

BMJ Open Caregivers' challenges in engaging with the health system to optimise medication management of older care recipients: a qualitative study including home visits

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ABSTRACT

Objectives Medication management is a demanding task for family caregivers of older adults, adding to their care burden. The aim was to identify the challenges family caregivers experience in managing medications of older care recipients to obtain caregiver-centred evidence for developing social and health services to meet their needs.

Design The qualitative data were collected during two consecutive home visits using thematic interviews with a narrative approach during the period of October 2017 to September 2018. The interview data were qualitatively analysed using the framework method with a combination of the inductive and deductive approaches. Human error theory with systems approach and prospective risk management was used as a theoretical framework.

Setting Family caregiving of older adults.

Participants 21 officially contracted family caregivers and their older (≥65 years) care recipients using >1 prescription medicine from the capital region of Finland.

Results Three conceptual models were constructed: (1) to position family caregiving in the public social and healthcare system, (2) to identify challenges and (3) needs for development in medication management prioritised from challenges. Family caregivers were not well integrated as a part of the health system, but left alone to manage the care recipient's medications. When urgent treatment-related matters arose, caregivers were not able to reach the physician. The major development needs concerned (1) identification of the caregivers as family caregivers in healthcare and community pharmacies, (2) making familiar healthcare professionals accessible, (3) ensuring sufficient customised support for managing medications at home (up-to-date medication list, monitoring and medicines information), (4) more active involvement and communication in the care process and (5) adopting compatible electronic health records between primary and secondary care, and pharmacies and social services.

Conclusions Family caregiving practices and support services should be developed in cooperation with the caregivers to meet their needs and place the families at the centre of the medication use process. Strengthening the integration of family caregiving to the social and

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The study reflects the views of the family caregiving families, bringing out their voice, which is often neglected in studies favouring social and healthcare providers' perspectives.
- ⇒ Data collection method with two consecutive home visits was time-consuming but comprehensive, providing in-depth and rich information about medication management practices in family caregiving of older care recipients.
- ⇒ Qualitative analysis applying the prospective risk management framework was suitable for constructing conceptual models crystallising the real-life medication management practices, challenges and role of social and healthcare services in family caregiving families.
- ⇒ Used rich qualitative data based on thematic interviews and narrative conversations during home visits supplemented each other and confirmed the findings, deepening understanding of challenges in medication management practices.
- ⇒ Due to the recruiting technique, the participating caregiving families may have been more active and involved in the care process than non-participants, possibly providing too positive picture of how family caregivers and older care recipients coped with the everyday care, especially with medication management.

healthcare system is vital, for example, by making easy access to family physician and involving pharmacists more actively in supporting medication management.

INTRODUCTION

Family caregiving is care given by a non-professional carer, such as a close relative, friend or neighbour to a chronically ill or disabled care recipient.¹⁻⁴ Family caregiving is essential but often neglected part of the social and healthcare system^{5 6} that is becoming more common globally, because



populations are ageing and healthcare resources are limited.^{3 7–10} Ageing contributes to a growing number of family caregivers and challenges their work as older care recipients often have multiple diseases and complex care procedures.^{8 9 11} Finland has prioritised home care and reduced resources from institutional care without sufficiently investing in home care services due to economic retrenchment.¹² Informal caregivers have filled the care gaps.¹² In Finland, without family caregiving, the costs of care for older adults have been estimated to be annually €2.8 billion higher.¹³ In the USA, the estimated economic value of family caregiving was US\$600 billion as in 2021.⁸ The development of family caregiving has been prioritised internationally and in the national government programmes since the early 2010s.^{4 14–19}

The caregivers' multifaceted responsibilities include management of the care recipient's medications together with the care recipient or being fully responsible for it. Medication management is more challenging in the care of older adults, because they usually have several long-term illnesses and medications. This may add to the overall care burden of family caregivers who are often also old. However, little is known about medication management in family caregiving of older adults. Earlier studies have concerned all caregiving families, despite the age of the care recipient, and older adults' family caregiver's perspective has been only part of the findings.^{9 20} Some studies have had a wider perspective, and medication management has been presented as a part of other findings.^{6 21 22} Some studies have been disease-specific,^{5 23 24} exploring, for example, cancer medication management or explored only one phase of the medication use process, for example, transition from hospital to home.²⁵ One of the previous research lines has focused on assessing the stressfulness of medication management.^{26–28} Furthermore, earlier research has found that medication safety can be enhanced by strengthening healthcare integration of home care services for older residents.²¹ Few studies have focused on understanding medication management in family caregiving of older adults.^{11 21 29} These studies have applied focus group discussions^{11 29} and multiple methods including home visits.²¹ However, none of the studies with home visits have focused on the experiences of caregiving families in medication management, bringing out their voice explicitly. Hence, little is known of the challenges and gaps in the public social and healthcare system in the perspective of the family caregiving families when managing medications of their older care recipients and what are their needs for support from the social and healthcare system in this respect.^{8 11 21} The caregiver or care recipient factors associated with the overall caregiving burden have an impact on medication management. However, these are more studied in contrast to system-related factors related to medication management.^{29–33}

The aim of this study was to identify the challenges and gaps in the public social and healthcare system in the perspective of the family caregiving families when

managing medications of their older care recipients. The purpose was to obtain caregiver-centred evidence to develop social and health services to meet their needs.

METHODS

Study context

In Finland, at the time of study, there were approximately 48 000 officially contracted family caregivers.³⁰ An official contract about care and payments was made between the municipality and the caregiver.¹ Municipalities paid contracted family caregivers care benefits, consisting of the services provided to the care recipient and the care allowance, caregiver's days off and services supporting family care as defined in the contract.¹ Services supporting family care could include, for example, health check and guidance and advice to ensure the caregiver's capability to take care of the patient.¹ Contracted family caregivers were positioned between formal and informal social and healthcare systems, belonging legally to social services.²²

Study design

The data for this study were collected during two consecutive home visits to a selective sample of older contracted caregivers and their care recipients recruited from the capital region of Finland (figure 1). The study applied a qualitative approach to have a comprehensive understanding of the challenges family caregivers experience when managing medications. The data were collected using (1) thematic interviews with narrative parts focusing on medication management,³⁴ (2) observation during the home visits and (3) medication reviews. This paper is mainly based on the interview data collected during two home visits (figure 1). Background information was collected via structured questionnaires.^{9 31 35–40}

A systems approach to preventive risk management, as presented in the human error theory, was used as a theoretical framework.⁴¹ Applied to medication risk management, the systems approach indicates that medication risks should be identified before they cause errors and harm to the patient. The risks should be managed proactively by developing the social and healthcare system and its processes. This study concentrated on identifying such proactive system-based means to managing medication risks in family caregiving.

Recruitment and selection of participants

A purposive, selective sampling was used to recruit participants. The inclusion criterion was an older (≥65 years) family care recipient with at least one prescription medicine in use and the caregiving contract with the municipality.

