

# The role of family caregivers in medication adherence of elderly in Asian setting: a scoping review

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## ABSTRACT

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Family caregivers for elderly play a very important role in implementing drug adherence, especially in Asian countries. Various determinants of medication adherence included family support. Although the relationship between family support is not always significant, understanding the factors of family support on medication adherence is important, especially when improving adherence in Asian countries. The following scoping review was conducted to provide an overview of family support, and its relationship to medication adherence in Asian settings. PRISMA-ScR guideline and checklist was used for the search process and to guide reporting. Review selection and characterization were performed by reviewers independently. In total, 22 papers were included in the review, published from 2011 to 2021. The studies varied in terms of purpose, methodology, and detail of reporting. Family support is an important determinant of medication adherence, especially for areas where extended family culture is still strong, such as in Asia. Understanding the local culture, aspects of family burden and economic, as well as the role of the health profession, including increasing number of pharmacists in health services are needed to improve adherence. Therefore, further research with quality methods is needed.

## ABSTRAK

Pengasuh keluarga untuk lansia memainkan peran yang sangat penting dalam kepatuhan pengobatan, terutama pada negara-negara di Asia. Berbagai faktor penentu kepatuhan minum obat, diantaranya adalah dukungan keluarga. Meskipun hubungan antara dukungan keluarga tidak selalu signifikan, namun memahami faktor dukungan keluarga terhadap kepatuhan minum obat adalah penting, terutama untuk meningkatkan kepatuhan di Asia. *Scoping Review* berikut dilakukan untuk memberikan gambaran tentang peran dan dukungan keluarga, dan hubungannya dengan kepatuhan pengobatan di negara Asia. Pedoman dan daftar periksa PRISMA-ScR digunakan untuk proses pencarian dan untuk memandu pelaporan. Pemilihan tinjauan dan pengklasifikasian dilakukan oleh tim peneliti secara independen. Secara total, 22 makalah dimasukkan dalam tinjauan, yang diterbitkan dari tahun 2011 hingga 2021. Evaluasi studi dilakukan secara bervariasi dalam hal tujuan, metodologi, dan detail pelaporan. Dukungan keluarga merupakan faktor penentu kepatuhan minum obat yang penting, terutama untuk daerah yang budaya keluarga besarnya masih kuat, seperti di Asia. Pemahaman budaya setempat, aspek beban dan latarbelakang keluarga serta peran profesi kesehatan, termasuk peningkatan jumlah apoteker dalam pelayanan kesehatan sangat diperlukan untuk meningkatkan kepatuhan. Oleh karena itu, sangat diperlukan penelitian lebih lanjut terkait hal tersebut, dengan metode yang lebih berkualitas.

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## **INTRODUCTION**

Ageing is a natural phenomenon that is inevitable with any demographic transition. Population ageing is a major concern both in the developed and developing countries. The aging population in Asia is projected to reach nearly 923 million in the first half of this century.<sup>1</sup> Due to an increasing proportion of the population being older, there is an increasing prevalence of chronic diseases. In addition to chronic diseases, elderly people will experience a general decline in body structure and function along with organ damage, neglected hearing and vision problems.

Being one of the vulnerable and high-risk group in terms of public health status, there are many challenges in paying attention to the health of the elderly. Usually geriatric patients will have multiple comorbidities due to polypharmacy results. The elderly patients are usually frail, have a high prevalence of cognitive impairment and often have complex care needs.<sup>1,2</sup> They have medicines regimens consisting of multiple administrations, various types of drugs, complex treatment schemes, and administration instructions.<sup>3,4</sup> A cross-sectional study in Kuwait showed that a large proportion of patients from specialized geriatric clinics reported suffering varying degrees of medication-related burden among elderly patients.<sup>5</sup> It has been reported that the higher the medication-related burden the lower the level of medication adherence among geriatric patients.<sup>5</sup> Therefore, drug preparation and administration is an important aspect of safe and high-quality care in the elderly.

