were, for example, that they experienced side or therapeutic effects or no therapeutic effects.

> "I don't use the furosemide anymore; I don't have any problems with urinating anymore. I didn't ask the physician if I could stop using the medications." - **Participant 33 (male, 90 years)**

A few participants mentioned that they did not experience positive effects of the prescribed analgesics. They therefore discontinued the use of those analgesics and started using cannabis oil produced from plants from their own garden.

II Organizing the disposal of leftover and expired medications

Disposal actions for leftover and/or expired medications differ. Participants mentioned that they a) returned the medications to the pharmacy or to a chemical depot in their neighborhood by themselves or via informal caregivers or home care professionals, or b) stored medication in case they need or want to use it in the future, c) disposed of medication in the garbage or via the toilet or sink, or d) gave medications to other people. Some of the participants believed that medications will be disposed of in the pharmacy in the normal garbage or that professionals of the pharmacy sells the medications to non-developed countries. Others were not aware that medications need to be disposed of at chemical depots.

> "I throw it in the garbage bin. The medications will be disposed of in the garbage bin in the pharmacy, so I may do that at home as well." - **Participant 1 (male, 93 years)**

> "The pharmacist will throw the medication in the garbage; it is a pity, so I give the medication to people in other countries." - **Participant 32, (male, 83 years)**

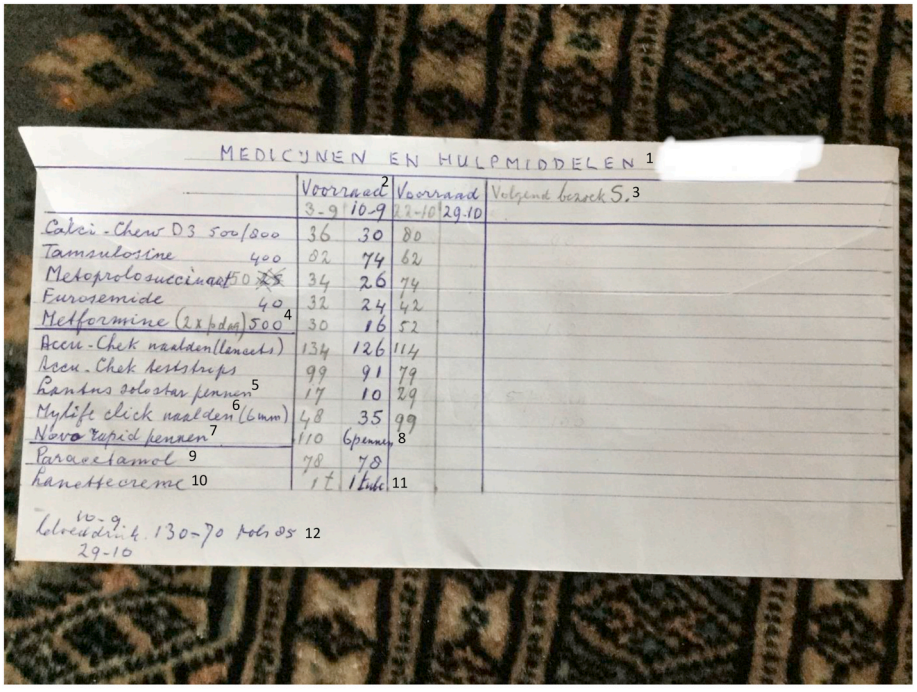
Boxes that contained medications for later use sometimes had expired medications or large amounts of medications. The box in Fig. 11 included among other things, 17 packages containing unused fentanyl tablets and a package containing unused pregabalin tablets.

Discussion

This study provides insight into considerations and decisions that lead to older peoples' medication self-management behaviors. This research shows that older people have multiple behaviors for which they have considerations and decisions. Some of their behaviors could lead to unsafe situations, including problems in the organization of their medication intake, inadequate discussion of medication-related information with healthcare professionals, and incorrect and undesirable storage and disposal of medications. Each of the behaviors is described hereafter, followed by ways in which healthcare professionals can assist older people with these behaviors.

The first behavior concerns problems in the organization of medication

Fig. 9. Tablets stored outside the blister - **Participant 17 (Female, 91 years).**



[1] Medications and aids; [2] Stockpile; [3] Next meeting S; [4] Metformine (two times per day) 500; [5] Lantus SoloStart pens (6 mm); [6] MyLife ClickFine needles; [7] NovoRapid Insulin pens; [8] six pens; [9] Acetaminophen; [10] Lanette protection cream; [11] One flacon; [12] Blood pressure 130-70, Heart rhythm 85

Fig. 10. List of medications of the medication stockpiling - **Participant 14 (Male, 91 years)**.