Volunteer family caregiving recipients and caregivers were recruited through The Association of Carers in the capital region by a newspaper announcement and recruitment letters. Registration was made by a telephone call to the main researcher (AK). If the inclusion criteria were

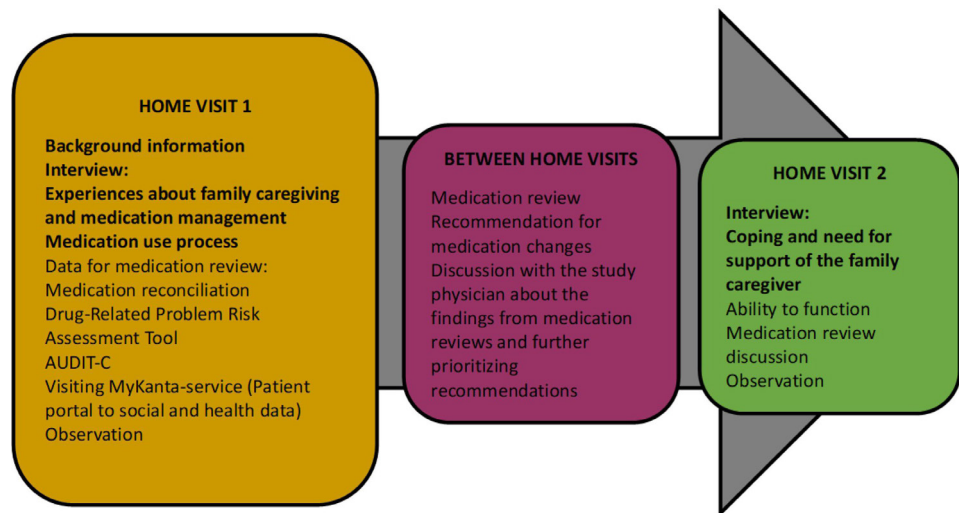


Figure 1 Study design with two consecutive home visits to understand how family caregivers (n=21) manage the medications of their older care recipients.^{37 62–64} The data used in this study are shown in bold. AUDIT-C, Alcohol Use Disorders Identification Test.

met, the first home visit with the caregiver and the care recipient would be scheduled during the call.

The newspaper announcement yielded only three volunteer families who agreed to participate. Therefore, a new recruitment attempt was made by sending recruitment letters to 200 randomly selected family caregiving families derived from the registered members of the Association of Carers in the capital region (yielding 18 families). After interviews, the need for another recruitment letter to involve more families was evaluated. As no new themes emerged during the last two interviews, the material was considered saturated and no additional study participants were needed. Saturation means collecting more data no longer brings up new theoretical views, nor reveals new theoretical categories.⁴²

Interview guide and data collection

An interview guide combining a semistructured and narrative approach was developed by using systems thinking in medication safety as a base⁴¹ (online supplemental appendices 1 and 2). The main themes of the first interview focused on how family caregivers and care recipients managed with the everyday care and medication management. The core of the first interview guide was a figure illustrating the medication use process^{43 44} (online supplemental appendix 3). The medication use process was assessed throughout, from diagnosis of the disease, prescription of the medication, medicines information, supply of the medication, storage of medications, dispensing medications, administration and taking medications, to follow-up of the medication. Under the main themes, specific questions were formed by using medication safety risks identified in the national guide for Safe Pharmacotherapy in social and healthcare by the Ministry of Social Affairs and Health^{45 46} and the Family Caregiver Medication Administration Hassles Scale.²⁷ The themes of the second interview were the medication review

discussion, caregiver's coping and need for support and both the caregiver's and the care recipient's functional ability, which were derived and deepened from the questionnaire conducted between interviews.^{9 27 31 35–40} Other data collection instruments are presented in figure 1.

The first two families performed as pilots and were included in the findings. Pilot interviews were used to fine-tune study methods, for example, to pretest the interview guide and to familiarise the main researcher (AK) with the study context. Minor clarifications were made.

Data collection

The principal investigator (AK) conducted all home visits, and one of the three pharmacy students assisted in making notes and observations in 40/42 of home visits. The principal investigator was an MSc Pharm and had several years of work experience from the community pharmacies at the time of the study. The study group consisted of pharmacists and an experienced geriatrician, who was also the official family caregiver at the time of the study. The home visits and interviews were conducted during the period of October 2017 to September 2018, each lasting approximately 2 hours. Depending on the diseases and functional ability of the care recipient, either the care recipient and caregiver or only the caregiver participated in the interviews. A figure illustrating the medication use process was used to stimulate the discussion^{43 44} (online supplemental appendix 3). The interviews were audio recorded with the permission of the study participants. The family caregiving families were numbered, and all identification information was removed from the research data to protect the privacy of the study participants.⁴⁷

Data analysis

The data were qualitatively analysed using the framework method, applying both inductive and deductive approaches during the years 2018–2020.⁴⁸ Complementary

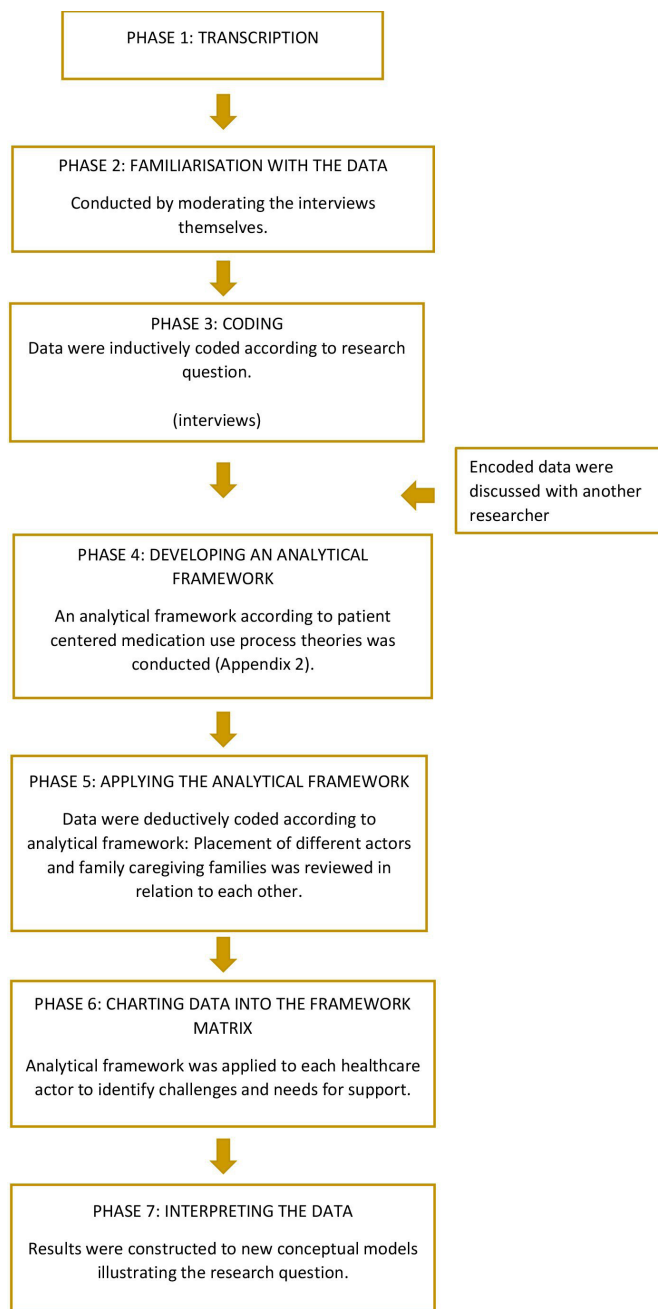


Figure 2 Qualitative analyses process with the framework method.⁴⁸

analysis to fine-tuning has been conducted in 2024. Analysis was conducted in seven phases using ATLAS.ti V.8.3.0 and Excel V.2016 (figure 2). Caregiving families' interviews were transcribed verbatim by a company specialised in transcription of audio records for written text (phase I). Researchers (AK and EL) who made the home visits and moderated the interviews during the visits conducted the analysis, facilitated by the fact that they were both very familiar with the data (phase II).

