

## Care Burden of Family Caregivers of Elderly Relatives with Breast Cancer in the Asian Culture: Integrative Review

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### Abstract

Breast cancer is the most common type of cancer and a major cause of death in elderly women. In Asia, the roles and responsibilities of family caregivers of elderly relatives with breast cancer vary across cultural and social contexts, but the care burden and its impacts on caregivers' quality of life have been reported globally. Therefore, this review aims to summarize existing evidence of the care burden and experiences of family caregivers caring for elderly relatives with breast cancer in Asian cultures. This integrative review used databases, including MEDLINE, Cumulative Index of Nursing and Allied Health Literature (CINAHL), and Scopus, to conduct a comprehensive search of all studies published in English between 1994 and 2016 in relation to the topic at hand, yielding 322 articles, eight of which met the eligibility criteria and were included in the review. Three domains of the care burden, including physical, psychological, and financial, were identified and reported as varying in degree across cultures. Caring for elderly patients with breast cancer in Asian cultures was found to be performed on passionate grounds involving love, sympathy, relationships, and attachments. The positive and negative experiences among family caregivers were found to be associated with cultural factors, including beliefs, social norms, traditional practices, and religion. A stronger family bond and sense of togetherness within the family were expressed as positive, whereas caring for the elderly was described as burdensome, or negative. While the caregiver role is perceived as integral to the Asian family caregiver's life, they nonetheless experience physical, psychological, and financial burdens related to the care. Thus, the deep insight into the burden of family caregivers offered herein warrants the provision of appropriate support from health professionals to family caregivers.

**Keywords:** Asian culture, breast cancer, care burden, elderly patient, family caregiver

### Abstrak

**Beban Pengasuhan Pelaku Rawat di Keluarga dalam Merawat Lansia dengan Kanker Payudara di Asia: Tinjauan Integratif.** Kanker payudara adalah jenis kanker yang paling umum dan merupakan penyebab utama kematian pada perempuan lansia. Dalam konteks sosial dan budaya di Asia, peran dan tanggung jawab yang dimiliki oleh family caregiver dalam mendampingi pasien lansia dengan kanker payudara bervariasi. Meskipun demikian, beban pengasuhan dan dampaknya terhadap kualitas hidup caregiver dilaporkan dialami di seluruh dunia. Oleh karena itu, studi ini bertujuan untuk mengumpulkan bukti tentang beban pengasuhan dan pengalaman family caregiver di Asia dalam merawat kerabat lansia yang menderita kanker payudara. Tinjauan integratif ini menggunakan kumpulan data dari MEDLINE, Cumulative Index of Nursing and Allied Health Literature (CINAHL), dan Scopus, untuk melakukan pencarian komprehensif dari semua studi terkait topik beban family caregiver yang diterbitkan dalam bahasa Inggris antara tahun 1994 dan 2016. Pencarian komprehensif ini menemukan 322 artikel yang delapan di antaranya memenuhi kriteria kelayakan untuk ditinjau secara integratif. Identifikasi terhadap tiga domain dari beban pengasuhan; fisik, psikologis, dan keuangan, menemukan bahwa tingkat beban tersebut bervariasi antara satu budaya dan yang lainnya. Ditemukan bahwa merawat pasien lansia dengan kanker payudara dalam budaya Asia dilakukan atas dasar dorongan jiwa yang melibatkan cinta, simpati, hubungan, dan keterikatan. Pengalaman positif dan negatif yang dialami oleh family caregiver diasosiasikan dengan faktor budaya, termasuk kepercayaan, norma sosial, praktik tradisional, dan agama. Ikatan keluarga yang lebih kuat dan rasa kebersamaan dalam keluarga diekspresikan sebagai pengalaman positif, sedangkan merawat lansia digambarkan sebagai beban yang bersifat negatif. Meskipun peran sebagai pengasuh dianggap sebagai bagian yang penting dari kehidupan family caregiver di Asia, mereka tetap mengalami beban fisik, psikologis, dan keuangan. Studi ini bertujuan memberikan pengetahuan yang mendalam tentang beban family caregiver agar dapat digunakan dalam menjamin penyediaan dukungan yang tepat dari tenaga kesehatan profesional kepada family caregiver.

