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Roles and experiences of informal caregivers of older adults in community and healthcare system navigation: a scoping review

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ABSTRACT

Objective Informal caregivers are playing a vital role in improving the degree to which older adults access community and healthcare systems in a more seamless and timely manner, thereby fulfilling their complex needs. It is critical to understand their experiences and perspectives while navigating these systems. This review aimed to identify and organise the research findings on the roles and experiences of informal caregivers of older adults while navigating community and healthcare systems.

Design This scoping review was undertaken according to the Joanna Briggs Institute's Reviewer manual. Four databases were used: AgeLine, PsycINFO, CINAHL and Medline to capture literature with a focus on informal caregivers whose care recipients are aged 55 years or older. Articles were included if they focused on examining the experience, perspective and/or role of informal caregivers in providing care for their older care recipients, while articles were excluded if they only focused on healthcare professionals or older adults.

Results A total of 24 studies were identified that met the study inclusion criteria. This review elucidated the roles of caregivers as a primary system navigator and as an advocate for older adults. Numerous challenges/barriers in system navigation were uncovered, such as lack of consistency in fragmented systems, as well as facilitators, including interface/coordination roles. Finally, recommendations for better system navigation such as caregiver engagement and integration of continuity of care services were identified.

Conclusion The need to raise the visibility of the roles and experiences of informal caregivers in system navigation was highlighted. Further research needs to focus on implementing interventions for informal caregivers incorporating a care coordinator to fill the care gap within community and healthcare systems. This review has the potential to foster greater integration of community and healthcare systems.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ This is the first scoping review to systematically review and synthesise research findings on the roles and experiences of informal caregivers while navigating community and healthcare systems.
⇒ The present scoping review was conducted based on the Joanna Briggs Institute's reviewer manual, following the recommended systematic search strategy.
⇒ This review identified not only the challenges and barriers that caregivers face in system navigation, but also factors that may facilitate accessing the systems with or on behalf of their older care recipients.
⇒ One limitation is that we may have overlooked literature on this topic in languages other than English.
⇒ Another limitation is that as grey literature was not included, some relevant studies and knowledge may have been overlooked during the screening process in non-peer reviewed publications.

INTRODUCTION

Informal (unpaid) caregivers assist people with functional limitations with a variety of tasks that enable them to function in daily life, including personal care, basic activities of daily living, transportation and sometimes accessing community and healthcare services.[1 2] This type of care is usually provided by family members, such as the person's adult child or spouse.[3] It is well established that as people get older, they will experience an increasing likelihood of chronic disease, including physical/mental health problems, and multimorbidity. Approximately two-thirds of older adults have multimorbidity in most countries with advanced healthcare systems, and 90% have at least one chronic illness.[4–8] As older people have multifaceted care needs, they often require complex treatment and care across different settings (ie, community and healthcare).[9] Informal caregivers frequently navigate the complex community and healthcare systems to obtain the information, services, medicines and equipment needed to fulfil the health and functioning needs of their care recipients.[10] Informal caregivers, who have been

recognised as the backbone of the healthcare system,[11 12] are playing a vital role in improving the degree to which older adults access community and healthcare services in a more seamless and timely manner, which we define as 'system navigation.' They are fulfilling important navigation and support roles that foster greater coordination and integration across the complex community and healthcare systems. This role is contextualised based on their understanding pertaining to detailed characteristics of the care recipients that are often unidentified by formal care providers.[13]

Given the pivotal role of informal caregivers, it is critical to understand their experiences and perspectives while navigating these systems. This information, in turn, can lead to more effective community and healthcare services and interventions, as well as enhanced caregiver and care recipient well-being. While there is a substantial body of literature that examines the experience of patients and healthcare professionals (HCPs),[14–18] studies that have focused specifically on experiences of informal caregivers are comparatively lacking. Furthermore, to our knowledge, no study has attempted to systematically review and synthesise research findings regarding the roles and experiences of informal caregivers navigating these complex systems.

This scoping review focuses on the experiences, perspectives and roles of informal caregivers of older adults while navigating community and healthcare systems to obtain care for their care recipient. We will attempt to identify not only the challenges that caregivers face, but also facilitators of informal caregivers in accessing these systems with or on behalf of their care recipients. Based on this study, relevant recommendations to improve the challenges and to fill the gaps within the community and healthcare systems can be proposed.