In the next phase, one of the researchers (EL) inductively encoded and grouped the expressions in the data to identify present factors affecting medication management (phase III). She discussed difficulties experienced

in coding first with the other researcher familiar with the data (AK). If necessary, the discrepancies were further discussed in the research group to be solved by consensus.

After the coding phase, the researcher (AK), familiar with the systems thinking and earlier analyses of the data, developed an analytical framework (phase IV). The framework was constructed by combining existing patient-centred medication use process models^{15 43 44} (online supplemental appendix 4). The models place the patient at the centre of the medication use process. Here, the patient (microlevel) was placed in the centre of all, and different public social and healthcare actors (mesolevel) were around the patient.⁴⁴

The analytical framework (medication use process model) was applied, and the data were deductively coded (phase I). Placement of different actors and positioning of family caregiving families into the public social and healthcare system was reviewed from the family caregivers' perspective (AK). In the next phase, the analytical framework guided the placement of the coded data (phase VI). This was done by applying the analytical framework (medication use process model) to each social and healthcare actors: primary care physician, community pharmacy, home care, specialised healthcare, practical nurses/nurses and nursing home to identify challenges and needs for support. New inductively rising challenges related to the medication management in family caregiving were added (phase VII).

A new conceptual model illustrating the position of family caregiving in the public social and healthcare system and existing challenges experienced by the caregiving families in the medication management of the care recipient was constructed (phase VII). Furthermore, a more detailed list of development needs based on the identified challenges was created to make visible what support family caregivers need for providing safe care for their older care recipients. The identified needs for development were prioritised based on emphasising how common they were in the whole data in the perspective of the overall public social and healthcare. The main development needs are prioritised from challenges from the perspective of the whole medication use process. Different social and healthcare providers involved were visualised in different colours. Emphasised challenges are illustrated with a red colour and higher prevalence of the challenge with a thicker frame. Emphasised means family caregiving families strongly highlighted the challenge, or they had a strong opinion about it. Common were the most numerous in terms of quantity.

Patient and public involvement

In the planning phase, the study design was discussed with the Association of Carers in Helsinki and Vantaa, Finland. Older care recipients and carer viewpoints were considered throughout the research process, as one of the senior researchers (S-LK) used to be a contracted caregiver for her old spouse while the research project was planned and conducted. Pilot interviews were used to

build up methods and to familiarise the main researcher (AK) with the context.

RESULTS

Participants

23 caregiving families participated. Two of them were excluded after registration, yielding a total number of 21 participating caregiving families with an older care recipient. One family dropped out due to the care recipient's death, and another was excluded since the care recipient's age was under 65 years. The families have had the official family caregiving contract for an average of 5 years (0–20 years). The mean age of the caregivers was 77 years (range 59–87) and care recipients 80 years (range 65–96). 12 of the caregivers were women (n=12/21), and 11 of the care recipients were men (n=11/21). In the majority of the families (n=19/21), the care recipient was the caregiver's spouse. In two families, the care recipient was the caregiver's mother or father. Except for one caregiver, all caregivers were retired.

Most of the caregivers (n=15/21) self-evaluated (excellent, good, moderate, poor, very poor) their own health status as moderate. Caregivers used on average 4.5 prescription and over-the-counter medications (ranged 0–10) and care recipients used 9.7 medications (ranged 3–16). The most common reasons for family caregiving were memory impairment (n=13) and deterioration of physical function (n=13) (one could choose multiple reasons). Almost half (n=9/21) of the families assessed that the care recipient would need round-the-clock institutional care without family caregiving, while a few families thought the patient would manage with the help of home care service.

Challenges family caregivers experience in managing medications of care recipients

Family caregivers were left alone with the health problems to manage their care recipients' medicines. When urgent treatment-related questions arose, it was challenging to contact the familiar healthcare professional. The shift from the centre of the medication use process to the corner alone was evident (figure 3).

All family caregiving families used primary care physician and community pharmacy services, and eight families were supported by home care services. Family caregivers reported experiencing many kinds of challenges in managing medications of their care recipients, but most challenges were with the primary care physician and community pharmacies, which are highlighted in the findings (figure 3). The most emphasised challenges concerned the fact that the carers were not identified as family caregivers in the healthcare and community pharmacies. They did not have access to health services when they had urgent treatment-related questions, medicines information and follow-up of medication or health was inadequate, and they encountered problems with prescribing and dispensing. While the most commonly

mentioned were challenges with schedule, interaction and communication problems, inadequate medicine information, no family physician and frequent turnover of the social and healthcare professionals.

Regardless of the social and healthcare actors, families had noticed that information transfer did not work between organisations. "When you're in a primary care physician's office, they don't have the information. That's also the fact that no matter how much I give permission, you can't allow all the doctors in Finland to use my health information, it won't work technically" (Family 18).

The most commonly mentioned challenges in the perspective of primary care physicians were frequent turnover, lack of family physicians, inadequate medicine information and problems with interaction and communication. While the most emphasised challenges were no access to health services when caregivers had treatment-related questions, prescribing problems, inadequate medicines information, monitoring of the medication or health and caregiving not documented (figure 4).

Lack of documenting caregiving in the electronic health record was seen as a risk for the care recipient. "I've tried many times to make sure it is documented that I am caregiver, in our healthcare, in any hospital, when I've been to the physician myself, and also when X has been. I've always wanted it to make it clear that I'm a caregiver because the important thing is that what if something happens to me and if I'm in a hospital somewhere, they need to know that somehow X will be taken care of." (Family 2). No access was reflected in the lack of appointment times and in the fact that physicians were impossible to contact when families had treatment-related questions. Inadequate support for discontinuation of medication, lack of medication review, reconciliation and follow-up controls were problems evident when monitoring the medication or health. Family caregivers found renewal of the prescription difficult, which escalated in one family as the medication ran out (Family 15).

Eight family caregiving families had home care services. Schedule too loose (the time interval for one visit was long) was the most commonly mentioned challenge when the home care was managing family care recipient's medicines. One family caregiver concretised the problem as "medicine helping to fall asleep might be given dosed between 5–9 pm" (Family 10). The most emphasised challenge was inadequate monitoring of the medication or health, which was evident as a lack of medication review, reconciliation, laboratory tests and follow-up controls.

When dispensing medicines in pharmacy, the most emphasised challenges were inadequate medicine information, carers not identified as family caregivers in the pharmacy and lack of identification of used medications (lack up-to-date medication list) when dispensing medicines (figure 5). The most commonly mentioned challenge in the perspective of pharmacy was inadequate medicine information.

