

**Addressing Informal Caregiver Burden: Technology and Toolkit for Medication Management in
Older Adults**

by

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Author's Declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners. I understand that my thesis may be made electronically available to the public.

Abstract

Background: Older adults with multiple chronic conditions often manage complex medication regimens. Age-related physical and cognitive impairments further complicate this process and increase the risk of medication errors and non-adherence. Informal caregivers, including family, friends, and neighbors, play a crucial role in supporting this process. However, many caregivers feel unprepared for the complex and time-consuming tasks involved in medication management. As a result, they may experience significant caregiver burden, which affects their emotional, social, financial, and physical well-being and can contribute to anxiety, poor self-care, sleep disruption, social isolation, or even suicidal thoughts.

Objectives: 1. To evaluate the impact of an automated medication dispenser (AMD) on compassion fatigue, satisfaction, and medication administration hassles. 2. To develop a medication management toolkit to support family caregivers with medication management at home.

Methods: Study one is a pilot mixed-methods study that recruited 7 pairs of family caregivers and their older care recipients. Caregivers completed the Family Caregiver Medication Administration Hassles Scale (FCMAHS) and the Professional Quality of Life Scale (ProQoL) at baseline, 2 weeks, and 3 months after implementing AMD in care recipients' homes. Caregivers were interviewed before and after using AMD. The interviews were recorded, transcribed, and thematically analyzed. Study two is a qualitative study in which 16 family caregivers participated in focus group discussions to identify medication management challenges and solutions that will inform the development of the toolkit.

Results: In study one, Friedman tests showed no significant change in FCMAHS subscale scores over time after Bonferroni correction ($\alpha = 0.0125$; all $p > 0.0125$). The total score (primary outcome) was assessed without correction ($\alpha = 0.05$) and was not significant. Wilcoxon Signed-Rank Tests showed a similar pattern, except for a significant reduction in total score from baseline to 3 months ($p=0.02$). Both tests showed no significant change in scores for the subscales of ProQoL after Bonferroni correction ($\alpha=$

0.0167); all $p > 0.0167$). Three themes emerged from the pre-intervention interviews: becoming a caregiver, approaches to support medication management, and caregiver experience and well-being. Four themes emerged from the post-intervention interview analysis: usability and functionality, experience with remotely delivered pharmacy services, caregiver experience and well-being, and impact on the caregiver–recipient relationship. Six themes emerged from study two: caregiver–recipient relationship and caregiving context; challenges with medication management; medication management strategies; non-medication management tasks; caregivers’ preferences for toolkit format and content; and additional support with medication management.

Conclusion: Study one shows that the long-term use of AMD has the potential to be beneficial for caregiving burden related to medication management but is influenced by the caregiver’s adjustment period. Future research should verify these pilot findings. Study two shows that family caregivers manage medications across several domains in which they face challenges, including scheduling doses, supporting adherence, tracking medication supplies, and communicating with healthcare professionals. To assist with these tasks, caregivers often rely on simple and traditional tools and strategies.

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List of Abbreviations

ProQoL	The Professional Quality of Life Scale
FCMAHS	Family Caregiver Medication Administration Hassles Scale
IADLS	Instrumental activities of daily living
ADLS	Activities of daily living
BSFC	Burden Scale for Family Caregivers
CSAQ	Caregiver Self-Assessment Questionnaire
CHE-s	Caregiving Health Engagement Scale
CAS	Caregiving Appraisal Scale
CSI	Caregiver Strain Index
ZBI	Zarit Burden Interview
CBI	Caregiver Burden Inventory
MRQ8	Medication Risk Questionnaire
MedMaIDE	Medication Management Instrument for Deficiencies in the Elderly
MDC	Medication Deficiency Checklist
CCSM	Caregiver Confidence in Sign and Symptom Management Scale
MCI	Medication Complexity Index
MSB	Medication-Saving Behaviours Scale

Chapter 1

1. Introduction

The global population of older adults is rapidly increasing, rising from 8% (524 million) in 2010 to a projected 16% (1.6 billion) by 2050.^{1,2} Canada is experiencing similar growth, with the proportion of adults aged 65 and older expected to increase from 16.9% in 2018 to 21% in 2028.^{1,2} This demographic shift in Canada and other developed countries has contributed to an epidemiological transition marked by greater morbidity from chronic and degenerative diseases.^{3,4} Older adults commonly develop multiple chronic conditions, which can lead to complex medication regimens and poor health-related quality of life.⁵⁻⁸ Although correct medication administration and adherence are essential for therapeutic outcomes, age-related cognitive and physical limitations contribute to medication non-adherence and errors.⁹⁻¹² Consequently, many older adults require assistance from family members to manage their medications while living in the community.^{9,10,13} This adds substantial responsibility to informal caregivers, who provide up to 75% of the care for older Canadians and often perform these tasks with minimal training, which can lead to caregiver distress.¹³⁻¹⁵

1.1. Multimorbidity Among Older Adults

Multimorbidity has emerged as a public health concern in Canada due to the aging population and the growing burden of chronic health conditions.¹⁶ The prevalence of older adults with two or more chronic health conditions ranges from 55% to 98%.¹⁶ Older adults with multiple chronic conditions often find it challenging to manage these conditions and struggle to care for themselves.^{9,10,12,17} Multimorbidity is linked to negative health outcomes, including decreased physical function, cognitive impairment, diminished quality of life, increased healthcare utilization and expenses, and a higher likelihood of adverse events such as hospitalization.^{6,7,16,18}

1.2. Complexity of Drug Regimens Among Older Adults

According to the Canadian Institute for Health Information, the number of medications used by older adults increases with age.¹⁹ In 2012, 39.3% of those aged 85 and older were prescribed 10 or more drug classes, compared to 20.0% of adults aged 65 to 74.¹⁹ Chronic medication use among older adults is frequently linked to the treatment of chronic conditions, with approximately half of the older adult population using medications for two or more conditions.^{19,20} As a result, polypharmacy contributes to increasingly complex medication regimens that require a high degree of cognitive and physical skill for safe medication self-management.^{21,22} This complexity becomes difficult to manage as older adults experience a decline in cognitive and physical functioning, which can impair their ability to self-manage medications.^{21,22} According to Maddigan et al., the functional ability to self-manage medications is defined as the cognitive and physical capacity to take medication as prescribed.^{17,22} The gradual loss of functional ability leads to unintentional medication nonadherence and medication errors.^{11,21} Nonadherence behaviors can be broadly categorized into two types: intentional and unintentional.²¹ Intentional nonadherence occurs when patients deliberately choose not to follow prescribed medication regimens due to attitudes, beliefs, or expectations, while unintentional nonadherence results from capacity limitations such as forgetfulness, vision impairment, dexterity deficits, or difficulty accessing prescriptions.^{21,23,24} These limitations place older adults at high risk for missed or incorrect medication administration, especially given the high prevalence of disability in this population; 33.0% of adults aged 65 to 74 and 56.3% of those aged 75 and older experience disabilities affecting mobility, agility, pain, hearing, or vision.^{17,25–28} A clinical study evaluating functional capacity revealed that 41% of older adults could not perform one or more tasks essential for administering their medication regimen, such as opening or removing tablets from a container.^{20,29} Another study involving both community-based and

institutionalized older adults found that 9.4% could not read instructions on a medicine bottle label.^{20,29,30} It was found that 32% of older adults had difficulty opening snap-lid bottles, 14% had difficulty opening screw-cap bottles, and 10% were unable to open blister packs.³¹ Sino et al. evaluated the medication management abilities of 95 geriatric patients who were taking five or more medications and discovered that only 48.4% could manage their medications independently at home.^{10,20} Approximately 40% of participants could not recall the names of their medications, even with a medication list, and around 25% reported difficulty opening medication packages.^{10,20} Moreover, studies have reported that 27% of older adults who have physical difficulty opening their containers receive medication assistance.³¹ Accordingly, older adults' ability to manage their medications can be improved with the introduction of various types of support.^{17,22} Human support from caregivers or health professionals, physical support using pill organizers, and digital support via applications can all contribute to better medication management.^{17,22}

1.3. Informal Caregivers

The term informal caregiver refers to an unpaid family member, friend, or neighbor who provides care to someone with an acute or chronic condition.³² These caregivers assist with a wide range of tasks, including taking medications, tube feeding, ventilator care, bathing, and dressing.³² In 2018, about one in four Canadians aged 15 and older, totaling 7.8 million people, provided care to a family member or friend with a long-term health condition, a mental or physical disability, or age-related issues.¹³ Unpaid caregiving by family and friends has become an essential role in society.¹³ This form of caregiving helps reduce the social costs of institutionalization and health services. Furthermore, care recipients benefit by being able to stay at home and enjoy a better quality of life.¹³ Informal caregivers undertake a variety of tasks that vary in intensity and degree of physical and emotional demands.¹³ While most caregivers (64%) dedicated less than 10 hours per week to caregiving duties, 15% spent 10 to 19 hours, and 21% devoted 20 hours or more.¹³ In 2018, nearly half of all caregivers (47%) in Canada primarily provided care

for their parents or parents-in-law.¹³ This was the most common type of caregiving reported by family caregivers between the ages of 45 and 64.³³ Women represent the majority of informal caregivers, accounting for 57% of individuals aged 45 or older who provide care to older adults.³³ Family caregivers providing support to parents or parents-in-law typically spend about four hours per week on caregiving duties.¹³ Around 84% of this category of family caregivers who helped reported that the most common assistance provided was transportation, attending medical appointments or shopping.¹³ Additionally, house cleaning and meal preparation were also common tasks, reported by 64% of family caregivers.¹³ Approximately 13% of caregivers indicated they provided care to their spouse or partner.¹³ These caregivers tended to be older compared to those caring for parents or parents-in-law and dedicated approximately 14 hours per week to caregiving responsibilities.¹³ Other types of care recipients include neighbors, colleagues, or close friends (13%), grandparents (9%), or extended family members (10%).¹³ Caregivers providing care for these groups generally dedicate fewer hours to caregiving responsibilities.¹³ Caregiving can vary from a brief period of post-acute care following hospitalization to more than 40 years of continuous care for individuals with chronic medical conditions that require constant care. Informal caregivers typically devote 4.3 years to this role.³² Four out of ten caregivers spend five or more years providing support, and two out of ten have dedicated a decade or more to caring for their family members. This responsibility is continuous and demands constant attention.³² Many researchers in the caregiving field typically define family caregiving as assistance with instrumental activities of daily living (IADLs) and activities of daily living (ADLs).³² However, these concepts fail to fully demonstrate the stressful and complex nature of caregiving.³² For example, simply assisting with bathing does not demonstrate the challenges of bathing a resistant person.³² Similarly, helping with medication management overlooks the complexities of medication administration, particularly when dealing with multiple medications throughout the day, including inhalers, injections, eye drops, and crushed tablets.³² For example, making

treatment decisions on behalf of a family member or monitoring them for medication side effects are serious responsibilities that informal caregivers frequently find stressful and challenging.^{15,32} Informal caregivers often feel unprepared and lack sufficient knowledge to manage complex medication regimens as they receive minimum guidance from healthcare practitioners.^{15,32} Informal caregivers do not perform caregiving duties separate from other life roles and responsibilities.³⁴ A significant number of Canadian caregivers experience distress, including 26% of those providing care for older adults and 45% of those providing care for individuals with dementia.¹⁴ This distress leads to various negative outcomes, such as worsening physical and mental health, strained family and social relationships, as well as increased risk of mortality.¹⁴

1.4. Medication Management Challenges Among Informal Caregivers

There is a trend toward shifting long-term care from medical institutions to home-based or community-based settings.³⁵ As a result, informal caregivers are expected to be involved in managing the complex drug regimens of dependent older adults in the family, who may be taking various prescription and over-the-counter medications for multiple chronic conditions.^{18,36-38} Many caregivers may feel unprepared to perform the complex task of medication management as they find it difficult, stressful, and time-consuming.¹⁵ Medication administration hassles refer to the daily or minor irritants encountered by informal caregivers while assisting a dependent older family member with medication regimens.³⁸ Daily occurrences of medication administration hassles, if left unaddressed and allowed to accumulate over time, can have negative effects on the mental well-being of the caregivers, such as anxiety, depression, intolerance, and disturbed sleep. Additionally, this can potentially impact the health outcomes of the care recipient, as the informal caregivers may struggle to fulfill their role effectively due to increased caregiver burden and compassion fatigue.³⁹ In a study conducted by Travis et al., medication administration hassles were classified into three domains: scheduling logistics, administration procedures, and safety issues.

The most common medication administration hassles reported by family caregivers in each domain include working administration schedules into care routines, giving medication to an uncooperative or confused person, and recognizing side effects.³⁸ In a second study by Travis et al., this typology was further developed to include four domains which are information seeking and information sharing, scheduling logistics, safety issues and polypharmacy, resulting in the development of the Family Caregiver Medication Administration Hassles Scale (FCMAHS).³⁶ Informal caregivers commonly report medication administration to be the most challenging task compared to other responsibilities associated with medication management that contribute to caregiver burden.^{40,41} As a result, it is one of the most extensively studied aspects of medication management across the literature.^{38,42–48} Medication management is one of the most common medical tasks performed by informal caregivers.^{15,49} Examples include ordering medication from the pharmacy, administering medications to the patient at the correct dose and time, monitoring adverse drug reactions, making clinical judgments, maintaining regular communication with healthcare professionals, and keeping track of medication availability at home.^{15,49} In most cases, informal caregivers receive minimal or no medication administration training to perform the various components of medication management, such as deciding when to discontinue, hold, or alter a medication, ensuring medication adherence, and monitoring the safety and efficacy of the medication.^{38,49} Informal caregivers often learn how to perform medication management tasks on their own, which can be demanding and overwhelming.^{15,50,51} In addition, the tasks of medication management become more challenging, especially when medications change or the care recipient's medical condition changes, for example, being discharged from a hospital.^{15,50,51}

1.5. Compassion Fatigue and Satisfaction Among Informal Caregivers

Family caregivers may be driven to provide care to older adults out of love, a sense of responsibility, inner satisfaction, devotion, guilt, or social pressure.^{52 53,54} However, in the long-term, the burden of medication

management and the demanding nature of the caregiving process can lead to considerable stress on the family caregivers.⁵⁵ Informal caregivers may experience a state of burnout which can be experienced as physical, mental, and emotional exhaustion while caring for older adults. Stressed caregivers may feel tired, anxious, withdrawn and depressed which can negatively impact the psychological, physical, financial, and social aspects of their lives.^{54,56} Many studies showed that informal caregivers bear a substantial burden when caring for their loved ones. Informal caregiver burden refers to the load or the strain that family caregivers experience during the caregiving process for a disabled, chronically ill or an old adult in the family.⁵⁷ Nevertheless, while numerous research studies have explored caregiver burden and strategies to alleviate it, most of these studies predominantly emphasize the negative consequences of the caregiving journey solely.⁵⁸⁻⁶⁰

Despite the extensive study of caregiver burden, the concept lacks clarity as it focuses only on the negative aspects of the caregiving process.⁵⁸⁻⁶⁰ This narrow perspective overlooks the positive elements, leading to an incomplete understanding of the caregiving process of informal caregivers.⁵⁸⁻⁶⁰ The caregiving process includes some positive aspects, such as improved patient prognosis, personal satisfaction, and the joy derived from assisting older adults in the family.^{60,61} In 1992, the concept of compassion fatigue was introduced in the healthcare sector as a distinct form of burnout, particularly experienced by those in caring professions.^{54,62} Researchers have provided various definitions for compassion fatigue; however, the most widely accepted definition is that it is a negative outcome of providing care to individuals in need.^{55,62-64} Compassion fatigue results in caregivers experiencing symptoms of depression, anger, and apathy and can be described as a state of physical, psychological, or social exhaustion that arises when caregivers are extensively exposed to compassion stress or become overly involved in the emotions and suffering of care recipients following traumatic events.^{54,55,65} Initially, the concept of compassion fatigue was exclusively applied to professional care providers such as physicians, nurses, psychologists, and

social workers.^{55,66–68} However, it was noticed that same concept applies to family caregivers, as they experienced many of the symptoms of compassion fatigue.⁵⁵ Furthermore, informal caregivers are more prone to report increased caregiving burden due to medication management tasks and may face a heightened risk of developing compassion fatigue.^{54,55,63,69} Informal caregivers experiencing compassion fatigue face an increased likelihood of discontinuing the caregiving relationship with the care recipient, either by relocating them to nursing homes or seeking another family member to take on the responsibility.^{70,71} Moreover, family caregivers who develop compassion fatigue may neglect the care recipient, increasing the risk of a deteriorating prognosis and an elevated likelihood of hospitalization due to negligence.^{55,70,71} A summary of the development of compassion fatigue and its outcomes is illustrated in Figure 1.

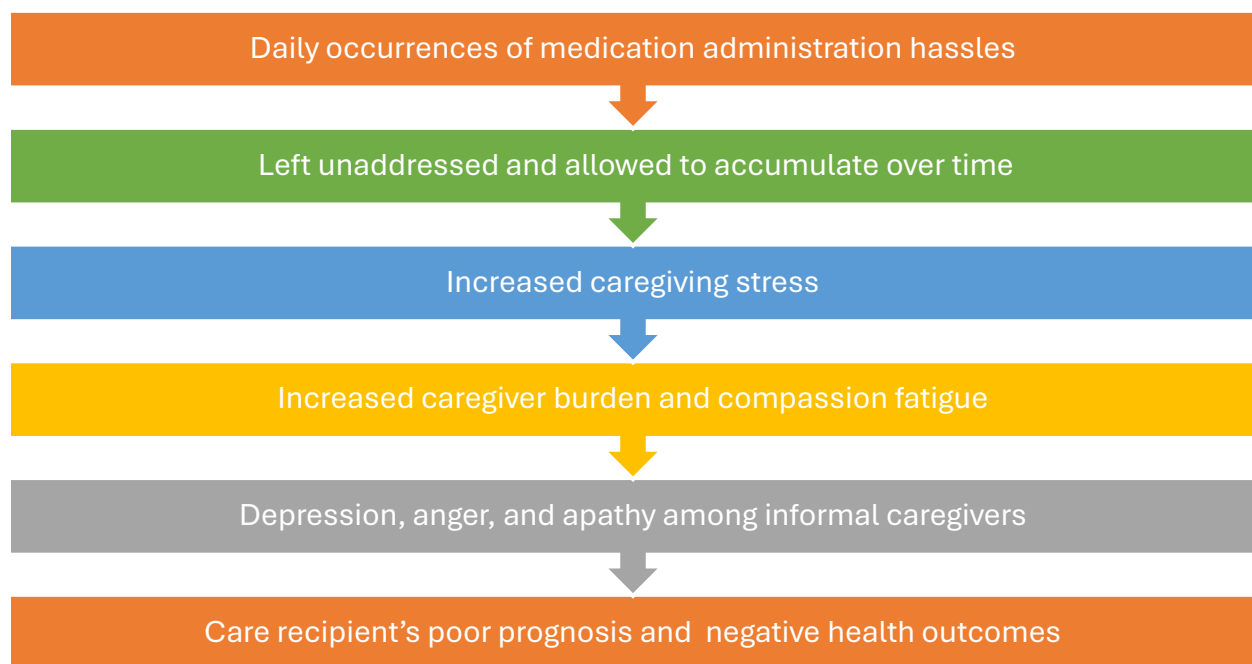


Figure 1: Illustrates the development of compassion fatigue and its outcomes

According to the available literature, patients receiving care at home face lower risks of morbidity and mortality compared to those in medical facilities.⁷² Therefore, enhancing the quality of life for informal caregivers through support in medication management tasks is crucial for their mental and emotional

well-being and the patient's prognosis.⁵⁵ The second type of compassion that informal caregivers experience while caring for older adults is compassion satisfaction.⁷³ Compassion satisfaction refers to the feeling of pleasure that comes from providing care and assistance to those in need.⁷⁴ Compassion satisfaction is often positively related to the ability to adapt, learn, and grow from challenging experiences in caregiving.⁵⁴ According to current literature, compassion fatigue and compassion satisfaction can co-exist, and informal caregivers may experience both simultaneously.⁷³ The critical factor is which feeling dominates the other; an increase in compassion fatigue might reduce the informal caregiver's capacity to experience compassion satisfaction.^{73,75} Compassion fatigue, burnout, and compassion satisfaction are three interconnected concepts.^{54,76} The caregiving stress process often begins with compassion fatigue, which develops after prolonged exposure to compassion stress, coping with the suffering of others for an extended period, and maintaining an ongoing sense of responsibility toward the care recipient.⁵⁶ This, in turn, results in traumatic memories, depression, and anxiety, which can lead to burnout. Burnout occurs when this stress builds up over time and is characterized by emotional exhaustion, a feeling of being less connected to the care recipient, and low self-accomplishment.^{54,56,77} Burnout can occur alone or in combination with compassion fatigue. In contrast, compassion satisfaction is the positive feeling that arises from being able to help others.^{78,79} Understanding why family caregivers continue to provide care despite these challenges requires consideration of how caregiving roles are accepted and sustained over time.⁸⁰ Acceptance of caregiving roles by informal family caregivers is influenced by commitment to family relationships, cultural expectations, and feelings of gratitude toward older family members.⁸⁰ The Acceptance Theory of Family Caregiving explains how family caregivers come to accept their role and how this acceptance affects how they adjust their behavior and manage caregiving responsibilities over time.⁸⁰ The theory suggests that cultural expectations shape whether older adults expect their children to care for them as they age, and that accepting the caregiving role also means accepting its financial, physical,

spiritual, and psychological impacts.⁸⁰ Family members who accept the possibility of health decline in older adults are more prepared to take on caregiving responsibilities effectively.⁸⁰ Throughout the caregiving process, access to resources plays an important role in helping caregivers manage their responsibilities.⁸⁰ Overall, the theory highlights that acceptance of the caregiving role influences caregiving outcomes, including the quality of care provided to older adults, the prevention of caregiver burden, and the development of strong family and social relationships.⁸⁰ Given the complex and multidimensional nature of caregiving outcomes described by this theory, appropriate measurement tools are needed to capture both the demands and emotional experiences of family caregivers. In an integrative review by Domeisen Benedetti F et al., several self-assessment instruments (SAIs) were identified that address different aspects of caregiver burden.⁸¹ Some instruments measure objective burden, such as the time and intensity involved in caregiving tasks, while others focus on subjective burden, including psychological stress and other caregiving-related effects.⁸¹ The instruments in which 50% or more of the items focused on psychological stress included the Burden Scale for Family Caregivers (BSFC), the Caregiver Self-Assessment Questionnaire (CSAQ), the Caregiving Health Engagement Scale (CHE-s), the Family Caregiver Distress Assessment Tool, and the Caregiving Appraisal Scale (CAS).⁸¹ Other SAIs measured psychological stress in less than 50% of items and also assessed socio-economic, physical, and/or time-related stress.⁸¹ These included the Caregiver Strain Index (CSI), the Zarit Burden Interview (ZBI), and the Caregiver Burden Inventory (CBI). All tools capture caregiving as a multidimensional process, considering time-related, developmental, social, physical, and emotional aspects of the caregiving experience.⁸¹ However, none of these instruments measure compassion fatigue and compassion satisfaction, which capture both the negative and positive aspects of caregiving. Therefore, the Professional Quality of Life Scale was selected for use in study 1 of this thesis. This scale is described in detail in Chapter 2.^{82,83} According to the literature, technology-based interventions can help reduce

caregiver burden, anxiety, and depression, and support caregivers' access to self-care resources.^{84,85} These interventions may improve caregivers' coping skills, quality of life, communication, relationships with care recipients, and support overall well-being for both caregivers and care recipients.^{84,85}

1.6. Support Available to Informal Caregivers for Medication Management

1.6.1 Technology and Medication Management

Digital health can be defined as “the application of information and communication technologies in the field of medicine and other health-related professions to manage disease conditions, and health risks and encourage wellness.”⁸⁴ This broad concept includes telehealth, mobile health, wearable devices, automated medication dispensers, health information systems, and telemedicine.^{84–86} Two systematic reviews of digital health technologies found evidence of a positive impact on caregivers' support and well-being.^{84,87} Chi and Demiris (2014), conducted a systematic review to evaluate the effectiveness of telehealth interventions in supporting informal caregivers in which they examined various technologies such as web-based platforms, video, telephone-based systems, and telemetry.⁸⁷ The review found that more than 95% of the studies showed meaningful improvements in caregiver outcomes, and caregivers reported high levels of comfort and satisfaction with telehealth.⁸⁴

Zhai et al. conducted an updated systematic review to examine interventions using digital health tools to support family caregivers.⁸⁴ This review builds on earlier work by Chi and Demiris (2014).⁸⁷ The updated review found that digitally enhanced health interventions were effective in providing high-quality support to caregivers, leading to improvements in psychological well-being, caregiving skills, self-efficacy, social support, quality of life, and coping strategies.⁸⁴ The three domains of digital health technologies identified in the updated review were telemedicine, telehealth, and mobile health (mHealth).⁸⁴

Telemedicine involves real-time, two-way communication between healthcare professionals, counselors or educators and patients or clients.⁸⁴ Telehealth consists of the use of digital and remote

technologies to provide self-care support, education, medical care, and health information.⁸⁴ It was grouped into four types: static web resources that provide the same information to all users; interactive web resources that require active user engagement; web resources with expert human interaction, commonly delivered through learning management systems (LMS); and web resources with non expert interaction, such as online discussion boards or peer support groups where users share information and support.⁸⁴ Mobile health (mHealth) involves delivering health services, information, and data collection through mobile devices such as smartphones, tablets, or personal digital assistants.⁸⁴ The purposes of interventions using digital health tools were classified into five categories, following the classification developed by Chi and Demiris.^{84,87} Education was the most common purpose, accounting for 78% of interventions, and focused on helping caregivers understand patients' conditions, learn self-care strategies, build positive relationships with patients, and become familiar with healthcare procedures. Education was delivered through interactive web programs, multimedia tools, learning management systems (LMS), and videoconferencing.⁸⁴ Real-time communication was another purpose, allowing caregivers to receive information to support decision-making, ask questions, and obtain self-care advice through live interactions with coordinators, coaches, or therapists via instant messaging, videoconferencing, and discussion boards.⁸⁴ Data collection and monitoring interventions focused on continuous tracking, most commonly through Assistive Technology and Telecare (ATT), which was often used with older adults with dementia living independently.⁸⁴ Psychotherapy interventions were primarily based on cognitive behavioral therapy (CBT) and aimed to reduce caregivers' stress and improve problem-solving and coping skills, often delivered through interactive or static websites with coaching feedback, peer interaction, or mobile health tools.⁸⁴ Finally, connection and support interventions focused on helping caregivers to connect with others in similar situations, share information, and receive

professional or peer support, mainly through social media platforms and secure online discussion forums.⁸⁴

The rapid advancement of technology, especially in the healthcare field, has made it possible to replace traditional tools and strategies informal caregivers use, such as pill organizers, checklists, medication lists, calendars, and reminder systems, to assist with medication administration.^{15,88} Integrating innovative technology, such as automated medication dispensers, could potentially alleviate the challenges informal caregivers face.⁸⁹ Automated medication dispensers are devices that organize, schedule, and deliver patient medication with the touch of a screen.⁹⁰ Automated medication dispensers are designed to streamline the medication management process. For instance, pharmacists prepackage medicines and arrange them in cartridges for caregivers at home to load into the device. The device aims to deliver medications at specified times and assist with accurate dosing. This could potentially reduce the workload for informal caregivers by addressing tasks such as ordering, scheduling, administering medications, and managing refills. However, the actual impact on caregivers' responsibilities remains to be fully understood.^{91,92} Additionally, automated medication dispensers feature real-time tracking and remote monitoring, which may offer greater flexibility for caregivers. For example, caregivers may not need to be physically present to check on adherence. These devices are intended to provide information on whether medications have been taken on time or missed, potentially easing the stress of manual tracking.⁹⁰ Furthermore, automated medication dispensers may help manage the complexities of coordinating multiple medications and aligning medication schedules with those of care recipients.⁹⁰

The existing literature revealed only two studies investigating the impact of automated medication dispensers on caregiver burden.^{91,93} The first pilot study, conducted by our lab, showed a notable reduction in caregiver burden among 11 participants after using an automated medication dispenser for 6 months.

⁹¹ Caregiver burden scores decreased from an average of 7/10 at baseline (SD 2.6; range 1–10) to 3/10 after product use (SD 2.8; range 0–8), a statistically significant difference ($P < .001$; CI 2.11–5.98).⁹¹ However, this finding is exploratory, as the study was not designed to specifically examine caregiver burden and relied on a single visual analog scale question, which limits insight into the specific caregiving challenges related to medication management.⁹¹ Because of these promising results, it was recommended that future research examine the impact of the AMD on caregiver burden using a validated scale.⁹¹ The second study was a case report describing the experiences of four older adults with Alzheimer’s disease and other comorbidities who have used automated medication dispensers for 3 to 4.5 years, along with their caregivers, who reported a reduction in caregiver burden when the device was used.⁹³ Nevertheless, this case report has limitations, including a small sample size of 4 participants. Additionally, the scale used to measure caregiver burden was developed by the authors and not validated, raising concerns about its reliability.⁹³ Together, these findings highlighted the need for a more focused evaluation of medication-related caregiver burden, which provided the rationale for conducting our pilot study to explore this aspect in greater depth. In a systematic review by Melissa Gench and Mouna J. Sawan et al., several tools were identified to evaluate caregivers' medication management capacity for people with dementia.⁹⁴ These included the Family Caregiver Medication Administration Hassles Scale (FCMAHS), which measures caregiver burden in all areas of medication management; the Medication Risk Questionnaire (MRQ8) and the Medication Management Instrument for Deficiencies in the Elderly (MedMaIDE), which identify challenges related to medication administration, review, and supply; the Medication Deficiency Checklist (MDC), which identifies caregiver deficiencies in medication administration and supply; the Caregiver Confidence in Sign and Symptom Management (CCSM) Scale, which evaluates caregiver confidence in medication selection, administration, review, and monitoring; the Medication Complexity Index (MCI), which identifies complexities related to medication administration; and the Medication-Saving Behaviours

Scale (MSB), which identifies problems related to medication administration.⁹⁴ Among these tools, the FCMAHS is the most comprehensive measure of caregiver burden related to medication management.³⁸ For this reason, it was selected for use in Study 1 of this thesis. This scale is described in more detail in Chapter 2.