Research questions

1. What is currently known about the roles and experiences of informal caregivers of older adults while navigating the community and healthcare systems?
2. What are the challenges/barriers and facilitators in system navigation?
3. What are the gaps in knowledge related to roles and experiences among informal caregivers of older adults while navigating the community and healthcare systems?

METHODS

Search strategy

A scoping review of the literature was undertaken according to the Joanna Briggs Institute's Reviewer Manual[19] using a three-stage search strategy (the full search strategy is presented in online supplemental file 1). The first step included an initial search of targeted online databases—AgeLine, PsycINFO, CINAHL and Medline (on 2 March 2023). Studies published from January 2005 to December 2022 were included. This step was followed by an analysis of the title and abstract text of retrieved papers, and of the index keyword terms used to describe the articles. The second step entailed a comprehensive search using all identified keywords and index terms across all included databases. The last step was to employ a hand search the reference list of identified articles for additional sources. The initial electronic search was also supplemented by reviewing the reference lists of any identified systematic review articles to identify missing studies.

Inclusion and exclusion criteria

Literature with a focus on informal caregivers whose care recipients are aged 55 years or older was included. While age 65 and over is used in some studies,[20] we selected age 55 and over since many studies use an age range that encompassed this age span, thus maximising our coverage. In the case of articles without specific age criteria for the study participants, we calculated the mean or median age according to the data availability of each article to ensure that at least a majority of persons are aged 55. The specific inclusion criteria are: (1) studies with a focus on examining the experience, perspective, and/or role of informal caregivers in providing care for their older care recipients, (2) studies regarding informal caregivers whose care recipients aged 55 or over, (3) studies with any type of design, including quantitative, qualitative, mixed or multimethods research, (4) studies published between 2005 and 2022, and (5) studies published in English. An article was excluded if it: (1) only focused on HCPs, paid caregivers or older adults, (2) was specifically related to an integrated care programme for older adults and their caregivers (eg, programme description study, feasibility study, evaluation study), (3) was an intervention study related to informal caregivers and older adults, (4) was about an acute care setting, (5) focused on specific topics such as IT/technology for older adults, end-of-life care and transitional care, and (6) was a review article or conference paper.

Procedure

The screening procedure was conducted using the Covidence online platform (https://www.covidence.org/). Sources that met the inclusion criteria were imported to Covidence and duplicates were excluded. Two independent reviewers completed two rounds of screening for the review. The first stage was a title and abstract review based on the eligibility criteria. Disagreements during the process were resolved by discussion with a third independent reviewer. Studies such as grey literature or conference papers were excluded. The second stage was a full-text review. Systematic reviews/scoping reviews and study protocols were excluded. Detailed reasons for exclusion are presented in a Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram (figure 1).

Data analysis

Two reviewers independently extracted, tabled in Excel, and reviewed the data of the first 20% of included studies.