Family caregiving families were not identified as family caregivers at the pharmacy. "At the pharmacy, they can see

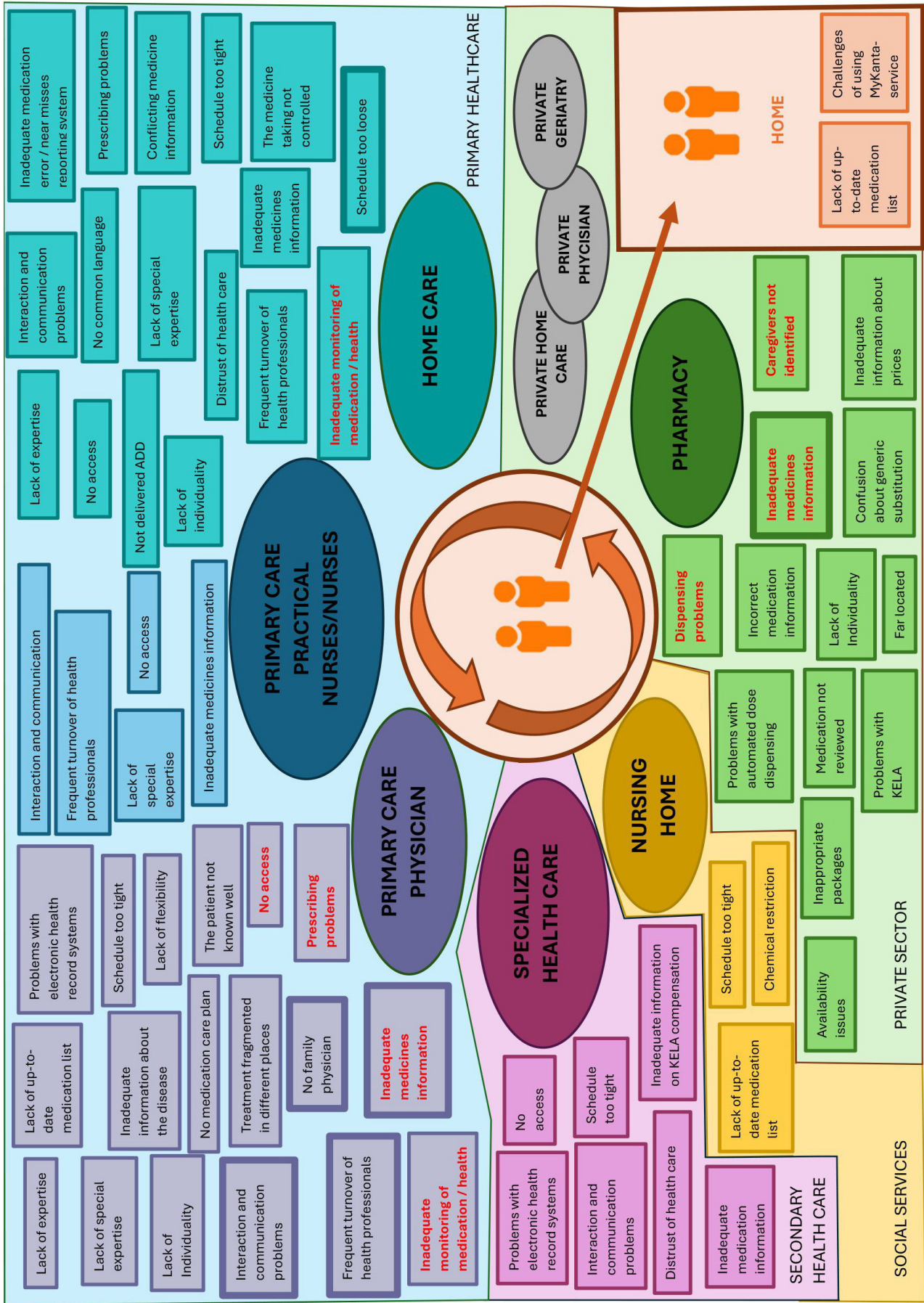


Figure 3 The challenges family caregivers experience in managing medications of care recipients in the context of the public social and health service (red coloured) challenges were emphasised, thicker framed challenges were common). Automated dose dispensing (ADD), Kela Finnish social security institution (KELA), MyKanta-service (patient portal to social and health data).

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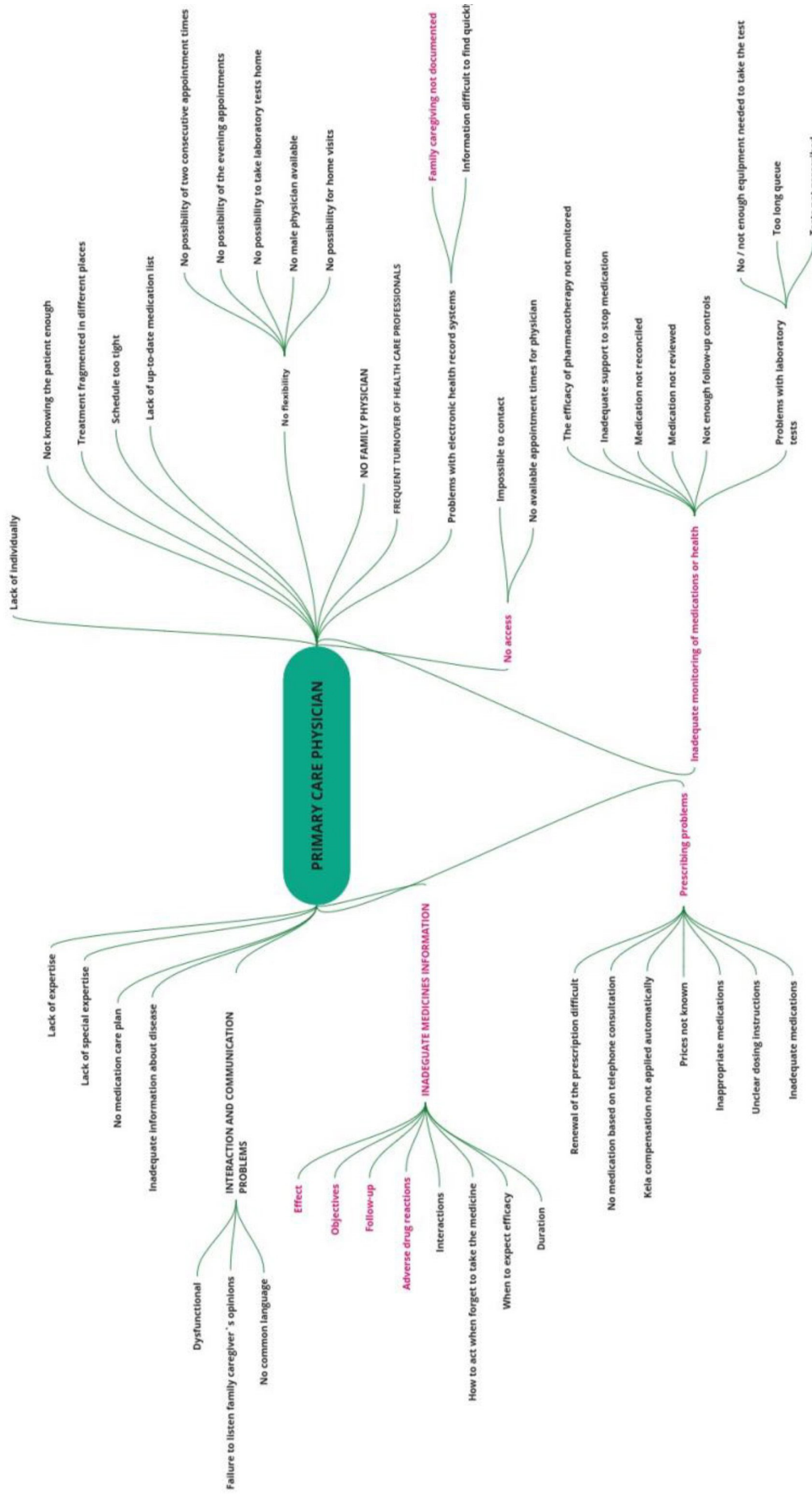


Figure 4 The primary care physician-related challenges experienced by family caregivers (n=21) in managing medications of their family care recipients (red colour means a challenge emphasised by the caregivers, uppercase refers to challenges often appearing according to caregivers).