**Kata Kunci:** beban pengasuhan; budaya Asia; family caregiver; kanker payudara; pasien lansia

## **Introduction**

Globally, breast cancer was reported to be the most common cancer in 2020, with approximately 2.3 million new cases (11.7% of all cancer cases) and 685,000 deaths (Sung et al., 2021), exposing the disease as the biggest killer in more than 100 countries worldwide, particularly low- to middle-income countries (Lei et al., 2021; Sung et al., 2021); in China, breast cancer accounts for approximately 24% of all cancer cases nationwide (Cao et al., 2021). It is generally acknowledged that breast cancer impacts entire families, not only the affected individual, as the families might carry a heavy burden in and responsibility for supporting and caring for cancer patients at home (Beaver & Witham, 2007). Breast cancer places a burden not only on life, but also on caregivers' physical, psychological, and financial conditions (Schwartz et al., 2021; Vashistha et al., 2019). Therefore, there is no doubt that the quality of life of caregivers of cancer patients has been reduced by factors related to the caring role and its responsibilities (Meecharoen et al., 2013). The important roles of informal family caregivers unfortunately lead to added responsibilities in caring for cancer patients, including routine care related to food intake, medicine intake, home treatments, and any arrangements for urgent care. In addition, caregivers must abandon some of their activities of daily living and related to their usual role when undertaking the numerous tasks involved in caring (National Cancer Institute, 2021; PDQ Supportive and Palliative Care Editorial Board, 2016).

In Asia, the roles and responsibilities of family members when caring for elderly relatives with breast cancer vary across cultural and social contexts, but the care burden and its impact on the quality of life of caregivers have been reported globally. There are various viewpoints among both males and females who provide care to a family member in a Western or Asian country. Perspectives of care requirements in these two contexts differ in terms of background, culture, relationships, religion, and

facilities (Kristanti et al., 2021; Takahashi et al., 2022). Family caregivers have been recognized in Western countries and been assigned significance in terms of their individual needs, the facilities, and the quality of life of the cancer patient for whom they care. In contrast, Asian countries are more concerned with spiritual health, family obligations and care tasks, and economic circumstances (Takahashi et al., 2022). As such, in these regions, becoming a caregiver is a difficult decision, because most are unprepared to shoulder the subsequent burden, which may impact their quality of life (Fried et al., 2021; Pickering et al., 2021). There is limited evidence of a knowledge of cultural norm in relation to the burden of care among family caregivers of patients with breast cancer in the Asian context. As such, this review aims to summarize existing evidence of the burden and experiences of family members providing care to elderly relatives with breast cancer in Asian cultures.

## **Methods**

This review deployed an integrative literature review method, including a range of evidence and diverse methodologies, both quantitative and qualitative, to establish a comprehensive overview and insight of a particular topic. The current review was undertaken through the updated methodology for an integrative review (Torraco, 2005; Whittemore & Knafl, 2005), and it aligns with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines and checklist for the reporting of systematic reviews (Moher et al., 2015). Further, the review was performed using the Critical Appraisal Skills Programme (CASP) (2018).

**Information Sources and Search.** A comprehensive search was undertaken in the MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Scopus databases for articles published in English between 1994 and 2016. Four concepts were used to choose keywords, as follows: 1) “caregiver,” “family caregiver,” “carer,” and “caregiving”;

2) “burden,” “burdensome,” “difficulty,” “family burden,” “responsibility,” and “experience”; 3) “breast cancer in older women,” “elderly patient with breast cancer,” “breast cancer,” “older women,” and “senior women”; and 4) “Asian,” “Asian culture,” “Asian countries,” and “Asian context.”

To broaden the results, an advanced search with the Boolean operator “or” was conducted for each concept, and to obtain the specific search results, the Boolean operator “and” was used to combine all search results. Finally, to achieve a comprehensive search, the reference lists of the reviewed articles were manually searched, and all search results were managed using an End-NoteX9 Library.