1.6.2 Medication Management Training and Resources to Support Informal Caregivers

Family caregivers rely on simple, routine-based tools to manage medications at home. The literature shows that caregivers tend to prefer simple, traditional methods such as household items, handwritten notes, and other low-tech strategies over digital tools.⁹⁵ Although digital medication adherence technologies may help in some cases, the literature notes that these tools can unintentionally increase caregiver stress because they require additional learning, monitoring, and adaptation.^{85,95} Several interventions have attempted to support family caregivers with medication management, but the evidence shows mixed results.⁹⁶ Lingler and colleagues developed a multicomponent training program delivered over 2–3 home visits plus 16 weeks of telephone follow-up.⁹⁶ Caregivers found the training helpful and relevant, but the intervention did not produce significant improvements on the Medication Management Instrument for Deficiencies in the Elderly ($p = 0.093$) or the Med Deficiency Checklist ($p = 0.292$).⁹⁶ This indicates limited measurable impact on medication knowledge, administration skills, or error reduction, areas that are well-recognized challenges for family caregivers.^{15,36,96} Similarly, Yu and colleagues evaluated a 16-week intervention called Health and Social Collaborative Case Management (HSC-CM), which included a caregiver needs assessment and individualized referrals to workshops such as medication management workshops. This study showed an improvement in caregiver burden in the intervention group compared with usual care as measured by the Caregiver Burden Inventory ($p = 0.03$).⁹⁶ Although promising, these types of programs often rely on structured education, occur within clinical or quasi-clinical settings, and may be difficult to scale or sustain widely across diverse caregiving

populations. Together, these studies highlight important gaps in existing supports. This is where toolkits may offer a more accessible alternative.^{97,98} The concept of a “toolkit,” introduced in the 1980s, refers to a set of educational materials packaged to support specific tasks or learning objectives.⁹⁷ In healthcare, toolkits can include videos, instruction sheets, checklists, templates, and posters, available in both physical and digital formats.⁹⁷ They are designed to support a broad range of users, including patients, practitioners, organizations, policymakers, and the public, and are widely used as a knowledge translation (KT) strategy.⁹⁷ According to a systematic review by Yamada et al. (2015), toolkits are considered practical tools for translating evidence into practice.⁹⁸ A recent example is a co-designed medication management toolkit created to improve medication-related health literacy among people with dementia and their caregivers during hospitalization and discharge, a period associated with high medication burden and fragmented communication.⁹⁹ This study demonstrates how co-designed resources can address gaps in healthcare tools and improve support for caregivers.⁹⁹ Similarly, the present study aims to address the gap in supporting family caregivers with medication management at home. By developing an accessible, home-based medication management toolkit, this work seeks to provide structured, practical guidance tailored to the real-world challenges caregivers face.

Chapter 2

2. Research Project- Study 1

2.1. Objectives

1. To examine the impact of the use of an automated medication dispenser on compassion fatigue, satisfaction, and medication administration hassles on informal caregivers

2.2. Study Design

This study used a mixed-method approach, in which qualitative and quantitative research techniques are combined to enhance and solidify the study findings.^{100,101} According to Creswell and Clark, there are three basic types of mixed-method study designs: convergent parallel design, explanatory sequential design, and exploratory sequential design (Figure 2).¹⁰² This prospective pilot study used a pre-post convergent parallel mixed-method approach, combining both qualitative and quantitative data collection and analysis. This approach allows for a thorough comparison of findings to gain a comprehensive understanding of the study results.

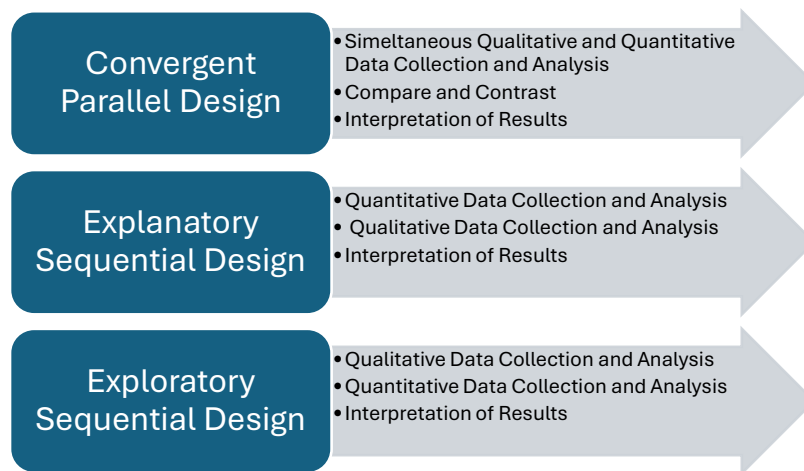


Figure 2: Types of basic mixed-methods research designs

2.3. Ethical Consideration

The University of Waterloo Research Ethics Board approved this study. Informed consent was obtained prior to data collection from participants.

2.4. Study Setting

This study was conducted in person at the University of Waterloo and online via video chat on Microsoft Teams version 25255 with study participants who could not come in person.

2.5. Sample Size

Purposive and convenience sampling methods were used to recruit caregivers and care recipients for this study. Convenience sampling is often used in research where the focus is on obtaining an initial understanding of a phenomenon rather than generalizing findings to a larger population.¹⁰³ We aimed to recruit 30 pairs of caregivers and their care recipients.

2.6. Eligibility Criteria of Participants

2.6.1. Inclusion Criteria for Informal Caregivers

1. Ability to speak and read English
2. Residing in Ontario
3. Unpaid caregiver
4. Has been providing support with at least one medication management task at least once per week for at least 6 months

2.6.2. Exclusion Criteria for Informal Caregivers

Not willing to sign the informed consent, and not living in Ontario

2.6.3. Inclusion Criteria for Care-recipients

1. 65 years of age or older
2. Willing to use the automated medication dispenser

3. Has been prescribed 5 medications or more and is living in Ontario

2.6.4. Exclusion Criteria for Care-recipients

1. Not willing to sign the informed consent
2. Receiving support with medication management tasks from a paid caregiver
3. Self-declared dementia diagnosis

2.7. Study Procedures

2.7.1 Screening and Recruitment

A screening questionnaire was used to assess potential participants' eligibility according to the study's inclusion criteria. The screening process was conducted by phone or via an online meeting at the convenience of the study participants. The participants were recruited from the different sources listed below:

1. Potential clients of the industrial partner
2. Participants who participated in previous studies and expressed interest in being contacted again for future research.
3. Retirement homes

2.7.2. Informed Consent

Pairs of informal caregivers and their older adult care recipients who met the eligibility criteria of the study were asked to sign informed consent before data collection.

2.7.3. Data Collection

2.7.3.1. Pre-Intervention Stage

Eligible informal caregivers and their care recipients met with the researcher at baseline before using the automated medication dispenser. During this initial meeting, the researcher collected demographic information about the caregivers and their older adult care recipients using demographic data collection

forms. Additionally, caregivers were asked to complete the Professional Quality of Life Scale (ProQoL) and the Family Caregiver Medication Administration Hassles Scale (FCMAHS), (Appendix A).^{38,82,83} The study procedures summary is in Figure 3. The Professional Quality of Life Scale (ProQoL) is an assessment scale used to measure the positive and negative impacts of caregiving on caregivers, especially those who have experienced traumatic stress.^{82,83} The ProQoL is a questionnaire that consists of 30 items which is divided into three subscales that measure compassion satisfaction (items 3, 6, 12, 16, 18, 20, 22, 24, 27, 30), burnout (items 1, 4, 8, 10, 15, 17, 19, 21, 26, 29), and secondary traumatic stress (items 2, 5, 7, 9, 11, 13, 14, 23, 25, 28). Each subscale consists of 10 items, and each item is rated on a 5-point scale (1 = never to 5 = very often).^{82,83} Items 1, 4, 15, 17, and 29 should be reverse scored according to the ProQoL manual instructions.⁸³ This is a validated scale with Cronbach's alpha of 0.90 on compassion satisfaction, 0.78 on the caregiver's burnout scale, and 0.82 on the secondary traumatic stress scale, thus indicating good reliability.^{82,83} High scores (42 or more) on compassion satisfaction and low scores (22 or less) on burnout and secondary traumatic stress are generally interpreted as indicating optimal professional quality of life; any individual typically scores in the moderate range for compassion satisfaction and burnout, reflecting a moderate professional quality of life.^{82,83} However, moderate to high scores on secondary traumatic stress suggest that the individual may benefit from additional support.^{82,83} The interpretation of the ProQoL scores is presented in Table 1.

Table 1: Interpretation of the ProQol scores

Subscales on the Professional Quality of Life Scale	Raw Score	Level
Compassion satisfaction	22 or less	Low
	Between 23 and 41	Moderate

	42 or more	High
Burnout	22 or less	Low
	Between 23 and 41	Moderate
	42 or more	High
Secondary traumatic stress	22 or less	Low
	Between 23 and 41	Moderate
	42 or more	High

The Family Caregiver Medication Administration Hassles Scale (FCMAHS) is a multidimensional and convenient measurement tool used to assess the daily irritants that informal caregivers encounter associated with medication administration. These minor irritants could lead to long-term stress and increased caregiver burden.³⁸ The FCMAHS includes four subscales for medication administration hassles: information seeking and information sharing, scheduling logistics, safety issues, and polypharmacy.³⁸ The information-seeking and information-sharing items focus on the various communication aspects of caregiving, such as speaking with the doctor, knowing what questions to ask, and understanding instructions and information.³⁸ The scheduling logistics subscale assesses the challenges of fitting medication administration into the daily routines of the family caregiver.³⁸ The safety issues subscale addresses concerns like admitting mistakes, identifying side effects, and knowing what actions to take if dosage or administration changes are needed.³⁸ Lastly, the polypharmacy subscale includes items related to keeping prescriptions filled, planning for keeping prescriptions filled over the weekends and holidays and managing prescriptions from multiple doctors.³⁸ The FCMAHS is a validated

scale consisting of 24 items.³⁸ Items are rated on a scale from 0 (not a hassle) to 5 (one of the worst of all hassles). Information seeking and information sharing (range 0–45), scheduling logistics (range 0–35), safety issues (range 0–25), and polypharmacy (range 0–15).^{38,104} The FCMAHS is easily scored, providing both subscale scores and an overall score for assessing medication administration hassles.³⁸ A total score is calculated by summing all items, resulting in a range of 0 to 120.^{38,104} Higher scores on both the subscales and the overall scale indicate more significant levels of perceived hassle. Also, the average scores of the items that comprise each subscale can be calculated, and higher scores represent greater hassle intensity.³⁸ Moreover, the FCMAHS has a Cronbach's alpha score of 0.95, indicating that the scale has a very high internal consistency and would effectively measure the underlying construct it intended to capture.³⁸ In addition, the FCMAHS has an overall scale test-retest reliability of 0.84, demonstrating that the scale produces consistent and reliable results over time.³⁸

Prior to and following the end of the study, participants were also invited to participate in semi-structured interviews. Look et al. informed the semi-structured interview guide, which classified medication management activities into two main groups: direct activities, which involve physically handling medications, such as preparing pill organizers and ordering or picking up medications; and indirect activities, which require greater cognitive effort, such as organizing medications, communicating with healthcare providers, and making treatment decisions.¹⁵ In addition, the approaches used by family caregivers to support medication management were categorized into tools, such as pill boxes, calendars, and medication lists, and strategies, such as verbal reminders and labeling pill boxes or other medication containers.¹⁵ These approaches could be adapted or adjusted to fit the specific caregiving situation.¹⁵ The interview covered a range of topics, including the type, nature, and length of the relationship between the caregiver and the care recipient, the non-medication-related tasks performed, the caregiver's role within the caregiving process, daily medication management tasks and associated challenges, coping strategies

and tools used, and the satisfaction of the caregivers with their caregiving role. Through this interview, the researcher gathered valuable insights into caregivers' experiences, including their challenges, strategies, and overall satisfaction with caregiving. The semi-structured interview sessions were recorded, and the interview data were transcribed using Otter AI Version 3.101.0 and analyzed using thematic analysis as described by Braun and Clarke.¹⁰⁵

2.7.4. Intervention Stage

The intervention involved integrating the automated medication dispenser into the homes of older adults receiving care. This included onboarding (instructions for using the AMD and device setup) and transferring medications to the AMD-certified pharmacy, which supplied the medications and pharmacy services to participants for the duration of the 3-month study. Informal caregivers completed the ProQoL and the FCMAHS two weeks after the AMD was integrated into the care recipient's home.

2.7.5. Post Intervention Stage

At the end of the study, after 3 months of using the spencer™, informal caregivers were contacted to complete the ProQoL and the FCMAHS. Additionally, they were invited to participate in a final semi-structured interview. This interview was designed to provide the research team with in-depth insights into the informal caregivers' experiences with using the AMD (spencer™). Specifically, the interview explored how the automated medication dispenser has influenced tasks previously managed manually, the satisfaction derived from using the device, and any observed impacts on the caregiver's relationship with the care recipient. Through this process, the researcher sought to understand the different effects of AMD on caregivers' experiences, emotions, and relationships throughout the caregiving journey.

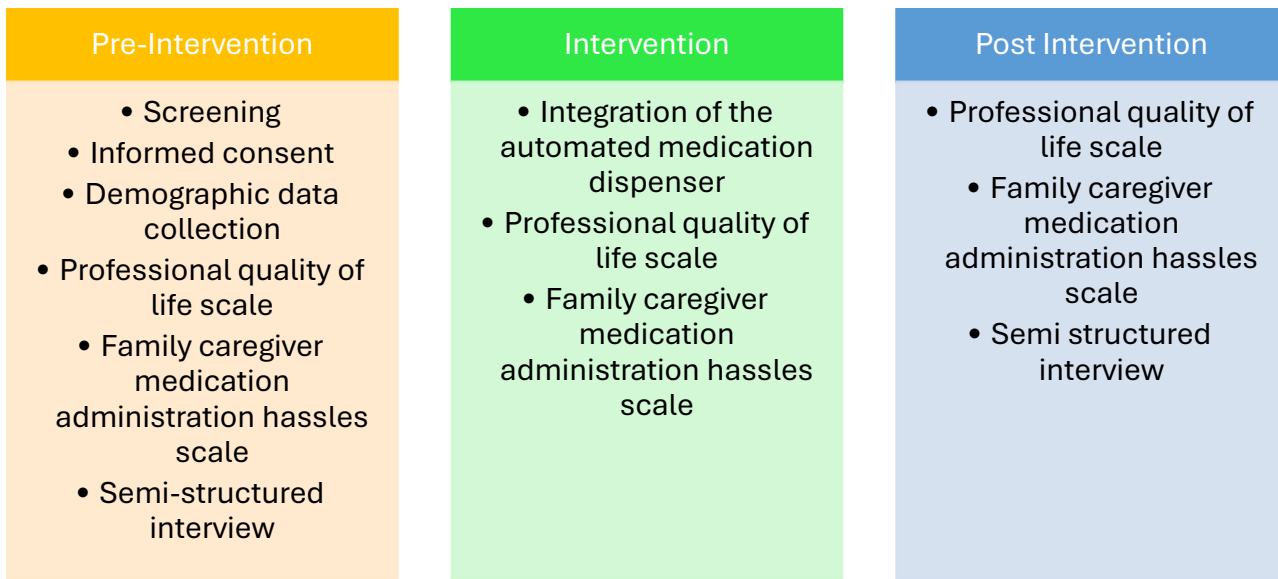


Figure 3: Summary of the procedures of study 1

2.8. Data Analysis

2.8.1. Quantitative Data Analysis

Descriptive statistics were computed using means, standard deviation, medians, and interquartile ranges to summarize sample characteristics and outcomes. These statistics were calculated for the (ProQoL) and its three subscales, compassion satisfaction, burnout, and secondary traumatic stress, as well as for the (FCMAHS), including its subscales: information seeking and information sharing, scheduling logistics, safety issues, and polypharmacy, and the total scale score. Missing data were handled using the proration method, where the participant's own mean score on the subscale with the missing item was used to replace the missing value.¹⁰⁶ Only one participant had missing data: one item on subscale 4 of the FCMAHS at baseline, and one item on the secondary traumatic stress subscale of the ProQoL at baseline. For this participant, the corresponding items at the 2-week and 3-month time points were complete. All other participants had complete data with no missing values. To assess changes across the three time points: baseline, 2 weeks, and end of study, the Friedman test was used for each ProQoL and FCMAHS subscale, as well as for the FCMAHS total score. In addition, the Wilcoxon

signed-rank tests compared baseline and end-of-study scores for ProQoL and FCMAHS subscales and the total FCMAHS score, excluding the 2-week time point.

2.8.2. Qualitative Data Analysis

The semi-structured interview sessions were recorded, and the interview data were transcribed and analyzed using thematic analysis. The semi-structured interview guide is available in Appendix B. Verbatim transcripts of the audio recordings were prepared using Otter AI Version 3.101.0 to facilitate thematic analysis, and all interview transcripts were cross-checked against the audio recordings for accuracy. The data analysis proceeded through several steps, including step 1: become familiar with the data; step 2: generate initial codes; step 3: search for themes; step 4: review themes; step 5: define themes; and step 6: write up. Two researchers, KG and BB, independently read the transcripts multiple times to familiarize themselves with the content. The pre-intervention interviews were independently coded by both KG and BB using an inductive approach. After coding each transcript, the researchers met to compare codes and discuss any discrepancies until agreement was reached. An inter-coder reliability of 80% was achieved after the two researchers independently coded four pre-intervention interviews, after which KG coded the remaining three. KG and BB then met to agree on the grouping of codes, creation of themes and subthemes, and the definitions of these themes. For the post-intervention interviews, KG and BB again independently coded the transcripts using an inductive approach until they reached the desired inter-coder reliability of 80%. KG then coded the remaining four transcripts. The researchers met to discuss the grouping of codes, creation of themes and subthemes, and the definitions of these themes. Finally, the researchers met with the principal investigator to review the arrangement of themes and subthemes, confirm definitions, and agree on the final codebook for both the pre-intervention and post-intervention data. A summary of the data analysis methods is illustrated in Figure 4.

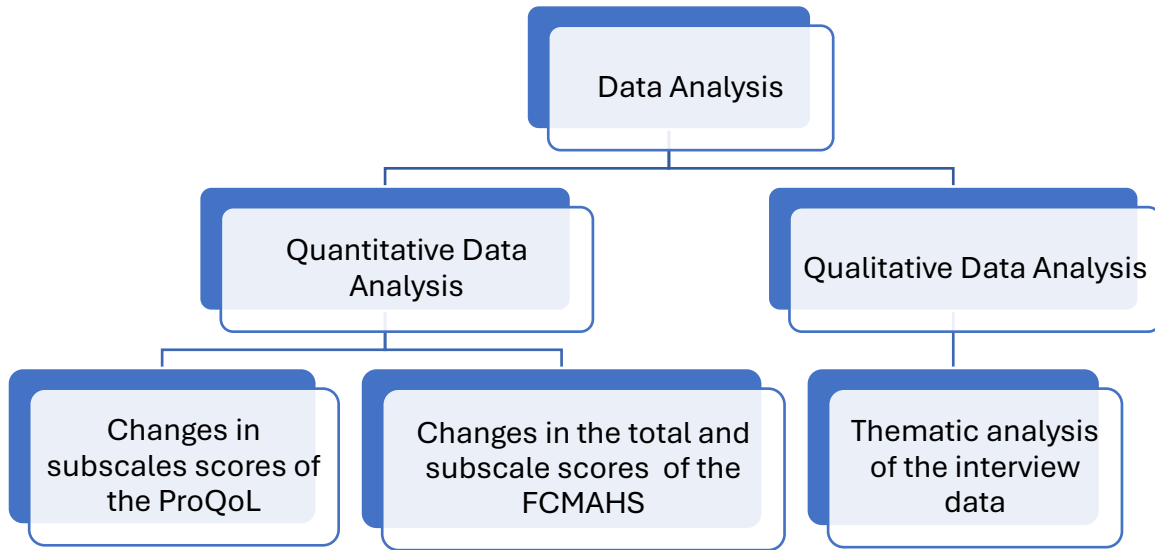


Figure 4: Summary of data analysis procedure

2.9. Results

2.9.1. Quantitative Results

2.9.1.1. Descriptive Statistics

A convenience sample of 7 pairs of older adult care recipients and their informal caregivers was recruited to participate in the study. However, in one case, the secondary informal caregiver of a care recipient participated in both the pre- and post-intervention interviews alongside the primary informal caregiver. The median age (Q1-Q3) of informal caregivers was 63 years (57-75), and the median age (Q1-Q3) of the care recipients was 81 years (70-92). Most informal caregivers (57%) had completed 12–16 years of education, lived with the care recipient (71%), and were spouses (57%). All participants had known the care recipient for more than 24 months, and the majority (86%) had been providing care for over 24 months. More than half obtained medications from the pharmacy monthly (57%), never directly administered medications (57%), and made monthly decisions about dosing changes or new medications (57%). The most common way to prompt the care recipient to take medications was daily reminders (43%). Also, 43% of the informal caregivers were involved in weekly medication organization. Non-

medication management activities included monthly driving to medical appointments (57%). Most of the care recipients were males (57%), had completed 12–16 years of education (86%), and lived in their own home (86%). The majority lived with someone (71%), most often a spouse (57%). All participants required assistance with medication management (100%) and were taking medications, with a mean of 11.14 (SD = $\pm$ 4.41) prescriptions and over-the-counter medications. Table 2 shows detailed demographic information for the caregivers, and Table 3 shows the same for the care recipients.

Table 2: Caregivers' demographics

Variable	Category	N (%)	Median age (Q1-Q2)
Age	-	7 (100%)	63 years (57-75)
Sex	Male	0 (0%)	-
	Female	7 (100%)	-
Occupation	Employed	2 (29%)	-
	Retired	4 (57%)	-
	Home maker	1 (14%)	-
Education	12 to 16 years	4 (57%)	-
	16 or years	3 (43%)	-
Living with the care recipient	No	2 (29%)	-
	Yes	5 (71%)	-
Relationship to care recipient	Spouse	4 (57%)	-
	Child	3 (43%)	-
Duration of the relationship	More than 24 months	7 (100%)	-
Duration of caregiving	More than 24 months	6 (86%)	-

	6-12 months	1 (14%)	-
Frequency of obtaining medication from the pharmacy	Every 2 months	1 (14%)	-
	Monthly	4 (57%)	-
	Biweekly	2 (29%)	-
Frequency of reminding the care recipient to take medications	Daily	3 (43%)	-
	Multiple times a day	1 (14%)	-
	Weekly	2 (29%)	-
	Biweekly	1 (14%)	-
Frequency of directly administering medications	Never	4 (57%)	-
	less than 20% of doses	3 (43%)	-
Frequency of medication organization	Weekly	3 (43%)	-
	Other: Occasionally	1 (14%)	-
	Never	2 (29%)	-
	Daily	1 (14%)	-
Frequency of reviewing and/or completing health-related documents	Monthly	5 (71%)	-
	Daily	1 (14%)	

	Never	1 (14%)	
Frequency of scheduling health-related appointments	Never	1 (14%)	-
	Monthly	3 (43%)	-
	Other: when needed	2 (29%)	-
	Other: every 3 months	1 (14%)	-
Frequency of attending medical appointments	Monthly	5 (71%)	-
	Other: as needed	2 (29%)	-
Frequency of driving care recipients to medical appointments	Monthly	4 (57%)	-
	Daily	1(14%)	-
	Never	1(14%)	-
	Other: as needed	1(14%)	-
Frequency of deciding on dosing changes or new medication	Monthly	4 (57%)	-
	Other: not applicable	2 (29%)	-
	Other: when needed	1 (14%)	-

Table 3: Care recipients' demographics

Variable	Category	N (%)	Median (Q1-Q3)	Mean ± SD
Age	-	7 (100%)	81 (70-92)	-
Sex	Male	4 (57%)	-	-
	Female	3 (43%)	-	-
Education	12 to 16 years	6 (86%)	-	-
	Less than 12 years	1 (14%)	-	-
Residence	Own home	6 (86%)	-	-
	Retirement home	1(14%)	-	-
Living situation	Alone	2 (29%)	-	-
	Living with someone	5 (71%)	-	-
Living with someone	Spouse	4 (57%)	-	-
	Child	1 (14%)	-	-
	Not applicable	2 (29%)	-	-
Needs assistance with medication management	Yes	7 (100%)	-	-
Total number of medications	-	-	-	11.14 ± 4.41

2.9.1.2. Changes in Scores on the FCMAHS

The results showed no significant change in scores across the three time points when the Friedman test was applied to each subscale and to the total score of the FCMAHS. However, when the Wilcoxon signed-

rank test was applied to the four FCMAHS subscales and the total score from baseline to 3 months, a significant reduction in the total score was observed. The median scores and the first and third quartiles (Q1 and Q3) are presented in Table 4 for the four subscales, along with total scores for the three time points. Bonferroni correction was applied to the four subscales, resulting in an adjusted significance threshold of $\alpha = 0.0125$, but not to the total score, as it was the primary outcome. The Bonferroni correction was applied to control the family-wise error rate, given the increased risk of Type I error when multiple comparisons are conducted across the FCMAHS subscales.¹⁰⁷ Because the study had a predetermined primary outcome, which is the total FCMAHS score, no Bonferroni adjustment was applied to this measure.¹⁰⁷ The correction was applied only to the exploratory outcomes, which consisted of the four individual subscales.¹⁰⁷ For subscale 1, the scores declined from 11 (8–13) at baseline to 5 (3–11.5) at 2 weeks, then increased slightly to 7 (5.5–10) at 3 months. Neither the overall change (Friedman $p = 0.3172$) nor the baseline-to-3-month difference (Wilcoxon $p = 0.1275$) reached statistical significance when compared to the Bonferroni-adjusted significance threshold of $\alpha = 0.0125$. The scores for subscale 2 decreased from 9 (8–14) to 3 (2–13) at 2 weeks, then increased to 6 (1–6.5) at 3 months. The change approached significance but did not meet the Bonferroni-adjusted threshold of $\alpha = 0.0125$ (Friedman $p = 0.1627$; Wilcoxon $p = 0.0625$). On the other hand, the scores for subscale 3 declined steadily from 6 (4–7) at baseline to 4 (0.5–6.5) at 2 weeks and 3 (1–3.5) at 3 months. The reduction was statistically significant in both the overall test (Friedman $p = 0.0418$) and the baseline-to-3-month comparison (Wilcoxon $p = 0.0340$), although significance was lost after Bonferroni adjustment (adjusted significance threshold = 0.0125). The scores on subscale 4 decreased from 3 (3–6) to 0 (0–4.5) at 2 weeks, then increased slightly to 1 (0.5–2) at 3 months. Neither the overall change (Friedman $p = 0.0853$) nor the baseline-to-3-month difference (Wilcoxon $p = 0.0220$) reached statistical significance when compared to the adjusted significance threshold of $\alpha = 0.0125$. The total score decreased from 35 (28–37) at baseline to 16 (6–33) at

2 weeks and 17 (11.5–20.5) at 3 months. The Friedman test did not show a significant change ($p = 0.0663$), but the Wilcoxon test indicated a significant reduction between baseline and 3 months ($p = 0.0220$). Bonferroni correction was not applied to the total score, as it was analyzed as the primary outcome.

Table 4: Changes in scores on the FCMAHS.

FCMAHS subscales	Baseline	2 Weeks	3 Months	p-value ^a	p-value ^b
Subscale 1: Information seeking and information sharing (median (Q1-Q3))	11 (8-13)	5 (3-11.5)	7 (5.5-10)	0.3172	0.1275
Subscale 2: Scheduling logistics (median (Q1-Q3))	9 (8-14)	3 (2-13)	6 (1-6.5)	0.1627	0.0625
Subscale 3: Safety issues (median (Q1-Q3))	6 (4-7)	4 (0.5-6.5)	3 (1-3.5)	0.0418	0.0340
Subscale 4: Polypharmacy (median (Q1-Q3))	3 (3-6)	0 (0-4.5)	1 (0.5-2)	0.0853	0.0220
Total score (median (Q1-Q3))	35 (28-37)	16 (6-33)	17 (11.5-20.5)	0.0663	0.0220

^a Friedman test p-values, ^b Wilcoxon signed rank p-values

2.9.2.2. Change in Scores Across the Three Time Points for the ProQoL

Based on the ProQoL scoring guidelines, caregivers in this study demonstrated high compassion satisfaction throughout the study period, as their median scores consistently remained above 42. This indicates that caregivers generally felt fulfilled in their role and experienced positive emotional reward from providing care. The burnout subscale showed a baseline median of 26, placing caregivers at a moderate level, with scores continuing to decrease at 2 weeks and 3 months. This pattern suggests that

caregivers experienced a reduction in burnout over time, likely supported by the use of the AMD and the reduced workload associated with medication management. The secondary traumatic stress subscale reflected a moderate level at baseline and 2 weeks and a low level at the end of the study, indicating that caregivers were experiencing some emotional strain related to their caregiving role, which is common in family caregiving. Overall, these findings suggest that while caregivers were emotionally affected by their caregiving responsibilities, they maintained strong positive feelings about their role, and some aspects of caregiver strain improved over the study period. The median scores and the first and third quartiles (Q1 and Q3) for the three subscales of the ProQoL at baseline, 2 weeks, and 3 months are shown in Table 5. A Bonferroni correction was applied to the three subscales, resulting in an adjusted significance threshold of $\alpha = 0.0167$. The Bonferroni correction was used to control the family-wise error rate, given the increased risk of Type I error when multiple comparisons are conducted across the ProQoL subscales.¹⁰⁷ The total score for the compassion satisfaction items remained relatively stable over time, with medians of 44 (37–44.5) at baseline, 45 (36–48) at 2 weeks, and 43 (38–46.5) at 3 months. No significant changes were detected in the Friedman test ($p = 0.1913$) or the baseline-to-3-month comparison ($p = 0.2809$). For the burnout items, the median scores declined from 26 (16–31) at baseline to 18 (12.5–33) at 2 weeks and 16 (13–23.5) at 3 months. The Friedman test indicated no significant overall change ($p = 0.1017$), while the Wilcoxon test showed a statistically significant decrease ($p = 0.0343$) before adjustment. However, this did not meet the Bonferroni-adjusted significance threshold ($\alpha = 0.0167$). The secondary traumatic stress scores were stable over time, with medians of 23 (20.5–24.5), 23 (15–30.5), and 20 (18.5–25) at baseline, 2 weeks, and 3 months, respectively. Neither the Friedman test ($p = 1.0000$) nor the Wilcoxon test ($p = 0.3938$) indicated statistical significance. After applying the Bonferroni correction, none of the subscales demonstrated a statistically significant change over time. Although the burnout subscale showed a

significant baseline-to-3-month reduction in the unadjusted Wilcoxon test, this result did not remain significant under the adjusted $\alpha = 0.0167$

Table 5: Change in scores across the three time points on the ProQoL scale

ProQoL subscales	Baseline	2 Weeks	3 Months	p-value ^a	p-value ^b
Compassion satisfaction (median (Q1-Q3))	44 (37-44.5)	45 (36-48)	43 (38-46.5)	0.1913	0.2809
Burnout (median (Q1-Q3))	26 (16-31)	18(12.5-33)	16 (13-23.5)	0.1017	0.0343
Secondary traumatic stress (median (Q1-Q3))	23 (20.5-24.5)	23 (15-30.5)	20 (18.5-25)	1	0.3938

^a Friedman test p-values, and ^bWilcoxon signed rank test p-values

2.10. Qualitative Results:

2.10.1. Pre-Intervention Interview Results

The pre-intervention interviews revealed three main themes: Becoming a caregiver, Approaches to support medication management, and caregivers' experience and well-being, each with its own sub-themes. Becoming a caregiver included five sub-themes: relationship dynamics, transition into caregiving role, medication management, caregiver challenges, and the role of the caregiver beyond medication. Approaches to support medication management included three sub-themes: the use of pill organizers, the use of blister packs, and caregiver strategies to support medication management. The final theme, caregivers' experience and well-being, consisted of two sub-themes: caregivers' satisfaction and burden, and self-care and stress management.

