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Role of informal carers in medication management for people with long-term conditions: a systematic review

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ABSTRACT

Objectives To explore the literature about the role of unpaid informal carers in medication management for people with long-term conditions.

Design Systematic review designed according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines.

Information source MEDLINE (Ovid), Embase (Ovid), PsycINFO, Cumulated Index in Nursing and Allied Health Literature (EBSCO), Scopus and Web of Science were searched from inception until April 2024. Additional papers were identified by searching backwards and forwards the reference lists of included papers.

Eligibility criteria Primary research studies were included if they reported medication-related activities undertaken by carers for people with long-term conditions. Qualitative and mixed methods studies were considered without restriction on language or country.

Data extraction and synthesis Relevant data were extracted and summarised in a table. The Mixed Method Appraisal Tool was used for quality assessment. Data were narratively synthesised.

Results From 12 473 identified records, 107 underwent full text screening and 20 studies were included. Family carers were the predominant type of carer. Spouses and adult children constituted the largest caregiving dyads. Based on the required skills, two groups of roles were identified: physical roles, such as prescription management, and cognitive roles, such as decision-making. Carers used different strategies and tools to undertake medication-related activities including compliance aids and alarms. However, carers reported challenges in their experiences of caregiving, flagging up their need for additional support and education to commence such activities.

Conclusion Informal carers undertake a wide variety of medication-related activities. The studies emphasised the need to support families as partners in health outcomes. This systematic review identifies the importance of bridging the gap between carers and healthcare providers. More efforts are needed to empower carers towards better and safer caregiving. Future work could address how to optimise carer involvement and engagement and provide best practice recommendations for carers' support.

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STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ To our knowledge, this is the first systematic review investigating the role of informal carers in medication management for people with long-term conditions.
- ⇒ Inclusion criteria were applied with no restrictions on language or country.
- ⇒ It was not possible to perform a metasynthesis due to the heterogeneity in several aspects.
- ⇒ The outcomes for carers and care-recipients were described broadly.

INTRODUCTION

The increase in long-term conditions (LTCs) among the population poses challenges to the health and social care system, increasing morbidity, mortality and economic burden.[1,2] According to the Department of Health, LTC is used to describe 'the condition that cannot, at present, be cured but is controlled by medication and/or other treatment/therapies'.[3] Alongside the rise in LTCs, there is increasing concern about the concurrent intake of multiple medications per person, referred to as polypharmacy.[4–6] Although five or more medications are commonly used to describe polypharmacy, there is no consensus on a specified number for polypharmacy definition.[5,7] Previous research has highlighted the likelihood of medication management complexity for people with LTCs.[8] Up to 50% of people with LTCs do not take their medications as prescribed, leading to adherence problems.[9] In addition, there is a higher probability of medication-related problems including drug-drug interactions, side effects and medication misuse.[4–6] People with LTCs often require co-management and support with medication use, which can be offered by informal carers.[10,11]

An informal carer is an umbrella term used to describe 'anyone who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid' (National Health Service (NHS) England p9).[12] According to the International Alliance of Carer Organizations (IACO), there are more than 63 million carers globally.[13] In the UK, there are 5.8 million people acting as carers, including 3.5 million female carers.[14] In spite of this, the figure might be higher due to the nature of informal caregiving, which is often not reported.[14] In 2021, the UK carers' input was estimated to be worth £162 billion annually, which is equivalent to the NHS annual expenses in England and Wales.[15]

People with LTCs frequently receive support from carers alongside healthcare providers as part of *'care triads'*.[16–19] People with LTCs and their carers are more likely to require accessibility to pharmacy services and continuous dealing with medications.[20] Pharmaceutical care services help carers to alleviate the burdens associated with their medication management roles.[21] The caregiving role can vary from basic daily assistance with bathing, eating or dressing to more complex medical tasks such as administering injections.[22] According to a scoping review, there is a large number of studies conducted on the informal caregiving experience of older adults with a single chronic condition.[23] The literature has typically focused on specific or broad disease states such as cancer, dementia and palliative care, which in many cases are life-limiting.[24 25] However, there is a paucity of studies investigating this topic within other LTCs.[23]

Less attention has been paid to the carers of people with LTCs; the carer role has been underestimated and the carer's need for support is not well understood.[26] There is, however, no systematic review that explores the role of carers among people with LTCs. Therefore, this review was conducted to answer the following question: what are the experiences of informal carers in managing medications for people with LTCs?