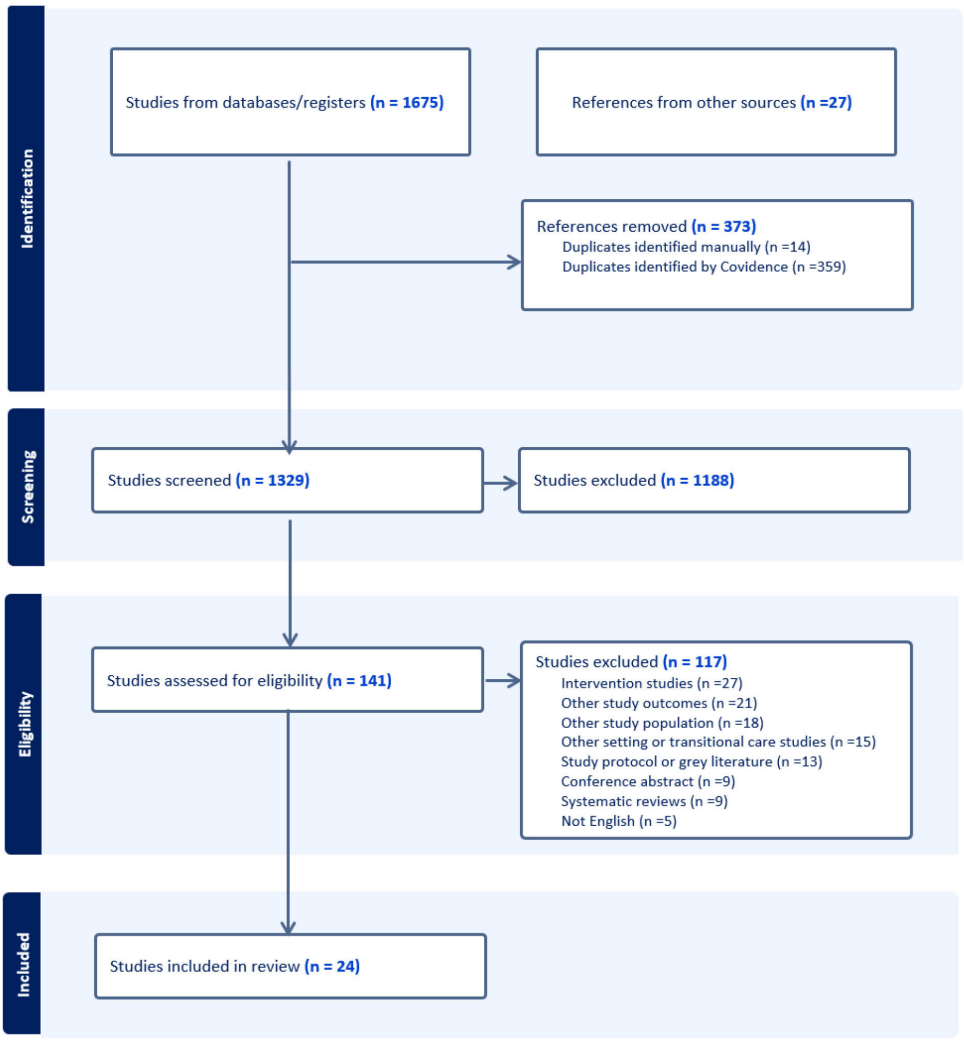

Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram (uploaded as separate file).

Data extraction included: study details (study aims, sample size, study location, method, etc), characteristics of study participants (age, caregiver/care receiver relationship, chronic condition/health status), key findings of the study based on the research questions, and so on (see online supplemental file 2). Following this, adjustments were made by comparing and discussing each data extraction table between reviewers. This step allowed early calibration and correction of potential discrepancies that may have arisen during the process. The remainder of the extraction was completed by one main reviewer and double-checked with the second and the third reviewer. Thematic analysis was conducted to identify, analyse and interpret key themes across the included studies.[21 22] This method is flexible and powerful in terms of systematically generating robust research findings by identifying patterns, common themes, topics and ideas within and across data in relation to participants' lived experiences, perspectives, behaviours and practices.[23–25] Based on this approach, our study specifically organised major themes/patterns regarding the experiences, roles and/or challenges of informal caregivers while navigating the community and healthcare systems to obtain care for their older care recipients.

Patient and public involvement

Patients and/or public were not involved in this research.

RESULTS

Study selection flow

A total of 1675 studies were retrieved from the search of selected electronic databases. After removing the duplicates, 1329 titles and abstracts were screened, with 1188 studies excluded. The full-text review was conducted with 141 studies, 24 of which were identified based on all criteria. The most common reasons for exclusion during the full-text review included intervention studies (n=27), other study outcomes (n=21), other study populations (n=18) and other settings or transitional care studies (n=15).

Characteristics of the selected studies

Selected studies were published between 2007 and 2021, with most of them (n=19) published after 2015. Ten

studies were conducted in Canada, four in Australia, and three in the UK. Other countries include Mexico, Czech Republic, New Zealand, Germany, Poland, Ireland and Sweden. Many studies described the challenges and experiences of informal caregivers while navigating the community and healthcare systems with their care recipients. The age of the caregivers among the included studies varied, while their care recipients were mostly aged 65 or over. There were no notable patterns regarding the age characteristics of caregivers across the studied literature. Most of the studies (n=23) adopted a qualitative approach exploring the challenges and perspectives of caregivers in depth. Among them, 22 studies used interviews and/or focus groups while the other one adopted an integrated knowledge translation approach by holding a targeted conference for various stakeholders. One quantitative study used a self-administered questionnaire to identify the caregivers' reasons for continuing or terminating family care and measured their subjective levels of exhaustion. Among studies that identified caregiver–recipient relationship, most informal caregivers in the included studies were the spouse of the care recipient (n=9) or their adult children (n=5). Others were mixed. To a smaller extent caring relatives or friends were involved. Regarding gender, the most common was female. Many care recipients of the studies had dementia (n=9) or multiple chronic conditions (n=8).