1. Becoming a caregiver

1.2. Relationship dynamics

This subtheme addresses the type, duration, and nature of the relationship, as well as the support provided by the caregiver to the care recipient. Most caregivers in the sample were family members, either spouses or adult children caring for their parents. These relationships were lifelong for adult children and long-term for spouses. The nature of the caregiver–care recipient relationship varied. Some described it as fun, easygoing, and rooted in a deep emotional connection and teamwork. Others experienced emotional distance, where the relationship had shifted from a familial bond to a more clinical dynamic, taking on the qualities of a personal support worker (PSW) or nurse caring for a patient.

“Well, married for almost 40 to 41 and a half years....You know, kind of I have his back, he has my back.

Like we just, we work great as a team. Very much a team.” Caregiver 001

“Strangely, and it seems like we’re not a couple. I’m the caregiver, he’s the care receiver, and it’s become

PSW, patient, nurse, patient, not a couple.” Caregiver 007

Caregivers provided emotional support in various ways, including promoting and encouraging the care recipient’s independence to complete tasks independently. Caregivers would typically step in only when needed or when assistance was requested. In these cases, the caregiver's role was more about monitoring and checking in to ensure tasks were completed correctly, rather than doing them entirely. Moreover, caregivers supported self-advocacy, engaged in collaborative discussions about healthcare decisions with the care recipient, and advocated or spoke on behalf of the care recipient when needed.

"I let him put it in because, to me, that's as much a management for him to do it, put his own meds in, as it is for me to do it for him." Caregiver 004

"It would be more likely for me to have that discussion with my mom, and then let her be the one to discuss it with the doctor, or call the doctor’s office, or follow up with the doctor herself." Caregiver 010

1.3. Transition into caregiving role

Caregiving was primarily initiated due to the aging or decline in the care recipient's health, including hospitalization and/ or an increased number of chronic conditions, all of which required the caregiver to become more involved and attentive to the care recipient's health needs. The duration of the caregiving has ranged from a couple of years to more than a decade of providing care.

"Just basically, when he was diagnosed with his eye disease and he started having issues with his eyes, so sometimes I have to just I double check to make sure that he's put his medicine in the right container when things need to be reordered, I'm the one that has to reorder them because he can't read the numbers very well." Caregiver 001

1.4. Medication management

Caregivers were involved in various tasks related to medication management. These included organizing medications or checking that the care recipient had correctly sorted their medications into a pill organizer, a task typically done once a week. They also assisted with medication administration, including giving injections or eye drops, and helped with opening and ripping off blister packs. In addition, caregivers supported medication preparation by splitting or cutting tablets, preparing liquid solutions, ordering medications or supplements from the pharmacy, requesting prescription renewals from the doctor's office, and picking up medications.

"At night, after she's gone to bed, I take the strip of the blister pack, put it on her table with her little case with all the days of her vitamins in a pill set, a dosset, and then I put her buffer out, so in the morning she has it in front of her." Caregiver 009

"For him to have his Ozempic, I get ready and, like the pen, you know, the dose he needs to take. A lot of times he just pulls his top up and wants me to inject it. So I've got that." Caregiver 007

Caregivers also played an active role in seeking information about medications. They often used online sources, preferably those written in simple language, and were careful about choosing reliable websites. They also relied on medication leaflets and consulted healthcare professionals such as pharmacists and nurses when needed.

“Well, they always, they always include say I shouldn't say always, but most of the time they include the information sheets with the drugs. So that's a good way to start and then if it turns out that you know, we throw them out or whatever, then I just go to my the Internet. Google it and then go to that website and all the information's there.” Caregiver 008

“We were in family regularly because it's a little local pharmacy, and we go in for different things. So this, there's a weekend pharmacist, obviously, and there's a weekly and we could, they know us, and they will talk to us.” Caregiver 004

Caregivers were further involved in monitoring-related activities, including watching for side effects such as changes in behavior, energy levels, and daily functioning. They also monitored the care recipient's overall health and responses to treatment. In some cases, caregivers used their judgment to make clinical decisions, such as adjusting medication dosages or safely removing medical devices, like needles, when necessary.

“Oh, absolutely. I mean, I was screaming at a hospital one time that there was something wrong with him, and they kept trying different medicines. And I'm saying this is not working. It's not working. Change the medicine, and then his legs blew up. And I said, they said, Oh, it's just to do with his illness. And I said, No, this is not right. And so we found out that instead of, was it decreasing his Eliquis, they stopped the Eliquis. And so his legs started to blow up, and so there was a real mismanagement of medicine at the hospital. And so I was on that 24/7.” Caregiver 007

Moreover, caregivers played a crucial role in ensuring medication adherence and safety by checking the accuracy of doses, monitoring ongoing treatment, and ensuring the care recipient followed the prescribed instructions. They also communicated regularly with healthcare providers. However, their experiences varied; some caregivers were satisfied with the accessibility and quality of care, while others reported challenges such as delays in getting timely answers, difficulty accessing physicians when needed, and limited time during medical consultations.

“You know, just the warfarin, we just have to really be on top of that, because it's you don't want his blood too thin, but more importantly, you don't want it too thick either, because that can have an impact on his valve, so that can have a tremendous impact on his health if he's not that the Warfarin is not correct, especially if it's low.” Caregiver 001

“We’re having a hard time transitioning to the new way of healthcare, where you know everything is you can't sit and talk to your doctor anymore.” Caregiver 004

1.5. Caregiver challenges

Caregivers reported facing several challenges related to medication management. One issue was the irregular intake of supplements, which sometimes occurred when multiple caregivers were involved, and routines were not well-coordinated. Another common challenge was giving medications on time. Moreover, ensuring medication adherence became harder during changes in routine, such as during vacations.

“It's a matter of scheduling is her challenge, because she doesn't have a regular schedule for anything like she doesn't. She doesn't get up at eight and have, you know, breakfast right away, and she might get up at 10 and not have breakfast until 11:30 so it's that's really the bigger challenge that we have.”

Caregiver 010

Medication changes added a separate layer of difficulty. When updates to the treatment plan were not reflected in the blister pack, caregivers were often left unsure whether the care recipient was following the correct instructions. Adjusting medication dosages at home was also stressful, especially if the caregiver tried to make changes themselves by opening the blister pack and correcting the dose based on new instructions, rather than returning it to the pharmacy to be updated properly.

“My daughter helped out because they wanted to have half a dose. So they changed her the one medicine for half a dose, so the blister packs can be opened up and then reclosed. So we went through the medicine that we had, she did and made the medicine change. Then the next blister pack had the new prescription in it. So it would have been a little nerve wracking, if I had to do it myself, but I trusted my daughter, and so it worked out.” Caregiver 009

Caregivers also found it challenging to identify side effects, either because they did not know the specific signs to watch for or because it was unclear whether changes in the care recipient’s condition were due to the medication, aging, or another health issue.

“So there's that we are going to see another doctor. She's a seniors mental health doctor, because she's experiencing some confusion. That's new. It's not, it's not her norm. She's very, she's very cognitive, and I'm just we need to check that out so we're still ongoing, going to figure things out. She's very she's starting to be less confident and easily agitated. So whether those are side effects from the medicines, I'm not sure. Whether it's the natural aging process. I'm not sure, but I we're investigating it.”

Caregiver 009

Other challenges included remembering to order or pick up medications, especially those not included in the blister pack, such as inhalers or injections, which led to concerns about running out of medications or medical supplies. Some caregivers also struggled to remember the purpose of each medication (its

indication) and reported difficulty identifying emergencies, as they were unsure of the warning signs or symptoms that require urgent medical attention.

"Well, it was just that in the afternoon he was just, umm, kind of like in a fog, I guess. And then he was kind of slurring his words, but not really, so I didn't know if it was just him, you know, not making an effort to speak properly or what. So then the next morning, he was kinda like more slurring and kind of like a little dozy, so I took him to the emerge, and that's when they said he had a stroke. So I learned now about strokes." Caregiver 008

1.6 Role of the caregiver beyond medication

Caregivers played an active role in attending medical appointments with the care recipients, offering support by advocating on their behalf, taking notes, asking questions, and serving as a second set of ears, thereby ensuring that instructions and information from the doctor were understood. Moreover, caregivers were actively involved in overseeing the care recipients' nutrition and diet, as well as monitoring key health metrics such as blood pressure, oxygen levels, and weight. They also encouraged physical activity as part of maintaining overall well-being. In addition, caregivers provided transportation support by driving care recipients to medical and other appointments.

"I run down and get it. I'm over there around seven o'clock in the morning to make sure that, like when she gets up and she's on a program that checks her monitors her blood pressure, her oxygen and her weight.

It's the five month program, so I'm over there to help her do those things with an iPad." Caregiver 009

Caregivers often assisted with personal hygiene tasks, including bathing. They also took on responsibilities such as grocery shopping and managing both indoor and outdoor household chores. For some, these duties were shared with the care recipient, but others reported being solely responsible for everything, such as cooking, cleaning, doing laundry, and even cutting the lawn. To manage the workload,

some caregivers sought external help by hiring housekeepers to assist with cleaning or by placing the care recipient in a retirement home, where meals and housekeeping were provided by staff.

“OK, well, my job is to cook the meal, and I clean up a bit, and then his job is to finish washing, like pots and pans and stuff like that. That might take him 10–15 minutes to clean the countertops and stuff, and then he gets like, very tired out. He just says, 'I have to lay down, I have to sit down,' but he does make a big effort to finish his job. Sometimes he doesn't, but a lot of times he does. And then the laundry—I do the laundry. He does the odd load, but he usually always helps folding clothes.” Caregiver 008

2. Approaches to support medication management

2.1. Use of pill organizers

For some caregivers, using the pill organizer was convenient and easy, as it only needed to be sorted once a week. However, others found it confusing, especially when the care recipient was on multiple medications. They worried about medication sorting errors and found the organizer too small to fit all the pills. If it fell on the floor, it would open and scatter the medications, requiring reorganization. Some caregivers weren't confident that the care recipient was sorting it correctly, which led them to advocate for switching to a blister pack. During travel, the organizer was also inconvenient, as it could open in the suitcase, which was a hassle.

“I find the biggest thing is just that pill organizer is the easiest thing for us that works really well for us. Just because it's all done, we do it once a week, and it's completed.” Caregiver 001

“Now you gotta make sure they're all in that order, and you have to make sure that the pill container doesn't drop, because everything will pop open and be all over the place. And they have to do it again, so they're not the best things.” Caregiver 007

2.2. Use of blister packs

Blister packs were seen as more convenient and easier to use, as medications were pre-organized by the pharmacist, so the caregiver did not need to sort them. Blister packs also reduced worries about running out of medication; if a refill was required, the pharmacy team would contact the doctor or notify the caregiver to book an appointment. Each blister pack came with a list of medications that could be easily torn off and taken to medical appointments.

“Well, this one run out, and I forgot to tell because she has to make an appointment to see him, and then he'll refill it. So that was more of a hassle. Now, with the blister pack, the pharmacist sees, okay, you're running out here, so they fax over to the doctor, and if the doctor isn't going to fill it, then they call and we make an appointment, so the blister packs has helped that.” Caregiver 009

However, caregivers noted several challenges. The packaging was not always user-friendly for older adults, who often needed help popping out the pills. The label font was small and light, making it hard to read. When corrections were made, the packs were resealed with tape, making them harder to open and increasing the risk of pills spilling. Blister packs worked well when prepared correctly and not reopened by the pharmacy team. However, for care recipients with complex regimens, some morning medications had to be split between breakfast and lunch compartments. This could be confusing if multiple caregivers were involved, unless clear communication is maintained. A final concern was that pre-packaged medications reduced the care recipient's awareness of their pills, since they just popped them out without paying attention to names or indications.

“But what I do see happening with the blister pack is that she's no longer as aware of what it is she's taking and why. Like, she doesn't know the medication names. She wouldn't look at it. Some of them she would know, but some of them she would look at and say, 'What do I take that for? I don't know. Or if you

asked her to recite them, she wouldn't be able to do that now, which she used to be able to do. It takes that mental awareness away." Caregiver 010

2.3. Caregiver strategies to support medication management

Caregivers implement various strategies at home to support the care recipient's adherence to their medication regimen. One strategy involves helping the care recipient develop a routine, such as getting into the habit of counting pills and prioritizing the intake of smaller tablets before larger ones, especially in the case of visually impaired individuals, to prevent small pills from being lost.

"I'll go and I won't check the container, because the container is empty, but I'll just, you know, I'll say to him, I'm trying to get him into the habit of counting his pills to make sure that the right of number is in there, and then he knows that he's taken them all." Caregiver 001

Another approach is the strategic placement of medications in visible and consistent locations, often linked to a daily habit, to encourage timely and regular intake. Caregivers also modify medication packaging by rewriting instructions on blister packs to include dates and times for taking medications in a larger font size, rewriting on medication vials the updated doses, or adding stickers on blister packs to indicate the appropriate time of day for taking the medication, thereby reducing the confusion for the care recipient. Verbal reminders were also commonly used. Caregivers may remind the care recipient in person, check in periodically, or make phone calls if they are not physically present, to ensure the medication has been taken as prescribed. However, for one caregiver, keeping the sleeping pills in a visible location led the care recipient to take a double dose. As a result, the caregiver adopted a strategy of restricting access by moving the medication to a more secure location.

"We leave it on the kitchen counter by the orange, you know, with the glass that he's going to have the orange juice in, so he never misses the iron." Caregiver 004

“Because what happens is that night when he can't sleep then, ohh I'd I need. I need to take this or I need to take that so he goes out and takes the pill, but sometimes he takes twice the pill. So now I've just moved everything into a different spot, and actually he's much better now.” Caregiver 008

Moreover, one caregiver adopted a strategy to ensure accurate sorting of pills in the organizer by placing the medication bottles on one side of the organizer and moving each bottle to the other side after it was used to fill the correct slot. When traveling, the caregiver placed the pill organizer in a Ziploc bag to contain any pills in case the organizer accidentally opened. This made it easier to put the medications back in the correct slot if needed.

“We'll take that pill organizer the seven days, and we slip it into it, like a large ziploc bag, and then we zip it shut, so if for whatever reason it opened, it's all self contained in that Ziploc bag. So any medications that might have come out, if it for whatever reason it opened, then they're all still contained within the bag, and we can just put them in their proper spot.” Caregiver 001

Strategies to avoid running out of medications included ordering refills in advance, typically one to two weeks before the supply runs out. This allowed enough time for the pharmacy team to order any medications that might not be in stock, ensuring the care recipient received them on time. Some caregivers signed up for pharmacy delivery services, which ensure the timely delivery of medications to the home. Another strategy was to establish a reminder system, such as moving nearly empty medication bottles from the bathroom to the kitchen as a visual cue to place a refill order. Additionally, reminder calls from the pharmacy team helped caregivers stay informed when the care recipient was running low on medications.

“You know the system is that. I mean, we were in an apartment, we have bathroom. That's where the medications are, but if it's getting low, the bottle comes into the kitchen where and near a laptop, and

that's when we would order if it's getting low and the pharmacy is very good too. They also will call us once in a while and say you're getting low on two, three.” Caregivers 004

In situations where caregivers run out of medications or medical supplies, such as sensors used by diabetic care recipients, they have developed strategies to cope. For example, caregivers used included paying out of pocket to purchase needed medications when the pharmacy was closed, creating a backup supply at home by saving missed or dropped doses, using these stored doses temporarily until a refill was obtained, and in some cases, temporarily reducing the medication dose during long holidays to make the remaining supply last until the pharmacy reopened.

“So as much as I am trying to remember, you get busy and you forget. So this way, we kind of decided that we'll just now have everything delivered and then we don't have to worry....I was very worried, yeah, because I know that's a discomfort for him and I did tell him that, and he we, what we ended up doing was, I think he had enough pills where we just he ended up taking, I think, one, instead of taking two a day, he took a one day and one the next day.” Caregiver 001

To stay on top of medication management, caregivers created medication lists that included the names, indications, and dosages of the medications the care recipient was taking. The level of detail and format of these lists varied between caregivers. Some caregivers preferred to bring the medication list to medical appointments instead of carrying the entire bag of medications, allowing the doctor to review the necessary information as needed. When care recipients had difficulty swallowing large tablets, the caregiver sought alternative dosage forms, such as capsules, which were smoother and easier to swallow compared to tablets.

“Ohh, just because the doctors every time you went into for a doctor's appointment, they ask you, OK, what medications are you on? Oh my God. Or they would say bring your bottles. Well, we bring a great big plastic bag full of bottles. It's huge and then really they don't really even wanna look at those bottles. So

they much prefer is a list, so I make an extra copy and I say here you can have it so they're happy to have that." Caregiver 008

3. Caregivers' experience and well-being

3.1. Caregivers' satisfaction and burden

Caregivers generally expressed satisfaction with their caregiving role. Some viewed the journey as a form of teamwork, while others saw it as a meaningful and rewarding responsibility, rooted in the strong connection they shared with the care recipient which reflects high levels of compassion satisfaction. For some, caregiving was accepted as a normal part of life, a priority and a family responsibility, carried out not only out of gratitude but also out of a sense of duty, as long as the caregiver could provide care. Providing care itself was not typically seen as a burden. Instead, it was the accumulation of other life responsibilities that made caregiving feel burdensome at times. In these cases, the caregiver did not see the care recipient as the burden, but rather the added responsibility of caregiving on top of an already demanding set of responsibilities. Some caregivers also expressed partial satisfaction, feeling that while specific needs and expectations were being met, it still did not feel like enough. They thought they could or should be doing more.

"As far as care, I know as long as I take care of him, he's going to last a bit longer.....That's a priority to me...making sure he's healthy is part of my job as a wife or as part of the team." Caregiver 004

"I'm very honored to be able to do this for my mom. I feel I have a lot I have girlfriends that say you're so blessed to have your mom still with you, because they don't. So it gets a little frustrating at times, but that's life that you just family helps family, and she raised me that way" Caregiver 009

On the other hand, physical fatigue was also noted as a negative outcome of caregiving, where the caregiver complains of an injury due to the heavy lifting of the care recipient's wheelchair. Caregiving can keep the caregiver busy and may affect their rest, even when they try to prioritize sleep. Caregiving can

place a significant emotional burden on the caregiver. The experience is often difficult to fully understand for those who have not been in the role. While people may offer suggestions for managing stress, the caregiver may feel that even a short break could leave them falling behind on the responsibilities waiting for them at home. The caregiving role can negatively influence the caregiver's relationship with their partner and other family members. Dedicating more time to the care recipient may affect the quality of the relationship, even if the partner is supportive and understanding. Moreover, frustration was expressed when the care recipient forgot to take medications or did not follow medication instructions.

"So, um, and then I'm lifting the wheelchair in, or the walker in or out of the car. So I've got that my back is now giving me issues because it's heavy." Caregiver 007

"If my mom was a little bit more independent, then that would ease our relationship, like with my husband, better, like that would be better, but he's very supportive and encouraging me to spend the time that I need to.....I have two grandchildren, and they're young, four and two, and there's times when I would like to look after them, but I'm looking after my mom, and my mom can't be around them."

Caregiver 009

The caregiving role can negatively impact the caregiver's social life. Caregivers may find it difficult to engage in hobbies or social activities, as much of their time is dedicated to caregiving tasks at home. For those who are also working, there can be a sense of responsibility to spend their remaining time with the care recipient, which further limits opportunities for social engagement. Financial strain was not commonly reported in our sample; however, when it was reported, it was primarily related to the out-of-pocket purchase of medical equipment that was not covered by insurance. Caregivers' stress was commonly associated with the multiple responsibilities they were juggling simultaneously. This stress was not limited to medication management but extended to other daily demands, including providing care to

multiple care recipients at home, managing non-medication-related caregiving tasks, balancing work and family responsibilities, and finding time for self-care.

“He wants his meds in the morning, that's fine, but then I'm getting (step son) up and fed and dressed, and I've got to drive him to his place now, so I've all these other things on my plate, and so sometimes I'm I'll miss it, like maybe I do need a checklist in front of me every morning to say, Have you done this? Have you done this? You know? But, yeah, it's with, you know, appointments too. You've got a you know, I've got them in my phone, I've got them on a calendar, I think come up on the computer, but I need all these reminders. I have caregiver burnout.” Caregiver 007

3.2. Self-care and stress management

Caregivers have adopted various strategies to manage stress and improve self-care. These include engaging in physical activity or exercise, sharing caregiving responsibilities among family members to reduce the burden, and addressing stress by adapting to the situation. Having a flexible work schedule or the ability to work from home also helped caregivers balance their responsibilities. Some sought external support by attending hospice workshops or arranging for someone to care for the care recipient while they went on a holiday. Others used practical supports such as having meals delivered to the care recipient instead of preparing them personally. Transitioning the care recipient to a retirement home reduced stress for the caregiver, as the staff took over responsibilities such as meal preparation.

“I've done yoga for nearly 50 years. So those are all my tools for not letting stress get in the way.”

Caregiver 004

“I'm just tired, and I've got support, because our hospice here offers caregiving programs. So they offer various workshops. I belong to the caregivers' group, so we meet once a month and talk...and you can get your feelings out there. You can cry, you can laugh, you know. So that helps a bit.” Caregiver 007

2.10.2. Post-Intervention Interview Results

The thematic analysis of the post-intervention interviews revealed four main themes: usability and functionality, experience with remotely delivered pharmacy services, caregiver experience and wellbeing, and impact on caregiver-recipient relationships.

1. Usability and functionality:

1.1. Design features

Caregivers reported that the AMD provides incomplete support with the organization of PRN medications, medications that require constant dosage adjustment, and supplements. Moreover, one of the caregivers mentioned the difficulty of including a newly prescribed medication or adjusting for a medication change mid-cycle, as the participants received a new medication cartridge every 2 weeks. However, another participant mentioned that she expected accommodating medication changes to be complex, but her experience was the opposite.

“I find the biggest, I think the biggest thing I don't like is I, even though his medications are being like given to him, we still have to fill out a pill caddy, because it doesn't include a supplement, and he also takes Coumadin, which can possibly change. So none of that can go into the none of that goes into the spencer. So I feel like sometimes we're doing twice the work.” Caregiver 001

“Could be difficult, because you had added pills, yet they're separate from the machine, because I get these pills in advance, but like pill packs in advance, so you can't send them back and get these pills added, and then get them back in time to take them.” Caregiver 007

A few participants noted that the medication pouches are difficult to open by hand because the score marks on the pouch are not clear, and they would need to use scissors every time they wanted to open it to retrieve their medications. It was also appreciated that the pouches were labeled with the date and time, as this allowed caregivers to track whether a dose had been taken by checking the used pouches

and confirming the date and time printed on them. There was positive feedback about the fact that the cartridges were labeled with dates, as this helps the caregiver know which one to insert first, which would be especially helpful if the cartridges contain a different medication each week. One caregiver raised a concern that the font size on the pouches was too small for older adults to read. This made the caregiver worry about whether the care recipient could take the correct medication at the right time, especially when the care recipient had to administer the medication themselves from the cartridge due to technical problems.

Now, the only other thing I would say is that when the pouches come out, where you rip them isn't very clear. There's a little score mark, but you can't see it. Even we can't see it. I think there's a little black line where you tear it, and it should be scored either across the top or farther down because they can't see it.

So my mom had to use scissors every time." Caregiver 006

"That way, if she didn't remember if she took it, we could tell her to go to the clear box and look at the top one, and if it said 10 o'clock. PM, then we knew that. We said, Oh, you took it, you know, like so it was, it

was helpful to that it was print one" Caregiver 006

"And so whereas the little pouches, although they have the information on the pouch, if my mom doesn't have her glasses on, that might not be something that we're really that I would be 100% confident that

she has the right pouch." Caregiver 010

Additionally, caregivers appreciated the device's alarm sound, which served as an effective reminder for care recipients to take their medications on time. The adjustable volume was also valued, as it ensured the alarm could be heard clearly and would continue to sound until the medication was removed from the AMD. However, if the care recipient has a hearing impairment, the caregiver found it challenging to ensure the care recipient took their morning medication, as the AMD produces an alarm sound to remind them. Even though the alarm feature was acknowledged for reminding care recipients to take their medications

on time, it did not guarantee adherence. It was reported that care recipients might remove the medication from the AMD, get distracted, or set it aside and forget to take it. Moreover, medication pouch jamming was one of the typical inconveniences that caregivers faced during medication retrieval.

“He relies on spencer the alarm, he goes, gets it, you know, the alarm stops. He goes, gets the pills. But he doesn't necessarily take it right then and there. He might leave it there and forget about it till the end of the day.” Caregiver008

“The only time that it wasn't easy to use is when one of the pills packages got stuck, and then you had to sort it out and take a few packages ahead to get it going.” Caregiver 007

The space occupied by the empty cartridges on the countertop, the empty medication pouches, and the device itself, which already took up space, was a source of inconvenience for one of the caregivers. Caregivers found the feature of “meds on the go” very useful since it provided flexibility in terms of getting the medication dispensed ahead of time in case the caregiver and the care recipient would not be at home at the time of taking the medication, or if the caregiver wanted to dispense the morning medication at night and keep it ready for the care recipient the next morning. Some caregivers appreciated the AMD's questions after dispensing each dose, as they believed these prompts encouraged care recipients to reflect on other aspects of their health, such as physical activity and emotional well-being, which, in turn, contributed to improved mood. Some caregivers also acknowledged that the instructions displayed on the AMD screen were easy to understand and implement. For example, during jamming, the device displays the appropriate steps to resolve the issue, or during cartridge changes.

“It asks you questions. How are you feeling today? Have you exercised today? So it makes the person think about other things outside of the medication” Caregiver 004

“When it did jam, it came up with instruction as to try to unjam it. So at least you weren't kind of like sitting there wondering what to do it. Did give you instructions on how to do it, and they I think there might have been one or two times that we were able to fix it ourselves” Caregiver 008

Portability was another advantage of the AMD. One of the caregivers appreciated that all medications were pre-packaged and ready for use, and that the device did not require reprogramming when moved from one location to another. It was already set up, making it easy for caregivers to unplug and plug it in again, which is helpful during holidays or travel. However, one caregiver wished the AMD were wireless, as this would allow them to place the device in the most convenient location for the care recipient, rather than being limited to where a power outlet was available.

“Well, my mom stays at home with us in her own little granny suite, but for us to have a holiday, we might have her go to a respite care home for a week, and we can just unplug spencer, plug it in. I don't have to reprogram it or anything. It'll just take up where it left off, and she will have the thing convenience of her medicines, her environment might change, which will be enough to maybe be unsettling for her, but knowing that her medicines are still the same is a consolation, a good consolation, for both of us, for her and us.” Caregiver 009

The pre-packaging feature of the AMD, where the pharmacist organizes all medications into a cartridge that is inserted into the device at home by the caregiver or the care recipient, raised concerns about a perceived lack of control. This was especially true for a care recipient who preferred organizing their medications themselves using a pill organizer, as it gave them a sense of control and awareness over what they were taking and when. With the AMD, the caregiver expressed that, although the pouches were labeled with medication details, the care recipient was taking the medications based on trust in the pharmacy team's organization. This led to a feeling of reduced awareness and involvement in his medication routine. There was also a concern about power outages, as the AMD needs to be consistently

plugged in to function. While it may continue to work for a few hours when unplugged, the caregiver was unsure what would happen if a power outage lasted longer. The size of the AMD was considered larger compared to other organizational tools, and caregivers expressed a preference for a smaller design.

"He likes when he puts his pills in; he likes to see which pills they are. And he finds with the spencer, he doesn't have that anymore. Even though it's written on it, he can't read that, so he doesn't really feel he knows which pills he's taking when. Even though they're still the same pills, it's just in his mind he's taking them, but in his mind, he's taking them with a degree of trust." Caregiver 001

1.2 Adaptation

Among all caregivers, only one showed resistance to changing the medication-taking routine and preferred to stick to the previously established schedule of the care recipient before using the AMD. The care recipient used to take a medication every morning before using the AMD, but when the medication was packaged in the AMD, it was dispensed in the evening. Instead of adapting to the new timing, the care recipient would dispense the medication in the evening and set it aside to take in the morning, as per the old routine. Moreover, the AMD may dispense the morning medication earlier than the care recipient's usual breakfast time, so they would take the pouch out when it is dispensed and set it aside to take later with breakfast. Neither the caregiver nor the care recipient was proactive in contacting the AMD-certified pharmacy to request a timing adjustment for the following cartridge refill. Instead, they chose to continue with their workaround. This disruption in routine occasionally led to missed doses, as the pouch was placed on top of the care recipient's pill organizer and sometimes forgotten. The care recipient also expressed feeling a loss of control, as he was previously used to organizing his medications himself, something he could no longer do due to the pre-packaging feature of the AMD. Both the caregiver and care recipient felt that the AMD lacked flexibility, as medications were dispensed at set times. This issue could have been avoided if they had used the "meds on the go" feature, but they did not.