METHODS

Design

This systematic review is reported following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines (see online supplemental material 1).[27] The research question is narrowly focused on the context of medication management. Thus, the systematic review approach was selected over the scoping review for the following reasons: confirm current practices, address variations, identify new practices and highlight areas for future research.[28]

Search strategy

The following databases were searched from inception until April 2024: MEDLINE (Ovid), Embase (Ovid), PsycINFO, Cumulated Index in Nursing and Allied Health Literature (EBSCO), Scopus and Web of Science. The terms used in the search strategy were related to medication management, informal carers and LTCs (see online supplemental material 2). The search strategy was modified for each database to suit its indexing structure, syntaxes and subject headings. Reference lists of all

Table 1 Sample, Phenomenon of Interest, Design, Evaluation, Research type criteria

Criteria	Inclusion	Exclusion
Sample	► Adults living in the community with one or more long-term conditions.	Papers focused on: ► People below 18 years. ► People in settings where they receive additional assistance with their medication (in-patients or nursing homes, home carers, Macmillan or hospice at home care). ► People at the immediate end of life. ► People with acute illness or injury.
Phenomenon of interest	► Medication management activities provided by an adult informal carer or equivalent.	Papers focused on: ► Paid carers only. ► Young carers below 18 years. ► Unspecified age of young carers.
Design	► Primary peer-reviewed papers. ► From inception until April 2024. ► Any language. ► Any country.	► Systematic reviews, literature reviews and realistic reviews. ► Conference abstract, editorial, book chapter, report papers, leaflets, meeting notes and dissertations. ► Not available as full-text papers.
Evaluation	► Carers' activities in medication management including: (i) care-recipients, carers and healthcare providers' experience of carer role; (ii) care-recipient and/or carer outcomes such as barriers, burdens and facilitators; (iii) the nature of carer-recipient dyads.	N/A
Research type	► Qualitative and mixed methods studies including qualitative elements of medication management.	No qualitative data.

included papers were screened backwards and forwards to identify additional papers.

Study selection

Inclusion criteria for studies were determined in line with the Sample, Phenomenon of Interest, Design, Evaluation, Research type tool (see table 1). Initial screening of titles and abstracts was completed by the primary researcher (MA) and checked by CR and LL. Full-text studies were screened and reviewed independently by at least two members of the research team (MA, CR and LL) using the same criteria. Disagreements were solved through discussion. Studies that did not fulfil the inclusion criteria were excluded.

Data extraction and evaluation

Data were extracted and summarised by MA using a standardised data extraction form (see online supplemental material 3). The Mixed Methods Appraisal Tool (MMAT) was used to appraise qualitative and mixed methods studies.[29] The overall assessment was scored as follows: low quality (0–1), medium quality (2-3) and high quality (4-5). Quality assessment was completed by two authors independently. While the primary focus was on qualitative data, mixed methods papers were included, and these were compressively assessed for their methodological approaches using the relevant section(s) of the MMAT. Disagreements were solved through discussion (see online supplemental material 4).

Data synthesis

Narrative synthesis was used to present findings in three steps.[30] First, developing a preliminary synthesis of the findings of the included studies. This step was conducted by constructing a descriptive summary of the included studies by tabulating studies' details and identifying types of provided activities. Second, exploring relationships within and between studies by categorising and structuring into themes based on the carer activities. Third, to draw a generalisable conclusion based on this synthesis. No planned metasynthesis considering the expected heterogeneity of the included studies in terms of care-recipient conditions, carer demographics, carer dyads and medication management activities. Therefore, in such complex heterogeneity, narrative synthesis is the primary choice.[30]

Patient and public involvement

Patients and/or the public were not involved in this study.