The multiple themes that emerged from the data analysis are organised into four categories. These include (1) informal caregivers' role in system navigation, (2) challenges and barriers in system navigation, (3) factors facilitating system navigation, and (4) recommendations for improving system navigation. Primary themes based on each category are presented in table 1.

Table 1 Description of the categories and themes

Category	Theme
Informal caregivers' role in system navigation	► Primary system navigator ► Advocate for older adults
Challenges and barriers in system navigation	► Lack of consistency in fragmented systems ► Difficulties accessing services ► Managing multimorbidity
Factors facilitating system navigation	► Interface and coordination roles ► Relationship-based Support ► Person-centred approach
Recommendations for improving system navigation	► HCPs/caregivers education ► Caregiver engagement ► Centralised, accessible resources ► Integrated system with continuity of care

HCP, healthcare professionals.

Category 1: informal caregivers' role in system navigation

Primary system navigator

The findings of the studies confirmed that informal caregivers are acting as a primary system navigator for their older care recipients.[7 26–29] Caregivers were typically found to be the only consistent form of support for the care recipient as they moved between settings and formal care providers. Given the long-term relationship between the caregiver and the care recipient, the caregiver often held a great deal of detailed knowledge of patient needs and preferences that were unidentified by formal care providers.[26] Some caregivers were playing a role as the main navigator in the help-seeking process, employing prior experience in using services and personal connections.[27] In addition to being the primary navigator, informal caregivers were required to manage a variety of tasks to operationalise the care as directed by HCPs. Caregivers followed up on practical tasks, such as contacting home care services, arranging appointments, and providing transportation to appointments. They were also responsible for keeping records of test results and managing multiple medications for older adults with complex needs.[7 28 29] Overall, informal caregivers were playing a significant role in coordinating care, navigating community and healthcare systems and facilitating continuity of care.[29]

Advocate for older adults

One of the essential roles of informal caregivers identified from the selected studies was serving as an advocate for their care recipients.[29–32] It has been recognised that advocating for the rights of care recipients is especially significant for people living with dementia (PLWD),[33–37] individuals who are likely to have difficulty arranging and navigating necessary services on their own. Informal caregivers were often proactive in facilitating continuity in care and negotiating access to services on the care recipients' behalf. This included, for instance, acting as an advocate for their family member with dementia, noticing when something was wrong and seeking help, and helping HCPs to make treatment decisions.[29 38]

Category 2: challenges and barriers in system navigation

Lack of consistency in fragmented systems

Informal caregivers have been found to have significant difficulties navigating fragmented and complex systems with their care recipients due to lack of consistency in a wide range of fields. Such challenge in the community and home care was identified in several studies.[7 26 28 39–41] In terms of individual and organisational level, caregivers often must repeatedly provide information about their care recipients' needs, preferences and treatment regimens to different home care providers due to high turnover of staff.[26 42] Informal caregivers described their home care experiences as challenging due to the frequent changes of staff and inconsistent performance received from service providers. These issues were frustrating for the caregiver and perceived as disruptive for older people with complex needs.[40] They were likely to feel most

comfortable when they received support from a familiar provider, especially in the case of a care recipient experiencing cognitive decline.[26] Consequently, constantly changing staff may leave care recipients nervous and anxious in their daily lives and cause additional stress for caregivers.

At the system level, caregivers across the studies articulated that many issues in system navigation arise from a lack of integration among various sectors. They argued that existing services for older adults with complex needs are fragmented and not comprehensive.[38 41–44] The siloed nature of health and community care systems was characterised as separated by disparate information formats and styles that contribute to a breakdown of communication.[7] In particular, communication gaps exist between the hospital, home care and the family doctor, and across sectors and organisations. As a result, caregivers recount the same experiences and information to various care providers.