“Well, we noticed there were two pills that he used to take in the morning, and when they were added to the spencer, they were added in the evening. So what we ended up doing was taking those two pills from the evening and putting them in the following morning, because he was used to taking them in the morning, not in the evening.” Caregiver 001

On the other hand, another caregiver had a very different experience. For them, the AMD helped make the day more organized for the care recipient and reduced the chances of missed doses. The device supported a more structured, planned morning routine, which eased the caregiver’s responsibilities. Another form of adaptation involved a strategy to ensure that care recipients took their medications on time. The caregivers placed the used medication pouches in a designated box at home to monitor adherence. If the care recipient was unsure whether a dose had been taken, they could check the box and confirm by reading the date and time on the pouch. One of the care recipients had a hearing impairment and could not hear the first alarm in the morning. The caregiver adapted by asking someone else to help ensure the care recipient woke up and listened to the alarm for their first medication dose of the day.

“What I've been doing is we have a little place where she puts a little container, where she puts the little packages they have the day and the time. So when she put some there, I can look to see that she took them.” Caregiver 009

1.3 Technical problems and device reliability

Safety and reliability concerns were raised by only one caregiver. In her experience, the AMD had completely stopped working and failed to dispense medications, which was very frustrating. She assumed the medications were being dispensed on time, but after returning home from a long day at work, she would be surprised to find that they hadn’t been. This left her having to address the issue later in the day, when she could have managed it more effectively earlier if she had known. On other occasions, the AMD displayed error codes such as incorrect dates for upcoming doses or false notifications that a dose had

been missed when it had not. These issues led the caregiver to remove the medications manually from the cartridge and administer them herself.

“Sometimes I wouldn't know that it wasn't dispensing properly until like late in the day, if my mom I just trusted everything was going okay, and then as like, as I'm getting ready for bed, my mom would say, oh, it's not working properly. It's not been working all day. So that was very frustrating, because, well, I could have had more opportunity to try and get it going earlier in the day, I guess.” Caregiver 010

“I don't know, it gave an error code I'd never seen before. It wasn't really making the grinding noise at all. But then it started saying, started giving different dates, like it would say when we loaded the new cartridge, it started off automatically. Would say, oops, it looks like you've missed 11 doses when we haven't. And then and then it would say, it looks like your next dose is tomorrow at not at 7pm when we still had all today's doses to dispense.” Caregiver 010

These incidents caused the caregiver increased stress and concern. She worried that her mother might mix up or take the wrong medications, especially since they were now being dispensed manually. The medications in the cartridge come in a rolled strip, and the font on each pouch is very small. The caregiver did not trust that the care recipient could always read the labels clearly. She also felt that, in cases where she had to dispense the medications manually, the packaging was not as visually organized or user-friendly as a traditional blister pack. However, the caregiver acknowledged that when the AMD was functioning properly, it provided the care recipient with more autonomy and helped ensure consistent medication intake. Overall, these technical issues affected the caregiver's perception of the device's reliability and her confidence in its ability to replace her role in managing medications.

“Increased my worry too, like, because, I mean, I'm not here all the time, so, you know, I don't know. I don't want my mom to get things mixed up and, like, at least when she had the blister pack, she could

see, physically, she would, like, immediately be able to see, oh, I have to take these ones, whatever. So I found that kind of, yeah, not as effective.” Caregiver 010

1.4. AMD versus other medication adherence technology

Some caregivers began comparing the AMD to the organizational tools they used before its introduction. A few advantages of the AMD were noted in comparison to the traditional blister pack. For instance, the AMD restricts access to medications, meaning the care recipient cannot access doses unless it is time to take them. This feature enhances medication safety, especially for high-risk drugs like narcotics. Additionally, the caregiver no longer needs to perform the task of ripping off the blister pack, as the AMD handles medication dispensing automatically. The pouch packaging of the AMD was also appreciated, as it doesn't break open easily, making it more convenient for travel. However, some still found blister packs more practical for travel, as they allow all medications and supplements to be organized together, reducing the caregiver's workload and concerns. The visual layout of blister packs was also valued. With clearly labeled slots for different times of the day, caregivers found them especially useful when they encountered technical issues with the AMD and had to dispense medications manually.

“Unfortunately, with the blister pack, he could take the pills when he wanted more so where spencer holds on to them and gives you when he wants you to have them, right? So if he wanted an extra pain med, he can't get it because it's stuck in spencer.” Caregiver 007

“So in that respect, like, that's nice, because it's just, you know, you pop one blister pack in the morning and one blister pack at night, and it's done. Where, with the spencer, we still had to do two different things.” Caregiver 001

1.5. Simplicity and learnability

All caregivers acknowledged that the AMD was easy and simple to learn and use. Its operation was straightforward, and once caregivers became accustomed to it, using the device became effortless.

Although some caregivers and care recipients were initially hesitant about using technology, fearing they might press the wrong button or accidentally cause a problem, they found the AMD to be user-friendly and easy to navigate. The step-by-step instructions made it easy to understand and use the different features of the device. Additionally, simple technical issues were easy to fix, as the troubleshooting steps were clear and easy to follow. Once the caregiver learnt how to handle these issues, they felt more confident navigating future problems, knowing exactly what to do. It was also noted that the caregiver would have preferred having an instruction booklet, either in paper or online format, to help navigate the AMD and resolve any technical issues independently from the start.

“I think it was pretty easy to learn how to use the machine. I think, like with a lot of computerized things, my mom was afraid to be pressing the wrong buttons, or those sorts of things. But I didn't find it hard to learn to use, and even after, I had technical difficulties, even resolving, like most of the simple ones, I didn't have problem resolving those or, you know, actually kind of knew what to do after the first after the first incident. Then when I when we had the same problem again, I'd be like, Oh, I already know how to do this and fix it that way.” Caregiver 008

1.6. Capability-centered design improvement and recommendations

The caregivers suggested several design and packaging changes to the AMD based on their care recipients' abilities. For visually impaired care recipients, it was recommended to improve the color and contrast of the medication pouch for better readability. For instance, using a white background with black text was suggested instead of the current design, which uses black text on a transparent background and is difficult for those with vision impairment to read. Also, the score mark for opening the medication pouch is unclear to a care recipient with vision impairment. The caregiver appreciated the device; however, it needs some improvement to work for their condition.

"It needs to be programmed black and white. So either a white background with bold black letters would be best, or, as a second choice, black with white letters, but they have to be bold because the worst color for him to see anything is blue. So if anything is written on blue, or blue writing on white paper, or a blue background, he has a tough time seeing it. So less color and more bold writing would be better for him."

Caregiver 001

For care recipients with hearing impairments, it was recommended to increase the volume of the AMD's voice instructions (i.e., boost the speaking voice that gives instructions), as it was considered too low for care recipients with hearing loss to hear clearly. Although the caregivers acknowledged that the alarm sound was loud, they noted that making it even louder would be helpful for users with hearing difficulties. To further support medication adherence, it was also suggested to include a camera feature to monitor whether the care recipient takes the medication or to incorporate a system that asks questions after each dose to confirm medication intake.

"We had to turn it right up, because my mom has hearing problems. She had to get in the habit of putting her hearing aids on right away, because without her hearing aids, she may not hear it in the morning. So the volume on that could be up a little higher so that people with hearing problems, because you can always turn it down right and adjust, but I don't know, as if it's really loud enough for people with hearing problems" Caregiver 009

Moreover, the AMD was recommended for individuals who self-manage their medications at home, as it provides pre-packaged, organized doses and alerts them when it is time to take their medications. Also, it was recommended for individuals with memory issues or dementia, as it can help them remember to take their medications. Additionally, if they begin using the device early, they are less likely to struggle with learning a new system later. It was also seen as helpful for individuals with multiple limitations; however, some modifications are needed to accommodate certain capabilities, such as vision impairment. The

device was perceived as providing medication safety, convenience, and ease of use, which is why one of the caregivers recommended it to others.

“For people that have maybe more limitations, I personally don't feel it's a great product yet for somebody who's visually impaired, I think they still need to do a lot of tweaking for somebody like him, where, you know, the way his disability is, he needs those upgrades so that he is able to use it if I'm not around.” Caregiver 001

2. Experience with mail-delivered pharmacy services

2.1. Communication and medication delivery

The timely delivery of medication refill boxes was appreciated. However, at times, communication between the pharmacy team and caregivers regarding delivery times was lacking. For example, a caregiver described it as frustrating when a medication refill box was sent out without prior notification, possibly because the caregiver either did not receive or did not see the notification message. Despite this communication gap, the refill boxes were consistently delivered on time throughout the study period.

“I mean, they were very good at sending the medicine on time it came through the mail easily enough”

Caregiver 007

There were also instances of miscommunication between caregivers and the pharmacy team regarding preferred times for medication administration. In one case, the caregiver and care recipient preferred a medication to be given in the morning, but it was scheduled for the evening. However, the caregiver did not follow up with the pharmacy to request a correction to their preferred schedule. On a positive note, there was favorable feedback on the pharmacy team's communication with the caregiver via phone and email. In contrast, one caregiver who experienced technical issues with the AMD reported difficulty reaching the technical support team over the weekend.

“But I’m sure that the pharmacy there helped me navigate it through. No problem. I called them, I talked to them, email back and forth, so I don’t anticipate anything I can’t see anything negative about spencer.”

Caregiver 009

In-person communication with the pharmacist was a key part of the caregiver–pharmacist relationship and was deeply valued by the caregiver. This aspect of the relationship was missed during remote pharmacy service delivery, as the caregiver preferred the in-person counseling they received from their pharmacist over phone or video calls, which are typically used with remote services. According to the caregiver, these remote interactions lacked personalization and did not allow for the same rapport to develop. The relationship often went beyond medications; caregivers would chat with the pharmacist about personal matters or look forward to a call checking in on how the medication was working. The caregiver expressed concern about potential emergencies if a distant pharmacy dispensed medication. For instance, if a rash or ear infection developed, their local pharmacy might not be able to help effectively, as they would no longer be familiar with the patient’s medication history. In such cases, a local pharmacist would not only be more familiar with the patient but could also physically assess the condition, such as seeing the rash, and recommend or prescribe treatment accordingly. The caregiver acknowledged that this perspective might be more common in their generation, as younger caregivers may not place the same value on the pharmacist relationship and might prefer the convenience of mail delivery. The caregiver also felt that personalized care and rapport could only be built with a local, small-business pharmacy, not with larger chain pharmacies.

“Because we’re finding that these video calls are not personal, you know, it’s just another you know, I can. Ask them how their kids are. I can ask them, you know, are you going here? Have a good weekend, like you don’t get that rapport over telephone? Yeah, it’s just not the same rapport. You build up a report. They know what meds you’re on. They can discuss it. They can ask you, okay, so you’ve got that new med.

How's it working out? I don't think you'll get a phone call from a bigger pharmacy saying, and how did that work out today? “ Caregiver 007

2.2. Environmental concerns

Environmental concerns were raised about the delivery of medications, as they had to be shipped from Toronto to the caregiver's residence, which is far away, and this was considered environmentally unfriendly.

“You know, I'm not a huge environmentalist, but to have the delivery come from a Toronto pharmacy seemed a bit what to say. What's the word? Environmentally not good.” Caregiver 004

3. Caregiver experience and the well-being

3.1. Caregiver burden and satisfaction

The impact of the AMD on caregiver burden and satisfaction varied. For one caregiver, her workload increased. She still had to manage other medications and supplements not included in the AMD, especially those that required frequent changes, which meant using both the pill organizer and the AMD at the same time. She also had to check the medications dispensed from the AMD daily to make sure they were correct, because the care recipient had difficulty reading the medication pouch due to vision impairment. The black text on the transparent background made it hard for him to read, so he relied on her for confirmation. The care recipient also needed help opening the pouches, something he did not need before using the AMD. As a result, the caregiver's responsibilities doubled, and the AMD did not take much stress off her shoulders, since the level of support she had to provide remained the same.

“To me, I don't really think it was negative, but it didn't take tremendous stress off me or particularly impact anything I did, because I still have to check things for him due to his limitation of being able to see it. Dispensing the pills wasn't the problem, but if he wanted to look at them, just to remind himself what he was taking, that part I'd have to do for him because he couldn't see it.” Caregiver 001

Additionally, when technical problems arose, the caregiver's burden increased further due to the time spent contacting technical support and troubleshooting. This was described as aggravating and frustrating, contributing to their emotional and mental fatigue. In this case, the use of the AMD didn't dramatically reduce the caregivers' responsibilities or free up significant time; it simply made daily routines a bit easier when things worked as intended.

"And then, and added to that, to then the technical aspect of trying to figure out why it's not working, let's get it working. You know, calling the people leaving voicemails when they're not when it's after hours, that those sorts of things that was more aggravating and more frustrating" Caregiver 010

In contrast, other caregivers found that the AMD reduced the time and effort required for medication management. It provided peace of mind and freed up time to rest or focus on other responsibilities. These caregivers felt that the device helped ease their emotional and mental fatigue by taking over many of the medication-related tasks they previously handled. The AMD allowed them to offload the constant tracking of medication times mentally, replaced the need for medication pick-up and organization, and enhanced overall medication safety. Knowing that the correct medication would be dispensed at the right time gave caregivers confidence that the care recipient would not mix up their medications, even when they were not physically present. As a result, caregivers were better able to balance their caregiving responsibilities with other aspects of life, engaging in activities they enjoy with less stress and worry about whether medications had been taken correctly and safely.

"Well, I don't have to dispense like. I don't have to dispense it right. I don't have to go into the bottles and take them out and put it in each day of the dossette. Make sure that it's the right pills. Make sure number of pills. All that fat management part I don't do anymore. Neither does my husband, so it's all done for us. So that part is very helpful, and you trust them, that is correct." Caregiver 008

“So I was sitting outside on the pad, working away on my computer. So I didn't think about that. I didn't worry about it, because I knew that he was going to go tell (the care recipient) in his own language that you got to get over here and take your pills, so that kind of left room for me to do what I was doing.”

Caregiver 008

The use of the AMD promoted convenience and independence by shifting the responsibility of medication-taking back to the care recipients, increasing their autonomy, and reducing the caregiver's need to be present every time. When the device functioned as intended, care recipients followed a more consistent schedule and felt more in control of their medication routine.

“Well, when it when it worked, I felt like I, I felt like my mom was more in control for herself, and I wasn't reminding her as often. You know, have you taken your pills? I mean that. So when it worked, that part was good, just so, so definitely, I felt like there were lots of days where I didn't have to think about that

part of it.” Caregiver 010

Since medication management was often the most stressful part of caregiving, the AMD helped relieve some of the emotional and mental fatigue. However, while this responsibility was eased, caregivers continued to manage other, less stressful tasks such as driving the care recipient to appointments or assisting with bathing.

“Oh, it makes my one of my responsibilities. It just kind of disappeared. I still have other things, like getting her to appointments and getting her to have a bath, what have you and but those the medicine was the most stressful for me, but I don't have medical background, the biggest pressure off my shoulders.....it took a big load off my shoulders and not having the time restriction on me to make sure my mom had her medicines on time is a big I can do other things. So, very helpful” Caregiver 009

Caregivers viewed caregiver burden as a multidimensional strain that they experienced as their role extended beyond managing medications. For instance, a caregiver could be navigating the challenges of

their partner's physical decline and reduced mobility. This ongoing situation is emotionally difficult for both, but they try to remain as active and positive as possible within their limits.

“Because it's not so much just about the medication. It's just the whole thing, like, because he can't get around as much as he used to, and he's weaker than he used to be, so a lot of it is physical things that we have to deal with. And he's not happy to be that way, and I'm not happy that he's that way, either, but we make the best of it, and we try to be active as much as is possible. So there's not just the medication part of the relationship, there's the health part of it, physical part of it.” Caregiver 008

While the medication support helped to some extent, for some caregivers, it did not dramatically reduce their responsibilities or free up significant time; it simply made daily routines a bit easier when things worked as intended.

“It's just one less of the day to day activities. I wouldn't say it freed me up to do a lot more. Just, was just one less thing. Yeah, I can't, I don't know how I can specify that. It's not like, it was like, Oh, I have a whole half an hour that I can go, you know, do a hobby or something. It didn't. It didn't free me up like that. It just made things in the day to day a little easier when it worked.” Caregiver 010

Moreover, when the caregiver was responsible for multiple care recipients, even though the AMD managed medications for one person, it did not reduce the caregiver's overall stress because care had to be provided for others without the same support.

“Although I still had to go to the pharmacy because I had to pick up stuff for myself, I had to pick up stuff for my son, so I'm still going to the pharmacy. So if only one person is on spencer, it's not relieving the rest of the people of the house.” Caregiver 007

Most caregivers had a positive experience with the AMD, especially when it functioned smoothly without technical issues. None of the medication management tasks were reported to have worsened with the use of the device, which contributed to overall caregiver satisfaction.

“She didn't take the wrong one. I was there to make sure she didn't. So it's freed up my time and it's given me a lot of peace of mind that the medicine is going to be delivered. The right medicine is going to be delivered at the right time, and she's taking them.” Caregiver 009

4. Caregivers-care recipients' relationship

4.1. Impact on the nature of the relationship

Exchanging information between the caregiver and care recipient about medication-taking became easier with the AMD, as the instructions remained consistent each time. The care recipient had more control over medication-taking, which led to less criticism from caregivers and, in turn, improved communication for some.

“I just, I think, because my mom then took pride in what she was doing this on her own, and it was working, and so then that made her and better, and then I wasn't bothering her, criticizing her, whatever, for not taking things on time, so definitely communication wise, that would make a difference.”

Caregiver010

Few caregivers reported that the AMD did not affect how they interacted or connected, while others noticed less frustration in their relationships and there were fewer conflicts or arguments about medication taking.

“Like, that's just how we work....we're married almost 42 years, so it's like, that's just the way we operate.” Caregiver 001

“Well, I have less of a burden. I guess I do a bit, because he can't fight this venture about. Getting these meds out. spencer gives them when he gives them, whereas, you know, if he says, oh, I want to take my afternoon pills now, well, no, it's not afternoon. Why are you doing that? So there's less conflict between us, because he can have the conflict with spencer.” Caregiver 007

“I think our relationship is good, but it's always been Good. I think I had less moments of frustration about surrounding it with interprets as anger, but I'm not angry. I'm just kind of frustrated, but I think we have a good relationship.” Caregiver 010

The dynamic shifted from a caregiver–care recipient relationship to a more familial and emotionally connected bond. One caregiver described how she and her mother were able to enjoy their time together more, engaging in conversations unrelated to medications and playing games.

“Well, before I could go and visit her as a daughter and not have to nag her about whether she took her medicine or whether she didn't, and she is better for it, so she's not on a roller coaster jumping from medicine to medicine. Things are stable now for her, for now, and we can just play cards or talk about the weather, or she can tell me what that haircut or not. So it's really helped our relationship move from caregiver to back to Mother, being her daughter instead of her, her mom.” Caregiver 009

Caregivers also emphasized that having a positive, emotionally supportive relationship with the care recipient played a key role in reducing the perceived burden of care. Caregivers emphasized that the strength of the existing relationship influenced how burdened they felt. When asked to rate the quality of their relationship with the care recipient on a scale from 0 to 10, most rated it highly positive. Their ratings of caregiving burden were similarly low. Caregivers explained that when there is a strong emotional relationship and the care recipient is not giving them grief, particularly in spousal caregiving, the tasks do not feel burdensome. For adult children caring for parents, caregiving was described as an expression of love, affection, and gratitude for still having their parents in their lives.

“Oh, big time. Yes. If I if there wasn't a relationship, the time would be a person could get resentful for the amount of time. I had them over there, but she's my mom, and I have many girlfriends who are saying, You're so blessed to have your mom with you. So I'm just treasuring every moment and very grateful that I

can find ways to make her life easier and keep her dignity that's so very important for her and for me.”

Caregiver 009

“Well, if he wasn't a nice person to get along with, it would probably be a 10 for the burden. But he's very easygoing. He usually has a happy disposition. He doesn't give me grief. So I think because of that, that's what makes our relationship better.” Caregiver 008

2.11. Discussion

The findings of this pilot study show that the use of the AMD has the potential to reduce caregiver burden related to medication management. Although burnout scores decreased over the study period, compassion satisfaction remained relatively stable. This pattern may suggest that the AMD supported aspects of caregivers' emotional fatigue but did not influence their sense of fulfillment or positive feelings associated with caregiving. It is also possible that compassion satisfaction, as a construct, is more stable and less sensitive to short-term changes than burnout, which may explain why only burnout showed noticeable movement in the descriptive data. However, because of our small sample size (7 caregiver–care recipient dyads), the study results must be interpreted with caution. Even though the total FCMAHS score decreased significantly from baseline to the end of the study, there was no statistically significant difference in compassion fatigue or satisfaction. Apart from the small sample size, another possible reason for the lack of significant findings on the ProQoL is that the scale was designed for formal caregivers. While research shows that compassion fatigue and satisfaction also apply to family caregivers,⁷⁹ the ProQoL does not fully capture the relational aspects of caregiving. These relationship-based elements are central to family caregivers' experiences⁷⁹ and may explain why the scale did not reflect the changes seen in our qualitative results.

The FCMAHS scores showed a consistent pattern: burden decreased from baseline to 2 weeks but increased again between 2 weeks and 3 months, except for subscale 3 (safety issues), which steadily

decreased. Despite these fluctuations, all subscales showed an overall reduction in burden from baseline to the end of the study. This suggests that the AMD may reduce caregiver burden when used long-term, and that early fluctuations may reflect caregivers' adjustment period to a new technology, as they navigate technical issues or disruptions to their established routines. The steady decrease in subscale 3 scores may have been due to the AMD's design features that restrict access to medications and to the fact that medications are pre-packaged by the pharmacist and released automatically by the AMD; therefore, caregivers have less responsibility for preparation and administration. These features likely contributed to fewer errors and increased confidence in medication safety. For subscale 1: information seeking and information sharing, scores decreased from baseline to 2 weeks, then increased from 2 weeks to 3 months. According to the post-intervention interviews, this fluctuation may be due to challenges in communication between caregivers and the pharmacy or technical support teams. Subscale 2: scheduling logistics could have been influenced by technical issues. Post-intervention interviews revealed malfunctions, such as jamming or device failure, which could potentially explain the increase in scores between 2 weeks and 3 months, as these issues limited the support the AMD was intended to provide during those times.

For Subscale 4: polypharmacy, the increase in scores between 2 weeks and 3 months may reflect ongoing challenges in managing prescriptions from multiple specialists, something the AMD does not directly address. Although interviews did not highlight this issue, it is possible that prescription coordination became more difficult for some caregivers during this time. However, caregivers did express satisfaction with the timely delivery of medications, suggesting that challenges with refills or holiday planning were not a significant concern. The results suggest that, over time, as caregivers adapted to using the AMD and learned to manage technical issues, the device may have a long-term potential in reducing the burden of medication management.

According to the literature, only two studies have investigated the impact of automated medication dispensers (AMD) on caregiver burden.⁹¹ However, neither of these studies used validated tools specifically designed to measure medication management-related burden.⁹¹ Instead, both relied on scales developed by the authors themselves.⁹¹ Despite this, both studies reported a reduction in caregiver burden when AMDs were used.⁹¹ The first was a pilot study involving 11 participants, which found a decrease in caregiver burden after six months of using an AMD.⁹¹ The second was a case report involving four older adults with Alzheimer's disease and other comorbidities, whose caregivers reported reduced burden over a period of 3 to 4.5 years of AMD use, compared to when the device was not used.⁹³ Our pilot study contributes to the existing literature by being the first to assess the impact of an AMD on medication administration hassles using a validated tool, the Family Caregiver Medication Administration Hassles Scale (FCMAHS), which measures explicitly the burden related to medication management.³⁸

Our pre-intervention interviews findings align with the existing literature, which shows that informal caregivers have diverse responsibilities and that medication management, while demanding, is embedded within a broader set of caregiving duties.¹⁵ Previous studies have shown that assisting older adults with medications contributes to caregiver burden due to the complexity of the task;⁹² however, the AMD replaced many of these high-burden tasks when functioning as intended, which helps explain the observed reductions in caregiver burden and burnout, and the improvements in caregiver–care recipient relationships seen in the post intervention interview. However, the experience with the AMD varied depending on the care recipient's health condition, ability to use the device, openness to change, and the frequency of technical problems. This highlights that technology is not a one-size-fits-all solution. Still, when it works well, it can promote greater independence for care recipients and reduce caregiver burden. This pilot study also adds to the existing literature by identifying a noticeable gap in how caregiver compassion fatigue and satisfaction are assessed in relation to medication management. Although the

literature on compassion fatigue and satisfaction among family caregivers is limited, existing research shows that these constructs are relevant to informal caregivers.^{65,79} Studies by Perry et al. and Ward-Griffin, St-Amant, and Brown reported that caregivers commonly experience moderate levels of compassion satisfaction and burnout, along with varying levels of secondary traumatic stress.⁷⁹ This is very close to the descriptive data of our sample, who had high compassion satisfaction, moderate burnout, and secondary traumatic stress at baseline. The results of this pilot study, therefore, provide a foundation for examining how medication-related challenges may influence caregivers' emotional well-being.

2.12. Feasibility of the Study

Our project faced significant challenges in recruiting participants to use the automated medication dispenser at home. One of the main barriers to recruitment for this study was the reluctance of eligible caregiver–care recipient dyads to switch pharmacies to obtain the AMD, since the device was available only through one pharmacy in Ontario. This reluctance stemmed from concerns about disrupting the care recipient's routine for a three-month study, especially when the care recipient was on a complex medication regimen, prone to hospitalization, going through frequent medication changes, or living with cancer. In these situations, caregivers felt it was safer to remain with their local pharmacy and pharmacist, who already knew the care recipient's complete medical history. Even when the care recipient's condition was stable, both caregivers and care recipients declined to participate because they valued their long-standing relationship with their pharmacist.

Many caregivers described their pharmacist as more than a healthcare provider; they described them as someone they trusted, felt comfortable with, and even saw as part of the family. Caregivers would often visit the pharmacy to talk and share personal stories, not only to pick up medications. This strong personal connection was also one of the main reasons some caregivers chose to return to their original pharmacy

after the study rather than continue using the AMD. In the literature, however, there is a noted gap in understanding pharmacist–caregiver communication. While there is extensive research on pharmacist–patient interactions, very little focuses on how pharmacists communicate with family caregivers. One study showed that although 71% of family caregivers had sought medication-related information from pharmacists, only 21% considered pharmacists their primary source of medication information.¹⁰⁸ This highlights a missed opportunity in the healthcare system, especially given our recruitment experience, which clearly shows that caregivers valued the pharmacist’s role and viewed pharmacists as central to medication management. We contacted 271 potential participants, but only seven caregiver–care recipient pairs participated in the study. To support recruitment efforts, we expanded our community outreach by contacting retirement homes, community centers, libraries, churches, temples, caregiver support organizations, and patient advocacy groups, and requesting that they share our recruitment poster with their members. In addition, we held educational sessions at five retirement homes, two churches, and at the Parkinson’s Society to engage directly with the community and provide information about our pilot study. Moreover, we have modified our eligibility criteria for care recipients to include those with varying levels of cognitive function to expand recruitment and reach the required sample size. The modified care recipient inclusion criteria were age 65 years and older, prescribed 5 or more medications, willing to integrate automated medication dispensers, able to communicate in English, declaring the ability to learn and use the automated medication dispenser, and capable of providing informed consent. The modified exclusion criteria were receiving medication management support from a formal caregiver (e.g., a paid support worker or nurse), unwilling or unable to provide informed consent. Despite these efforts, the primary recruitment barrier (the need to switch pharmacies) persisted and continued to limit participation.

2.13. Conclusion

Overall, the study's findings highlight that AMD's ability to replace many medication management tasks helped reduce caregiver burden, which, in turn, had a positive impact on caregivers' emotional and mental well-being and improved the caregiver–care recipient relationship. This improvement may be reflected as a positive effect on compassion fatigue and compassion satisfaction, since when examining these concepts among family caregivers, we must consider empathy, the psychological response, and the caregiving relationship as key elements, as described by Lynch and Lobo.⁷⁹ The experience with the AMD varied based on the care recipient's abilities, willingness to adapt to new technology, and the frequency of technical problems. This highlights that technology is not a one-size-fits-all solution; however, when it works well, it can promote greater independence for care recipients and reduce medication-related burden for caregivers. To make these benefits more widely available, access to automated medication dispensers should be expanded by increasing their availability across more pharmacies and locations. These steps would also support larger-scale studies to confirm these findings.

Chapter 3

3. Research Project- Study 2

This research project presents the first phase of a two-part project. The first phase is a qualitative study to gather the necessary data to develop a medication management toolkit for caregivers of older adults. The second phase, planned for future work, will focus on validating the toolkit's content using the Delphi consensus method.

3.1. Objectives of the first phase of the project

1. To develop a medication management toolkit by actively involving informal caregivers in identifying and defining its essential components through collaborative participation.

3.2. Study Design

This is a prospective mixed-method study. The goal of employing a mixed-method research design is to provide a more comprehensive understanding by offering a holistic view that enriches the description and comprehension of the study results.^{100,101} This study employed the exploratory sequential design to answer the research question.¹⁰² This type of mixed-method research design approach begins with the qualitative phase, involving the collection and analysis of data from focus groups or semi-structured interviews, followed by quantitative data collection and analysis.¹⁰² The exploratory sequential study design is primarily used to inform the development of a new instrument or classification system for the quantitative phase. In this research project, a qualitative study was conducted, involving focus groups. The qualitative findings were used to inform the key components of the medication management toolkit. In the second phase of the project (the quantitative phase), the Delphi consensus technique will be employed to refine and validate the toolkit's content.¹⁰⁹

3.3. Ethical Consideration

The University of Waterloo Research Ethics Board reviewed this study for approval before recruitment and data collection commenced. Informed consent was obtained during the recruitment process, before data collection from participants.

3.4. Study Setting

This study was conducted online via video chat with participants using the Microsoft Teams platform version 25255.