### Eligibility Criteria

**Types of Participants.** This review considered studies that involve family caregivers of women patients with breast cancer in Asian countries.

**Types of Interest.** Studies that investigated or explored the burden of care among family caregivers of women with breast cancer are considered.

**Types of Studies.** This review included observational studies that employed a quantitative or qualitative method or a mix of the two approaches at levels I to IV of the National Health and Medical Research Council (NHMRC) evidence hierarchy (NHMRC, 2009), and this review excluded review or meta-analysis articles.

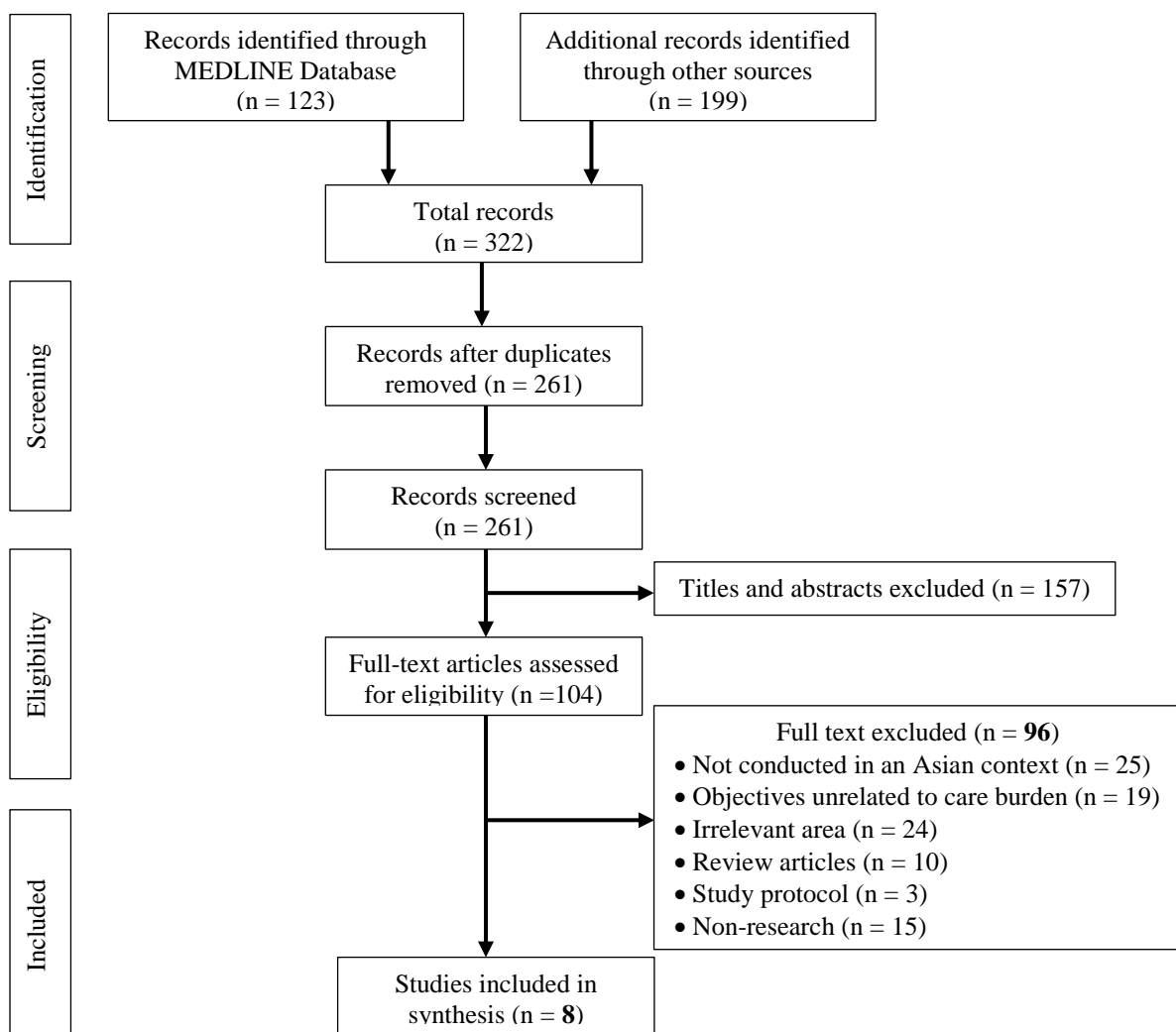


Figure 1. Selection Flow Diagram

**Types of Outcomes.** This review included studies that measured at least one of the burden of care domains: physical, psychological, and financial.

**Methods of Review and Data Extraction.** The comprehensive search was conducted by the second author (KHT), the search results were managed using an EndNoteX9 Library (CK and KHT), and two reviewers (CK and KHT) independently assessed eligible articles. Any conflicts that arose during the selection process were resolved through discussion, and all selected articles were classified using an evidence hierarchy (NHMRC) and research designs. Relevant variables were extracted and managed in tabular form using the Microsoft Excel® spreadsheet software (KHT and CK), and methodological quality assessments were performed and reported in narrative and tabular forms (KHT). The burden of responsibility across three domains—physical, psychological, and financial—was extracted and managed in tabular form (CK), and the impacts of culture on the burden and experiences were extracted and managed in tabular form (CK, KHT).

## Results

The comprehensive search yielded 322 relevant articles, 261 of which were duplicate articles and were removed and 157 of which were excluded following a title and abstract review, leaving 104 articles to be assessed for eligibility. A further 96 articles were excluded at the full-text selection stage, leaving only eight articles that met the eligibility criteria and that were included in this review (Figure 1).

