

Knowledge, Practice and Needs of Family Caregiver in the Care of Older People: A Review

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ABSTRACT

Family caregivers play a significant role in the care of older people. However, their knowledge, practice and needs in the care of older people often overlooked. Therefore, this review was performed to provide an overview of family caregivers' knowledge, practice and needs in the care of older people. A literature search was conducted using the following electronic databases: ProQuest Health and Medical Complete, Wiley Online Library, EBSCO Host, Science Direct and Scopus. Search terms used were "older people", "family caregiver", "knowledge", "practice" and "needs". Two reviewers independently screened the studies and the extracted data. A total of 2115 eligible studies were identified after database search. Only nine studies met the inclusion criteria after full article screening and were included for data extraction. This review of the articles presents a summary of (1) family caregivers' knowledge about the care of older people, (2) family caregivers' practice in the care of older people and (3) family caregivers' needs in the care of older people. The analysis reveals that most of the caregivers addressed a lack of knowledge and poor practice in the care of older people. This review also offers important insight into the needs of family caregivers. Hence, this review recommends further studies on knowledge, practice and needs in the care of older people to identify contextual challenges and provide evidence-based solutions to improve family caregivers' knowledge, practice and needs in the care of older people.

Keywords: Older people; Caregiver; Knowledge; Practice; Needs

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Article History:

Submitted: 4 September 2022
Accepted: 23 November 2022
Published: 30 November 2022

DOI: 10.31436/ijcs.v5i3.269
ISSN: 2600-898X

INTRODUCTION

The ageing population is a worldwide phenomenon that has shown an evident rise in both developing and developed countries. A report estimates that the world population will increase to 9.8 billion by 2050 (1). This will pose a significant challenge in countries all across the globe (2). Inevitably, Malaysia's population is also rapidly ageing. Currently, Malaysia has 1.9 million older adults, accounting for 6.2% of the total population. It is estimated that in 2030, the older population will reach 15%, making Malaysia an aged nation (3). Due to the demographic shift, the number of older people living with chronic diseases is also increasing. According to the National Health and Morbidity Survey (NHMS) 2019 by the Ministry of Health (MOH), about 8.1% of the adult population in Malaysia, which consists of 1.7 million people, have all three risk factors for diabetes, hypertension and high cholesterol. These main non-communicable diseases are usually associated with long-term care (4), severity and decreased functional abilities (5), thereby increasing the need for health care (6).

The limited resources of the Malaysian health care system are insufficient to meet the needs and management of the rapidly growing ageing population. Therefore, the health care system relies heavily on family caregivers to support the care for older people (7). In addition, there are lack of nursing homes in the respondents' areas in Malaysia, which increases the responsibility of family caregivers. Moreover, placing the older people in nursing homes is a taboo in Malaysian culture and unacceptable to society (8). As a result, family caregivers are obliged to fully provide their parents with the support they require.

In most Asian countries, the family is the traditional social institution providing care for older people (9). A family can give older people familiar surroundings, love, emotional ties, a sense of belonging and a feeling of being wanted. Traditionally, Asian countries, such as Japan, China, Singapore, Malaysia, Indonesia, Thailand and the Philippines, view that the family members should take responsibility for taking care of the elderly as an expression of the cultural value of "filial piety" (10). They pay full respect and honour to their older relatives; therefore, caring for older relatives is a natural

responsibility or part of their obligation to those who have cared for them (11).

Family caregivers are defined as relatives and friends who provide care for free to individuals with chronic or debilitating conditions (12). Family support is also very important in countries like Malaysia because of the absence of long-term care insurance and social security benefits (13). Malaysians mostly rely on informal care comprising family members of the patients (14). Very few Malaysian families can afford paid caregivers, whether trained or untrained (13). These family caregivers are expected to assist their older relatives with performing activities of daily living, preventing falls and elderly abuse. Generally, they play a role in the physical, emotional, psychosocial and sometimes financial assistance of older family relatives who are unable to care for themselves.

Studies have shown that many caregivers did not have adequate skills and knowledge to care for the people they assisted. Lack of knowledge, practice and information needs result in devastating consequences to both the older people and family caregivers. Family caregivers often feel unprepared to provide care, have inadequate knowledge to deliver proper care, and receive little guidance from health care professionals (15). Due to inadequate knowledge and skill, family caregivers may be unfamiliar with the type of care they must provide, or the amount of care needed. Furthermore, family caregivers may not know when they need community resources and may not know how to access, and best utilize available resources (16). Therefore, family caregivers report feelings of uncertainty, emotional distress and the need for training and information (17). They are more likely to have depressive symptoms and report fair to poor physical health, higher strain, and are less likely to engage in health promotion activities than non-caregivers (18). Additionally, it may have a negative impact on the health and wellbeing of older persons, including their cognitive and physical abilities. In the worst case, older people who receiving care at home are prone to complications such as bedsores, respiratory infections, urinary infections, and joint stiffness (19). Improving knowledge, practice and meeting the needs of family caregivers should be a priority. Therefore, this

review aims to understand the family caregivers' knowledge, practice and needs in the care of older people.