RESULTS

Data extraction and evaluation

The search identified a total of 12 473 articles; additionally, 13 articles were identified through manual searching. After removing duplicate records, *5947* studies were screened. 107 articles were eligible for full-text screening. A total of 20 studies were included in the review (see figure 1).

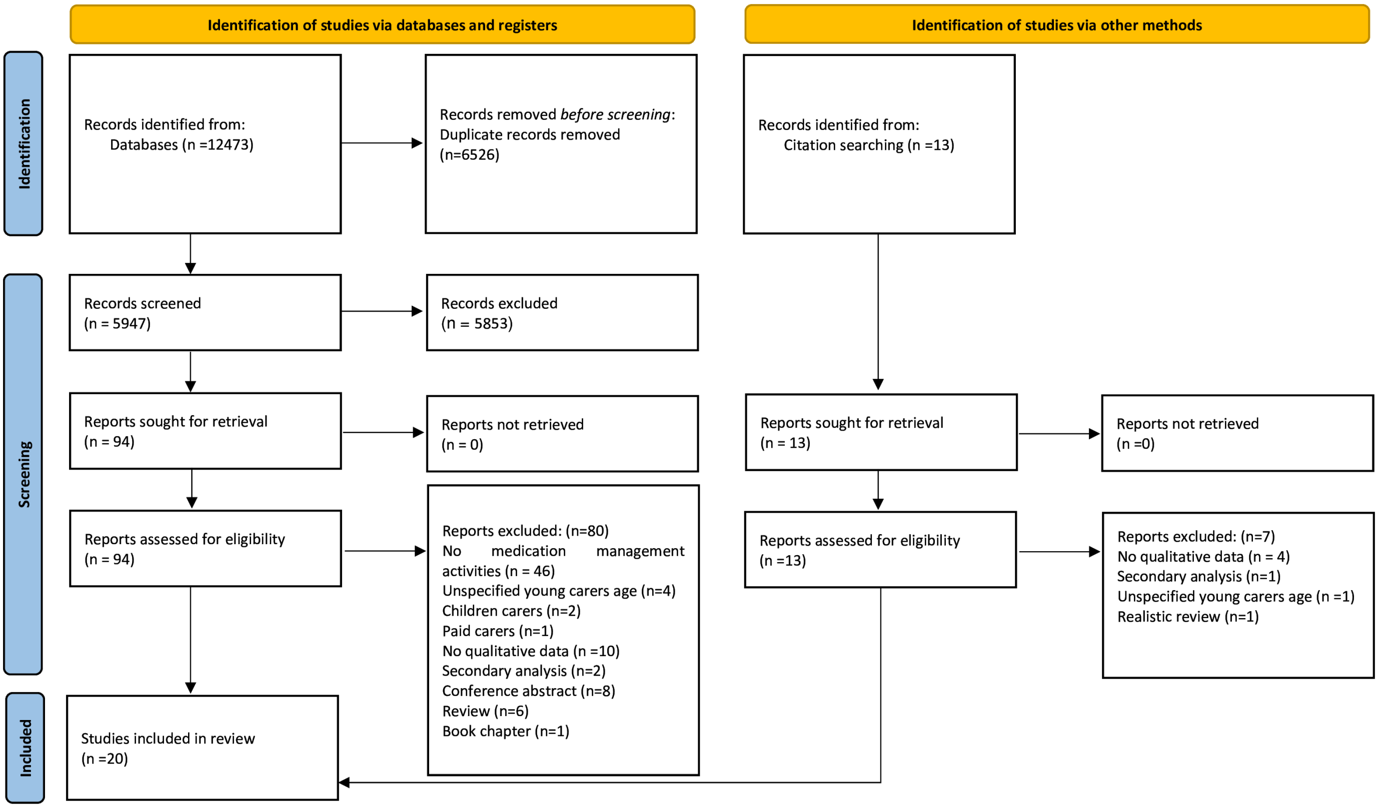

Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram.