**Methodological Quality.** In total, 810 participants from eight papers were included in this review (Table 1), where the average mean age was 46 years, ranging between 40 (Vahidi et al., 2016) and 54 (Makabe & Nomizu, 2006) years. All studies recruited caregivers who are a family member or relative of a woman patient with breast cancer. These research projects were conducted in six Asian countries, including

China (Zhu et al., 2014), Iran (Khanjari et al., 2014; Vahidi et al., 2016), Japan (Makabe & Nomizu, 2006), Korea (Chung & Hwang, 2012), Malaysia (Jaafar et al., 2014; Mahadevan et al., 2013), and Thailand (Junda, 2004), four research designs were identified; two correlational studies, three cross-sectional studies, two descriptive studies, and one ethnographic study. The sample size ranged between 14 (Chung & Hwang, 2012) and 243 participants (Zhu et al., 2014), and data collection was performed using various tools: interviews (Chung & Hwang, 2012; Jaafar et al., 2014; Junda, 2004; Khanjari et al., 2014; Makabe & Nomizu, 2006), questionnaires (Jaafar et al., 2014; Mahadevan et al., 2013; Makabe & Nomizu, 2006; Vahidi et al., 2016; Zhu et al., 2014), and medical record reviews (Jaafar et al., 2014). Data analyses were performed appropriately; quantitative data were analyzed using suitable statistical tests and qualitative data were analyzed using thematic analysis. The two qualitative studies (Chung & Hwang, 2012; Junda, 2004) achieved methodological rigor in relation to an appropriate design with a relevant conceptual framework, appropriate methods, and relevant reporting. The key message concerning the burden of care among family caregivers vary among the eight studies (Table 1).

**Burden of Responsibility.** All studies reported ‘overloaded or lack of information of the disease and caregiving’ as a common physical burden, and negative impacts on caregivers’ daily routines and physical health were identified by most of the reviewed studies. The psychological burden was reported in the form of emotional and social concerns, such as anxiety, feeling uncertain about the future, and acceptance of the patient’s condition. Most of the reviewed studies revealed negative experiences, such as financial strain and an uncertain future direction, as well as ongoing healthcare and living costs. A summary of findings from the eight papers in three domains of the burden of care of family caregivers is presented in Table 2.