Medication non-adherence is generally associated with worsening condition, increased comorbidities, increased health care costs, and death.<sup>6</sup> Factors associated with non-adherence include sociodemographic variables, treatment complexity and psychosocial factors, such as depression, social/family support, and health literacy, although this is not always consistent.<sup>7</sup> Studies of

international variations in adherence rates have highlighted the need to explore cultural context of non-adherence and consider transcultural issues when designing intervention programs.<sup>8,9</sup> Cultural values and practices unique to Asian populations, such as family role may predict medication no adherence in chronic conditions.<sup>10</sup>

The values of interdependence and collectivism, which characterize Asian culture emphasize the importance of the family in self-management. In addition, Asian culture key family members are usually expected to be involved in decision-making related to health and disease management and so make self-management decisions collectively. Asian countries have extended family cultures that enables the elderly to live with their families. While there is increasing numbers of elderly using multiple medications, support from family or family caregivers becomes crucial for elders to maintain their medication adherence. Little is known about how family caregivers play the roles in medication adherence of elderly, especially in Asian settings. This scoping review aims to locate and assess existing studies on family caregivers in relation to medication adherence of elderly in Asian setting.

## **MATERIALS AND METHODS**

### **Design and reporting**

A structured scoping review was undertaken to obtain a broad view on the available information and evidence by including a wide range of study designs. The Preferred Reporting items for Systematic Reviews and Meta-Analyses extension for Scoping Review (PRISMA-ScR) guideline and checklist was used for the search process and to guide reporting.<sup>11</sup> Following the review, a thematic analysis was undertaken to synthesize the literature and identify key themes. Findings were then collated, summarized, and reported.

## **Search strategy and data sources**

A systematic search on PubMed, Cochrane Library, Scopus, Google Scholar, and Garuda (Indonesian National Digital References) was carried out for studies on family caregivers in relation to medication adherence of elderly in Asian setting. A combination of search terms for family caregivers, patient compliance, aged, and Asia, in English and Bahasa Indonesia was used. Reference lists from included articles were screened to identify additional articles. The full search criteria for each database are included in the Supplementary 1.

## **Eligibility criteria**

### Definition of family caregivers

Family caregivers, or also called informal caregivers, are any relative, partner, friend or neighbour who provides a broad range of assistance for an older person or an adult with a chronic or disabling condition, usually without payment. For this review we will focus the caregiving task on medication management of the elderly.

### Included studies

The present scoping review considered studies that evaluated the role of family and/or family caregivers in Asian people, studies conducted in Asian countries, or Asian immigrant in any country. Experimental studies, observational studies, surveys, as well as qualitative and mixed-method studies, were eligible for inclusion. Study protocols, reviews, comments, and editorials were excluded. Articles in languages other than English and Bahasa Indonesia were removed.

### Main outcomes

We expect outcomes related to medication adherence, although these

outcomes are not necessarily the primary outcomes as defined by the authors of the included studies.

### Data extraction

Information that will be extracted include the following: author, year of publication, country in which the study was conducted, study design, determinants or interventions, definition of outcomes, instruments used, participants age, diseases, ethnic/race, analysis, and results.

## **Selection process**

Three authors (CW, NWW and SS) developed the search strategy (supplementary file/ appendix file). To evaluate the quality of the available literature, a critical appraisal was undertaken by two independent authors (CW and NWW). However, before the appraisal was undertaken, the criteria of each question were discussed among all authors (CW, NWW and SS) and interpretation of criteria was agreed upon to ensure consistency. Potentially eligible articles were retrieved as full texts and examined for final inclusion by CW and NWW individually. They checked all potentially relevant records and independently extracted the following information on a data extraction form: author, year of publication, country in which the study was conducted, study design, determinants or interventions, definition of outcome, instrument uses, participants age, diseases, ethnic/ race, analysis, and results. For minimizing biases and increasing reliability, selecting the studies for this review was conducted through dual revision by two researchers. Cohen's Kapa coefficient statistic was used for reporting the agreement. A scoring system was created to allow for appropriate appraisal of quality of evidence, with an answer of "Yes" scoring 1, and an answer of "No" or "Unsure" scoring 0. The interrater result

will be measured as; values  $\leq 0$  = no agreement, 0.01–0.20 = none to a slight agreement, 0.21–0.40 = fair agreement, 0.41–0.60 = moderate agreement, 0.61–0.80 = substantial agreement and 0.81–1.00 = perfect agreement. In case of discrepancies between the reviewers, a third reviewer revisit the criteria.