Difficulties accessing services

Challenges in accessing and navigating the systems among informal caregivers were noted across almost all studies.[7 27 30 31 40–43 45 46] First, issues related to long wait times were identified. Study participants perceived that long wait times for acute care and specialised services, and limited access to primary care, often result in the unnecessary use of emergency care.[42 45] In particular, caregivers who were balancing caregiving duties with full-time employment were frustrated due to long wait times, coupled with long waiting periods for results, and between appointments.[41] Such long wait times may place increased social burdens on care recipients and caregivers, leading to loss of well-being and quality of life.[40 42 46] Second, lack of information was noted as one of the main contributors for challenges in accessing and navigating systems among caregivers. There was a lack of knowledge about community services. The information that is available is found across different organisations and at times is inaccessible since there is no centralised website or phone number, or locale to look up or access services. Caregivers also do not know about all relevant available resources, and instead, often rely on a wide network of non-professionals.[7 43] Moreover, caregivers reported that HCPs do not have sufficient time to provide information about the evolution and management of complex diseases of their patients. They recognised that family or specialist physicians did not always have up to date information, or were unaware of the patient's complete medical history. Given a wide range of difficulties that caregivers face and the lack of information on the service/programmes in which they are involved, some caregivers seek necessary information about addressing their recipients' care needs through courses, the Internet, printed materials or questioning others.[27 30 31]

Managing multimorbidity

In order to provide care to older adults with complex needs, informal caregivers are encountering serious challenges managing their care plans. Lack of adherence to care plans and drug noncompliance were noted, often due to the disease complexity and the difficulty of managing multimorbidity.[41] Caregivers across studies highlighted the challenge related to a lack of knowledge especially in the area of dementia among formal service providers. In the home care setting, it has been identified that staff often do not know the nature of the care required nor whether the care recipient is cognitively impaired. Thus, the worker are often unaware of what to do in order to address the needs of the care recipient.[40] Although patients and caregivers typically assumed that dementia training had been provided to home care workers, they questioned whether it was being applied appropriately and uniformly in applied settings. Conversely, appropriate knowledge of dementia enabled a positive experience of receiving care. It was assumed that if there was effective support based on appropriate knowledge on complex needs of care recipients, a connection could be forged between care recipients, caregivers and formal service providers.[44]

Category 3: factors facilitating system navigation

Interface and coordination roles

Informal caregivers indicated the strong need for interface/coordination roles such as care navigators or integrated care coordinators, who work at the intersections where primary care, secondary care and social services meet.[39 42] Without having a care coordinator while navigating these complex systems, caregivers have played an active role as an informal care coordinator in order to address the complex needs of their care recipients. Dealing with deficits in the care system was frustrating for them because they had to 'be on top of everything' to get what they needed. In this sense, caregivers emphasised the need for a 'point person' to manage the patient's care and to support communication and decision-making across the various specialists.[41] These interface/coordination roles were viewed as critical in facilitating integration among service providers by bridging gaps across sectoral boundaries. Care coordinators were described as crucial not only in addressing the everyday health and social care of older adults with complex needs but also in providing support and advice to caregivers when navigating these systems.[39]

Relationship-based support

While navigating community and healthcare systems, informal caregivers and older adults with complex needs encounter a wide range of service providers in various sectors. Informal caregivers perceived their relationship building with providers as a holistic, interconnected and dynamic process.[47] However, inadequate training of staff about the client's health (eg, cognitive impairment), and inconsistent performance by service

providers may discourage caregivers from playing their integrative role to address the complex needs of care recipients.[28 40 42] Given the importance of the relationship between formal service providers and informal caregivers, it was recognised that formal service providers should be available, well-intended, committed to supporting their clients/caregivers and eager to explore ways to engage with and support them in new ways.[7] Indeed, it has been confirmed that the relationship-based caregiver supports improved service uptake by the carer-care receiver dyad.[48]

Person-centred approach

Being viewed as a person and not merely as an illness was appreciated among care recipients and their caregivers throughout the included studies.[7 12 38 44] Care recipients expressed appreciation for receiving care that fits their needs and their caregivers appreciated formal service providers who took the time to see their care recipients as a person. Both care recipients and their caregivers praised providers who tailored treatment specifically to their individual situations.[12 38] In particular, study participants often explained how a home care worker's person-centred approach influenced the care experience for PLWD and their caregivers in a positive manner. Person-centred care required knowledge of dementia and familiarity with the needs and preferences of PLWD. In addition, person-centred care was strengthened when caregivers could negotiate and inform home care workers of the best way to tailor tasks and activities in a way that reflected the individual needs of their care recipient. When formal service providers focused on the person rather than the tasks, they demonstrated quality of care that had a significant positive effect on PLWD and their caregivers.[44]