Fig. 11. Stockpile with left-overs - **Participant 15 (Female, 88 years).**

intake. Sometimes, the organization was incorrect, and participants did not take medication as prescribed. Based on their considerations, we identified several factors that contributed to this behavior, such as insufficient knowledge, visual impairment, memory problems, changes in the brands of medication, and intentional non-adherence. Previous studies have identified the same causes of organizational problems.[10,29–32] A study by Sino, Sietzema, Egberts, and Schuurmans described that decreased cognitive skills and knowledge was related to inadequate medication management capacities, including the intake of medications.[10] We found that not starting a therapy or stopping a therapy is a result of either the expectation that medications will give side effects or the belief that the medication is not needed, since the health complaints have been solved. Horne et al.[33] call this intentional non-adherence when peoples' beliefs, attitudes, and expectations influence their motivation to start and to persist with a medication therapy. In the case of incorrect organization or even the wrong intake of medications, older people will potentially not benefit optimally from those medications. This may result in increased morbidity, mortality, and societal costs.[34,35] In a study by Notenboom et al.,[9] it was found that organization problems, such as the intake of unequal halves of tablets and difficulties with the identification of medications, could have clinically relevant consequences.

Healthcare professionals should pay attention to whether older people understand, remember, and apply the intake instruction; are able to read those instructions; or have problems with changes in the brand of medication. Furthermore, healthcare professionals are encouraged to ask patients whether they have questions or concerns regarding information described in the patient information leaflet.

Another remarkable behavior is an insufficient provision of medication-related information such as current medication use, the use of OTC medication, and allergies to healthcare professionals.

We found that some participants have little awareness about the potential for interactions between prescription and OTC medication and having allergies. This information is important for healthcare professionals, to evaluate possible interactions and therapeutic duplication and to suggest and implement adequate therapeutic changes.[36,37] Furthermore, our study identified suboptimal information provision about health complaints, which could be side effects, to healthcare professionals. Some participants missed the awareness that their health complaints could be the result of medications. This may explain why older people do not discuss health complaints with a healthcare professional. Therefore, such professionals should pay attention to patients' awareness of the potential for interactions and side effects, and they should encourage patients to share accurate and complete medication-related information.

Finally, we explored the incorrect and undesirable storage and disposal of medications. We found that some older people have insufficient knowledge of the correct storage and disposal instructions. Incorrect storage and disposal has been reported in previous studies,[15–17] and it can lead to medications having diminished efficacy or even becoming harmful. In the study by Vlieland et al.[17] it was found that about half of the participating people (48.5% out of 170 older people) did not comply with the storage recommendations. The researchers found medications that had passed the expiration date; medications that were not stored according to the recommendations for temperature, light, and humidity; and medications that were not correctly stored in the packages.

Healthcare professionals who visit older people in their homes should thus be encouraged to check peoples' understanding of the storage and disposal instructions and to provide information about the correct instructions. The home situation is the most suitable area to gain insight into this behavior.[38–41]

Several recommendations for healthcare professionals have been described above. However, older people and informal caregivers are responsible for ensuring rational medication management by adhering to the instructions of healthcare professionals, as well as for of consulting a healthcare professional when they experience problems or confusions regarding the medication self-management. Some informal caregivers in this study were not fully capable of managing the therapy correctly. Previous research supports this and describes that informal caregivers are inadequately equipped to manage the medication therapy.[7] Since informal caregivers will have a greater participating role in medication management in coming years, and because they regularly make autonomous decisions,[8] future research is recommended with a focus on needs and interventions

that can support safe medication management by informal caregivers.

Strengths and limitations

A strength of this study is that we interviewed many older people in their own homes. In the home situation, older persons must perform many behaviors to self-manage medications. Therefore, we had the best opportunity to explore their medication self-management.

Reaching older people for participation in research is often difficult, because they do not necessarily want to be actively involved in research or because old age is accompanied by deteriorated health conditions that do not enable participation.[42] However, we did not experience problems with including sufficient older people for participation. The participation of many older persons in this study could be explained by the fact that they were able to stay at home during the interview and that they had sufficient time to participate. Another possible explanation is that the participants already knew the interviewers and, a sense of partnership and trust was hence already established, which made them willing to participate. Partnership and trust are facilitators for participation of older people in research.[42]

One of the limitations of this study could be that the participants did not reveal all their behaviors, because of feeling ashamed or guilty about inefficiency or undesirable behaviors. Another limitation is that data were collected by many different interviewers, which may have caused differences in the quality of the data. These limitations could result in an underestimation of older peoples' problems with regard to self-management of medication therapy; therefore, there could potentially be more behaviors that should be addressed by healthcare professionals.

Conclusion

This study provided insight into the considerations and decisions that shape the medication self-management behavior of older people. These considerations and decisions of older people led to the following issues: problems in organizing medication intake, inadequate discussion of medication-related information with healthcare professionals, and incorrect and undesirable medication storage and disposal. This study shows the need for the observation and monitoring of medication self-management behaviors and support by healthcare professionals. The home situation is the most suitable area in which to do this and to assist older people with inadequate mediation self-management.

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CRediT authorship contribution statement

Nienke E. Dijkstra: Conceptualization, Methodology, Validation, Formal analysis, Investigation, Data curation, Writing - original draft, Visualization, Project administration. **Carolien G.M. Sino:** Conceptualization, Methodology, Validation, Writing - review & editing, Supervision, Project administration. **Marieke J. Schuurmans:** Conceptualization, Methodology, Validation, Writing - review & editing, Supervision, Project administration. **Lisette Schoonhoven:** Validation, Writing - review & editing, Supervision, Project administration. **Eibert R. Heerdink:** Conceptualization, Methodology, Validation, Writing - review & editing, Supervision, Project administration.

Declaration of competing interest

None.

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Appendix A. Supplementary data

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