## RESULTS

There were 509 records identified via database search, which it consists of 3 Cochrane; 33 PubMed; 205 Scopus; 29 Garuda; and 239 Google Scholar. Furthermore, 28 duplicate articles were removed, therefore only 481 records were screened by title and abstract. A total of 459 records were excluded for various reasons including irrelevant (270), no full text or available only in university repository (37), not Asian (23), not elderly (78), not original research (50) and article translation (1).

Therefore, the full-text articles assessed for eligibility was 22, which no full-text articles excluded, as shown in FIGURE 1.

Studies included in this scoping review were 22, of which 9 articles were in English and 13 articles were in Indonesian. Agreement between reviewers (CW and NWW) for title and abstract screening was 98.7%, with a kappa value of 0.44 or moderate agreement. The quality of the studies varied, based on a quality appraisal tool that systematically reviews disparate forms of evidence and methodologies. Of the 22 included studies, 4 were qualitative studies; 17 were quantitative; 1 constituted mixed methods studies. Majority of the studies were conducted in Indonesia, the rest were in several Asian countries.<sup>12-20</sup> The study periods covered ranged from 2011 to 2021. Study methodologies mostly consist of survey in cross-sectional studies, 15/22 (68.2%), as shown in TABLE 1.

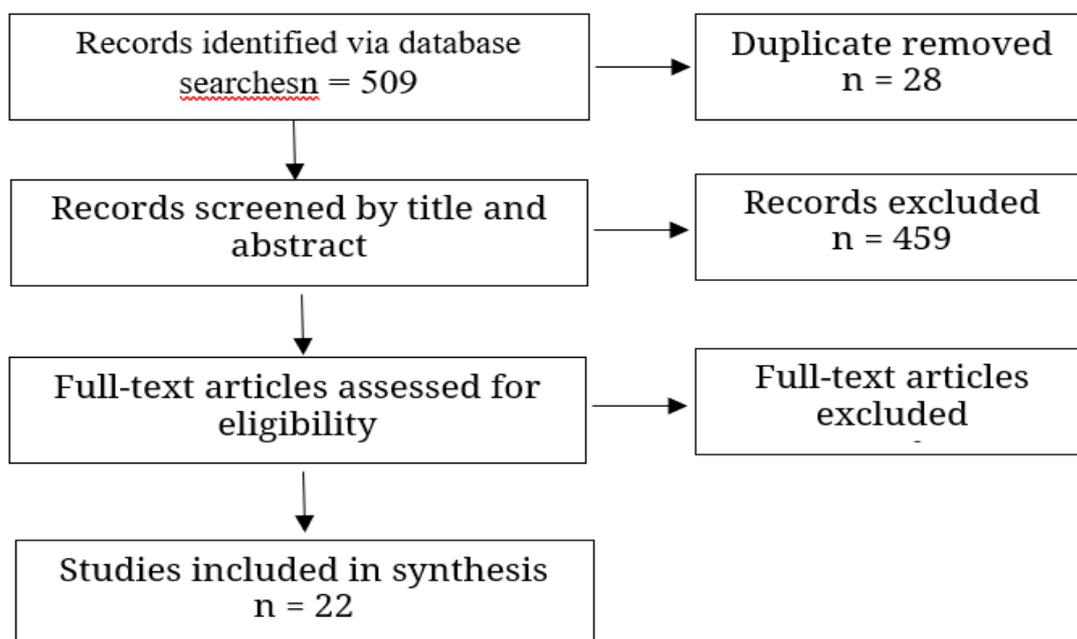


FIGURE 1. Study selection flowchart.