Category 4: recommendations for improving system navigation

HCPs/caregivers education

The importance of providing education to caregivers as well as to HCPs was highlighted in several studies reviewed.[12 26 49] Caregivers identified the need for more information and direction for themselves, particularly tools to better advocate for their care recipients. They implied a need to acquire the language to work together with HCPs for the well-being of their care recipient.[12] Caregivers expressed that it was important to know how and where to seek supports particularly in the earlier stages of caregiving, to avoid unnecessary, longer-term hardship.[26] The significance of implementing caregiver empowerment with education was especially noticeable for caring older adults with complex needs. Greater access and uptake of education strategies to improve understanding of the nature, consequences and management of the care recipient's conditions was highlighted. Participants in this study reported that they could be more empowered to manage care recipients' complex needs through improved education on specific topics including disease self-management, and involving more detailed explanations during medical consultations.[49]

Recognising that a lack of knowledge especially in the area of dementia among HCPs has become one of the issues that pose significant challenges for smooth system navigation, providing education to formal service providers such as HCPs, nurses, social workers was also emphasised in order to enhance system navigation.[12 38 40 44] Caregivers contended that, with education, HCPs will have greater confidence and more compassion when working with PLWD. Specifically, caregivers suggested more training for HCPs regarding recognition of, and intervention for, delirium and different types of dementia, intervention strategies, decision-making capacity assessment, etc.[12] Furthermore, it was noted that in order to achieve interprofessional collaboration, all primary care providers would need to be further educated on each other's roles to understand how their scope of practice would fit within the larger care team to operate more efficiently.[38]

Caregiver engagement

Many caregivers discussed the importance of involvement of caregivers and family members as active participants in the care process.[38 40 45] Caregivers expressed a desire to be part of the multidisciplinary team and to be included in the care decision-making. Since caregivers viewed themselves as a vital link between older adults and the healthcare system, some caregivers expressed anger and frustration at being excluded from assessments and care planning. They felt that vital information on the behaviours and preferences of the care recipient were being overlooked and that respectful and appropriate individualised care was not being provided.[40]

Centralised, accessible resources

Informal caregivers often identified a deficit of the existing community and healthcare infrastructure, in which sharing of information across different sectors is not supported.[7 29 45 50] HCPs from all sectors suggested ways of helping patients/caregivers navigate multiple encounters with different professionals. However, while this indicated a recognition of the need to bridge the gap between different services, few resources exist that facilitate the system navigation of patients/caregivers.[29] Considering this issue, a centralised database for caregivers to identify necessary resources for the client as well as themselves would be beneficial.[7] Caregivers also described the need for well-developed resources and information to ensure that caregivers and families are informed and educated in an appropriate and timely manner to prepare them for anticipated health declines of care recipients.[29 45 50] Supports and services such as community resources, workshops and respite services were noted. In addition, caregivers expressed the need for more timely and available resources at the time of diagnosis. Resources from the system and community are regarded as especially crucial at the start of the caregiving journey.[12]

Integrated system with continuity of care

Given the various challenges that caregivers have encountered due to care gaps in community and healthcare systems, caregivers suggested a need for a new, more integrated care system with a single-entry point, continuity of care, and a multidisciplinary team for assessment and treatment.[38 42 44 51] The study authors therefore recommended the restructuring of the existing fragmented systems, as well as a move towards more comprehensive preventative medicine including more frequent home visits and preventative screening by HCPs. Caregivers and older adults with complex needs noted that a reformed system must ensure continuity of care.[42] To implement continuity of care within the system, informal caregivers highlighted the importance of improving the collaboration between themselves and HCPs. They wanted to share the knowledge and skills they had developed, to enable effective care for older adults with complex needs. Consistency between home care workers and continuity of care was valued by all study participants.[44]

DISCUSSION

This scoping review and synthesis of 24 studies provided detailed descriptions of the challenging experiences, perspectives and roles of informal caregivers while navigating community and healthcare systems. To the best of our knowledge, this is the first scoping review that focuses on the roles and experiences of informal caregivers in system navigation. Our study found that many studies reviewed described the experiences of caregivers focusing on the perspectives of older adults within the dyad or with other stakeholders such as HCPs, indicating the lack of attention on the identification of caregivers' specific experiences on system navigation.