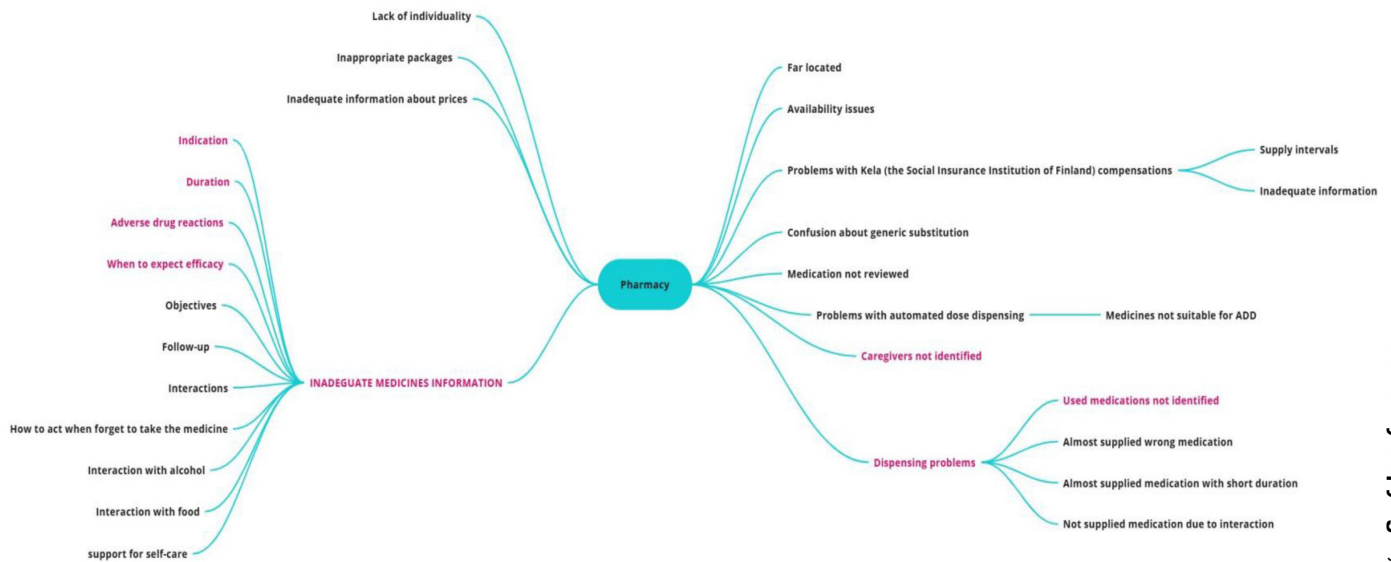


Figure 5 The community pharmacy-related challenges family caregivers experienced by family caregivers (n=21) experience in managing medications of their family care recipients (red colour means a challenge emphasised by the caregivers, Uppercase refers to challenges often appearing according to caregivers). ADD, automated dose dispensing.

that I get her medicine too, but they don't know that I'm a caregiver. They've never even seen her. We have never been there together. They just know that I'm getting my wife's medicine. Pharmacies could support family care givers better, if they knew I'm a caregiver" (Family 14). Availability issues caused extra visits to the pharmacy, which were for some families difficult to organise due to the condition of the care recipient. "The medicines my husband needs have always not been in stock, but then they have been ordered and a message has been sent from there that the medicine is now available and

that this is how it has worked. This causes this pointless running" (Family 13). "I change the pharmacy because they never had those medicines there when I rarely got there – I don't even have taken out the trash because of her" (Family 9).

Priority needs for development

The identified prioritised needs for development are based on emphasising how common they were in the whole data in the perspective of the overall public social and healthcare (figure 6). (1) Family caregivers should

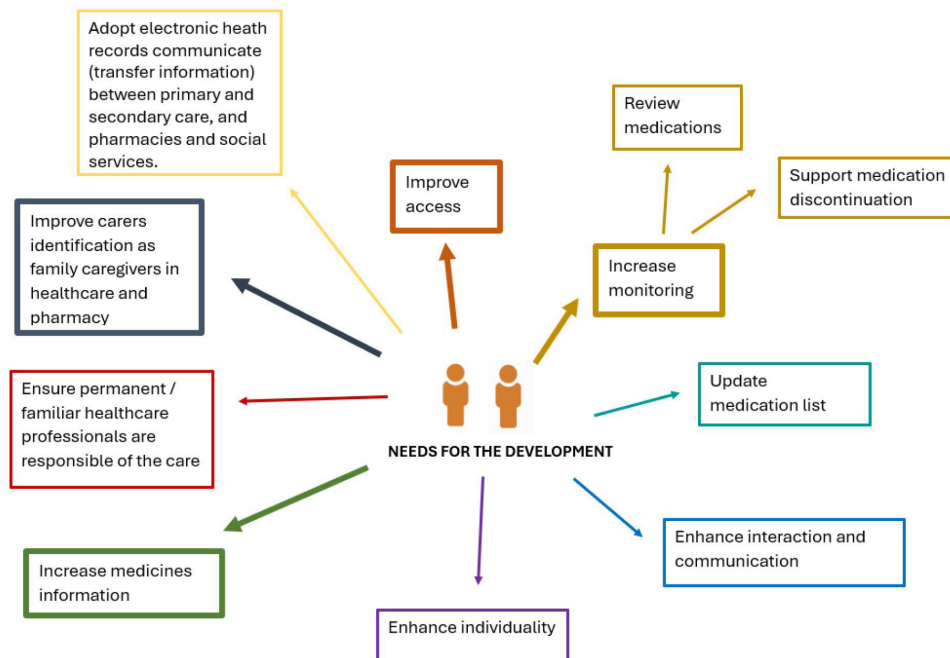


Figure 6 The priority needs for development in the perspective of family caregivers. (thicker framed development needs were emphasised).

be identified as family caregivers in the healthcare and pharmacy in order to better support the medication management in family caregiving. (2) Family caregivers need easy access to a familiar physician and other social and healthcare professionals and stronger integration to social and healthcare system. (3) Personalised services based on individual patient needs and sufficient support, for example, medicines information should be developed due to the fact that consistent and correct medication information is the key to ensuring medication safety in family caregiving. Sufficient medication and health monitoring and follow-ups should be developed, emphasising the up-to-date medication list, medication reviews and support when discontinuing medications. (4) The interaction and communication need to be clear, and social and healthcare should more actively involve family caregiving families in the care process. (5) Electronic health records should be integrated for interoperability so as to communicate among systems between primary and secondary care, and pharmacies and social services.