TABLE 1. Study characteristics

| Authors                                     | Year | Title  | Study location | Method  |
|---|------|--|----------------|---|
| Withidpanyawong <i>et al.</i> <sup>12</sup> | 2019 | Patient education and counseling family-based intervention by pharmacists for type 2 diabetes: A randomised controlled trial   | Thailand       | Randomized control trial                          |
| Aloudah <i>et al.</i> <sup>13</sup>         | 2018 | Medication adherence among patients with Type 2 diabetes: A mixed methods study  | Saudi Arabia   | Mixed-methods                                     |
| Bastani <i>et al.</i> <sup>14</sup>         | 2021 | Medication adherence among the elderly: applying grounded theory approach in a developing country  | Iran           | Qualitative study, grounded theory                |
| Ben-Natan <i>et al.</i> , <sup>15</sup>     | 2011 | Factors affecting older persons' adherence to prescription drugs in Israel   | Israel         | Cross-sectional, quantitative study               |
| Hussain <i>et al.</i> <sup>16</sup>         | 2018 | Medication adherence in post myocardial infarction patients  | Pakistan       | Cross-sectional quantitative study                |
| Johnson <i>et al.</i> <sup>17</sup>         | 2019 | Compliance and its determinants to pharmacologic management of hypertension  | India          | A population based cross sectional survey         |
| Jun <i>et al.</i> <sup>18</sup>             | 2018 | Access and adherence to medications for the primary and secondary prevention of atherosclerotic cardiovascular disease in Singapore: a qualitative study               | Singapore      | In-depth, semi-structured interviews              |
| Leung <i>et al.</i> <sup>19</sup>           | 2015 | Prevalence of medication adherence and its associated factors among community-dwelling Chinese older adults in Hong Kong: Medication adherence in Chinese elderly      | Hong Kong      | Secondary analysis                                |
| Woodham <i>et al.</i> <sup>20</sup>         | 2018 | Medication adherence and associated factors among elderly hypertension patients with uncontrolled blood pressure in rural area, Northeast Thailand                     | Thailand       | Cross-sectional, quantitative study               |
| Anggriani <i>et al.</i> <sup>21</sup>       | 2021 | Aspects of caregiver burden on geriatric patients and its relationship to medication adherence in Bugis ethnics in Wajo District, South Sulawesi                       | Indonesia      | Observational cross-sectional, quantitative study |
| Alam <i>et al.</i> <sup>22</sup>            | 2015 | Analysis of factors that influence non-adherence to treatment of elderly people with hypertension in the working area of the Pampang Public Health Center              | Indonesia      | Qualitative study, phenomenological approach      |
| Apsari <i>et al.</i> <sup>23</sup>          | 2021 | The relationship between family support and the role of pharmacists in adherence to taking antihypertensives   | Indonesia      | Cross-sectional, quantitative study               |
| Dolo <i>et al.</i> <sup>24</sup>            | 2021 | Analysis of factors influencing adherence to treatment for elderly people with hypertension during the COVID-19 pandemic at the Bulili Public Health Center, Palu City | Indonesia      | Cross-sectional, quantitative study               |

TABLE 1. Study characteristics (cont...)