3.5. Sample Size

Determining an appropriate sample size for qualitative research can be challenging. The aim is to choose a sample that provides in-depth data to understand the subject under investigation thoroughly.¹¹⁰ Sample sizes can vary widely based on each study's specific characteristics. The concept of saturation, in which no new information is obtained from additional data, is the most commonly used guideline for evaluating whether a purposive sample is sufficient.¹¹¹ A purposive sampling method was used to recruit informal caregivers. A convenience sample of 20 informal caregivers was the targeted sample size for this study. A convenience sample is a non-probability sampling method in which participants are selected based on their accessibility and proximity to the researcher. According to Patton (2002), purposeful sampling is a commonly used qualitative research technique aimed at identifying and selecting cases rich in information to make the best use of limited resources.¹¹⁰ According to Cresswell & Plano Clark (2011), this approach involves selecting individuals or groups with significant knowledge or experience relevant to the research topic.^{110,112}

According to Bernard (2002) and Spradley (1979), it is important to focus on the following criteria when selecting participants using purposive sampling, along with knowledge and experience:¹¹⁰

1. Participants who are available and willing to take part in the study.

2. Participants who can express their thoughts and experiences clearly and reflectively.

A purposive sampling technique was used in this study, as it enabled the researcher to select specific individuals (informal caregivers) who could provide deep insights into medication administration hassles. The purposive sampling technique would allow the researcher to engage with participants who have hands-on experience with medication management tasks, gather practical suggestions, and provide feedback on the content of the medication management toolkit. According to Guest et al, on average, conducting two to three focus groups is sufficient to capture 80% of themes, including the most common ones, in a homogenous study population using a semi-structured discussion guide.^{113,114} To capture 90% of themes, three to six focus groups are recommended. Consequently, we aimed to conduct 4 focus groups, each with 5 participants.

3.6. Eligibility Criteria of Participants

3.6.1 Inclusion Criteria for Informal Caregivers

The initial inclusion criteria required active caregivers; however, past caregivers expressed interest in participating, so the inclusion criteria were revised to include them. The final inclusion criteria for informal caregivers were as follows:

1. Ability to speak and read in English
2. Unpaid care partners (e.g., family members, friends, or neighbors) who currently support or have previously supported an older adult 65 years or older with at least one medication management task.
3. The unpaid caregiver must be 18 years of age or older

3.6.2 Exclusion Criteria for Informal Caregivers

1. Not willing to sign the informed consent
2. Not able to speak and read in English

3.7. Study Procedures

3.7.1. Screening and Recruitment Process

A screening questionnaire was used to assess potential participants' eligibility according to the study's inclusion criteria. The participants were recruited from the different sources listed below:

1. Participants who participated in our previous research studies and expressed interest in being contacted for future research.
2. Through study recruitment posters displayed at retirement homes.

3.7.2. Informed Consent

Participants who met the study's eligibility criteria were asked to sign informed consent before data collection.

3.7.3. Data Collection

Initially, participants were asked to actively document the medication management challenges they experienced over one week before attending the focus group discussion, using a documentation sheet provided by the researcher. However, since former (past) caregivers also expressed interest in participating, the procedure was modified to allow retrospective documentation of challenges rather than active documentation before the discussion. The purpose of documenting medication management challenges, whether prospectively or retrospectively, was to facilitate a more meaningful and focused discussion. Focus group discussions were used in the qualitative study to collect data from informal caregivers.^{115,116} Focus groups are a form of group interview that uses participant communication to gather data.^{115,116} Unlike conventional group interviews, which often focus on quickly and conveniently collecting information from several individuals at once, focus groups emphasize interaction among participants as a fundamental part of the process.^{115,116} Instead of the researcher directing questions to individuals in turn, participants are encouraged to engage with each other by asking questions, sharing stories, and

commenting on each other's experiences and perspectives.¹¹⁶ This method is particularly effective for exploring participants' knowledge and experiences, allowing researchers to understand not only what people think but also how and why they think that way.¹¹⁶ This data collection method was chosen because it facilitates bringing informal caregivers together, thereby enabling in-depth discussions of the various medication-related activities they perform. The interactions among participants were used to generate detailed insights into the challenges and problems informal caregivers face in managing their care recipients' medications, as well as to identify the tools and strategies they used to address these challenges.¹¹⁵ In this qualitative study, focus groups were conducted with 16 informal caregivers. According to Krueger in *Focus Groups: A Practical Guide for Applied Research*, a focus group study is a systematically organized set of discussions to gather opinions on a specific topic in a welcoming, non-intimidating environment.¹¹⁷ Each session involves 5-10 participants and is facilitated by an experienced interviewer or moderator. This qualitative study included four focus groups, each with 2-5 participants, for a total of 16 participants. A focus group facilitator led the focus group sessions, and the assistant moderator took notes. The sessions were recorded and lasted approximately 90-120 minutes. All focus group sessions were conducted online via video chat using Microsoft Teams version 25255. The Patient Work System (PWS) model illustrates how interactions between persons (patients, informal caregivers, and healthcare professionals), tasks, tools, and context (physical-spatial, social-cultural, and organizational environments) collectively shape performance processes and outcomes within healthcare settings.¹¹⁸ The interview guide was structured to explore various aspects of medication management among informal caregivers, following the Patient Work System (PWS) model.¹¹⁸ The guide explores medication management tasks, prompting caregivers to describe their typical routines and any challenges they encounter. It explores the tools and technology currently used, assessing their effectiveness and identifying potential improvements. The physical environment section examined the setting in which

medication management occurs, identifying aspects that facilitate or hinder the process.¹¹⁸ Moving to the organizational environment, caregivers were asked about their interactions with healthcare providers and the support received. The social environment section explores the role of friends, family, and support groups in medication management, collecting information about the support currently received and additional support that would be helpful.¹¹⁸ The guide then focused on developing the toolkit, seeking input on key components that would help with the different challenges faced during medication management and the preferred format for the toolkit.¹¹⁸ The interview guide is attached in Appendix C.

3.7.4. Member Checking

In qualitative research, the researcher often serves as both the data collector and the data analyst, which can introduce bias.¹¹⁹ Researchers might unintentionally project their own beliefs and interests onto the research process, resulting in their perspectives dominating those of the participants.¹¹⁹ To reduce this bias, researchers can involve participants in reviewing and confirming the study findings. This practice, known as member checking or participant validation, involves returning interview transcripts or analyzed data to participants to ensure the accuracy and trustworthiness of the findings.¹¹⁹ There are various methods of member checking, such as sending verbatim transcripts to participants, conducting member check interviews, organizing member check focus groups, and using synthesized analyzed data for member checking.¹¹⁹ In this study, the chosen method is member checking of synthesized analyzed data.

¹¹⁹ This approach was chosen for this study as it is the most suitable for determining if the study findings align with the participants' experiences.¹¹⁹ The process of member checking of the synthesized analyzed data combines elements of both positivist and constructionist approaches.¹¹⁹ This method involved presenting synthesized or analyzed data to participants for validation as well as allowing participants to comment on the interpretations made by the researcher and provide feedback.¹¹⁹ The member checking process was conducted after completing the data analysis of all focus groups. The focus group transcripts

were analyzed using the framework analysis method as outlined by Gale, N.K., Heath, G., Cameron, E. , et al¹²⁰. The participants received an email with a cover letter accompanying the member-checking document, explaining that it summarizes the results of the analysis of all the focus group discussions.¹¹⁹ Participants were invited to review the document and provide feedback on whether the synthesized results accurately reflected their experiences, and if there were any changes they would suggest.¹¹⁹

3.8. Data Analysis

3.8.1. Framework Analysis

The framework analysis method was used to analyze the transcripts from the four focus groups. The steps of framework analysis include transcription, familiarization with the transcripts, coding, developing a working analytical framework, applying the analytical framework (indexing), charting data into a matrix, and interpreting the data. The process began with transcription using Otter AI version 3.101.0, where all focus group discussions were transcribed verbatim. This was followed by familiarization, during which two researchers (KG and BB) read and re-read the transcripts to gain a deep understanding of the data. Next was the coding stage, where KG and BB independently coded the transcripts of the four focus groups using an inductive approach, allowing codes to emerge directly from the data. After coding each transcript, KG and BB met regularly to discuss and resolve any discrepancies, ensuring consistency and agreement in the coding process. KG and BB generated themes based on emerging patterns and collaboratively developed a working analytical framework by organizing similar codes into broader categories. The analytical framework was not applied in an additional indexing phase. During the charting stage, the data were summarized and organized into a matrix, with each row representing a participant and each column a theme. This format allowed the researchers to compare data across participants and themes easily. Finally, in the interpretation stage, the researcher reviewed the matrix to identify key patterns and write the study findings.

3.9. Results

3.9.1. Demographics

A total of 16 caregivers participated in the study, with a median age (Q1-Q3) of 68 years (61-76). The majority were females (81.25%), while 12.5% were males. In terms of gender identity, most participants identified as women (n = 13), followed by men (n = 2) and one participant who identified as a trans woman. Nearly all participants identified as White (n = 15), with one identifying as East Asian. Table 6 provides a detailed description of the study participants.

Table 6: Demographics of the caregivers

Variable	Category	N (%)	Median (Q1-Q3)	Mean ± SD
Age	-	16 (100%)	68 (61-76)	-
Sex at birth	Male	2 (12.5%)	-	-
	Female	13 (81.25%)	-	-
	Prefer not to say	1 (6.25%)	-	-
Gender	Man	2 (12.5%)	-	-
	Woman	13 (81.25%)	-	-
	Transwoman	1 (6.25%)	-	-
Ethnicity	White	15 (93.75%)	-	-
	East Asian	1 (6.25%)	-	-
Occupation	Retired	12 (75%)	-	-

	Employed	3 (18.75%)	-	-
	Prefer not to say	1 (6.25%)	-	-
Highest level of education	High school diploma	5 (31.25%)	-	-
	Undergraduate degree	6 (37.5%)	-	-
	Graduate degree and higher	4 (25%)	-	-
	Other- College/Diploma	1 (6.25%)	-	-
Relationship to the caregiver	Spouse	11 (68.75%)	-	-
	Parent	5 (31.25%)		
Duration of the caregiver-care recipient relationship	-	-	-	48.5 years (± 13.30)
Duration of the caregiving relationship	-	-	-	7.94 years (± 9.95)
Number of medications managed by the caregiver	-	-	-	8.38 (± 5.07)
Caregiver currently living with the care recipient	Yes	14 (87.5 %)	-	-
	No	1 (6.25 %)	-	-
Lived with the care recipient before death	Yes	1 (6.25 %)	-	-

Caregivers providing support with medication management	Yes	16 (100%)	-	-
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Table 7: Medication management tasks performed by family caregivers

Medication management tasks	Category	N (%)
Picking up medications from the pharmacy	Monthly	5 (31.25)
	Weekly	2 (12.5)
	biweekly	4 (25)
	Every 3 months	3 (18.75)
	Every 2 months	2 (12.5)
Reminding the care recipient to take medications	Daily	8 (50)
	Weekly	3 (18.75)
	Multiple times a day	3 (18.75)
	Never	2 (12.5)
Directly administering medications	Never	7 (43.75)
	Every dose	5 (31.25)
	Less than 50% of the doses	1 (6.25)
	Less than 20% of the doses	2 (12.5)
	Less than 70% of the doses	1 (6.25)
Organizing medications	weekly	6 (37.5)

	biweekly	3 (18.75)
	Never	6 (37.5)
	Daily	1 (6.25)
Communicating with healthcare providers	Weekly	2 (12.5)
	Monthly	10 (62.5)
	Other- as needed	1 (6.25)
	Other- occasionally	2 (12.5)
	Biweekly	1 (6.25)
Deciding on dosing changes or new medications	Weekly	1 (6.25)
	Monthly	3 (18.75)
	Other- as needed	5 (31.25)
	Never	7 (43.75)

3.9.2. Qualitative Results

The framework analysis for this study resulted in six themes: (1) caregiver–care recipient relationship and caregiving context, (2) challenges with medication management, (3) medication management strategies, (4) non-medication management tasks, (5) caregivers’ preferences for toolkit format and content, and (6) additional support with medication management. In our sample, four caregivers were supporting care recipients with dementia, and one participant was a past caregiver, the only past caregiver included in this study.

3.9.2.1. Theme 1: Caregiver-Recipient Relationship and Caregiving Context

This theme describes the type and length of caregiving, focusing on the feelings, behaviors, and communication between the caregiver and the person receiving care. It also explains when caregiving began, how long it has continued, and the daily tasks involved in managing medications. The findings of this theme reveal that caregivers were primarily family members, mainly spouses and adult children with long-term personal relationships ranging from lifelong to over 10 years. Caregiving relationships typically lasted from a few years to over a decade. Caregiving was often triggered by changes in the care recipient's health condition, such as hospitalizations, sudden medical issues, age-related deterioration, or the use of multiple medications within a complex regimen. The personal relationships between caregivers and care recipients ranged widely. Some reflected strong emotional bonds where love drove a sense of responsibility. Others showed close connections marked by good communication and mutual understanding, sometimes without words. In some cases, relationships were friendly, while in others, there were some conflicts and frictions, particularly in dementia care.

“It's we've reached that stage of role reversal where my mom is 82 I'm 62 I am her power of attorney and her primary caregiver, the only one in the country, because my two brothers both live very far internationally, and our relationship has moments of friction because the their dementia, I'm trying to make decisions, but they're not ones that she necessarily wants to be aware of or accept. So I'd say 75% of the time we're okay, but there's 25% of the time it's not comfortable for either of us.” Speaker 6 focus group 2

Caregiving relationships varied in quality, some were positive, promoting independence and respect for the care recipient's autonomy. Others were not uniformly easy or difficult. Some caregivers described the relationships as continuous, demanding, and exhausting, especially when dealing with health-related changes or the care recipient's emotional difficulties. Some faced challenges with argumentative behavior

or frustration due to non-compliance, whether intentional or unintentional. Caregiving could also involve teamwork and shared responsibility. For some caregivers, the relationships shifted from a familial dynamic to a caregiver–care recipient dynamic as the care recipient's health declined. Increasing dependence due to worsening health or cognitive decline led caregivers to become more involved, sometimes becoming decision-makers in cases of dementia. Caregivers also provided emotional support and reassurance during times of health transition.

“In my case, yeah, we've been married over 42 years so and we do both we're both retired, so do a lot of stuff together. Most stuff together, actually” Speaker 3 focus group 2

“ I am taking care of both my parents and yeah, they're still quite independent. There's quite a few chronic health issues or conditions that we're juggling “ Speaker 4 focus group 3

Medication management tasks included organizing medications, reminding the care recipient to take them on time, monitoring for side effects, communicating with healthcare providers, advocating for the care recipient, cutting or splitting pills, administering medications, overseeing overall health, reordering medications from the pharmacy, and maintaining the medication inventory at home.

“So now I just have to pick it up and rip a strip off for the whole day, morning, noons, night. It's pretty easy to do it that way. The top of the blister pack has the list of the medications and a picture of them that each day, for Monday, Tuesday, etc, each or, I'm sorry, breakfast, lunch, dinner lists.....I have to make sure that he's if he's used his last puff in the buffer, he needs to tell me that he's used that up, because I don't always know. It depends on how many puffs he takes.” Speaker 6 focus group 1

3.9.2.2. Theme 2: Challenges With Medication Management

1. Care-recipient-related barriers affecting caregivers' medication management

Caregivers faced challenges arising from the care recipient's health or behaviour, such as resistance or refusal behaviours, confusion, and forgetfulness, which can make medication management more difficult for caregivers.

1.1. Resistance to advice

Caregivers reported that some care recipients showed resistance to guidance, which made medication management difficult. Some care recipients believed they fully understood their medications and therefore refused the caregiver's advice.

"They think that they're, they know enough now that they can become the doctor." Speaker 2, Focus group 1

Others argued about medication timing, ignored reminders, or required repetitive prompting to take their doses. These behaviors made it more challenging for caregivers to ensure that medications were taken as prescribed.

"Well, I would, for example, he takes the first medications at eight o'clock in the morning. So I would remind him, okay, it's eight o'clock and you take your pills..... We'd have a lot of arguments about even starting the pills first thing of the day, and I was being really tired of listening my own voice nagging, yeah.....It was that that kind of thing require a lot of negotiation." Speaker 4, Focus Group 1

Caregivers also noted that some care recipients were inconsistent in monitoring their health metrics, such as blood pressure and blood sugar levels, further complicating the caregiving process.

"My husband's that way about sugar. He wants to eat and love the sugar, but doesn't want to check his sugar." Speaker 4, focus group 1

1.2. Physical and dexterity-related challenges

Caregivers described problems ensuring medication was swallowed and not dropped or lost during administration. Care recipients with dexterity problems sometimes dropped pills on the floor, while those with visual impairments lost tiny tablets that got stuck between their fingers or fell without being noticed.

“I have to make sure to look and make sure that she's taking them all or and again, there's, there's the odd time that, because of the physical dexterity, probably do drop on the floor, the odd time she might”

Speaker 2, focus group 2

“If he just pops everything in his mouth, which he usually does, and I do that too, just to get it over and done with, but if it gets caught in between his fingers, then that pill doesn't get swallowed. And sometimes it can fall on the floor, but it's so tiny that he can't see it like any pill that falls on the floor.”

Speaker 3, focus group 2

1.3. Dementia-related challenges affecting medication management

Caregivers of people with dementia described several behavior-related challenges with medication management. Some dementia patients refused to take medication because of changes in the pill's color, taste, or texture, or because they believed it was not the same pill they usually took. Others chewed and spat out medications, hid or hoarded pills, or refused to follow medication's specific instructions, such as taking medication on an empty stomach. Forgetfulness and confusion were also common, leading to missed or double doses when the person could not remember if they had already taken their medication. Verbal reminders over the phone were not helpful, as instructions were quickly forgotten. Care recipients with dementia often needed frequent help with medication administration because they did not know how many tablets to take. Preparing medications early sometimes caused confusion, as the care recipient kept asking if it was time to take them. Caregivers also found it hard to rely on care recipients with dementia to use weekly pill organizers independently due to the risk of double-dosing.

“But two years ago, it started to become problematic, you know..I call it the dementia, she'd ask him, have you taken your meds? He would look at the pill pack, and he would double dose.....He didn't like the textures. He wouldn't take it and then fine, when the manufacturer change the color slightly. He didn't recognize that his dementia was advanced, and he wouldn't recognize and then he kept saying, No, I don't take this...the pills that are capsules he will chew and spit out. I keep putting, spit it out. ” Speaker

6, Focus group 2

2. Knowledge and understanding of medications

Caregivers reported difficulties understanding and managing medication-related information. Some found it challenging to know the indication and administration time for each medication, as well as to determine which medication might be causing specific side effects. Distinguishing whether a symptom or behavioral change was caused by a medication or by the underlying health condition, such as Parkinson's disease, was also difficult.

“You open up the medicine cabinet and there's 30 pill containers in there, and then figuring out which pill goes for what container and what it's for. And that was my challenge at that time” Speaker 5, focus group

1

“Many of my husband's medications have the same side effects as each other, so it's hard to know which one's responsible for the side effect, and the medical conditions also have what appeared to be side effects as a symptom of the disease. So it's really challenging” Speaker 4 focus group 1

Some caregivers struggled to decide whether to stop a medication that appeared to be causing side effects when immediate medical support was not available.

“I mean, this is one drug...they put her on, and her whole attitude or mentality changed 180 degrees from a sweet person she was ready to get on a broomstick and go with her mother, back to Nova Scotia, but, but no, I'm serious. We took her right off it even before the doctor said so. My wife said, we got to take me

off this. And then we told the doctor what's going on. Doctor finally said, Okay, well, put her on something else...it was a challenge” Speaker 5, Focus group 1

Caregivers noted that information about side effects varied significantly across websites from different countries, making it difficult to find reliable and trustworthy medication-related information. The use of AI-generated responses further complicated this process, as the information was drawn from multiple sources and not always verified. Medication leaflets provided by pharmacies were described as dense and difficult to read due to their formatting. Additionally, not knowing the expiry dates of unused medications at home added to their uncertainty.

“AI has made things challenging too, because they're consolidating information from numerous websites, which may be contradictory as well.” Speaker 4, focus group1

“I find, I find that the handout that comes from the pharmacy, at least pharmacy that we deal with like, it's very, sort of standardized and sort of like, the way that information is laid out is not very like, is quite dense of a read like, whatever. So there's, you know, very little spacing, and it's just words bunched together.” Speaker 4 Focus group 3

3. Medication organization and tools-related challenges

Caregivers described several challenges when using medication compliance aids such as pill organizers, blister packs, and automated medication dispensers (AMD).

3.1. Pill organizers

Some mentioned that they were not suitable for complex medication schedules, such as those requiring five doses per day, because they did not clearly indicate the specific times medications should be taken. The compartments often wore out with constant use or were too small to fit larger pills. Organizing multiple medications was time-consuming, and some caregivers forgot to refill the pill organizer or to remind the

care recipient to take their medications. In addition, caregivers found that pill organizers could not hold all the medications that the care recipient is taking.

“From my perspective, is he wouldn't tell you when to take the pills. So if you take one pill five times a day, you have five of those pills in there. That's confusing” Speaker 2 Focus group 1

“They're all different sizes, and pills are all different sizes, so they don't always all fit. Sometimes the paint wears off from opening and closing them, so that you've just left with like, a raised ridge for the day of the week, rather than the colors often. So I guess what I'm saying there, is that they don't last too long.”

Speaker 3 Focus group 3

3.2. Blister packs

Blister packs were also associated with multiple challenges. Caregivers noted that these packs had limited capacity to hold all medications and vitamins. They also mentioned that blister packs were not suitable for certain dosage forms, such as injectables. Tiny tablets occasionally got stuck inside the packs, making them hard to retrieve. Blister packs were not suitable for care recipients with memory problems because caregivers still needed to remind them to take their medications, and there was a risk of double-dosing.

“Although they got bigger blister packs. But I'm just saying it says, like I have certain pills and blister packs, and then I have other medications, I think that do not go into blister packs, that they have to be taken, like once every like once a once a week. Okay? Like my Ozempic injections, they're once every week, so they can't go into blister pack. Okay, so there are some medications that you cannot put into blister pack.” Speaker 5 Focus group1

3.3. Automated medication dispensers (AMD)

Caregivers using automated medication dispensers reported difficulties adding new prescriptions or adjusting medications after prescription changes. Problems such as medication jamming, misplacement of cartridges by delivery personnel, and delays in loading new medications were mentioned. Some caregivers faced challenges when they were asked to change pharmacies to use the AMD or get the medication cartridges from a centralized distribution point far from home. This caused inconvenience, especially for those who preferred face-to-face communication with their local pharmacy team. Delivery problems, such as delays during the Canada Post strike, were also challenging. Cost was also a concern. Caregivers also expressed difficulty managing vitamins and minerals that were not included in the dispenser. Some challenges were not specific to one organizational tool. Caregivers mentioned problems such as the lack of suitable tools for organizing powders and liquid medications. Cutting or splitting small tablets was also difficult, and handling tablets that disintegrated quickly made administration challenging.

“And that comes down to trust. And I agree because when I, when I followed through, they mail them, they mail these special packs, and you stick into a machine. And it was out of Mississauga, centralized credential distribution point. And I, too, felt very uncomfortable concept of, if I need to change something in a moment, who am I talking to? Like, I need that personally. I also need that face to face continuity with the pharmacy” Speaker 6 focus group 6

“I Liquids are hard and powders, I think if you can figure something out, that would be wonderful.”

Speaker 1 focus group 3

4. Staying on track with medications

Caregivers described several challenges in ensuring that the care recipient took the correct medication, at the right dose, and at the right time as prescribed.

4.1. Timing and adherence

Caregivers reported difficulty staying current on medication management and giving medications on time. Maintaining consistent timing for time-sensitive medications was challenging, especially when daily routines varied. Scheduling medications multiple times throughout the day, such as in the case of Parkinson's disease, was also difficult. Some caregivers found it hard to ensure that medications were taken after giving verbal reminders as care recipients forgets to take their medication or to confirm that the medication was swallowed. In households with multiple care recipients, caregivers worried that medications could be mixed up, particularly when both individuals used pill organizers or when automated medication dispensers dispensed doses simultaneously.

"My problem was mainly making sure that he took the right pill at the right time in the right quantity"

Speaker 4 focus group 1

"The only struggle I had was I had the box that was the 30 days or 28 days. I was worried my mother was gonna take my dad's pills, because they were kind of on the same medication, I think. But my dad was a couple different things." Speaker 1 Focus group 3

4.2. System-related challenges

Some caregivers experienced medication administration errors in healthcare settings due to poor communication or a lack of follow-up. Others reported pharmacy errors, such as medications missing from blister packs, requiring them to stay vigilant.

"His blood pressure pill was missed, so he went for a number of days without his blood pressure pill, which isn't great. So they and I told the doctor, he normally takes blood pressure pill, but it's not in this blister pack. And so then he the neurologist then prescribed blood pressure pill for him, so he was getting it every day, but, and that was one of the reasons I kind of thought, I don't know if this is such a good plan,

because, again, I don't have control." Speaker 3 focus group 2

4.3. Complex medication regimens

Managing complex medication regimens was difficult. Caregivers struggled with scheduling multiple medications throughout the day, tracking dose changes, and adjusting to evolving regimens over time. In some cases, complex eye drops schedules following surgery required frequent administration, which was challenging to manage. Managing and tracking medications became even more complicated during hospital stays or emergencies abroad, where new prescriptions, leftover medications, and language barriers added confusion. Caregivers also struggled with uncertainty about medication changes, especially when they were not present during medical appointments. This often left them confused about which medications had been stopped or modified.

“My husband has Parkinson's so he takes medications every three and a half hours.... it was all over the place. He would take them. First one sometimes on time, and the next one was too early or too late or. Not sure if he took it. So, yes, keeping track of the scheduling was really, really challenging, and he can't work his phone, so a timer on the phone wouldn't have helped at all.” Speaker 4 focus group 1

“I knew off my heart at that time what exactly he needed to take. And then his anti convulsive meds, they changed. So then the ones that we had, I just stuck in a zip lock bag and put it in my purse, because I had all these leftover meds, and I'm not going to leave them there, because they didn't know if he would have to go back on them, which he eventually did go back. So that was probably my biggest challenge, was other than the, you know, the language barrier.” Speaker 3 focus group 2

5. Communication and access to healthcare providers

Caregivers described several challenges related to accessing healthcare providers and communicating about medications.

5.1. Access to physicians and medical support

Caregivers reported difficulties accessing physicians when needed. Some mentioned not having a family doctor or experiencing a lack of professional medical support. Others noted that physicians were not easily accessible, with long waiting times, delayed responses to new prescription requests, and difficulty scheduling follow-up appointments. In some cases, caregivers said it was difficult to reach a doctor in emergencies, such as when a care recipient experienced a medication side effect.

“If there's going to be a follow up, I book the appointment right then and there. Otherwise, don't wait another three weeks to get in for half a year or longer, COVID. We saw the neurologist every 18 months.”

Speaker 4 focus group 1

5.2. Coordination between healthcare providers

Lack of coordination between multiple specialists was commonly described. Caregivers noted that, in the absence of a family doctor who could look at the patient holistically, coordination between specialists was poor, and each specialist was often unaware of the medications prescribed by others. Prescription-related coordination was also a common problem. Caregivers reported challenges with changes in prescriptions not being communicated to them promptly, as well as difficulties coordinating prescriptions between providers and pharmacies. The process of having prescriptions faxed from the doctor's office to the pharmacy was described as complicated. When refills ran out, caregivers often had to follow up repeatedly with both the doctor's office and the pharmacy to ensure that a new prescription was sent. Obtaining vacation refill authorizations from multiple healthcare providers was also challenging. In some cases, caregivers received partial refills from the pharmacy, leading to confusion about whether the given quantity would last for the required duration.

“I have to call the pharmacy to get them to fax the request over to the doctor, to get the doctor to send the fax back to the pharmacy saying it's okay you can give them these medications. So before I would just call the doctor's office, talking to secretary, and say, listen, I need these new medications or repeats, but

now I got to call the pharmacy, to fax the doctor, to fax the pharmacy to let you get your medications.

That's right. So that's the problems we're having with that” Speaker 5 focus group 1

“He's got a lot of different specialists that we see. And so keeping our connecting with all those specialists, making sure they're aware of what the other specialist is doing or saying, is a big part of what I do when I go to those meetings and or part of my follow up. You know, one is recommending something and the other doctor has said something else. I find that a real challenge to make sure all those doctors are in the loop with what medications are being recommended.” Speaker 4 focus group 2

5.3. Communication challenges

Caregivers reported challenges in communicating effectively with healthcare providers. Some described non-supportive or dismissive health care providers who did not take the time to listen to their concerns or answer questions about medications. Others mentioned that healthcare providers rushed appointments and did not spend enough time explaining the medication. Due to the limited number of doctors available, caregivers felt there was little opportunity for thorough communication. Caregivers expressed uncertainty about whom to contact when a medication refill was needed. They also described challenges in correctly communicating information about the medications being taken and in understanding the information shared during medical appointments, especially regarding possible side effects to watch for.

“Actually, the only time I've ever had a problem was back in July, my wife, she was to hospitalize for pneumonia, and I took up the medication sheet and a couple of days worth of medication, and I talked to the nurse who just happened to be in the room at that time, and I tried to hand them to her, and I was basically dismissed. I was just told, don't you worry. We take care of things. And I mean, I don't, I don't mind having a good discussion with people and talking it out, but I will not be dismissed off hand.”

Speaker 2 focus group 2

“I'm not sure who's how we're going to get those other medications, prescriptions refilled. No idea.”

Speaker 6 focus group 1

6. Medication supply and refills

Caregivers described several challenges related to ordering and maintaining an adequate supply of medications for their care recipients.

6.1. Tracking and ordering medications

Caregivers reported difficulties keeping track of remaining refills and ensuring that medications did not run out. Remembering to order medications on time was challenging, especially when caregivers were occupied with other responsibilities. Some caregivers mentioned that it could be challenging to pick up medications from the pharmacy, especially when it was far from home or during winter.

“Because I got a lot of my mind too, so I can't really remember everything.” Speaker 1 focus group 3

“It only takes 10 minutes from my place, I have no problem, but I can see other people who are living further away from the drugstore, especially if they can't drive or the wintertime” Speaker 3 focus group 3

6.2. Medication availability

Drug shortages were reported as a concern, with caregivers experiencing uncertainty about when medications would be back in stock. Some also mentioned not receiving the preferred generic brand that the care recipient was used to, leading to worries about potential side effects or differences in response due to brand changes.

“But what sometimes can get really challenging is that, you know, there's not really any certainty that the pharmacies can give as to what about if they're generic brand, or whatever that they look for, there's not really any clarity that we can find out from the pharmacies when it might return to being in stock.”

Speaker 4 focus group 3

7. Medication storage

Caregivers described several concerns related to storing medications safely at home and while traveling

7.1. Storage space and safety at home

Some caregivers reported limited space for storing medications in their apartments. Safe storage around children was also a concern, particularly for drugs such as narcotics, as caregivers worried about the risk of accidental ingestion.