Of the 20 included studies, two used mixed methods[31,32] and four were substudies, conducted as a part of larger studies.[33–36] Three studies were published before 2010,[31,32,37] seven were published between 2020 and 2024,[33,36,38–42] with most published between 2010 and2019.[34,35,43–50]

According to the World Bank classification of countries by the WHO,[51] most of the studies were conducted in high-income areas[31–35,37,38,40–50] in the UK,[31,32,37,38,40,42,44,47,49,50] Canada,[43,45,48] the USA,[33,35,46] Germany[34] and Switzerland.[41] Another study was conducted in China, a country classified as upper-middle-income country[39] and one in Malawi, a low-income country.[36]

According to the MMAT, all studies apart from two ranked as high quality, based on the qualitative criteria of assessment.[31–33,36–50] The two studies rated as medium were substudies, and there was a lack of clarity regarding how the data were collected relative to the original study.[34,35] No studies were excluded based on the quality assessment.

Carers demographics and challenges

Carers helped both family and non-family members. Carer-recipient dyads were predominantly familial,[31–50] primarily including spouses,[31–33,35–39,41–44,46,48–50] adult children,[31–33,35,37,38,41–44,46,49,50] relatives,[31,32,34] siblings,[35,37,42] adult grandchildren[32,35,43] and parents.[48] Support was also provided by friends[31–34,40,42,43,45] and neighbours.[31,32,42,43,45]

In terms of care-recipients, nine studies were conducted on older adults with polypharmacy as reported by the authors.[31–33,37,38,40,41,43,46] 11 studies focused on investigating specific conditions including chronic obstructive pulmonary disease,[44] dementia,[45,47,49,50] glaucoma,[49] heart failure,[35] HIV,[36] inflammatory arthritis,[48] Parkinson's disease[42] and type 2 diabetes.[34,39]

Carers prioritised care-recipients' health over their own needs.[37,39,43–45,47] Some studies reported that carers and care-recipients held contrasting beliefs about medications' effectiveness and need, which complicated medication use and management.[31,37,41,44,50] Furthermore,carers had poor skills in handling medications, resulting in safety concerns.[37,39,43,45]

Carers frequently experienced difficulty in accessing healthcare providers and services.[37,38,40,42,47,50] They were critical about the limited consultation timeframe which made it challenging to ask questions.[43,47,48,50] There were some concerns about the exclusion of care-recipients from the conversation during consultations when the carer attended.[50] Sometimes, carers were not informed about prescription changes, either due to absence or exclusion from consultations.[50] Challenges were more likely to occur when new medications were added.[38,41,45,50] It was reported that poor relationships with healthcare providers resulted in difficult medication management.[31,35,38]

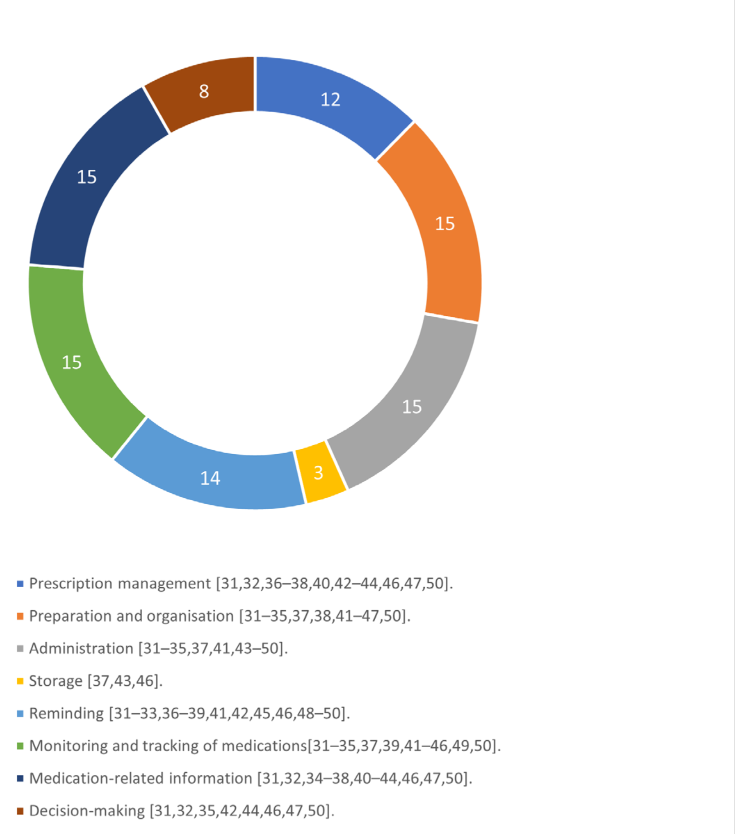

Figure 2 Medication management roles.