| Authors                                  | Year | Title   | Study location | Method                                       |
|--|------|---|----------------|--|
| Firdausi <i>et al.</i> <sup>25</sup>     | 2019 | Relationship between family support and adherence to physical exercise and insulin therapy in patients with type 1 diabetes mellitus at the Internal Medicine Polyclinic at Abdoer Rahem Situbondo Distrik Hospital | Indonesia      | Cross-sectional, quantitative study          |
| Ifrohatis <i>et al.</i> <sup>26</sup>    | 2019 | Family social support and medication adherence in elderly with hypertension   | Indonesia      | Cross-sectional, quantitative study          |
| Makkulawu <i>et al.</i> <sup>27</sup>    | 2020 | Profile analysis and factors influencing medication adherence behavior for elderly patients with diabetes mellitus  | Indonesia      | Cross-sectional, quantitative study          |
| Nade & Rantung <sup>28</sup>             | 2020 | Family support with adherence to taking pulmonary tuberculosis medication in the working area of the Gading Rejo Public Health Center   | Indonesia      | Cross-sectional, quantitative study          |
| Oktaviani <i>et al.</i> <sup>29</sup>    | 2021 | Family support controls adherence to taking anti-hypertension in the elderly during the COVID-19 pandemic   | Indonesia      | Cross-sectional, quantitative study          |
| Prabasari <sup>30</sup>                  | 2021 | Self efficacy, self care management, and adherence in elderly with hypertension (phenomenological study)  | Indonesia      | Qualitative study, phenomenological approach |
| Sulistiyana <sup>31</sup>                | 2019 | Relationship between family support and medication adherence and dietary control in patients with hypertension  | Indonesia      | Cross-sectional, quantitative study          |
| Sumantra <i>et al.</i> <sup>32</sup>     | 2017 | The relationship between informative and emotional family support with adherence to taking medication in elderly with hypertension at the Ranomuut Public Health Center in Manado City                              | Indonesia      | Cross-sectional, quantitative study          |
| Widyaningrum <i>et al.</i> <sup>33</sup> | 2019 | The relationship between family support and adherence to taking medication in elderly with hypertension   | Indonesia      | Cross-sectional, quantitative study          |

Mostly the main objectives of the research were to investigate determinants and the relationship between the determinants of adherence variables either in quantitative or qualitative studies, where there were some with additional specific to measure medication adherence or family support quantitatively. Several studies aim to investigate direct relationship between family support and medication adherence, while other studies vary either to determine the model of medication adherence, to determine the burden of medication non-adherence,

or to investigate the effectiveness of interventions.

There were 2 types of instruments used, namely to measure family/ social support and to measure patient adherence. The instruments used were obtained in a various way, some used existing questionnaire tools, some others were developed by their own/ researchers themselves, or developed based on existing theories, especially with behavioral theory. In addition, there were also studies that did not report the instruments used.

The results of the scoping review

regarding the role of family caregivers in medication adherence of elderly in Asian settings can be categorized into the following themes.

### **Various terms used for medication adherence and family support**

The studies obtained provide various terms related to obedience and family support. Some studies defined medication adherence and family support along with the source of the definition, some did not define each clearly at all. There are several reasons, such as medication adherence and family support are not the main variables of their research objectives.

In general, studies that define adherence in principle are as follows, “the degree to provider,<sup>13,14,30</sup> and is measured using an adherence tools or pill count.<sup>13,14,16,17,31,32</sup> The terms adherence and compliance are often used with the same meaning, as can be seen from the instruments used, which are essentially related to behavior in taking medication.

Various terms appear in studies related to family support including family caregiver, family support, social support, and family social supports. Only two studies specifically define family support, i.e., attitudes, actions and family acceptance of sick people,<sup>24,31</sup> where Sulistyana<sup>31</sup> divided family support into 2 factors that influence it, namely internal factors and external factors of the family.

Studies that use the term social support in their research are intended to be the involvement of other people, both family and non-family, in reminding patients to use drugs.<sup>27</sup> Meanwhile, family social support is a support or assistance that includes emotional, esteem, instrumental, and informative assistance that is obtained through a process of interaction between individuals and other family members,<sup>23,26,29</sup> where there are several studies define each of these domains.<sup>32</sup> However, there is a study that mention social support as part or separate

from emotional support.<sup>27</sup> Furthermore, there is also a study which state that family support was a part of the domain of social influence on adherence,<sup>13</sup> in addition there was a direct relationship between patients and doctors as social factors/support.<sup>13</sup>

### **Cultural factors in medication adherence**

Cultural background is a possible factor to explain adherence.<sup>20</sup> In Asia, drug use and adherence to taking medication according to prescriptions are related to all cultural, social, and religious aspects of society. In Asian circles, culture with strength in religion, family is very closely related to adherence.<sup>14</sup> According to Bastani *et al.*<sup>14</sup> socio-cultural factors were themes related to factors that need to be understood if you want to understand elderly medication adherence.