The findings of our scoping review highlight the integrative role of caregivers by filling care gaps. While caregivers are already fulfilling a wide range of tasks for their care recipients, they often must also navigate complex community and healthcare systems. This was necessary to obtain the appropriate information and services for their care recipients due to the absence of a formal coordinator to support their help-seeking process. Indeed, informal caregivers turned out to be the primary system navigator across the studies by means of coordinating care and facilitating continuity of care for their care recipients. In addition, our findings further show another essential role of caregivers—as an advocate for older adults. This role has been identified as especially critical in the case of older people experiencing cognitive decline. While several reviews[52–56] have been conducted to examine the experiences of service users and/or service providers during the care process, our review specifically focused on the roles that informal caregivers have actively played in system navigation.

However, it should be noted that there still remain gaps in recognition and responses to a variety of pivotal roles of caregivers compared with other stakeholders in the systems despite the clear findings of this review. One study demonstrated that there was little recognition of the role of caregivers, and a lack of system supports for negotiating how or when caregivers' views can be incorporated into care planning, which can result in them feeling undervalued or excluded from care planning and decision-making.[29] Another study also confirmed that caregivers generally felt unrecognised in their role and knowledge, and desired to be acknowledged.[26] This shows that there is an existing gap in knowledge within community and healthcare systems of the role that caregivers are playing in providing coordinated care for older adults with complex needs. Our review also demonstrated that system navigation challenges are caused by a lack of continuity of care within the fragmented system. Such findings are aligned with previous reviews[53 54 57] which have described the challenges of caregivers and older adults caused due to a lack of coordination of services. In addition, our review shows the challenges in terms of caring older adults with complex needs (eg, comorbidity, multimorbidity). As older adults suffering multimorbidity need health and social care services from a wide range of fields, concomitant problems including a lack of adherence to care plans and noncompliance were identified.

Several important factors that may support and facilitate the navigation process of caregivers were also identified. First, a need for a formal care coordinator was noted in the studies, whereby they should be positioned to support integrative practices of caregivers during the help-seeking process. Similar findings have been reported in other reviews examining the experience of service users/caregivers, recommending system innovation and reform care settings especially in multiple.[54 57] Second, relationship-based support from formal service providers was highlighted. This aspect of caregiver–provider relationship was identified in the other review as well.[55] It found that a positive caregiver–provider relationship enhanced experiences of continuity and coordination of care across care transitions or the health and social care system, being provided with timely information and longer term monitoring, and tailoring of care to meet individual needs. An additional review highlighted the unidirectional characteristic of caregiver–provider relationships.[58 59] It was concluded that informal caregivers perceived their relationship with formal providers as unidirectional, and that they saw themselves as care managers merely monitoring the quality of care provided by these providers.[60] The relationship was considered as low or weak when expectation and needs were not met, or services and staffing were inadequate.[61] When caregivers perceived the relationship as unidirectional and weak, they felt isolated and vulnerable. In contrast, when caregivers perceived the relationship as reciprocal, negative feelings decreased and trust towards the providers increased. The findings from our review correspond with these studies by demonstrating the significance of caregiver–provider relationships in system navigation and the importance of well-intended attitudes of health providers to support their clients/

caregivers. One of these is the salience of a person-centred care approach. Caregivers appreciated receiving formal care that considers their specific needs and caregiving context and communicating with HCPs who take enough time to see them as a person. This finding aligns with the conclusion of another scoping review that identified that the need for more person-centred approaches to service delivery including, communication methods, was a major theme.[54 62–64]

Recognising the barriers and challenges in system navigation among informal caregivers, our review identified several recommendations to address these issues. The need for providing education and training not only to service users/caregivers but also to providers corroborates previous literature. One review[54] found that healthcare providers wanted more training on polypharmacy and protocol options.[65] Moreover, some physicians felt they lacked clinical confidence dealing with multiple complex issues, as clinical guidelines focused on one single condition leading to polypharmacy.[66] Taken together, the findings indicate that the education/training for HCPs would be most effective in terms of caring older adults with dementia and/or complex needs. While these reviews suggest the need of additional education and training for service users/caregivers as well as providers, they focused on the experiences of providers themselves, rather than the views of caregivers. In comparison, our review specifically identified this recommendation from the point of view of informal caregivers to enhance system navigation.