Medication management roles

A wide range of medication management roles and related activities were offered by carers across the included studies (see figure 2). Depending on the skills required, the roles carers were involved in could be considered either cognitive or physical.[46]

Carers' involvement in medication management was varied and highlighted as an obligation.[37,41,43,47] Carers pointed out that their role in medication management had evolved from 'obligation' to 'automatism' and 'habit'.[41] The involvement of carers was varied, ranging from participation in some activities to taking full responsibility for medication management.[31,32,37–40,43–46,50] Care-recipients often requested carers' assistance regardless of their physical and cognitive capabilities.[37,41,49] Respecting care-recipients' autonomy and independence was valued by carers, leading to partial or no involvement of carers.[33]

Physical roles

Prescription management

In 12 studies, prescription management was reported.[31,32,36–38,40,42–44,46,47,50] This role involved several activities, including ordering,[31,32,37,40,42–44,46,47,50] collecting,[31,32,36,37,40,42–44,46,47,50] buying over-the-counter medications,[31,32,40] maintaining adequate stock[31,32,38,40,43,44,47,50] and purchasing equipment for prescribed medications,[32,44] such as nebuliser parts.[44]

Carers reported difficulties navigating ordering systems or procedures.[31,32,37,50] Also, carers hassled with managing medication supplies.[31,38,40,44,47] Keeping track of supplies was challenging in certain circumstances such as running out of stock during the weekend,[47] postdischarge[38] or the COVID-19 pandemic[40] and obtaining medications from multiple locations.[40]

Preparation, organisation and administration

Carers contributed to medication preparation and organisation in 15 studies.[31–35,37,38,41–47,50] Carers used pill-boxes to arrange medications.[32,33,35,41,43,45–47,50] Pill-boxes were filled away from the care-recipient for higher accuracy.[35] Carers complained about the slot size and space.[46] Conversely, some carers acknowledged the usefulness of pill boxes in tracking and receiving the correct medication.[47,50] However, more concerns were raised about errors and mistakes.[50]

Carers used other types of containers to organise medications such as coloured box lids,[41] coloured coded jars,[32] plates,[32,43,46] glasses,[32,46] pots[37,38] and ordered bottles per dose.[33] When necessary, carers prepared doses in advance by setting inhalers,[43] opening containers,[31,32,42,43] dissolving,[42,45] diluting,[44] splitting[32,46] and crushing[45] doses. Beyond preparing doses, carers took responsibility for cleaning and maintaining nebulisers.[44]

Carers participated in medication administration across 15 studies.[31–35,37,41,43–50] Care-recipients received assistance with several pharmaceutical formulations or devices[31–35,37,41,43–50] (see online supplemental material 5). Carers reported challenges with the lengthy process of nebuliser-related activities and possible technical problems.[44] Dealing with different inhaler devices caused problematic experiences.[44] It was challenging for carers to provide frequent support throughout the day.[31] Also, it was confusing to prepare and provide multiple medications with similar characteristics, such as being a white colour.[35,46] Carers used strategies to address these issues by writing indications or strengths on the bottles.[46] Frequent dosing was flagged in other included studies as a broader challenge in medication management.[32,35,42,44,45,47]

Storage

The practice of storing medications by carers was reported in three studies.[37,43,46] Storing medications in multiple places impacted care-recipient safety and adherence.[43] For example, in one study, care-recipients experienced difficulties finding medications that were lost between cupboards.[43] Carers stored the medications away from care-recipients to minimise the risk of medication errors, especially for people with dementia.[37,46] Large quantities of medication were kept in a lockbox.[43,46]