Table 1. Summary of Included Studies

| Authors                 | Country  | Study Design/Size                       | Data Collection                                     | Caregiver Age (years $\pm$ SD) | Key Focus   |
|-------------------------|----------|---|---|--------------------------------|---|
| Chung & Hwang (2012)    | Korea    | Descriptive Study<br>N = 14             | Interview   | 51                             | The couples experienced substantial distress and some unresolved hardships that required mutual effort toward resolving.  |
| Jaafar et al. (2014)    | Malaysia | Cross-sectional study<br>N = 130        | Medical record review;<br>Self-report;<br>Interview | 43 $\pm$ 14.5                  | Caregivers' mean age was 10 years younger than that of the patients. The rates of major depressive disorder and dysthymia among caregivers were significantly associated with patients' functional status and caregivers' education level.                        |
| Junda (2004)            | Thailand | Ethnographic study<br>N = 17            | Observation;<br>Interview                           | 44                             | Multiple methods were used to manage breast cancer, including family support, sociocultural, and Buddhist beliefs. Limited knowledge and ineffective communication between families and health professional were reported.  |
| Khanjari et al. (2014)  | Iran     | Descriptive prospective study<br>N = 88 | Interview   | 41 $\pm$ 13.9                  | Psychological impact was the major factor influencing quality of life, particularly family health and relationships. Positive aspects of life were also reported.   |
| Mahadevan et al. (2013) | Malaysia | Cross-sectional Study<br>N = 130        | Questionnaires                                      | 43 $\pm$ 14.5                  | Duration of caregiving and the shared burden of caregiving were associated with stress among caregivers. There were three significant factors predicting caregivers' stress: age of patient, patient's functional status, and sharing of caregiving burden.       |
| Makabe & Nomizu (2006)  | Japan    | Correlational study<br>N = 38           | Questionnaires<br>Interview                         | 54 $\pm$ 9.3                   | There was a positive correlation between the psychological state of caregivers and the physical state of patients. By contrast, social supports were found negatively correlated with the psychological states among patients and their spouses prior to surgery. |
| Vahidi et al. (2016)    | Iran     | Correlational study<br>N = 150          | Questionnaire                                       | 40 $\pm$ 13.8                  | Factors associated with caregiver burden included daily living, level of education, gender, and financial status.   |
| Zhu et al. (2014)       | China    | Cross-sectional study<br>N = 243        | Questionnaire                                       | 50 $\pm$ 9.4                   | Sacrifice, loss of control, embarrassment/anger, and dependency were found correlated with caregivers' quality of life. The total caregiver burden and mental health had the strongest correlation.   |

**Impact of Culture on Burden and Experience.** The findings of the reviewed studies reveal that caring for elderly patients with breast cancer in Asian cultures is performed on passionate grounds, involving family bonds, societal obligations, social support, and interpersonal relationships. Further, the impacts of culture on

the care burden and experience among family caregivers in an Asian context vary across countries in terms of traditional practices, beliefs and attitudes, social norms, family bonds and structure, religion, and the relationship between health professionals and family caregivers. A summary of positive and negative impacts of culture

on the care burden and experience is presented in Table 3.

## Discussion

This integrative review summarized evidence derived from both quantitative and qualitative studies conducted in Asian countries. The family caregiver role in the Asian context, as reported in the reviewed articles, is given to a blood-related family member (e.g., father, mother, sister, brother, son, daughter, nephew,

or niece) or an individual with a legal relationship to the patient (e.g., husband, wife, daughter-in-law, son-in-law, or mother-in-law) who lives in the same house as the loved one with cancer and who will provide unpaid care to the cancer patient.