DISCUSSION

Main results

The findings yield caregiver-centred evidence to develop social and health services to meet family caregiving families' needs. Family caregivers were left alone with care recipients' health problems to manage their medicines. When urgent treatment-related questions arose, it was impossible to contact the familiar physician. The family caregiving families' shift from the centre of the medication use process to the corner alone was evident. The social and healthcare professionals, particularly physicians, were inaccessible when they had treatment-related questions. The main needs for development identified reflect weaknesses in the social and healthcare system. By targeting these weaknesses, medication safety risks in the family caregiving of the older adults could be managed nationally. In Finland, social and healthcare reform started in 2023, and development of the system will continue. Changes also concern family caregiving families. Development in family caregiving should be done with family caregivers to shift them to the centre of the medication use process. Attention should be paid to the system failures, but solutions should be personalised according to each family's personal needs.

Law/legislation and the agreement of the family caregiving

The contract previously formed with the municipality, and nowadays with the well-being services counties, positions family caregivers between formal and informal social and healthcare systems without truly given them access to services (eg, quick consultation with familiar healthcare professionals) as the findings highlight. Caregivers are left with responsibility without sufficient support. Responsibility also concerns medication errors.⁹ Caregivers do not have liability insurance for errors happening at home

when administering medications, such as healthcare professionals have.

At the time of the study, municipalities (nowadays, well-being services counties) were obligated to give guidance and advice according to the law to ensure caregiver's capability to take care of the care recipient.¹ Based on our findings, education about the care of the recipient should include medicines information, medication management and how to actively co-operate with public social and healthcare providers. Education and medicines information also improve medication adherence,⁴⁹ which is the base for safe medication use. Due to the COVID-19 pandemic, many of the education courses have been conducted remotely. Many of the social and health services have also moved to web based. Older adults might not be able to use web-based services or attend remote courses. Alternative methods should be preferred.

Improving integration

Care pathways can be complex and involve multiple care providers, leading to a not user-friendly social and healthcare system.⁵⁰ The fragmentation of the care process, inconsistent quality, lack of continuity of care and the inconvenience caused by the healthcare system are significant sources of the medication-related burden to chronically ill patients. Fragmentation and access problems were evident in our findings. Family caregivers identified most challenges with primary care physician and community pharmacy, which should be paid most attention to when developing family caregiving families' integration into the healthcare. Family caregiving families should be integrated into the social and healthcare system by actively involving them. One way to improve it could be, they could be provided with a checklist about the things that need to be taken care of (eg, reminder of yearly medication review). Caregivers' encouragement to collaborate with healthcare is vital to improving medication safety.

Earlier research has also found that by strengthening the healthcare integration in the seniors' home care, medication safety can be enhanced.²¹ Gaps in the healthcare system integration identified were issues in transition in care, lack of integrated electronic health records and communication failures. The last two were also emphasised in our study. Integrated electronic health records and an electronic up-to-date medication list could be keys to solving some communication barriers. Communication between healthcare and family caregiver is vital. By having the same physician and nurse and/or care team, communication could be secured inside the organisation, which could strengthen the interaction and communication, continuity of care and accessibility. In addition, medication monitoring and medicines information could be more complete and more consistent. The same care team ensures information flow in one organisation. The same electronic health record in primary and secondary care guarantees information flows between different organisations. Shared electronic health records enhance medication safety and would save money and time.⁵¹



Family caregiving is a part of social service. It includes activities related to healthcare, such as medications and treatment of diseases. Family caregiving is the interface between social care and healthcare. Integration between social and healthcare is an ongoing project in Finland. Nevertheless, electronic health records do not discuss with each other. Client data in social services and patient data in healthcare services are mostly handled with different electronic health records.⁵² Transferring client and patient data between various electronic health records will be possible in 2026 through the Kanta Services.^{52 53} At the time of the study, information was transferred by phone or on paper. Family caregiving families use both social and healthcare services, and information exchange is crucial to manage medication-related risks. Strengthening the integration between families and healthcare, but also between social and healthcare, and treating family caregivers as a part of the system could narrow gaps in the care system integration.

Pharmacists' role

Pharmacies can provide medicines information for family caregivers, help other healthcare professionals with the identification of the family caregivers as family caregivers and by providing tailored services (eg, repeat prescription reminders, home deliveries and pharmacist advice).^{2 54} Inadequate medicines information and lack of identification of the caregivers as family caregivers came out in our findings. Pharmacists are an underused resource in pharmacies but also in care units. Family caregivers visit pharmacies at least every 3 months to supply medicines. Pharmacies should be integrated into the social and healthcare system and accessed to electronic health records in order to truly use this resource. At the moment, pharmacists in the pharmacies give medicines information, review, for example, doses, appropriateness of the medications for older adults and interactions between medications, food and alcohol. Medicines information is the core competence of pharmacists and should be prioritised and continuously developed to ensure quality. The follow-up could be more strongly supported by pharmacies with medicines information and by documenting follow-up information for other healthcare professionals.

The political and economic climate may not encourage pharmacies to offer targeted services to family caregivers.² Pharmacies are under retrenchment by the government,¹⁸ and economic pressure hinders the development of clinical pharmacy services. Pharmacies do not have incentives to develop clinical pharmacy services such as medication review, since these services are not financially supported by the government, although pharmacies can charge patients for these services. The main barriers to implementing services such as medication reviews and recording the follow-up information are lack of patient information and access to electronic health records.⁵⁵ Despite these shortcomings, pharmacists can update medications lists and review the interactions. In addition, according to our findings and earlier research,

pharmacies could strongly promote services such as planning the simultaneous medication supplies for families, home delivery,⁵⁴ guidance and advice to improve medication management and assistance when renewing prescriptions. Renewing all prescriptions at the same time would enable simultaneous supplies and create a list of the used medications.⁵⁶

Multiple electronic health records that are unable to communicate are medication safety hazards.⁵⁷ Medication reconciliation is inevitable to ensure an up-to-date medication list and safe care.⁵⁸ Lack of an up-to-date medication list was evident in our findings. Not even all caregivers had an up-to-date list of care recipient's medications. Pharmacists in the care units are in a good position to do medication reconciliation, medication review and record follow-up information due to the access to the electronic health records.⁵⁹ Updating the medication list in the electronic health records makes it accessible for other healthcare professionals and patients. While updating the medications list, pharmacists have the possibility to document other information to patients and other healthcare professionals. Pharmacists could identify family caregivers as family caregivers and document it in the electronic health system. Documentation could be done as risk information (alert) which is visible to all professionals handling patient information. This could guarantee that the care recipient is taken care of if the caregiver is, for example, hospitalised and led stronger involvement of the family caregiver to medicines information process.

Family caregivers and care recipients feel unprepared to manage medications after discharge.^{6 25} Inadequate and contradictory medicines information came up in our findings. Consistent and correct medicines information is the key for better medication management, which also could prepare caregivers after hospitalisation medication management. Family caregivers as a lay person have the responsibility of medication management of someone else, since the medicines information is essential for them. Pharmacists in the care units should have stronger involvement in the discharge process in order to prepare family caregivers for new and changed medication regimes and medication management.

In Finland, caregivers' associations and local organisations organise guidance for caregivers, for example, group lectures. Pharmacists should be more actively involved at these events. The same applies to municipalities/welfare areas' counselling for caregivers.

Strengths and weaknesses of the study

While the study was conducted in Finland, the information can be worthy for policymakers in other countries despite different public social and healthcare systems. The study reflects the views of the family caregiving families which bring out their voice explicitly, but the perspective of social and healthcare professionals is left out. The study focused on the challenges and gaps in the public social and healthcare system in the perspective of the

family caregiving families when managing medications of their care recipients, excluding the family caregiver or care recipient related factors, which also have an impact on medication management in the family caregiving context.