METHODS

The study chose a scoping review because of its ability in mapping of new concepts, types of evidence and associated gaps in the available evidence (20). A literature search was conducted with the following electronic databases: ProQuest Health and Medical Complete, Wiley Online Library, EBSCO Host, Science Direct and Scopus. A combination of the following key terms with Boolean operators (e.g. AND, OR, NOT) was used: "older people", "caregiver", "knowledge", "practice" and "needs". The search on the online databases was limited to articles with full text and peer-reviewed format from 2010 to 2020. Articles were chosen based on these inclusion criteria: 1) studies that used caregivers (spousal, relatives, adult child) who were taking care of older people aged 60 years and above 2) studies that focused on the topic of interest - knowledge, practice and needs in the care of older people, and 3) studies that were written in the English language. Studies that involved formal caregivers, health professionals and other areas or informal caregivers of institutionalised elderly (e.g. nursing homes, day centres and hospitals) were excluded. Selection of articles is illustrated as a Preferred Reporting Items for Systematic and Meta-Analyses (PRISMA) flow chart (Figure 1). The articles were screened by two independent authors. Data such as author, country, study design, sample and results were extracted from each article. The information was extracted separately by two reviewers and then cross-checked. Any discrepancies were clarified with a third reviewer.

RESULTS

A total of 2115 eligible studies were identified from the databases searched (Figure 1). 1117 studies were retained after duplicate removal. A total of 130 studies were excluded after the title and abstract screening conducted by two researchers. 870 studies were excluded because of no full text thus reducing the articles eligible for full-article screening to 117 articles. After the full-article screening, 9 articles were finally included for data extraction in the review. The summary of the nine studies is presented in

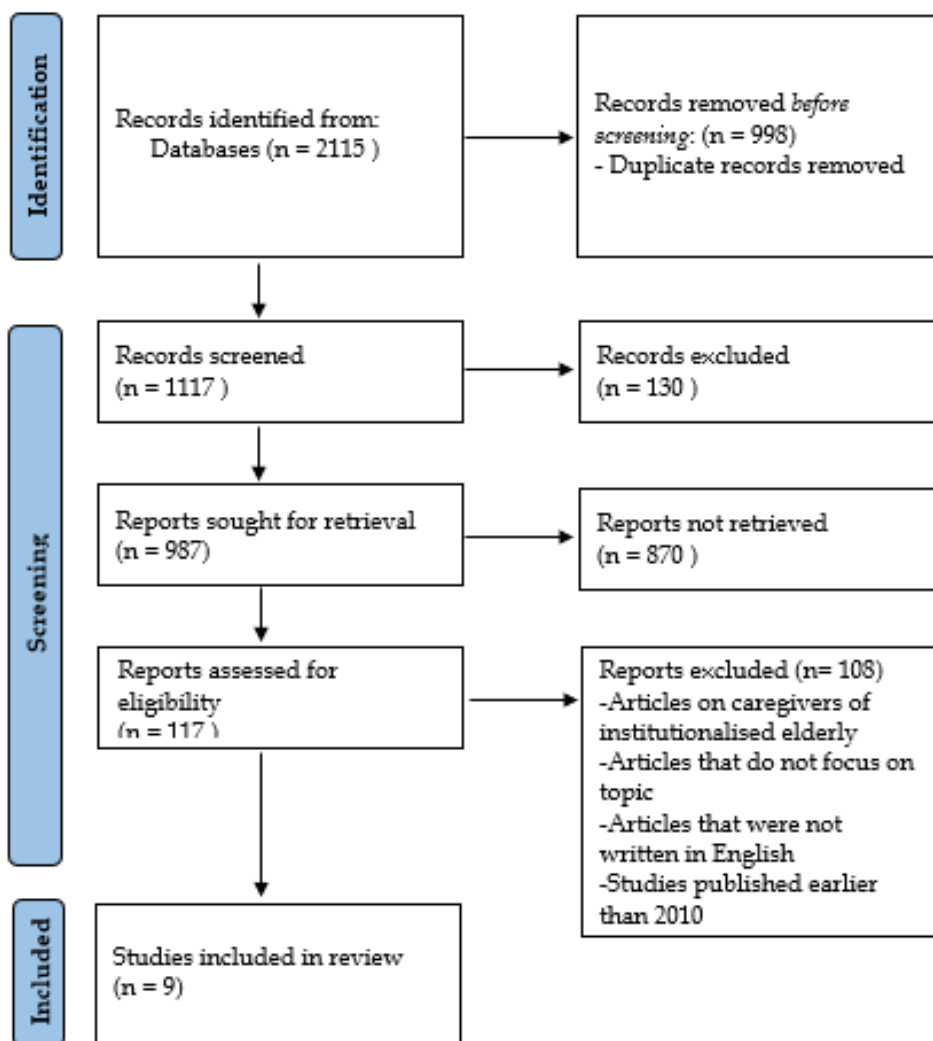
Table 1. Six cross-sectional studies (21-26), two mixed method studies (27-28) and one integrative review (29) were found. Four studies were conducted in Brazil (21, 24, 27, 28). A study was conducted in Japan (23), Cameroon (25), United States (22), Portugal (29) and Malaysia (26), respectively. Of the selected studies, only two were conducted in Asian countries: one in Japan and another in Malaysia. Overall, it can be deduced that most studies were conducted within the western hemisphere, including the American continent and Europe. Very few studies were found to have taken place in Asian settings. This shows the scarcity of information related to family caregivers' knowledge, practice and needs in the care of older people in Southeast Asia settings, including Malaysia.