All reviewed studies reported a care burden at least in one of the three domains: physical, psychological, and financial, which impact quality of life in the short and long terms. This message is consistent with the existing research evidence

Table 2. Three Domains of the Care Burden of Family Caregivers

| Domain               | Care Burden   | Evidence   |
|----------------------|---|--|
| Physical burden      | Ongoing and long-hour caregiving duties and fatigue;  | Chung & Hwang, 2012; Jaafar et al., 2014; Junda, 2004; Mahadevan et al., 2013; Vahidi et al., 2016; Zhu et al., 2014   |
|                      | Impacts on caregiver’s daily routine and work schedule;   | Chung & Hwang, 2012; Junda, 2004; Mahadevan et al., 2013; Vahidi et al., 2016; Zhu et al., 2014  |
|                      | Impacts on caregivers’ physical health  | Junda, 2004; Khanjari et al., 2014; Zhu et al., 2014   |
|                      | Overloaded or a lack of information of the disease and caregiving responsibilities  | Chung & Hwang, 2012; Jaafar et al., 2014; Junda, 2004; Khanjari et al., 2014; Mahadevan et al., 2013; Makabe & Nomizu, 2006; Vahidi et al., 2016; Zhu et al., 2014 |
| Psychological burden | Acceptance of patient’s condition   | Chung & Hwang, 2012; Junda, 2004; Khanjari et al., 2014  |
|                      | Stress, anxiety and depression, emotional pressure, or emotional control (e.g., anger, embarrassment, conflict)   | Chung & Hwang, 2012; Jaafar et al., 2014; Junda, 2004; Khanjari et al., 2014; Mahadevan et al., 2013; Makabe & Nomizu, 2006; Vahidi et al., 2016; Zhu et al., 2014 |
|                      | Tiredness, sleeplessness, and loss of concentration   | Chung & Hwang, 2012; Jaafar et al., 2014; Khanjari et al., 2014; Mahadevan et al., 2013; Vahidi et al., 2016; Zhu et al., 2014                                     |
|                      | Feeling uncertain about the disease status, treatment outcomes, and future  | Chung & Hwang, 2012; Jaafar et al., 2014; Khanjari et al., 2014; Mahadevan et al., 2013; Makabe & Nomizu, 2006; Vahidi et al., 2016; Zhu et al., 2014              |
| Financial burden     | Ongoing direct and indirect healthcare costs, such as medications, traditional and modern treatment, specific diets, special equipment, and health insurance. | Jaafar et al., 2014; Junda, 2004; Khanjari et al., 2014; Mahadevan et al., 2013; Vahidi et al., 2016   |
|                      | Financial strain beyond healthcare costs, such as making merit, travel, and living costs.   | Junda, 2004; Khanjari et al., 2014; Vahidi et al., 2016; Zhu et al., 2014  |
|                      | Uncertainty of future in relation to financial-related concerns, such as poor economic situation, losing job.   | Jaafar et al., 2014; Khanjari et al., 2014; Mahadevan et al., 2013; Vahidi et al., 2016; Zhu et al., 2014  |

Table 3. Impacts of Culture on Care Burden and Experience

| Factor                            | Impacts of culture on care burden  | Evidence  |
|-----------------------------------|--|---|
| Positive impacts/Enablers to care | Societal obligations to look after family members create a great sense of responsibility among family caregivers in Asian cultures.  | Chung & Hwang, 2012; Junda, 2004; Khanjari et al., 2014; Makabe & Nomizu, 2006; Vahidi et al., 2016; Zhu et al., 2014   |
|                                   | Family bonds and interpersonal relationships within Asian families help solve family members' conflicts during the care period. Social support through spirituality, rituals, and religion provides caregivers strategies to cope with the psychological burden. | Chung & Hwang, 2012; Junda, 2004; Khanjari et al., 2014; Makabe & Nomizu, 2006; Vahidi et al., 2016<br>Jaafar et al., 2014; Junda, 2004; Mahadevan et al., 2013 |
| Negative impacts/Barriers to care | The social norm of hiding health conditions and hesitating to seek care may worsen the burden of care, because caregivers will not be fully informed.  | Chung & Hwang, 2012; Makabe & Nomizu, 2006; Zhu et al., 2014  |
|                                   | The traditional belief that males should not express emotions or take on care roles places greater pressure on male caregivers   | Chung & Hwang, 2012; Makabe & Nomizu, 2006  |
|                                   | Social hierarchies lead to imbalances in relationships between health professionals and family caregivers, creating one-way communication between doctors and families/patients, which results in a lack of understanding between the two parties.               | Junda, 2004   |
|                                   | Sources of conflict, such as a lack of support, an inappropriate form of support, and support at inappropriate times, will increase the psychological burden on patients and family caregivers.  | Chung & Hwang, 2012; Jaafar et al., 2014; Junda, 2004; Mahadevan et al., 2013; Makabe & Nomizu, 2006; Vahidi et al., 2016                                       |