“If we're traveling and we're staying at my daughter's house with young children, you have to be careful of your meds. Yes, we carry a lock box, but we also carry Narcan with us. Could there be an overdose?”

Speaker 6 focus group 1

7.2. Storage during travel

Caregivers reported difficulty maintaining proper medication storage while traveling, especially for medications that require specific temperature or storage conditions.

“So I don't have any of those experiences, but I know from having to do liquid medication....that does become an issue. You can't go anywhere without carrying an ice pack.” Speaker 6 focus group 2

7.3. Disposal of sharp objects

Caregivers also reported difficulties with safely disposing of sharp objects, such as lancets used to check the care recipient's blood sugar levels.

“The only thing I have a problem is, I check my mother's blood sugar every week in the needle. I don't know how to get rid of it.” Speaker 1 focus group 3

8. Financial burden

Caregivers described potential concerns about out-of-pocket expenses for medications and related supplies. Some caregivers expressed concern about the possible financial burden if the care recipient were to be admitted to a long-term care facility or retirement home, as the cost of medication administration in these settings can be high. Others mentioned that medication costs could become a

problem during drug shortages when only brand-name products are available instead of lower-cost generic options.

“It was \$300 a month. So cost is a factor whether you're so, yeah, if you're not at home. So if you're only dealing with home caregivers, it's different if your person's in a residence,” Speaker 6 focus group 1

9. Medication management and adult day programs

Caregivers described challenges in managing medications for care recipients who attended adult day programs. Some caregivers reported that staff at these programs were not permitted to administer medications to attendees. Others mentioned that different adult day programs had varying rules about how medications needed to be packaged, which created additional challenges for caregivers.

“Where the VON runs activity days, and they are not allowed, as somebody else said, many people, many of these people, are not allowed to give medication...That's the only real problem.” Speaker 2 focus group 2

10. Handling emergencies

Caregivers described challenges related to responding to urgent or unexpected health situations involving the care recipient. Some caregivers expressed difficulty knowing how to help when the care recipient collapsed or experienced a medical emergency.

“Yeah, when it was COVID and he collapsed.....the second time, when he collapsed, just collapsed. I couldn't get him up, and it was evening.” Speaker 3 focus group 3

3.9.2.3. Theme 3: Medication Management Strategies

1. Solutions to behavioral barriers to medication taking

Caregivers described various strategies to manage and overcome behavioral challenges that affected medication adherence among care recipients.

1.1. Resistance to guidance

1.1.1. Engaging healthcare providers

Some caregivers suggested getting help from physicians or pharmacists to explain the importance of medication adherence to the care recipient, particularly when dealing with resistance to advice.

“Enlist the physician and or pharmacist to help out. With that, then that, at least in my case, has been somewhat effective.” Speaker 4 focus group 1

1.1.2. Respecting autonomy and providing verbal reminders

For care recipients without dementia, caregivers provided verbal reminders to take medications at the correct time while respecting the care recipient’s autonomy and decision-making capacity.

“I’ll remind him, you know you’re going to fall asleep if you take that now. But his choice there’s, I mean, he still has decision making capabilities. Speaker 6 focus group 1

1.2. Dementia care

1.2.1. Verbal and visual reminders

Caregivers supporting individuals with dementia relied on repeated verbal reminders to ensure medication adherence. Strategies included placing medications in visible locations, providing constant verbal reminders throughout the day, and making phone calls to remind care recipients to take their medications and staying on the line until the task was completed. Caregivers created visual reminder systems, such as lining up pill containers in a fixed location and moving them once the doses were taken. It was pointed out that it is important to develop new approaches to convince care recipients with dementia to take medications. Personalized video messages or video calls from loved ones were also used to motivate dementia care recipients to take their medications.

“But she’s just she needs to be constantly reminded.” Speaker 1 focus group 3

“So, I wonder if doing a little video like your grandchild, having the grandchild do a video that you would show him, you know, every second day, or would help a little bit, you know, or that video, or FaceTime even do a quick look FaceTime, and then they're asking for the grandparent, you know, to take that like me and to consider caring then for recommendation.” Speaker 4 focus group 2

1.2.2. Pre-organization and supervision

Some caregivers pre-organized medications and gave clear instructions about when to take them. Others prepared medications only at the scheduled time to prevent early dosing. Supervising administration was a common approach; caregivers placed pills directly into the care recipient's hand, watched them swallow, and checked the surroundings afterward to ensure that no pills were dropped or missed. Ongoing monitoring and verbal checks were also used, including repeatedly asking whether medications had been taken or swallowed.

“So now it is putting in the hand and watching her take as I could put it on the table, but we still have to check, have you taken them? Have you swallowed them? And then now new thing is checking on the floor because of pills dropping, and then I'm getting to the mouth if I'm not there watching.” Speaker 6 focus group 2

1.2.3. Adapting communication and instruction methods

Patience and simple, repeated step-by-step instructions were important when supporting dementia care recipients. Some caregivers renamed medications as “vitamins” to encourage adherence or asked another person, someone not routinely involved in medication management, to help convince the care recipient to take the medication.

“You have to be very like, how to say it, like, explaining everything, okay, like, “okay, Mom, pick up the box. Okay, you got the blue box in your hand.” “What color do you have in your hand?” Like you got to just kinda to repeat yourself all the time.” Speaker 1 focus group 3

“When I say it’s a vitamin, you should take that. Yeah that’s okay, he he’ll take it. But he does know it’s his, whatever is in there is his.” Speaker 3 focus group 3

1.2.4. Addressing refusal behavior

To overcome refusal related to unpleasant taste, caregivers offered extra water to make swallowing easier. In some cases, medications were hidden in food or fruits to ensure intake, although this method was not always effective. Other caregivers used small rewards, such as offering candy after medication. Wherever possible, caregivers suggested involving a healthcare provider to change the dosage form, such as changing from oral tablets to subcutaneous injections, to overcome refusal and hiding behaviors. Some caregivers also used distraction techniques, such as delaying meals, to ensure that medications were taken at the correct time before food.

“Only one I was hiding in any food, or give them a tiny. The other thing that did help for a while, a little piece of candy along with the pill.....That was the doctor’s suggestion, we’ll put him on Ozempic and that’ll at least get, you know, the insulin in them and some other things.....It’s like, oh, well, that works.....so that’ll eliminate a few pills” Speaker 5 focus group 2

2. Solutions to challenges related to knowledge and understanding of medications

Caregivers described several strategies to improve their understanding of medications and find medication-related information

2.1. Labeling medications

Caregivers reported using labeling techniques to help identify medications and their purposes. Strategies included labeling vials with the medication’s indication, creating medication lists with detailed information about the medication regimen.

“So I started writing right on the label on the bottle, saying high blood pressure, cholesterol, that’s the only way I could do it, is write it right on but then I had to do it every refill.” Speaker 2 focus group 1

“The thing is, what my table is. Every single time I get a new medication, I update the table and then resave it. So it's always, it's always got the latest...It's got, it's got the drug, the dosage. How many refills are on there? The drug number itself. So I, when I call the pharmacy for a drug, I give them the drug number that's off the bottle, the last refill, the quantity remaining, the next refill date, and what it's used for.” Speaker 5 focus group 1

2.2. Recording and monitoring side effects

To keep track of possible adverse effects, caregivers wrote down the major side effects of each medication in a list or table. They also monitored the care recipient for behavioral changes or complaints that might indicate side effects. Some mentioned that having a personal support worker (PSW) visit occasionally as a second observer could help in identifying behavioral changes related to medication use.

“So if it's the same person every single time, that person will recognize a change, especially because they're not sitting here 24/7....So they will see if that person's personality has changed, or if their medical condition is changing, they will notice that right away, because they're not looking at it. 24/7....You can't tell unless you're an outside observer” Speaker 5 focus group 1

2.3. Consulting pharmacists and healthcare professionals

Many caregivers relied on pharmacists as a primary source of medication-related information. They reported participating in annual medication reviews covered by the pharmacy and consulting the pharmacist about new prescriptions or potential drug interactions. Caregivers emphasized the value of having a consistent pharmacy and working with the same pharmacist, which made it easier to ask questions and clarify instructions. When pharmacy pamphlets were dense or difficult to read, caregivers sought direct explanations from the pharmacist, especially when starting new medications. If side effects were observed, caregivers suggested contacting Telehealth Ontario to speak with a nurse for advice since they are available 24/7.

“You can call the nurses Federation of Ontario, or something like that. I got it on the fridge, and you can get a hold of the nurse 24/7 So if you have any problems, you can call them, and they will tell you what's going on. So and they're nurses, they're registered nurses” Speaker 5 focus group 1

“Consulting with the pharmacist on what's being given for any drug interactions.” Speaker 6 focus group 2

2.4. Using written and online information sources

Caregivers used various sources to find medication-related information. Some referred to medication leaflets provided by the pharmacy or used them to look up specific details about medications. Others looked for information online when the leaflets were lost or difficult to read. They described checking reputable online websites, getting information from advocacy or support groups, and books to find medication-related information. Some verified accuracy by cross-referencing multiple websites and considered information reliable when it appeared consistently across sources. Caregivers also mentioned that their prior experience with medications helped them recognize trustworthy websites. Several caregivers reported keeping contact information for Telehealth Ontario nurses posted in a visible place, such as on the refrigerator. The 24/7 access to these nurses provided a resource for addressing urgent medication-related questions or having a direct conversation with the pharmacist.

“I'll get my information from the Internet, from support groups and from purposes. A lot of written materials, like books above that include large chapters on the medication, since there have been so few new medications in the last 50 years. So there's quite a bit of information out there” Speaker 4 focus group 1

“If I have any serious questions, I'll go to the pharmacist, if I have some serious questions. And normally, if it's a new medication, a pharmacist will take me aside and say, Listen, this is what's going on with this med” Speaker 5 focus group 1

3. Solutions to organizational tool problems

Caregivers described several strategies to overcome challenges related to the use of medication organizational tools, such as automated medication dispensers (AMD), pill organizers, and blister packs.

3.1. Automated medication dispensers (AMD)

Caregivers reported several ways to address problems associated with automated medication dispensers. In cases where the dispenser cartridge was misplaced, caregivers filled prescriptions directly from the local pharmacy. When technical issues occurred, caregivers contacted the technical support team for assistance. Some caregivers used an automated medication dispenser as an alternative when blister packs or pill organizers were not preferred or when using a pill organizer was time-consuming. Others chose to use blister packs instead of the AMD because the blister packs were easier to adjust when medication changes occurred. When medication changes occurred, some caregivers visited the care recipient's home daily to remove discontinued medications until the new prescription was filled and added to the medication dispenser cartridge.

“Since we've gone to the blister pack, it's been much better....I didn't want spencer because it was so far away. I want to be have connection with the pharmacist. I didn't want to have to go to Toronto or have to wait two weeks to change, etc. I feel that, I just feel that it's that the communication is that they understand it.” Speaker 6 focus group 1

3.2. Pill organizers

Several strategies were reported to make pill organizers easier to manage. Establishing a routine of 10–15 minutes each night to organize medications made the task more manageable. Caregivers suggested labeling each compartment of the pill organizer with the correct time of day using markers or purchasing organizers that were already labeled. Some labeled each medication bottle with the name, time, and dosage, using these labels as a guide when filling the pill organizer. Visual reminders, such as yellow

stickers or handwritten notes, were also used to indicate medication timing. Caregivers created medication lists that included administration times and used them to guide the placement of pills into the correct compartments. These lists were kept in the same area where medication vials were stored. When pill organizers could not accommodate all medications, caregivers used small dishes or additional containers, such as egg cups, to hold the remaining pills. To avoid confusion while filling the pill organizer, the caregiver would leave one day in to ensure the rest of the days are filled correctly.

“I have a list on the cabinet door, and it says the time and which pills go in, where in the in the pack...It says, at 7am you take this pill and this pill and this pill, and you put it in the 7am pack, and then at three o'clock, or 11 o'clock, you do it here. Three o'clock you do these. So I it's taped right into the door so I can always know which pills I have to set up for the night before for the next day” Speaker 5 focus group 1

“I have a system, I always leave one full day in the organizer, so I'm just visual. Just pop them all in the same as that one day I left in there. Easy.” Speaker 3 focus group 4

3.3. Blister packs

Caregivers used several approaches to improve the usability of blister packs. Some preferred using blister packs to ensure medications were taken as prescribed or as an alternative to pill organizers when those were not suitable. For tiny tablets that got stuck in blister packs, caregivers transferred them into clear, round-bottomed containers, such as shot glasses, to make them easier to retrieve. They also double-checked that the care recipient had taken the medication after the caregiver transferred it.

“I transfer them from the blister pack, because she can't get them out, and I put into like a shot glass for her clear glass. Now, because we tried different things and different shapes and pills would get stuck the small ones or cut in half, or whichever, so now we've gone to completely clear round bottom thing.... I have to check for the fact that everything's come out” Speaker 6 focus group 2

3.4. Managing vitamins, powders, and medications that disintegrate quickly upon contact

Due to limited space in blister packs, caregivers used separate containers to organize vitamins and supplements. Some prepared a separate dossette specifically for supplements to help track them more easily when they were not included in the blister packs. Powders were organized using Tupperware containers labeled for the required days of the week. Caregivers also used measuring cups/spoons that came with liquid medications to administer tablets that disintegrated quickly upon contact, allowing them to give the medication without touching it directly.

“I have to put them in little like Tupperware containers, like Monday, Tuesday, Wednesday on it.” Speaker

1 focus group 3

“So I would get them on a spoon...just take your pills. So you take whatever was on the spoon, so it's a tiny pill that can be disintegrated. Speaker 5 focus group 2

3.5. Cutting and splitting of pills

Caregivers used tablet cutters to cut pills when needed or asked the pharmacy team to cut the tablets for them. Caregivers suggested going to compounding pharmacies to prepare smaller dosages if cutting was difficult. Moreover, when caregivers had difficulty cutting tablets, they used blister packs prepared by the pharmacy instead.

“You can get a pill splitter. I've got one...Our pharmacy, our pharmacy does it for us. We don't have to do that.” Speaker 4 focus group 1

4. Solutions to staying on track with medications

Caregivers described several strategies to ensure that care recipients took the correct medications at the right times and in the correct doses.

4.1. Use of reminders and cues

Caregivers used multiple reminder systems to promote timely medication taking. These included setting alarms on phones, watches, and automated medication dispensers to remind either the caregiver or the care recipient when it was time for the next dose. Some used alarms with pleasant tones for medications requiring frequent administration. Alarms were also used to prompt caregivers to call or video call the care recipient as a reminder. In some cases, television reminders, phone calls, and FaceTime conversations were recommended as reminders to take medications. Visual reminders, such as handwritten notes, yellow stickers, and written signs, were also used to indicate the correct time.

“I'll put a yellow or write on the bottle, and we'll just say, take it 8am And that sometimes helps....Yes, they're included in the spencer unit already, and the pill bottle sits next to spencer. Or sometimes I'll put a little arrow on it posted pointing to where the pill bottle is located” Speaker 4 focus group 1

4.2. Linking medication taking to daily routines

Strategic placement of medications helped caregivers and care recipients remember doses. Medications and vitamins were kept in visible locations or linked to daily activities, such as mealtimes, serving as reminders. Organizing medications in ways that connected them to daily routines was also used to help with adherence.

“And I set out the pill boxes the dossets in the morning right beside his coffee, because I know that's the first thing he's going to go and get in the morning. So he grabs the dosset, takes it for that day.” Speaker 2 focus group 1

4.3. Use of organizational tools

Caregivers used various organizational tools to support adherence. Weekly pill organizers with compartments for morning, noon, and evening doses helped track complex regimens and maintain correct intervals between doses. Some used portable pill containers to carry medications while away from home. Blister packs were used to ensure medications were taken as prescribed, and supplements were

stored separately in other containers. For care recipients managing multiple prescriptions, caregivers verified blister packs prepared by healthcare providers by checking that the pills and quantities were correct. Automated medication dispensers were used to manage complex medication regimens and ensure timely administration. These devices dispensed medications at the correct times and were connected to the caregiver's network, sending notifications when the care recipient took their medication. Some caregivers preferred AMDs for care recipients with memory issues because of their built-in alarms, sensors, and time displays. Adjustments, such as changing dispensing times or labeling the dispenser with the care recipient's name, helped prevent confusion in homes with multiple care recipients.

"It alarms, and it goes, "beep beep beep", and it will keep doing that until the person actually takes out the package. It has like a sensor on the bottom. And once she pulls it out, it'll stop alarming. But then when you look at the screen, it has the time again. And then it will say, "Oh, your next dose is at 7:45" so I can, kind of, when I talk to her, I can tell that she got her morning dose, because it says she's gonna get the next dose at 7:45. That's why I like this machine a lot, you know." Speaker 1 focus group 3

"And what I came up was, let's change the time by like 10 minutes. And then the dispenser, I had to put, like, a big sign on the top saying my dad had my dad's name on it, so she knew when it spit out, she knew "that was his pills" and she knew what was hers." Speaker 1 focus group 3

4.4. Creating and monitoring schedules

Caregivers created medication management lists and schedules that included drug names, doses, frequency, indications, refill details, and prescription numbers. These lists were updated whenever new medications were added. Some caregivers developed written medication administration schedules, especially for eye drops that required frequent dosing, and sought help from family members or healthcare workers to help administer them.

“The thing is, what my table is. Every single time I get a new medication, I update the table and then resave it. So it's always, it's always got the latest...It's got, it's got the drug, the dosage. How many refills are on there? The drug number itself. So I, when I call the pharmacy for a drug, I give them the drug number that's off the bottle, the last refill, the quantity remaining, the next refill date, and what it's used for.” Speaker 5 focus group 1

4.5. Communication

Effective communication between care partners was seen as important for successful medication management, particularly when multiple caregivers supported the same care recipient. Caregivers highlighted the need for shared understanding between themselves and the care recipient to ensure adherence to complex medication schedules. In some cases, caregivers used Medic Alert services to communicate medication-related information in the presence of a language barrier between the caregiver and the healthcare providers.

“So there's, I wouldn't say, interaction, but if there's shared accountability, and ensuring good communication between accountability partners, and again.....For my step-dad, he had no clue he could only talk Greek at that point in time, although he was learning to speak English. So for those kinds of things, but the Medic Alert....has made a difference.” Speaker 6 Focus group

4.6. Ensuring adherence and avoiding errors

Caregivers double-checked that medications were taken correctly, verifying each morning and evening that doses were not missed. For a visually impaired care recipient who took multiple pills at once, the caregiver suggested taking smaller tablets first and checking the floor afterward to ensure no pills were dropped. In households with multiple care recipients, caregivers used two different colored pill organizers to prevent mix-ups. When an automated medication dispenser was used, the caregiver adjusted the dispensing times so that each person received their medications separately.

“The only struggle I had was I had the box that was the 30 days or 28 days. I was worried my mother was gonna take my dad's pills, because they were kind of on the same medication, I think. But my dad was a couple different things, so I had to make sure I had two different colored boxes. So when I called them, I had to say, okay, “Mom, Dad has the blue box, bring it and give him his medication”. I was always worried that she was gonna take his, and he was going to take hers” Speaker 1 focus group 3

4.7. Involving healthcare providers

Some caregivers involved healthcare workers, such as nurses, to assist with medication administration at home, particularly for eye drops. Assistance from family members was recommended when frequent administration was required throughout the day.

“Someone has to put the drops in her eyes like I don't know. Either you have to hire someone to come to the house, like healthcare worker, I don't think a PSW would do this but, like hire a private company that has nursing and they can do it.” Speaker 1 focus group 3

5. Solutions to challenges related to communication and access to healthcare providers

Caregivers described several strategies to improve communication and coordination with healthcare providers and to ensure timely access to medical support.

5.1. Relying on pharmacists and nurses for support

Many caregivers relied on pharmacists for medical care and medication-related support, as pharmacists were easier to reach by phone or in person compared to physicians. They frequently consulted pharmacists about new medications, potential drug interactions, and dosage-related questions. Medication reviews conducted by pharmacists, often covered once a year, were used to ensure safe medication use and to identify possible interactions between prescriptions from multiple specialists. Caregivers also received help from pharmacists when medication adjustments were within the pharmacist's prescribing scope or when they requested that pharmacists extend prescriptions due to a

lack of timely access to a doctor. Some caregivers kept the contact information for Telehealth Ontario nurses present in a visible place, such as on the refrigerator, to have access to advice at any time. According to the caregiver, these nurses could also send patient information to the appropriate department or extend pre-existing prescriptions when immediate physician access was unavailable. To prevent confusion and reduce the risk of medication interactions, caregivers preferred to use a single pharmacy and maintain a relationship with one pharmacist. This consistency allowed pharmacists to flag interactions that might occur when multiple prescribers were involved. Caregivers highlighted the importance of direct communication between the doctor's office and the pharmacy without involving the caregiver to ease the process of prescription renewals and reduce delays in refills.

“So other than that, the doctor faxes the pharmacy if he's got a new prescription, so he'll just send it straight over to the pharmacy. And if the pharmacy needs a prescription, they just fax over to the doctor.

So because of technology, a lot of this is becoming easier.” Speaker 6 focus group 1

5.2. Accessing healthcare services

Caregivers used several approaches to ensure timely access to healthcare providers. They suggested visiting after-hours or walk-in clinics to obtain new prescriptions or make medication changes when a family doctor was unavailable. Some used phone consultations with doctors for issues that did not require in-person visits, and others suggested getting help from nurse practitioners when the problem was within their scope of practice.

“They have clinics open from four o'clock on, okay, four o'clock till 10 o'clock or something like that. You're allowed to go into one of those clinics see a doctor that's in that clinic, and that doctor can either prescribe or change. If you don't have a physician of your own, they can do that.” Speaker 5 focus group 1

5.3. Caregiver advocacy

Caregivers took an active role in managing appointments and communicating with healthcare providers. Some attended medical appointments with the care recipient, advocated for their needs, and documented important information in notebooks. Some brought a medication bag or list to medical appointments to reduce errors when prescriptions came from multiple specialists. They also read dispensing notes and medication leaflets before visits to prepare questions for the pharmacist or doctor. Caregivers described learning to become advocates during appointments by asking all necessary questions and seeking clear answers to protect the health of their loved ones. Carrying both digital and printed copies of power of attorney documents was considered helpful for supporting advocacy during medical visits.

“So we just pack them up in a bag and we take them along. And he literally will go through every single one of them, which I think is amazing, great. Every specialist, even the dentist, they said that we'd like to see a list of your medications.” Speaker 3 focus group 2

“I carry that digital copy on my phone and a hard copy as well for situations where I have to be able to advocate and confirm what's being done.” Speaker 6 focus group 2

“So I think what we would want to emphasize in this document is really be prepared to be an advocate and make sure you're getting the answers and information you need because that's your loved one's health and is what you're feeling as caregiver.” Speaker 4 focus group 2

5.4. Collaboration with healthcare providers

Caregivers mentioned that healthcare providers should view them as important partners in medication management rather than as interfering or controlling. They also highlighted the importance of system integration so that all doctors involved in a care recipient's treatment can access complete medication information, reducing the risk of medication-related problems.

“And I know that they've been in the hospitals are working on a database that will interact with more hospitals and for doctors to be able to access, you know, the information about the patient. And of course, that information is only as good as what gets entered into the database.” Speaker 4 focus group 2

6. Solutions to challenges related to medication supply and refills

Caregivers described several strategies to avoid running out of medications at home and to maintain an adequate stock of necessary medical supplies.

6.1. Planning

Caregivers mentioned the importance of planning in advance to prevent delays in obtaining medications. Some ordered medications ahead of time to allow the pharmacy to prepare and supply them on time. Some caregivers wrote down the time for the next refill in their calendar to help keep track of upcoming refills. Creating and maintaining a medication list or program that included the drug name, dose, frequency, indication, remaining refills, refill date, and prescription number was also reported as helpful. This list was updated every time a new medication was received.

“Like, the only thing that the pharmacy is that I had to give them, like, a week's notice, she takes, like, nose spray, and she has, like, the strip to test her sugar. I have to kind of give them a week's notice to refill that, because I guess they have to order it. And then they set up and ship it, which is every two weeks for me.” Speaker 1 focus group 3

6.2. Monitoring medication supply

Strategic placement of medications in visible locations enabled caregivers to easily notice when supplies were running low and determine the best time to request refills. The use of pre-packaged tools, such as blister packs or a pill organizer, also helped caregivers keep track of medications and remaining quantities.

“Um, I fill his little pill carriers for him. Um. And we have two. We have a set of two that we use. And I don't pick up his medications for him, but when he's getting low, I'll put them aside for him, like the bottle aside so he knows, I guess, order it again so he can take care of that. He can pick them up. So mostly, yeah, just getting set up for the week with his medications.” Speaker 3 focus group 4

6.3. Communication with the pharmacy team

Caregivers recommended signing up for pharmacy delivery services to ensure medications were received on time. Some suggested adding a note in the pharmacy file specifying that the care recipient preferred not to substitute their regular medication brand.

“So I have to have this, how to say- the generic or the good one. I cannot have the artificial medication because it doesn't work for me, so it's in the drugstore, and in the drugstore, they have my file, they have “no substitute” on it, so that's for my husband.” Speaker 3 focus group 3

6.4. Staying informed about medication availability

To manage medication shortages, caregivers referred to government websites where drug manufacturers reported restock dates. This helped them stay informed about when medications would be available again.

“I mean, I also came across websites that, you know, I was, you know- I forgot who told me about it, but it turns out that drug manufacturers in Canada, if there is going to be a drug shortage, they're supposed to report on this government website, and that's what's sort of provided me some insight into you know, when about is drug X going to return to shelves so that I don't feel like I'm in the dark” Speaker 4 focus group 3

7. Solutions to challenges related to medication storage

Caregivers described several strategies for safely storing medications at home and while traveling.

7.1. Safe storage at home

Caregivers reported the importance of keeping medications out of reach of children, especially when grandchildren were visiting. Some used lock boxes to ensure the secure storage of medications at home. The caregiver highlighted the importance of having a Narcan kit at home in case of a narcotic overdose when narcotics were used at home.

“Yes, we carry a lock box, but we also carry Narcan with us. Could there be an overdose?” Speaker 6

focus group 1

7.2. Medication storage during travel or time away from home

Caregivers used portable pill containers and alarms to help ensure medications were taken on time when away from home. For longer periods outside the home, such as during summer activities, caregivers brought a week’s supply of medications in a container. When traveling, medications were pre-packaged to maintain the usual routine, and blister packs were used to keep them organized. Ice packs were used for medications that required refrigeration during travel.

“I got a little pill container that you can put in your pocket, and I'll say, I'll put her pills in there for the time that we're going to be away. So we know we're going to be away for three o'clock pills. So I'll put her three o'clock pills in a little container, put it in my pocket. And whenever her watch goes off that I hear that she doesn't.....I'll just tell her take her three o'clock pills.” Speaker 5 focus group 1

7.3. Safe disposal

Caregivers agreed that expired medications and sharp objects should be returned to the pharmacy for safe disposal.

“I take it back to the pharmacy.” Speaker 5 focus group 3

8. Solutions to challenges related to medication management in adult day programs

Caregivers described several strategies to manage medications for care recipients attending adult day programs. Caregivers mentioned the importance of understanding that different adult day programs have their own rules regarding medication management and administration. To accommodate these differences, caregivers packed medications according to each program's requirements. To help remember the different rules, some caregivers suggested preparing a checklist until they became familiar with the specific requirements of each organization. Additionally, some caregivers prepared small pill bottles with written notes and provided copies of the prescriptions to ensure that medications were administered correctly at the adult day program.

“So in terms of the toolkit, I think we do need to have future caregivers, be aware that different organizations have different rules around managing the meds and how they will administer them”

Speaker 6 focus group 2

9. Solutions to challenges related to handling emergencies

Caregivers described several strategies to manage urgent or unexpected health situations involving the care recipient. In emergencies, caregivers reported calling the emergency phone number for immediate assistance. Some suggested contacting Telehealth Ontario nurses, who could send the patient's file to the nearest department or extend an existing prescription when access to a physician was not possible. Some caregivers also kept a fridge magnet that included the care recipient's name, key medical information, and medication list, as paramedics are trained to look for this information during emergencies.

“He would just, you know, freak out probably, or go to the neighbors. And then I've got the information on the fridge, and so everybody would know my situation, what medication, what blood type I have my health card is on it in my next of kin emergency phone number.” Speaker 3 focus group 3

3.9.2.4. Theme 4: Non-Medication Management Tasks

Caregivers reported being responsible for a wide range of daily and household tasks. These included cooking, meal preparation, meal planning, grocery shopping, cleaning, managing finances, bill payments, scheduling, and coordinating or attending medical and non-medical appointments. Several caregivers also mentioned driving the care recipient to appointments, doing yard work, household repairs, and shoveling snow. Caregivers described attending appointments with the care recipient, advocating for them, and taking notes during visits. In dementia care, caregivers explained that they became fully responsible for all personal and household tasks as the care recipient's ability to perform daily activities declined. Support with personal hygiene was described, including helping with dressing, bathing, hair washing, and reminders about showers, meals, and drinking water. Some caregivers sought help from personal support workers (PSWs) for hygiene and daily care tasks when needed. Others reported assisting with mobility, such as helping the care recipient walk with a walker, ensuring safety, and preventing falls. A few caregivers used organizational tools to manage appointments and events. One caregiver created a large wall calendar with six weeks displayed at a time and placed it on the door for visibility. Others used phone calendars to keep track of appointments, bills, and social events.

"I do my shopping still and when I go, sometimes I take husband along because I don't want to leave him alone too much. And if I, if he has an appointment with the doctors or the dentist, I go along. Or if there is another appointment that he needs to go to.....I know that he can't drive anymore, so I do, and I do the cooking and the shopping, and he likes to go along, but sometimes he sits in the car" Speaker 3 focus

group 3

3.9.2.5. Theme 5: Caregivers' Preferences for Toolkit Format and Content

Caregivers expressed different preferences for the format and presentation of the medication management toolkit. Some caregivers preferred the tab format because it is quick and easy to locate

information. Others recommended presenting the information in bullet points with concise content. Logical grouping of topics, such as side effects, medication administration, and consulting with healthcare providers, was suggested. Indexing or cross-referencing was also viewed as helpful for locating information quickly, especially in urgent situations. Caregivers mentioned that the toolkit should be available in both paper and online formats. Paper format was preferred by older adults who have difficulty reading on screens for long periods or by those living in areas with limited internet access. An online format was suggested for younger caregivers. Some caregivers suggested offering a downloadable format for offline access or using a QR code to access the toolkit online, with the option to search using keywords.