A recent systematic review[52] examined the experience of stakeholders including the involvement of caregivers in the decision-making process. Caregivers perceived that they could make decisions by advocating for their care recipients based on their detailed knowledge about them. Another review[55] also found that a number of different stakeholder groups perceived that active caregivers engagement in discussions and decisions about the older adults' care improved the quality of integrated care provided. However, caregivers sometimes were discouraged from taking an active role in the decision-making processes or from playing the role of supporters, advocates or representatives,[67–69] which may make them feel a loss of control. It implies the need for implementing strategies to further engage caregivers in decision-making processes not only for the care recipients but also for caregivers.

Finally, integrated care with continuity of care was identified as a system-level recommendation for better system navigation among caregivers. It is assumed that this component encompasses various organisational facilitators/recommendations described earlier (eg, interface/coordination role, person-centred care, training for HCPs) in order to be successfully implemented. A recent systematic review emphasised improved continuity and coordination of care, and multidisciplinary team working for better integrated care for older adults with complex needs.[55] While this review generally examined the stakeholders' perspectives including older adults, caregivers and providers, it was suggested that many factors need to be present to implement continuity of care. The care coordinator or case manager roles should be positioned to improve experiences of continuity of care. Health providers emphasised the importance of trained workers to facilitate continuity and coordination of care to improve management of health and social care needs of service users/caregivers. From our vantage point, a coordination role and training for providers should be implemented first in order to successfully implement integrated care for older adults with complex needs.

LIMITATIONS

First, the methodological quality or risk of bias assessment has not been conducted. Since scoping reviews can be distinguished from systematic reviews given that they are generally conducted to provide an overview of available evidence,[70] the current review explores the experience/role and challenges of informal caregivers in system navigation to provide general overview. Second, only articles written in English were considered. Thus, there might be some relevant studies and knowledge that were overlooked during the screening process. Third, limited number of databases were used to capture relevant literature. Fourth, since this is an emerging area, there may be further information gaps to be filled. Fifth, we did not include research focusing exclusively on transition from community to long-term care residences, given that this comprises a separate study, given unique dimensions of system navigation. Finally, not all community and healthcare systems are the same in the countries included in the review, and therefore, some of the results need to be contextualised.

IMPLICATIONS FOR FURTHER RESEARCH

Despite the clear role of informal caregivers identified from this study to fill the care gap across the complex systems, our review found that there is still a lack studies paying attention to the integrated and coordinated practices/roles of informal caregivers in system navigation. Additionally, given that the emphasis of many studies was on the caregiver, greater attention needs to be devoted to the experiences of the care recipient. There is also a need for multimethod studies that triangulate qualitative and quantitative findings. In addition, innovative interventions specifically designed for informal caregivers to improve system navigation should be implemented and evaluated. The need to place a care coordinator or case manager into the care system was strongly emphasised through the findings of this study, and this suggested reform requires further exploration. Further, community-based research should address this issue targeting various stakeholders such as HCPs, decision-makers and health administrators to facilitate better system access, integration and navigation. Additionally, the COVID-19 pandemic has revealed many impediments and deleterious outcomes for informal caregivers, when care systems are affected by natural disasters factors.[71 72] A deeper understanding of these effects would facilitate the development of more integrated systems.

While the pandemic has clearly had a profound effect on caregiving experiences and requires a separate scoping review, the number of studies focusing on system navigation during COVID-19 is not extensive enough for this work at present.

CONCLUSIONS

This scoping review identified and organised the research findings of included literature regarding the role, challenges/barriers and facilitators in system navigation among informal caregivers of older adults with complex needs. Overall, the need to raise the visibility of the perspectives, lived experiences and roles of caregivers in system navigation has been elucidated in this review. The challenges and barriers of caregivers while navigating the system were also uncovered, highlighting the need to implement feasible strategies and health policies to support caregivers to navigate the complex community and healthcare systems for more seamless access and utilisation. Recommendations for improvements were identified in our review that could form a foundation to reforms. Further research needs to focus on implementing interventions/programmes for informal caregivers incorporating an integrated care coordinator component to fill the care gap within the community and healthcare systems. Indeed, the current scoping review has the potential to foster greater integration of community and healthcare systems.

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