in the Asian and global contexts (Meecharoen et al., 2013; National Cancer Institute, 2021; Rajasekaran et al., 2016; Schwartz et al., 2021). The psychological burden has both positive and negative aspects; for example, it is beneficial in that its impact enables patients and their caregivers to adapt to their physical difficulties (Chung & Hwang, 2012; Jaafar et al., 2014; Junda, 2004; Mahadevan et al., 2013; Vahidi et al., 2016; Zhu et al., 2014). On the other hand, the disadvantages of the psychological burden on daily life and health, such as tiredness, fatigue, and disrupted rest and quality of life, can lead to negative emotions and thoughts, including anxiety, stress, depression, sadness, and fear of loss. The man is the leader of the family

in Asian cultures, and he must hide his emotions when caring for a partner with cancer, as it is the social norm in Asian communities for men to show leadership and strength. Conversely, female caregivers may empathize, understand, and express themselves through touch and encouragement.

Most caregivers in the Asian culture employ religious principles to heal their minds and cope with the psychological burden (Chung & Hwang, 2012; Junda, 2004; Khanjari et al., 2014). Meanwhile, the financial burden causes only a negative impact on families due to direct and indirect healthcare and living costs. Asian family caregivers inevitably face an overload hour in

working to gain extra income to meet everyone's needs (Junda, 2004; Khanjari et al., 2014; Vahidi et al., 2016; Zhu et al., 2014). As such, the limited funding available to support family caregivers in Asian countries must be considered to relieve these burdens.

The findings of this review provide a big picture of the cultural factors influencing the burden of care and both negative and positive experiences among Asian family caregivers. It offers essential information to health professionals for understanding family caregivers and for integrating evidence-based practices into the Asian context. In addition, the summary can assist health providers in advocating for and managing appropriate supports that meet family caregivers' needs and enhance their role performance. Differences in cultures could be considered when adapting models of care from one community to another; in other words, a successful model of care and practices in a particular context does not guarantee implementation success in another context with a different culture. To ensure the quality of practices and to support family caregivers in Asian cultures, future research focusing on the in-depth details of cultural and social contexts is warranted.

**Limitations.** This integrative review included studies from six Asian countries, though the findings may not represent all Asian countries. In addition, the differences in culture within individual countries has not been addressed. However, reports derived from the eight reviewed studies were consistent and in line with the previous evidence. Another limitation of this review is by only including articles that published in English. Nonetheless, more than 80% of all the studies related to the topic have been published in English and were available worldwide.

## Conclusion

In Asian cultures, caregiving role in families is perceived as an integral part of family responsibilities and relationship. Regardless, family

caregivers in the Asian context still experience the burden of care the same as those in other contexts in terms physical, psychological, and financial factors. The differences in data collection methods, types of family caregivers (e.g., blood-related or legal relative), and patient stage could lead to different perspectives of the burden of care.

The understanding of family caregivers' experiences and their burden would enable the development of appropriate strategies to advocate for and support family caregivers. Therefore, further research to gain deeper insights into the burden of care among family caregivers is warranted, and the welfare system and health policy concerning support for caregivers are also advised to provide sufficient aid to family caregivers who are assisting patients with breast cancer in Asian countries.

## Acknowledgements

The authors acknowledge and profoundly appreciate the great support from Boromarajonani College of Nursing, Chiang Mai, Thailand.

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