There is one study that specifically describes about culture on family support in influencing medication adherence.<sup>21</sup> The article describes about the Bugis culture, which is one of the largest ethnic groups in Indonesia. The Bugis traditional philosophy emphasizes strong solidarity or togetherness and the ability to accept others as they are.<sup>21</sup> Thus, the Bugis culture tends to use caregivers mostly women who provide family health care.<sup>21</sup>

In Asia, elderly generally live with their families either joint or extended family type,<sup>17</sup> such as in Thailand mostly elderly live with family members, and only a few live alone,<sup>20</sup> where they will be very supportive in caring for them when their families (especially the elderly) are sick.<sup>20</sup> Joint or extended family type was a facilitator for adherence.<sup>17</sup> Helping and supporting partners in treatment can also be linked to social and cultural norms,<sup>16</sup> especially for the woman as the spouse/partner.<sup>16</sup> Therefore, considering the culture of the community is necessary to help solve adherence problems and plan strategies to improve medication adherence.<sup>14</sup>

## **Burden aspect and economic background**

Caregiver burden is considered as an important outcome in the patient care process. The burden borne by the caregiver can be influenced by various factors, such as the caregiver's physical and mental condition, family status, as well as other obligations that can affect the value aspect of the obligation and care (Angraini). Socioeconomic factors also affect patient adherence to treatment (Jun). Economic and family capacity has an impact on affordability and ability to get treatment (Jun).

## **The role of the family in adherence**

The review results of the 22 selected journal articles show that many factors determine adherence, including family support. Some studies show that family support were meaningful for patients to achieve better adherence medications. The family support can affect adherence in various ways, including directly influencing behavior related to preparing medicines, taking medicines,<sup>15</sup> it is estimated that > 30% of the drugs that are prescribed to older persons are not self-administered in accordance with the instructions. This research examines which factors affect the adherence to prescription drugs of older Israelis and tests whether the Theory of Planned Behavior (TPB),<sup>23</sup> delivering access to health services,<sup>22,28</sup> reminding of drug use,<sup>13,19,33</sup> influencing belief or motivation,<sup>22,23,30,31-33</sup> providing social support,<sup>30</sup> or helping medical expenses.<sup>18</sup> However, this support can diminish due to the burden on caregivers.<sup>21</sup> This is because caregivers have limited time to do other activities.<sup>21</sup>

Although marital status was not significant as a predictor of adherence,<sup>13,16,17</sup> however this review highlights the importance of spouse<sup>12,13,16</sup> or woman<sup>12,17,20</sup> in the family which appears to be highly supportive of medication adherence. In addition,

study conducted by Woodham *et al.*<sup>20</sup> also pointed out a significant association between patients whose caretaker was a daughter. The reason possibly the help and support provided by the partner in drug use.<sup>16</sup> Females are more anxious about their spouse's health than their own.<sup>17</sup> This is supported by the results of the study Withidpanyawong *et al.*<sup>12</sup> which shows that having a partner as a family member or a woman as part of the family is the strongest predictor of adherence.

Several studies evaluated the relationship between family support and patient adherence to medication. Mostly they showed a significant relationship ( $p < 0.05$ ) between family support and adherence.<sup>20,24,26,29,31-33</sup> However, there are several studies which show that the relationship is not significantly different ( $p > 0.05$ ),<sup>27,28</sup> such as shown by Makkulawu *et al.*,<sup>27</sup> where the percentage of adherent elderly patients who live alone and live with family/other people was not significantly different ( $p = 0.643$ ).