Although the data were collected during the period of October 2017 to September 2018, it is still relevant and timely as the social and healthcare reform in Finland is still ongoing with no big changes implemented in services for family caregiving. The presented challenges remain in healthcare from the family caregiving perspective.

The family caregiving families with an official contract were selected as study participants. A much higher number of caregivers take care of their family members without official contract and payment from the public funding. They might be even in a worse position according to the achieved support for medication management. However, the development suggestions could provide more support for them also when managing medications of their care recipient. Future research should focus on the family caregivers without an official contract.

The recruited families may be active families due to the recruiting technique. However, families were diverse according to the demands of the treatment, medications and social and healthcare services used.

Used rich qualitative data and narrative interviews ensured the data supplemented from other material or question, for example, if families were not able to name any problems in the prescription phase, but later in the interview these problems came up. The data collection method was comprehensive and self-complementary but was time-consuming due to two quite long consecutive home visits.

The sample size of 21 families, in the light of the used methods; the interview study with two home visits (lasting 2 hours each) and medication reviews can be considered sufficient^{42 60 61} since in qualitative research the sample size needs to be small enough for deep analysis. Data saturated for the 18th family. Therefore, the data and the sample size can be considered sufficient. Qualitative analysis within the prospective risk management framework was suitable for constructing conceptual models crystallising the real-life medication management practices and challenges of family caregiving families. Future research should focus on the medication errors, contributing factors and used safeguards in family caregiving to improve medication safety at home. To improve medication adherence, attention should be paid to family caregivers' knowledge of medications and health literacy in future research.

CONCLUSION

Development in family caregiving should be done with family caregivers to shift them to the centre of the medication use process. The social and healthcare professionals, particularly physicians, were inaccessible when they had treatment-related questions. The main needs

for development identified (access to familiar healthcare professionals, integration to social and healthcare, lack of individuality, carers' identification as family caregivers in healthcare and pharmacy, frequent turnover of the professionals, inadequate medication monitoring, interaction and communication, inadequate medicines information and lack of up-to-date medication list) reflect weaknesses in the social and healthcare system. Attention should be paid to the system failures, but solutions should be personalised according to each family's needs.

Strengthening the integration of family caregivers to social and healthcare, for example, by allowing easy access to family physicians is vital. Pharmacists should be more actively involved in medication management. Pharmacists in the care unit are in a key position when reconciling medications to identify family caregivers as family caregivers, give medicines information and record follow-up information.

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Patient consent for publication Consent obtained directly from patient(s).

Ethics approval In this study, good ethical and scientific practice will be followed according to the Finnish National Advisory Board on Research Integrity and WMA Declaration of Helsinki Ethical Principles for Medical Research Involving Human Subjects. For this study, ethical evaluation has made by the Hospital district of Helsinki and Uusimaa (HUS) Ethics Committee (HUS/3537/2017). An informed written consent was voluntarily signed by patients in the beginning of the first home visit. The privacy statement was made in May 2018, according to the EU General Data Protection Regulation. The privacy statement was provided to all study participants during the first interview. The privacy statement clarified how the research data are handled, stored and destroyed after completing the study.

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REFERENCES

- Ministry of Social Affairs and Health in Finland. Act on Support for Informal Care. 2005.
- McMillan SS, Wheeler AJ, Sav A, *et al*. Caring for carers in community pharmacy A pharmacy carer support service: obtaining new insight into carers in the community Support for Australian carers from community pharmacy: Insight into carer perspectives of a novel service The ideal healthcare: priorities of people with chronic conditions and their carers. *Res Social Adm Pharm* 2017;13:254–6.
- Goldstein R, Rivers P, Close P. Good quality pharmaceutical care — implications for carers with elderly dependants. *Int J Pharm Pract* 2011;2:65–70.
- Public law 115–119 115th congress. An act to provide for the establishment and maintenance of a family caregiving strategy, and for other purposes.
- Gusdal AK, Josefsson K, Adolfsson ET, *et al*. Informal Caregivers' Experiences and Needs When Caring for a Relative With Heart Failure: An Interview Study. *J Cardiovasc Nurs* 2016;31:E1–8.
- Coleman EA, Roman SP. Family Caregivers' Experiences During Transitions Out of Hospital. *J Healthc Qual* 2015;37:12–21.
- Chari AV, Engberg J, Ray KN, *et al*. The opportunity costs of informal elder-care in the United States: new estimates from the American Time Use Survey. *Health Serv Res* 2015;50:871–82.
- Reinhard SC, Caldera S, Houser A, *et al*. *Valuing the invaluable 2023 update: strengthening supports for family caregivers*. Washington DC: AARP Public Policy Institute, 2023.
- Tillman P, Kallioma-Puha L, Mikkola H. [Rakas mutta raskas työ Kelan omaishoitohankkeen ensimmäisiä tuloksia]. Kela, the Social Insurance Institution of Finland; Contract No.: 2323-9239. 2014.
- United Nations, Department of Economic and Social Affairs, Population Division. World Population Ageing. 2019. Contract No.: (ST/ESA/SER.A/444). 2019.
- Look KA, Stone JA. Medication management activities performed by informal caregivers of older adults. *Res Social Adm Pharm* 2018;14:418–26.
- Kröger T, Leinonen A. Transformation by stealth: the retargeting of home care services in Finland. *Health Soc Care Community* 2012;20:319–27.
- Kehusmaa S. Containing the costs for care. Use of services, informal care and rehabilitation of frail elderly living at home. Kela, The Social Insurance Institution of Finland; Contract No.: Studies in social security and health 131. 2014.
- Australian Government. National Carer Strategy. 2011.
- Ministry of Social Affairs and Health. Rational Pharmacotherapy Action Plan Final report Helsinki; Contract No.: 19/2018. 2018.
- Euro Carers. Enabling carers to care: An EU Strategy to support and empower informal Carers 2018–2021. 2018.
- Tarricone R, Tsouros AD. *Home care in Europe*. World Health Organization Europe, 2008.
- Finnish Government. A strong and committed Finland – the Government's vision. 2023.
- Finnish Government. Programme of Prime Minister Jyrki Katainen's Government. 2011.
- Parand A, Garfield S, Vincent C, *et al*. Carers' Medication Administration Errors in the Domiciliary Setting: A Systematic Review. *PLoS One* 2016;11:e0167204.
- Lang A, Macdonald M, Marck P, *et al*. Seniors managing multiple medications: using mixed methods to view the home care safety lens. *BMC Health Serv Res* 2015;15:548.
- Tikkanen U. *The everyday life and bonds of the spousal care of the elderly*. Helsinki: University of Helsinki, 2016.
- Schumacher KL, Plano Clark VL, West CM, *et al*. Pain medication management processes used by oncology outpatients and family caregivers part I: health systems contexts. *J Pain Symptom Manage* 2014;48:770–83.
- Schumacher KL, Plano Clark VL, West CM, *et al*. Pain medication management processes used by oncology outpatients and family caregivers part II: home and lifestyle contexts. *J Pain Symptom Manage* 2014;48:784–96.
- Xiao Y, Hsu YJ, Hannum SM, *et al*. Assessing patient work system factors for medication management during transition of care among older adults: an observational study. *BMJ Qual Saf* 2024;34:8–17.
- Travis SS, McAuley WJ, Dmochowski J, *et al*. Factors associated with medication hassles experienced by family caregivers of older adults. *Patient Educ Couns* 2007;66:51–7.
- Travis SS, Bernard MA, McAuley WJ, *et al*. Development of the family caregiver medication administration hassles scale. *Gerontologist* 2003;43:360–8.
- 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:M412–7.
- Look KA, Stone JA. Contextual factors influencing medication management by rural informal caregivers of older adults. *Res Social Adm Pharm* 2019;15:1223–9.
- Ministry of Social Affairs and Health. Development of informal care and family care in 2015–2018 Conclusions and recommendations for further measures. Contract No.: Reports and Memorandums of the Ministry of Social Affairs and Health 61/2018. 2019.
- Aromaa A, Koskinen S. Health and functional capacity in Finland. Baseline results of the Health 2000 health examination survey. Helsinki: National Public Health Institute; Contract No.: Publication of the National Public Health Institute B3/2022. 2002.
- Lau DT, Berman R, Halpern L, *et al*. Exploring factors that influence informal caregiving in medication management for home hospice patients. *J Palliat Med* 2010;13:1085–90.
- Wang S, Cheung DSK, Leung AYM, *et al*. Factors associated with caregiving appraisal of informal caregivers: A systematic review. *J Clin Nurs* 2020;29:3201–21.
- Astedt-Kurki P, Heikkinen RL. Two approaches to the study of experiences of health and old age: the thematic interview and the narrative method. *J Adv Nurs* 1994;20:418–21.
- Whooley MA, Avins AL, Miranda J, *et al*. Case-finding instruments for depression. Two questions are as good as many. *J Gen Intern Med* 1997;12:439–45.
- McKee KJ, Philp I, Lamura G, *et al*. The COPE index—a first stage assessment of negative impact, positive value and quality of support of caregiving in informal carers of older people. *Aging Ment Health* 2003;7:39–52.
- Saunders JB, Aasland OG, Babor TF, *et al*. Development of the Alcohol Use Disorders Identification Test (AUDIT): WHO Collaborative Project on Early Detection of Persons with Harmful Alcohol Consumption-II. *Addiction* 1993;88:791–804.
- Troyer AK, Rich JB. Psychometric properties of a new metamemory questionnaire for older adults. *J Gerontol B Psychol Sci Soc Sci* 2002;57:P19–27.
- Jylhä M. *[Oman terveyden kokeminen eläkeiässä]*. University of Tampere, 1985.
- Heikkinen E, Waters WE, Brzezinski Z. *The elderly in eleven countries: a sociomedical survey*. World Health Organization, Regional Office for Europe, 1983.
- Reason J. Human error: models and management. *BMJ* 2000;320:768–70.
- Vasileiou K, Barnett J, Thorpe S, *et al*. Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. *BMC Med Res Methodol* 2018;18:148.
- Hakoinen S, Laitinen-Parkkonen P, Airaksinen M. [Lääkekaaosken hallinta sote-muutoksessa – nykytila, haasteet ja ratkaisuehdotukset]. The Foundation for Municipal Development; Contract No.: Research series 106. 2017.
- Mononen N, Pohjanoksa-Mäntylä M, Airaksinen MS, *et al*. How far are we from a medication use process aiming at well-informed