This report is divided into three parts, namely:
 Part 1: Family caregivers' knowledge about the care of the older people,
 Part 2: Family caregivers' practice in the care of the older people,
 Part 3: Family caregivers' needs in the care of the older people.
 Part 1: Family caregivers' knowledge about the care of the older people

In general, all articles reported that most family caregivers lacked knowledge about the care of older people. Kuratal et al (23) employed a cross-sectional study design to assess family caregivers' knowledge and perceptions of physical restraint used with elders living at home in Japan. They found that family caregivers were much less aware of recognised prohibited physical restraint procedures. However, they recognised the harmful effects of physical restraint.

In another study, Avila et al (24) explored the level of family caregiver's knowledge about fall prevention and found that only 42.7% of family caregivers had knowledge of fall prevention, and less than half of the participants (48.3%) believed it was possible to prevent falls in the elderly. In contrast, a study by Mamani et al (21) on the family caregiver's knowledge about falls and their prevention revealed that more than half of the family caregivers (53.6%) were aware of falls and identified them as a problem. Moreover, they were also aware of the main causes of the occurrence of falls and prevention measures,

Figure 1: Flow diagram (PRISMA) of the process of identifying and including references.



such as changes in balance, loss of muscle strength, carelessness or lack of attention, loose mats at home and wet floors.

Similarly, the study in Cameroon by Bassah et al (25) assessed family caregivers’ knowledge, practice and needs in the care of older adults at home. The family caregivers in this study generally possessed knowledge of common problems of the elderly, such as joint pains (95.2%) and difficulty walking (95.2%). However, most of them were unaware of complex problems, such as bowel (33.1%) and urinary (31%) incontinence, as well as elderly care resources within their communities (88.1%). Therefore, the authors in this study

suggest the need for education on the care of older people.

A similar condition was observed in Malaysia. One example is a local study conducted by Tan et al (26) on 128 caregivers of stroke patients. The result found that the caregivers obtained a mean score of 14.9 ± 4.32 (SD) in terms of knowledge. In other words, family caregivers displayed poor knowledge, such as about the positioning of patients. This study supported the necessity for further exploration of the issue of poor knowledge among family caregivers.