Cognitive roles

Reminding

14 studies reported the role of carers in reminding care-recipients to take their medication regularly.[31–33,36–39,41,42,45,46,48–50] Different strategies were used to facilitate this role (see online supplemental material 6). Carers expressed concern about the care-recipient's dependency on carers to provide frequent dose reminders.[49] Reminding strategies were used either to remind carers themselves or care recipients.[46] Routine markers including placing notes or medication in visible places or linking doses to daily routines were frequently used.[31–33,37,41,46,49] However, routine markers were not effective for some care-recipients, especially for those with memory issues or where notes were disregarded by care-recipients.[46,49]

Monitoring and tracking of medications

Tracking and monitoring health conditions and/or medications were cited across 15 studies.[31–35,37,39,41–46,49,50] This entailed side effects monitoring,[31,32,37,41,44,46,50] tracking medication intake[33,35,42,45,46,49,50] and checking whether prescriptions are correct.[31,42] Carers created or used a printed medication list to track medication-related information and activities or guide care-recipients.[34,35,43,46] Carers raised some concerns about side effects and medication tolerance.[37,41,44,50] As a result of monitoring and tracking, carers were able to detect potential side effects before healthcare providers did.[46] The results in two studies showed that carers also undertook disease parameter monitoring such as monitoring biochemical readings and markers, for example, coagulation, glucose and other health monitoring.[39,46]

Carers needing medication-related information for decision-making

Carers were involved in obtaining and/or sharing medication-related information in 15 studies.[31 32 34–38 40–44 46 47 50] Carers searched for information relating to medications or disease management from varied sources including general practices,[44 50] other healthcare providers,[31 32 37 38 40–42 46 47 50] the internet,[38 42 43 46 50] libraries,[42 46] medicine leaflets,[31 32 38 41 44 50] prescription printouts,[46] magazines,[50] local support groups,[42] charities[42] and manufacturing manuals.[44] Other family members with medication experience were consulted for information.[34 42–44] As in other carers, peers acted as a source to exchange information and experiences.[34]

For carers, it was important to get the right information and to understand the instructions.[47] Carers struggled to understand the patient information leaflet in two studies,[31 50] but were keen to read prescription instructions and medication names carefully, in order to avoid potential errors.[42] Furthermore, it was reported that healthcare providers gave incomplete or unclear instructions.[44] The risk of poor medication labelling, inadequate documentation and not having user-friendly documents was a source of carers' frustration.[31 43] Several carers reported lacking knowledge and understanding of medication-related information.[31 35 37–44 47 50] Carers emphasised their need for more information about the indication,[31 50] frequency[44 50] and side effects[31 37 44 50] of medications. Particularly, information about new medications was a critical need for carers.[38 41 45 50]

In eight studies, carers debated the risks and benefits of the care-recipient's medications.[31 32 35 42 44 46 47 50] Suggestions by carers to change medications were varied and included initiating,[32 44] adjusting[31 32 35 42 44 46 47] and stopping medication.[31 35 44 50] Changes in dose timing were made by carers in response to their own commitments and care-recipients' needs.[31 32]

Carers required medication-related information to monitor care-recipients and coordinate care with healthcare providers[46] and influence care-recipient adherence.[32] In particular, carers shared information with care-recipients[31 32 34 36 43 50] and healthcare providers.[35 37 46] A lack of medication-related information was associated with difficulty in decision-making.[37 44 50] Healthcare providers had commented on the importance of carers' and care-recipients' education to promote adherence.[45] Similarly, care-recipients suggested educating family members about their medications.[48]

DISCUSSION

This review highlights the diversity of carer roles and activities related to medication management and highlights the need to recognise carers having expertise in the patient's lived experience. Carers support people with LTCs with cognitive and/or physical elements of medication management. Physical roles include: (a) prescription management and (b) preparation, organisation and administration. Storage and cognitive roles include: (a) reminding, (b) monitoring and tracking of medications and (c) medication-related information and decision-making. In the studies, carers took an integral and multifaceted role ranging from basic physical assistance to independent decision-making, and it is likely that the identified activities were interlinked. For example, monitoring for disease symptoms corresponds to administering medications and further actions. Carers' involvement was varied owing to changes in the care-recipients' medications, conditions and needs.