## **Family caregiver collaboration with health professionals in increasing adherence**

The studies obtained were generally of an intervention study design.<sup>12,23</sup> The results of interventions carried out by pharmacists on patients with family assistance, showed success in increasing adherence in patients with type 2 DM<sup>12</sup> and hypertension.<sup>23</sup> The results of a mixed-method study, in which participants were interviewed, also showed that there was a relationship between family collaboration and health professionals on medication adherence<sup>13,23</sup>, although this relationship is not always positive for patients.

There are some factors other than family support influence medication adherence in elderly, such as patient-related factors, condition-related factors, therapy-related factors, healthcare provider factors, system-based factors, and socioeconomic factors.<sup>29-32</sup>

Technology is one example of where medication adherence in elderly can be facilitated. Unfortunately, there is still lack of study addressing how family can help with technology to facilitate medication adherence.

## DISCUSSION

The quality of the articles obtained for scoping reviews varied greatly, and approximately more than half were in Indonesian. Some English articles discuss elderly, Asian, family, and medication adherence, but they are linked to other things, for example knowledge or self-management, not family vs adherence. On the other hand, there are many studies in Indonesia (family support for medication adherence), although the scope is much smaller, the sample size is small, the quality is dubious (not included in this review because most of them target non-elderly/not specifically elderly). Even though several articles have similar aims, the methods including tools, subjects, number of samples and data collection are varied, so that the conclusions cannot be used in general. Various terms and definitions related to family caregivers are used in the 22 selected studies. The terms and definitions used between articles vary widely and with different sources. In fact, the clarity of the definition of each of these terms is not only very important for the researcher, but also important for the research participants, since these problems may result in different perceptions of researchers and participants, even readers. Based on the characteristics, scope of the methodology and challenges reported in the articles, we propose recommendations to improve the quality of research by improving the methods used.

In terms of research on family or informal caregivers, many have started in Asia, but many have focused on children, adults of all ages, or caregiver burden. The results of the scoping review show how women play an important role

in family care. Several articles<sup>12,13,16-18</sup> show that patriarchal values are still strong in Asia. The patriarchal values are represented in how women get along with household work, women are considered subordinate and inferior, and show their dependence on men.<sup>34</sup> Although the culture of extended family in Asia still exists, and it is not normal to leave one's parents in an orphanage, however research on this subject is still limited. Most studies show that the family was generally very important role in adherence through various ways, whether helping in providing motivation or directly intervening adherence. Economic problems on family support are also an important point in medication adherence. Family factors such as income, family structure, parental welfare, parental care or neglect and parental care is a prominent aspect that affects medication adherence.<sup>35</sup> However, the relationship between family support and adherence still needs further review regarding the extent of the relationship and which family members play a role in medication adherence. This is because the differences in methods and results between the studies, as well as the quality of the research, are still obstacles in conducting this review.

Family support led by health professionals is very helpful to improve medication adherence. The articles selected for the scope of this review demonstrate the success of pharmacists in collaborating with patient families in improving adherence.<sup>12,23</sup> Therefore, collaboration of family support with health professionals should be recommended in health care, especially in the Asian region. However, in reality, the number of pharmacists who provide services directly to each individual patient is still limited. This may be due to the limited number of pharmacists in health services. For example, in primary health services in Indonesia, the availability of pharmacists is still limited, and they are already overloaded with managerial activities.<sup>36</sup> The results

of this review provide an overview and suggestions on the role of the family and the practical implications of increasing adherence. The current results suggest researchers, policy makers or health care personnel should provide more attention to medical adherence among elderly, especially in Asia. Quality research and strategies to improve medical adherence are urgently needed.

## CONCLUSION

The results of the scoping review can illustrate how important family support is in medication adherence. Although many articles related to the role of the family on adherence have been published, however the quality of research related to family support and medication adherence in Asia still varies widely. Understanding local culture, as well as increasing the role of the health profession, including the number of pharmacists in the health service are essential if adherence is to be improved. Therefore, it is important for researchers to continue to improve the quality of their research.

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