Table I: Summary characteristics of the included studies

Author/ year	Country	Study design	Sample	Relevant findings
Mamani et al (21)	Brazil	Cross-sectional	97 caregivers	<ul style="list-style-type: none"> About 53.6% caregiver had knowledge about falls and its prevention and 89.7% of caregivers reported that fall is possible to prevent. About 99.0% caregivers reported practising it in their daily care. The main preventive measures mentioned were vigilance (57.7%), orientation to walk with caution (18.6%), restriction of their activities (12.4%), avoiding loose mats in the house (28.9%), avoiding the floor wet (23.7%) and installing support bars in the bathroom and other environments (12.4%). Caregivers knowledge is superficial and limited to common sense information. They do not practice the measures in order to ensure the prevention of the occurrence of fall.
Kuratal et al (23)	Japan	Cross-sectional	494 caregivers	<ul style="list-style-type: none"> Family caregivers were significantly less aware of prohibited physical restraint procedures and recognised harmful effects of physical restraints
Avila et al (24)	Brazil	Cross-sectional	89 caregivers	<ul style="list-style-type: none"> About 42.7% of family caregivers had knowledge of fall prevention and 48.3% believed it was possible to prevent falls in the elderly. Majority of family caregivers considered not having knowledge about preventing falls in the elderly.
Bassah et al (25)	Cameroon	Cross-sectional	126 caregivers	<ul style="list-style-type: none"> Family caregivers had good knowledge of common problems of the elderly, such as joint pains (95.2%) and difficulty walking (95.2) and unaware of complex problems, such as bowel (33.1%) and urinary (31%) incontinence and elderly care resources (88.1%). Family caregivers reported engaging in the practice of some highly skilled healthcare tasks, like providing their elderly relatives with auto medications (14.3%) and revealed the unsatisfactory practice of fall prevention (55.6%). Family caregivers wanted information on the care of older adults, training on elderly care, financial assistants, support for family caregivers, assistance from health and social care professionals and employers' flexible work programmes.
Tan et al (26)	Malaysia	Cross-sectional	128 caregivers	<ul style="list-style-type: none"> Family caregivers obtained a mean score of 14.9 ± 4.32 (SD) in terms of knowledge of positioning. Family caregivers have poor knowledge such as about the positioning of patients.
Silva et al (29)	Portugal	Integrative review	14 empirical studies	<ul style="list-style-type: none"> Family caregivers needed to receive information on the followings: the disease process, supporting health care resources and access to health services.
Black et al (22)	United States	Cross-sectional	246 caregivers	<ul style="list-style-type: none"> More than 85% of family caregivers had unmet needs. Family caregivers have unmet needs related to care, services and support.
Stirling et al (27)	Brazil	Mixed exploratory study	20 caregivers	<ul style="list-style-type: none"> Family caregivers' needs related to the performance of instrumental support activities fear of not providing proper care, family dynamics, lack of information on the health condition and total dedication to caring and financial expenses.
Bierhals et al (28)	Brazil	Mixed exploratory study	39 caregivers	<ul style="list-style-type: none"> Family caregivers felt their needs were related to information about instrumental support activities and subjective aspects of care and normative needs.

Part 2: Family caregivers' practice in the care of the older people

A study on practices of fall prevention among older people by family caregivers from Brazil indicated that almost all of them (99.0%) reported practising it in their daily care (21). The main preventive measures mentioned and related to the behaviour of the elderly were vigilance (57.7%), orientation to walk with caution (18.6%) and restriction of their activities (12.4%). Furthermore, the fall prevention practices of caregivers related to the environment included avoiding loose mats in the house (28.9%), avoiding the floor wet (23.7%) and installing support bars in the bathroom and other environments (12.4%). According to the authors, these family caregivers knew superficially about falls and their prevention, and it seemed to influence their practices regarding the prevention of falls (21).

In Cameroon, the study on family caregivers regarding their practices in the care of older adults at home mostly reported assisting older relatives with activities of daily living. However, a few of these relatives also reported engaging in the practice of some highly skilled healthcare tasks, like providing their elderly relatives with auto medications (14.3%). This study also revealed the unsatisfactory practice of fall prevention among family caregivers, with a significant number (55.6%) of the caregivers reporting not arranging their homes to be age-friendly. The authors concluded that there was a need to teach family caregivers of older people in Cameroon how to prevent falls (25).

Part 3: Family caregivers' needs in the care of the older people

An integrative review of 14 empirical studies by Silve et al (29) on the needs of family caregivers observed that caregivers needed to receive information on the followings: the disease process, supporting health care resources and access to health services. In further supporting the above, a study conducted by Black et al (22) among family caregivers in the United States aimed to determine the prevalence and correlations of unmet needs in community-residing persons with dementia and their informal caregivers. The authors revealed that more than 85% of

family caregivers had unmet needs for resource referrals and caregiver education.

However, in a mixed method study conducted in Brazil, the authors found that the family caregivers' needs were more closely related to the performance of instrumental support activities (bathing, dressing, diaper changing or medications care), fear of not providing proper care, family dynamics, lack of information on the health condition and total dedication to caring and financial expenses (28).

A similar study by Bierhals et al (28) on the needs of family caregivers' in-home care for older adults found that the caregivers felt their needs were related to information about instrumental support activities and subjective aspects of care. Family caregivers in this study also presented normative needs (distinguished by health care professionals) related to medication care. According to the authors, the result could indicate a lack of knowledge about the management of medication, probably because healthcare professionals do not consider it necessary to provide detailed relevant information to family caregivers (30).