- adherent patients with long-term medications in Finland? Qualitative study. *BMJ Open* 2020;10:e036526.
- 45 Ministry of Social affairs and Health. Safe pharmacotherapy national guide for pharmacotherapy in social and health care ministry of social affairs and health; contract no.: publications of the ministry of social affairs and health 2009:10. 2009.
 - 46 Ishikawa K. Guide to Quality Control. 1976.
 - 47 European Union EU. General Data Protection Regulation GDPR, Available: <https://gdpr-info.eu>
 - 48 Gale NK, Heath G, Cameron E, *et al.* Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol* 2013;13:117.
 - 49 Kvarnström K, Westerholm A, Airaksinen M, *et al.* Factors Contributing to Medication Adherence in Patients with a Chronic Condition: A Scoping Review of Qualitative Research. *Pharmaceutics* 2021;13:1100.
 - 50 Mikkola H, Dimitrow M, Hämeen-Anttila K, *et al.* Understanding medication-related burden from patient perspectives: a qualitative study testing the applicability of the conceptual model among chronically ill outpatients in Finland. *BMJ Open* 2023;13:e077214.
 - 51 Remen VM, Grimsmo A. Closing information gaps with shared electronic patient summaries: how much will it matter? *Int J Med Inform* 2011;80:775–81.
 - 52 Valvira National Supervisory Authority for Welfare and Health. Information systems for social welfare and healthcare. 2024. Available: <https://valvira.fi/en/information-systems-for-social-welfare-and-healthcare>
 - 53 Kanta Services, The Social Insurance Institution of Finland. Consent and denials of consent to data sharing in social welfare services, 2024. Available: <https://www.kanta.fi/en/professionals/sharing-of-social-welfare-client-data>
 - 54 McMillan SS, Kelly F, Sav A, *et al.* Australian community pharmacy services: a survey of what people with chronic conditions and their carers use versus what they consider important. *BMJ Open* 2014;4:e006587.
 - 55 Kallio S, Kumpusalo-Vauhkonen A, Järvensivu T, *et al.* Towards interprofessional networking in medication management of the aged: current challenges and potential solutions in Finland. *Scand J Prim Health Care* 2016;34:368–76.
 - 56 Oravainen T, Airaksinen M, Hannula K, *et al.* How Physicians Renew Electronic Prescriptions in Primary Care: Therapeutic Decision or Technical Task? *Int J Environ Res Public Health* 2021;18:10937.
 - 57 Dean JE, Hutchinson A, Escoto KH, *et al.* Using a multi-method, user centred, prospective hazard analysis to assess care quality and patient safety in a care pathway. *BMC Health Serv Res* 2007;7:89.
 - 58 Mekonnen AB, McLachlan AJ, Brien J-AE. Effectiveness of pharmacist-led medication reconciliation programmes on clinical outcomes at hospital transitions: a systematic review and meta-analysis. *BMJ Open* 2016;6:e010003.
 - 59 Schepel L, Aronpuro K, Kvarnström K, *et al.* Strategies for improving medication safety in hospitals: Evolution of clinical pharmacy services. *Res Social Adm Pharm* 2019;15:873–82.
 - 60 Hennink MM, Kaiser BN, Marconi VC. Code Saturation Versus Meaning Saturation: How Many Interviews Are Enough? *Qual Health Res* 2017;27:591–608.
 - 61 Fusch P, Ness L. Are We There Yet? Data Saturation in Qualitative Research. *TQR* 2015.
 - 62 Dimitrow MS, Leikola SN, Kivelä S-L, *et al.* Feasibility of a practical nurse administered risk assessment tool for drug-related problems in home care. *Scand J Public Health* 2015;43:761–9.
 - 63 Dimitrow MS, Mykkänen SI, Leikola SNS, *et al.* Content validation of a tool for assessing risks for drug-related problems to be used by practical nurses caring for home-dwelling clients aged ≥65 years: a Delphi survey. *Eur J Clin Pharmacol* 2014;70:991–1002.
 - 64 Kanta Services. The Social Insurance Institution of Finland, Available: <https://www.kanta.fi/en/my-kanta-pages>