“Put down medication problems or medication date and times. Okay, have different tab headings, because we have that in some of our books, too. And you have different tab headings, and then you just go to that problem, and there, here's a list of all the problems people have seen and heard, and these are the solutions they've used.....whenever we go back, whenever we go back, to whether it's paper or online or whatever, make it downloadable. So I can download it onto my computer, and then that way, that way, I don't have to worry about the internet.” Speaker 5 focus group 1

It was noted that the cost of printing paper toolkits could be a challenge, and it was suggested to partner with pharmaceutical companies to cover the cost. Others recommended partnering with patient support organizations, pharmacies, and pharmacists to assist with dissemination. Caregivers mentioned the importance of accessibility, suggesting that the toolkit include large print and be designed according to accessibility standards, especially for users with vision impairment or cognitive decline. Portability was also mentioned as necessary, with caregivers preferring the toolkit to be easy to carry from place to place.

“So you know, my pharmacist can say we have a toolkit online or on our app. There's a toolkit that you could use and Alzheimer's on it, Parkinson's Association, whatever they also know about partnering up for as a thing. But is that something that you're considering in terms of partnering with pharmaceutical

organizations or Pharmaceutical Association, or in trying to do direct to them, to direct to consumer.”

Speaker 6 focus group 2

Suggestions for toolkit content included providing information about reliable websites, tips on medication storage based on the route of administration, and information on what to do if a dose is missed. The toolkit should also contain practical strategies, such as managing medications for individuals who cannot swallow pills, by crushing them and mixing them with applesauce. Caregivers also recommended adding translation options for caregivers who face language barriers during medical appointments and translating the toolkit into different languages. Caregivers suggested that the toolkit include concise information with short visuals and provide a space for personalization, such as a blank sheet to write key information relevant to the care recipient’s condition. It was noted that the medication management toolkit could help ensure consistency among multiple formal caregivers who assist family caregivers by making it easier for them to understand what to do.

“How do you do pills if the person can take them properly, so crushing them up, even Apple saw things like that. Using suggestions like that.” Speaker 5 focus group 1

3.9.2.6. Theme 6: Additional Support with Medication Management

Most of the caregivers reported receiving no additional support with medication management for the care recipient and described doing everything on their own. In most cases, no one else was involved in medication management except for the pharmacy team. Some caregivers mentioned receiving support from other family members in providing care, though the primary caregiver remained responsible for all decisions related to the care recipient. Others described seeking help from neighbors to administer medications when the primary caregiver was not available. Pharmacy check-ins a few days after starting new medications were mentioned as helpful. However, caregivers noted that such follow-ups were often not possible due to the large number of prescriptions handled daily by the pharmacists. A few caregivers

expressed resistance to accepting external help, citing a lack of trust or a belief that they knew how to care for the recipient better than anyone else.

“Or if you start a new medication, maybe they give you a call, maybe four days after you started, to see how it's going. But they're busy too at the pharmacy- I can't see that.” Speaker 1 focus group 3

Caregivers highlighted the need for additional support for new caregivers, especially those who are unfamiliar with medication management or advocating with healthcare providers. Support was also considered important for newcomers to Canada who may not be familiar with the healthcare system, as well as for caregivers whose English is a second language and who may face communication barriers when advocating for their loved ones. Suggestions for improving support included attending hospice programs and workshops organized for caregivers that provide education about medication management, as well as joining caregiver support groups to share experiences and receive emotional support. Some caregivers mentioned that a medication management toolkit would be particularly helpful for new caregivers, whereas those with more experience felt they already knew how to manage medications and communicate with healthcare providers. Additional sources of support mentioned included patient support organizations and counseling for the care recipient following major health events.

“I belong. I go to our hospice in town, and our hospice offers a program called caregiving 101, so it's a six week course that you can take, and they go through finance and power of attorney and preparing for death and all these things. And this management is one of the, you know, the managing of the pills, etc.”

Speaker 4 focus group 1

3.10. Results of the Member Checking

Ten participants responded to the member checking document, resulting in a response rate of 62.5%. All ten participants agreed with the findings of the data analysis. Three participants provided further insights

that they felt were important to include. Caregivers noted that when assisting care recipients with mobility and safety, they often need to research and purchase physical safety and accessibility products, such as bathing aids and bed safety equipment, and are responsible for installing these items. Some caregivers explained that they are reluctant to accept external help with medication management because they perceive the consequences of medication errors as serious and are unwilling to delegate this responsibility without first providing proper orientation and training. One caregiver reported keeping a copy of the care recipient's medical and medication history in the care recipient's wallet for emergencies. Caregivers also described engaging care recipients with dementia in activities such as coloring and puzzles to help keep them mentally active. Some participants noted that caregiving may begin at the time of diagnosis of a chronic condition. Additional challenges discussed included the high cost of automated medication dispensers, troubleshooting difficulties, and technical issues. Moreover, prescription errors were reported. One caregiver reported using whiteboards as visual reminders with written instructions and verifying prescriptions for accuracy before leaving the clinic or physician's office, ensuring that all refills were included. Caregivers also described providing personal and household care tasks when care recipients were unable to do so due to cognitive or physical limitations. Although personal support worker (PSW) assistance may be assessed and provided by service agencies to help family caregivers, participants noted that PSWs are not permitted to administer medications and are limited to providing reminders only. Any additional care beyond this support was reported to be privately funded.

3.11 Discussion

This study identified a wide range of challenges that family caregivers face when managing medications for older adults, reflecting the complex nature of this responsibility. These findings are consistent with earlier qualitative studies that documented similar medication-related difficulties. For example, Ranelli

and Aversa, as well as Ranelli and Hansen, found that medication management contributed to caregiver stress among family carers in North Florida.¹²¹ Likewise, Goldstein and Rivers, in their study of informal carers in the UK, reported that caregivers struggled with scheduling difficulties, organizing medications for forgetful care recipients, compliance problems, and accessing timely professional advice.¹²² The challenges described by caregivers in our study closely mirror these earlier findings, showing that medication-related burden is a persistent issue across caregiving contexts.¹⁵ While much of the existing research focuses on caregivers of people with dementia, due to the complexity of their care needs, our findings confirm that caregivers in less complex caregiving situations also face medication management-related challenges.¹⁵ This aligns with previous studies showing that medication management difficulties are not limited to dementia care but occur across diverse caregiving roles.¹⁵ The caregivers in our study, similar to those in earlier literature, described a range of problems, including scheduling medications, ensuring adherence, recognizing side effects, finding reliable medication-related information, and navigating poor access to professional guidance, indicating that these challenges are not condition-specific.³⁶ Once more, our study's findings are consistent with previous literature, which categorizes caregiver medication administration hassles into three main domains: scheduling logistics (29.5%), administration procedures (32%), and safety issues (38.5%).³⁶ This study found that caregivers faced challenges across all stages of the medication management process, from planning and organization to administration and safety monitoring. Consistent with the literature, caregivers in our study reported scheduling and timing challenges, particularly when managing complex medication regimens with multiple daily doses.³⁶ The issue of administration procedures was also strongly reflected in our study since caregivers faced difficulties giving medications to care recipients, who were uncooperative or argumentative, especially among those with dementia.³⁶ Further, caregivers expressed worry about medication side effects and the potential for double-dosing, particularly among care recipients with

memory problems. Difficulties identifying whether symptoms were caused by the illness or the medication itself echo the safety-related concerns described in prior studies.^{15,36}

Moreover, our study found that family caregivers used a range of practical and creative strategies and tools to manage the daily challenges of medication regimens for older adults. These findings are consistent with previous research showing that caregivers seek consistency in their medication routines to ensure they are taken as prescribed.^{15,95} As in earlier studies, the majority of caregivers in our sample relied on low-tech tools and simple methods already available to them, such as containers, pill boxes, handwritten notes, and other household items, to organize medications or remind care recipients to take their doses.^{15,95} The strategies used by caregivers in our study also align with the literature, which describes how caregivers combine tools with personalized strategies adapted to the needs of their specific caregiving situation.¹⁵ For instance, caregivers in our study also used reminders, visual cues, simple instructions, and supervision to ensure that medications were taken correctly.¹⁵ For people with dementia, caregivers adapted these reminders by using repetitive instructions or small rewards to encourage cooperation, reflecting how reminders may take different forms depending on the care recipient's cognitive abilities.¹⁵ In the literature, some caregivers are reluctant to adopt technology for medication management for reasons including feeling confident in their current strategies, having had negative experiences with previous tools, or anticipating difficulties with new devices.⁹⁵ In our study, reluctance to use the automated medication dispenser was primarily due to its limited availability and cost. Given caregivers' preference for simple tools and established routines, the toolkit can act as a single, home-based resource listing common medication management problems with practical solutions. By drawing on strategies already used by caregivers, it can help them find new approaches that fit their needs, making medication management easier and increasing their confidence and sense of control. The development of the medication management toolkit in this study was grounded in a participatory research approach, which is

a form of co-design.¹²³ The literature describes co-design as a user-centric approach used to solve specific problems or challenges, emphasizing partnership with the community and focusing on systems change and improving human experience.¹²³ In line with this definition, our participatory approach ensured that family caregivers directly informed the toolkit's components to support user-centered outcomes. Ensuring caregiver priorities are addressed and that the content remains relevant, thereby increasing the likelihood that the toolkit will be adopted in routine practice.⁹⁹

3.12. Conclusion

Our study showed that family caregivers experienced a wide range of medication management challenges, consistent with earlier research. Caregivers relied mainly on simple, routine-based tools and strategies, highlighting the ongoing need for practical support. These findings emphasize the value of developing a medication management toolkit that brings together common challenges and practical solutions into a single accessible resource. Using a participatory approach ensured that the toolkit's content and design were shaped directly by caregivers, making it more relevant and aligned with their needs.

Chapter 4

4. General Discussion and Future Directions

4.1. Thesis Overview and Discussion

This thesis examined the medication management experiences of family caregivers supporting older adults at home. Across both studies, the findings consistently demonstrated that family caregivers, primarily spouses and adult children, play a central and often overwhelming role in ensuring safe and accurate medication use. Caregivers frequently lack formal training yet must take on complex, time-consuming responsibilities that contribute to stress, anxiety, and caregiver burden.^{15,94,121,122} These results mirror previous research showing that caregivers routinely struggle with medication supply, organization, administration, clinical decision-making, and communication with healthcare providers.^{15,94,121,122}

4.1.1. Medication Management Burden Across Caregiving Contexts

Both studies included in this thesis showed that medication-related burden is not limited to dementia care.¹⁵ While the literature often focuses on caregivers of individuals with dementia due to the complexity of their needs, our findings demonstrate that caregivers supporting older adults with less complex conditions also face significant challenges.¹⁵ Caregivers described difficulty maintaining schedules, ensuring adherence, recognizing side effects, accessing reliable information, and responding to emergencies. These challenges align with the medication hassle typology of scheduling logistics, administration procedures, and safety issues described in previous literature.³⁶

4.1.2. Caregiver Strategies and Gaps in Support

Across both studies, caregivers relied on simple, practical tools and strategies to manage medication regimens.¹⁵ These strategies helped them stay organized and maintain adherence, but also revealed the absence of accessible, structured support. Consistent with earlier literature, caregivers often preferred

traditional tools over technology due to familiarity, previous negative experiences, or fear of increasing their workload.⁹⁵ Study one highlighted that technology, such as automated medication dispensers (AMD), can reduce caregiver burden when functioning well. Caregivers reported reduced emotional and mental fatigue, improved communication, fewer conflicts, and a more positive caregiver–care recipient relationship. Some caregivers even described a shift from a “caregiving role” back to their natural family relationship. Although these positive relational outcomes did not show a statistically significant difference, likely due to the small sample size and limitations of the ProQoL scale, they were reflected qualitatively. Study one also revealed significant recruitment barriers, particularly the limited availability of the AMD. Many caregivers declined participation because using the device required switching pharmacies, disrupting trust-based relationships with their long-standing pharmacists. Caregivers valued pharmacists as accessible sources of medication knowledge, especially when physicians were difficult to reach. This indicates an important gap in the healthcare system: while pharmacists are central to caregivers’ medication-related decision-making, there is limited research on pharmacist–caregiver communication.¹⁰⁸

4.1.3. Need for Practical Home-Based Resources

Despite using numerous strategies, caregivers still faced persistent challenges. The literature highlights that while educational interventions can support caregivers, it remains unclear how often such programs are implemented in practice. Medication adherence aids may help, but technology can also increase burden when poorly matched to caregiver or care recipient needs. These gaps highlight the need for simple, practical, and adaptable home-based resources. Study two directly addressed this gap by developing a caregiver-focused medication management toolkit. The participatory, co-design approach ensured that the toolkit reflected caregivers’ real experiences, priorities, and design preferences.^{97–99,124} Caregivers provided detailed input on content and format, recommending a toolkit that is easy to navigate,

available in both paper and online formats, accessible for users with visual or cognitive limitations, and capable of offering practical solutions to common medication challenges. These insights strengthened the toolkit's relevance and potential for adoption.

4.1.4. Importance of Supporting a Broader Range of Caregivers

The literature and our findings show that caregivers across different chronic conditions, not only dementia, face similar medication-related problems, including administration difficulties, supply issues, and communication barriers.³⁶ Existing medication-management toolkits are typically disease-specific.^{99,125} Therefore, our findings reinforce the importance of developing a general medication management toolkit that can support a broader range of caregivers whose needs have been overlooked.

4.2. Strengths and Limitations of the Project

In Study one, we used a mixed-methods design, which was a strength of the study because it provided a more complete understanding of caregivers' experiences.^{112,126} The FCMAHS and ProQoL questionnaires captured structured, quantitative information, but they are limited to the items on their respective scales. The pre- and post-intervention interviews helped address this limitation by allowing caregivers to explain their experiences in more detail and raise topics that were not covered in the questionnaires. Together, these methods offered a fuller picture of the intervention's impact. In study two, the use of focus groups was also a strength because the group setting allowed caregivers to discuss medication management challenges, generate ideas together, and share the solutions they used, which created a richer and more holistic view of the topic. In addition, intercoder reliability was calculated in study one, and the second coder did not begin independent coding until both researchers reached 80% agreement. For study two, all transcripts were independently coded by two researchers, who met regularly to reach consensus on the coding. We also conducted member checking with the focus group participants, which strengthened the rigor of the analysis and helped ensure that the findings accurately reflected caregivers' experiences.

However, this project also had some limitations. Both studies had small sample sizes, and data saturation was not reached in either the interviews or the focus groups. The sample was relatively homogenous, consisting mainly of older adult caregivers, most of whom were females and living with the care recipient. Because we used convenience sampling and lacked representation from younger caregivers or those not living with the care recipient, the findings may not be generalizable to the broader caregiver population.

4.3. Positionality and Reflexivity

Positionality and reflexivity are commonly discussed in qualitative research, especially within critical theory approaches, where researchers are encouraged to be aware of their own position and how it influences how knowledge is created and interpreted.¹²⁷ Qualitative research involves close interaction between the researcher and participants, meaning that the researcher's relationship with the participants and involvement in the research process can influence the study's results.¹²⁷ Positionality refers to the role or position a researcher takes within a study. It involves the researcher reflecting on their own identity, background, and perspectives so that readers can understand how these may influence the research topic, the participants, and the research process.^{127,128} On the other hand, reflexivity is a type of critical thinking in which the researcher reflects on their own identity and position by clearly acknowledging their assumptions and actively questioning them.^{127,129} The researcher thinks carefully about how the study was conducted and explains to the reader how they reached their conclusions, with the goal of providing a more honest and trustworthy account of the research.¹²⁹ I bring multiple perspectives to this research based on my personal, cultural, and professional background. I previously worked as a community pharmacist in the United Arab Emirates for three years. Although I am not a licensed pharmacist in Canada, this experience has influenced how I approached the research topic, built relationships with participants, and interpreted the study findings. However, my education and role as a pharmacist are not

the only factors shaping my perspective. I am also a woman and a daughter from a family-oriented Middle Eastern cultural background, which brings personal experiences and values related to family responsibility, caregiving, and intergenerational relationships into this research. Although I am not an informal caregiver myself, my relationships with my parents and siblings may increase my sensitivity to caregivers' emotional burden, sense of responsibility, and desire to provide care for a family member.

As a Middle Eastern woman and the eldest daughter in my family, I feel a strong moral obligation toward my parents, and I would be more than willing to assist with medication management or other caregiving responsibilities if needed. I would also naturally expect my siblings to be involved in caring for our parents. These expectations may have influenced how I understood emotional fatigue and how I interpreted statements from family caregivers who described providing care for their parents out of affection, love, and respect for what their parents had given them throughout their lives. Because I share similar characteristics with many family caregivers, particularly women caring for parents, I was able to relate to their emotional and mental well-being when discussing caregiving and medication management, as I could imagine myself in their position and understand how overwhelming this role can feel.

Growing up observing my parents' relationship and how they care for one another also influenced how I interpreted statements from spousal caregivers. I was able to understand accounts from spouses who did not view supporting medication management as a burden, but rather as a way of keeping their partner with them for a longer time. This perspective reflects deeply affectionate relationships in which partners work as a team, and a strong pre-existing relationship supports caregiving without resentment. Having witnessed a similar dynamic in my parents' relationship, this theme stood out to me during analysis and was not overlooked.

All participants in study one were women, and as a woman, I shared this identity, which may have influenced how comfortable participants felt opening and speaking freely about their experiences. It is

important to consider whether female participants would have shared the same information or discussed their caregiving roles in the same way if the interviewer had been male or whether their responses may have been more conservative. In addition, my education and training in pharmacy, as well as my professional role, may have influenced how I established rapport with participants. In my culture, pharmacists are often viewed as trusted and accessible healthcare professionals, sometimes regarded as extended family members. During my practice in the Middle East, patients frequently expressed trust, appreciation, and familiarity, including coming to the pharmacy simply to talk, seek advice, or share personal stories about their health and well-being. I believe my ability to listen, show empathy, and create a supportive environment influenced the level of trust established with participants, leading to in-depth, rich data.

This trust was reflected in participants' engagement with the research. Several participants from Study 1 chose to take part in study two and expressed happiness about contributing further to the research, believing in the value of the work. This willingness was not only related to the relationships established during the research process, but also to participants' recognition of the importance of the research topic and their desire to help other family caregivers through contributing to meaningful research.

At the same time, I recognize that my background as a researcher in medication management among family caregivers of older adults may involve implicit assumptions that I am not always consciously aware of, such as expectations about what constitutes "good" caregiving, implicit normalization of burden, beliefs about which medication management strategies are practical and feasible in the home setting and how I interpreted and prioritized medication management challenges, for example by focusing more on medication safety or adherence issues raised by caregivers. Through my professional experience, I have seen how medication management can be extremely challenging, particularly when family caregivers view these challenges as a regular and unquestioned part of their role. I recall supporting a care partner who

was new to the country and overwhelmed by managing multiple medications for her parents. By helping organize the medications and identify affordable options, I was able to reduce her stress, reinforcing my belief that pharmacists can play an important role in easing caregiver burden beyond medication dispensing and counselling.

Reflecting on this experience, I believe that if this care partner had access to an automated medication dispenser and a structured, home-based guide such as the toolkit being developed in this research, her experience may have been less stressful. Recognizing that these perspectives may influence interpretation, I engaged in ongoing reflexive practices throughout the research process. These included independent coding by two researchers until an intercoder agreement of 80% was achieved in study one, continued independent coding throughout study two, frequent reference to participants' own words and transcripts, and regular meetings with the principal investigator to discuss codes, themes, and subthemes. Seeking feedback through peer and supervisory discussions helped introduce alternative perspectives, minimize personal bias, and enhance confirmability. Throughout the analysis, I remained conscious of how my background could shape interpretation and consistently prioritized maintaining participants' voices to support a balanced, transparent, and trustworthy account of the research.

4.4. Future Directions

This thesis highlights the need for further research to examine how interventions that reduce medication-related caregiver burden may affect compassion fatigue and compassion satisfaction among informal caregivers. These interventions should not focus solely on technology but also include educational interventions, which have shown promising results in reducing caregiver burden⁹⁶ and should be examined to see whether they also influence compassion fatigue and satisfaction. In our study, we intended to examine whether reductions in FCMAHS scores were correlated with reductions in compassion fatigue and increases in compassion satisfaction. However, due to our small sample size, we were unable to

conduct this correlation analysis. Therefore, future studies with larger sample sizes are needed to confirm the findings of this pilot study and to determine whether a reduction in medication-related caregiver burden is associated with improvements in compassion fatigue and satisfaction. For a larger study to be feasible, the AMD must be available at multiple pharmacies across the province so that family caregivers can access it through their local pharmacists without having to switch pharmacies. This shifts the focus toward addressing the barriers that currently restrict the technology to a single location. These barriers may involve pharmacists' reluctance to adopt new technologies due to added workload or other challenges related to technology acceptance among caregivers, who may prefer traditional tools. All these issues should be explored in future studies to increase access to the technology so that larger studies can be conducted to assess its impact on caregiver burden-related to medication management, compassion fatigue, and compassion satisfaction. Moreover, once the medication management toolkit is developed, further research will be needed to evaluate its usability among family caregivers and to evaluate its impact and determine whether it reduces caregiver burden-related to medication management

References

1. Robyn Gibbard. Meeting the Care Needs of Canada's Aging Population. Ottawa: The Conference Board of Canada .
2. Suzman R BJ. Global Health and Aging. World Health Organization. National Institute on Aging National Institutes of Health. NIH Publication no. 11-7737 .
3. Hacker K. The Burden of Chronic Disease. *Mayo Clin Proc Innov Qual Outcomes*. 2024;8(1):112-119. doi:10.1016/j.mayocpiqo.2023.08.005
4. Gillespie R, Mullan J, Harrison L. Managing medications: the role of informal caregivers of older adults and people living with dementia. A review of the literature. *J Clin Nurs*. 2014;23(23-24):3296-3308. doi:10.1111/jocn.12519
5. Canada, P.H.A. of (2022) Government of Canada, Canada.ca. Available at: <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/aging-chronic-diseases-profile-canadian-seniors-report.html> (Accessed: 05 July 2024). .
6. Skou ST, Mair FS, Fortin M, et al. Multimorbidity. *Nat Rev Dis Primers*. 2022;8(1):48. doi:10.1038/s41572-022-00376-4
7. Navickas R, Petric VK, Feigl AB, Seychell M. Multimorbidity: What Do We Know? What Should We Do? *J Comorb*. 2016;6(1):4-11. doi:10.15256/joc.2016.6.72
8. Tugwell P, Knottnerus JA. Multimorbidity and Comorbidity are now separate MESH headings. *J Clin Epidemiol*. 2019;105:vi-viii. doi:10.1016/j.jclinepi.2018.11.019
9. Ibrahim NA, Wong YY, Lean QY, et al. Medication self-management among older adults with cognitive frailty. *Research in Social and Administrative Pharmacy*. 2024;20(2):172-181. doi:10.1016/j.sapharm.2023.11.001
10. Sino CGM, Sietzema M, Egberts TCG, Schuurmans MJ. Medication management capacity in relation to cognition and self-management skills in older people on polypharmacy. *J Nutr Health Aging*. 2014;18(1):44-49. doi:10.1007/s12603-013-0359-2
11. Elliott RA, Marriott JL. Review of Instruments used in Clinical Practice to Assess Patients' Ability to Manage Medications. *Journal of Pharmacy Practice and Research*. 2010;40(1):36-42. doi:10.1002/j.2055-2335.2010.tb00723.x
12. Elliott R, Goeman D, Beanland C, Koch S. Ability of older people with dementia or cognitive impairment to manage medicine regimens: a narrative review. *Curr Clin Pharmacol*. 2015;10(3):213-221. doi:10.2174/1574884710666150812141525
13. Government of Canada, S.C. (2020) Caregivers in Canada, 2018, The Daily - . Available at: <https://www150.statcan.gc.ca/n1/daily-quotidien/200108/dq200108a-eng.htm> (Accessed: 01 July 2024). .
14. Stall N. We should care more about caregivers. *Can Med Assoc J*. 2019;191(9):E245-E246. doi:10.1503/cmaj.190204

15. Look KA, Stone JA. Medication management activities performed by informal caregivers of older adults. *Research in Social and Administrative Pharmacy*. 2018;14(5):418-426. doi:10.1016/j.sapharm.2017.05.005
16. Rodrigues LP, de Oliveira Rezende AT, Delpino FM, et al. Association between multimorbidity and hospitalization in older adults: systematic review and meta-analysis. *Age Ageing*. 2022;51(7). doi:10.1093/ageing/afac155
17. Advinha AM, Nunes C, de Barros CT, Lopes MJ, de Oliveira-Martins S. Key factors of the functional ability of older people to self-manage medications. *Sci Rep*. 2021;11(1):22196. doi:10.1038/s41598-021-01434-9
18. Wimmer BC, Bell JS, Fastbom J, Wiese MD, Johnell K. Medication Regimen Complexity and Polypharmacy as Factors Associated With All-Cause Mortality in Older People. *Annals of Pharmacotherapy*. 2016;50(2):89-95. doi:10.1177/1060028015621071
19. Canadian Institute for Health Information. Drug use among seniors on public drug programs in Canada. Ottawa: CIHI; 2012: Revised October 2014. Report No.: 978-1-77109-318-7.
20. Bolina M, Jones CA, Koshman S, Heintz E, Sadowski CA. Documentation of Functional Medication Management in Older Adults: A Retrospective Chart Review in Acute Care Hospitalization. *Drugs Real World Outcomes*. 2016;3(4):401-407. doi:10.1007/s40801-016-0092-3
21. Badawoud AM, Salgado TM, Lu J, Peron EP, Parsons P, Slattum PW. Medication self-management capacity among older adults living in low-income housing communities. *Journal of the American Pharmacists Association*. 2024;64(1):88-95. doi:10.1016/j.japh.2023.10.026
22. Maddigan SL, Farris KB, Keating N, Wiens CA, Johnson JA. Predictors of Older Adults' Capacity for Medication Management in a Self-Medication Program. *J Aging Health*. 2003;15(2):332-352. doi:10.1177/0898264303251893
23. Park HY, Seo SA, Yoo H, Lee K. Medication adherence and beliefs about medication in elderly patients living alone with chronic diseases. *Patient Prefer Adherence*. 2018;Volume 12:175-181. doi:10.2147/PPA.S151263
24. Jimmy B, Jose J. Patient Medication Adherence: Measures in Daily Practice. *Oman Med J*. 2011;26(3):155-159. doi:10.5001/omj.2011.38
25. Tordoff J, Simonsen K, Thomson WM, Norris PT. "It's just routine." A qualitative study of medicine-taking amongst older people in New Zealand. *Pharmacy World & Science*. 2010;32(2):154-161. doi:10.1007/s11096-009-9361-5
26. MacLaughlin EJ, Raehl CL, Treadway AK, Sterling TL, Zoller DP, Bond CA. Assessing Medication Adherence in the Elderly. *Drugs Aging*. 2005;22(3):231-255. doi:10.2165/00002512-200522030-00005
27. Canada, E. and S.D. (2022a) Government of Canada, Canada.ca. Available at: <https://www.canada.ca/en/employment-social-development/programs/disability/arc/federal-report2011/section1.html> (Accessed: 01 July 2024). .
28. *Now and Tomorrow Excellence in Everything We Do Disability Facts about Seniors*.
29. ATKIN PA, FINNEGAN TP, OGLE SJ, SHENFIELD GM. Functional Ability of Patients to manage Medication Packaging: A Survey of Geriatric Inpatients. *Age Ageing*. 1994;23(2):113-116. doi:10.1093/ageing/23.2.113

30. Beckman AGK, Parker MG, Thorslund M. Can elderly people take their medicine? *Patient Educ Couns*. 2005;59(2):186-191. doi:10.1016/j.pec.2004.11.005
31. Beckman A, Bernsten C, Parker MG, Thorslund M, Fastbom J. The Difficulty of Opening Medicine Containers in Old Age: A Population-Based Study. *Pharmacy World & Science*. 2005;27(5):393-398. doi:10.1007/s11096-005-7903-z
32. Reinhard, S.C. (2004) Supporting family caregivers in providing care, Patient Safety and Quality: An Evidence-Based Handbook for Nurses. Available at: <https://www.ncbi.nlm.nih.gov/books/NBK2665/> (Accessed: 01 July 2024). .
33. Informal caregiving for seniors (2012) Statistics Canada: Canada's national statistical agency / Statistique Canada : Organisme statistique national du Canada. Available at: <https://www150.statcan.gc.ca/n1/pub/82-003-x/2012003/article/11694-eng.htm> (Accessed: 01 July 2024). .
34. Schulz, R. (2016) Family caregiving roles and impacts, Families Caring for an Aging America. Available at: <https://www.ncbi.nlm.nih.gov/books/NBK396398/> (Accessed: 01 July 2024). .
35. Alsaeed D, Jamieson E, Gul MO, Smith FJ. Challenges to optimal medicines use in people living with dementia and their caregivers: A literature review. *Int J Pharm*. 2016;512(2):396-404. doi:10.1016/J.IJPHARM.2015.12.050
36. Travis SS, Bethea LS, Winn P. Medication Administration Hassles Reported by Family Caregivers of Dependent Elderly Persons. *J Gerontol A Biol Sci Med Sci*. 2000;55(7):M412-M417. doi:10.1093/gerona/55.7.M412
37. Manias E, Bucknall T, Hughes C, Jorm C, Woodward-Kron R. Family involvement in managing medications of older patients across transitions of care: a systematic review. *BMC Geriatr*. 2019;19(1):95. doi:10.1186/s12877-019-1102-6
38. Travis SS, Bernard MA, McAuley WJ, Thornton M, Kole T. Development of the Family Caregiver Medication Administration Hassles Scale. *Gerontologist*. 2003;43(3):360-368. doi:10.1093/geront/43.3.360
39. DeLongis A, Coyne JC, Dakof G, Folkman S, Lazarus RS. Relationship of daily hassles, uplifts, and major life events to health status. *Health Psychology*. 1982;1(2):119-136. doi:10.1037/0278-6133.1.2.119
40. Noureldin M, Plake KS. Correlates of caregivers' involvement in the management of older adults' medications. *Research in Social and Administrative Pharmacy*. 2017;13(4):840-848. doi:10.1016/j.sapharm.2016.09.009
41. Liu Z, Heffernan C, Tan J. Caregiver burden: A concept analysis. *Int J Nurs Sci*. 2020;7(4):438-445. doi:10.1016/j.ijnss.2020.07.012
42. George NR, Steffen AM. Predicting perceived medication-related hassles in dementia family caregivers. *Dementia*. 2017;16(6):797-810. doi:10.1177/1471301215618570
43. Kurz A, Schulz M, Reed P, et al. Personal perspectives of persons with Alzheimer's disease and their carers: A global survey. *Alzheimer's & Dementia*. 2008;4(5):345-352. doi:10.1016/j.jalz.2008.06.002
44. Levy HB, Steffen AM. Validating the Medication Risk Questionnaire with Family Caregivers of Older Adults. *The Consultant Pharmacist*. 2016;31(6):329-337. doi:10.4140/TCP.n.2016.329