Bassah et al (25) studied family caregivers' knowledge, practice and needs in the care of older adults at home. They found that these caregivers generally experienced challenges relating to serving medications to older people and feeling that their care-recipient did not like them. More specifically, they wanted information on the care of older adults, training on elderly care, financial assistants, support for family caregivers, assistance from health and social care professionals and employers' flexible work programmes.

DISCUSSION

Despite a large number of articles that focused on family caregivers, several articles have examined the caregivers' knowledge, practice and needs in the care of older people. After a thorough and meticulous search of the literature, nine articles that met the inclusion criteria were identified. The results of this review show that family caregivers have limited knowledge about caring of older people. Besides helping older people with activities of daily living, they also involved in highly skilled health-related activities such as

administering medication and performing wound dressings. Moreover, they found it was challenging to administer medication. As a result, they expressed the need for information on care of older people and support from health, social care and other professionals.

Most studies addressed a lack of knowledge about the care of older people at home. Family caregivers who have inadequate knowledge in the care of older people may cause unintentional harm to the older people (25). Moreover, it also can lead to a negative impact on older people's health and well-being, including cognitive and physical function (30). On the other hand, family caregivers may be unfamiliar with caring for older people due to insufficient knowledge. Thus, family carers often face practical problems related to caring techniques, community resource utilization and a lack of adequate knowledge to perform caregiving tasks (25). As a result, family caregivers experience stress due to inadequate knowledge. Providing information and instructions that are appropriate for family caregiver may increase their understanding of the important quality of care for older people. Thus, the burden on family carers caused by insufficient knowledge about caring for older people can be alleviated.

This review shows that most participants in the included studies experienced poor practices in caring for older people. Mamani et al (21) and Bassah et al (25) indicate that the majority of family caregivers are deficient of the practices in providing care of older people, such as unsatisfactory practice of fall prevention. Mamani et al. (21) concluded that family caregivers needed both knowledge and skills to provide adequate care. Therefore, training on the care of older people at home, including how to access help and support from health and social care professionals by nurses or other health care professionals to improve a family caregiver's knowledge and practice, may provide a good quality of caregiving service for older people.

Caring for older people at home, however, often becomes overwhelming or a burden for some families, and so they need additional levels of support. Family carers often face practical problems related to caring techniques, community resource utilisation and lack of

adequate knowledge to carry out the caregiving responsibility (27). The finding from this review highlights the lack of information (in particular, the inconsistent information about health services), inadequate professional support, ineffective communication and the lack of knowledge about legal and financial issues. The findings from this review also suggest that healthcare professionals have to meet their own needs to assist family caregivers better. As a result, the identified needs of caregivers enable nurses to develop care strategies and plan interventions focusing on these needs. In addition, the findings of this study could be useful for the Ministry of Health to develop new public policies and educational programmes to support family caregivers in improving knowledge and practise and to meet the needs of family caregivers of older people in Malaysia

Strengths and limitations

The strength of this review is its description of the current evidence regarding the knowledge, practice and needs of family caregivers in the care of older people. The findings of this review should pave the way for more future research in this topic and assist in future policies for family caregivers of older adults. However, there are a few limitations in reviewing the studies. First, the present review resulted from the heterogeneity of the studies that made up the sample and the different methods used by them. Moreover, only studies in English were included. Excluding studies published in other languages may have caused the absence of some local and international studies on the examined subject. Finally, most of the articles included in this review used cross-sectional study design and this type of design does not proof causality.

CONCLUSION

This paper provides an overview of the literature on the family caregivers' knowledge, practice and needs in the care of older people. Family caregivers' knowledge and practice relating to the care of older people are not satisfactory in most of the study settings in this study review. This review identified that family carers have a range of needs such as: Information on activities of daily living, health services, legal and financial issues; support

from healthcare professionals and training on elderly care. To reduce the unmet needs of family caregivers, they need to be better supported in managing their caregiving tasks. Hence, this review recommends further studies on knowledge, practice and needs in the care of older people to identify contextual challenges and provide evidence-based solutions to improve family caregivers' knowledge, practice and needs in the care of older people.

CONFLICT OF INTEREST

The author declares that there is no conflict of interests regarding the publication of this paper.

ACKNOWLEDGEMENT

The authors are thankful to the International Islamic University Malaysia (IIUM) for support. This research was supported in part by IIUM Flagship Research Initiative Grant Scheme (IRF19-009-0009).

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