Familial caregiving was the predominant type of carer-recipient dyad across the included studies. The findings of this review support the work of Manias *et al*, who reported the role of family carers in managing medication complexity and participating in decision-making.[52] This work, however, only focused on elderly people across transitions of care.[52] In this review, there was a range of dyads included, but there was no noticeable difference between the dyads in the nature of the medication management activities that carers were involved in.

Caring for people with LTCs was often associated with complexity. This experience can be explained by the lack of supportive resources while dealing with (a) multiple medications, (b) different needs and (c) frequent activities. Given that carers' involvement appears to be key in the medication management process, the findings suggest the need to better support carers for people with LTCs. According to the reviewed evidence, a systematic approach to support carers was lacking. Fragmentation was captured between carers and healthcare providers in terms of communication, education and training. Although carers are involved in several medication-related activities, they do not receive structured training or education in this area. Carers have created their own strategies for medication management and modifying the available tools. This also aligns with previous findings, which showed that carers tend to discover undertaking their responsibilities by trial and error.[53] Of particular concern is that most carers are not able to establish communication and partnerships with healthcare providers to fulfil their needs. A similar position was offered by Gillespie *et al*, who emphasised that lack of information, training and poor relationship with healthcare providers were the most common factors that negatively affect carers' experiences.[54] Similarly, Pu *et al* reported the failure of carers to be actively involved in pain management for people living with dementia due to the same factors.[55] Lawson *et al* highlighted the need to support carers with information and training to mitigate caregiving burdens.[56] In the context of care transition and discharge planning, similar needs were flagged by carers.[52 57]

Most of the studies included in this review indicate that carers were not actively involved with healthcare providers. More actions are needed to empower carers in medication management roles. This should entail involving carers in consultations and decision-making alongside care-recipients and healthcare providers.

Along the same lines, Eriksen *et al* recommended that healthcare providers need to escalate efforts in communicating and involving social networks in medication-related experiences for people with polypharmacy.[58] Pharmacies are one place recognised to have potential for better supporting carers.[59] Furthermore, familiarising carers with prescription management activities and processes, medication management tools and strategies were anticipated to facilitate carer roles. However, different perspectives and attitudes were noted regarding using compliance aids and reminder strategies across the included studies. Therefore, better evidenced tools and strategies could be designed with carers in mind, as the end users.

To our knowledge, this is the first systematic review that aimed to explore the role of carers in medication management for people with LTCs. The inclusion criteria do not impose any restrictions on language or country, ensuring that all the relevant literature on medication management and carers is captured. Studies that were not specifically designed to explore carers' medication-related activities but did report some relevant data were included, and as such, it was not possible to perform a metasynthesis. The reason for this is threefold: (a) the heterogeneity of included studies, (b) the range and variety of medication-related activities and (c) the variation in care-recipients' conditions. In this review, most of the evidence is from Europe, and the UK constitutes 50% of the papers, which might limit the generalisability of the findings to high-income countries. While the primary focus was to address the varied roles of carers in medication management, the outcomes for carers and care-recipients were considered secondary and linked broadly to their experiences in each role as possible. Obtaining and sharing information activities tended to be incorporated as part of care-recipient disease management information. Therefore, it was difficult to identify discrete information about medication-related information across some studies.

This review contributes to knowledge around understanding the current roles and needs of carers and people with LTCs around medication management. Further work is needed to evaluate carers' lived experiences in undertaking medication management roles and related activities. A preliminary step towards identifying supportive mechanisms for carers is to appreciate carers' roles and needs. Carers' and healthcare providers' perspectives can inspire successful caregiving experiences and better service utilisation. An initiative to establish network channels between carers and healthcare providers could be discussed.

CONCLUSION

The results of this review showed that informal carers contribute to the medication management process in the community for people with LTCs. They provide interlinked activities that can require frequent adaptations. Healthcare providers need a mechanism to better support carers in these activities, outline their involvement and address their needs in their caring role. Hearing carers' voices is vital to developing the best recommendations and guidance for carers' involvement and support to allow them to better provide care in medication management in a safe and effective manner without overburdening the carer.

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