45. Lingler JH, Sereika SM, Amspaugh CM, et al. An intervention to maximize medication management by caregivers of persons with memory loss: Intervention overview and two-month outcomes. *Geriatr Nurs (Minneap)*. 2016;37(3):186-191. doi:10.1016/j.gerinurse.2015.12.002
46. Piggott CA, Zimmerman S, Reed D, Sloane PD. Development and Testing of a Measure of Caregiver Confidence in Medical Sign/Symptom Management. *American Journal of Alzheimer's Disease & Other Dementiasr*. 2017;32(7):373-381. doi:10.1177/1533317517711247
47. Schmidt NE, Steffen A, Meuser TM. Impairment for Medication Management in Older Adults: Validity of a Family Report Measure. *Clin Gerontol*. 2020;43(3):350-362. doi:10.1080/07317115.2019.1703064
48. VanDyke MM, Steffen AM. Medication Saving Behaviors of Older Adults: Scale Developed to Assess Family Caregiver Perspectives. *Clin Gerontol*. 2017;40(4):258-267. doi:10.1080/07317115.2016.1276114
49. Reinhard S. HOME ALONE REVISITED: FAMILY CAREGIVERS PROVIDING COMPLEX CARE. *Innov Aging*. 2019;3(Supplement_1):S747-S748. doi:10.1093/geroni/igz038.2740
50. Blair J, Volpe M, Aggarwal B. Challenges, Needs, and Experiences of Recently Hospitalized Cardiac Patients and Their Informal Caregivers. *Journal of Cardiovascular Nursing*. 2014;29(1):29-37. doi:10.1097/JCN.0b013e3182784123
51. Coleman EA, Roman SP. Family Caregivers' Experiences During Transitions Out of Hospital. *Journal for Healthcare Quality*. 2015;37(1):12-21. doi:10.1097/01.JHQ.0000460117.83437.b3
52. C Eisdorfer. Caregiving: an emerging risk factor for emotional and physical pathology. *Bull Menninger Clin*. 1991;55(2):238-247.
53. Greenwood N, Smith R. Motivations for being informal carers of people living with dementia: a systematic review of qualitative literature. *BMC Geriatr*. 2019;19(1):169. doi:10.1186/s12877-019-1185-0
54. Liao X, Wang J, Zhang F, Luo Z, Zeng Y, Wang G. The levels and related factors of compassion fatigue and compassion satisfaction among family caregivers: A systematic review and meta-analysis of observational studies. *Geriatr Nurs (Minneap)*. 2022;45:1-8. doi:10.1016/J.GERINURSE.2022.02.016
55. Day JR, Anderson RA. Compassion fatigue: an application of the concept to informal caregivers of family members with dementia. *Nurs Res Pract*. 2011;2011:408024. doi:10.1155/2011/408024
56. Perry B, Dalton JE, Edwards M. Family caregivers' compassion fatigue in long-term facilities. *Nurs Older People*. 2010;22(4):26-31. doi:10.7748/nop2010.05.22.4.26.c7734
57. Ahmad Zubaidi ZS, Ariffin F, Oun CTC, Katiman D. Caregiver burden among informal caregivers in the largest specialized palliative care unit in Malaysia: a cross sectional study. *BMC Palliat Care*. 2020;19(1):186. doi:10.1186/s12904-020-00691-1
58. Jones PS, Winslow BW, Lee JW, Burns M, Zhang XE. Development of a Caregiver Empowerment Model to Promote Positive Outcomes. *J Fam Nurs*. 2011;17(1):11-28. doi:10.1177/1074840710394854

59. Bastawrous M. Caregiver burden? A critical discussion. *Int J Nurs Stud*. 2013;50(3):431-441. doi:10.1016/j.ijnurstu.2012.10.005
60. Lynch SH, Shuster G, Lobo ML. The family caregiver experience – examining the positive and negative aspects of compassion satisfaction and compassion fatigue as caregiving outcomes. *Aging Ment Health*. 2018;22(11):1424-1431. doi:10.1080/13607863.2017.1364344
61. Greenwood N, Mackenzie A, Cloud GC, Wilson N. Informal carers of stroke survivors–factors influencing carers: A systematic review of quantitative studies. *Disabil Rehabil*. 2008;30(18):1329-1349. doi:10.1080/09638280701602178
62. &NA; COPING WITH COMPASSION FATIGUE. *Nursing (Brux)*. 1992;22(4):116-121. doi:10.1097/00152193-199204000-00035
63. Adams RE, Figley CR, Boscarino JA. The Compassion Fatigue Scale: Its Use With Social Workers Following Urban Disaster. *Res Soc Work Pract*. 2008;18(3):238-250. doi:10.1177/1049731507310190
64. Keidel GC. Burnout and compassion fatigue among hospice caregivers. *American Journal of Hospice and Palliative Medicine*®. 2002;19(3):200-205. doi:10.1177/104990910201900312
65. Lynch SH, Lobo ML. Compassion fatigue in family caregivers: a Wilsonian concept analysis. *J Adv Nurs*. 2012;68(9):2125-2134. doi:10.1111/j.1365-2648.2012.05985.x
66. Figley CR. Compassion fatigue: Psychotherapists' chronic lack of self care. *J Clin Psychol*. 2002;58(11):1433-1441. doi:10.1002/jclp.10090
67. MCHOLM F. Rx for Compassion Fatigue. *Journal of Christian Nursing*. 2006;23(4):12-19. doi:10.1097/00005217-200611000-00003
68. Sabo BM. Compassion fatigue and nursing work: Can we accurately capture the consequences of caring work? *Int J Nurs Pract*. 2006;12(3):136-142. doi:10.1111/j.1440-172X.2006.00562.x
69. Aguglia E, Onor ML, Trevisiol M, Negro C, Saina M, Maso E. Stress in the caregivers of Alzheimer's patients: An experimental investigation in Italy. *American Journal of Alzheimer's Disease & Other Dementiasr*. 2004;19(4):248-252. doi:10.1177/153331750401900403
70. Schumacher K, Beck CA, Marren JM. FAMILY CAREGIVERS: caring for older adults, working with their families. *AJN, American Journal of Nursing*. 2006;106(8):40-49. doi:10.1097/00000446-200608000-00020
71. Taylor DH, Ezell M, Kuchibhatla M, Østbye T, Clipp EC. Identifying Trajectories of Depressive Symptoms for Women Caring for Their Husbands with Dementia. *J Am Geriatr Soc*. 2008;56(2):322-327. doi:10.1111/j.1532-5415.2007.01558.x
72. Van Houtven CH, Norton EC. Informal care and health care use of older adults. *J Health Econ*. 2004;23(6):1159-1180. doi:10.1016/j.jhealeco.2004.04.008
73. Dehlin M, Lundh LG. Compassion fatigue and compassion satisfaction among psychologists: Can supervision and a reflective stance be of help? *J Pers Oriented Res*. 2018;4(2):95-107. doi:10.17505/jpor.2018.09

74. Sinclair S, Norris JM, McConnell SJ, et al. Compassion: a scoping review of the healthcare literature. *BMC Palliat Care*. 2016;15(1):6. doi:10.1186/s12904-016-0080-0
75. Radey M, Figley CR. The Social Psychology of Compassion. *Clin Soc Work J*. 2007;35(3):207-214. doi:10.1007/s10615-007-0087-3
76. Figley CR. Compassion fatigue: Psychotherapists' chronic lack of self care. *J Clin Psychol*. 2002;58(11):1433-1441. doi:10.1002/jclp.10090
77. Sorenson C, Bolick B, Wright K, Hamilton R. Understanding Compassion Fatigue in Healthcare Providers: A Review of Current Literature. *Journal of Nursing Scholarship*. 2016;48(5):456-465. doi:10.1111/jnu.12229
78. Gérain P, Zech E. Informal Caregiver Burnout? Development of a Theoretical Framework to Understand the Impact of Caregiving. *Front Psychol*. 2019;10. doi:10.3389/fpsyg.2019.01748
79. Lynch SH. Looking at Compassion Fatigue Differently: Application to Family Caregivers. *Am J Health Educ*. 2018;49(1):9-11. doi:10.1080/19325037.2017.1369197
80. Feliciano A, Feliciano E, Palompon D, Gonzales F. Acceptance Theory of Family Caregiving. *Belitung Nurs J*. 2022;8(2):86-92. doi:10.33546/bnj.2004
81. Domeisen Benedetti F, Hechinger M, Fringer A. Self-Assessment Instruments for Supporting Family Caregivers: An Integrative Review. *Healthcare (Basel)*. 2024;12(10). doi:10.3390/healthcare12101016
82. Stamm BH. Professional quality of life: Compassion satisfaction and fatigue version 5. 2009. www.proqol.com. .
83. Stamm B. H. (2010). The concise ProQOL manual (2nd ed.). ProQOL.org.
84. Zhai S, Chu F, Tan M, Chi NC, Ward T, Yuwen W. Digital health interventions to support family caregivers: An updated systematic review. *Digit Health*. 2023;9:205520762311719. doi:10.1177/20552076231171967
85. Espírito-Santo M, Santos S, Estêvão MD. Digital Solutions Available to Be Used by Informal Caregivers, Contributing to Medication Adherence: A Scoping Review. *Pharmacy*. 2024;12(1):20. doi:10.3390/pharmacy12010020
86. Yeung AWK, Torkamani A, Butte AJ, et al. The promise of digital healthcare technologies. *Front Public Health*. 2023;11. doi:10.3389/fpubh.2023.1196596
87. Chi NC, Demiris G. A systematic review of telehealth tools and interventions to support family caregivers. *J Telemed Telecare*. 2015;21(1):37-44. doi:10.1177/1357633X14562734
88. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden: a clinical review. *JAMA*. 2014;311(10):1052. doi:10.1001/jama.2014.304
89. Faisal S, Ivo J, Patel T. A review of features and characteristics of smart medication adherence products. *Canadian Pharmacists Journal / Revue des Pharmaciens du Canada*. 2021;154(5):312-323. doi:10.1177/17151635211034198

90. Spencer Features and Benefits - Spencer Health Solutions. Spencer Health Solutions -. Published November 9, 2022. Accessed February 12, 2024. <https://spencerhealthsolutions.com/home/meet-spencer/featuresandbenefits/>.
91. Patel T, Ivo J, Pitre T, Faisal S, Antunes K, Oda K. An In-Home Medication Dispensing System to Support Medication Adherence for Patients With Chronic Conditions in the Community Setting: Prospective Observational Pilot Study. *JMIR Form Res*. 2022;6(5):e34906. doi:10.2196/34906
92. Polenick CA, Stanz SD, Leggett AN, Maust DT, Hodgson NA, Kales HC. Stressors and Resources Related to Medication Management: Associations With Spousal Caregivers' Role Overload. *Gerontologist*. 2020;60(1):165-173. doi:10.1093/geront/gny130
93. Kamimura T. Older Adults with Alzheimer's Disease Who Have Used an Automatic Medication Dispenser for 3 or More Years. *Clin Gerontol*. 2019;42(1):127-133. doi:10.1080/07317115.2017.1347594
94. Gench M, Sawan MJ, Langford A, Gnjdjic D. Tools to evaluate medication management for caregivers of people living with dementia: A systematic review. *Health Expectations*. 2021;24(5):1570-1581. doi:10.1111/hex.13318
95. LaValley SA, Brady LA, Nguyen M, Jacobs D. Family Caregivers of Older Adults: Strategies, Tools, and Technologies for Medication Management. *J Gerontol Soc Work*. 2023;66(2):291-302. doi:10.1080/01634372.2022.2100856
96. Wagle KC, Skopelja EN, Campbell NL. Caregiver-Based Interventions to Optimize Medication Safety in Vulnerable Elderly Adults: A Systematic Evidence-Based Review. *J Am Geriatr Soc*. 2018;66(11):2128-2135. doi:10.1111/jgs.15556
97. Barac R, Stein S, Bruce B, Barwick M. Scoping review of toolkits as a knowledge translation strategy in health. *BMC Med Inform Decis Mak*. 2014;14(1):121. doi:10.1186/s12911-014-0121-7
98. Yamada J, Shorkey A, Barwick M, Widger K, Stevens BJ. The effectiveness of toolkits as knowledge translation strategies for integrating evidence into clinical care: a systematic review. *BMJ Open*. 2015;5(4):e006808. doi:10.1136/bmjopen-2014-006808
99. Sawan MJ, Clough AJ, Jokanovic N, et al. Co-design of medication management guidance tools for people living with dementia and carers at discharge. *Alzheimer's & Dementia*. 2025;21(5). doi:10.1002/alz.70257
100. Wasti SP, Simkhada P, van Teijlingen E, Sathian B, Banerjee I. The Growing Importance of Mixed-Methods Research in Health. *Nepal J Epidemiol*. 2022;12(1):1175-1178. doi:10.3126/nje.v12i1.43633
101. Schoonenboom J, Johnson RB. How to Construct a Mixed Methods Research Design. *KZfSS Kölner Zeitschrift für Soziologie und Sozialpsychologie*. 2017;69(S2):107-131. doi:10.1007/s11577-017-0454-1
102. Munce SEP, Guetterman TC, Jaglal SB. Using the Exploratory Sequential Design for Complex Intervention Development: Example of the Development of a Self-Management Program for Spinal Cord Injury. *J Mix Methods Res*. 2021;15(1):37-60. doi:10.1177/1558689820901936
103. In J. Introduction of a pilot study. *Korean J Anesthesiol*. 2017;70(6):601. doi:10.4097/kjae.2017.70.6.601

104. Erickson SR, Yang Y. Hassles with medication management perceived by caregivers of adults who have intellectual or developmental disabilities. *Int J Clin Pharm*. 2019;41(1):131-140. doi:10.1007/s11096-018-0771-0
105. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2006;3(2):77-101. doi:10.1191/1478088706qp063oa
106. Mazza GL, Enders CK, Ruehlman LS. Addressing Item-Level Missing Data: A Comparison of Proration and Full Information Maximum Likelihood Estimation. *Multivariate Behav Res*. 2015;50(5):504-519. doi:10.1080/00273171.2015.1068157
107. Hooper R. To adjust, or not to adjust, for multiple comparisons. *J Clin Epidemiol*. 2025;180:111688. doi:10.1016/j.jclinepi.2025.111688
108. Noureldin M, Henkaline A, Botros K, Chen AMH. Exploring community pharmacists' roles as information providers to family caregivers of older adults. *Research in Social and Administrative Pharmacy*. 2025;21(11):914-923. doi:10.1016/j.sapharm.2025.06.101
109. Savic LC, Smith AF. How to conduct a Delphi consensus process. *Anaesthesia*. 2023;78(2):247-250. doi:10.1111/anae.15808
110. Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N, Hoagwood K. Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research. *Administration and Policy in Mental Health and Mental Health Services Research*. 2015;42(5):533-544. doi:10.1007/s10488-013-0528-y
111. Hennink M, Kaiser BN. Sample sizes for saturation in qualitative research: A systematic review of empirical tests. *Soc Sci Med*. 2022;292:114523. doi:10.1016/j.socscimed.2021.114523
112. Guest G, Fleming P. Mixed Methods Research. In: *Public Health Research Methods*. SAGE Publications, Inc.; 2015:581-614. doi:10.4135/9781483398839.n19
113. Guest G, Namey E, McKenna K. How Many Focus Groups Are Enough? Building an Evidence Base for Nonprobability Sample Sizes. *Field methods*. 2017;29(1):3-22. doi:10.1177/1525822X16639015
114. Guest G, Namey E, Chen M. A simple method to assess and report thematic saturation in qualitative research. *PLoS One*. 2020;15(5):e0232076. doi:10.1371/journal.pone.0232076
115. Colucci E. "Focus Groups Can Be Fun": The Use of Activity-Oriented Questions in Focus Group Discussions. *Qual Health Res*. 2007;17(10):1422-1433. doi:10.1177/1049732307308129
116. Kitzinger J. Qualitative Research: Introducing focus groups. *BMJ*. 1995;311(7000):299-302. doi:10.1136/bmj.311.7000.299
117. Carilli, T. et al. (2024) Focus Groups, SAGE Publications Inc. Available at: <https://us.sagepub.com/en-us/nam/book/focus-groups-6> (Accessed: 05 July 2024). .
118. Holden RJ, Schubert CC, Mickelson RS. The patient work system: An analysis of self-care performance barriers among elderly heart failure patients and their informal caregivers. *Appl Ergon*. 2015;47:133-150. doi:10.1016/j.apergo.2014.09.009

119. Birt L, Scott S, Cavers D, Campbell C, Walter F. Member Checking. *Qual Health Res*. 2016;26(13):1802-1811. doi:10.1177/1049732316654870
120. 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. doi:10.1186/1471-2288-13-117
121. Ranelli PL, Aversa SL. Medication-related stressors among family caregivers. *Am J Hosp Pharm*. 1994;51(1):75-79.
122. Smith F, Francis SA, Gray N, Denham M, Graffy J. A multi-centre survey among informal carers who manage medication for older care recipients: problems experienced and development of services. *Health Soc Care Community*. 2003;11(2):138-145. doi:10.1046/j.1365-2524.2003.00415.x
123. Moll S, Wyndham-West M, Mulvale G, et al. Are you really doing ‘codesign’? Critical reflections when working with vulnerable populations. *BMJ Open*. 2020;10(11):e038339. doi:10.1136/bmjopen-2020-038339
124. Slattery P, Saeri AK, Bragge P. Research co-design in health: a rapid overview of reviews. *Health Res Policy Syst*. 2020;18(1):17. doi:10.1186/s12961-020-0528-9
125. Guilcher SJT, Cadel L, He A, et al. Medication self-management toolkits for adults with multiple sclerosis: A scoping review. *Exploratory Research in Clinical and Social Pharmacy*. 2023;10:100282. doi:10.1016/j.rcsop.2023.100282
126. Fetters MD, Curry LA, Creswell JW. Achieving Integration in Mixed Methods Designs—Principles and Practices. *Health Serv Res*. 2013;48(6pt2):2134-2156. doi:10.1111/1475-6773.12117
127. Wilson C, Janes G, Williams J. Identity, positionality and reflexivity: relevance and application to research paramedics. *Br Paramed J*. 2022;7(2):43-49. doi:10.29045/14784726.2022.09.7.2.43
128. Goundar PR. Researcher Positionality: Ways to Include it in a Qualitative Research Design. *Int J Qual Methods*. 2025;24. doi:10.1177/16094069251321251
129. Faisal S. Lessons in reflexivity of a pharmacist conducting ethnographic research. *Research in Social and Administrative Pharmacy*. 2021;17(10):1849-1855. doi:10.1016/j.sapharm.2021.02.015

Appendix A: ProQoL and FCMAHS

The Professional Quality of Life Scale

ProQOL - Version 5

Helping others as a caregiver and the compassion you experience towards those you help impacts you in several ways. The following questions aim to assess these effects and are concerned with your role as a caregiver. Select the number on the scale that most accurately reflects how frequently you have experienced each statement in the last 30 days.

1=“Never” 2=“Rarely” 3=“Sometimes” 4=“Often” 5=“Very Often”

1. I am happy.	1	2	3	4	5
2. I am preoccupied with more than one person I help.	1	2	3	4	5
3. I get satisfaction from being able to help people.	1	2	3	4	5
4. I feel connected to others.	1	2	3	4	5
5. I jump or am startled by unexpected sounds	1	2	3	4	5
6. I feel invigorated after working with those I help.	1	2	3	4	5
7. I find it difficult to separate my personal life from my life as a helper.	1	2	3	4	5
8. I am not as productive at work because I am losing sleep over traumatic experiences of a person I help.	1	2	3	4	5

9. I think that I might have been affected by the traumatic stress of those I [help].	1	2	3	4	5
10. I feel trapped by my job as a helper.	1	2	3	4	5
11. Because of my helping, I have felt “on edge” about various things.	1	2	3	4	5
12. I like my work as a helper.	1	2	3	4	5
13. I feel depressed because of the traumatic experiences of the people I help.	1	2	3	4	5
14. I feel as though I am experiencing the trauma of someone I have helped.	1	2	3	4	5
15. I have beliefs that sustain me.	1	2	3	4	5
16. I am pleased with how I am able to keep up with helping techniques and protocols.	1	2	3	4	5
17. I am the person I always wanted to be.	1	2	3	4	5
18. My work makes me feel satisfied.	1	2	3	4	5
19. I feel worn out because of my work as a helper.	1	2	3	4	5
20. I have happy thoughts and feelings about those I help and how I could help them.	1	2	3	4	5

21. I feel overwhelmed because my work load seems endless.	1	2	3	4	5
22. I believe I can make a difference through my work.	1	2	3	4	5
23. I avoid certain activities or situations because they remind me of frightening experiences of the people I help.	1	2	3	4	5
24. I am proud of what I can do to help.	1	2	3	4	5
25. As a result of my helping, I have intrusive, frightening thoughts.	1	2	3	4	5
26. I feel “bogged down” by the system.	1	2	3	4	5
27. I have thoughts that I am a “success” as a helper.	1	2	3	4	5
28. I can’t recall important parts of my work with trauma victims.	1	2	3	4	5
29. I am a very caring person.	1	2	3	4	5
30. I am happy that I chose to do this work.	1	2	3	4	5

B. Hudnall Stamm, 2009. *Professional Quality of Life: Compassion Satisfaction and Fatigue Version 5* (ProQOL). www.proqol.org.

The Family Caregiver Medication Administration Hassles Scale

As a caregiver, please rate each of the following medication management tasks based on how much of a hassle they are for you.

This scale ranges from **0 = “not a hassle”** to **5 = “one of the worst of all hassles”**

Subscale 1: Information Seeking and Information Sharing						
Knowing what to do if an emergency occurs	0	1	2	3	4	5
Finding clear information about the medication	0	1	2	3	4	5
Knowing why a medication is being given and if it is having the desired effect	0	1	2	3	4	5
Being comfortable talking to the doctor about medications	0	1	2	3	4	5
Having someone available to answer questions	0	1	2	3	4	5
Getting information within a reasonable time frame	0	1	2	3	4	5
Feeling comfortable about making medication decisions.	0	1	2	3	4	5
Knowing what questions to ask the physician.	0	1	2	3	4	5

Understanding the directions and information I am given.	0	1	2	3	4	5
Subscale 2: Scheduling Logistics						
Giving medications on time	0	1	2	3	4	5
Scheduling multiple medications throughout the day	0	1	2	3	4	5
Arguing with the care-recipient about when to take medications	0	1	2	3	4	5
Working medication schedules into my daily routine	0	1	2	3	4	5
Coordinating my medication schedules with those of the care-recipient	0	1	2	3	4	5
Sharing the responsibility with the care-recipient for keeping medication schedules	0	1	2	3	4	5
Remembering to give medications according to schedule	0	1	2	3	4	5
Subscale 3: Safety Issues						

Admitting to the physician or others that I made a mistake	0	1	2	3	4	5
Knowing when to hold, increase, decrease a dose or discontinue the medication	0	1	2	3	4	5
Understanding when medications can be crushed, mixed, dissolved, etc.	0	1	2	3	4	5
Recognizing adverse (bad) side effects	0	1	2	3	4	5
Knowing how to give medication safely	0	1	2	3	4	5
Subscale 4: Polypharmacy						
Keeping medication prescriptions filled	0	1	2	3	4	5
Planning ahead to keep prescriptions filled over weekends and holidays	0	1	2	3	4	5
Managing medication prescriptions written by multiple physicians	0	1	2	3	4	5

Travis SS, Bernard MA, McAuley WJ, Thornton M, Kole T. Development of the family Caregiver Medication Administration Hassles scale. *The Gerontologist*. 2003;43(3):360–8. doi:10.1093/geront/43.3.360

Appendix B: Semi-Structured Interview Guide for Study 1

Automated Medication Dispensing Technology, Caregiver Burnout and Compassion Fatigue: A Pilot pre-post Mixed Methods Study

Qualitative Interview Questions for Caregiver

Pre-Intervention

1. What is your relationship with your care-recipient and how long have you known them for?
 - Prompts: type of relationship (spouse, child, grandchild, etc); nature of relationship (burden/positive feedback), length of relationship; how did the relationship for caregiving begin
2. Can you tell us a bit about your role as a caregiver and what your tasks tend to be on a weekly basis?
 - Prompts: driving to appointments, attending physician appointments, other non-medication related activities
3. Could you describe how involved you are with your care recipient's medication management?
 - Prompts: ordering medication refills, picking up, organizing, reminders, making sure meds are being taken, use of medication organizers, splitting tablets, etc
4. What challenges do you face as a caregiver?
 - Prompts: challenges with picking up meds, changing doses, administration of meds, etc
5. What strategies, devices or tools do you use to currently manage your loved ones medications?

What are some of the benefits or challenges with using them?
6. How do you organize your care recipients' medications?

- Use of any reminders (calendar, checklist, notes, alarms, etc)
- Frequency of organization: day by day or long-term

7. Have you made any mistakes when managing medications for your care recipient?

- Describe what happened
- How did you feel about it
- What did you change
- What could have prevented it

8. How satisfied do you feel about your role as a caregiver and the extent to which you are fulfilling your duties?

- Prompts: fatigue with med management tasks, irritability, their own life challenges

Post Intervention

1. Describe your experience with using automated dispensing technology.

- Prompts: Was it difficult/easy to use? Was it difficult/easy to learn?
- What features of automated dispensing technology did you find most/least useful?
- Would you recommend this device to others? Why or why not?

2. Think back to before you were using the automated medication dispenser...How has the automated dispensing technology impacted your tasks related to managing medications?

- Prompts – what aspects of managing medications have helped?
- What aspects of managing medications are worse?
- What strategies/devices/tools have been impacted using this technology?

3. How satisfied do you feel as a caregiver after having implemented automated dispensing technology?

- Prompts: fatigue with med management tasks, irritability, their own life challenges

4. How would you describe your relationship with your care-recipient after integrating the automated dispensing technology?

- Prompts: change nature of relationship (burden/positive feedback)

Appendix C: Semi-Structured Interview Guide for Study 2

Development of a Medication Management Toolkit for Care Partners of Older Adults

Semi-Structured Interview/Focus Group Discussion Guide

Background Information

1. Relationship between the caregiver and the care recipient

- How are you related to the person you care for, and how long have you known them?
 - Prompts (type and nature of relationship with the care-recipient, how they became caregivers, the length and starting point of their caregiving experience, etc.)

Tasks

2. Medication Management Tasks and other caregiver-related tasks

- What are some of the non-medication-related tasks and responsibilities you handle?
 - Prompts (grocery shopping, cooking meals, household work, laundry, driving to medical appointments, etc.)
- Can you describe your typical tasks when managing medications for your loved one?
 - Prompts (ordering medication refills, picking up, organizing, reminders, making sure meds are being taken, using medication organizers, splitting tablets, etc.)

- What specific challenges do you face in managing these tasks? (participants will be asked to list them down)
 - Prompts (challenges with scheduling your loved one's medication into your daily routine, remembering to give medication on time, changes to the dosing regime, recognizing medication side effects, etc.)

Tools and Technology

3. Current Tools and Technology:

- What tools or technologies do you currently use to help manage medications?
 - Prompts (blister packs, pill organizers, electronic devices, smart devices, etc.)
- How effective are these tools in helping you manage medications?
 - Prompts (advantages and disadvantages)
- Are there any tools or technologies you wish you had to assist with medication management?
 - Prompts (toolkit for caregivers, etc.)

Toolkit Development

- How could a toolkit be designed to address your medication management challenges?
 - Prompts (a guide offers strategies for handling challenging scenarios (such as aggressive behaviors from care recipients, forgetfulness and confusion, difficulty following instructions, etc.), a resource for recognizing side effects and responding

to medical emergencies, and a step-by-step guide for managing urgent medical situations, etc.)

- Based on your experiences, what potential solutions could help overcome the challenges encountered?
 - Prompts (a medication schedule template, like a daily planner, educational materials from healthcare professionals, general guide with strategies to overcome challenging situations, such as dealing with uncooperative care recipients or care recipients having difficulty swallowing, a guide that helps in recognizing side effects and medical emergencies, a guide with steps to be taken in cases of medical emergencies, etc.)
- Based on the challenges identified and the solutions suggested, what do you think would be essential to include in the medication management toolkit?
 - Prompts (scheduling logistics domain, administration procedures domain, safety issues domain, etc.)
- How do you think these solutions could improve your medication management experience?
 - Prompts (enhance confidence level, provide guidance to navigate difficult scenarios related to medication, improve your ability to respond effectively in emergencies, etc.)
- What format would be most helpful for you in a toolkit?

- Prompts (printed guide, app, website, etc.)

Physical Environment

5. Medication Management Environment:

- Can you describe the physical space where you manage medications?
 - Prompts (own home, retirement home, etc.)
- What aspects of the physical environment help or hinder your ability to manage medications effectively?
 - Prompts (designated area for storing medications, space for organizing and handling medications, storage conditions, distractions that make managing medications difficult, etc.)

Organizational Environment

6. Healthcare System Interaction:

- How do you interact with healthcare providers regarding medication management?
 - Prompts (frequency of communicating with healthcare providers, methods of interaction (e.g., phone, email, in-person visits), comfort level of discussing medication concerns, keeping track of recommendations and instructions, etc.)
- What challenges do you face when coordinating with healthcare providers (e.g., doctors, pharmacists)?

- Prompts (experience any difficulties in understanding instructions, issues with getting timely responses to your queries, facing problems with prescription errors or misunderstandings, managing appointments and follow-ups related to medications?)
- How could healthcare providers better support you in managing medications?
- Prompts (additional information or resources that would be helpful, more frequent check-ins or reminders from providers, etc.)

Social Environment

7. Support System:

- Who else is involved in helping you manage medications for your loved one?
 - Prompts (friends, family, or support groups assist you in medication management, etc.)
- What additional support would be helpful?
 - Prompts (educational sources, tools, technologies, etc.)